

STAT

The ice bucket challenge, made famous by ALS patient Pete Frates, raised millions. Here's how the money was used

By [Rebecca Robbins](#) @rebeccadrobbins

July 3, 2017



Massachusetts Gov. Charlie Baker participates in the ice bucket challenge alongside Pete Frates (center). *Charles Krupa/AP*

Pete Frates, the ALS patient behind the fundraising juggernaut known as the “ice bucket challenge,” has been hospitalized — news that touched off a spate of appreciative tweets on Monday lauding his contributions to the efforts to find a cure for amyotrophic lateral sclerosis, also known as Lou Gehrig’s disease.

A former Boston College baseball player who was diagnosed with ALS at the age of 27, Frates didn’t dream up the ice bucket challenge, but he was its most effective marketer. When it took off in the summer of 2014, videos of people pouring freezing water on their heads spread like wildfire on social media. The efforts raised \$115 million for the ALS Association, along with millions more to other ALS charities.

Where has all that money gone? Here’s a partial list:

Finding a new genetic clue

The ALS Association dedicated two thirds of the fundraising haul — [\\$77 million](#)¹ — to research. A recent payoff: the discovery of a [variant](#)² of a gene called NEK1 that's linked to 3 percent of ALS cases and could offer a potential new target for drug development. The association is now funding research in mice to better understand how that defective gene plays out in the progression of ALS.

To try to make more such discoveries, the association is pouring money into tracing other genetic variants linked to the disease. (Such mutations are believed to be responsible in about 10 percent of ALS cases.) Researchers at Columbia University got \$3.5 million to do genetic sequencing of 1,500 people with ALS. Another project got a \$2.5 million grant to sequence the tissues of deceased ALS patients.

[Related:](#)³

[While no one says 'cure,' the pipeline for ALS treatments looks more promising.](#)³

Investing in community support

The ALS Association has dedicated [\\$23 million](#)¹, or one-fifth of the ice bucket money, to support patients and their communities. In Tennessee, that means grants to give patients more sessions with speech pathologists and iPads to help them communicate when speech becomes difficult. In Rhode Island, it means modest grants to help patients pay for handicapped ramps and stair lifts. And in western Pennsylvania, it means free training for caregivers and grief counseling for people who've lost a loved one with ALS.

Fueling the hunt for biomarkers

There are [not yet](#)⁴ any validated biomarkers for ALS that could be monitored through simple tests and used to track progression of the disease. Part of the ice bucket money is supporting such research. Scientists in St. Louis got [\\$1 million](#)⁵ to try to figure out how to track a protein known as TDP-43, which is almost always found in ALS cases. And a Boston researcher got \$1 million to upgrade a repository of blood and spinal fluids being tested as part of the search for biomarkers.

At Cedars-Sinai in Los Angeles, a researcher got a \$1.9 million grant to try to identify inflammatory biomarkers by collecting blood and skin samples from people with and without ALS. That same researcher got another \$400,000 to work with General Electric to try to develop a nanoparticle for magnetic resonance imaging that has potential as a biomarker.

[Related:](#)⁶

[Post-telethon, Muscular Dystrophy Association tries to find its footing.](#)⁶

Pushing for better communication technology

Investments in early-stage research won't help today's patients, so some of the fundraising haul went to tech research with potential for nearer-term payoff. Last December a \$400,000 prize [went to two groups](#)⁷: a team of Dutch researchers working on an interface to allow ALS patients to communicate by what's known as selective attention, and a Massachusetts company working on a system to help patients who can't move control their laptops, phones, and home robotics.

Shepherding promising compounds along

There are plenty of compounds that have impressed scientists with what they can do in the Petri dish or in mice. But they won't get anywhere near human trials without more funding. Ice bucket money is helping provide that boost. A biotech called miRagen Therapeutics, for instance, has been awarded \$400,000 to try to move forward a compound targeting neuro-inflammation.

And a University of Massachusetts researcher got \$2.5 million for a project that aims to deliver DNA molecules to the brain and spinal cord using transport viruses. The goal is to silence genes that sometimes trigger the toxicity involved in ALS.

Inspiring similar efforts by other charities

The spectacular success of the ice bucket challenge has made it a case study for [other charities](#)¹⁰. Experts have identified key factors that made it work: the spirit of competition. The perfect timing in the dog days of summer. The interactive nature, ideal for social media and alluring to celebrities.

But some of it was pure serendipity — as illustrated by the fact that ALS charities themselves haven't been able to recapture the magic in trying to make the challenge an annual August event. Despite a corporate partnership with Major League Baseball, the ALS Association raised just \$500,000 through nearly the full month of August 2015.

As for Frates, now 32, he responded playfully to inaccurate reports on Monday morning that he had died — by posting [a video on Twitter](#)¹¹ of himself moving his eyes accompanied by the soundtrack of Pearl Jam's "Alive."

About the Author



[Rebecca Robbins](#)¹²

San Francisco Correspondent

Rebecca covers the life sciences industry in the Bay Area.

rebecca.robbs@statnews.com¹³

[@rebeccadrobbins](#)¹⁴

Tags

Links

1. <http://www.alsa.org/fight-als/ibc-infographic.html>
2. <http://www.nature.com/ng/journal/v48/n9/full/ng.3626.html>
3. <https://www.statnews.com/2017/05/25/pipeline-als-treatments/>
4. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4718795/>
5. <https://alsadotorg.wordpress.com/2017/03/13/dr-timothy-miller-and-team-win-the-1-million-tdp-43-biomarker-grand-challenge/>
6. <https://www.statnews.com/2016/09/01/muscular-dystrophy-association-telethon/>
7. <http://www.alsa.org/news/media/press-releases/assist-tech-winners-120716.html>

8. <https://www.statnews.com/signup/>
9. <https://www.statnews.com/privacy/>
10. <https://blogs.wsj.com/experts/2014/09/15/lets-do-an-ice-bucket-challenge-for-dementia/>
11. <https://twitter.com/PeteFrates3/status/881874734190919680>
12. <https://www.statnews.com/staff/rebecca-robbins/>
13. <https://www.statnews.com/2017/07/03/pete-frates-ice-bucket-als-funds/mailto:rebecca.robbins@statnews.com>
14. <https://twitter.com/rebeccadrobbins>
15. <https://www.statnews.com/tag/drug-development/>
16. <https://www.statnews.com/tag/finance/>
17. <https://www.statnews.com/tag/neuroscience/>
18. <https://www.statnews.com/tag/patients/>
19. <https://www.statnews.com/tag/research/>

© 2018 STAT