

Alfiero & Lucia Palestro Foundation, Inc.

A Tax Exempt Private Foundation

333 Sylvan Avenue, Suite # 100

Englewood Cliffs, NJ 07632

Phone (201) 568-8000 Fax (201) 568-6973

E-mail: info@palestroni.com

2025 ALFIERO & LUCIA PALESTRONI FOUNDATION GRANT APPLICATION

Use this format only to apply for a grant

1. Name of Organization: Friedreich's Ataxia Research Alliance (FARA)

2. Address of Headquarters Office: 533 W Uwchlan Ave
Downington, PA 19335

3. Telephone: 484 879 6160 Fax: NA
E-mail: felicia.derosa@curefa.org
Website: curefa.org

4. Date Organized: September 29, 1998

5. Date and Place of Incorporation: 1998, Washington DC

6. Federal Tax Exempt Status: 501c3
Please include IRS Code Determination and a Copy of IRS letter as Exhibit 1.

7. Staff Head

Name: Jennifer Farmer
Title: Chief Executive Officer
Volunteer or Compensated: Compensated
Amount of Compensation/Benefits (if any): \$170,678

8. Staff Head

Name: Ronald Bartek
Title: President
Volunteer or Compensated: Compensated
Amount of Compensation/Benefits (if any): \$113,811

Kindly list Officer/Members or the Board of Directors with Compensation/Benefits (if any) if they serve as Management as Exhibit 2.

9. Chief Purpose of the Organization: FARA's mission is to marshal and focus the resources and relationships needed to cure Friedreich's Ataxia (FA) by raising funds for research, promoting public awareness, and aligning scientists, patients, clinicians, government agencies, pharmaceutical companies and other organizations dedicated to curing FA and related diseases. FARA focuses on funding and facilitating FA research through a grant making program as well as projects directed by the organization's research team. The organization's goal is to slow, stop, reverse, and ultimately —cure FA. Due to the progressive nature of the disease and the promise of treatments in development, there is urgency in our efforts.

10. Brief History of the Organization: FARA began as an all-volunteer organization in 1998 and remained so until 2005. From that time to present, the organization established an operational team to carry out research priorities, community engagement and education, strategic fundraising, and advocacy. Today, the organization has 16 full-time employees, 7 part-time employees or contractors, and 2 volunteer staff.

FA is a progressive neuromuscular disease that affects about 5,000 children and adults in the United States and 15,000 worldwide. What begins as difficulty with balance and coordination progresses over a short period of time to a life altering loss of mobility, energy, speech, and hearing. FA also presents serious risk of diabetes and life shortening cardiac disease.

FARA's Leadership and numerous patient families and friends have raised critical funds over the years to support FA research. Thanks to the brilliant and committed efforts of many FA scientists, we now understand the cause of FA and specific mechanisms leading to damage in FA patients. These understandings allow for more targeted approaches to treatment which are currently being developed for clinical trials.

In 2023, the FDA approved SKYCLARYS® (omaveloxolone) — the first treatment for FA — on Rare Disease Day, followed by European Commission approval in 2024 for people over 16 years of age. This was a major milestone for our community. The treatment slows disease progression and improves neurological symptoms, giving people more time at their current level of function, but it is not a cure. There is still much more work to be done.

11. Brief Description of the Organization's Programs in the Most Recent Year:
Please include descriptive materials, publications, etc. as Exhibit 3.

FARA invested over \$9 million in research in 2024 and is on track to do the same in 2025, supporting 37 research labs across five continents and 10 countries. In 2023, FARA launched the FA Global Clinical Consortium, which now includes more than 30 sites collecting natural history data from over 2,800 individuals with FA, many of which are also running clinical trials. This model accelerates treatment development in FA and provides a practical blueprint that other rare

disease groups can adapt as they build their own research infrastructure. In 2026, FARA-funded researchers will complete TRACK-FA, the largest global neuroimaging study to date, which is providing important insights into how to target therapies to specific brain regions early in the disease process. We have enclosed an impact one-sheet as Exhibit 3 and our most recent Donor Impact report, which reflects the organization's program accomplishments in 2024, as Exhibit 7.

12. Names of Six Major Contributors:

Please include amount of support given by each last year.

FARA's donor privacy policy requires that we keep donor information private. The major contributors to FARA have historically been private individuals personally affected by Friedreich's ataxia. A copy of FARA's 2024 Donor Impact report, which lists contributors giving \$5,000 and above, has been included Exhibit 7 of this application.

13. Three Most Important Needs for Funding by the Palestroni Foundation and the amount you seek for each:

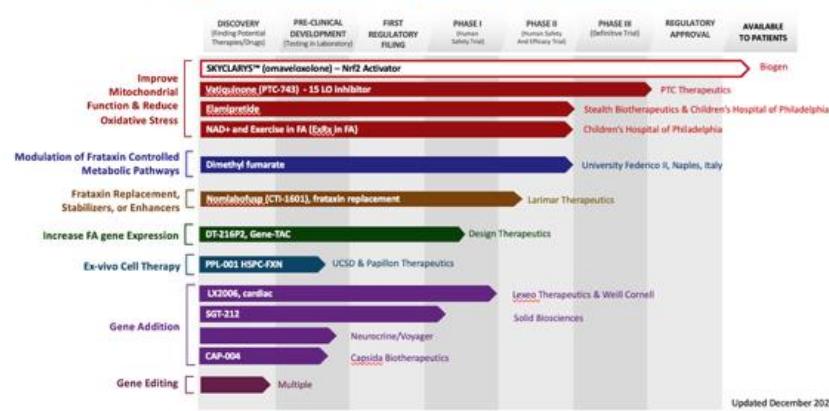
Please list in order of priority.

1. Filling the Pipeline with New Therapies and Mechanisms of Action

Friedreich's ataxia is a multi-system disease affecting energy metabolism, the nervous system, and the heart. No single therapy is likely to address all aspects of the disease. FARA's strategy is to advance a diversified pipeline across different mechanisms of action, with the expectation that the use of multiple therapies will ultimately provide the greatest benefit.

The pipeline below depicts active programs either in or approaching clinical trials. FARA

FRIEDREICH'S ATAXIA DRUG DEVELOPMENT PIPELINE



partners with pharmaceutical companies to advance these programs that aim to treat FA either by improving mitochondrial function, modulating metabolic pathways, addressing the protein that's low in FA (frataxin), or targeting FXN gene itself.

In addition to these active programs, FARA has identified 12 promising treatment concepts that require targeted preclinical work before entering the pipeline. Continued investment allows us to advance the most promising ideas and sustain momentum as current therapies progress. There are

new treatment concepts for the pipeline being explored across existing mechanisms of action such frataxin replacement, stabilizing, or enhancement as well as efforts to study other approaches like neuroinflammation or combination therapies. FARA aims to support the research into these potential new treatment approaches in FA through grant funding and directed research projects. One example of such targeted preclinical research follows below:

Can we improve heart health in FA with a multi-drug approach?

Currently, only one drug—Omaveloxolone (Omav)—is approved in the U.S. for FA, and its effects on heart disease in FA haven't been fully studied. Researchers at Weill Cornell Medicine (Drs. Annarita Di Lorenzo and Giovanni Manfredi) have explored whether combining three drugs—Omav, Idebenone (IDB), and Telmisartan (TS)—could treat cardiac disease in FA.

The rationale for combining these drugs lies in their different mechanisms of action:

- Omav boosts the body's natural antioxidant defenses.
- IDB helps improve energy production in cells.
- TS is a blood pressure drug that also protects the heart and positively affects mitochondria.

In preclinical studies, FA mice treated with the three-drug combination showed remarkable improvements in survival, body weight, and heart function—effects comparable only to those seen with gene therapy. While these results are very encouraging, a follow-up study is needed to validate the findings in a second cohort and to investigate the mechanisms behind the observed cardio-protection.

The Investigators:

- Annarita Di Lorenzo, PhD – Professor of Pathology and Laboratory Medicine at Weill Cornell Medicine, specializing in lipid metabolism and cardiovascular health.
- Giovanni Manfredi, MD, PhD – Professor of Clinical and Research Neurology at Weill Cornell Medicine and co-chair of FARA's Scientific Advisory Board, focusing on mitochondrial metabolism in disease.

Amount: \$25,000

2. The UNIFAI Natural History Study for Understanding FA

The UNIFAI Natural History Study is a major global research initiative to better understand Friedreich's Ataxia (FA), a rare inherited condition that causes progressive neurological and cardiac symptoms. UNIFAI brings together two long-standing research efforts (FACOMS and EFACTS) into one unified, global research program. UNIFAI follows people living with FA for up to 25 years, with annual visits collecting comprehensive information

including medical history, neurological exams, walking and upper limb tests, quality of life questionnaires, and optional assessments of speech, vision, fatigue, balance, and cognition.

By unifying and expanding existing networks, UNIFAI strengthens data collection and enhances collaboration through the FA Global Clinical Consortium. UNIFAI brings together data spanning 5 continents, 15 countries, and over 30 participating sites. This geographic diversity allows us to capture a broad view of FA worldwide.

The study aims to track the natural course of FA across ages and disease stages, inform clinical trial design, and support the development of new outcome measures and biomarkers. Tracking disease severity using standardized measures at each visit provides crucial insight into the pace and pattern of progression in FA. These assessments help families and clinicians understand how FA changes over time, and they also play a key role in designing future clinical trials. This information can help inform decisions about which stages are most suitable for measuring treatment effects and how long it may take to observe meaningful changes.

FARA provides funding to support both the collection of data at natural history study visits as well as the cost of patient travel to participating sites. With thousands of participants across a global network, UNIFAI creates an unprecedented resource for understanding FA.

Note: The Children's Hospital of Philadelphia is one of the lead sites in the UNIFAI study.

Amount: _____ \$25,000 _____

3. Expansion of the Retrospective Cardiac Natural History Study and Development of Hypotheses on Putative Clinical Markers.

Purpose:

Cardiac disease is a major cause of early death in individuals with Friedreich's ataxia (FA), yet there is insufficient understanding of how FA heart disease progresses over time and a lack of viable cardiac clinical outcome measures for efficient clinical trials. In 2022, FARA initiated a retrospective cardiac natural history study, enrolling 150 participants. We are seeking additional funding to expand the number of sites and participants, which will enhance the study's power to detect statistically significant results and accelerate data collection and analyses.

Aims:

- Identify early echocardiographic changes associated with major adverse cardiac events (MACE) in FA.
- Identify cardiac abnormalities that emerge before a decline in ejection fraction in FA.

Impact:

The lack of established clinical outcome measures and clinical trial inclusion criteria presents significant challenges in designing and conducting clinical trials aimed at demonstrating

evidence of benefit for the cardiac manifestations of FA. Developing standardized, sensitive biomarkers predictive of long-term clinical outcomes will enable drug developers to assess treatment effects in the heart. Additionally, the infrastructure created through this project will establish a network of centers for prospective studies and interventional trials focusing on FA cardiac disease.

Amount: \$25,000

14. Are Funds Donated to or Raised by the Organization Passed on to Other Charities?
If yes, please list the charities and the amounts given to each in the last two years.

No. FARA funds scientific grants to investigators at academic institutions and occasionally small biotech

15. Gross Income in 2024: \$14, 573,368
Program Expense in 2024: \$12,740,958
Management and General Costs in 2024: \$436,942
Fund Raising Costs in 2024: \$1.349.672

16. Copy of the Most Recent Financial Audit or Year End Financial Report.
Please enclose as Exhibit 4.

17. Copy of the Most Recent IRS 990 and Schedule A..
Please enclose as Exhibit 5.

18. Copy of Current Budget.
Please enclose as Exhibit 6.

19. Copy of the Current Annual Report if available.
Please enclose as Exhibit 7.

PLEASE ENCLOSE ANY OTHER DOCUMENTATION WHICH YOU FEEL WOULD BE OF INTEREST AND/OR ASSISTANCE TO THE TRUSTEES AS EXHIBIT 8.

WE REQUIRE ONE FULL SET OF GRANT APPLICATION AND ATTACHMENTS IN ORDER TO PROCESS APPLICATION.
WE ALSO ASK THAT YOU SEND THE APPLICATION ELECTRONICALLY TO INFO@PALESTRONI.COM

PLEASE SEND THE ONE COPY OF THE GRANT APPLICATION ALONG WITH ALL REQUESTED MATERIALS TO:

Alfiero & Lucia Palestro Foundation, Inc.
Attn: Kristine Sayrafe, Foundation Manager
333 Sylvan Avenue, Suite 100
Englewood Cliffs, NJ 07632

AS TRUSTEES MEET THROUGHOUT THE YEAR TO CONSIDER GRANT APPLICATIONS, WE ENCOURAGE YOU TO SEND THE COMPLETED FORMS AND EXHIBITS AT YOUR EARLIEST CONVENIENCE.

P.O. Box 2508
Cincinnati OH 45201-0250
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In reply refer to: 0248360116
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ARAH BOHATIJA
METRALE L DIAMOND
TYREE NOE OT
TERRAVIA RUMMEL

FRIEDREICH'S ATAXIA RESEARCH
ALLIANCE FARA
RONALD J BARTEK
PO BOX 1537
SPRINGFIELD VA 22151

004292

Employer ID Number: 52-2122720
Form 990 required: YES

Dear Taxpayer:

This is in response to your request dated Jan. 21, 2016, regarding your tax-exempt status.

We issued you a determination letter in MAY 1999, recognizing you as tax-exempt under Internal Revenue Code (IRC) Section 501(c)(3).

Our records also indicate you're not a private foundation as defined under IRC Section 509(a) because you're described in IRC Sections 509(a)(1) and 170(b)(1)(A)(vi).

Donors can deduct contributions they make to you as provided in IRC Section 170. You're also qualified to receive tax deductible bequests, legacies, devises, transfers, or gifts under IRC Sections 2055, 2106, and 2522.

In the heading of this letter, we indicated whether you must file an annual information return. If a return is required, you must file Form 990, 990-EZ, 990-N, or 990-PF by the 15th day of the fifth month after the end of your annual accounting period. IRC Section 6033(j) provides that, if you don't file a required annual information return or notice for three consecutive years, your exempt status will be automatically revoked on the filing due date of the third required return or notice.

For tax forms, instructions, and publications, visit www.irs.gov or call 1-800-TAX-FORM (1-800-829-3676).

If you have questions, call 1-877-829-5500 between 8 a.m. and 5 p.m., local time, Monday through Friday (Alaska and Hawaii follow Pacific Time).

ALLIANCE FARA
PO BOX 1537
SPRINGFIELD VA 22151
31 13008

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FRIEDREICH'S ATAXIA RESEARCH
ALLIANCE FARA
% RONALD J BARTEK
PO BOX 1537
SPRINGFIELD VA 22151

RONALD J BARTEK
ALLIANCE FARA
PO BOX 1537
SPRINGFIELD VA 22151
31 13008

Sincerely yours,

Doris P. Kenwright

Doris Kenwright, Operation Mgr.
Accounts Management Operations

**Exhibit 2- Officer/Members or the Board of Directors
with Compensation/Benefits**

Board of Directors with Staff Roles & Compensation for Staff Roles:

Ronald J. Bartek President \$113,811

Ruth C. Acton Treasurer/ Director of Finance \$67,964

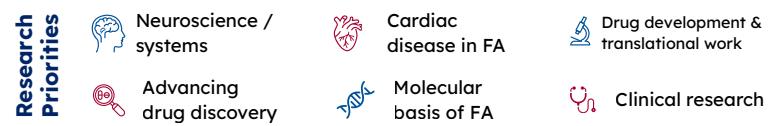
Our Work and Its Impact

Powering Discovery

We believe transformative change lies at the intersection of people and science.

\$9+ million
in research funding
awarded annually

>1/4 of publications on Friedreich's Ataxia
are based on FARA-funded research



Diversified Research Investment Strategy



Translating Discovery into Treatment

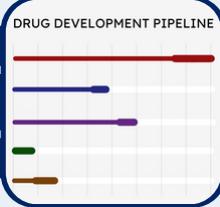
The future of FA treatment will not rest on a single therapy but multiple approaches that work to slow, stop, reverse and ultimately cure this disease.

6 Mechanisms of action

12 Treatment candidates in the pipeline

1 Approved treatment

100% of treatment candidates in the pipeline reflect insights from FARA-funded research



Educating an Engaged FA Community

An informed and engaged FA community is essential to advancing research through active participation, which accelerates the path to effective treatments.

8 annual in-person and virtual FARA education events

100 FARA Ambassadors from 32 states and 14 countries

30+ events to share the patient voice with pharma, researchers, regulators, etc.

Building Infrastructure that Drives Clinical Research

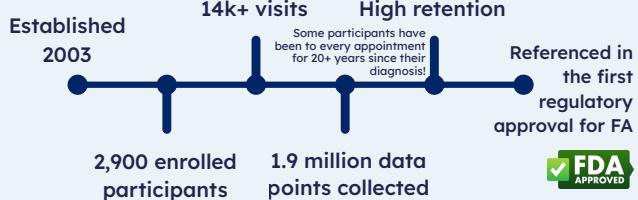
Global collaboration enables natural history data collection that is the backbone of efficient drug development.



34 sites | 5 continents

An international group of clinical research centers that work together to advance treatments and clinical care for individuals with FA.

UNIFAI Natural History Study



FARA is an excellent steward of donations, with the highest Charity Navigator rating



TOGETHER, WE WILL CURE FA!

Learn more at curefa.org



**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE
AND STICHTING FRIEDREICH'S ATAXIA
RESEARCH ALLIANCE EUROPE**

CONSOLIDATED FINANCIAL STATEMENTS

**DECEMBER 31, 2024 and 2023
(with supplementary information)**

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

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EisnerAmper LLP

One Logan Square

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INDEPENDENT AUDITORS' REPORT

To the Board of Directors of
Friedreich's Ataxia Research Alliance

Report on the Audit of the Financial Statements

Opinion

We have audited the financial statements of Friedreich's Ataxia Research Alliance and Stichting Friedreich's Ataxia Research Alliance Europe (nonprofit organizations), which comprise the consolidated statements of financial position as of December 31, 2024 and 2023, and the related consolidated statements of activities and changes in net assets, functional expenses, and cash flows for each of the years then ended, and the related notes to the financial statements.

In our opinion, the accompanying financial statements present fairly, in all material respects, the consolidated financial position of Friedreich's Ataxia Research Alliance and Stichting Friedreich's Ataxia Research Alliance Europe as of December 31, 2024 and 2023, and the changes in its net assets and its cash flows for each of the years then ended in accordance with accounting principles generally accepted in the United States of America.

Basis for Opinion

We conducted our audits in accordance with auditing standards generally accepted in the United States of America ("GAAS"). Our responsibilities under those standards are further described in the Auditors' Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of the Friedreich's Ataxia Research Alliance and Stichting Friedreich's Ataxia Research Alliance Europe and to meet our other ethical responsibilities, in accordance with the relevant ethical requirements relating to our audits. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Responsibilities of Management for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America, and for the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about Friedreich's Ataxia Research Alliance and Stichting Friedreich's Ataxia Research Alliance Europe's ability to continue as a going concern for one year after the date that the financial statements are available to be issued.

Auditors' Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditors' report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and, therefore, is not a guarantee that an audit conducted in accordance with GAAS will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with GAAS, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Friedreich's Ataxia Research Alliance and Stichting Friedreich's Ataxia Research Alliance Europe's internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise substantial doubt about the Friedreich's Ataxia Research Alliance and Stichting Friedreich's Ataxia Research Alliance Europe's ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control-related matters that we identified during the audit.



Report on Supplementary Information

Our audits were conducted for the purpose of forming an opinion on the financial statements as a whole. The supplementary information contained in the consolidating schedules of financial position as of December 31, 2024 and 2023 and the consolidating schedules of activities and changes in net assets for the years ended December 31, 2024 and 2023 is presented for purposes of additional analysis and is not a required part of the financial statements. Such information is the responsibility of management and was derived from and relates directly to the underlying accounting and other records used to prepare the financial statements. The information has been subjected to the auditing procedures applied in the audit of the financial statements and certain additional procedures, including comparing and reconciling such information directly to the underlying accounting and other records used to prepare the financial statements or to the financial statements themselves, and other additional procedures in accordance with auditing standards generally accepted in the United States of America. In our opinion, the information is fairly stated in all material respects in relation to the financial statements as a whole.

EisnerAmper LLP

EISNERAMPER LLP
Philadelphia, Pennsylvania
June 16, 2025



EisnerAmper LLP
www.eisneramper.com

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

Consolidated Statements of Financial Position

| | December 31, | |
|------------------------------------|---------------------|---------------------|
| | 2024 | 2023 |
| ASSETS | | |
| Cash and cash equivalents | \$ 1,959,581 | \$ 3,993,332 |
| Restricted cash | 2,350,400 | 963,779 |
| Contributions receivable, net | 682,067 | 747,478 |
| Prepaid expenses | 67,503 | 49,155 |
| Investments | <u>2,137,780</u> | <u>1,870,166</u> |
| Total current assets | <u>7,197,331</u> | <u>7,623,910</u> |
| Right-of-use asset | 46,404 | 103,796 |
| Other assets | <u>5,458</u> | <u>5,458</u> |
| Total other assets | <u>51,862</u> | <u>109,254</u> |
| Total assets | <u>\$ 7,249,193</u> | <u>\$ 7,733,164</u> |
| LIABILITIES AND NET ASSETS | | |
| Liabilities: | | |
| Accounts payable | \$ 689,951 | \$ 1,164,034 |
| Deferred revenues | 10,630 | 4,567 |
| Current portion of lease liability | <u>49,940</u> | <u>68,826</u> |
| Total current liabilities | <u>750,521</u> | <u>1,237,427</u> |
| Long-term lease liabilities | - | 43,221 |
| Total liabilities | <u>750,521</u> | <u>1,280,648</u> |
| Net assets: | | |
| Without donor restrictions | 4,148,272 | 5,488,737 |
| With donor restrictions | <u>2,350,400</u> | <u>963,779</u> |
| Total net assets | <u>6,498,672</u> | <u>6,452,516</u> |
| Total liabilities and net assets | <u>\$ 7,249,193</u> | <u>\$ 7,733,164</u> |

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

Consolidated Statements of Activities and Changes in Net Assets

| | Year Ended December 31, | | |
|--|---------------------------------------|------------------------------------|------------------------------------|
| | 2024 | | 2023 |
| | Net Assets Without Donor Restrictions | Net Assets With Donor Restrictions | Net Assets With Donor Restrictions |
| Support and revenue: | | | |
| Contributions and conferences | | | |
| Special events (net of direct benefits to donors of \$168,115 and \$145,569 for 2024 and 2023, respectively) | \$ 2,497,238 | \$ 7,039,529 | \$ 9,536,767 |
| 4,084,079 | - | - | 4,084,079 |
| 606,359 | - | - | 606,359 |
| 346,163 | - | - | 346,163 |
| In-kind contributions | 5,652,908 | (5,652,908) | - |
| Investment return, net | | | |
| Net assets released from restrictions | | | |
| Total support and revenue | 13,186,747 | 1,386,621 | 14,573,368 |
| Expenses: | | | |
| Program services: | | | |
| Education, awareness and outreach | 503,566 | - | 503,566 |
| Patient registry and FA GCC | 1,496,437 | - | 1,496,437 |
| Research and grant program | 10,376,978 | - | 10,376,978 |
| Research conferences | 363,617 | - | 363,617 |
| Total program services | 12,740,598 | - | 12,740,598 |
| Supporting services: | | | |
| Fundraising services: | | | |
| Special events | 1,101,034 | - | 1,101,034 |
| Other | 248,638 | - | 248,638 |
| Total fundraising services | 1,349,672 | - | 1,349,672 |
| General and administrative | | | |
| 436,942 | - | - | 436,942 |
| 1,786,614 | - | - | 1,786,614 |
| 14,527,212 | - | - | 14,527,212 |
| Total supporting services | (1,340,465) | 1,386,621 | 46,156 |
| Total expenses | 5,488,737 | 963,779 | 6,452,516 |
| Change in net assets | \$ 4,148,272 | \$ 2,350,400 | \$ 6,498,672 |
| Net assets at beginning of year | | | |
| Net assets at end of year | | | |
| | | | \$ 963,779 |
| | | | \$ 6,452,516 |

See notes to consolidated financial statements.

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

Consolidated Statement of Functional Expenses
Year Ended December 31, 2024

| | Program Services | | | | | | Supporting Services | | |
|---|----------------------------------|-----------------------------|----------------------------|-------------------|----------------------|---------------------|----------------------|-------------------|----------------------------|
| | Education Awareness and Outreach | Patient Registry and FA GCC | Research and Grant Program | | Research Conferences | Totals | Fundraising Services | | General and Administrative |
| | | | \$ | \$ | | | Special Events | Other | |
| Expenses: | | | | | | | | | |
| Auction items | \$ 80,000 | \$ 827,817 | \$ 9,606,747 | \$ - | \$ - | \$ 10,514,564 | \$ 52,054 | \$ - | \$ 52,054 |
| Awards and grants | - | - | - | - | - | - | - | - | \$ 10,514,564 |
| Registration fees | 102,441 | 216,473 | 181,357 | 191 | 49,116 | 549,387 | 335,279 | 26,332 | 568 |
| Contracted services | 22 | - | - | - | - | 213 | 72,547 | 17,347 | 996,397 |
| Credit card and bank fees | - | - | - | - | 1,000 | 1,000 | 238,504 | - | 90,838 |
| Facilities and equipment | 14,174 | 3,735 | 11,205 | 3,735 | - | 32,849 | 32,575 | 6,676 | 12,151 |
| Occupancy and telecom | 3,639 | 259,490 | 14,838 | 2,574 | - | 280,541 | 12,191 | 25,848 | 80,429 |
| Subscriptions and licensing fees | 595 | - | - | - | - | 595 | 12,586 | - | 319,417 |
| Hospitality | 139 | - | - | - | 341 | 480 | 11,479 | 4,691 | 14,901 |
| Postage | 730 | - | 200 | 3,161 | 4,091 | 14,316 | 8,138 | 394 | 17,044 |
| Printing and copying | - | 1,164 | - | 831 | 1,995 | 73,633 | - | - | 27,670 |
| Supplies | - | - | - | - | - | - | 451 | 5,023 | 81,102 |
| Event entertainment | - | - | - | - | - | 21,146 | - | - | 21,146 |
| Insurance | - | 98 | 2,388 | - | - | 2,486 | 5,669 | 3,322 | 9,213 |
| Miscellaneous | 303 | 158 | - | - | 461 | 787 | 101 | 14,482 | 15,831 |
| Membership dues | 2,600 | - | 1,220 | - | 3,820 | - | - | - | 3,820 |
| Payroll, taxes and benefits | 272,711 | 181,279 | 540,831 | 153,693 | 1,148,514 | 288,271 | 143,615 | 247,144 | 1,827,544 |
| Sales taxes paid | - | - | - | - | - | 7,919 | - | - | 7,919 |
| Conferences, meetings and travel | 26,212 | 6,223 | 18,001 | 149,166 | 199,602 | 86,437 | 4,290 | 47,520 | 337,849 |
| Total expenses | 503,566 | 1,496,437 | 10,376,978 | 363,617 | 12,740,598 | 1,269,149 | 248,638 | 436,942 | 14,695,327 |
| Less: direct benefits to donors | - | - | - | - | - | (130,500) | - | - | (130,500) |
| Facilities and equipment | - | - | - | - | - | (14,119) | - | - | (14,119) |
| Supplies | - | - | - | - | - | (10,500) | - | - | (10,500) |
| Event entertainment | - | - | - | - | - | (12,996) | - | - | (12,996) |
| Conferences, meetings and travel | - | - | - | - | - | (168,115) | - | - | (168,115) |
| Total expenses per statements of activities and changes in net assets | \$ 503,566 | \$ 1,496,437 | \$ 10,376,978 | \$ 363,617 | \$ 12,740,598 | \$ 1,101,034 | \$ 248,638 | \$ 436,942 | \$ 14,527,212 |

See notes to consolidated financial statements.

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

Consolidated Statement of Functional Expenses
Year Ended December 31, 2023

| | Program Services | | | | | | Supporting Services | | |
|---|----------------------------------|-----------------------------|----------------------------|------------|----------------------|--------------|----------------------|------------|----------------------------|
| | Education Awareness and Outreach | Patient Registry and FA GCC | Research and Grant Program | | Research Conferences | Totals | Fundraising Services | | General and Administrative |
| | | | Special Events | Other | | | Special Events | Other | |
| Expenses: | | | | | | | | | |
| Auction items | \$ - | \$ - | \$ 301,173 | \$ - | \$ 8,680,904 | \$ - | \$ 8,982,077 | \$ - | \$ 79,474 |
| Awards and grants | - | - | - | - | - | - | - | - | - |
| Registration fees | - | 71,016 | 556,509 | 138,994 | 33,383 | 799,902 | 262,774 | 5,216 | 793 |
| Contracted services | - | - | 210 | - | 210 | 70,639 | 25,610 | 90,371 | 9,064 |
| Credit card and bank fees | - | - | - | - | - | 13,177 | 13,177 | - | 84,026 |
| Facilities and equipment | - | - | - | - | - | 218,313 | - | - | 223,084 |
| Occupancy and telecom | 15,049 | 4,061 | 12,182 | 4,061 | 35,353 | 32,019 | 7,361 | 8,956 | 83,689 |
| Subscriptions and licensing fees | 4,153 | 271,931 | 11,104 | 3,641 | 290,829 | 24,733 | 16,583 | 12,809 | 344,954 |
| Hospitality | 19 | - | 416 | - | 435 | 5,717 | - | - | 6,327 |
| Postage | 179 | - | 1,783 | 659 | 2,621 | 10,714 | 6,028 | 1,807 | 21,170 |
| Printing and copying | 1,861 | - | - | 4,134 | 5,995 | 14,870 | 6,968 | 534 | 28,367 |
| Supplies | 3 | - | 1,547 | 1,240 | 2,790 | 86,022 | 15,078 | 4,399 | 108,289 |
| Event entertainment | - | - | - | - | - | 18,045 | - | - | 18,045 |
| Insurance | - | - | - | - | - | 5,186 | 11,256 | 2,737 | 19,179 |
| Miscellaneous | - | - | 45 | - | 45 | 351 | - | 2,946 | 3,342 |
| Membership dues | 2,600 | - | 1,152 | 440 | 4,192 | 642 | - | - | 4,834 |
| Payroll, taxes and benefits | 245,052 | 157,501 | 538,706 | 139,765 | 1,081,024 | 260,724 | 142,001 | 214,438 | 1,698,187 |
| Sales taxes paid | - | - | - | - | - | 8,936 | - | - | 8,936 |
| Conferences, meetings and travel | 17,686 | 1,816 | 26,422 | 115,179 | 161,103 | 95,834 | 81 | 47,476 | 304,494 |
| Total expenses | 357,618 | 1,292,991 | 9,413,465 | 302,502 | 11,366,576 | 1,198,048 | 249,359 | 392,212 | 13,206,195 |
| Less: direct benefits to donors | - | - | - | - | - | (145,569) | - | - | (145,569) |
| Facilities and equipment | - | - | - | - | - | (111,250) | - | - | (111,250) |
| Supplies | - | - | - | - | - | (13,232) | - | - | (13,232) |
| Event entertainment | - | - | - | - | - | (10,500) | - | - | (10,500) |
| Conferences, meetings and travel | - | - | - | - | - | (10,587) | - | - | (10,587) |
| Total expenses per statements of activities and changes in net assets | \$ 357,618 | \$ 1,292,991 | \$ 9,413,465 | \$ 302,502 | \$ 11,366,576 | \$ 1,052,479 | \$ 249,359 | \$ 392,212 | \$ 13,060,626 |

See notes to consolidated financial statements.

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

Consolidated Statements of Cash Flows

| | Year Ended December 31, | |
|---|------------------------------------|---------------------|
| | 2024 | 2023 |
| Cash flows from operating activities: | | |
| Change in net assets | \$ 46,156 | \$ (377,909) |
| Adjustments to reconcile change in net assets to net cash used in operating activities: | | |
| Amortization of right-of-use asset | 57,392 | 57,914 |
| Net realized (gains) loss on sale of securities | (26,710) | 94,983 |
| Net unrealized gains on securities | (173,831) | (231,231) |
| Donated securities | (460,344) | (284,652) |
| Proceeds from sale of donated securities | 461,387 | 282,334 |
| (AIncrease) decrease in: | | |
| Contributions receivable | 65,411 | (377,866) |
| Prepaid expenses | (18,348) | 3,243 |
| Increase (decrease) in: | | |
| Accounts payable | (474,083) | 887,072 |
| Deferred revenue | 6,063 | (6,923) |
| Lease liabilities | (62,107) | (51,124) |
| Net cash used in operating activities | (579,014) | (4,159) |
| Cash flows from investing activities: | | |
| Proceeds from sale of securities | 645,455 | 998,025 |
| Purchase of securities | (713,571) | (1,000,875) |
| Net cash used in investing activities | (68,116) | (2,850) |
| Net decrease in cash, cash equivalents and restricted cash | (647,130) | (7,009) |
| Cash, cash equivalents and restricted cash at beginning of year | 4,957,111 | 4,964,120 |
| Cash, cash equivalents and restricted cash at end of year | \$ 4,309,981 | \$ 4,957,111 |
| Supplemental non-cash disclosures: | | |
| Obtaining a right-of-use asset in exchange for a lease liability | \$ - | \$ 21,274 |
| Donated professional services | \$ 176,250 | \$ 176,250 |
| Donated auction items | \$ 430,109 | \$ 552,454 |

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE

Notes to Financial Statements December 31, 2024 and 2023

NOTE A - ORGANIZATION

Friedreich's Ataxia Research Alliance ("FARA") was incorporated under the laws of the District of Columbia as a nonprofit corporation. FARA obtained foreign entity status in Pennsylvania in 2019 and Florida in 2020. The stated purposes of FARA are to marshal and focus the resources and relationships needed to treat and cure Friedreich's Ataxia ("FA") by raising funds for research, promoting public awareness and aligning scientists, patients, clinicians, government agencies, pharmaceutical companies and other organizations dedicated to treating and curing Friedreich's Ataxia.

Stichting Friedreich's Ataxia Research Alliance Europe ("FARA Europe") was incorporated in the Netherlands in 2023. FARA Europe receives grants and donations from FARA and other entities and individuals and contracts with European clinical sites conducting natural history studies. The transactions between FARA Europe and FARA are recorded in U.S. dollars. FARA Europe's strategic priorities include unifying, consolidating, and supporting the FA clinical infrastructure across Europe. Through collaboration with FARA, FARA Europe aims to establish and support, the FA Global Clinical Consortium ("FA GCC"), with the goal of informing and accelerating the development of new treatments for FA.

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

[1] Principles of consolidation:

The accompanying financial statements of FARA and FARA Europe (collectively, the "Organization") have been prepared using the accrual basis of accounting and conform to accounting principles generally accepted in the United States of America ("U.S. GAAP") as applicable to not-for-profit organizations. The consolidated financial statements include the accounts of FARA and FARA Europe. FARA Europe is governed by the common board of directors of FARA. All significant intercompany accounts and transactions have been eliminated.

[2] Classification of net assets:

Resources in the financial statements are classified for accounting and reporting purposes in classes of net assets according to the existence or absence of donor-imposed restrictions. The accompanying financial statements may include the following classes of net assets:

(i) *Net assets without donor restrictions:*

Net assets without donor restrictions are used to account for funds which have not been restricted by donors and over which the Board of Directors has discretionary control.

(ii) *Net assets with donor restrictions:*

Net assets with donor restrictions are subject to donor-imposed or certain grantor-imposed restrictions. Some donor-imposed restrictions are temporary in nature, such as those that will be met by the passage of time or other events specified by the donor. Other donor-imposed restrictions are perpetual in nature, where the donor stipulates that resources be maintained in perpetuity. Donor-imposed restrictions are released when a restriction expires, that is, when the stipulated time has elapsed, when the stipulated purpose for which the resource was restricted has been fulfilled, or both.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE

Notes to Financial Statements December 31, 2024 and 2023

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

[3] Cash and cash equivalents:

The Organization considers all highly liquid investments with maturities of three months or less when purchased to be cash equivalents. Cash and cash equivalents include checking and money market accounts. The Organization normally deposits its cash with seven financial institutions.

[4] Contributions receivable:

Contributions receivable consist primarily of funds due for fund-raising events on the Organization's behalf that were not remitted to the Organization until the following year. No receivables are expected to remain outstanding for more than one year. Receivables are stated at the amount management expects to collect from outstanding balances. Management provides for probable uncollectible amounts through a provision for bad debt expense and an adjustment to a valuation allowance based on its assessment of the current status of individual receivables. Balances that are still outstanding after management has used reasonable collection efforts are written off through a charge to the valuation allowance and credit to the account receivable. The Organization deemed the allowance for doubtful accounts to be immaterial as of December 31, 2024 and 2023.

[5] Investments:

The Organization carries investments in marketable securities with readily determinable fair market values and all investments in debt securities at their fair values in the consolidated statements of financial position. Unrealized gains and losses and impairment loss on investment in common stock are included in the change in net assets in the accompanying consolidated statements of activities and changes in net assets.

[6] Leases:

Operating leases are recorded as operating lease right-of-use ("ROU") assets and operating lease liabilities on the accompanying consolidated statements of financial position. Operating lease ROU assets and the related lease liabilities are recognized based on the present value of the future minimum lease payments over the lease term at commencement date. As the Organization's leases do not provide an implicit rate, an incremental borrowing rate based on the information available at the commencement date or the adoption date is used as a practical expedient in determining the present value of future payments. The operating lease ROU assets exclude lease incentives and initial direct costs incurred.

The Organization's policy with respect to short-term leases is to exempt such agreements from the requirements of the Financial Accounting Standards Board ("FASB") Accounting Standards Codification ("ASC") 842 and account for the associated lease cost within real estate maintenance and insurance on the consolidated schedule of functional expenses on a straight-line basis over the lease term. No right-of-use asset nor lease liability is established on FARA's consolidated statements of financial position with respect to short-term leases. Short-term leases are generally defined as with an original term of twelve months or less upon commencement.

Finance leases are recorded as finance lease ROU assets and finance lease liabilities on the accompanying consolidated statements of financial position. Finance lease ROU assets and the related lease liabilities are recognized based on the present value of the future minimum lease payments over the lease term at commencement date. If an implicit rate is not available, an incremental borrowing rate based on the information available at commencement date is used as a practical expedient in determining the present value of future payments.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE

Notes to Financial Statements December 31, 2024 and 2023

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

[7] Revenue recognition:

Contributions and grants:

Funding for the Organization's activities is achieved almost entirely through foundation, corporate and other support, contributions, and in-kind contributions, including unconditional promises to give. These donations provide funding to be used to support the Organization's mission. As the donors are not receiving a benefit as a result of these transactions, the donations are considered to be contributions to the Organization. Some contributions require that funds be expended for a specific purpose, and are considered to be net assets with donor restrictions. There were no conditional government grants as of December 31, 2024 that will be recognized in subsequent years as costs are incurred and service requirements are met.

The Organization recognizes unconditional contributions when cash, securities or other assets, or an unconditional promise to give is received, and are recorded after discounting to the present value of the expected future cash flows (if the unconditional contributions are scheduled to be paid over multiple years). Conditional promises to give, that is, those with a measurable performance or other barrier and a right of return, are not recognized until the conditions on which they depend have been met.

Special events:

The Organization earns revenue from contracts with customers through special events.

Fee-for-service revenue related to special events is recognized when or as the performance obligations in each contract are satisfied for the amount of consideration the Organization expects to be entitled to receive for the related service.

The Organization records special events revenue equal to contribution revenue less the cost of direct benefits to donors which is included in special events revenue on the consolidated statements of activities and changes in net assets. The recognition of revenue is conditional on the event taking place, as this is the point in time when the performance obligation of hosting the event occurs, and attendees can no longer request a refund for their ticket purchases. The amounts are collected at the time of ticket purchase and are included in deferred revenue until recognized. As of December 31, 2024 and 2023, there were conditional contributions associated with special events of \$10,630 and \$4,567, respectively, which are included in deferred revenue on the consolidated statements of financial position. There were no other contract assets or contract liabilities at either December 31, 2024 or 2023.

In-kind:

The Organization receives various forms of gifts-in-kind, which are contributions of nonfinancial assets including professional services or auction items. Donated services are recognized in the financial statements if they (i) create or enhance financial assets or require specialized skills, (ii) are provided by individuals possessing these skills, and (iii) would typically need to be acquired if not provided by donation. The donated services are valued at the estimated prevailing rate for like services in the principal marketplace for use at the time the services are provided and reported as an expense concurrently as utilized. During each of the years ended December 31, 2024 and 2023, the Organization recorded contributed legal and communication professional services of \$176,250.

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

**Notes to Financial Statements
December 31, 2024 and 2023**

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

[7] Revenue recognition: (continued)

In-kind: (continued)

Contributed auction items are recorded at the proceeds for which they were sold, which amounted to \$430,109 and \$552,454 for the years ended December 31, 2024 and 2023, respectively.

Contributed materials and services are reflected as revenue in the accompanying consolidated statements of activities and changes in net assets. The related offsetting expense is recorded in the same amount on the consolidated statements of activities and changes in net assets. In addition to those included above, the Organization also receives donated services from unpaid volunteers. These services do not meet the criteria for recognition as contributed services and are therefore not included in the accompanying financial statements.

[8] Concentrations of credit risk:

Cash deposits that potentially subject the Organization to concentrations of credit risk consist of cash accounts not covered by FDIC insurance. At December 31, 2024, \$3,199,337 of FARA's bank balances of \$4,309,981 was exposed to credit risk. At December 31, 2023, \$3,862,075 of FARA's bank balances of \$4,957,111 was exposed to credit risk.

[9] Federal tax status:

The Internal Revenue Service has classified FARA as exempt from federal income taxes under Section 501(c)(3) of the Internal Revenue Code. FARA Europe was formed as a non-profit entity under the laws of the Netherlands and is exempt from income taxes.

Accounting for uncertainty in income taxes clarifies the accounting for uncertainty in income taxes recognized in an enterprise's financial statements. Management has analyzed the tax positions taken by the Organization, and has concluded that as of December 31, 2024, there are no uncertain tax positions taken or expected to be taken that would require recognition of a liability or disclosure in the financial statements. The Organization recognizes accrued interest and penalties associated with uncertain tax positions, if any. There were no income tax related interest or penalties recorded for the year ended December 31, 2024.

[10] Use of estimates:

The preparation of financial statements in conformity with accounting principles generally accepted in the United States of America requires management to make estimates and assumptions that affect certain reported amounts and disclosures. Accordingly, actual results could differ from those estimates.

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

**Notes to Financial Statements
December 31, 2024 and 2023**

NOTE B - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (CONTINUED)

[11] Functional expenses:

The costs of providing the Organization's program and other supporting services have been summarized on a functional basis in the consolidated statements of functional expenses. Accordingly, the expenses directly related to the program are combined with allocations of certain common costs of the Organization which have been allocated based on estimates made by management. Common costs allocated are payroll, taxes and benefits, as well as rent, utilities, legal, and other professional service fees. Payroll, taxes and benefits, legal, and other professional service fees are allocated based on estimates of time and effort. Rent and utilities are allocated on a square-footage basis.

[12] Reclassifications:

Certain reclassifications have been made to the 2023 presentation to conform to the 2024 presentation. A research grant of \$325,000 was reclassified from Research and grant program to Patient registry and FA GCC on the consolidated statement of functional expenses and the consolidating schedule of activities and changes in net assets.

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

**Notes to Financial Statements
December 31, 2024 and 2023**

NOTE C - LIQUIDITY

The following tables reflect the Organization's financial assets available for general expenditures within one year from December 31, 2024 and 2023, after accounting for assets with donor restrictions. Financial assets are considered unavailable when illiquid, not convertible to cash within one year, or subject to donor restrictions not expected to be released within one year.

| | December 31, 2024 | | |
|--|---|------------------------------------|---------------------|
| | Without Donor Restrictions | With Donor Restrictions | Total |
| Liquidity resources: | | | |
| Cash and cash equivalents | \$ 1,959,581 | \$ 2,350,400 | \$ 4,309,981 |
| Contributions receivable | 682,067 | - | 682,067 |
| Investment | 2,137,780 | - | 2,137,780 |
| Contracted restricted resources to be received in 2025 for existing commitments as of December 31, 2024 | - | 2,435,313 | 2,435,313 |
| Assets without commitments as of December 31, 2024 | - | (460,500) | (460,500) |
| Total liquidity resources | 4,779,428 | 4,325,213 | 9,104,641 |
| Liquidity liabilities and commitments: | | | |
| Current liabilities including leases | (739,891) | - | (739,891) |
| 2025 Fundraising commitments and program commitments - Restricted for time | (10,630) | (283,336) | (293,966) |
| 2025 Program commitments - Ataxian Athlete | - | (14,452) | (14,452) |
| 2025 Program commitments - Data subscription and contract service commitments | (94,003) | (125,997) | (220,000) |
| 2025 Staffing commitments to support research and special projects | | (434,204) | (434,204) |
| 2025 Research and Grant program commitments: Institutional research programs | - | (2,445,086) | (2,445,086) |
| Directed research projects | (225,000) | (1,012,138) | (1,237,138) |
| Grant program and patient registry & FA GCC | (1,963,315) | (10,000) | (1,973,315) |
| Total 2025 Research and Grant program commitments | (2,188,315) | (3,467,224) | (5,655,539) |
| Total liquidity liabilities and commitments | (3,032,839) | (4,325,213) | (7,358,052) |
| Remaining assets available for general expenditures within one year | \$ 1,746,589 | \$ - | \$ 1,746,589 |

The Organization structures its financial assets to be available as general expenditures and research program commitments come due. Assets with donor restrictions are released when restrictions have been satisfied. Research program commitments assume that certain benchmarks or other criteria are met. The Organization invests excess cash in short-term investments (money market funds) and maintains an unrestricted investment reserve (investments) in highly liquid marketable securities.

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

**Notes to Financial Statements
December 31, 2024 and 2023**

NOTE C - LIQUIDITY (CONTINUED)

| | December 31, 2023 | | |
|--|---|------------------------------------|--------------------|
| | Without Donor Restrictions | With Donor Restrictions | Total |
| Liquidity resources: | | | |
| Cash and cash equivalents | \$ 3,993,332 | \$ 963,779 | \$ 4,957,111 |
| Contributions receivable | 747,478 | - | 747,478 |
| Investment | 1,870,166 | - | 1,870,166 |
| Contracted restricted resources to be received in 2024 for existing commitments as of December 31, 2023 | - | 2,896,406 | 2,896,406 |
| Assets without commitments as of December 31, 2023 | - | (426,753) | (426,753) |
| Total liquidity resources | 6,610,976 | 3,433,432 | 10,044,408 |
| Liquidity liabilities and commitments: | | | |
| Current liabilities including leases | (1,232,860) | - | (1,232,860) |
| 2024 Fundraising commitments | (4,567) | (75,000) | (79,567) |
| 2024 Program commitments - Ataxian Athlete | - | (2,279) | (2,279) |
| 2024 Staffing commitments to support research and special projects | - | (391,842) | (391,842) |
| 2024 Research and Grant program commitments: | | | |
| Institutional research programs | - | (2,445,086) | (2,445,086) |
| Directed research projects | (1,440,690) | (519,225) | (1,959,915) |
| Grant program and patient registry & FA GCC | (1,648,031) | - | (1,648,031) |
| Total 2024 Research and Grant program commitments | (3,088,721) | (2,964,311) | (6,053,032) |
| Total liquidity liabilities and commitments | (4,326,148) | (3,433,432) | (7,759,580) |
| Remaining assets available for general expenditures within one year | \$ 2,284,828 | \$ - | \$ 2,284,828 |

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE

Notes to Financial Statements December 31, 2024 and 2023

NOTE D - CASH AND CASH EQUIVALENTS

The following table provides a reconciliation of cash, cash equivalents and restricted cash reported within the consolidated statements of financial position that sums to the total of the same such amounts shown in the consolidated statements of cash flows for the years ended December 31, 2024 and 2023:

| | 2024 | 2023 |
|---|----------------------------|----------------------------|
| Cash and cash equivalents | \$ 1,959,581 | \$ 3,993,332 |
| Cash restricted for donor restricted purposes | <u>2,350,400</u> | <u>963,779</u> |
| | <u>\$ 4,309,981</u> | <u>\$ 4,957,111</u> |

NOTE E - INVESTMENTS AND FAIR VALUE MEASUREMENTS

FASB ASC 820, *Fair Value Measurements and Disclosures*, provides the framework for measuring fair value. The framework provides a fair value hierarchy that prioritizes the inputs to valuation techniques used to measure fair value, and defines fair value as the price that would be received to sell an asset or paid to transfer a liability (i.e., the "exit price") in an orderly transaction between market participants.

The hierarchy gives the highest priority to unadjusted quoted prices in active markets for identical assets (Level 1 measurements), and the lowest priority to unobservable inputs (Level 3 measurements). The three levels of the fair value hierarchy are described as follows:

- Level 1: Inputs to the valuation methodology are unadjusted quoted prices for identical assets or liabilities in active markets.
- Level 2: Inputs to the valuation methodology include (a) quoted prices for similar assets or liabilities in active markets; (b) quoted prices for identical or similar assets or liabilities in inactive markets; (c) inputs other than quoted prices that are observable for the asset or liability; or (d) inputs that are derived principally from or corroborated by observable market data by correlation or other means.
- Level 3: Inputs to the valuation methodology are unobservable and significant to the fair value measurement. Assets utilizing Level 3 inputs are funds held in trust by others.

The financial instrument's level within the fair value hierarchy is based on the lowest level of any input that is significant to the fair value measurement. The valuation levels are not necessarily an indication of the risk or liquidity associated with the underlying assets.

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

**Notes to Financial Statements
December 31, 2024 and 2023**

NOTE E - INVESTMENTS AND FAIR VALUE MEASUREMENTS (CONTINUED)

As of December 31, 2024 and 2023, FARA's investments consist of the following:

| | 2024 | 2023 |
|-----------------------------|---------------------|---------------------|
| U.S. Government debts | \$ 60,340 | \$ 235,529 |
| Common stocks and ETF's | 23,271 | - |
| Mutual funds - fixed income | 593,755 | 417,532 |
| Mutual funds- equity | 1,460,414 | 1,217,105 |
| | \$ 2,137,780 | \$ 1,870,166 |

These investments are valued at the closing market price on the stock exchange where they are traded, and are considered to be Level 1 on the aforementioned fair value hierarchy. There were no Level 2 or Level 3 assets at December 31, 2024 or 2023.

NOTE F - LEASES

FARA has a lease agreement that has been recorded in accordance with ASC 842 as an operating lease.

The liabilities under the operating lease are recorded at the present value of the minimum lease payments. During the years ended December 31, 2024 and 2023, lease expenses of \$64,111 and \$71,071, respectively, relating to the operating lease, are included in management and general on the consolidated statements of activities and changes in net assets. There are no costs related to variable lease components.

The following maturity analysis of the annual undiscounted cash flows of the operating lease liabilities as of December 31, 2024 is approximately as follows:

| | Year Ending December 31, | |
|--|-------------------------------------|-------------------|
| | 2024 | 2023 |
| 2024 | \$ - | \$ 68,826 |
| 2025 | 51,620 | 51,620 |
| Less: present value discount | (1,680) | (8,399) |
| Total | \$ 49,940 | \$ 112,047 |
| Weighted average remaining lease term: | 0.75 years | 1.75 years |
| Weighted average discount rate: | 8.0% | 8.0% |

**FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND
STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE**

**Notes to Financial Statements
December 31, 2024 and 2023**

NOTE G - NET ASSETS WITH DONOR RESTRICTIONS

Net assets with donor restrictions are available for the following purposes:

| | 2024 | 2023 |
|---|---------------------|-------------------|
| Multi-year staff growth for research and special projects | \$ 434,204 | \$ 784,253 |
| Research and grant programs | 1,567,908 | 77,247 |
| Future fundraising events | 283,336 | 100,000 |
| Patient education, engagement and advocacy | 50,500 | - |
| Ataxian Athlete Initiative | 14,452 | 2,279 |
| | \$ 2,350,400 | \$ 963,779 |

Net assets were released from donor restriction by incurring expenses satisfying the restricted purpose specified by the donors as follows for the years ended December 31, 2024 and 2023:

| | 2024 | 2023 |
|---|---------------------|---------------------|
| Satisfaction of purpose restrictions: | | |
| Research, conferences, and grant programs | \$ 5,082,258 | \$ 3,719,959 |
| Ataxian Athlete Initiative | 9,878 | 14,647 |
| FA GCC Operations | 55,240 | - |
| Future fundraising events | 125,000 | 155,000 |
| | \$ 5,652,908 | \$ 4,294,300 |
| Satisfaction of purpose and time restrictions: | | |
| Multi-year staff growth for research and special projects | 380,532 | 404,694 |

NOTE H - RELATED PARTIES

During the years ended December 31, 2024, and 2023, Board members and affiliated organizations provided \$5,938,769 and \$4,784,585 in revenue and support to FARA, respectively. This excludes the value of donated services described in Note B. The increase in Board member contributions from 2023 to 2024 was due primarily to the timing of restricted gifts received in 2024 for 2025 programs including for Institutional Research Programs described in Note J (\$500,000 restricted to 2025) and for Directed Research Projects (\$500,000 restricted to 2025) for TRACK FA neuroimaging study.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE

Notes to Financial Statements December 31, 2024 and 2023

NOTE I - RESEARCH AND PROGRAM COMMITMENTS

Many of the research grants that FARA funds are for multiple years which means that FARA has commitments to funding ongoing research and grant programs, assuming that certain benchmarks or other criteria are met by the grant recipients by a certain point in time. As of December 31, 2024 and 2023, FARA had commitments of \$3,210,226 and \$3,607,946, respectively, for the following year from the Grant Program and Directed Projects. The grants will fund various research projects, including drug discovery, gene and stem cell therapy, mechanism or pathway of disease, biomarker discovery and validation, cardiac research, TRACK-FA neuroimaging study and FA GCC natural history study. This is an addition to commitments of \$2,445,086 as of December 31, 2024 and 2023, for Institutional Research described in Note J. All commitments as of December 31, 2024 and 2023 are classified as with or without donor restrictions in Note D.

NOTE J - INSTITUTIONAL RESEARCH PROGRAMS

FARA has identified opportunities to fund research at institutions where there are multiple investigators with an expertise and commitment to FA research and/or opportunity to leverage technologies, innovation or new growth to the FA community. By establishing these institutional research programs FARA is able to promote collaboration and synergy across basic, translational and clinical research, provide a longer-term commitment for research, attract new investigators, and leverage the institutions resources and engagement.

The FA Center of Excellence ("COE") was established at the Children's Hospital of Philadelphia/University of Pennsylvania in 2014 with the Hamilton & Finneran families making a multi-year commitment to FARA and the COE. The COE is a translational research and clinical care center devoted to FA: expediting basic science and drug discovery findings to new treatments and dedicating resources to clinical research and care to further understand the disease, inform drug development and improve outcomes for individuals living with FA. FARA has maintained this funding partnership with the CureFA Foundation (established by the Hamilton and Finneran families) to advance research through the COE. In 2023, FARA, in partnership with the CureFA Foundation, signed a new agreement with the Children's Hospital of Philadelphia to contribute funds for COE research over the next three years. The agreement called for a charitable gift of \$500,000 per year for 3 years (through 2025). As of December 31, 2024 and 2023, the commitment by the CureFA Foundation and payment obligations for the COE for the second year and first year, respectively, have been met and recorded on FARA's financial statements.

The Friedreich's Ataxia Accelerator ("FAA") at the Broad Institute of MIT and Harvard was established in 2020 with a multi-year commitment from End-FA, CureFA Foundation and FARA. The FAA compromises a portfolio of complementary projects that are creating a growing Boston-based community committed to FA research. This portfolio includes gene editing strategies, small molecule drug discovery, frataxin bypass therapeutic approaches, genetic modifier studies and cardiac research. In October of 2023, FARA, in partnership with the CureFA Foundation and EndFA, signed a new agreement with the Broad Institute to contribute funds for FA research for the next three years, beginning October 1, 2023. The agreement called for a charitable gift of \$1,945,086 per year for 3 years (through 2025). As of December 31, 2023, FARA had received \$1,945,086 from co-funding partners toward the October 1, 2023 first year pledge and FARA had met payment obligations of \$1,945,086. As of December 31, 2024, FARA has received \$1,945,086 from co-funding partners toward the October 1, 2024, second-year pledge and FARA has met payment obligations of \$1,945,086. As of December 31, 2024, FARA has also received \$500,000 from co-funding partners toward the October 1, 2025 pledge as reported in restricted assets in Note C.

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE AND STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE

Notes to Financial Statements December 31, 2024 and 2023

NOTE K - FA GCC

Launched in 2023, the mission of the FA GCC is to accelerate the development of treatments for Friedreich's Ataxia by empowering patients and researchers, understanding natural history, conducting research and developing infrastructure that facilitates clinical research across the globe. The consortium is comprised of a funding board (FARA and FARA Europe), scientific steering committee, operations and management team, working groups, patient advocacy/advisory team and the investigator members of each clinical site; participation includes investigators from 33 sites representing 18 countries.

Each FA GCC clinical site is provided funding to participate in the UNIFIED Natural History Study (UNIFAI) and to:

- Identify and validate clinical outcome measures and biomarkers in FA that are necessary for clinical trials;
- Facilitate the implementation and delivery of clinical trials;
- Share data and resources to advance treatments for FA;
- Define best clinical practices for FA and provide the highest level of clinical care for patients.

In 2024, the FA GCC began a second study, A Study to Learn More About the Long-Term Safety of BIIB141 (Omaveloxolone) in Participants With Friedreich's Ataxia Who Are Prescribed it by Their Own Doctors, <https://clinicaltrials.gov/study/NCT06623890>, sponsored by Biogen. This is a post-market study of the first approved treatment for FA. In addition, several FA GCC clinical sites were involved in industry sponsored clinical trials of new potential treatments. FARA presented on the FA GCC and the UNIFAI study at multiple international conferences. The Organization believes that continued investment in clinical research infrastructure, globally, and continuation of natural history studies are essential to accomplish its mission.

NOTE L - EMPLOYEE BENEFIT PLAN

On January 1, 2017, FARA adopted a 401(k) profit-sharing plan and trust that covers all qualified employees. The plan provides for a discretionary profit-sharing contribution, as well as a matching employer contribution. The Plan provides for matching contributions up to 3% on deferrals from eligible employees. FARA made employer matching contributions of \$38,372 and \$36,390 during the years ended December 31, 2024 and 2023, respectively.

NOTE M - RISKS AND UNCERTAINTIES

FARA maintains its cash in bank accounts in amounts which, at times, may exceed federally insured limits. FARA has not experienced any losses in such accounts, and management believes that FARA is not exposed to any significant risk of loss on these accounts.

FARA invests in a professionally managed portfolio that contains short-term investments, U.S. Government issues, and mutual funds (equities and fixed income). Such investments are exposed to various risks, such as market and credit risks. Due to the level of risk associated with such investments, and the level of uncertainty related to changes in value of such investments, it is at least reasonably possible that changes in risk in the near term could materially affect investment balances and the amounts reported in the consolidated financial statements.

NOTE N - SUBSEQUENT EVENTS

Management has evaluated subsequent events through June 16, 2025, which is the date the financial statements were available to be issued.

**Application for Extension of Time To File an Exempt Organization
Return or Excise Taxes Related to Employee Benefit Plans**

OMB No. 1545-0047

File a separate application for each return.

Go to www.irs.gov/Form8868 for the latest information.

Electronic filing (e-file). You can electronically file Form 8868 to request up to a 6-month extension of time to file any of the forms listed below except for Form 8870, Information Return for Transfers Associated With Certain Personal Benefit Contracts. An extension request for Form 8870 must be sent to the IRS in a paper format (see instructions). For more details on the electronic filing of Form 8868, visit www.irs.gov/e-file-providers/e-file-for-charities-and-non-profits.

Caution: If you are going to make an electronic funds withdrawal (direct debit) with this Form 8868, see Form 8453-TE and Form 8879-TE for payment instructions.

All corporations required to file an income tax return other than Form 990-T (including 1120-C filers), partnerships, REMICs, and trusts must use Form 7004 to request an extension of time to file income tax returns.

Part I - Identification

| | | |
|--|--|---|
| Type or Print | Name of exempt organization, employer, or other filer, see instructions. FRIEDREICH'S ATAXIA RESEARCH ALLIANCE | Taxpayer identification number (TIN) 52-2122720 |
| File by the due date for filing your return. See instructions. | Number, street, and room or suite no. If a P.O. box, see instructions. P.O. BOX 1537 | |
| | City, town or post office, state, and ZIP code. For a foreign address, see instructions. SPRINGFIELD, VA 22151 | |

Enter the Return Code for the return that this application is for (file a separate application for each return) **01**

| Application Is For | Return Code | Application Is For | Return Code |
|--|-------------|------------------------------------|-------------|
| Form 990 or Form 990-EZ | 01 | Form 4720 (other than individual) | 09 |
| Form 4720 (individual) | 03 | Form 5227 | 10 |
| Form 990-PF | 04 | Form 6069 | 11 |
| Form 990-T (sec. 401(a) or 408(a) trust) | 05 | Form 8870 | 12 |
| Form 990-T (trust other than above) | 06 | Form 5330 (individual) | 13 |
| Form 990-T (corporation) | 07 | Form 5330 (other than individual) | 14 |
| Form 1041-A | 08 | Form 990-T (governmental entities) | 15 |

- After you enter your Return Code, complete either Part II or Part III. Part III, including signature, is applicable only for an extension of time to file Form 5330.

- If this application is for an extension of time to file Form 5330, you must enter the following information.

Plan Name _____
 Plan Number _____
 Plan Year Ending (MM/DD/YYYY) _____

Part II - Automatic Extension of Time To File for Exempt Organizations (see instructions)The books are in the care of **JENNIFER FARMER****533 W. UWCHLAN AVENUE - DOWNTON, PA 19335**Telephone No. **484-879-6160**

Fax No. _____

- If the organization does not have an office or place of business in the United States, check this box
- If this is for a Group Return, enter the organization's four-digit Group Exemption Number (GEN) If this is for the whole group, check this box If it is for part of the group, check this box ... and attach a list with the names and TINs of all members the extension is for.

1 I request an automatic 6-month extension of time until **NOVEMBER 15**, 20 **25**, to file the exempt organization return for the organization named above. The extension is for the organization's return for:

calendar year 20 **24** or
 tax year beginning _____, 20 _____, and ending _____, 20 _____

2 If the tax year entered in line 1 is for less than 12 months, check reason: Initial return Final return
 Change in accounting period

| | | | |
|---|-----------|----|-----------|
| 3a If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter the tentative tax, less any nonrefundable credits. See instructions. | 3a | \$ | 0. |
| b If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter any refundable credits and estimated tax payments made. Include any prior year overpayment allowed as a credit. | 3b | \$ | 0. |
| c Balance due. Subtract line 3b from line 3a. Include your payment with this form, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions. | 3c | \$ | 0. |

For Privacy Act and Paperwork Reduction Act Notice, see instructions.

Form **8868** (Rev. 1-2025)

Form 8879-TE

**IRS E-file Signature Authorization
for a Tax Exempt Entity**

OMB No. 1545-0047

Department of the Treasury
Internal Revenue Service

For calendar year 2024, or fiscal year beginning _____, 2024, and ending _____, 20____

Do not send to the IRS. Keep for your records.

Go to www.irs.gov/Form8879TE for the latest information.**2024**

Name of filer

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

EIN or SSN

52-2122720

Name and title of officer or person subject to tax

**JENNIFER FARMER
CHIEF EXECUTIVE OFFICER****Part I Type of Return and Return Information**

Check the box for the return for which you are using this Form 8879-TE and enter the applicable amount, if any, from the return. Form 8038-CP and Form 5330 filers may enter dollars and cents. For all other forms, enter whole dollars only. If you check the box on line **1a, 2a, 3a, 4a, 5a, 6a, 7a, 8a, 9a, or 10a** below, and the amount on that line for the return being filed with this form was blank, then leave line **1b, 2b, 3b, 4b, 5b, 6b, 7b, 8b, 9b, or 10b**, whichever is applicable, blank (do not enter -0). But, if you entered -0- on the return, then enter -0- on the applicable line below. **Do not** complete more than one line in Part I.

- | | | | | |
|------------|---------------------------------------|-------------------------------------|---|-----------------------------------|
| 1a | Form 990 check here | <input checked="" type="checkbox"/> | b Total revenue, if any (Form 990, Part VIII, column (A), line 12) | 1b 13 , 135 , 426 . |
| 2a | Form 990-EZ check here | <input type="checkbox"/> | b Total revenue, if any (Form 990-EZ, line 9) | 2b _____ |
| 3a | Form 1120-POL check here | <input type="checkbox"/> | b Total tax (Form 1120-POL, line 22) | 3b _____ |
| 4a | Form 990-PF check here | <input type="checkbox"/> | b Tax based on investment income (Form 990-PF, Part V, line 5) | 4b _____ |
| 5a | Form 8868 check here | <input type="checkbox"/> | b Balance due (Form 8868, line 3c) | 5b _____ |
| 6a | Form 990-T check here | <input type="checkbox"/> | b Total tax (Form 990-T, Part III, line 4) | 6b _____ |
| 7a | Form 4720 check here | <input type="checkbox"/> | b Total tax (Form 4720, Part III, line 1) | 7b _____ |
| 8a | Form 5227 check here | <input type="checkbox"/> | b FMV of assets at end of tax year (Form 5227, Item D) | 8b _____ |
| 9a | Form 5330 check here | <input type="checkbox"/> | b Tax due (Form 5330, Part II, line 19) | 9b _____ |
| 10a | Form 8038-CP check here | <input type="checkbox"/> | b Amount of credit payment requested (Form 8038-CP, Part III, line 22) | 10b _____ |

Part II Declaration and Signature Authorization of Officer or Person Subject to Tax

Under penalties of perjury, I declare that I am an officer of the above entity or I am a person subject to tax with respect to (name of entity) _____, (EIN) _____ and that I have examined a copy of the

2024 electronic return and accompanying schedules and statements, and, to the best of my knowledge and belief, they are true, correct, and complete. I further declare that the amount in Part I above is the amount shown on the copy of the electronic return. I consent to allow my intermediate service provider, transmitter, or electronic return originator (ERO) to send the return to the IRS and to receive from the IRS **(a)** an acknowledgement of receipt or reason for rejection of the transmission, **(b)** the reason for any delay in processing the return or refund, and **(c)** the date of any refund. If applicable, I authorize the U.S. Treasury and its designated Financial Agent to initiate an electronic funds withdrawal (direct debit) entry to the financial institution account indicated in the tax preparation software for payment of the federal taxes owed on this return, and the financial institution to debit the entry to this account. To revoke a payment, I must contact the U.S. Treasury Financial Agent at 1-888-353-4537 no later than 2 business days prior to the payment (settlement) date. I also authorize the financial institutions involved in the processing of the electronic payment of taxes to receive confidential information necessary to answer inquiries and resolve issues related to the payment. I have selected a personal identification number (PIN) as my signature for the electronic return and, if applicable, the consent to electronic funds withdrawal.

PIN: check one box only

I authorize **EISNER ADVISORY GROUP LLC** to enter my PIN **22151**
ERO firm name
Enter five numbers, but
do not enter all zeros

as my signature on the tax year 2024 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I also authorize the aforementioned ERO to enter my PIN on the return's disclosure consent screen.

As an officer or person subject to tax with respect to the entity, I will enter my PIN as my signature on the tax year 2024 electronically filed return. If I have indicated within this return that a copy of the return is being filed with a state agency(ies) regulating charities as part of the IRS Fed/State program, I will enter my PIN on the return's disclosure consent screen.

Signature of officer or person subject to tax

Jen Farmer

Date 10/16/2025 | 3:26:29 AM PD

Part III Certification and Authentication

ERO's EFIN/PIN. Enter your six-digit electronic filing identification number (EFIN) followed by your five-digit self-selected PIN.

23518222151

Do not enter all zeros

I certify that the above numeric entry is my PIN, which is my signature on the 2024 electronically filed return indicated above. I confirm that I am submitting this return in accordance with the requirements of **Pub. 4163, Modernized e-File (MeF) Information for Authorized IRS e-file Providers for Business Returns**.

ERO's signature

Hil M. Mat

Date

10/15/25

**ERO Must Retain This Form - See Instructions
Do Not Submit This Form to the IRS Unless Requested To Do So**

For Privacy Act and Paperwork Reduction Act Notice, see instructions.

Form 8879-TE (2024)

EXTENDED TO NOVEMBER 17, 2025

Return of Organization Exempt From Income Tax**Form 990**Department of the Treasury
Internal Revenue Service

OMB No. 1545-0047

2024Open to Public
Inspection

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)
 Do not enter social security numbers on this form as it may be made public.
 Go to www.irs.gov/Form990 for instructions and the latest information.

A For the 2024 calendar year, or tax year beginning**and ending**

| | | | | |
|--|--|--|--|--|
| B Check if applicable: | C Name of organization FRIEDREICH'S ATAXIA RESEARCH ALLIANCE | | | D Employer identification number 52-2122720 |
| Address change | Doing business as | | | E Telephone number 484-879-6160 |
| Name change | | | | G Gross receipts \$ 14,956,926. |
| Initial return | | | | H(a) Is this a group return for subordinates? Yes <input checked="" type="checkbox"/> No |
| Final return/terminated | | | | H(b) Are all subordinates included? Yes <input checked="" type="checkbox"/> No |
| Amended return | | | | If "No," attach a list. See instructions |
| Application pending | | | | H(c) Group exemption number |
| I Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) () (insert no.) 4947(a)(1) or 527 | | | | J Website: WWW.CUREFA.ORG |
| K Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other | | | | L Year of formation: 1998 M State of legal domicile: VA |

Part I Summary

| | | | |
|---|--|---------------------------------|--|
| Activities & Governance | 1 Briefly describe the organization's mission or most significant activities: TO TREAT AND CURE FRIEDREICH'S ATAXIA (FA) BY ADVANCING RESEARCH, AWARENESS AND PARTNERSHIPS. | | |
| | 2 Check this box if the organization discontinued its operations or disposed of more than 25% of its net assets. | | |
| | 3 Number of voting members of the governing body (Part VI, line 1a) | 3 | |
| | 4 Number of independent voting members of the governing body (Part VI, line 1b) | 4 | |
| | 5 Total number of individuals employed in calendar year 2024 (Part V, line 2a) | 5 | |
| | 6 Total number of volunteers (estimate if necessary) | 6 | |
| | 7a Total unrelated business revenue from Part VIII, column (C), line 12 | 7a | |
| | b Net unrelated business taxable income from Form 990-T, Part I, line 11 | 7b | |
| | | Prior Year | Current Year |
| | 8 Contributions and grants (Part VIII, line 1h) | 12,011,078. | 13,517,065. |
| | 9 Program service revenue (Part VIII, line 2g) | 0. | 0. |
| Revenue | 10 Investment income (Part VIII, column (A), lines 3, 4, and 7d) | 35,631. | 172,331. |
| | 11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) | -843,666. | -553,970. |
| | 12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12) | 11,203,043. | 13,135,426. |
| | 13 Grants and similar amounts paid (Part IX, column (A), lines 1-3) | 9,307,077. | 10,467,810. |
| | 14 Benefits paid to or for members (Part IX, column (A), line 4) | 0. | 0. |
| | 15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) | 1,461,477. | 1,572,657. |
| | 16a Professional fundraising fees (Part IX, column (A), line 11e) | 0. | 0. |
| | b Total fundraising expenses (Part IX, column (D), line 25) | 368,460. | |
| | 17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) | 1,432,219. | 1,236,769. |
| | 18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) | 12,200,773. | 13,277,236. |
| | 19 Revenue less expenses. Subtract line 18 from line 12 | -997,730. | -141,810. |
| Expenses | | Beginning of Current Year | End of Year |
| | 20 Total assets (Part X, line 16) | 7,752,276. | 6,946,549. |
| | 21 Total liabilities (Part X, line 26) | 1,605,648. | 676,182. |
| | 22 Net assets or fund balances. Subtract line 21 from line 20 | 6,146,628. | 6,270,367. |
| | | | |
| Part II Signature Block | | | |
| Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge. | | | |
| Sign Here | Signature of officer <i>Jennifer Farmer</i> | Date <i>10/15/25</i> | |
| | JENNIFER FARMER, CHIEF EXECUTIVE OFFICER | | |
| | Type or print name and title | | |
| Paid | Preparer's name HELEN M. MARTIN | Preparer's signature | Date 10/15/25 |
| Preparer | Firm's name EISNER ADVISORY GROUP LLC | | Check if self-employed P01330899 |
| Use Only | Firm's address 130 NORTH 18TH STREET, SUITE 3000 PHILADELPHIA, PA 19103-2757 | Firm's EIN 87-1353108 | Phone no. (215) 881-8800 |

May the IRS discuss this return with the preparer shown above? See instructions

 Yes No

LHA For Paperwork Reduction Act Notice, see the separate instructions.

432001 12-10-24

Form **990** (2024)

Part III Statement of Program Service AccomplishmentsCheck if Schedule O contains a response or note to any line in this Part III

- 1 Briefly describe the organization's mission:

TO MARSHAL AND FOCUS THE RESOURCES AND RELATIONSHIPS NEEDED TO CURE FA BY RAISING FUNDS FOR RESEARCH, PROMOTING PUBLIC AWARENESS AND ALIGNING SCIENTISTS, PATIENTS, CLINICIANS, GOVERNMENT AGENCIES AND PHARMACEUTICAL COMPANIES DEDICATED TO CURING FA AND RELATED DISORDERS.

- 2 Did the organization undertake any significant program services during the year which were not listed on the

Yes No

If "Yes," describe these new services on Schedule O.

- 3 Did the organization cease conducting, or make significant changes in how it conducts, any program services?
-
- Yes
-
- No

If "Yes," describe these changes on Schedule O.

- 4 Describe the organization's program service accomplishments for each of its three largest program services, as measured by expenses.

Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code: _____) (Expenses \$ **10,330,478.** including grants of \$ **9,606,747.**) (Revenue \$ _____)

RESEARCH AND GRANT PROGRAM –

SEE SCHEDULE O

4b (Code: _____) (Expenses \$ **1,354,745.** including grants of \$ **781,063.**) (Revenue \$ _____)

CLINICAL RESEARCH INFRASTRUCTURE

IN ADDITION TO RESEARCH GRANTS, FARA FUNDS THE ONGOING DEVELOPMENT OF DOMAIN RESOURCES IN THE FORM OF VITAL CLINICAL RESEARCH INFRASTRUCTURE. CLINICAL RESEARCH INFRASTRUCTURE REFERS TO THE RESOURCES NEEDED TO FACILITATE ANY TYPE OF RESEARCH, INCLUDING CLINICAL TRIALS THAT INVOLVE PATIENTS. THESE RESOURCES INCLUDE PROGRAMS LIKE:

FRIEDREICH'S ATAXIA GLOBAL PATIENT REGISTRY: THE FRIEDREICH'S ATAXIA GLOBAL PATIENT REGISTRY (FAGPR) IS THE ONLY WORLDWIDE REGISTRY OF FRIEDREICH'S ATAXIA PATIENTS. THE GOALS OF THE FAGPR ARE TO COLLECT INFORMATION ON ALL FA PATIENTS IN ONE REGISTRY, TO DEVELOP THE REGISTRY INTO A POWERFUL RESOURCE FOR RESEARCH, AND TO ENGAGE THE FA COMMUNITY IN STUDIES AIMED AT ADVANCING OUR KNOWLEDGE (CONTINUED IN SCHEDULE O)

4c (Code: _____) (Expenses \$ **491,179.** including grants of \$ **80,000.**) (Revenue \$ _____)

AWARENESS, EDUCATION, AND OUTREACH PROGRAMS:

AWARENESS: FRIEDREICH ATAXIA (FA) IS A RARE DISEASE; AFFECTING 1 IN 50,000 INDIVIDUALS. FARA IS DEDICATED TO ADVOCACY AND RAISING AWARENESS FOR FA. FARA HAS UTILIZED BOTH TRADITIONAL AND SOCIAL MEDIA STRATEGIES TO BRING GREATER AWARENESS TO FA IN THE GENERAL PUBLIC AND TO ENGAGE AND EDUCATE THE FA COMMUNITY. FOR EXAMPLE, FARA CONDUCTS AN ANNUAL A SOCIAL MEDIA CAMPAIGN THAT ENCOURAGES COMMUNITY PARTICIPATION LEADING UP TO FA AWARENESS DAY.

ADVOCACY: FARA AND THE NATIONAL ATAXIA FOUNDATION (NAF) PARTNERED ON SEVERAL ADVOCACY INITIATIVES RELEVANT TO THE ATAXIA COMMUNITY. MOSTLY NOTABLY, THE EFFORTS OF THE TWO ORGANIZATIONS RESULTED IN THE CONTINUED INCLUSION OF HEREDITARY ATAXIA AS PART OF (CONTINUED IN SCHEDULE O)

- 4d Other program services (Describe on Schedule O.)

(Expenses \$ **357,617.** including grants of \$ _____) (Revenue \$ _____)

4e Total program service expenses **12,534,019.**

Form 990 (2024)

Part IV Checklist of Required Schedules

| | Yes | No |
|---|--|-----------|
| 1 Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A</i> | 1 X | |
| 2 Is the organization required to complete <i>Schedule B, Schedule of Contributors?</i> See instructions | 2 X | |
| 3 Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i> | 3 X | |
| 4 Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II</i> | 4 X | |
| 5 Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Rev. Proc. 98-19? <i>If "Yes," complete Schedule C, Part III</i> | 5 X | |
| 6 Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I</i> | 6 X | |
| 7 Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i> | 7 X | |
| 8 Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i> | 8 X | |
| 9 Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV</i> | 9 X | |
| 10 Did the organization, directly or through a related organization, hold assets in donor-restricted endowments or in quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i> | 10 X | |
| 11 If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X, as applicable. <ul style="list-style-type: none"> a Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI</i> b Did the organization report an amount for investments - other securities in Part X, line 12, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII</i> c Did the organization report an amount for investments - program related in Part X, line 13, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII</i> d Did the organization report an amount for other assets in Part X, line 15, that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX</i> e Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i> f Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X</i> | 11a X 11b X 11c X 11d X 11e X 11f X | |
| 12a Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i> | 12a X | |
| b Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i> | 12b X | |
| 13 Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i> | 13 X | |
| 14a Did the organization maintain an office, employees, or agents outside of the United States? b Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV</i> | 14a X 14b X | |
| 15 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV</i> | 15 X | |
| 16 Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV</i> | 16 X | |
| 17 Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I. See instructions</i> | 17 X | |
| 18 Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II</i> | 18 X | |
| 19 Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i> | 19 X | |
| 20a Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i> | 20a X | |
| b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return? | 20b X | |
| 21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or domestic government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i> | 21 X | |

Part IV Checklist of Required Schedules (continued)

| | Yes | No |
|---|------------|-----------|
| 22 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III | 22 X | |
| 23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? If "Yes," complete Schedule J | 23 X | |
| 24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a | 24a X | |
| b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? | 24b | |
| c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds? | 24c | |
| d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? | 24d | |
| 25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I | 25a X | |
| b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If "Yes," complete Schedule L, Part I | 25b X | |
| 26 Did the organization report any amount on Part X, line 5 or 22, for receivables from or payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons? If "Yes," complete Schedule L, Part II | 26 X | |
| 27 Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? If "Yes," complete Schedule L, Part III | 27 X | |
| 28 Was the organization a party to a business transaction with one of the following parties? (See the Schedule L, Part IV, instructions for applicable filing thresholds, conditions, and exceptions): | | |
| a A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? If "Yes," complete Schedule L, Part IV | 28a X | |
| b A family member of any individual described in line 28a? If "Yes," complete Schedule L, Part IV | 28b X | |
| c A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? If "Yes," complete Schedule L, Part IV | 28c X | |
| 29 Did the organization receive more than \$25,000 in noncash contributions? If "Yes," complete Schedule M | 29 X | |
| 30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? If "Yes," complete Schedule M | 30 X | |
| 31 Did the organization liquidate, terminate, or dissolve and cease operations? If "Yes," complete Schedule N, Part I | 31 X | |
| 32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete Schedule N, Part II | 32 X | |
| 33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I | 33 X | |
| 34 Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1 | 34 X | |
| 35a Did the organization have a controlled entity within the meaning of section 512(b)(13)? | 35a X | |
| b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2 | 35b | |
| 36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? If "Yes," complete Schedule R, Part V, line 2 | 36 X | |
| 37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI | 37 X | |
| 38 Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19? | 38 X | |

Note: All Form 990 filers are required to complete Schedule O

Part V Statements Regarding Other IRS Filings and Tax ComplianceCheck if Schedule O contains a response or note to any line in this Part V

| | Yes | No |
|--|------------|-----------|
| 1a Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable | 1a 19 | |
| b Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable | 1b 0 | |
| c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners? | 1c X | |

Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

| | Yes | No |
|--|-----|-------------------------------------|
| 2a Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return | 2a | 19 |
| b If at least one is reported on line 2a, did the organization file all required federal employment tax returns? | 2b | <input checked="" type="checkbox"/> |
| 3a Did the organization have unrelated business gross income of \$1,000 or more during the year? | 3a | <input checked="" type="checkbox"/> |
| b If "Yes," has it filed a Form 990-T for this year? <i>If "No" to line 3b, provide an explanation on Schedule O</i> | 3b | |
| 4a At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)? | 4a | <input checked="" type="checkbox"/> |
| b If "Yes," enter the name of the foreign country _____ See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR). | 4b | |
| 5a Was the organization a party to a prohibited tax shelter transaction at any time during the tax year? | 5a | <input checked="" type="checkbox"/> |
| b Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction? | 5b | <input checked="" type="checkbox"/> |
| c If "Yes" to line 5a or 5b, did the organization file Form 8886-T? | 5c | |
| 6a Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions? | 6a | <input checked="" type="checkbox"/> |
| b If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible? | 6b | |
| 7 Organizations that may receive deductible contributions under section 170(c). | 7c | <input checked="" type="checkbox"/> |
| a Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor? | 7d | |
| b If "Yes," did the organization notify the donor of the value of the goods or services provided? | 7e | <input checked="" type="checkbox"/> |
| c Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282? | 7f | <input checked="" type="checkbox"/> |
| d If "Yes," indicate the number of Forms 8282 filed during the year | 7g | |
| e Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract? | 7h | |
| f Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract? | 8 | |
| g If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required? | 9a | |
| h If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C? | 9b | |
| 8 Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year? | 10a | |
| 9 Sponsoring organizations maintaining donor advised funds. | 10b | |
| 10 Section 501(c)(7) organizations. Enter: | 11a | |
| a Initiation fees and capital contributions included on Part VIII, line 12 | 11b | |
| b Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities | 12a | |
| 11 Section 501(c)(12) organizations. Enter: | 12b | |
| a Gross income from members or shareholders | 13a | |
| b Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.) | 13b | |
| 12a Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041? | 13c | |
| b If "Yes," enter the amount of tax-exempt interest received or accrued during the year | 14a | <input checked="" type="checkbox"/> |
| 13 Section 501(c)(29) qualified nonprofit health insurance issuers. | 14b | |
| a Is the organization licensed to issue qualified health plans in more than one state? | 15 | <input checked="" type="checkbox"/> |
| Note: See the instructions for additional information the organization must report on Schedule O. | 16 | |
| b Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans | 17 | |
| c Enter the amount of reserves on hand | 14c | |
| 14a Did the organization receive any payments for indoor tanning services during the tax year? | 14d | |
| b If "Yes," has it filed a Form 720 to report these payments? <i>If "No," provide an explanation on Schedule O</i> | 14e | |
| 15 Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? | 15 | <input checked="" type="checkbox"/> |
| If "Yes," see the instructions and file Form 4720, Schedule N. | 16 | |
| 16 Is the organization an educational institution subject to the section 4968 excise tax on net investment income? | 16 | <input checked="" type="checkbox"/> |
| If "Yes," complete Form 4720, Schedule O. | 17 | |
| 17 Section 501(c)(21) organizations. Did the trust, or any disqualified or other person engage in any activities that would result in the imposition of an excise tax under section 4951, 4952 or 4953? | 17 | |
| If "Yes," complete Form 6069. | 17 | |

Part VI Governance, Management, and Disclosure. For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on Schedule O. See instructions.

Check if Schedule O contains a response or note to any line in this Part VI X

Section A. Governing Body and Management

| | | Yes | No |
|----|---|-----|----|
| 1a | Enter the number of voting members of the governing body at the end of the tax year | 1a | 19 |
| | If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain on Schedule O. | | |
| 1b | Enter the number of voting members included on line 1a, above, who are independent | 1b | 17 |
| 2 | Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee? | 2 | X |
| 3 | Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person? | 3 | X |
| 4 | Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? | 4 | X |
| 5 | Did the organization become aware during the year of a significant diversion of the organization's assets? | 5 | X |
| 6 | Did the organization have members or stockholders? | 6 | X |
| 7a | Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body? | 7a | X |
| b | Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body? | | |
| 8 | Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: | | |
| a | The governing body? | 8a | X |
| b | Each committee with authority to act on behalf of the governing body? | 8b | X |
| 9 | Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses on Schedule O | 9 | X |

Section B. Policies

(This Section B requests information about policies not required by the Internal Revenue Code.)

| | | Yes | No |
|-----|--|-----|----|
| 10a | Did the organization have local chapters, branches, or affiliates? | 10a | X |
| b | If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes? | | |
| 11a | Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? | 11a | X |
| b | Describe on Schedule O the process, if any, used by the organization to review this Form 990. | | |
| 12a | Did the organization have a written conflict of interest policy? If "No," go to line 13 | 12a | X |
| b | Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? | 12b | X |
| c | Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe on Schedule O how this was done | 12c | X |
| 13 | Did the organization have a written whistleblower policy? | 13 | X |
| 14 | Did the organization have a written document retention and destruction policy? | 14 | X |
| 15 | Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? | | |
| a | The organization's CEO, Executive Director, or top management official | 15a | X |
| b | Other officers or key employees of the organization | 15b | X |
| | If "Yes" to line 15a or 15b, describe the process on Schedule O. See instructions. | | |
| 16a | Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a taxable entity during the year? | 16a | X |
| b | If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements? | 16b | X |

Section C. Disclosure

- 17 List the states with which a copy of this Form 990 is required to be filed AL, AK, AZ, AR, CA, CO, CT, FL, GA, IL, KS, KY
- 18 Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, if applicable), 990, and 990-T (section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply.
 Own website Another's website Upon request Other (explain on Schedule O)
- 19 Describe on Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year.
- 20 State the name, address, and telephone number of the person who possesses the organization's books and records
JENNIFER FARMER - 484-879-6160
533 W. UWCHLAN AVENUE, DOWNTON, PA 19335

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated Employees, and Independent Contractors

Check if Schedule O contains a response or note to any line in this Part VII

Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.

- List all of the organization's **current** officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation.

Enter -0- in columns (D), (E), and (F) if no compensation was paid.

- List all of the organization's **current** key employees, if any. See the instructions for definition of "key employee."

who received reportable compensation (box 5 of Form W-2, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) of more than \$100,000 from the organization and any related organizations.

• List all of the organization's **former** officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.

- List all of the organization's **former directors or trustees** that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

See the instructions for the order in which to list the persons above.

Check this box if neither the organization nor any related organization compensated any current officer, director, or trustee.

| (A) Name and title | (B) Average hours per week (list any hours for related organizations below line) | (C) Position (do not check more than one box, unless person is both an officer and a director/trustee) | | | | | (D) Reportable compensation from the organization (W-2/1099-MISC/ 1099-NEC) | (E) Reportable compensation from related organizations (W-2/1099-MISC/ 1099-NEC) | (F) Estimated amount of other compensation from the organization and related organizations |
|--|---|--|-----------------------|---------|--------------|---------------------------------|--|--|--|
| | | Individual trustee or director | Institutional trustee | Officer | Key employee | Highest compensated employee | | | |
| (1) BARBARA A TATE CHIEF SCIENTIFIC OFFICER | 40.00 | | | | X | | 250,000. | 0. | 5,527. |
| (2) JENNIFER M FARMER CHIEF EXECUTIVE OFFICER | 40.00 | | X | | | | 165,000. | 0. | 5,678. |
| (3) ELISABETTA SORAGNI DIRECTOR OF RESEARCH | 40.00 | | | | X | | 115,851. | 0. | 16,023. |
| (4) FELICIA DEROSA VP FUNDRAISING & COMMS | 40.00 | | | | X | | 106,351. | 0. | 12,292. |
| (5) RONALD BARTEK PRESIDENT/DIRECTOR | 40.00 | X | X | | | | 110,000. | 0. | 3,811. |
| (6) RUTH ACTON TREASURER/DIRECTOR FINANCE | 25.00 | X | X | | | | 51,000. | 0. | 16,964. |
| (7) PAUL AVERY CHAIRMAN/ DIRECTOR | 10.00 | X | X | | | | 0. | 0. | 0. |
| (8) MAUREEN JUIP SECRETARY/ DIRECTOR | 10.00 | X | X | | | | 0. | 0. | 0. |
| (9) DR. SANJAY BIDICHANDANI DIRECTOR | 10.00 | X | | | | | 0. | 0. | 0. |
| (10) BRIGID BRENNAN DIRECTOR/ GENERAL COUNSEL | 20.00 | X | | | | | 0. | 0. | 0. |
| (11) THOMAS BRENNINKMEIJER DIRECTOR | 10.00 | X | | | | | 0. | 0. | 0. |
| (12) ALEX FIELDING DIRECTOR | 10.00 | X | | | | | 0. | 0. | 0. |
| (13) JENNIFER GOOD DIRECTOR | 10.00 | X | | | | | 0. | 0. | 0. |
| (14) THOMAS HAMILTON DIRECTOR | 10.00 | X | | | | | 0. | 0. | 0. |
| (15) DR. HOLLY HEDRICK DIRECTOR | 10.00 | X | | | | | 0. | 0. | 0. |
| (16) DEREK G. HENNECKE DIRECTOR | 10.00 | X | | | | | 0. | 0. | 0. |
| (17) WARREN HUFF DIRECTOR | 10.00 | X | | | | | 0. | 0. | 0. |

Part VII**Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees (continued)**

| (A) Name and title | (B) Average hours per week (list any hours for related organizations below line) | (C) Position (do not check more than one box, unless person is both an officer and a director/trustee) | | | | | (D) Reportable compensation from the organization (W-2/1099-MISC/ 1099-NEC) | (E) Reportable compensation from related organizations (W-2/1099-MISC/ 1099-NEC) | (F) Estimated amount of other compensation from the organization and related organizations |
|--|---|---|-----------------------|---------|--------------|---------------------------------|--|--|--|
| | | Individual trustee or director | Institutional trustee | Officer | Key employee | Highest compensated employee | | | |
| (18) DR. STEVE KLASKO DIRECTOR | 10.00 | X | | | | | 0. | 0. | 0. |
| (19) DR. KATHY MATHEWS DIRECTOR | 10.00 | X | | | | | 0. | 0. | 0. |
| (20) DR. JAMES MCARTHUR DIRECTOR | 10.00 | X | | | | | 0. | 0. | 0. |
| (21) TONY PLOHOROS DIRECTOR | 10.00 | X | | | | | 0. | 0. | 0. |
| (22) PATRICK RITSCHEL DIRECTOR | 10.00 | X | | | | | 0. | 0. | 0. |
| (23) DR. JAMES R. RUSCHE DIRECTOR | 10.00 | X | | | | | 0. | 0. | 0. |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| 1b Subtotal | | | | | | | 798,202. | 0. | 60,295. |
| c Total from continuation sheets to Part VII, Section A | | | | | | | 0. | 0. | 0. |
| d Total (add lines 1b and 1c) | | | | | | | 798,202. | 0. | 60,295. |

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization

5

- | | Yes | No |
|--|-----|----|
| 3 Did the organization list any former officer, director, trustee, key employee, or highest compensated employee on line 1a? If "Yes," complete Schedule J for such individual | 3 | X |
| 4 For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? If "Yes," complete Schedule J for such individual | 4 | X |
| 5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person | 5 | X |

Section B. Independent Contractors

- 1** Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

| (A) Name and business address | (B) Description of services | (C) Compensation |
|--|---------------------------------------|---------------------|
| CAMENE BVBA-MYRIAM ABOUAZAR-RAI, BRUSSELBAAN 473, SINT-PIETERS-LEEUW, | INTERNATIONAL RESEARCH AND ADVOCAC | 132,135. |
| | | |
| | | |
| | | |
| | | |

- 2** Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization

1

Form 990 (2024)

Part VIII Statement of RevenueCheck if Schedule O contains a response or note to any line in this Part VIII

| | | (A) Total revenue | (B) Related or exempt function revenue | (C) Unrelated business revenue | (D) Revenue excluded from tax under sections 512 - 514 |
|---|---|--------------------------|--|--------------------------------------|---|
| Contributions, Gifts, Grants and Other Similar Amounts | 1 a Federated campaigns | 1a 7,072. | | | |
| | b Membership dues | 1b | | | |
| | c Fundraising events | 1c 3,362,180. | | | |
| | d Related organizations | 1d | | | |
| | e Government grants (contributions) | 1e | | | |
| | f All other contributions, gifts, grants, and similar amounts not included above ... | 1f 10,147,813. | | | |
| | g Noncash contributions included in lines 1a-1f | 1g \$ 881,511. | | | |
| | h Total. Add lines 1a-1f | | 13,517,065. | | |
| Program Service Revenue | | Business Code | | | |
| | 2 a | | | | |
| | b | | | | |
| | c | | | | |
| | d | | | | |
| | e | | | | |
| | f All other program service revenue | | | | |
| | g Total. Add lines 2a-2f | | | | |
| Other Revenue | 3 Investment income (including dividends, interest, and other similar amounts) | | 145,621. | | 145,621. |
| | 4 Income from investment of tax-exempt bond proceeds | | | | |
| | 5 Royalties | | | | |
| | 6 a Gross rents | 6a (i) Real | | | |
| | | 6b (ii) Personal | | | |
| | c Less: rental expenses | | | | |
| | d Rental income or (loss) | | | | |
| | d Net rental income or (loss) | | | | |
| | 7 a Gross amount from sales of assets other than inventory | 7a (i) Securities | | | |
| | | 7b (ii) Other | | | |
| | b Less: cost or other basis and sales expenses | 645,455. | | | |
| | c Gain or (loss) | 7b 618,745. | | | |
| | d Net gain or (loss) | 7c 26,710. | | | 26,710. |
| | 8 a Gross income from fundraising events (not including \$ 3,362,180. of contributions reported on line 1c). See Part IV, line 18 | 8a | | | |
| | | 8b 648,785. | | | |
| | b Less: direct expenses | | | | |
| | c Net income or (loss) from fundraising events | 8b 1,202,755. | | | -553,970. |
| | 9 a Gross income from gaming activities. See Part IV, line 19 | 9a | | | |
| | | 9b | | | |
| | b Less: direct expenses | | | | |
| | c Net income or (loss) from gaming activities | | | | |
| | 10 a Gross sales of inventory, less returns and allowances | 10a | | | |
| | | 10b | | | |
| | b Less: cost of goods sold | | | | |
| | c Net income or (loss) from sales of inventory | | | | |
| Miscellaneous Revenue | | Business Code | | | |
| | 11 a | | | | |
| | b | | | | |
| | c | | | | |
| | d All other revenue | | | | |
| | e Total. Add lines 11a-11d | | | | |
| | 12 Total revenue. See instructions | 13,135,426. | 0. | 0. | -381,639. |

Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

Check if Schedule O contains a response or note to any line in this Part IX

| <i>Do not include amounts reported on lines 6b, 7b, 8b, 9b, and 10b of Part VIII.</i> | (A) Total expenses | (B) Program service expenses | (C) Management and general expenses | (D) Fundraising expenses |
|--|-----------------------|------------------------------------|---|--------------------------------|
| 1 Grants and other assistance to domestic organizations and domestic governments. See Part IV, line 21 | 7,117,301. | 7,117,301. | | |
| 2 Grants and other assistance to domestic individuals. See Part IV, line 22 | 13,350. | 13,350. | | |
| 3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16 | 3,337,159. | 3,337,159. | | |
| 4 Benefits paid to or for members | | | | |
| 5 Compensation of current officers, directors, trustees, and key employees | 352,453. | 235,494. | 77,129. | 39,830. |
| 6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) | | | | |
| 7 Other salaries and wages | 1,005,136. | 743,605. | 145,566. | 115,965. |
| 8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions) | 22,699. | 17,493. | 3,331. | 1,875. |
| 9 Other employee benefits | 94,846. | 79,156. | 5,460. | 10,230. |
| 10 Payroll taxes | 97,523. | 72,766. | 15,658. | 9,099. |
| 11 Fees for services (nonemployees): | | | | |
| a Management | | | | |
| b Legal | | | | |
| c Accounting | 28,777. | | 28,777. | |
| d Lobbying | 7,550. | 7,550. | | |
| e Professional fundraising services. See Part IV, line 17 | | | | |
| f Investment management fees | | | | |
| g Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Sch O.) | 487,223. | 383,230. | 10,373. | 93,620. |
| 12 Advertising and promotion | | | | |
| 13 Office expenses | 16,786. | 1,995. | 5,023. | 9,768. |
| 14 Information technology | | | | |
| 15 Royalties | | | | |
| 16 Occupancy | 47,789. | 32,849. | 8,264. | 6,676. |
| 17 Travel | | | | |
| 18 Payments of travel or entertainment expenses for any federal, state, or local public officials | | | | |
| 19 Conferences, conventions, and meetings | 250,194. | 198,384. | 47,520. | 4,290. |
| 20 Interest | | | | |
| 21 Payments to affiliates | | | | |
| 22 Depreciation, depletion, and amortization | | | | |
| 23 Insurance | 15,021. | 2,486. | 9,213. | 3,322. |
| 24 Other expenses. Itemize expenses not covered above. (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A), amount, list line 24e expenses on Schedule O.) | | | | |
| a SUBSCRIPTIONS & LICENSES | 306,389. | 280,541. | 0. | 25,848. |
| b CREDIT CARD & BANK FEES | 27,790. | 213. | 397. | 27,180. |
| c FACILITIES & EQUIPMENT | 15,239. | 1,000. | 14,239. | 0. |
| d PRINTING AND COPYING | 13,354. | 4,091. | 1,125. | 8,138. |
| e All other expenses | 20,657. | 5,356. | 2,682. | 12,619. |
| 25 Total functional expenses. Add lines 1 through 24e | 13,277,236. | 12,534,019. | 374,757. | 368,460. |
| 26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720) | | | | |

Part X Balance SheetCheck if Schedule O contains a response or note to any line in this Part X

| | | (A) Beginning of year | | (B) End of year |
|------------------------------------|---|-----------------------------|----|--------------------|
| Assets | 1 Cash - non-interest-bearing | 3,076,159. | 1 | 1,776,063. |
| | 2 Savings and temporary cash investments | 1,880,952. | 2 | 2,220,120. |
| | 3 Pledges and grants receivable, net | 766,590. | 3 | 693,221. |
| | 4 Accounts receivable, net | | 4 | |
| | 5 Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons | | 5 | |
| | 6 Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B) | | 6 | |
| | 7 Notes and loans receivable, net | | 7 | |
| | 8 Inventories for sale or use | | 8 | |
| | 9 Prepaid expenses and deferred charges | 49,155. | 9 | 67,503. |
| | 10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D | 10a | | |
| | b Less: accumulated depreciation | 10b | | 10c |
| | 11 Investments - publicly traded securities | 1,870,166. | 11 | 1,705,100. |
| | 12 Investments - other securities. See Part IV, line 11 | | 12 | 432,680. |
| | 13 Investments - program-related. See Part IV, line 11 | 5,458. | 13 | 5,458. |
| | 14 Intangible assets | | 14 | |
| | 15 Other assets. See Part IV, line 11 | 103,796. | 15 | 46,404. |
| | 16 Total assets. Add lines 1 through 15 (must equal line 33) | 7,752,276. | 16 | 6,946,549. |
| Liabilities | 17 Accounts payable and accrued expenses | 1,489,034. | 17 | 615,612. |
| | 18 Grants payable | | 18 | |
| | 19 Deferred revenue | 4,567. | 19 | 10,630. |
| | 20 Tax-exempt bond liabilities | | 20 | |
| | 21 Escrow or custodial account liability. Complete Part IV of Schedule D | | 21 | |
| | 22 Loans and other payables to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons | | 22 | |
| | 23 Secured mortgages and notes payable to unrelated third parties | | 23 | |
| | 24 Unsecured notes and loans payable to unrelated third parties | | 24 | |
| | 25 Other liabilities (including federal income tax, payables to related third parties, and other liabilities not included on lines 17-24). Complete Part X of Schedule D | 112,047. | 25 | 49,940. |
| | 26 Total liabilities. Add lines 17 through 25 | 1,605,648. | 26 | 676,182. |
| Net Assets or Fund Balances | Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33. | | | |
| | 27 Net assets without donor restrictions | 5,182,849. | 27 | 3,919,967. |
| | 28 Net assets with donor restrictions | 963,779. | 28 | 2,350,400. |
| | Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33. | | | |
| | 29 Capital stock or trust principal, or current funds | | 29 | |
| | 30 Paid-in or capital surplus, or land, building, or equipment fund | | 30 | |
| | 31 Retained earnings, endowment, accumulated income, or other funds | | 31 | |
| | 32 Total net assets or fund balances | 6,146,628. | 32 | 6,270,367. |
| | 33 Total liabilities and net assets/fund balances | 7,752,276. | 33 | 6,946,549. |

Part XI Reconciliation of Net AssetsCheck if Schedule O contains a response or note to any line in this Part XI

| | | |
|---|----|-------------|
| 1 Total revenue (must equal Part VIII, column (A), line 12) | 1 | 13,135,426. |
| 2 Total expenses (must equal Part IX, column (A), line 25) | 2 | 13,277,236. |
| 3 Revenue less expenses. Subtract line 2 from line 1 | 3 | -141,810. |
| 4 Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A)) | 4 | 6,146,628. |
| 5 Net unrealized gains (losses) on investments | 5 | 173,831. |
| 6 Donated services and use of facilities | 6 | |
| 7 Investment expenses | 7 | |
| 8 Prior period adjustments | 8 | |
| 9 Other changes in net assets or fund balances (explain on Schedule O) | 9 | 91,718. |
| 10 Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B)) | 10 | 6,270,367. |

Part XII Financial Statements and ReportingCheck if Schedule O contains a response or note to any line in this Part XII

| | Yes | No |
|--|-----|----|
| 1 Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other | | |
| If the organization changed its method of accounting from a prior year or checked "Other," explain on Schedule O. | | |
| 2a Were the organization's financial statements compiled or reviewed by an independent accountant? | 2a | X |
| If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: | | |
| <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis | | |
| b Were the organization's financial statements audited by an independent accountant? | 2b | X |
| If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: | | |
| <input type="checkbox"/> Separate basis <input checked="" type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis | | |
| c If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? | 2c | X |
| If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O. | | |
| 3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Uniform Guidance, 2 C.F.R. Part 200, Subpart F? | 3a | X |
| b If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why on Schedule O and describe any steps taken to undergo such audits | 3b | |

Form 990 (2024)

SCHEDULE A
(Form 990)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

Complete if the organization is a section 501(c)(3) organization or a section

4947(a)(1) nonexempt charitable trust.

Attach to Form 990 or Form 990-EZ.

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2024

Open to Public
Inspection

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number

52-2122720

Part I Reason for Public Charity Status. (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 12, check only one box.)

- 1 A church, convention of churches, or association of churches described in **section 170(b)(1)(A)(i)**.
- 2 A school described in **section 170(b)(1)(A)(ii)**. (Attach Schedule E (Form 990).)
- 3 A hospital or a cooperative hospital service organization described in **section 170(b)(1)(A)(iii)**.
- 4 A medical research organization operated in conjunction with a hospital described in **section 170(b)(1)(A)(iii)**. Enter the hospital's name, city, and state: _____
- 5 An organization operated for the benefit of a college or university owned or operated by a governmental unit described in **section 170(b)(1)(A)(iv)**. (Complete Part II.)
- 6 A federal, state, or local government or governmental unit described in **section 170(b)(1)(A)(v)**.
- 7 An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 8 A community trust described in **section 170(b)(1)(A)(vi)**. (Complete Part II.)
- 9 An agricultural research organization described in **section 170(b)(1)(A)(ix)** operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or university: _____
- 10 An organization that normally receives (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions, subject to certain exceptions; and (2) no more than 33 1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See **section 509(a)(2)**. (Complete Part III.)
- 11 An organization organized and operated exclusively to test for public safety. See **section 509(a)(4)**.
- 12 An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in **section 509(a)(1)** or **section 509(a)(2)**. See **section 509(a)(3)**. Check the box on lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
 - a **Type I.** A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. **You must complete Part IV, Sections A and B.**
 - b **Type II.** A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). **You must complete Part IV, Sections A and C.**
 - c **Type III functionally integrated.** A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). **You must complete Part IV, Sections A, D, and E.**
 - d **Type III non-functionally integrated.** A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). **You must complete Part IV, Sections A and D, and Part V.**
 - e Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
 - f Enter the number of supported organizations
 - g Provide the following information about the supported organization(s).

| (i) Name of supported organization | (ii) EIN | (iii) Type of organization (described on lines 1-10 above (see instructions)) | (iv) Is the organization listed in your governing document? | | (v) Amount of monetary support (see instructions) | (vi) Amount of other support (see instructions) |
|------------------------------------|----------|---|---|----|---|---|
| | | | Yes | No | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| Total | | | | | | |

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Section A. Public Support

| Calendar year (or fiscal year beginning in) | (a) 2020 | (b) 2021 | (c) 2022 | (d) 2023 | (e) 2024 | (f) Total |
|---|-----------|----------|-----------|-----------|-----------|-----------|
| 1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") | 12628384. | 7808772. | 11604349. | 12011078. | 13517065. | 57569648. |
| 2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf | | | | | | |
| 3 The value of services or facilities furnished by a governmental unit to the organization without charge | | | | | | |
| 4 Total. Add lines 1 through 3 | 12628384. | 7808772. | 11604349. | 12011078. | 13517065. | 57569648. |
| 5 The portion of total contributions by each person (other than a governmental unit or publicly supported organization) included on line 1 that exceeds 2% of the amount shown on line 11, column (f) | | | | | | 16878960. |
| 6 Public support. Subtract line 5 from line 4. | | | | | | 40690688. |

Section B. Total Support

| Calendar year (or fiscal year beginning in) | (a) 2020 | (b) 2021 | (c) 2022 | (d) 2023 | (e) 2024 | (f) Total |
|---|-----------|----------|-----------|-----------|-----------|--------------------------|
| 7 Amounts from line 4 | 12628384. | 7808772. | 11604349. | 12011078. | 13517065. | 57569648. |
| 8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources ... | 38,997. | 47,170. | 65,540. | 130,614. | 145,621. | 427,942. |
| 9 Net income from unrelated business activities, whether or not the business is regularly carried on | | | | | | |
| 10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) | | | | | | |
| 11 Total support. Add lines 7 through 10 | | | | | | 57997590. |
| 12 Gross receipts from related activities, etc. (see instructions) | | | | | 12 | |
| 13 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here | | | | | | <input type="checkbox"/> |

Section C. Computation of Public Support Percentage

| | | | |
|--|----|-------|--------------------------|
| 14 Public support percentage for 2024 (line 6, column (f), divided by line 11, column (f)) | 14 | 70.16 | % |
| 15 Public support percentage from 2023 Schedule A, Part II, line 14 | 15 | 74.78 | % |
| 16a 33 1/3% support test - 2024. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here . The organization qualifies as a publicly supported organization | | X | |
| b 33 1/3% support test - 2023. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here . The organization qualifies as a publicly supported organization | | | <input type="checkbox"/> |
| 17a 10% -facts-and-circumstances test - 2024. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here . Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization | | | <input type="checkbox"/> |
| b 10% -facts-and-circumstances test - 2023. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the facts-and-circumstances test, check this box and stop here . Explain in Part VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization | | | <input type="checkbox"/> |
| 18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions | | | <input type="checkbox"/> |

Schedule A (Form 990) 2024

Part III Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 10 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

| Calendar year (or fiscal year beginning in) | (a) 2020 | (b) 2021 | (c) 2022 | (d) 2023 | (e) 2024 | (f) Total |
|--|----------|----------|----------|----------|----------|-----------|
| 1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.") | | | | | | |
| 2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose | | | | | | |
| 3 Gross receipts from activities that are not an unrelated trade or business under section 513 | | | | | | |
| 4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf | | | | | | |
| 5 The value of services or facilities furnished by a governmental unit to the organization without charge | | | | | | |
| 6 Total. Add lines 1 through 5 | | | | | | |
| 7a Amounts included on lines 1, 2, and 3 received from disqualified persons | | | | | | |
| b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year | | | | | | |
| c Add lines 7a and 7b | | | | | | |
| 8 Public support. (Subtract line 7c from line 6.) | | | | | | |

Section B. Total Support

| Calendar year (or fiscal year beginning in) | (a) 2020 | (b) 2021 | (c) 2022 | (d) 2023 | (e) 2024 | (f) Total |
|--|----------|----------|----------|----------|----------|-----------|
| 9 Amounts from line 6 | | | | | | |
| 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources | | | | | | |
| b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975 | | | | | | |
| c Add lines 10a and 10b | | | | | | |
| 11 Net income from unrelated business activities not included on line 10b, whether or not the business is regularly carried on | | | | | | |
| 12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.) | | | | | | |
| 13 Total support. (Add lines 9, 10c, 11, and 12.) | | | | | | |

14 First 5 years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here**

Section C. Computation of Public Support Percentage

| | | |
|--|----|---|
| 15 Public support percentage for 2024 (line 8, column (f), divided by line 13, column (f)) | 15 | % |
| 16 Public support percentage from 2023 Schedule A, Part III, line 15 | 16 | % |

Section D. Computation of Investment Income Percentage

| | | |
|---|----|---|
| 17 Investment income percentage for 2024 (line 10c, column (f), divided by line 13, column (f)) | 17 | % |
| 18 Investment income percentage from 2023 Schedule A, Part III, line 17 | 18 | % |

19a 33 1/3% support tests - 2024. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization

b 33 1/3% support tests - 2023. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization

20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions

Part IV Supporting Organizations

(Complete only if you checked a box on line 12 of Part I. If you checked box 12a, Part I, complete Sections A and B. If you checked box 12b, Part I, complete Sections A and C. If you checked box 12c, Part I, complete Sections A, D, and E. If you checked box 12d, Part I, complete Sections A and D, and complete Part V.)

Section A. All Supporting Organizations

| | Yes | No |
|------------|------------|-----------|
| 1 | | |
| 2 | | |
| 3a | | |
| 3b | | |
| 3c | | |
| 4a | | |
| 4b | | |
| 4c | | |
| 5a | | |
| 5b | | |
| 5c | | |
| 6 | | |
| 7 | | |
| 8 | | |
| 9a | | |
| 9b | | |
| 9c | | |
| 10a | | |
| 10b | | |

1 Are all of the organization's supported organizations listed by name in the organization's governing documents? If "No," describe in **Part VI** how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.

2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? If "Yes," explain in **Part VI** how the organization determined that the supported organization was described in section 509(a)(1) or (2).

3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer lines 3b and 3c below.

b Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? If "Yes," describe in **Part VI** when and how the organization made the determination.

c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? If "Yes," explain in **Part VI** what controls the organization put in place to ensure such use.

4a Was any supported organization not organized in the United States ("foreign supported organization")? If "Yes," and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.

b Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? If "Yes," describe in **Part VI** how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.

c Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? If "Yes," explain in **Part VI** what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.

5a Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in **Part VI**, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).

b Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?

c Substitutions only. Was the substitution the result of an event beyond the organization's control?

6 Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in **Part VI**.

7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? If "Yes," complete **Part I** of Schedule L (Form 990).

8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? If "Yes," complete **Part I** of Schedule L (Form 990).

9a Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? If "Yes," provide detail in **Part VI**.

b Did one or more disqualified persons (as defined on line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? If "Yes," provide detail in **Part VI**.

c Did a disqualified person (as defined on line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? If "Yes," provide detail in **Part VI**.

10a Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? If "Yes," answer line 10b below.

b Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)

Part IV Supporting Organizations (continued)

| | Yes | No |
|---|-----|----|
| 11 Has the organization accepted a gift or contribution from any of the following persons? | | |
| a A person who directly or indirectly controls, either alone or together with persons described on lines 11b and 11c below, the governing body of a supported organization? | 11a | |
| b A family member of a person described on line 11a above? | 11b | |
| c A 35% controlled entity of a person described on line 11a or 11b above? If "Yes" to line 11a, 11b, or 11c, provide detail in Part VI. | 11c | |

Section B. Type I Supporting Organizations

| | Yes | No |
|--|-----|----|
| 1 Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, directors, or trustees at all times during the tax year? If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove officers, directors, or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year. | 1 | |
| 2 Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization. | 2 | |

Section C. Type II Supporting Organizations

| | Yes | No |
|---|-----|----|
| 1 Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s). | 1 | |

Section D. All Type III Supporting Organizations

| | Yes | No |
|---|-----|----|
| 1 Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided? | 1 | |
| 2 Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s). | 2 | |
| 3 By reason of the relationship described on line 2, above, did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year? If "Yes," describe in Part VI the role the organization's supported organizations played in this regard. | 3 | |

Section E. Type III Functionally Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).

- a The organization satisfied the Activities Test. Complete line 2 below.
- b The organization is the parent of each of its supported organizations. Complete line 3 below.
- c The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see instructions).

2 Activities Test. Answer lines 2a and 2b below.

- a** Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.

- b** Did the activities described on line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.

3 Parent of Supported Organizations. Answer lines 3a and 3b below.

- a** Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? If "Yes" or "No," provide details in Part VI.
- b** Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If "Yes," describe in Part VI the role played by the organization in this regard.

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations

1 Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 (*explain in Part VI*). **See instructions.**
All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

| Section A - Adjusted Net Income | | (A) Prior Year | (B) Current Year (optional) |
|---|-----------|----------------|--------------------------------|
| 1 Net short-term capital gain | 1 | | |
| 2 Recoveries of prior-year distributions | 2 | | |
| 3 Other gross income (see instructions) | 3 | | |
| 4 Add lines 1 through 3. | 4 | | |
| 5 Depreciation and depletion | 5 | | |
| 6 Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions) | 6 | | |
| 7 Other expenses (see instructions) | 7 | | |
| 8 Adjusted Net Income (subtract lines 5, 6, and 7 from line 4) | 8 | | |
| Section B - Minimum Asset Amount | | (A) Prior Year | (B) Current Year (optional) |
| 1 Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year): | | | |
| a Average monthly value of securities | 1a | | |
| b Average monthly cash balances | 1b | | |
| c Fair market value of other non-exempt-use assets | 1c | | |
| d Total (add lines 1a, 1b, and 1c) | 1d | | |
| e Discount claimed for blockage or other factors (<i>explain in detail in Part VI</i>): | | | |
| 2 Acquisition indebtedness applicable to non-exempt-use assets | 2 | | |
| 3 Subtract line 2 from line 1d. | 3 | | |
| 4 Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions). | 4 | | |
| 5 Net value of non-exempt-use assets (subtract line 4 from line 3) | 5 | | |
| 6 Multiply line 5 by 0.035. | 6 | | |
| 7 Recoveries of prior-year distributions | 7 | | |
| 8 Minimum Asset Amount (add line 7 to line 6) | 8 | | |
| Section C - Distributable Amount | | | Current Year |
| 1 Adjusted net income for prior year (from Section A, line 8, column A) | 1 | | |
| 2 Enter 0.85 of line 1. | 2 | | |
| 3 Minimum asset amount for prior year (from Section B, line 8, column A) | 3 | | |
| 4 Enter greater of line 2 or line 3. | 4 | | |
| 5 Income tax imposed in prior year | 5 | | |
| 6 Distributable Amount. Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions). | 6 | | |
| 7 <input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions). | | | |

Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)

| Section D - Distributions | | Current Year |
|---------------------------|---|--------------|
| 1 | Amounts paid to supported organizations to accomplish exempt purposes | 1 |
| 2 | Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity | 2 |
| 3 | Administrative expenses paid to accomplish exempt purposes of supported organizations | 3 |
| 4 | Amounts paid to acquire exempt-use assets | 4 |
| 5 | Qualified set-aside amounts (prior IRS approval required - <i>provide details in Part VI</i>) | 5 |
| 6 | Other distributions (describe in Part VI). See instructions. | 6 |
| 7 | Total annual distributions. Add lines 1 through 6. | 7 |
| 8 | Distributions to attentive supported organizations to which the organization is responsive (<i>provide details in Part VI</i>). See instructions. | 8 |
| 9 | Distributable amount for 2024 from Section C, line 6 | 9 |
| 10 | Line 8 amount divided by line 9 amount | 10 |

| Section E - Distribution Allocations (see instructions) | (i) Excess Distributions | (ii) Underdistributions Pre-2024 | (iii) Distributable Amount for 2024 |
|--|-----------------------------|--|---|
| 1 Distributable amount for 2024 from Section C, line 6 | | | |
| 2 Underdistributions, if any, for years prior to 2024 (reasonable cause required - <i>explain in Part VI</i>). See instructions. | | | |
| 3 Excess distributions carryover, if any, to 2024 | | | |
| a From 2019 | | | |
| b From 2020 | | | |
| c From 2021 | | | |
| d From 2022 | | | |
| e From 2023 | | | |
| f Total of lines 3a through 3e | | | |
| g Applied to under distributions of prior years | | | |
| h Applied to 2024 distributable amount | | | |
| i Carryover from 2019 not applied (see instructions) | | | |
| j Remainder. Subtract lines 3g, 3h, and 3i from line 3f. | | | |
| 4 Distributions for 2024 from Section D, line 7: \$ | | | |
| a Applied to underdistributions of prior years | | | |
| b Applied to 2024 distributable amount | | | |
| c Remainder. Subtract lines 4a and 4b from line 4. | | | |
| 5 Remaining underdistributions for years prior to 2024, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, <i>explain in Part VI</i> . See instructions. | | | |
| 6 Remaining underdistributions for 2024. Subtract lines 3h and 4b from line 1. For result greater than zero, <i>explain in Part VI</i> . See instructions. | | | |
| 7 Excess distributions carryover to 2025. Add lines 3j and 4c. | | | |
| 8 Breakdown of line 7: | | | |
| a Excess from 2020 | | | |
| b Excess from 2021 | | | |
| c Excess from 2022 | | | |
| d Excess from 2023 | | | |
| e Excess from 2024 | | | |

Schedule A (Form 990) 2024

Part VI

Supplemental Information. Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12;

Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a and 3b; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5, 6, and 8; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information.
(See instructions.)

SCHEDULE C
(Form 990)Department of the Treasury
Internal Revenue Service**Political Campaign and Lobbying Activities**

For Organizations Exempt From Income Tax Under Section 501(c) and Section 527

Complete if the organization is described below. Attach to Form 990 or Form 990-EZ.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2024Open to Public
Inspection**If the organization answered "Yes" on Form 990, Part IV, line 3, or Form 990-EZ, Part V, line 46 (Political Campaign Activities), then:**

- Section 501(c)(3) organizations: Complete Parts I-A and I-B. Do not complete Part I-C.
- Section 501(c) (other than section 501(c)(3)) organizations: Complete Parts I-A and I-C below. Do not complete Part I-B.
- Section 527 organizations: Complete Part I-A only.

If the organization answered "Yes" on Form 990, Part IV, line 4, or Form 990-EZ, Part VI, line 47 (Lobbying Activities), then:

- Section 501(c)(3) organizations that have filed Form 5768 (election under section 501(h)): Complete Part II-A. Do not complete Part II-B.
- Section 501(c)(3) organizations that have NOT filed Form 5768 (election under section 501(h)): Complete Part II-B. Do not complete Part II-A.

If the organization answered "Yes" on Form 990, Part IV, line 5 (Proxy Tax) (see separate instructions), or Form 990-EZ, Part V, line 35c (Proxy Tax) (see separate instructions), then:

- Section 501(c)(4), (5), or (6) organizations: Complete Part III.

Name of organization

Employer identification number (EIN)

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

52-2122720

Part I-A Complete if the organization is exempt under section 501(c) or is a section 527 organization.

1 Provide a description of the organization's direct and indirect political campaign activities in Part IV.

2 Political campaign activity expenditures \$ _____

3 Volunteer hours for political campaign activities _____

Part I-B Complete if the organization is exempt under section 501(c)(3).

1 Enter the amount of any excise tax incurred by the organization under section 4955 \$ _____

2 Enter the amount of any excise tax incurred by organization managers under section 4955 \$ _____

3 If the organization incurred a section 4955 tax, did it file Form 4720 for this year? Yes No4a Was a correction made? Yes No

b If "Yes," describe in Part IV.

Part I-C Complete if the organization is exempt under section 501(c), except section 501(c)(3).

1 Enter the amount directly expended by the filing organization for section 527 exempt function activities \$ _____

2 Enter the amount of the filing organization's funds contributed to other organizations for section 527
exempt function activities \$ _____3 Total exempt function expenditures. Add lines 1 and 2. Enter here and on Form 1120-POL,
line 17b \$ _____4 Did the filing organization file Form 1120-POL for this year? Yes No5 Enter the names, addresses, and EINs of all section 527 political organizations to which the filing organization made payments. For each
organization listed, enter the amount paid from the filing organization's funds. Also enter the amount of political contributions received that were
promptly and directly delivered to a separate political organization, such as a separate segregated fund or a political action committee (PAC).
If additional space is needed, provide information in Part IV.

| (a) Name | (b) Address | (c) EIN | (d) Amount paid from filing organization's funds. If none, enter -0-. | (e) Amount of political contributions received and promptly and directly delivered to a separate political organization. If none, enter -0-. |
|----------|-------------|---------|---|---|
| | | | | |
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For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule C (Form 990) 2024

Part II-A Complete if the organization is exempt under section 501(c)(3) and filed Form 5768 (election under section 501(h)).

- A** Check if the filing organization belongs to an affiliated group (and list in Part IV each affiliated group member's name, address, EIN, expenses, and share of excess lobbying expenditures).
- B** Check if the filing organization checked box A and "limited control" provisions apply.

| Limits on Lobbying Expenditures (The term "expenditures" means amounts paid or incurred.) | | (a) Filing organization's totals | (b) Affiliated group totals |
|--|--|---|--|
| 1a Total lobbying expenditures to influence public opinion (grassroots lobbying) | | 3 , 586 . | |
| b Total lobbying expenditures to influence a legislative body (direct lobbying) | | 11 , 586 . | |
| c Total lobbying expenditures (add lines 1a and 1b) | | 15 , 172 . | |
| d Other exempt purpose expenditures | | 12 , 827 , 374 . | |
| e Total exempt purpose expenditures (add lines 1c and 1d) | | 12 , 842 , 546 . | |
| f Lobbying nontaxable amount. Enter the amount from the following table in both columns. | | 792 , 127 . | |
| IF the amount on line 1e, column (a) or (b), is: | THEN the lobbying nontaxable amount is: | | |
| not over \$500,000 | 20% of the amount on line 1e. | | |
| over \$500,000 but not over \$1,000,000 | \$100,000 plus 15% of the excess over \$500,000. | | |
| over \$1,000,000 but not over \$1,500,000 | \$175,000 plus 10% of the excess over \$1,000,000. | | |
| over \$1,500,000 but not over \$17,000,000 | \$225,000 plus 5% of the excess over \$1,500,000. | | |
| over \$17,000,000 | \$1,000,000. | | |
| g Grassroots nontaxable amount (enter 25% of line 1f) | | 198 , 032 . | |
| h Subtract line 1g from line 1a. If zero or less, enter -0 | | 0 . | |
| i Subtract line 1f from line 1c. If zero or less, enter -0 | | 0 . | |
| j If there is an amount other than zero on either line 1h or line 1i, did the organization file Form 4720 reporting section 4911 tax for this year? | | | <input type="checkbox"/> Yes <input type="checkbox"/> No |

4-Year Averaging Period Under Section 501(h)

(Some organizations that made a section 501(h) election do not have to complete all of the five columns below.

See the separate instructions for lines 2a through 2f.)

Lobbying Expenditures During 4-Year Averaging Period

| Calendar year (or fiscal year beginning in) | (a) 2021 | (b) 2022 | (c) 2023 | (d) 2024 | (e) Total |
|---|-------------|-------------|-------------|-------------|-----------------|
| 2a Lobbying nontaxable amount | 629 , 867 . | 742 , 201 . | 757 , 339 . | 792 , 127 . | 2 , 921 , 534 . |
| b Lobbying ceiling amount (150% of line 2a, column(e)) | | | | | 4 , 382 , 301 . |
| c Total lobbying expenditures | 19 , 687 . | 20 , 584 . | 20 , 400 . | 15 , 172 . | 75 , 843 . |
| d Grassroots nontaxable amount | 157 , 467 . | 185 , 550 . | 189 , 335 . | 198 , 032 . | 730 , 384 . |
| e Grassroots ceiling amount (150% of line 2d, column (e)) | | | | | 1 , 095 , 576 . |
| f Grassroots lobbying expenditures | 3 , 570 . | 3 , 567 . | 3 , 700 . | 3 , 586 . | 14 , 423 . |

Part II-B Complete if the organization is exempt under section 501(c)(3) and has NOT filed Form 5768 (election under section 501(h)).

| For each "Yes" response on lines 1a through 1i below, provide in Part IV a detailed description of the lobbying activity. | (a) | | (b) |
|--|-----|----|--------|
| | Yes | No | Amount |
| 1 During the year, did the filing organization attempt to influence foreign, national, state, or local legislation, including any attempt to influence public opinion on a legislative matter or referendum, through the use of: | | | |
| a Volunteers? | | | |
| b Paid staff or management (include compensation in expenses reported on lines 1c through 1i)? | | | |
| c Media advertisements? | | | |
| d Mailings to members, legislators, or the public? | | | |
| e Publications, or published or broadcast statements? | | | |
| f Grants to other organizations for lobbying purposes? | | | |
| g Direct contact with legislators, their staffs, government officials, or a legislative body? | | | |
| h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any similar means? | | | |
| i Other activities? | | | |
| j Total. Add lines 1c through 1i | | | |
| 2a Did the activities in line 1 cause the organization to not be described in section 501(c)(3)? | | | |
| b If "Yes," enter the amount of any tax incurred under section 4912 | | | |
| c If "Yes," enter the amount of any tax incurred by organization managers under section 4912 | | | |
| d If the filing organization incurred a section 4912 tax, did it file Form 4720 for this year? | | | |

Part III-A Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6).

| | Yes | No |
|---|-----|----|
| 1 Were substantially all (90% or more) dues received nondeductible by members? | 1 | |
| 2 Did the organization make only in-house lobbying expenditures of \$2,000 or less? | 2 | |
| 3 Did the organization agree to carry over lobbying and political campaign activity expenditures from the prior year? | 3 | |

Part III-B Complete if the organization is exempt under section 501(c)(4), section 501(c)(5), or section 501(c)(6) and if either (a) BOTH Part III-A, lines 1 and 2, are answered "No;" OR (b) Part III-A, line 3, is answered "Yes."

| | | |
|---|----|--|
| 1 Dues, assessments, and similar amounts from members | 1 | |
| 2 Section 162(e) nondeductible lobbying and political expenditures (do not include amounts of political expenses for which the section 527(f) tax was paid): | | |
| a Current year | 2a | |
| b Carryover from last year | 2b | |
| c Total | 2c | |
| 3 Aggregate amount reported in section 6033(e)(1)(A) notices of nondeductible section 162(e) dues | 3 | |
| 4 If notices were sent and the amount on line 2c exceeds the amount on line 3, what portion of the excess does the organization agree to carryover to the reasonable estimate of nondeductible lobbying and political expenditures next year? | 4 | |
| 5 Taxable amount of lobbying and political expenditures. See instructions | 5 | |

Part IV Supplemental Information

Provide the descriptions required for Part I-A, line 1; Part I-B, line 4; Part I-C, line 5; Part II-A (affiliated group list); Part II-A, lines 1 and 2 (see instructions); and Part II-B, line 1. Also, complete this part for any additional information.

SCHEDULE D

(Form 990)

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service**Supplemental Financial Statements**

OMB No. 1545-0047

Complete if the organization answered "Yes" on Form 990,
Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.

Attach to Form 990.

Go to www.irs.gov/Form990 for instructions and the latest information.Open to Public
Inspection

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number

52-2122720

Part I**Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts.**

Complete if the organization answered "Yes" on Form 990, Part IV, line 6.

| | (a) Donor advised funds | (b) Funds and other accounts |
|---|-------------------------|--|
| 1 Total number at end of year | | |
| 2 Aggregate value of contributions to (during year) | | |
| 3 Aggregate value of grants from (during year) | | |
| 4 Aggregate value at end of year | | |
| 5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control? | | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit? | | <input type="checkbox"/> Yes <input type="checkbox"/> No |

Part II Conservation Easements. Complete if the organization answered "Yes" on Form 990, Part IV, line 7.

- 1 Purpose(s) of conservation easements held by the organization (check all that apply).

| | |
|---|---|
| <input type="checkbox"/> Preservation of land for public use (for example, recreation or education) | <input type="checkbox"/> Preservation of a historically important land area |
| <input type="checkbox"/> Protection of natural habitat | <input type="checkbox"/> Preservation of a certified historic structure |
| <input type="checkbox"/> Preservation of open space | |

- 2 Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year.

| | Held at the End of the Tax Year |
|----|---------------------------------|
| 2a | |
| 2b | |
| 2c | |
| 2d | |

- a Total number of conservation easements

- b Total acreage restricted by conservation easements

- c Number of conservation easements on a certified historic structure included on line 2a

- d Number of conservation easements included on line 2c acquired after July 25, 2006, and not on a historic structure listed in the National Register

- 3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year

- 4 Number of states where property subject to conservation easement is located

- 5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?

 Yes No

- 6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year

- 7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year

- 8 Does each conservation easement reported on line 2d above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)?

 Yes No

- 9 In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets.

Complete if the organization answered "Yes" on Form 990, Part IV, line 8.

- 1a If the organization elected, as permitted under FASB ASC 958, not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide in Part XIII the text of the footnote to its financial statements that describes these items.

- b If the organization elected, as permitted under FASB ASC 958, to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items.

| | |
|---|----------|
| (i) Revenue included on Form 990, Part VIII, line 1 | \$ |
| (ii) Assets included in Form 990, Part X | \$ |

- 2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items:

| | |
|---|----------|
| a Revenue included on Form 990, Part VIII, line 1 | \$ |
| b Assets included in Form 990, Part X | \$ |

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule D (Form 990) (Rev. 12-2024)

LHA 432051 01-02-25

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets (continued)

- 3 Using the organization's acquisition, accession, and other records, check any of the following that make significant use of its collection items (check all that apply).
- | | |
|--|---|
| a <input type="checkbox"/> Public exhibition | d <input type="checkbox"/> Loan or exchange program |
| b <input type="checkbox"/> Scholarly research | e <input type="checkbox"/> Other _____ |
| c <input type="checkbox"/> Preservation for future generations | |
- 4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.
- 5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? Yes No

Part IV Escrow and Custodial Arrangements Complete if the organization answered "Yes" on Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

- 1a Is the organization an agent, trustee, custodian, or other intermediary for contributions or other assets not included on Form 990, Part X? Yes No
- b If "Yes," explain the arrangement in Part XIII and complete the following table:
- | | Amount |
|----|--------|
| 1c | |
| 1d | |
| 1e | |
| 1f | |
- 2a Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability? Yes No
- b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII

Part V Endowment Funds Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

| | (a) Current year | (b) Prior year | (c) Two years back | (d) Three years back | (e) Four years back |
|--|------------------|----------------|--------------------|----------------------|---------------------|
| 1a Beginning of year balance | | | | | |
| b Contributions | | | | | |
| c Net investment earnings, gains, and losses | | | | | |
| d Grants or scholarships | | | | | |
| e Other expenditures for facilities and programs | | | | | |
| f Administrative expenses | | | | | |
| g End of year balance | | | | | |

- 2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:

- a Board designated or quasi-endowment _____ %
 b Permanent endowment _____ %
 c Term endowment _____ %

The percentages on lines 2a, 2b, and 2c should equal 100%.

- 3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:

- (i) Unrelated organizations?
- (ii) Related organizations?

| Yes | No |
|--------|----|
| 3a(i) | |
| 3a(ii) | |
| 3b | |

- b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R?

- 4 Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI Land, Buildings, and Equipment

Complete if the organization answered "Yes" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

| Description of property | (a) Cost or other basis (investment) | (b) Cost or other basis (other) | (c) Accumulated depreciation | (d) Book value |
|--------------------------------|--------------------------------------|---------------------------------|------------------------------|----------------|
| 1a Land | | | | |
| b Buildings | | | | |
| c Leasehold improvements | | | | |
| d Equipment | | | | |
| e Other | | | | |

Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, line 10c, column (B)) 0.

Part VII Investments - Other Securities

Complete if the organization answered "Yes" on Form 990, Part IV, line 11b. See Form 990, Part X, line 12.

| (a) Description of security or category (including name of security) | (b) Book value | (c) Method of valuation: Cost or end-of-year market value |
|--|----------------|---|
| (1) Financial derivatives | | |
| (2) Closely held equity interests | | |
| (3) Other | | |
| (A) ISHARES CORE S&P 500 EFT | 432,680. | END-OF-YEAR MARKET VALUE |
| (B) | | |
| (C) | | |
| (D) | | |
| (E) | | |
| (F) | | |
| (G) | | |
| (H) | | |
| Total. (Col. (b) must equal Form 990, Part X, line 12, col. (B)) | 432,680. | |

Part VIII Investments - Program Related.

Complete if the organization answered "Yes" on Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

| (a) Description of investment | (b) Book value | (c) Method of valuation: Cost or end-of-year market value |
|--|----------------|---|
| (1) | | |
| (2) | | |
| (3) | | |
| (4) | | |
| (5) | | |
| (6) | | |
| (7) | | |
| (8) | | |
| (9) | | |
| Total. (Col. (b) must equal Form 990, Part X, line 13, col. (B)) | | |

Part IX Other Assets

Complete if the organization answered "Yes" on Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

| (a) Description | (b) Book value |
|--|----------------|
| (1) | |
| (2) | |
| (3) | |
| (4) | |
| (5) | |
| (6) | |
| (7) | |
| (8) | |
| (9) | |
| Total. (Column (b) must equal Form 990, Part X, line 15, col. (B)) | |

Part X Other Liabilities

Complete if the organization answered "Yes" on Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 25.

| 1. (a) Description of liability | (b) Book value |
|--|----------------|
| (1) Federal income taxes | |
| (2) LEASE LIABILITIES, CURRENT PORTION | 49,940. |
| (3) | |
| (4) | |
| (5) | |
| (6) | |
| (7) | |
| (8) | |
| (9) | |
| Total. (Column (b) must equal Form 990, Part X, line 25, col. (B)) | 49,940. |

2. Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FASB ASC 740. Check here if the text of the footnote has been provided in Part XIII

Schedule D (Form 990) (Rev. 12-2024)

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

| | | |
|---|----|--|
| 1 Total revenue, gains, and other support per audited financial statements | 1 | |
| 2 Amounts included on line 1 but not on Form 990, Part VIII, line 12: | | |
| a Net unrealized gains (losses) on investments | 2a | |
| b Donated services and use of facilities | 2b | |
| c Recoveries of prior year grants | 2c | |
| d Other (Describe in Part XIII.) | 2d | |
| e Add lines 2a through 2d | 2e | |
| 3 Subtract line 2e from line 1 | 3 | |
| 4 Amounts included on Form 990, Part VIII, line 12, but not on line 1: | | |
| a Investment expenses not included on Form 990, Part VIII, line 7b | 4a | |
| b Other (Describe in Part XIII.) | 4b | |
| c Add lines 4a and 4b | 4c | |
| 5 Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.) | 5 | |

Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return

Complete if the organization answered "Yes" on Form 990, Part IV, line 12a.

| | | |
|--|----|--|
| 1 Total expenses and losses per audited financial statements | 1 | |
| 2 Amounts included on line 1 but not on Form 990, Part IX, line 25: | | |
| a Donated services and use of facilities | 2a | |
| b Prior year adjustments | 2b | |
| c Other losses | 2c | |
| d Other (Describe in Part XIII.) | 2d | |
| e Add lines 2a through 2d | 2e | |
| 3 Subtract line 2e from line 1 | 3 | |
| 4 Amounts included on Form 990, Part IX, line 25, but not on line 1: | | |
| a Investment expenses not included on Form 990, Part VIII, line 7b | 4a | |
| b Other (Describe in Part XIII.) | 4b | |
| c Add lines 4a and 4b | 4c | |
| 5 Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 18.) | 5 | |

Part XIII Supplemental Information

Provide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and 4; Part IV, lines 1b and 2b; Part V, line 4; Part X, line 2; Part XI, lines 2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide any additional information.

PART X, LINE 2:

THE INTERNAL REVENUE SERVICE HAS CLASSIFIED FARA AS EXEMPT FROM FEDERAL INCOME TAXES UNDER SECTION 501(C)(3) OF THE INTERNAL REVENUE CODE. FARA EUROPE WAS FORMED AS A NON-PROFIT ENTITY UNDER THE LAWS OF THE NETHERLANDS AND IS EXEMPT FROM INCOME TAXES.

ACCOUNTING FOR UNCERTAINTY IN INCOME TAXES CLARIFIES THE ACCOUNTING FOR UNCERTAINTY IN INCOME TAXES RECOGNIZED IN AN ENTERPRISE'S FINANCIAL STATEMENTS. MANAGEMENT HAS ANALYZED THE TAX POSITIONS TAKEN BY THE ORGANIZATION, AND HAS CONCLUDED THAT AS OF DECEMBER 31, 2024, THERE ARE NO UNCERTAIN TAX POSITIONS TAKEN OR EXPECTED TO BE TAKEN THAT WOULD REQUIRE RECOGNITION OF A LIABILITY OR DISCLOSURE IN THE FINANCIAL STATEMENTS. THE ORGANIZATION RECOGNIZES ACCRUED INTEREST AND PENALTIES ASSOCIATED WITH UNCERTAIN TAX POSITIONS, IF ANY. THERE WERE NO INCOME TAX RELATED INTEREST OR PENALTIES RECORDED FOR THE YEAR ENDED DECEMBER 31, 2024.

Part XIII Supplemental Information *(continued)*

SCHEDULE F
(Form 990)(Rev. December 2024)
Department of the Treasury
Internal Revenue Service**Statement of Activities Outside the United States**

Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16.

Attach to Form 990.

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public
Inspection

Name of the organization

Employer identification number

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

52-2122720

Part I General Information on Activities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 14b.

1 For grantmakers. Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? Yes No

2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.

3 Activities per Region. (The following Part I, line 3 table can be duplicated if additional space is needed.)

| (a) Region | (b) Number of offices in the region | (c) Number of employees, agents, and independent contractors in the region | (d) Activities conducted in the region (by type) (such as, fundraising, program services, investments, grants to recipients located in the region) | (e) If activity listed in (d) is a program service, describe specific type of service(s) in the region | (f) Total expenditures for and investments in the region |
|---|-------------------------------------|--|--|--|--|
| EUROPE | 0 | 1 | GRANTS TO RECIPIENTS LOCATED IN REGION | RESEARCH AND GRANT PROGRAM | 1,804,190. |
| EAST ASIA AND THE PACIFIC | 0 | 0 | GRANTS TO RECIPIENTS LOCATED IN REGION | RESEARCH AND GRANT PROGRAM | 970,045. |
| SOUTH AMERICA | 0 | 0 | GRANTS TO RECIPIENTS LOCATED IN REGION | RESEARCH AND GRANT PROGRAM | 93,500. |
| CANADA | 0 | 0 | GRANTS TO RECIPIENTS LOCATED IN REGION | RESEARCH AND GRANT PROGRAM | 427,972. |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| 3 a Subtotal | 0 | 1 | | | 3,295,707. |
| b Total from continuation sheets to Part I | 0 | 0 | | | 0. |
| c Totals (add lines 3a and 3b) | 0 | 1 | | | 3,295,707. |

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule F (Form 990) (Rev. 12-2024)

Part II Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

| 1 (a) Name of organization | (b) IRS code section and EIN (if applicable) | (c) Region | (d) Purpose of grant | (e) Amount of cash grant | (f) Manner of cash disbursement | (g) Amount of noncash assistance | (h) Description of noncash assistance | (i) Method of valuation (book, FMV, appraisal, other) |
|--------------------------------------|---|---------------------------|-----------------------------|---------------------------------|--|---|--|--|
| | | EAST ASIA AND THE PACIFIC | MEDICAL RESEARCH | 417,769. | WIRE | 0. | | |
| | | EAST ASIA AND THE PACIFIC | MEDICAL RESEARCH | 181,411. | WIRE | 0. | | |
| | | EAST ASIA AND THE PACIFIC | MEDICAL RESEARCH | 30,000. | WIRE | 0. | | |
| | | EAST ASIA AND THE PACIFIC | MEDICAL RESEARCH | 77,800. | WIRE | 0. | | |
| | | EAST ASIA AND THE PACIFIC | MEDICAL RESEARCH | 98,960. | WIRE | 0. | | |
| | | EAST ASIA AND THE PACIFIC | MEDICAL RESEARCH | 7,736. | WIRE | 0. | | |
| | | EAST ASIA AND THE PACIFIC | MEDICAL RESEARCH | 156,369. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 90,900. | WIRE | 0. | | |

2 Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as a tax exempt 501(c)(3) organization by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter 25

3 Enter total number of other organizations or entities 2

| Part II Continuation of Grants and Other Assistance to Organizations or Entities Outside the United States. (Schedule F (Form 990), Part II, line 1) | | | | | | | | |
|---|---|-------------------|-----------------------------|---------------------------------|--|--|---|--|
| 1 (a) Name of organization | (b) IRS code section and EIN (if applicable) | (c) Region | (d) Purpose of grant | (e) Amount of cash grant | (f) Manner of cash disbursement | (g) Amount of non-cash assistance | (h) Description of non-cash assistance | (i) Method of valuation (book, FMV, appraisal, other) |
| | | EUROPE | MEDICAL RESEARCH | 67,850. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 42,600. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 125,000. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 196,928. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 80,000. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 120,240. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 88,777. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 104,068. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 85,500. | WIRE | 0. | | |

| Part II Continuation of Grants and Other Assistance to Organizations or Entities Outside the United States. (Schedule F (Form 990), Part II, line 1) | | | | | | | | |
|---|---|-------------------|-----------------------------|---------------------------------|--|--|---|--|
| 1 (a) Name of organization | (b) IRS code section and EIN (if applicable) | (c) Region | (d) Purpose of grant | (e) Amount of cash grant | (f) Manner of cash disbursement | (g) Amount of non-cash assistance | (h) Description of non-cash assistance | (i) Method of valuation (book, FMV, appraisal, other) |
| | | EUROPE | MEDICAL RESEARCH | 124,923. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 130,750. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 407,105. | WIRE | 0. | | |
| | | EUROPE | MEDICAL RESEARCH | 139,548. | WIRE | 0. | | |
| | NORTH AMERICA - CANADA, MEXICO (NOT UNITED STATES) | MEDICAL RESEARCH | | 7,000. | WIRE | 0. | | |
| | NORTH AMERICA - CANADA, MEXICO (NOT UNITED STATES) | MEDICAL RESEARCH | | 10,913. | WIRE | 0. | | |
| | NORTH AMERICA - CANADA, MEXICO (NOT UNITED STATES) | MEDICAL RESEARCH | | 53,600. | WIRE | 0. | | |
| | NORTH AMERICA - CANADA, MEXICO (NOT UNITED STATES) | MEDICAL RESEARCH | | 356,459. | WIRE | 0. | | |
| | SOUTH AMERICA- ARGENTINA, BOLIVIA, BRAZIL, CHILE, COLUMBIA, | MEDICAL RESEARCH | | 58,500. | WIRE | 0. | | |

| Part II Continuation of Grants and Other Assistance to Organizations or Entities Outside the United States. (Schedule F (Form 990), Part II, line 1) | | | | | | | | |
|---|--|-------------------|-----------------------------|---------------------------------|--|--|---|--|
| 1 (a) Name of organization | (b) IRS code section and EIN (if applicable) | (c) Region | (d) Purpose of grant | (e) Amount of cash grant | (f) Manner of cash disbursement | (g) Amount of non-cash assistance | (h) Description of non-cash assistance | (i) Method of valuation (book, FMV, appraisal, other) |
| | SOUTH AMERICA- ARGENTINA, BOLIVIA, BRAZIL, CHILE, COLUMBIA, | MEDICAL RESEARCH | 35,000. | WIRE | 0. | | | |
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Part III Grants and Other Assistance to Individuals Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 16.

Part III can be duplicated if additional space is needed.

| (a) Type of grant or assistance | (b) Region | (c) Number of recipients | (d) Amount of cash grant | (e) Manner of cash disbursement | (f) Amount of noncash assistance | (g) Description of noncash assistance | (h) Method of valuation (book, FMV, appraisal, other) |
|---------------------------------|--|--------------------------|--------------------------|---------------------------------|----------------------------------|---------------------------------------|---|
| FARA FELLOWS AWARDS | EUROPE (INCLUDING ICELAND & GREENLAND) | 3 | 40,050. | WIRE | 0. | | |
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Part IV Foreign Forms

- 1 Was the organization a U.S. transferor of property to a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see the Instructions for Form 926)* Yes No
- 2 Did the organization have an interest in a foreign trust during the tax year? *If "Yes," the organization may be required to separately file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see the Instructions for Forms 3520 and 3520-A; don't file with Form 990)* Yes No
- 3 Did the organization have an ownership interest in a foreign corporation during the tax year? *If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect to Certain Foreign Corporations (see the Instructions for Form 5471)* Yes No
- 4 Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? *If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see the Instructions for Form 8621)* Yes No
- 5 Did the organization have an ownership interest in a foreign partnership during the tax year? *If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see the Instructions for Form 8865)* Yes No
- 6 Did the organization have any operations in or related to any boycotting countries during the tax year? *If "Yes," the organization may be required to separately file Form 5713, International Boycott Report (see the Instructions for Form 5713; don't file with Form 990)* Yes No

Part V Supplemental Information

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information. See instructions.

PART I, LINE 2:

GRANTS ARE REVIEWED BY INDEPENDENT SCIENTIFIC ADVISORS AND APPROVED BY BOARD. ONCE GRANTS ARE AWARDED THE ORGANIZATION REQUIRES REGULAR RESEARCH AND FINANCIAL REPORTS FROM THE INSTITUTIONS.

FARA INSTITUTED A PROGRAM TO SUPPORT YOUNG EMERGING SCIENTISTS (UP TO SIX PER YEAR) WITH THE FARA FELLOWS AWARD. APPLICATIONS ARE SUBMITTED BY THE FELLOWS AND THEIR MENTORS AND ARE REVIEWED BY INDEPENDENT SCIENTIFIC ADVISORS AND APPROVED BY THE BOARD.

**SCHEDULE G
(Form 990)**(Rev. December 2024)
Department of the Treasury
Internal Revenue Service**Supplemental Information Regarding Fundraising or Gaming Activities**

Complete if the organization answered "Yes" on Form 990, Part IV, line 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a.

OMB No. 1545-0047

Attach to Form 990 or Form 990-EZ.

Go to www.irs.gov/Form990 for instructions and the latest information.**Open to Public
Inspection**

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCEEmployer identification number
52-2122720**Part I Fundraising Activities.** Complete if the organization answered "Yes" on Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part.**1** Indicate whether the organization raised funds through any of the following activities. Check all that apply.

- | | |
|---|---|
| a <input type="checkbox"/> Mail solicitations | e <input type="checkbox"/> Solicitation of nongovernment grants |
| b <input type="checkbox"/> Internet and email solicitations | f <input type="checkbox"/> Solicitation of government grants |
| c <input type="checkbox"/> Phone solicitations | g <input type="checkbox"/> Special fundraising events |
| d <input type="checkbox"/> In-person solicitations | |

2 a Did the organization have a written or oral agreement with any individual (including officers, directors, trustees, or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? Yes No**b** If "Yes," list the 10 highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization.

| (i) Name and address of individual or entity (fundraiser) | (ii) Activity | (iii) Did fundraiser have custody or control of contributions? | | (iv) Gross receipts from activity | (v) Amount paid to (or retained by) fundraiser listed in col. (i) | (vi) Amount paid to (or retained by) organization |
|--|----------------------|---|-----------|--|---|--|
| | | Yes | No | | | |
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| Total | | | | | | |

3 List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing.

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For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule G (Form 990) (Rev. 12-2024)

Part II Fundraising Events. Complete if the organization answered "Yes" on Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000.

| | (a) Event #1 FARA ENERGY BALL (event type) | (b) Event #2 RIDEATAXIA PHILA (event type) | (c) Other events 16 (total number) | (d) Total events (add col. (a) through col. (c)) |
|---|---|---|--|--|
| 1 Gross receipts | 1,651,351. | 578,416. | 1,781,198. | 4,010,965. |
| 2 Less: Contributions | 1,153,631. | 562,366. | 1,646,183. | 3,362,180. |
| 3 Gross income (line 1 minus line 2) | 497,720. | 16,050. | 135,015. | 648,785. |
| 4 Cash prizes | | | | |
| 5 Noncash prizes | | | | |
| 6 Rent/facility costs | 144,106. | 3,206. | 16,028. | 163,340. |
| 7 Food and beverages | | | | |
| 8 Entertainment | 10,500. | | | 10,500. |
| 9 Other direct expenses | 416,430. | 107,521. | 504,964. | 1,028,915. |
| 10 Direct expense summary. Add lines 4 through 9 in column (d) | | | | 1,202,755. |
| 11 Net income summary. Subtract line 10 from line 3, column (d) | | | | -553,970. |

Part III Gaming. Complete if the organization answered "Yes" on Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a.

| | (a) Bingo | (b) Pull tabs/instant bingo/progressive bingo | (c) Other gaming | (d) Total gaming (add col. (a) through col. (c)) |
|--|---|---|---|--|
| 1 Gross revenue | | | | |
| 2 Cash prizes | | | | |
| 3 Noncash prizes | | | | |
| 4 Rent/facility costs | | | | |
| 5 Other direct expenses | | | | |
| 6 Volunteer labor | <input type="checkbox"/> Yes _____ % <input type="checkbox"/> No | <input type="checkbox"/> Yes _____ % <input type="checkbox"/> No | <input type="checkbox"/> Yes _____ % <input type="checkbox"/> No | |
| 7 Direct expense summary. Add lines 2 through 5 in column (d) | | | | |
| 8 Net gaming income summary. Subtract line 7 from line 1, column (d) | | | | |

9 Enter the state(s) in which the organization conducts gaming activities:

a Is the organization licensed to conduct gaming activities in each of these states? Yes No

b If "No," explain: _____

10a Were any of the organization's gaming licenses revoked, suspended, or terminated during the tax year? Yes No

b If "Yes," explain: _____

- 11** Does the organization conduct gaming activities with nonmembers? Yes No
- 12** Is the organization a grantor, beneficiary or trustee of a trust, or a member of a partnership or other entity formed to administer charitable gaming? Yes No
- 13** Indicate the percentage of gaming activity conducted in:
- | | | |
|-------------------------------------|-----|---|
| a The organization's facility | 13a | % |
| b An outside facility | 13b | % |
- 14** Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name **FELICIA DEROSA**Address **533 W. UWCHLAN AVENUE - DOWNTON, PA 19335**

- 15a** Does the organization have a contract with a third party from whom the organization receives gaming revenue? Yes No

- b** If "Yes," enter the amount of gaming revenue received by the organization \$ _____ and the amount of gaming revenue retained by the third party \$ _____
- c** If "Yes," enter the name and address of the third party:

Name _____

Address _____

- 16** Gaming manager information:

Name _____

Gaming manager compensation \$ _____

Description of services provided

_____ Director/officer Employee Independent contractor

- 17** Mandatory distributions:

- a** Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? Yes No
- b** Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year \$ _____

Part IV Supplemental Information. Provide the explanations required by Part I, line 2b, columns (iii) and (v); and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also provide any additional information. See instructions.

Part IV Supplemental Information *(continued)*

SCHEDULE I
(Form 990)

(Rev. December 2024)
Department of the Treasury
Internal Revenue Service

**Grants and Other Assistance to Organizations,
Governments, and Individuals in the United States**

Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.

OMB No. 1545-0047

Attach to Form 990.

Go to www.irs.gov/Form990 for instructions and the latest information.

**Open to Public
Inspection**

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number
52-2122720

Part I General Information on Grants and Assistance

- 1 Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? Yes No
- 2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

| 1 (a) Name and address of organization or government | (b) EIN | (c) IRC section (if applicable) | (d) Amount of cash grant | (e) Amount of noncash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of noncash assistance | (h) Purpose of grant or assistance |
|---|----------------|--|---------------------------------|---|--|--|---|
| BOARD REGENTS OF THE UNIVERSITY OF OKLAHOMA - FIVE PARTNERS PLACE, STE 3100, 201 STEPHENSON PARKWAY - NORMAN , OK 73019 | 73-1377584 | 501(C)(3) | 116,813. | 0. | | | MEDICAL RESEARCH |
| BOSTON COLLEGE 140 COMMONWEALTH AVE CHESTNUT HILL, MA 02467 | 04-2103545 | 501(C)(3) | 38,000. | 0. | | | MEDICAL RESEARCH |
| CALIFORNIA INSTITUTE OF TECHNOLOGY 1200 EAST CALIFORNIA BLVD PASADENA, CA 91125 | 95-1643307 | 501(C)(3) | 100,000. | 0. | | | MEDICAL RESEARCH |
| CHILDREN'S HOSPITAL OF PHILADELPHIA RESEARCH INSTITUTE - 34TH ST & CIVIC CENTER BLVD - PHILADELPHIA, PA 19104 | 23-1352166 | 501(C)(3) | 713,919. | 0. | | | MEDICAL RESEARCH |
| COLUMBIA UNIVERSITY 615 W. 131ST STREET, 6TH FLOOR, MC8 NEW YORK, NY 10027 | 13-5598093 | 501(C)(3) | 125,000. | 0. | | | MEDICAL RESEARCH |
| EMORY UNIVERSITY 1390 OXFORD ROAD NE, 3RD FLOOR ATLANTA, GA 30322 | 58-0566256 | 501(C)(3) | 5,991. | 0. | | | MEDICAL RESEARCH |

- 2 Enter total number of section 501(c)(3) and government organizations listed in the line 1 table **27.**
- 3 Enter total number of other organizations listed in the line 1 table **5.**

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule I (Form 990) (Rev. 12-2024)

Part II Continuation of Grants and Other Assistance to Domestic Organizations and Domestic Governments (Schedule I (Form 990), Part II.)

| (a) Name and address of organization or government | (b) EIN | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of noncash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|--|------------|-------------------------------|--------------------------|----------------------------------|---|--|------------------------------------|
| EPICRISPR BIOTECHNOLOGIES, INC 7000 SHORELINE COURT, SUITE 100 SOUTH SAN FRANCISCO, CA 94080 | 82-4177431 | | 100,000. | 0. | | | MEDICAL RESEARCH |
| JOHN HOPKINS UNIVERSITY 733 N BROADWAY, SUITE 117 BALTIMORE, MD 21205 | 52-0595110 | 501(C)(3) | 86,175. | 0. | | | MEDICAL RESEARCH |
| MASSACHUSETTS GENERAL HOSPITAL 55 FRUIT STREET BOSTON, MA 02114 | 04-3230035 | 501(C)(3) | 313,988. | 0. | | | MEDICAL RESEARCH |
| NATIONWIDE CHILDREN'S HOSPITAL 700 CHILDREN'S DR, COLUMBUS, OH 43205 | 31-1036372 | 501(C)(3) | 9,012. | 0. | | | MEDICAL RESEARCH |
| REGENTS OF THE UNIVERSITY OF MINNESOTA - 600 McNAMARA ALUMNI CENTER S.E., 200 SE OAK ST - MINNEAPOLIS, MN 55455 | 41-6007513 | 501(C)(3) | 339,615. | 0. | | | MEDICAL RESEARCH |
| RGENTA THERAPEUTICS, INC. 300 TRADECENTER DR SUITE 6600, WOBURNMA, MA 01801 | 23-7094113 | | 125,000. | 0. | | | MEDICAL RESEARCH |
| ST. JUDE CHILDREN'S RESEARCH HOSPITAL - 262 DANNY THOMAS PLACE - MEMPHIS, TN 38105 | 62-0646012 | 501(C)(3) | 67,138. | 0. | | | MEDICAL RESEARCH |
| STANFORD UNIVERSITY 450 JANE STANFORD WAY, STANFORD, CA 94305 | 94-1156365 | 501(C)(3) | 250,000. | 0. | | | MEDICAL RESEARCH |
| STEALTH BIOTHERAPEUTICS INC 123 HIGHLAND AVE STE 201 NEEDHAM, MA 02494 | 26-1512085 | | 185,182. | 0. | | | MEDICAL RESEARCH |

Part II Continuation of Grants and Other Assistance to Domestic Organizations and Domestic Governments (Schedule I (Form 990), Part II.)

| (a) Name and address of organization or government | (b) EIN | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of noncash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|--|------------|-------------------------------|--------------------------|----------------------------------|---|--|------------------------------------|
| THE BROAD INSTITUTE 415 MAIN STREET CAMBRIDGE, MA 02142 | 26-3428781 | 501(C)(3) | 1,945,086. | 0. | | | MEDICAL RESEARCH |
| THE HIGHEST ROAD FILM, LLC 1023 PHEASANT RIDGE DRIVE GRAPEVINE, TX 76051 | 99-2207841 | | 80,000. | 0. | | | DISEASE AWARENESS |
| THE NATIONAL CANCER INSTITUTE BUILDING 31 ROOM 11A-16, 9000 ROCKVILLE PIKE - BETHESDA, MD 20892 | 01-5208581 | 501(C)(3) | 124,922. | 0. | | | MEDICAL RESEARCH |
| THE REGENTS OF THE UNIVERSITY OF CALIFORNIA DAVIS - ONE SHIELDS AVE. - DAVIS, CA 95616 | 94-6036494 | 501(C)(3) | 150,000. | 0. | | | MEDICAL RESEARCH |
| THE REGENTS OF THE UNIVERSITY OF CALIFORNIA, SAN DIEGO - 9500 GILMAN DRIVE - LA JOLLA, CA 92093 | 95-6006144 | 501(C)(3) | 194,830. | 0. | | | MEDICAL RESEARCH |
| THE UNIVERSITY OF TEXAS SOUTHWESTERN MEDICAL CENTER - 5323 HARRY HINES BLVD - DALLAS, TX 75390 | 74-6000089 | 501(C)(3) | 74,768. | 0. | | | MEDICAL RESEARCH |
| THE WINIFRED MASTERTON BURKE MEDICAL RESEARCH INSTITUTE - 785 MAMARONECK AVENUE - WHITE PLAINS, NY 10605 | 13-3434924 | 501(C)(3) | 61,572. | 0. | | | MEDICAL RESEARCH |
| THE REGENTS OF THE UNIVERSITY OF CALIFORNIA LOS ANGELES - 10920 WILSHIRE BLVD, 5TH FLOOR - LOS ANGELES, CA 90024 | 95-6006143 | 501(C)(3) | 45,145. | 0. | | | MEDICAL RESEARCH |
| UNIVERSITY OF COLORADO 1800 GRANT STREET DENVER, CO 80203 | 84-6000555 | 501(C)(3) | 5,483. | 0. | | | MEDICAL RESEARCH |

Part II Continuation of Grants and Other Assistance to Domestic Organizations and Domestic Governments (Schedule I (Form 990), Part II.)

| (a) Name and address of organization or government | (b) EIN | (c) IRC section if applicable | (d) Amount of cash grant | (e) Amount of noncash assistance | (f) Method of valuation (book, FMV, appraisal, other) | (g) Description of non-cash assistance | (h) Purpose of grant or assistance |
|--|------------|-------------------------------|--------------------------|----------------------------------|---|--|------------------------------------|
| UNIVERSITY OF FLORIDA DEPT OF NEUROLOGY, L3-100 MCKNIGHT BRAIN INSTITUTE, NEWELL DRIVE - GAINESVILLE | 59-6002052 | 501(C)(3) | 359,182. | 0. | | | MEDICAL RESEARCH |
| UNIVERSITY OF MASSACHUSETTS 100 MORRISSEY BLVD. BOSTON, MA 02125 | 04-3167352 | 501(C)(3) | 300,000. | 0. | | | MEDICAL RESEARCH |
| UNIVERSITY OF ROCHESTER 515 HYLAN BUILDING, RC BOX 270140 ROCHESTER, NY 14627 | 16-0743209 | 501(C)(3) | 100,000. | 0. | | | MEDICAL RESEARCH |
| UPLIFTING ATHLETES PO BOX 574, 8 ATKINSON DRIVE DOYLESTOWN, PA 18901 | 34-1986485 | 501(C)(3) | 10,000. | 0. | | | MEDICAL RESEARCH |
| USF FOUNDATION 4202 E FOWLER AVE ALC100 TAMPA, FL 33620 | 59-0879015 | 501(C)(3) | 100,000. | 0. | | | MEDICAL RESEARCH |
| VESIGEN, INC 790 MEMORIAL DRIVE, SUITE 103, CAMBRIDGE, MA 02139 | 84-2449757 | | 204,136. | 0. | | | MEDICAL RESEARCH |
| WEILL MEDICAL COLLEGE OF CORNELL UNIVERSITY - 1300 YORK AVENUE, C-118 - NEW YORK, NY 10065 | 13-1623978 | 501(C)(3) | 274,855. | 0. | | | MEDICAL RESEARCH |
| CHILDREN'S HOSPITAL OF PHILADELPHIA FOUNDATION - 34TH ST & CIVIC CENTER BLVD - PHILADELPHIA, PA 19104 | 23-2237932 | 501(C)(3) | 500,000. | 0. | | | MEDICAL RESEARCH |
| | | | | | | | |

Part III

Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on Form 990, Part IV, line 22.
Part III can be duplicated if additional space is needed.

| (a) Type of grant or assistance | (b) Number of recipients | (c) Amount of cash grant | (d) Amount of non-cash assistance | (e) Method of valuation (book, FMV, appraisal, other) | (f) Description of noncash assistance |
|---------------------------------|--------------------------|--------------------------|-----------------------------------|--|---------------------------------------|
| FARA FELLOWS AWARD | 1 | 13,350. | 0. | | |
| | | | | | |
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| | | | | | |
| | | | | | |

Part IV **Supplemental Information.** Provide the information required in Part I, line 2; Part III, column (b); and any other additional information.

PART I, LINE 2:

GRANTS ARE REVIEWED BY INDEPENDENT SCIENTIFIC ADVISORS AND APPROVED BY BOARD. ONCE GRANTS ARE AWARDED THE ORGANIZATION REQUIRES REGULAR RESEARCH AND FINANCIAL REPORTS FROM THE INSTITUTIONS.

FARA INSTITUTED A PROGRAM TO SUPPORT YOUNG EMERGING SCIENTISTS (UP TO SIX PER YEAR) WITH THE FARA FELLOWS AWARD. APPLICATIONS ARE SUBMITTED BY THE FELLOWS AND THEIR MENTORS AND ARE REVIEWED BY INDEPENDENT SCIENTIFIC ADVISORS AND APPROVED BY THE BOARD.

SCHEDULE J
(Form 990)(Rev. December 2024)
Department of the Treasury
Internal Revenue Service**Compensation Information**

For certain Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees
Complete if the organization answered "Yes" on Form 990, Part IV, line 23.
 Attach to Form 990.
 Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public Inspection

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCEEmployer identification number
52-2122720**Part I Questions Regarding Compensation**

- 1a** Check the appropriate box(es) if the organization provided any of the following to or for a person listed on Form 990, Part VII, Section A, line 1a. Complete Part III to provide any relevant information regarding these items.

| | |
|--|--|
| <input type="checkbox"/> First-class or charter travel | <input type="checkbox"/> Housing allowance or residence for personal use |
| <input type="checkbox"/> Travel for companions | <input type="checkbox"/> Payments for business use of personal residence |
| <input type="checkbox"/> Tax indemnification and gross-up payments | <input type="checkbox"/> Health or social club dues or initiation fees |
| <input type="checkbox"/> Discretionary spending account | <input type="checkbox"/> Personal services (such as maid, chauffeur, chef) |

- b** If any of the boxes on line 1a are checked, did the organization follow a written policy regarding payment or reimbursement or provision of all of the expenses described above? If "No," complete Part III to explain

- 2** Did the organization require substantiation prior to reimbursing or allowing expenses incurred by all directors, trustees, and officers, including the CEO/Executive Director, regarding the items checked on line 1a?

- 3** Indicate which, if any, of the following the organization used to establish the compensation of the organization's CEO/Executive Director. Check all that apply. Do not check any boxes for methods used by a related organization to establish compensation of the CEO/Executive Director, but explain in Part III.

| | |
|--|---|
| <input checked="" type="checkbox"/> Compensation committee | <input type="checkbox"/> Written employment contract |
| <input type="checkbox"/> Independent compensation consultant | <input type="checkbox"/> Compensation survey or study |
| <input type="checkbox"/> Form 990 of other organizations | <input checked="" type="checkbox"/> Approval by the board or compensation committee |

- 4** During the year, did any person listed on Form 990, Part VII, Section A, line 1a, with respect to the filing organization or a related organization:

- a** Receive a severance payment or change-of-control payment?
- b** Participate in or receive payment from a supplemental nonqualified retirement plan?
- c** Participate in or receive payment from an equity-based compensation arrangement?

If "Yes" to any of lines 4a-c, list the persons and provide the applicable amounts for each item in Part III.

Only section 501(c)(3), 501(c)(4), and 501(c)(29) organizations must complete lines 5-9.

- 5** For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the revenues of:

- a** The organization?
- b** Any related organization?

If "Yes" on line 5a or 5b, describe in Part III.

- 6** For persons listed on Form 990, Part VII, Section A, line 1a, did the organization pay or accrue any compensation contingent on the net earnings of:

- a** The organization?

- b** Any related organization?

If "Yes" on line 6a or 6b, describe in Part III.

- 7** For persons listed on Form 990, Part VII, Section A, line 1a, did the organization provide any nonfixed payments not described on lines 5 and 6? If "Yes," describe in Part III

- 8** Were any amounts reported on Form 990, Part VII, paid or accrued pursuant to a contract that was subject to the initial contract exception described in Regulations section 53.4958-4(a)(3)? If "Yes," describe in Part III

- 9** If "Yes" on line 8, did the organization also follow the rebuttable presumption procedure described in Regulations section 53.4958-6(c)?

Yes**No****1b****2****4a****X****4b****X****4c****X****5a****X****5b****X****6a****X****6b****X****7****X****8****X****9****For Paperwork Reduction Act Notice, see the Instructions for Form 990.****Schedule J (Form 990) (Rev. 12-2024)**

Part II Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees. Use duplicate copies if additional space is needed.

For each individual whose compensation must be reported on Schedule J, report compensation from the organization on row (i) and from related organizations, described in the instructions, on row (ii). Do not list any individuals that aren't listed on Form 990, Part VII.

Note: The sum of columns (B)(i)-(iii) for each listed individual must equal the total amount of Form 990, Part VII, Section A, line 1a, applicable column (D) and (E) amounts for that individual.

| (A) Name and Title | (B) Breakdown of W-2 and/or 1099-MISC and/or 1099-NEC compensation | | | (C) Retirement and other deferred compensation | (D) Nontaxable benefits | (E) Total of columns (B)(i)-(D) | (F) Compensation in column (B) reported as deferred on prior Form 990 |
|--|--|-------------------------------------|-------------------------------------|--|-------------------------|---------------------------------|---|
| | (i) Base compensation | (ii) Bonus & incentive compensation | (iii) Other reportable compensation | | | | |
| (1) BARBARA A TATE CHIEF SCIENTIFIC OFFICER | (i) 250,000. | 0. | 0. | 4,833. | 694. | 255,527. | 0. |
| | (ii) 0. | 0. | 0. | 0. | 0. | 0. | 0. |
| (2) JENNIFER M FARMER CHIEF EXECUTIVE OFFICER | (i) 165,000. | 0. | 0. | 4,950. | 728. | 170,678. | 0. |
| | (ii) 0. | 0. | 0. | 0. | 0. | 0. | 0. |
| (i) | | | | | | | |
| (ii) | | | | | | | |
| (i) | | | | | | | |
| (ii) | | | | | | | |
| (i) | | | | | | | |
| (ii) | | | | | | | |
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| (i) | | | | | | | |
| (ii) | | | | | | | |
| (i) | | | | | | | |
| (ii) | | | | | | | |

Part III Supplemental Information

Provide the information, explanation, or descriptions required for Part I, lines 1a, 1b, 3, 4a, 4b, 4c, 5a, 5b, 6a, 6b, 7, and 8, and for Part II. Also complete this part for any additional information.

SCHEDULE M
(Form 990)

Department of the Treasury
Internal Revenue Service

Noncash Contributions

OMB No. 1545-0047

2024

Open to Public
Inspection

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number

52-2122720

Part I Types of Property

| | (a) Check if applicable | (b) Number of contributions or items contributed | (c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g | (d) Method of determining noncash contribution amounts |
|---|-------------------------------|---|--|--|
| 1 Art - Works of art | | | | |
| 2 Art - Historical treasures | | | | |
| 3 Art - Fractional interests | | | | |
| 4 Books and publications | | | | |
| 5 Clothing and household goods | | | | |
| 6 Cars and other vehicles | | | | |
| 7 Boats and planes | | | | |
| 8 Intellectual property | | | | |
| 9 Securities - Publicly traded | X | 12 | 460,344. | HI-LOW DATE OF GIFT |
| 10 Securities - Closely held stock | | | | |
| 11 Securities - Partnership, LLC, or trust interests | | | | |
| 12 Securities - Miscellaneous | | | | |
| 13 Qualified conservation contribution - Historic structures | | | | |
| 14 Qualified conservation contribution - Other .. | | | | |
| 15 Real estate - Residential | | | | |
| 16 Real estate - Commercial | | | | |
| 17 Real estate - Other | | | | |
| 18 Collectibles | | | | |
| 19 Food inventory | | | | |
| 20 Drugs and medical supplies | | | | |
| 21 Taxidermy | | | | |
| 22 Historical artifacts | | | | |
| 23 Scientific specimens | | | | |
| 24 Archeological artifacts | | | | |
| 25 Other (<u>AUCTION ITEMS</u>) | X | 495 | 421,167. | FAIR MARKET VALUE |
| 26 Other (_____) | | | | |
| 27 Other (_____) | | | | |
| 28 Other (_____) | | | | |

29 Number of Forms 8283 received by the organization during the tax year for contributions
for which the organization completed Form 8283, Part V, Donee Acknowledgement

29

30a During the year, did the organization receive by contribution any property reported on Part I, lines 1 through 28, that it
must hold for at least 3 years from the date of the initial contribution, and which isn't required to be used for
exempt purposes for the entire holding period?

b If "Yes," describe the arrangement in Part II.

31 Does the organization have a gift acceptance policy that requires the review of any nonstandard contributions?

32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash
contributions?

b If "Yes," describe in Part II.

33 If the organization didn't report an amount in column (c) for a type of property for which column (a) is checked,
describe in Part II.

| | Yes | No |
|-----|-----|----|
| 30a | X | |
| 31 | X | |
| 32a | X | |

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule M (Form 990) 2024

Part II

Supplemental Information. Provide the information required by Part I, lines 30b, 32b, and 33, and whether the organization is reporting in Part I, column (b), the number of contributions, the number of items received, or a combination of both. Also complete this part for any additional information.

SCHEDULE M, PART I, COLUMN (B):

FOR LINE 9, THE ORGANIZATION RECOGNIZES IN COLUMN B EACH UNIQUE STOCK CONTRIBUTION RECEIVED FROM A DONOR.

FOR LINE 25, THE COUNT OF AUCTION ITEMS REPRESENTS EACH INDIVIDUAL CONTRIBUTION BY A DONOR.

**SCHEDULE O
(Form 990)**

(Rev. December 2024)

Department of the Treasury
Internal Revenue Service**Supplemental Information to Form 990 or 990-EZ**

OMB No. 1545-0047

Complete to provide information for responses to specific questions on
Form 990 or 990-EZ or to provide any additional information.

Attach to Form 990 or Form 990-EZ.

Go to www.irs.gov/Form990 for instructions and the latest information.Open to Public
Inspection

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number
52-2122720**FORM 990, PART III, LINE 4A****RESEARCH AND GRANT PROGRAM**

FARA DEPLOYS FINANCIAL RESOURCES TO ACCELERATE RESEARCH FOR FRIEDREICH'S ATAXIA (FA). IN 2024, FARA AWARDED \$10+ MILLION IN RESEARCH FUNDING. THIS INCLUDED 46 GRANT PROJECTS THROUGH FARA'S INVESTIGATOR-INITIATED GRANT PROGRAM, INSTITUTIONAL BASED RESEARCH, AND FARA DIRECTED PROJECTS. IT ALSO INCLUDED FUNDING A PATIENT REGISTRY AND LONGITUDINAL NATURAL HISTORY THROUGH THE FA GLOBAL CLINICAL CONSORTIUM AND SUPPORT FOR COMMUNITY AWARENESS WHICH ARE DESCRIBED IN THE SECOND AND THIRD PROGRAM SECTIONS BELOW.

FARA GRANT PROGRAM:

FARA'S INVESTIGATOR-INITIATED GRANT PROGRAM AWARDED TWENTY-SIX NEW GRANTS AND APPROVED CONTINUED FUNDING FOR TWENTY GRANTS. RESEARCHERS ON FIVE CONTINENTS ARE RECEIVING RESEARCH FUNDING FROM FARA. THE PROGRAM IS A COMPETITIVE FUNDING MECHANISM THAT SUPPORTS RESEARCH TO FURTHER THE UNDERSTANDING OF FA AND PROMOTE THERAPEUTIC DISCOVERY AND DEVELOPMENT. FARA PRIORITIZES FUNDING PROJECTS THAT FILL GAPS IN KNOWLEDGE OF DISEASE MECHANISMS, SUPPORT EARLY DEVELOPMENT OF THERAPEUTIC INTERVENTIONS, ESTABLISH AND ADVANCE THE DEVELOPMENT OF TOOLS FOR DRUG DEVELOPERS AND ACADEMIC RESEARCHERS, AND FOCUS ON CLINICAL RESEARCH AND TRIALS. SEVERAL OF THESE GRANTS WERE CO-FUNDED WITH FARA'S FA ADVOCACY GROUP PARTNERS; THIS COLLABORATIVE APPROACH BOTH INCREASES THE NUMBER OF AVAILABLE RESEARCH DOLLARS AND HELPS TO MINIMIZE DUPLICATION OF EFFORT.

WITH FARA'S GOAL IN MIND OF INSPIRING AND SUPPORTING JUNIOR INVESTIGATORS AND BUILDING THE NEXT GENERATIONS OF FA SCIENTISTS, IN 2024, FARA AWARDED GRANTS TO 11 JUNIOR INVESTIGATORS.

FARA HAS ALSO IDENTIFIED OPPORTUNITIES TO FUND RESEARCH AT INSTITUTIONS WHERE THERE ARE MULTIPLE INVESTIGATORS WITH AN EXPERTISE AND COMMITMENT TO FA RESEARCH AND/OR OPPORTUNITY TO LEVERAGE TECHNOLOGIES, INNOVATION OR NEW GROWTH TO THE FA COMMUNITY. BY ESTABLISHING THESE INSTITUTIONAL FUNDING PROGRAMS, FARA CAN PROMOTE COLLABORATION AND SYNERGY ACROSS BASIC, TRANSLATIONAL AND CLINICAL RESEARCH, PROVIDE A LONGER-TERM COMMITMENT FOR RESEARCH, ATTRACT NEW INVESTIGATORS, AND LEVERAGE THE INSTITUTIONS RESOURCES AND ENGAGEMENT. FARA PROVIDES INSTITUTIONAL BASED RESEARCH SUPPORT FOR THE FA CENTER OF EXCELLENCE AT CHILDREN'S HOSPITAL OF PHILADELPHIA/ PENN MEDICINE (UNIVERSITY OF PENNSYLVANIA) AND THE FA ACCELERATOR PROGRAM AT THE BROAD INSTITUTE.

FRIEDREICH'S ATAXIA CENTER OF EXCELLENCE, PHILADELPHIA, PA:

THE FA CENTER OF EXCELLENCE (COE) IS A TRANSLATIONAL RESEARCH AND CLINICAL CARE CENTER DEVOTED TO FRIEDREICH ATAXIA: EXPEDITING BASIC SCIENCE AND DRUG DISCOVERY FINDINGS TO NEW TREATMENTS AND DEDICATING RESOURCES TO CLINICAL RESEARCH AND CARE TO FURTHER UNDERSTAND THE DISEASE, INFORM DRUG DEVELOPMENT AND IMPROVE OUTCOMES FOR INDIVIDUALS LIVING WITH FA. THE CENTER WAS ESTABLISHED IN MARCH 2014, WITH A COMMITMENT TO CHILDREN'S HOSPITAL OF PHILADELPHIA/ PENN MEDICINE (UNIVERSITY OF PENNSYLVANIA), PRESENTED BY FARA IN PARTNERSHIP WITH THE HAMILTON AND FINNERAN FAMILIES/ CUREFA FOUNDATION.

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number
52-2122720

PROJECTS AND INVESTIGATORS WITH CONTINUED FUNDING INCLUDED DR. ROB WILSON- DRUG DISCOVERY, DR. DAVID LYNCH- TRANSLATIONAL AND CLINICAL NEUROSCIENCE RESEARCH, DR. IAN BLAIR- BIOMARKER DISCOVERY, DR. CLEMENTINA MESAROS- BIOMARKER DISCOVERY, DR. KIM LIN- CARDIAC RESEARCH, AND DR. SHANA MCCORMACK- METABOLISM AND ENDOCRINOLOGY. THE COE ESTABLISHED RESEARCH INFRASTRUCTURE CONSISTING OF FOUR CORE AREAS- NEUROLOGY, CARDIAC, BIOMARKER, AND DRUG DISCOVERY. THE CENTER NOT ONLY SUPPORTS WORK WITHIN THESE DISCIPLINES BUT ALSO FOSTERS EFFICIENT COLLABORATION AND SYNERGY ACROSS THEM.

FOR EXAMPLE, 95% OF INDIVIDUALS WITH FA HAVE THE SAME GENE MUTATION, A GAA REPEAT EXPANSION, HOWEVER, 5% OF INDIVIDUALS HAVE NON-GAA REPEAT MUTATIONS. COE CLINICIANS OBSERVED THAT INDIVIDUALS WITH CERTAIN NON-GAA MUTATIONS HAVE DIFFERENT CLINICAL SYMPTOMS AND DISEASE PROGRESSION (BOTH MORE AND LESS SEVERE). THESE CLINICAL OBSERVATIONS SPARKED LAB-BASED STUDIES INTO HOW SPECIFIC MISSENSE MUTATIONS MAY AFFECT FRATAXIN'S FUNCTION BEYOND ITS WELL-KNOWN ROLE IN IRON-SULFUR CLUSTER SYNTHESIS. THIS WORK EXPLORES WHETHER FRATAXIN MAY HAVE ADDITIONAL CELLULAR ACTIVITIES, OFFERING BOTH A NEW LENS THROUGH WHICH TO UNDERSTAND DISEASE VARIABILITY AND THE EXPLORATION OF NEW THERAPEUTIC TARGETS.

FRIEDREICH'S ATAXIA ACCELERATOR AT THE BROAD INSTITUTE OF MIT AND HARVARD:

THE FRIEDREICH'S ATAXIA ACCELERATOR (FAA) AT THE BROAD INSTITUTE OF MIT AND HARVARD WAS ESTABLISHED IN AUGUST 2020. THE FAA IS A COLLABORATIVE, MULTI-DISCIPLINARY EFFORT AIMED AT GALVANIZING RESEARCH INTO FA AND SEEDING A GROWING COMMUNITY ACROSS BROAD, MIT, HARVARD AND AFFILIATED INSTITUTIONS COMMITTED TO TACKLING FA.

LED BY DR. VAMSI MOOTHA, THE FAA'S OVERARCHING GOAL IS TO NUCLEATE A RESEARCH COMMUNITY THAT LEVERAGES THE LATEST ADVANCES IN BIOMEDICAL RESEARCH TO DEVELOP NEW THERAPEUTIC STRATEGIES. DR. DAVID LIU HAS BEEN INVESTIGATING THERAPEUTIC APPROACHES THAT WOULD EDIT THE FRATAXIN GENE, WITH THE GOAL OF REMOVING THE GAA REPEATS (PRIME EDITING) OR INTERRUPTING THE GAA REPEATS (BASE EDITING) AND THUS REACTIVATING THE PROTEIN EXPRESSION. DR. GARY RUVKUN (A 2024 NOBEL LAUREATE) IS WORKING TO DISCOVER PROTEINS THAT INTERACT WITH FRATAXIN. DRS. JONATHAN AND CHRISTINE SEIDMAN ARE DISCOVERING CHANGES IN THE HEARTS OF PEOPLE WITH FA, INCLUDING AN INCREASE IN INFLAMMATION. THIS WORK IS FUNDED BY FARAF, IN COLLABORATION WITH THE CUREFA FOUNDATION AND ENDFA. IT DEEPENS OUR KNOWLEDGE OF FA, AND THESE LEARNINGS WERE SHARED BY FOUR MEMBERS OF THE FAA WHO PRESENTED THEIR WORK AT THE INTERNATIONAL CONGRESS FOR ATAXIA RESEARCH (ICAR) IN NOVEMBER IN LONDON.

FARA DIRECTED RESEARCH:

IN 2024, FARAF FUNDED DIRECTED RESEARCH PROGRAMS INCLUDING: 1. MAINTAINING A REPOSITORY OF FA CELL LINES FOR RESEARCH [HTTPS://LABS.UTSOUTHWESTERN.EDU/NAPIERALA-LAB](https://labs.utsouthwestern.edu/napierala-lab) 2. TRACK-FA, A GLOBAL NEUROIMAGING CONSORTIUM ESTABLISHED IN 2020, A NATURAL HISTORY STUDY DESIGNED TO TRACK THE CHANGES IN THE BRAIN AND THE SPINAL CORD IN FA. STUDY PROGRESS IN 2024 AT THE PARTICIPATING CLINICAL SITES IN USA, BRAZIL, CANADA, GERMANY, AND AUSTRALIA OF THE 279 PARTICIPANTS ENROLLED IN THE STUDY, 100% HAD COMPLETED THEIR BASELINE AND 12-MONTH VISITS, AND MORE THAN HALF HAD COMPLETED THEIR FINAL VISITS. THIS REMARKABLE PROGRESS KEEPS THE STUDY ON TRACK TO FINALIZE DATA

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

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52-2122720

COLLECTION OF NEUROIMAGING OF THE BRAIN AND SPINAL, ALONG WITH CLINICAL OUTCOMES AND BLOOD BIOMARKERS, IN 2025. 3. FOSTERING A COLLABORATIVE EFFORT BETWEEN RESEARCHERS AT UNIVERSITY OF OKLAHOMA, UNIVERSITY OF TEXAS SOUTHWESTERN, AND UNIVERSITY OF PENNSYLVANIA TO STUDY THE PRECISE MECHANISM OF THIS GENE SILENCING IN DIFFERENT TISSUES AND MODELS OVER TIME. 4. DEVELOPMENT AND VALIDATION OF A POTENCY ASSAY FOR USE IN THE DEVELOPMENT OF GENE AND PROTEIN REPLACEMENT THERAPIES. 5. LEADING WORK TO CREATE A NEW DISEASE MODEL FOR PRE-CLINICAL RESEARCH, AN FA RAT MODEL. 6. IDENTIFYING AND FUNDING RESEARCH TO UNDERSTAND THE THERAPEUTIC WINDOW (MINIMAL AMOUNT OF FRATAxin NEEDED FOR A THERAPEUTIC BENEFIT AND THRESHOLD FOR MAXIMUM AMOUNTS OR TOXIC AMOUNTS OF FRATAxin IN THE CELL. 7. ONGOING MAINTENANCE OF CLINICAL MANAGEMENT GUIDELINES IN FA FOR REFERENCE USE BY PHYSICIANS AND PATIENTS (PUBLISHED IN 2022): FRDAGUIDELINES.ORG 8. RETROSPECTIVE CARDIAC NATURAL HISTORY STUDY-THIS PROJECT RE-ANALYZES EXISTING ECHOCARDIOGRAMS TO QUICKLY ASSESS THE VALUE OF THESE DATA IN UNDERSTANDING AND PREDICTING THE PROGRESSION OF HEART DISEASE IN FA.

OF NOTE, FA SHARES SIMILAR SYMPTOMS AND DISEASE MECHANISMS WITH OTHER DISEASES, BOTH RARE AND COMMON. RESEARCH INTO FA CAN PROVIDE INSIGHTS AND ADVANCES IN OTHER DISEASES SUCH AS MITOCHONDRIAL DISEASES, MUSCULAR DYSTROPHIES, DIABETES, AND CARDIOMYOPATHY.

FORM 990, PART III, LINE 4B, PROGRAM SERVICE ACCOMPLISHMENTS:
CLINICAL RESEARCH INFRASTRUCTURE (CONT'D):

OF FA AND THE TREATMENTS BEING DEVELOPED. FARA PARTNERS WITH INTERNATIONAL PATIENT ADVOCACY ORGANIZATIONS THROUGH A GOVERNANCE BOARD TO ENSURE MULTI-STAKEHOLDER ENGAGEMENT AND OVERSIGHT OF THE FAGPR. MORE THAN 1000 INDIVIDUALS WITH FA ARE ENROLLED AND FAGPR WAS USED TO RECRUIT FOR SEVERAL CLINICAL TRIALS AND MANY CLINICAL RESEARCH STUDIES. TO LEARN MORE, VISIT CUREFA.NET/REGISTRY.

FA GLOBAL CLINICAL CONSORTIUM: FARA AND THE FA COMMUNITY'S DEDICATION TO COLLECTING NATURAL HISTORY STUDY DATA OVER THE PAST TWO DECADES PROVED INSTRUMENTAL IN THE APPROVAL OF THE FIRST-EVER TREATMENT FOR FA. THROUGH THE FA GLOBAL CLINICAL CONSORTIUM (FA GCC), FARA HAS REDOUBLED ITS INVESTMENT IN NATURAL HISTORY DATA BY ENABLING THE TRANSITION TO AN INDUSTRY-LEADING DATA COLLECTION PLATFORM AND A UNIFIED GLOBAL NATURAL HISTORY PROTOCOL (UNIFAI) RESULTING FROM THE HARMONIZATION OF TWO WELL-ESTABLISHED NATURAL HISTORY STUDIES, THE FA CLINICAL OUTCOME MEASURES STUDY (FA-COMS) AND THE EUROPEAN FRIEDREICH'S ATAXIA CONSORTIUM FOR TRANSLATIONAL STUDIES (EFACTS).

THE FA GCC AND THE UNIFAI STUDY HAVE BEEN EXPANDED TO MAKE PATIENT CONTRIBUTIONS TO NATURAL HISTORY EVEN MORE POWERFUL IN UNDERSTANDING FA, EVALUATING THE IMPACT OF TREATMENT OPTIONS FOR FA, ACCELERATING THE DEVELOPMENT OF NEW THERAPIES AND IMPROVING OUTCOMES FOR THOSE LIVING WITH FA. AT EACH UNIFAI STUDY VISIT THERE ARE MORE THAN 1400 DATA ELEMENTS RECORDED.

OVER THE LAST TWO YEARS, THE FA GCC HAD ACTIVE PARTICIPATION FROM 54 INVESTIGATORS FROM 33 SITES REPRESENTING 18 COUNTRIES ALONG WITH REPRESENTATIVES FROM PATIENT ADVOCACY AND RESEARCH ORGANIZATIONS.

FA GCC RESEARCH ACTIVITIES: THE FA GCC LEADERSHIP IDENTIFIED INITIAL SCIENTIFIC PRIORITIES AND CREATED WORKGROUPS TO ADDRESS THESE PRIORITIES. THE FOLLOWING WORK GROUPS, EACH MADE UP OF 5-10 CONSORTIUM

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MEMBERS, MET REGULARLY TO ADDRESS GAPS IN CURRENT FA RESEARCH: CARDIAC NATURAL HISTORY, LATE-STAGE SYMPTOMS, PEDIATRIC / PRESYMPOMATIC, BIO-SAMPLES, MOOD AND COGNITION, AND PATIENT ADVOCACY/ADVISORY TEAM.

QUARTERLY FULL GROUP MEETINGS SERVE AS A PLATFORM FOR INVESTIGATORS TO ESTABLISH COMMON RESEARCH INTERESTS, FORM COLLABORATIONS, AND SHARE THEIR GLOBAL EXPERIENCES WITH OMAVELOXOLONE.

IMPACT AND FUTURE DIRECTION: THE CONSORTIUM HAS A LONG-TERM OBJECTIVE OF FOSTERING MULTILATERAL RESEARCH AND COLLABORATION ACROSS CONTINENTS, UNIFYING GLOBAL OPINIONS TO REGULATORS AND INDUSTRY PARTNERS, ACCELERATING THE DEVELOPMENT OF NEW THERAPIES, AND IMPROVING OUTCOMES FOR THOSE LIVING WITH FA.

ADDITIONAL INFORMATION ABOUT FARA'S PROGRAMS IN 2024 CAN BE ACCESSED VIA THE ANNUAL REPORT AT: CUREFA.ORG

FORM 990, PART III, LINE 4C, PROGRAM SERVICE ACCOMPLISHMENTS:
ADVOCACY: (CONT'D)

THE CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM (CDMRP) AT THE DEPARTMENT OF DEFENSE IN FISCAL YEAR (FY) 24, RESULTING IN FOUR HEREDITARY ATAXIA RESEARCH GRANTS BEING RECOMMENDED FOR FUNDING TOTALING OVER \$12 MILLION. FARA AND NAF WERE ALSO SUCCESSFUL IN GETTING A RESOLUTION PASSED DECLARING SEPTEMBER 25, 2024 NATIONAL ATAXIA AWARENESS DAY AND HOSTING THE SIXTH UNITED AGAINST ATAXIA HILL DAY- WITH 94 CONGRESSIONAL MEETINGS FEATURING THE PARTICIPATION OF 113 FARA AND NAF ADVOCATES FROM 32 STATES.

EDUCATION:

IN AN ONGOING EFFORT TO SHARE INFORMATION AND EDUCATION, FARA LAUNCHED A NEW WEBSITE IN 2024. THE SITE REDesign PRIORITIZED THE USER EXPERIENCE FOR KEY STAKEHOLDERS INCLUDING PATIENT FAMILIES, RESEARCHERS, AND DONORS. THE NEW SITE COINTAINS UP-TO-DATE INFORMATION ON FA RESEARCH INCLUDING GRANTS FUNDED BY FARA, TREATMENT APPROACHES AND PROGRAMS IN THE DRUG DEVELOPMENT PIPELINE, RESEARCH RESOURCES, AND CLINICAL TRIAL OPPORTUNITIES. IT ALSO OFFERS GUIDANCE FOR FAMILIES NAVIGATING FA AND OPPORTUNITIES TO CONNECT WITH OTHERS AND GET INVOLVED.

ENGAGING WITH STAKEHOLDERS: AS EXPERTS IN LIVING WITH FA, INDIVIDUALS AND FAMILIES SHARED THEIR STORIES IN MANY FORUMS AND TO MANY AUDIENCES. IN 2024, OVER 50 INDIVIDUALS FROM THE FA COMMUNITY WORKED WITH FARA TO ENGAGE WITH PHARMACEUTICAL PARTNERS, RESEARCHERS, FUTURE HEALTHCARE PROFESSIONALS, MEDICAID COMMITTEES, AND THE FOOD AND DRUG ADMINISTRATION AT 33 DIFFERENT EVENTS. THEIR VOICES PROVIDE ESSENTIAL INSIGHTS THAT ADVANCE MEANINGFUL AND ACCESSIBLE TREATMENTS.

CULTIVATING COMMUNITY: THROUGHOUT 2024, FARA WORKED TO STRENGTHEN THE FA COMMUNITY BY FACILITATING OPPORTUNITIES FOR CONNECTION AND COLLABORATION THROUGH VIRTUAL AND IN-PERSON EVENTS. INDIVIDUALS NEW TO THE FA COMMUNITY HAD THE OPPORTUNITY TO MEET OTHER FA FAMILIES FOR THE FIRST TIME. THE FARA AMBASSADOR PROGRAM, A GROUP OF ADULTS WITH FA WHO VOLUNTEER TO SUPPORT FARA'S MISSION, GREW TO 100 MEMBERS FROM COUNTRIES AROUND THE WORLD. AMBASSADORS NOW REPRESENT 14 COUNTRIES GLOBALLY PLUS 32 STATES THROUGHOUT THE US.

TO HELP FURTHER FARA'S AWARENESS AND OUTREACH INITIATIVES, FARA ALSO

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

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FUNDED A GRANT FOR THE CREATION OF A DOCUMENTARY FILM ABOUT HOW THE FA COMMUNITY UNITES TO ADVANCE RESEARCH. THE FILM, UNDER THE WORKING TITLE "THE HIGHEST ROAD," FOCUSES ON THE FA COMMUNITY'S ROLE IN HELPING TO GET THE FIRST DRUG APPROVED FOR FA A STORY THAT IS TOLD IN PARALLEL WITH COMMUNITY MEMBERS ATTEMPTING TO CYCLE UP THE HIGHEST PAVED ROAD IN INDIA. THE FILM IS CURRENTLY IS POST PRODUCTION WITH THE AIM TO BE SHOWN IN FILM FESTIVALS IN 2026.

**FORM 990, PART III, LINE 4D, OTHER PROGRAM SERVICES:
WORKSHOPS, SYMPOSIA, & CONFERENCES**

INTERNATIONAL CONGRESS FOR ATAXIA RESEARCH IN NOVEMBER 2024, THE INTERNATIONAL CONGRESS FOR ATAXIA RESEARCH (ICAR) BROUGHT TOGETHER OVER 600 RESEARCHERS FROM AROUND THE WORLD. IT WAS THE LARGEST ICAR TO DATE AND A POWERFUL EXAMPLE OF HOW WE ACCELERATE PROGRESS WHEN EXPERTS ACROSS DIFFERENT TYPES OF ATAXIA COME TOGETHER TO SHARE IDEAS AND COLLABORATE. FARA WAS HONORED TO CO-HOST THE MEETING ALONG WITH ATAXIA UK, NATIONAL ATAXIA FOUNDATION, AND THE ATAXIA GLOBAL INITIATIVE.

THIS YEAR'S PROGRAM INCLUDED A MIX OF PLENARY SESSIONS, BREAKOUT WORKSHOPS, AND SCIENTIFIC DEBATE. THE DEBATE SPARKED THOUGHTFUL DISCUSSION ABOUT THE STRENGTHS OF IN VIVO VS. IN VITRO RESEARCH MODELS AND HIGHLIGHTED HOW BOTH APPROACHES HELP TO MOVE THE SCIENCE FORWARD. SOME INSIGHTS AND LEARNINGS FROM ICAR 2024 INCLUDED: 1. DISCOVERING THAT FRATAXIN ACTIVITY CAN BE BOOSTED BY TARGETING OTHER COMPONENTS OF THE IRON-SULFUR CLUSTER ASSEMBLY REVEALS A POTENTIAL NEW TREATMENT PATHWAY. 2. SOME GAA REPEAT INTERRUPTIONS ARE MORE COMMON THAN PREVIOUSLY KNOWN, IMPACTING CARRIER DETECTION AND OPENING NEW THERAPEUTIC OPPORTUNITIES. 3. INFLAMMATION MIGHT CONTRIBUTE TO NERVE DAMAGE IN FA. 4. CAPSID FOR AN IV GENE ADDITION THERAPY REACHED KEY BRAIN AND HEART AREAS IN ANIMAL MODELS 5. MULTIPLE THERAPIES ACROSS DIFFERENT MECHANISMS OF ACTION ARE SHOWING EARLY PROMISE.

FARA ALSO HOSTED FIVE RESEARCH RECEPTIONS AND SYMPOSIA TO SHARE INFORMATION ABOUT THE FA DRUG DEVELOPMENT PIPELINE, ONGOING CLINICAL TRIALS, CLINICAL MANAGEMENT, AND FARA RESOURCES. VIRTUAL EDUCATION SESSIONS INCLUDED FLASH TALKS WITH FARA-FUNDED RESEARCHERS, COMMUNITY CONVERSATION WEBINARS WITH FARA LEADERSHIP, AND INFORMATION SESSIONS WITH PHARMACEUTICAL PARTNERS.

EXPENSES \$ 357,617. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

FORM 990, PART VI, SECTION B, LINE 11B:

COPIES OF 990 ARE DISTRIBUTED TO BOARD MEMBERS FOR REVIEW AND APPROVAL PRIOR TO FILING.

FORM 990, PART VI, SECTION B, LINE 12C:

ALL NEW AND EXISTING BOARD MEMBERS ARE REQUIRED TO ANNUALLY REVIEW AND SIGN A CONFLICT OF INTEREST POLICY AND REPORT DISCLOSURES.

FORM 990, PART VI, SECTION B, LINE 15:

EVALUATION AND COMPENSATION COMMITTEE PERFORMS EMPLOYEE EVALUATIONS AND DETERMINES SALARY INCREASES ON A YEARLY BASIS FOR ALL EMPLOYEES. COMMITTEE EXAMINES BENCHMARK DATA IN DETERMINING SALARIES FOR PRESIDENT, CEO, CSO AND DIRECTOR FINANCE ADMINISTRATION.

FORM 990, PART VI, LINE 17, LIST OF STATES RECEIVING COPY OF FORM 990:

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCE

Employer identification number

52-2122720

AL, AK, AZ, AR, CA, CO, CT, FL, GA, IL, KS, KY, ME, MD, MS, MI, MN, MS, MO, NH, NJ, NM, NY, NC, ND
OH, OK, OR, PA, RI, SC, TN, UT, VA, WA, WV, WI, MA

FORM 990, PART VI, SECTION C, LINE 19:

FORM 990 IS AVAILABLE ON THE ORGANIZATION'S WEBSITE AS WELL AS
GUIDESTAR.ORG AND CHARITYNAVIGATOR.ORG FINANCIAL STATEMENTS ARE AVAILABLE
ON THE ORGANIZATION'S WEBSITE. THE GOVERNING DOCUMENTS, CONFLICT OF
INTEREST POLICY AND FORM 1023 ARE AVAILABLE UPON REQUEST.

FORM 990, PART XI, LINE 9, CHANGES IN NET ASSETS:

PRIOR YEAR GRANT REFUNDS INCLUDED IN SUPPORT ON FINANCIAL
STATEMENTS

91,718.

FORM 990, PART XII, LINE 2C

FARA'S AUDIT COMMITTEE CONSISTS OF THE FINANCE COMMITTEE, CEO AND ONE
AT-LARGE BOARD MEMBER. EACH YEAR THE AUDIT COMMITTEE SEEKS THE SERVICES
OF AN OUTSIDE ACCOUNTING FIRM AND CONTRACTS FOR A FULL AUDIT,
PREPARATION OF FINANCIAL STATEMENTS AND FILING OF THE 990. THE AUDIT
COMMITTEE IS RESPONSIBLE FOR REVIEWING RECOMMENDATIONS FROM THE AUDIT
AND PROPOSING NEW POLICIES AND PROCEDURES AS NECESSARY. THE AUDIT
COMMITTEE ALSO PARTICIPATES IN DETAILED REVIEW OF FINANCIAL STATEMENTS
AND 990 PRIOR TO SHARING WITH THE FULL BOARD FOR A VOTE.

ALL 990 INFORMATION IS VERIFIED FOR ACCURACY AND COMPLETENESS BY FARA'S
DIRECTOR OF FINANCE, FARA'S VP OF FUNDRAISING AND COMMUNICATIONS AND
FARA'S CEO. THE VERIFIED DRAFT IS REVIEWED BY THE FARA FINANCE
COMMITTEE AND SUBMITTED TO THE FULL FARA BOARD FOR REVIEW AND APPROVAL
PRIOR TO FILING.

**SCHEDULE R
(Form 990)**

(Rev. January 2025)

Department of the Treasury
Internal Revenue Service**Related Organizations and Unrelated Partnerships**
Complete if the organization answered "Yes" on Form 990, Part IV, line 33, 34, 35b, 36, or 37.

Attach to Form 990.

Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

Open to Public
Inspection

Name of the organization

FRIEDREICH'S ATAXIA RESEARCH ALLIANCEEmployer identification number
52-2122720**Part I Identification of Disregarded Entities.** Complete if the organization answered "Yes" on Form 990, Part IV, line 33.

| (a) Name, address, and EIN (if applicable) of disregarded entity | (b) Primary activity | (c) Legal domicile (state or foreign country) | (d) Total income | (e) End-of-year assets | (f) Direct controlling entity |
|--|-------------------------|---|---------------------|---------------------------|-------------------------------------|
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Part II Identification of Related Tax-Exempt Organizations. Complete if the organization answered "Yes" on Form 990, Part IV, line 34, because it had one or more related tax-exempt organizations during the tax year.

| (a) Name, address, and EIN of related organization | (b) Primary activity | (c) Legal domicile (state or foreign country) | (d) Exempt Code section | (e) Public charity status (if section 501(c)(3)) | (f) Direct controlling entity | (g) Section 512(b)(13) controlled entity? | |
|--|-------------------------|---|-------------------------------|---|---|--|----|
| | | | | | | Yes | No |
| STICHTING FRIEDREICH'S ATAXIA RESEARCH ALLIANCE EUROPE, JACHTHAVENWEG 111, 1081KM AMSTERDAM, NETHERLANDS | RESEARCH | NETHERLANDS | | | FRIEDREICH'S ATAXIA RESEARCH ALLIANCE | | X |
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For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule R (Form 990) (Rev. 1-2025)

Part III Identification of Related Organizations Taxable as a Partnership. Complete if the organization answered "Yes" on Form 990, Part IV, line 34, because it had one or more related organizations treated as a partnership during the tax year.

| (a) Name, address, and EIN of related organization | (b) Primary activity | (c) Legal domicile (state or foreign country) | (d) Direct controlling entity | (e) Predominant income (related, unrelated, excluded from tax under sections 512-514) | (f) Share of total income | (g) Share of end-of-year assets | (h) Disproportionate allocations? | | (i) Code V-UBI amount in box 20 of Schedule K-1 (Form 1065) | (j) General or managing partner? | (k) Percentage ownership |
|--|-------------------------|--|-------------------------------------|---|---------------------------------|--|---|----|---|---|--------------------------------|
| | | | | | | | Yes | No | | | |
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Part IV Identification of Related Organizations Taxable as a Corporation or Trust. Complete if the organization answered "Yes" on Form 990, Part IV, line 34, because it had one or more related organizations treated as a corporation or trust during the tax year.

| (a) Name, address, and EIN of related organization | (b) Primary activity | (c) Legal domicile (state or foreign country) | (d) Direct controlling entity | (e) Type of entity (C corp, S corp, or trust) | (f) Share of total income | (g) Share of end-of-year assets | (h) Percentage ownership | (i) Section 512(b)(13) controlled entity? | |
|--|-------------------------|---|-------------------------------------|--|---------------------------------|--|--------------------------------|---|----|
| | | | | | | | | Yes | No |
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Part V Transactions With Related Organizations. Complete if the organization answered "Yes" on Form 990, Part IV, line 34, 35b, or 36.

Note: Complete line 1 if any entity is listed in Parts II, III, or IV of this schedule.

1 During the tax year, did the organization engage in any of the following transactions with one or more related organizations listed in Parts II-IV?

- a Receipt of (i) interest, (ii) annuities, (iii) royalties, or (iv) rent from a controlled entity
- b Gift, grant, or capital contribution to related organization(s)
- c Gift, grant, or capital contribution from related organization(s)
- d Loans or loan guarantees to or for related organization(s)
- e Loans or loan guarantees by related organization(s)

- f Dividends from related organization(s)
- g Sale of assets to related organization(s)
- h Purchase of assets from related organization(s)
- i Exchange of assets with related organization(s)
- j Lease of facilities, equipment, or other assets to related organization(s)

- k Lease of facilities, equipment, or other assets from related organization(s)
- l Performance of services or membership or fundraising solicitations for related organization(s)
- m Performance of services or membership or fundraising solicitations by related organization(s)
- n Sharing of facilities, equipment, mailing lists, or other assets with related organization(s)
- o Sharing of paid employees with related organization(s)

- p Reimbursement paid to related organization(s) for expenses
- q Reimbursement paid by related organization(s) for expenses

- r Other transfer of cash or property to related organization(s)
- s Other transfer of cash or property from related organization(s)

2 If the answer to any of the above is "Yes," see the instructions for information on who must complete this line, including covered relationships and transaction thresholds.

| | (a) Name of related organization | (b) Transaction type (a-s) | (c) Amount involved | (d) Method of determining amount involved |
|-----|-------------------------------------|-------------------------------|------------------------|--|
| (1) | | | | |
| (2) | | | | |
| (3) | | | | |
| (4) | | | | |
| (5) | | | | |
| (6) | | | | |

Part VI Unrelated Organizations Taxable as a Partnership. Complete if the organization answered "Yes" on Form 990, Part IV, line 37.

Provide the following information for each entity taxed as a partnership through which the organization conducted more than five percent of its activities (measured by total assets or gross revenue) that was not a related organization. See instructions regarding exclusion for certain investment partnerships.

| (a) Name, address, and EIN of entity | (b) Primary activity | (c) Legal domicile (state or foreign country) | (d) Predominant income (related, unrelated, excluded from tax under sections 512-514) | (e) Are all partners sec. 501(c)(3) orgs? | | (f) Share of total income | (g) Share of end-of-year assets | (h) Disproportionate allocations? | | (i) Code V-UBI amount in box 20 of Schedule K-1 (Form 1065) | (j) General or managing partner? | (k) Percentage ownership |
|--|-------------------------|--|---|---|----|------------------------------------|--|---|----|---|---|--------------------------------|
| | | | | Yes | No | | | Yes | No | | | |
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Part VII Supplemental Information

Provide additional information for responses to questions on Schedule R. See instructions.

| FARA Budget Overview | |
|---|----------|
| Januay 1, 2025-December 31, 2025 | |
| Revenue | |
| Direct Public Grants | 1750046 |
| Direct Public Support | 6241700 |
| Indirect Public Support | 192500 |
| Other Types of Income | 0 |
| Program Income | 3269439 |
| Total Revenue | 11453685 |
| Expenses | |
| Awards and Grants | 9548999 |
| Business Expenses | 11500 |
| Contract Services | 614675 |
| Credit Card & Bank Fees | 92270 |
| Facilities and Equipment | 375500 |
| Operations | 505797 |
| Other Types of Expenses | 65850 |
| Payroll Expenses | 2077983 |
| Taxes Paid | 8500 |
| Travel and Meetings | 513525 |
| Total Expenses | 13814599 |
| Surplus (Deficit) | -2360914 |

*Note: Deficit reflcts temporaroly restricted funds received in a prior year to be used for projects in 2025.

Donor
Impact
Report
2024



2024 BOARD OF DIRECTORS

Ronald J. Bartek
President / Director / Co-Founder

Paul Avery
Chairman of the Board

Ruth Acton
Treasurer / Director

Maureen Juip
Secretary / Director

Sanjay Bidichandani, MBBS, PhD
Scientific Director

Brigid T. Brennan, Esq.
Director / General Counsel / Advocacy

Alex Fielding
Director

Jennifer L. Good
Director

Thomas Hamilton
Director

Holly Hedrick, MD, FACS
Director

Derek Hennecke
Director

Warren Huff
Director

Stephen Klasko, MD, MBA
Director

Katherine Mathews, MD
Director

James McArthur, PhD
Scientific Director

Tony Plohoros
Director

Patrick Ritschel
Director

James Rusche, PhD
Scientific Director

Transformative change lies at the intersection of people and science.



OUR HISTORY

FARA was founded in September 1998 by patient families and three of the world's leading FA scientists who have dedicated themselves to changing the course of FA.

OUR APPROACH

We work in collaboration and with a sense of urgency to build strong relationships, expand knowledge, and remove uncertainty.

OUR PROMISE

We've made a promise to treat and cure FA through research.

Dear Friends,

Reflecting on the progress we've made this past year, we are filled with gratitude for the dedication and support of our Friedreich's ataxia community – donors, fundraisers, researchers, industry partners, and FA families.

This year, your generosity enabled FARA to fund 46 groundbreaking research grants across 13 countries and five continents. This global collaboration attracts diverse expertise and ideas, ensuring we fund impactful research that leads to breakthroughs in knowledge and accelerates our pursuit of treatments and, ultimately, a cure.

Remarkably, one-fourth of all FA scientific publications this year were based on FARA-funded research. This significant contribution underscores how FARA is driving progress by broadening our understanding of FA.

Your support has also expanded our research infrastructure. In the last two years, we have doubled the number of sites now part of the FA Global Clinical Consortium (FA GCC). Because FA is a global disease, we need FA research centers where there are individuals with FA. These more than 30 sites create opportunities for people to participate in clinical research, which leads to more robust data and faster progress in finding treatments that benefit the whole FA community.

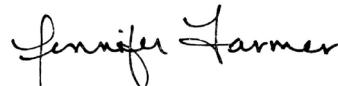
An important project that we've sponsored is TRACK-FA, the world's largest FA neuroimaging study. This research is helping us understand the complex ways FA affects the brain and spinal cord, paving the way for new ways to measure therapeutic impact in clinical trials. To the hundreds of volunteers who participated in this study, thank you!

Looking ahead, we remain committed to ensuring that children and adults worldwide have access to clinical trials and the latest advancements in FA treatments. We are focused on developing the necessary resources to support pediatric inclusion in clinical trials, and we continue to advocate for broader global access.

None of these achievements would be possible without you. Your contributions drive these accomplishments, and your continued support will keep the momentum going. Every grassroots fundraiser, every rideATAXIA event, every dollar raised at the Energy Ball, and every person who shares their story brings us closer to treating and curing FA.

Looking ahead, we are filled with optimism, knowing that we have the strength of this amazing community behind us.

With sincere appreciation,



Jennifer Farmer, Chief Executive Officer



Ronald J. Bartek, President



2024 MILESTONES

FUNDED \$10M+ IN RESEARCH

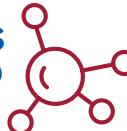
to support our mission to slow, stop, and reverse FA



ENRICHED THE FA TREATMENT PIPELINE

with novel and diverse approaches

HELPED EXPAND ACCESS TO THE FIRST APPROVED TREATMENT FOR FA



BUILT THE FA GLOBAL CLINICAL CONSORTIUM



to support next generation clinical trials

ADVOCATED FOR PEDIATRIC INCLUSION IN CLINICAL TRIALS

CO-HOSTED THE LARGEST INTERNATIONAL SCIENTIFIC MEETING FOR ATAXIA RESEARCHERS



GREW CENTERS OF EXCELLENCE

to new areas of investigation at world class universities



RESEARCH GRANT PROGRAM

Investing in the Next Breakthrough

Growing interest in FA research led to an increased number of grant application submissions to FARA and record research funding.

The FARA grant program drives discovery by funding research that expands our understanding of FA. The program prioritizes high-impact projects that address gaps in disease knowledge, supports early-stage therapeutic interventions, creates better research tools, and advances clinical research.

In 2024, FARA received more than 60 highly competitive grant applications from investigators across 13 countries. Nearly half of those applicants were new to FARA or FA research, reflecting the program's growing global reach and ability to attract experts with diverse ideas. This year also brought expanded international collaboration, with FARA co-funding grants alongside six nonprofit organizations worldwide.

As part of our commitment to continued innovation and the next generation of FA researchers, FARA awarded grants to 11 junior investigators last year. This is the highest number awarded in a single year.

Thanks to donor support, FARA is investing in the people and projects that are accelerating the path to treatments.





FEATURED GENERAL GRANT: PAIRED PRIME EDITORS TO TREAT FRIEDREICH'S ATAXIA

Jonathan Watts, PhD, Erik Sontheimer, PhD, Scot Wolfe, PhD and Wen Xue, PhD
University of Massachusetts Chan Medical School

This multi-disciplinary team of investigators is testing a set of novel prime editing tools to remove the GAA expansion in the FXN gene. Prime editing is an emerging form of gene editing that may offer greater safety than other editing approaches. One advantage of gene editing over gene addition therapy for FA is that, upon removal of the GAA repeats, the edited FXN gene remains under the control of its natural regulator, thus reducing concerns about the overexpression of frataxin and associated toxicity.

Co-sponsor: Muscular Dystrophy Association (MDA)

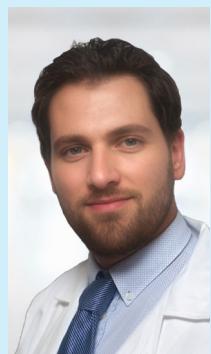


FEATURED AWARD FOR INNOVATIVE MINDSET: DELIVERABLE IN VITRO TRANSCRIBED mRNAs OF FRATAXIN AS A THERAPEUTIC APPROACH FOR FRIEDREICH'S ATAXIA

Lefkothea Papadopoulou, PhD, Aristotle University of Thessaloniki

Dr. Papadopoulou received an Award for Innovative Mindset (AIM) grant to explore an mRNA delivery platform as a potential treatment for FA. This approach builds on advances made during the COVID-19 pandemic and explores leveraging mRNA technologies to convert human cells into protein factories. With this technology, the mRNA expressing frataxin would be delivered to cells, resulting in the translation and production of this missing protein.

Co-sponsor: fara New Zealand



FEATURED POSTDOCTORAL FELLOWSHIP AWARD: UNDERSTANDING THE PATHOGENESIS OF FRIEDREICH'S ATAXIA BY SINGLE-CELL INTEGRATION OF GENE EXPRESSION, EPIGENETICS, AND CONNECTIVITY IN THE CEREBELLAR NUCLEI

Julian Cheron, MD, PhD, Johns Hopkins University

Dr. Cheron was awarded a Postdoctoral Fellowship to identify which specific cell types within the cerebellum are affected in FA and understand their role in disease progression. This project will use cutting-edge technologies to study the brain at a single-cell level in an FA mouse model. The goal is to gain new insights into disease mechanisms, including early changes in brain connectivity that may occur before cellular loss begins.

Co-sponsor: Association Francaise de l'Ataxia de Friedreich (AFAF)

>> Learn more about research grants awarded by FARA at curefa.org/funded-grants

FRIEDREICH'S ATAXIA CENTER OF EXCELLENCE (COE)

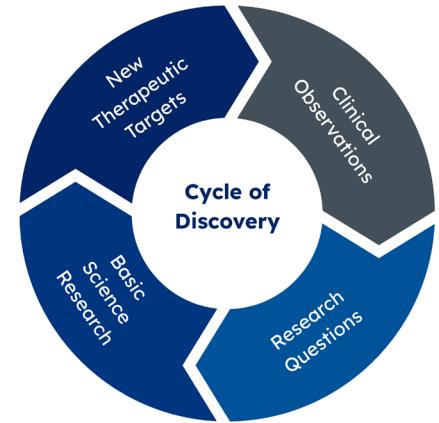
at Children's Hospital of Philadelphia (CHOP) and University of Pennsylvania



Since 2014, funding provided by FARA, in partnership with the CureFA Foundation and the Hamilton and Finneran families, has supported the FA COE's distinctive

model. This innovative approach to research consists of basic science researchers and clinicians working in close collaboration.

- COE clinicians observe FA in real-time, noticing subtle trends and unexpected features in people living with FA.
- These observations challenge our understanding of FA and raise new research questions, which are taken back to the COE.
- The COE labs investigate these questions, generating insights that feed directly back into clinical priorities.
- This collaboration extends beyond the COE to other FARA-funded researchers who share new tools and emerging data.



Projects and investigators with continued funding include:

Ian Blair, PhD: Biomarker Discovery
Kim Lin, MD: Cardiac Research
David Lynch, MD, PhD: Translational Clinical Neuroscience Research

Shana McCormack, MD, MTR: Metabolism and Endocrinology
Clementina Mesaros, PhD: Biomarker Discovery
Rob Wilson, MD, PhD: Drug Discovery

Discovery in Action: Learning from Non-GAA Repeat Mutations

95% of individuals with FA have the same gene mutation, a GAA repeat expansion, however 5% of individuals have non-GAA repeat mutations. COE clinicians observed that individuals with certain non-GAA mutations have different clinical symptoms and disease progression (both more and less severe). This led the clinicians to wonder why — would understanding how these point mutations impact the frataxin protein lead us to new insights into the role and function of the frataxin protein?

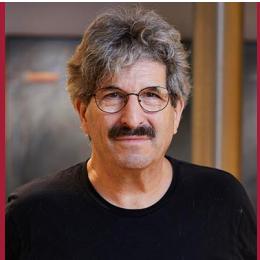
These clinical observations sparked lab-based studies into how specific missense mutations may affect frataxin's function beyond its well-known role in iron-sulfur cluster synthesis. This work explores whether frataxin may have additional cellular activities, offering both a new lens through which to understand disease variability and the exploration of new therapeutic targets.

THE FRIEDREICH'S ATAXIA ACCELERATOR (FAA) *at the Broad Institute of MIT and Harvard*



The Friedreich's Ataxia Accelerator at the Broad Institute of MIT and Harvard is committed to FA research. Led by Dr. Vamsi Mootha, the FAA's overarching goal is to nucleate a research community that leverages the latest advances in biomedical research to develop new therapeutic strategies. Dr. David Liu has been investigating therapeutic approaches that would edit the frataxin gene, with the goal of removing the GAA repeats (prime editing) or interrupting the GAA repeats (base editing) and thus reactivating the protein expression. Drs. Jonathan and Christine Seidman are discovering changes in the hearts of people with FA, including an increase in inflammation. This work is funded by FARA, in collaboration with the CureFA Foundation and EndFA. It deepens our knowledge of FA, and these learnings were shared by four members of the FAA who presented their work at the International Congress for Ataxia Research (ICAR) in November in London.

2024 Nobel Laureate



In December, FAA investigator Dr. Gary Ruvkun was awarded the Nobel Prize in Physiology or Medicine for the discovery of microRNA and its role in post-transcriptional gene regulation. His current work includes FA research where he is working to discover proteins that interact with frataxin.



Project Feature: At-Home Wearables

Investigators need robust, easy-to-use metrics to assess therapeutic candidates in clinical trials. The FAA has conducted a two-year project that has collected at-home quantitative data from wrist and ankle sensors. While longitudinal analysis of this data is still underway, this project is demonstrating the potential of building on this approach for future clinical trials.



Project Feature: Understanding the Heart

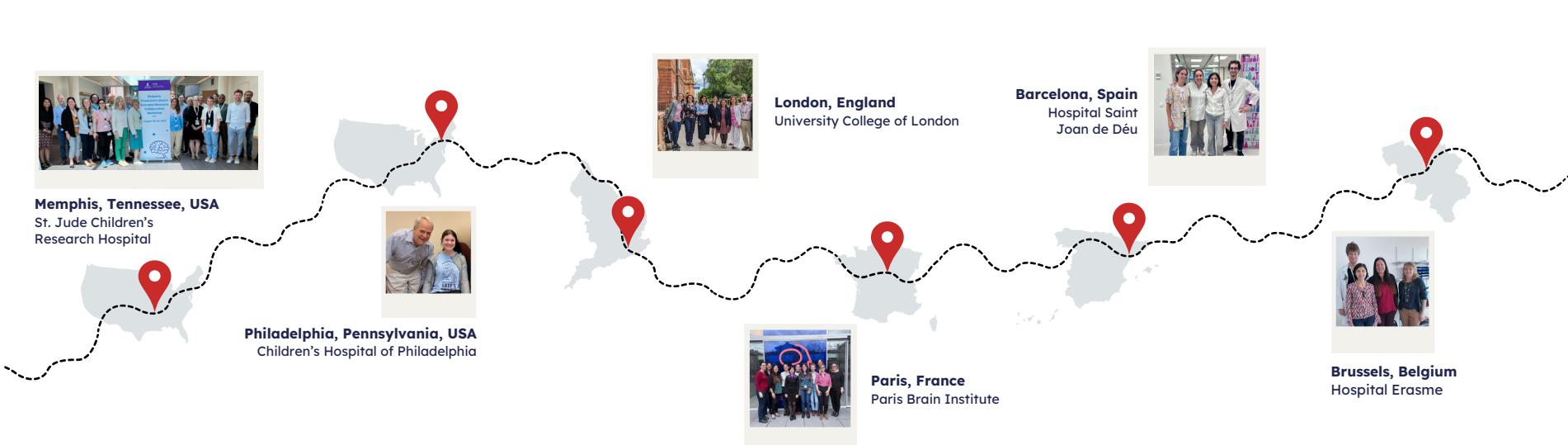
The Seidman lab is using cutting edge technology to understand the changes in the FA heart, including single nuclei RNA sequencing (snRNA-seq). They are learning how the cells present in the FA heart are different from those found in hearts with normal frataxin levels.



One of FARA's significant contributions to advancing FA research is to foster a global clinical research network and build a comprehensive natural history data set. FARA's investment in the Friedreich Ataxia Global Clinical Consortium (FA GCC) and the UNIFAI Natural History Study reflects our deep commitment to enabling clinical trials, responding to an expanding treatment pipeline, and ensuring that research continues to be informed by the patient experience. Over the past two years, FARA has doubled the number of the FA GCC sites to 34 institutions with clinical research teams devoted to FA.

This consortium growth helps:

- **Create a robust dataset** with diverse representation that enhances the statistical power and reliability of our findings and informs clinical trial design.
- **Facilitate patient recruitment** and increased participation in clinical trials.
- **Accelerate development** and access to therapies.
- **Improve the transfer of knowledge** through shared expertise of leading global experts.
- **Partner with global patient advocacy groups** to empower a patient-centered approach to shape therapies that truly address the challenges the FA community faces.



The Impact of FARA's Global Collaboration

The value of FARA's investment has been demonstrated in several ways. For example, the natural history data generated from individuals living with FA participating in research at FA GCC sites was used to support the regulatory decision of the first approved treatment for FA.

Now, the global effort to advance FA research and treatment under the FA GCC provides the infrastructure to support a growing number of clinical trials and to learn how new treatments impact the natural history of the disease. Furthermore, the collaboration between researchers in the FA GCC has allowed experts to build off of each other's work, enhancing the overall impact and efficiency of their research efforts.



Nijmegen, Netherlands
Radboud University Medical Center



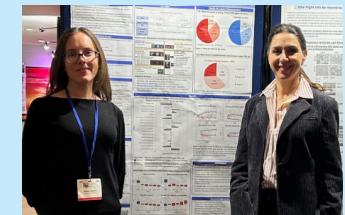
Prague, Czech Republic
Motol University Hospital



Aachen, Germany
RWTH University Hospital Aachen



New Delhi, India
All India Institute of Medical Sciences (AIIMS)



TRACK-FA is a neuro-imaging study to track disease progression and meet the urgent need for clinical-trial-ready biomarkers. Initiated in 2020, this FARA-sponsored longitudinal study is a collaboration among a consortium of clinical sites and researchers from Australia, Brazil, Canada, Germany, and USA as well as industry partners.

2024 Progress: We are proud to report that of the 279 participants enrolled in the study, 100% have completed their baseline and 12-month visits, and more than half have completed their final visits. This remarkable progress keeps us on track to finalize data collection in 2025. Helena Bujalka, PhD and Professor Nellie Georgiou-Karistianis (pictured above) represented the TRACK-FA consortium and presented baseline data and initial results at the 2024 International Congress for Ataxia Research.

Early Findings: TRACK-FA is the first multi-modal neuroimaging study to encompass both children and adults, with a special cohort of very young participants with FA who are 5-10 years old. This allows us to identify differences early in the disease. Early results indicate:

- For some measurements – such as the size of the spinal cord – differences can be detected even in very young children, and those differences increase with age.
- For other measurements in the brain, differences can be detected only later, in older children or adults.

Advocating to Create Change

ADVOCACY

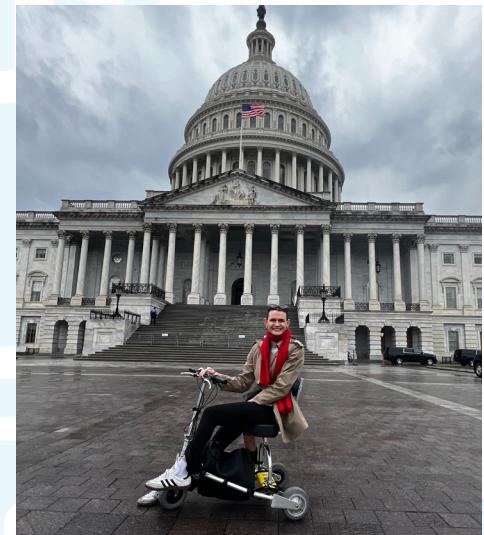
Whether it was meetings with elected officials, speaking at Medicaid hearings to secure access to treatment, or participating in awareness events, FARA and the FA community have continued to create change through advocacy in 2024!

In February 2024, FARA joined over 800 advocates in 330 Congressional meetings for Rare Disease Week on Capitol Hill. For the first time, the House Energy & Commerce Health Subcommittee held a hearing to highlight eighteen bills covering rare disease while the Biden White House Office of Science and Technology Policy's (OSTP) Health Outcomes Team held its first ever rare disease forum.

On September 25, 2024, FARA and the National Ataxia Foundation (NAF) celebrated the 6th Annual United Against Ataxia Hill Day. FARA and NAF were joined by 113 advocates from 32 states for 94 Congressional meetings. Advocates urged action on a number of policy priorities, including the continued inclusion of "Hereditary Ataxia" in the Congressionally Directed Medical Research Program (CDMRP), timely passage of the FY25 budget, robust funding for the Food and Drug Administration (FDA) and National Institutes of Health (NIH), and the extension of critical incentives for rare disease drug development. The Senate passed a resolution recognizing the day as "National Ataxia Awareness Day," led by Senator Hyde-Smith (MS) and co-sponsored by Senators Stabenow (MI), Moore Capito (WV), and Murphy (CT). Senators Amy Klobuchar (MN) and Bob Casey (PA) were honored as the 2024 Ataxia Research Champions (ARC).

The work done this past year has led to amazing results including four CDMRP grants being recommended for funding totaling over \$12.25 million for hereditary ataxia research, the creation of the FDA Rare Disease Innovation Hub, and passage of important legislation like the reauthorization of the Federal Aviation Administration which included significant reforms aimed at improving air travel for passengers with disabilities.

>> You too can advocate for FA research in 2025! Get started by signing up for the Advocacy Newsletter at curefa.org/newsletters



PEDIATRIC-FOCUSED RESEARCH AND ADVOCACY

FARA remains committed to ensuring that children are included early in clinical research for FA. Giving children earlier access to treatments creates more opportunities to slow or alter the course of disease.

In July 2024, FARA partnered with Leavitt Partners to host the Pediatric Inclusion Roundtable: Effective Inclusion of Children Early in Clinical Trials. The event brought together key stakeholders, including representatives from the Food and Drug Administration (FDA), National Institutes of Health (NIH), pharmaceutical and biotech industries, and patient advocacy groups, to explore strategies for accelerating pediatric drug development in rare diseases like FA.

This roundtable led to the formation of the Pediatric Inclusion Alliance, a dedicated working group that will continue advancing efforts to promote early pediatric inclusion in clinical trials. FARA's co-founder, Ron Bartek, now co-chairs this initiative.

FARA also continues to advocate for federal programs like the Pediatric Priority Review Voucher, which encourage pediatric-focused innovation in rare disease drug development.



INTERNATIONAL CONGRESS FOR ATAXIA RESEARCH



In November 2024, the International Congress for Ataxia Research (ICAR) took place in London and brought together over 600 researchers from around the world. It was the largest ICAR to date and a powerful example of how we accelerate progress when experts across different types of ataxia come together to share ideas and collaborate.

This year's program included a mix of plenary sessions, breakout workshops, and the always-popular scientific debate. The debate sparked thoughtful discussion about the strengths of *in vivo* vs. *in vitro* research models and highlighted how both approaches help to move the science forward.

Insights and Learnings from ICAR 2024

Potential New Therapeutic Target

Discovering that frataxin activity can be boosted by targeting other components of the iron-sulfur cluster assembly reveals a potential new treatment pathway.

Hidden Genetic Variant

Some GAA repeat interruptions are more common than previously known, impacting carrier detection and opening new therapeutic opportunities.

Inflammation as a Driver

Inflammation might contribute to nerve damage in FA.

Breakthrough in Gene Delivery

Capsid for an IV gene addition therapy reached key brain and heart areas in animal models.

Clinical Trials Show Momentum

Multiple therapies across different mechanisms of action are showing early promise.

FA research had a strong presence at the meeting. With multiple clinical trials underway and the first treatment now approved, there was a clear sense of momentum. Collaboration has always been core to FARA's mission, and ICAR reflected that — from global data sharing to joint projects with multiple institutions.

Importantly, the FA community was represented not just in the science but in the scientists themselves — three researchers living with FA presented their work. ICAR also invested in the future of the field by providing meaningful mentorship and networking opportunities for early-career researchers. These experiences are vital for building the next generation of leaders in ataxia research.



COMMUNITY ENGAGEMENT & EDUCATION

An engaged, educated, and connected community is a strong one, and the FA community excelled in all of these areas over the last year. Participation reached record levels and made a meaningful impact on fellow FA families as well as partner entities.

EDUCATION

FARA hosted five research receptions and symposiums to share information about the FA drug development pipeline, ongoing clinical trials, clinical management, and FARA resources.

Virtual education sessions included Flash Talks with FARA-funded researchers, Community Conversation webinars with FARA leadership, and information sessions with pharmaceutical partners.



ENGAGING WITH STAKEHOLDERS

As experts in living with FA, individuals and families shared their stories in many forums and to many audiences.

In 2024, over 50 individuals from the FA community worked with FARA to engage with pharmaceutical partners, researchers, future healthcare professionals, Medicaid committees, and the Food and Drug Administration at 33 different events.

Their voices provide essential insights that advance meaningful and accessible treatments.



CULTIVATING COMMUNITY

Throughout 2024, FARA worked to strengthen the FA community by facilitating opportunities for connection and collaboration through virtual and in-person events. Individuals new to the FA community had the opportunity to meet other FA families for the first time.

The FARA Ambassador Program, a group of adults with FA who volunteer to support FARA's mission, grew to 100 members from countries around the world. Ambassadors now represent 14 countries globally plus 32 states throughout the US.



GRASSROOTS FUNDRAISING



GRASSROOTS **\$1.6M+ RAISED**

Whether it's a musical soirée, a 5K walk/run, or a golf tournament, FARA grassroots fundraisers take on many different forms. These events are hosted by members of the FA community, and they reflect their creativity and passions while generating critical funds to advance FARA's research mission.

In 2024, both seasoned and new volunteer fundraisers hosted more than two dozen grassroots events.

The Race for Matt and Grace (RFMG) didn't let the rain get in the way of celebrating the incredible milestone of 15 years of fundraising. The DiIorio, Hopkins, and Fielding families united to host their signature RFMG 5K walk/run as well as other events throughout the year such as a golf tournament, pig roast, and Oktoberfest.

The Cure FA Soirée, led by the Gehr Family, rocked their way to the top of our fundraising charts with their 7th annual event, which featured live music, dinner, and an auction.

We were also excited to welcome Epic Game Day as one of the new events on the scene this year, where attendees enjoyed an array of board games and camaraderie. The event was organized by the family of Jack Mohamed, who lives with FA, and the concept was inspired by his love of chess and board games.

To everyone who planned, attended, or supported a grassroots event in 2024, thank you. Together, you raised over \$1.6 million for FA research. Your efforts are making a difference.

2024 Grassroots Campaigns (\$5,000+)

\$450,000+

Cure FA Soirée
Edmond, OK

\$100,000+

Burrows Hill Foundation: Night to Fight FA
Annapolis, MD

Juip Family | FBMJ Drive-In Movie Fundraiser
Livonia, MI

Pull for a Cure
Tampa, FL

Race for Matt & Grace
Providence, RI (15th Year)

Team FARA: TCS New York City Marathon
New York, NY

\$50,000-\$99,999

N.J. Seaside Stride
Seaside Heights, NJ

\$20,000-\$49,999

Epic Game Day
Henderson, NV

Fuzzy Buzzy Golf Tournament
Windham, NH (20th Year)

Living A Courageous Life:
An Evening to Cure FA
Branford, CT

Morrow Lacrosse Challenge
Baltimore, MD

Sadie's Dance
Opelika, AL

The Smith Family
Auburn, AL

\$10,000-\$19,999

#CureFA Baseball Game
Terre Haute, IN (5th Year)

Fine Arts for Friedreich's Ataxia
Sioux Falls, SD

Cousins for a Cure | GolfATAXIA
Commerce Charter Township, MI

The Leonard Family
Virginia

The Stoneham Open
Portsmouth, NH

Team FARA: David Welch
Boston, MA

\$5,000-\$9,999

F3 The Capital
Washington, DC

FA Indy
Indianapolis, IN

The Snead Family
Washington

The Stacks Family
Georgia

Tee It Up Flower Fundraiser
Marysville, OH





rideATAXIA is a national cycling program for people of all abilities that gathers FA families and their communities to be active, build connection, and fundraise for research. Over 100 FA families participated in the 2024 rideATAXIA program, which consisted of four national events and nine hometown events and raised over \$1.3 million.

rideATAXIA Hometown

Since its launch in 2023, rideATAXIA Hometown has continued to see incredible growth in both fundraising and participation. Local communities gathered for small neighborhood group rides or large trail rides and offered different ways for FA families to bring rideATAXIA to their hometown. In its second year, rideATAXIA Hometown grew to more than 500 participants and raised \$185,000 — an incredible 60% increase in participation and a 120% boost in fundraising!

rideATAXIA National Events

The rideATAXIA national events feature a variety of options to be active — different cycling routes, a walking path, and cheer stations — followed by lunch and a celebration of fundraising efforts. In addition to these core activities, the program has incorporated new elements to foster community engagement and fun.

rideATAXIA Gainesville was all about bringing people together. With the addition of a pre-ride meetup and a post-event gathering, participants had more opportunities to connect, share stories, and strengthen their sense of community.

rideATAXIA Chicago celebrated Team Spirit! Participants arrived with their best costumes, team t-shirts, and tent decorations, taking the event energy to the next level.

rideATAXIA Philly amped up the excitement with the rock 'n' roll energy of a live band, and cyclists also had the opportunity to refuel at a rest stop with signature Philly pretzels.

rideATAXIA Dallas took on a fresh look with a new beautiful venue at Railroad Park and scenic trail rides along the DCTA Rail Trail.

Thanks to all of the FA families, donors, committee members, and volunteers who make rideATAXIA a success!



THE FARA ENERGY BALL



The FARA Energy Ball raised over \$1.6 million, continuing the journey toward a cure.

The 16th FARA Energy Ball was a remarkable celebration of resilience, community, and progress. In a year marked by the challenges of Hurricanes Helene and Milton, the Tampa community showed unwavering support for families affected by FA. Despite the storms' impact on the region, the Tampa community rallied together, embodying the strength that has defined the FA community.

To kick-start the day, the University of South Florida (USF) and FARA co-hosted a research reception brunch. The event included impact updates from both organizations as well as panel discussions featuring representatives from pharmaceutical companies with clinical stage programs in FA and community members living with FA. Attendees gained an understanding of research advancement from the perspectives of both the drug developers and community members.

Later in the evening, over 400 guests gathered at the JW Marriott Tampa Water Street for the FARA Energy Ball gala, where the colorful “FARA Festival” came to life in a night of music, dancing, and celebration. Wendy Ryan, ABC News Anchor, shined as the evening’s emcee, and the Blonde Ambition band kept attendees dancing with everyone’s favorite high energy anthems.

This milestone “Sweet Sixteen” event was a celebration of the progress we’ve made, but also a reminder of the work that remains. The commitment from families, volunteers, and supporters has never wavered. The evening was filled with heartfelt moments of reflection on the strides made in FA research, but also a renewed commitment to pursuing treatments and a cure.



FINANCIALS

STATEMENTS OF FINANCIAL POSITION

December 31, 2024 and 2023

| ASSETS | 2024* | 2023* |
|---|--------------------|--------------------|
| CURRENT ASSETS | | |
| Cash & Cash Equivalents | \$1,959,581 | \$3,993,332 |
| Restricted Cash | 2,350,400 | 963,779 |
| Contributions Receivable, Net | 682,067 | 747,478 |
| Prepaid Expenses | 67,503 | 49,155 |
| Investments | 2,137,780 | 1,870,166 |
| TOTAL CURRENT ASSETS | 7,197,331 | 7,623,910 |
| OTHER ASSETS | | |
| | 51,862 | 109,254 |
| TOTAL ASSETS | \$7,249,193 | \$7,733,164 |
| LIABILITIES & NET ASSETS | | |
| LIABILITIES | | |
| Accounts Payable | \$689,951 | \$1,164,034 |
| Deferred Revenues | 10,630 | 4,567 |
| Lease Liabilities | 49,940 | 112,047 |
| TOTAL LIABILITIES | 750,521 | 1,280,648 |
| NET ASSETS | | |
| Without Donor Restrictions | 4,148,272 | 5,488,737 |
| With Donor Restrictions | 2,350,400 | 963,779 |
| TOTAL NET ASSETS | 6,498,672 | 6,452,516 |
| TOTAL LIABILITIES & NET ASSETS | \$7,249,193 | \$7,733,164 |

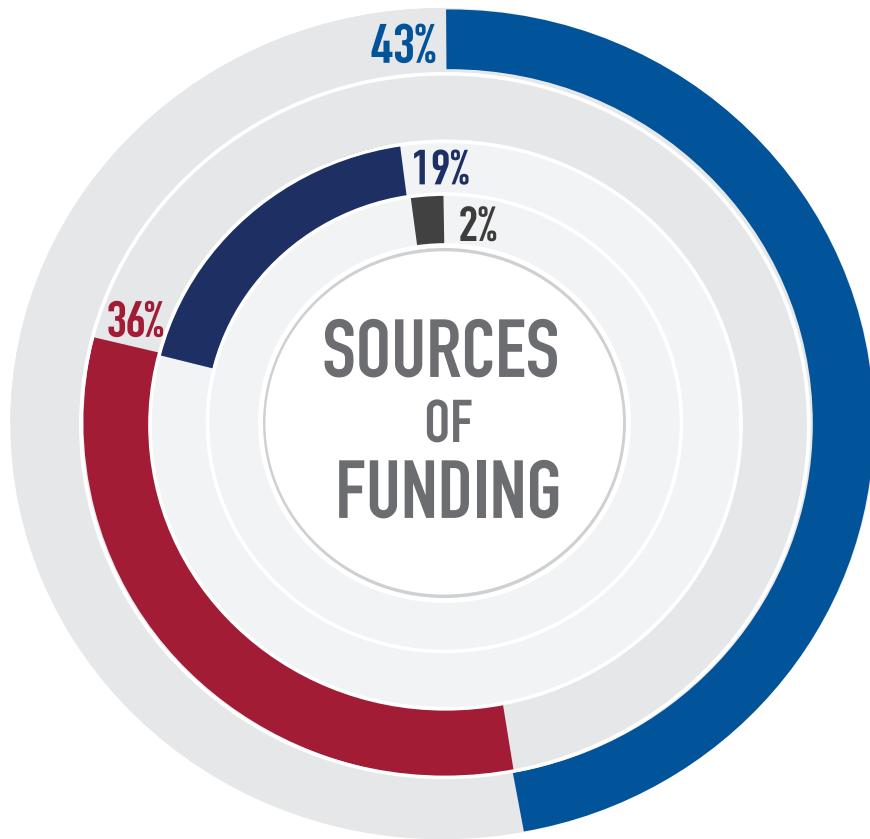
STATEMENTS OF ACTIVITIES

Years Ended December 31, 2024 and 2023

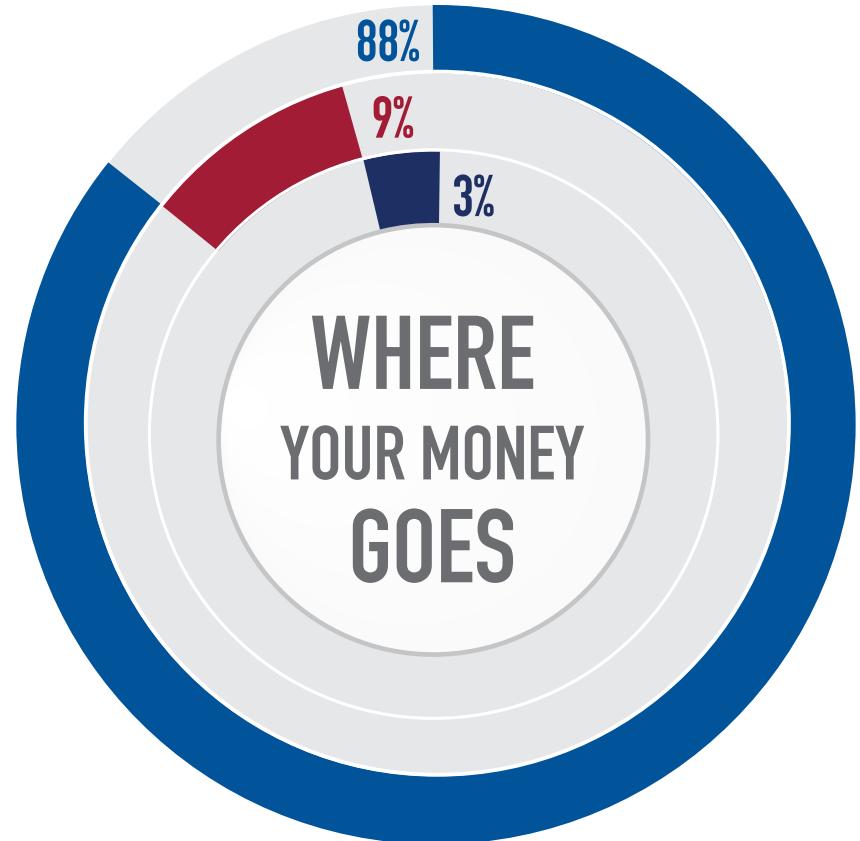
| NET ASSETS WITHOUT DONOR RESTRICTIONS | 2024* | 2023* |
|--|--------------------|--------------------|
| REVENUE & SUPPORT | | |
| Contributions, Conferences & Grants | \$2,497,238 | \$4,037,159 |
| Special Events & In-kind Contributions | 4,690,438 | 4,804,770 |
| Investment Return | 346,163 | 266,862 |
| Net Assets Released from Restrictions | 5,652,908 | 4,294,300 |
| TOTAL REVENUE & SUPPORT | 13,186,747 | 13,403,091 |
| EXPENSES | | |
| Program Services | 12,740,598 | 11,366,576 |
| Fundraising | 1,349,672 | 1,301,838 |
| General & Administrative | 436,942 | 392,212 |
| TOTAL EXPENSES | 14,527,212 | 13,060,626 |
| CHANGE IN NET ASSETS WITHOUT DONOR RESTRICTIONS | (1,340,465) | 342,465 |
| NET ASSETS WITH DONOR RESTRICTIONS | | |
| Contributions, Conferences, & Grants | 7,039,529 | 3,573,926 |
| Net Assets Released from Restrictions | (5,652,908) | (4,294,300) |
| CHANGE IN NET ASSETS WITH DONOR RESTRICTIONS | 1,386,621 | (720,374) |
| TOTAL NET ASSETS | | |
| CHANGE IN NET ASSETS | 46,156 | (377,909) |
| NET ASSETS AT BEGINNING OF YEAR | 6,452,516 | 6,830,425 |
| NET ASSETS AT END OF YEAR | \$6,498,672 | \$6,452,516 |

17 | *FARA and FARA Europe consolidated

FINANCIALS



- Donor-directed Contributions
- Special Events (Energy Ball, rideATAXIA & Grassroots)
- Contributions, Conferences, & Grants
- Investment



- Research & Programs
- Fundraising
- General & Administrative

DONORS & CONTRIBUTORS



\$1 Million+

Anonymous

CureFA Foundation*

\$250,000-\$499,000

Anonymous

\$100,000-\$249,999

Anonymous

The Avery Family Foundation

Brigid Brennan and Michael Henry

The Burrows Hill Foundation

The Crisp Family Fund

fara Australia (Friedreich Ataxia Research Association)*

Warren and Cecilia Huff

Kent and Emily McGaughy

Oak Foundation

The Ritschel Family

The Rose Family Foundation on behalf of Deedie Rose

Catherine and Will Rose

www.TheEventHelper.com

* Research Co-Funding Organization

List reflects donors from FARA and FARA Europe consolidated activities

\$50,000-\$99,999

Amalie Oil Company

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Many of these contributions came in the form of sponsorship for community-focused FARA events, including grassroots fundraisers, rideATAXIA, the FARA Energy Ball, the FA Research Reception series, and United Against Ataxia Hill Day, as well as for the Industry Advisory Summit (IAS).

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