The ALS "Ice Bucket Challenge" is working

By Abby Ohlheiser, the Washington Post on 08.02.16

A man takes the ice bucket challenge in Copley Square, Boston, Massachusetts, Aug. 7, 2014. The challenge, which involved dumping ice water on participants' heads to raise money for ALS, became a viral phenomenon. Photo: AP Photo/Elise Amendola

Maybe you did it, pouring a bucket of ice water on your head in order to raise money for charity. Maybe you hated the viral phenomenon with a burning passion. But no matter how you felt about the "Ice Bucket Challenge" when it took over the Internet in the fall of 2014, the meme is actually getting results, according to the main charity that benefited from the campaign.

With the millions raised for amyotrophic lateral sclerosis (ALS) research from the viral stunt, the ALS Association said it was able to fund research that identified a new gene, NEK1, that contributes to the disease, the nonprofit announced on Monday. The breakthrough is the subject of a paper published in Nature Genetics.

The Ice Bucket Challenge was inescapable in 2014, as it spread like a chain letter across Facebook. It was fundraising-as-meme. Justin Bieber, Lebron James, Oprah Winfrey, and Bill Gates were among the endless parade of celebrities who did it. It became a bad Halloween costume.
At the time, some worried that the campaign wouldn't actually "raise awareness" for ALS, because the disease seemed to be secondary to watching the spectacle of a bunch of people volunteering for temporary misery. Or, that all those ice bucket champions wouldn't actually follow through with the donations they promised as part of the challenge. And sure, the celebrities and bros who participated in the viral phenomenon may not have talked at length about ALS, and it seems fair to assume that not everyone who did a video made a donation. But the campaign still raised a ton of money to fund research.

The viral campaign raised more than $115 million for the ALS Association alone, in order to fund research into new treatments for the disease. ALS is also known as Lou Gehrig's Disease, a progressive neurological condition that causes muscle weakness and atrophy from the deterioration of nerve cells in the brain and spinal cord. The disease has no cure, and it is always fatal, often within less than a decade of diagnosis.

The gene discovery isn't even the only breakthrough for which the Ice Bucket Challenge is getting partial credit so far: last August — a year after the challenge went viral — scientists at Johns Hopkins said that the money raised from the campaign had a big effect on their work.

"Without it, we wouldn't have been able to come out with the studies as quickly as we did," said lead researcher Philip Wong, a professor at Johns Hopkins, to The Washington Post last year.

According to CNN, the ALS Association planned to spend $77 million of the $115 million raised through the challenge on research like the one that led to this particular discovery. The project in question, Project MinE, received just $1 million of that windfall.

Project MinE aims to sequence the genomes of at least 15,000 people with ALS. Lucie Bruijn, chief scientist of the ALS Association, said that big, data-driven projects like Project MinE "are designed to allow exactly this kind of research and to produce exactly this kind of result."

ALS, which is rare, can be either sporadic or genetic, with the vast majority of cases being the first. The new research was the result of the largest study in history of familial — or genetic — ALS, which accounts for about 10 percent of total cases. But it is likely, the ALS Association explains, that genetics play some role in a greater percentage of cases in that, just in a different way.

The next step is to understand exactly how NEK1 contributes to ALS, and to develop treatments based on that understanding.

"Global collaboration among scientists, which was really made possible by ALS Ice Bucket Challenge donations, led to this important discovery," said John Landers of the University of Massachusetts, who was one of the lead researchers, in a statement. "It is a prime example of the success that can come from the combined efforts of so many people, all dedicated to finding the causes of ALS. This kind of collaborative study is, more and more, where the field is headed."
Meanwhile, a question remains: Will the success of the Ice Bucket Challenge ever be re-created? Sure, it's possible. But like everything else that goes viral on the Internet, a success like the ALS Association’s probably won’t be the result of a deliberate attempt to reproduce it.
Quiz

1. Which of the following statements accurately represents the relationship between the article’s central ideas?
   (A) The Ice Bucket Challenge was a viral trend that raised awareness for ALS; as a result, donations helped fund research on the disease.
   (B) Scientists have discovered a new gene involved with ALS; more research is needed to see if this gene will reveal valuable information.
   (C) Many celebrities participated in the popular Ice Bucket Challenge; others worried that the challenge distracted attention from the real issue.
   (D) The Ice Bucket Challenge brought scientists together via social media; through intensive research, a cure for ALS was developed.

2. Which of the following sentences from the article BEST supports a central idea of the article?
   (A) The Ice Bucket Challenge was inescapable in 2014, as it spread like a chain letter across Facebook.
   (B) At the time, some worried that the campaign wouldn’t actually “raise awareness” for ALS, because the disease seemed to be secondary to watching the spectacle of a bunch of people volunteering for temporary misery.
   (C) The viral campaign raised more than $115 million for the ALS Association alone, in order to fund research into new treatments for the disease.
   (D) ALS, which is rare, can be either sporadic or genetic, with the vast majority of cases being the first.

3. The author develops the idea that the Ice Bucket Challenge promoted ALS research in each of the following ways EXCEPT:
   (A) naming celebrities who participated in the Ice Bucket Challenge
   (B) including information on how much money was raised for ALS research
   (C) describing scientific breakthroughs in ALS research
   (D) sharing the opinions of people with ALS on the Ice Bucket Challenge

4. How will the discovery of the NEK1 gene affect people with ALS?
   (A) It will allow people to catch the disease earlier on, making it less likely to be fatal.
   (B) It will provide scientists with more information about ALS so that treatments can be developed.
   (C) It will prevent people from passing the disease genetically to their children.
   (D) It will lead to the elimination of the ALS disease.