

## The New York Times

---

Please disable your ad blocker.

Advertising helps fund Times journalism.

**Unblock ads**

---

# *The 'Ice Bucket Challenge' Helped Scientists Discover a New Gene Tied to A.L.S.*

By **Katie Rogers**

July 27, 2016

It turns out those much-mocked Ice Bucket Challenge videos helped do a lot of good.

Two summers ago, the challenge, designed to raise money for research into amyotrophic lateral sclerosis, also known as Lou Gehrig's disease, took the internet by storm. Supporters ended up raising over \$115 million for the A.L.S. Association.

Over two years, money from the challenge has helped fund the research and development of treatment drugs and has been used as prize money to entice people to design technology for people living with the disease, which causes a rapid breakdown in a person's ability to control muscle movement.

The association released a chart last year showing where the funds went:

- \$77 million, or 67 percent, went to research.
  - \$23 million, or 20 percent, went to patient and community services.
  - \$10 million, or 9 percent, went to public and professional education.
  - \$3 million, or 2 percent, went to fund-raising.
- 

Please disable your ad blocker.

Advertising helps fund Times journalism.

**Unblock ads**

- And \$2 million, roughly another 2 percent, went to payment processing fees.

The latest development, announced by the association this week, falls into the research category: It's the discovery of NEK1, which scientists say is among the most common genes that contribute to the disease and is associated with 3 percent of A.L.S. cases. The discovery, published in Nature Genetics, is the result of a global gene-sequencing effort involving 11 countries and 80 researchers, called Project MinE.

The challenge money allowed the association to invest \$1 million in Project MinE, and "initiated the U.S. arm of this international effort," Carrie Munk, a spokeswoman for the association, said.

**You have 4 free articles remaining.  
Subscribe to The Times**

The discovery of NEK1 is significant but is not a breakthrough — some 30 genes tied to the disease have already been identified — according to Brian Frederick, executive vice president for communications and development for the A.L.S. Association.

Mr. Frederick said that the discovery of the gene could eventually mean that "treatments won't be limited to one subset of people with A.L.S., but that it might be a more broad group."

## Please disable your ad blocker.

Advertising helps fund Times journalism.

**Unblock ads**

The movement took the internet by storm in July 2014, and many supporters trace the tipping point to a video posted by Pete Frates, a former college baseball player who was diagnosed with the disease in 2012. Others followed suit, including celebrities from Mark Zuckerberg to Lena Dunham, who consented to having a bucket of water dumped over their heads for a good cause.

The challenge spread as wildly as it did because the premise involved people reaching out to each other on social media with a simple request: Film yourself getting water dumped over your head or donate money to A.L.S. research. Many did both, but critics disparaged the movement as “slacktivism” or an outright racket. A.L.S. awareness activists, however, say that the challenge reinvigorated a research community that was lacking attention and funds to produce scientific advancements.

“There’s an excitement and an energy in the A.L.S. research community that has not been there before,” Mr. Frederick said, adding: “There’s a real sense of hope and optimism among many people living with A.L.S. now.”