

Sometimes People with ALS Get Better.

Last summer the Ice Bucket Challenge took America by storm. Millions of social media users soaked themselves, dumping buckets of ice over their heads to raise awareness and money to fight the rare disease Amyotrophic Lateral Sclerosis (ALS). About 30,000 Americans are living with ALS, which attacks nerve cells and ultimately leads to total paralysis and death. Life expectancy is usually about two to five years from diagnosis.

What the challenge's participants did not know is that a small number of patients with ALS sometimes get better. Richard S. Bedlack, M.D., Ph.D, director of the Duke ALS Clinic, has initiated a new research program called ALS Reversals (www.alsreversals.com) to understand why some people with ALS are improving instead of getting worse, and how he and his team can make it happen more often for more people.

"Anytime you have a patient with ALS who is getting better, no matter what it is that they are doing, I think you should try to put a lot of effort into understanding that patient," says Bedlack, associate professor of neurology at Duke University School of Medicine.

Some patients diagnosed with ALS find that their condition stabilizes or even improves. Bedlack explains that there may be three possible reasons why this happens. First, the person may never have had the condition in the first place; he or she may have a disease that presents with similar symptoms but was misdiagnosed as ALS. Second, the person's body may contain something unique that helps fight the disease. Third, the patient may have tried a nontraditional treatment that proved beneficial in his or her case.

Bedlack seeks to analyze the rare cases of ALS patients who got better and to compare their gene sequences, gene expression data or antibody profiles to those of more typical ALS patients.

The idea for this pilot research program came to Bedlack while he was reviewing alternative and off-label therapies for ALS. In an effort to clarify misinformation on the Internet about such therapies, he had started ALSUntangled (www.alsuntangled.com). Patients tweet about various ALS therapies, and a group of scientists and clinicians study the evidence behind these therapies, eventually publishing an open review about them on the web. Surprisingly, the ALSUntangled team found that some alternative therapies—such as Lunasin, a peptide derived from soybean that is sold as a nutritional supplement—show potential as mainstream remedies and require additional exploration. In the case of Lunasin, Bedlack is planning to continue studying this dietary supplement through the ALS Reversals program. He hopes that this program and other recent ALS discoveries could one day lead to a cure.