



The ALS fundraising effort reached countries around the world, including the Philippines.

FUNDRAISING

The Ice Bucket Challenge delivers

In 2014, millions of people doused themselves in icy water to raise money for ALS. Was it worth it?

BY EMILY SOHN

In the spring of 2014, geneticist John Landers and colleagues submitted a request for US\$1 million to the US charity the ALS Association. The researchers wanted to take part in a worldwide effort to decipher the genetic basis of amyotrophic lateral sclerosis (ALS). They would use the money to join Project MinE — an international collaboration that aims to sequence the DNA of tens of thousands of people with and without the neuromuscular disease.

Such a project doesn't come cheap. Sequencing the whole genome of one person costs US\$2,000, and Project MinE's goal of 22,500 sequences will require \$45 million, Landers says, not including the equipment and work

hours needed to analyse the massive data set. The ALS Association — the largest funder of ALS research in the United States other than the federal government — loved the idea, says Landers. But it didn't have the money to fund it.

Then came the Ice Bucket Challenge, a fundraising campaign that went viral on social media in the summer of 2014. After dumping icy water on their heads and daring others to do the same, many participants sent money to ALS organizations, including the ALS Association, which soon started doling it out.

"They actually came back to us and said, 'We are now in a position where we can fund your research,'" says Landers, at the University of Massachusetts Medical School in Worcester, who then started the first US branch of Project MinE with colleagues from Emory University in

Atlanta, Georgia. "That got us off the ground."

The Ice Bucket Challenge involved more than 17 million people, who uploaded videos that were watched more than 10 billion times by about 440 million people around the world. High-profile participants included philanthropist Bill Gates, talk-show host Oprah Winfrey and cartoon character Homer Simpson.

Most participants were not famous, but their contributions added up. By the end of the summer, more than 28 million people had donated an estimated \$220 million worldwide, dwarfing previous ALS research budgets many times over.

But as money poured in, so too did criticism. Some called the movement 'slacktivism', a kind of narcissistic feel-good behaviour that doesn't actually accomplish much — such as signing online petitions or changing Facebook profile pictures to support a cause. Others were concerned that the surge in donations to ALS was siphoning money away from health issues that either caused more deaths — for example, heart disease — or that seemed more urgent, such as the Ebola outbreak in West Africa. In a drought-prevalent year, people even complained about the waste of water.

Three years later, studies funded by the challenge have begun to accumulate. And despite the criticisms, some researchers, including Landers, give the fundraiser credit for new gene discoveries, new stem-cell models and a better understanding of proteins involved in the fatal disease.

"Many, many, many people have told me it's probably one of the worst diseases you can imagine. It's horrendous," Landers says. "Having money donated to such a disease — I don't see how you can criticize that."

GOING GLOBAL

Although its exact origins are debated, the Ice Bucket Challenge seems to have started as a general stunt for inspiring charity donations. After jumping into, or getting doused with, cold water — all on video that is posted to social media — people would challenge others to do the same or make a donation to charity. Donations were solicited for causes ranging from cancer to a mayoral campaign.

In mid-July of 2014, Chris Kennedy, a professional golfer in Florida, took the challenge for ALS because a relative had the disease. From there, the phenomenon spread through well-established fundraising networks to Pete Frates, a former baseball player in Boston, Massachusetts, with ALS who had a large social-media following. Frates' supporters "really are credited with blowing it up and making it go global," says Brian Frederick, vice-president of communications and development at the ALS Association in Washington DC.

The ALS Association received \$115 million from the challenge, about half of the funds raised worldwide, and a huge jump from the \$2.8 million raised by the organization in the same period the previous year. Other recipients

of substantial funds included the ALS Society of Canada in Toronto and the Motor Neurone Disease Association in Northampton, UK.

Before the Ice Bucket Challenge, Frederick says, the ALS association allocated \$6 million annually to funding research projects. Since then, it's given about \$19 million per year and has so far spent \$71.5 million of the Ice Bucket money. By comparison, the US National Institutes of Health will spend an estimated \$55 million on the disease in 2017, up from \$39 million in 2013.

Money from the challenge has already started to have an impact on science. With this money, Landers' team was able to identify an ALS-related gene called *NEK1*. In a 2016 paper¹, the researchers reported that variations in the gene explain 3% of ALS cases, making it one of the most common known genetic causes of the disease, and potentially leading to insights into disease development and new avenues for treatment. Spurred on by that work, Landers' group is now writing a paper on another ALS gene.

Project MinE is just one of dozens of research grants and awards funded by the ALS Association with Ice Bucket money so far, along with funding for advocacy and patient care. One grant went to Philip Wong's group at Johns Hopkins University in Baltimore, Maryland. Wong credits the funding with helping his team produce three or four publications in the past two years.

Since 2006, Wong says, his group had been studying a protein called TDP-43, which clumps together in people with ALS. But the researchers were at an impasse. "We were stuck," he says. "We didn't understand the basic biology of this protein or what it does."

Money from the challenge funded RNA-sequencing analysis and a graduate student to do the work, Wong says. A year later, the team reported a new understanding about how TDP-43 clumping leads to cell death², offering possible targets for intervention. Ice Bucket money wasn't their only source of funding, Wong says, but the funds came at an opportune moment, when ALS research was already exploding. "These are exciting times," he says.

The pay-off from the challenge went beyond dollars, also raising awareness of the disease. Visits to the ALS Association website rose from an average of 20,000 per day to 4.5 million during the challenge's peak. Hits on the Motor Neuron Disease Association website went from a daily average of 1,400 to a peak of 153,000 in one day. Google searches and Twitter mentions of ALS spiked.

The awareness boom seems to have expanded the donor pool beyond those with a direct connection to the disease, to include people who don't usually donate to charity. Most donors to the ALS Association gave



Ex-baseball player Pete Frates, who is immobilized by ALS, inspired the challenge.

small amounts. According to some analyses, this debunks the idea that ALS took money away from other causes.

ALS went from being an obscure disease to a household word, Landers says. He used to get funny looks from people when he told them about his work. "I don't have that issue anymore," he says. "The awareness of ALS is well beyond what we ever could have imagined."

LONG-TERM PROSPECTS

What the Ice Bucket Challenge didn't do was last forever — or even for very long. By September 2014, donations had dropped to near pre-challenge levels. And although donations remain slightly higher than they were before the challenge, attempts to repeat the phenomenon have not come close.

It's a familiar pattern, says Sander van der Linden, a social psychologist at the University of Cambridge, UK. Campaigns that go viral also tend to taper off quickly, especially when the drive to donate comes not from internal beliefs, but from external social pressures. He has found that when motivated by prizes, university students used much less energy during the first three weeks of a month-long environmental competition³. But by the end, they were back to where they started.

In a 2017 study⁴, van der Linden searched for parallels to the Ice Bucket Challenge and found two other cases of 'viral altruism' — the contagious spread of beneficial acts through social networks. The Save Darfur movement was an anti-genocide campaign that recruited more than 1 million followers to a Facebook group in a short time. And the Facebook organ-donor initiative, which went viral in 2012, added 40,000 new enrolments in just two weeks. Campaigns like these tend to elicit strong emotions, such as empathy or outrage,

while looping in a moral element that makes people want to help.

The Ice Bucket Challenge got an extra boost from the 'martyrdom effect': people donate more, and they consider their donations more valuable, when pain or sacrifice is involved. It also expertly tapped into the power of social media to quickly create new norms of socially acceptable behaviour. And celebrity involvement accelerated its success.

The viral nature of the Ice Bucket Challenge might, however, have ultimately doomed its long-term prospects, van der Linden says. "When a billion people click on something, people no longer read it because they're interested in it," he says. "It becomes this superficial level of engagement."

Van der Linden contrasts the challenge with the Movember campaign for men's health, which encourages men to grow a moustache every November and brings in a smaller but steadier stream of money. One key difference, he suspects, is that Movember cultivates a sense of identity among participants with common values and concerns. The Ice Bucket Challenge, by contrast, required people to donate to a cause outside their own experience. When causes are rare diseases, or are abstract or far away, people tend to feel that they've done their part after a single gesture.

For some challenge participants, ALS may have been an afterthought, if they thought of it at all. In an analysis of 1,500 videos by the data-analysis company RJMetrics in Philadelphia, Pennsylvania, 26% didn't mention the disease at all. And among those who didn't mention it, only 5% donated to ALS. Even among people who mentioned ALS in their videos, only 25% went on to give money.

None of those trends discounts the value of the challenge for ALS research, says van der Linden. And researchers and patients are grateful. One of those is Pat Quinn, who, along with Frates and Kennedy, is credited with getting the Ice Bucket Challenge started for ALS by connecting the two athletes' networks. In 2011, at age 28, Quinn noticed twitching in his left arm that led to weakness in his hands, followed by his neck and then legs. He now uses a wheelchair and feeding tube. Talking is a struggle.

"The success of the challenge meant so much to me. It still does and always will," he e-mailed. "It really woke the world up to a devastating disease that needed a game-changing moment. The Ice Bucket Challenge was the beginning of ending ALS." ■

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2. Ling, J. P. *et al. Science* **349**, 650–655 (2015).
3. van der Linden, S. *Nature Clim. Change* **5**, 612–613 (2015).
4. van der Linden, S. *Nature Hum. Behav.* **1**, 0041 (2017).