

The Guardian



Remember the ice bucket challenge? It just funded an ALS breakthrough

The ALS Association says money raised by viral charity challenge, dismissed as ‘slacktivism’ by many, has helped identify a new gene associated with the disease

Nicky Woolf in San Francisco

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It is often easy to dismiss viral charity campaigns as “slacktivism”, which lacks in real-world impact (we never did catch the warlord Joseph Kony, after all) but a breakthrough discovery bankrolled by 2014’s ALS ice bucket challenge may give the lie to that cynicism.

The ice bucket challenge was a phenomenon in the summer of 2014 in which people dunked a bucket of iced water over their heads in order to solicit donations before nominating others to do the same.

Scores of celebrities including Mark Zuckerberg, Anna Wintour, Tom Cruise, Charlie Sheen, Robert Downey Jr and hundreds more made videos, but the campaign was criticised by some.

Slate wrote that “for most of the people posting ice bucket videos of themselves on Facebook, Vine, and Instagram, the charity part remains a postscript”, while Time called it “problematic in almost every way”, going on to say that “most of its participants ... didn’t mention the disease at all. The chance to jump on the latest trend was an end in itself. In fact, the challenge’s structure seems almost inherently offensive to those touched by ALS.”

But the proof of the pudding was in the eating: the campaign raised more than \$100m in a 30-day period, and was able to fully fund a number of research projects.

One of these was Project MinE, a large data-driven initiative funded by the ALS Association through ice bucket challenge donations, as well as donations from the organization’s Georgia and New York chapters. The project’s researchers announced on Monday that they have identified a new gene associated with the disease, which experts say could lead to new treatment possibilities.

Amyotrophic Lateral Sclerosis, also known ALS or Lou Gehrig’s Disease, is a neurological disorder in which the motor neurons that control muscle function slowly die. The disease can be either sporadic or inherited, and in either case there is currently no cure.

“It’s very exciting because it shows everyone who contributed to the ice bucket challenge that their donation had an impact on the research,” said Brian Frederick, executive vice-president of communications and development at the ALS Association. “The work that Project MinE is doing is really important, and the discovery of this new gene will help us better understand ALS.”

The newly discovered gene, NEK1, is only associated with 3% of ALS cases, but it is present in both inherited and sporadic forms of the disease, which researchers say gives them a new target for the development of possible treatments.

Project MinE has been working to sequence the genomes of 15,000 people with the disease, and the discovery, which was described in a paper published on Monday in the journal Nature Genetics, involved more than 80 researchers in 11 countries.

The discovery was significant, Frederick said, “because it helps us understand what’s triggering this and can help us better find a treatment,” though he added that “it’s still very early in our understanding of this particular gene, and we still have a ways to go with understanding ALS generally.”

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