

GRANTS PROGRAM, SPANISH VHL ALLIANCE – GENERAL GUIDELINES FOR APPLICATIONS FOR von HIPPEL-LINDAU DISEASE RESEARCH PROJECTS

The Spanish VHL Family Alliance was founded in 2001 by people with VHL and their families. The Spanish VHL Alliance is a voluntary, non-profit health organization that is integrated within the VHL Family Alliance, an international association. Its primary goals are:

1. To disseminate updated and accurate information about von Hippel-Lindau (VHL) disease to patients, family members, physicians, and other interested parties. The aim is to provide the means for patients and their relatives to share experiences, support each other, and improve their medical, psychological, and social care. In addition, it aims to improve the quality of life and the complete integration in society of VHL patients, with particular attention to those affected by a disability.
2. To encourage, advise, and establish standards for Medical Centers and clinicians specialized in the diagnosis and treatment of von Hippel-Lindau.
3. To encourage and support biomedical and other pertinent research on the von Hippel-Lindau syndrome.
4. To collaborate with local hospitals in the diagnosis and treatment of VHL disease, providing for and obtaining suggestions from VHL patients, and seeking support for the development of the VHL Alliance.
5. To gather and disseminate information through the mass media communications (in scientific journals and other channels) of the research, clinical, and technical advances in the treatment of VHL disease. To collaborate with research groups that investigate VHL disease.
6. To aid and encourage the formation of regional VHL Chapters and to provide assistance and guidance to enhance their effectiveness.

General Objective of the Research Grants Program

To provide temporary financial support for innovative basic and clinical research relevant to the cause, pathogenesis, or treatment of von Hippel-Lindau disease. The call for applications, as well as the results obtained by the applicants, must follow the guidelines herein.

Project Summary

A brief summary of the proposal must be submitted to Dr. Karina Villar, Chairman of the Research Committee, Spanish VHL Family Alliance, alianzavhl@alianzavhl.org. Proposals may be submitted to or discussed with Dr. Villar at any time during the year.

Upon review of this summary, the applicant will be told whether a full application is warranted. Applications may be submitted upon invitation only. The deadlines for submission of grant applications will be published on the Spanish VHL official page (www.alianzavhl.org).

Payment of Grants

The Spanish VHL grants program guidelines are listed below. For further information, please contact the director of the Research Grants program, Dr. Karina Villar.

1. Awards will be up to 50,000 euros and for a period of one year; future funding will be considered with re-application and demonstration of significant progress during the initial funding period. The number and amount of grants awarded will depend on the quantities obtained by fundraising each year.

2. Funds may cover all or part of the amount requested for the research project. The amount awarded will be determined in each case according to established criteria and the results obtained. The beneficiaries are the Principal Investigator and the home institution of the Principal Investigator.
3. It is the responsibility of the Principal Investigator to inform the Spanish VHL Alliance of possible conflicts relative to the existence of other funding sources for this project, provided by other funding agencies.
4. Consideration for a second year of funding will be made upon re-application and demonstration of significant progress during the first year of support.
5. Grants do not cover indirect costs.
6. The Spanish VHL Family Alliance should receive notification in advance of any publicity derived from the funded research, and one pdf copy of any article when published. All papers published will include an acknowledgement to the Spanish VHL Family Alliance.

All inquiries and requests for applications should be submitted electronically to:

Dr Karina Villar
President Research Committee
Alianza VHL, Spain
alianzavhl@alianzavhl.org

Policies and Guidelines Governing Research Grants

Program Description

Research grant awards are for new or established investigators wishing to develop a novel idea or concept clearly related to von Hippel-Lindau disease, when ongoing support is not available to fund the project.

Research priorities will be specified at each call for applications, although these may remain unchanged from one year to the next. All research awards are subject to observance of the regulations and policies of the Spanish VHL Alliance.

Review and Award

Applications must be submitted in English (MS-Word or PDF) by email to alianzavhl@alianzavhl.org. Notification of receipt will be sent via email within a week of receiving the application.

Applications may be submitted by investigators in public, private, and non-profit institutions who have a proven track record of productivity. Applications must be approved by the appropriate Institutional Financial Officer.

Documentation needed:

- Application form
- Summary of the research project (in English and Spanish)
- Copies of DNI (National Identity Card) or Passport of the Principal Investigator
- Disclosure of other grants or funding support (requested or awarded) for the research project
- CV for the Principal Investigator and each participant in the project; all CVs must be submitted in NIH biosketch format or FIS (Fondo de Investigacion Sanitaria) format.
- Report from the Research Committee of the requesting Center stating the viability of the research project

All applications are evaluated jointly by the Research Advisory Board of the Spanish VHL Alliance and the Research Council of the American VHL Family Alliance. The recommendations are reviewed by the Board of Directors of the Spanish VHL Family Alliance for final approval and funding.

Grant funding is based on the funds availability, the priority being established by the score obtained by each application. In this regard aspects to be evaluated are: the scientific and technical merit, the Principal Investigator's CV, the excellence of the research team, the feasibility of the proposed topic, the budget and time-table, the multi-center and multidisciplinary aspects of the proposal, and, most importantly, the relevance to VHL disease and to the improvement of health, clinical care, and quality of life of those affected by VHL. The last consideration carries the most weight in the award of funds.

The list of submitted proposals (as well as those which are incomplete) will be available on The Spanish VHL Alliance webpage (www.alianzavhl.org). Applicants with incomplete applications will have ten days during which they can provide the missing/correct documents; after this time, if not complete, the proposal will be considered withdrawn. Once the final award decision is announced, it will be considered definite without the possibility of rebuttal.

Contracts

For the applications selected, contracts will be effective after signing an agreement according to the general and specific guidelines of the proposal.

The document will be signed by the Principal Investigator and by the Institutional Financial Officer. If the amount awarded differs from the quantity initially requested, the Principal Investigator may be asked to adjust the budget and the goals of the proposal.

Any modifications to the proposal, including changes in methodology or research design, must be notified to the Spanish VHL Alliance before the contract is signed. Once the contract is signed, the Spanish VHL Alliance will transfer to the Principal Investigator's Institution the first payment (one-third of the annual amount).

Principal Investigators of the funded projects will send progress reports at the times specified in the guidelines, whereupon the second and third payments will be made. A final report will be provided after completion of the entire funding period.

The reports must include a summary of the original project, a summary of the research performed, the objectives achieved, the preliminary results if appropriate, the authorized modifications to methodologies and research plan, a summary of expenditures, and the articles and communications derived from the research performed. These reports must be signed by the Institutional Financial Officer.

Management of Awards

Funds will be awarded for 1 year, renewable for up to three years, for a maximum of 50,000 euros/year. They do not cover indirect costs. 1,000 euros/year can be used as travel funds for VHL conferences.

Payments will be disbursed three times during the year. The first payment will be made at the time of signing the contract, and the subsequent payments will be made upon receipt of the progress reports from the Principal Investigator (to be prepared in English).

Responsibilities

The Principal Investigator and the research center where he/she works are responsible for the VHL Project. Failure to comply with the above-mentioned rules and regulations may cause the denial or interruption of funding, if so determined by the Direction Committee of the Spanish VHL Alliance.

If the project is not carried out following the conditions established in the contract, a partial or total return of funds may be requested.

Publications or presentations by Awardee

The Principal Investigator agrees to:

- 1) Notifying the VHL Alliance Research Committee when a communication based on the work supported by an Alliance award, is accepted for presentation before a scientific organization. A suitable description of the presentation shall be forwarded to the Alliance following the acceptance, together with the name of the organization accepting it, and the dates and place of the meeting.
- 2) Notifying the VHL Alliance Research Committee when a paper based on the work supported by an Alliance award, is accepted for publication, sending one pdf copy of the paper to the Alliance following the acceptance of the paper, together with the name of the organization/journal accepting it.
- 3) Informing the Research Committee of the contribution of each author.
- 4) Presenting the final results at the following biennial VHL congress
- 5) Including in all the papers and presentations the acknowledgement to the Spanish von Hippel-Lindau Family Alliance

In summary, when a paper or communication based on the work supported by an Alliance award, is accepted for publication or presentation before a scientific organization, one pdf copy of the paper, or a suitable abstract of the communication shall be forwarded to the Alliance following acceptance, together with the name of the publication or the organization accepting it, and the dates and place of the meeting. This information shall be considered confidential by the Alliance until it is presented. All such papers and communications shall carry the acknowledgement to the Spanish VHL Family Alliance.

Intellectual Property

The intellectual advances derived from the results obtained from the research projects will be the property of the research group, as established by the institution from which the research group operates. In any publication or research presentation that contains results from this investigation, the support from the Spanish VHL Alliance must be mentioned and the Spanish VHL Alliance must be informed of the same.

If the funded project constitutes the basis for a patent or another commercial application, the Spanish VHL Alliance will be entitled to benefits proportional to the percentage of funds awarded to the project.

Publicity

No project will be published by any means other than through the usual professional or scientific journals, the results of his or her work previously notifying the Spanish VHL Family Alliance the intention to do so, and providing a copy of the material intended for release. All announcements to any media of public information pertaining to work to be

done or accomplished under a Spanish VHL Family Alliance award must have the approval of the Awardee, the Awardee's institution, and the Alliance.

Financial Reports

A final, audited financial report of grant expenditures and a refund of any money unexpended during the period of the grant, must be submitted to the Spanish VHL Family Alliance within 90 days after the termination of the entire award.

An annual financial report of total grant expenditures and a refund of any money unexpended during the period of the grant must be submitted within 90 days after the grant period. Financial reports should be signed by the responsible Institutional Financial Officer, as well as the Principal Investigator. Interim accounting may be requested by the Spanish VHL Family Alliance.

Other sources of support

It is the responsibility of the Principal Investigator and the institution to inform the VHL Family Alliance of possible conflicts relative to duplicate funding of this project by other funding agencies. Failure to inform the Alliance of other sources of support can result in loss of funds for the Spanish VHL Family Alliance projects.

Confidentiality and protection of personal information

The information given to the Spanish VHL Alliance will be included in a database and used exclusively for the purpose for which they were gathered.

The Principal Investigator may request to access, oppose, rectify or cancel the information provided to the Spanish VHL Alliance, as specified by law 15/1999, December 13.