

Challenge aims to help put ALS on ice

By **Peter Schworm** | GLOBE STAFF AUGUST 13, 2014

<https://www.bostonglobe.com/metro/2014/08/12/bucket/kZq1fDLkCms8KE1NHcELRK/story.html>



ARAM BOGHOSIAN/BOSTON GLOBE

Staff members at the Leonard Florence Center for Living in Chelsea took the challenge Tuesday.

CHELSEA — Steve Saling is not one to turn down a challenge. Even with the devastating neurodegenerative disease ALS slowly sapping his body, he found ways to jump from planes and go downhill skiing. By comparison, a bucket of ice over the head seemed tame.

But that act might have received more attention than almost anything else he has done. Recorded and posted on social media, in step with untold numbers of others who have joined an exploding viral “ice bucket challenge” to raise money and awareness, Saling’s frigid dousing got 10,000 Facebook likes in a matter of days.

On Tuesday, staff at the Leonard Florence Center for Living, a nursing facility and rehabilitation center on Admiral’s Hill, took the challenge, too.

The ice bucket challenge was already sweeping the country, with everyone from Matt Lauer and Martha Stewart to the most staid politicians posting videos and sending checks.

“It is simply amazing to me,” Saling said, communicating through an eye gaze computer. “It’s inspiring to see the awareness spread.”

Awareness of the disease, also known as Lou Gehrig’s Disease, is rising to new heights.

“This is about more than just putting water over our head,” said Ina Hoffman, director of admissions for the facility, which includes the nation’s first specialized residence for people with ALS.

Saling, who was diagnosed with ALS eight years ago, took the challenge for all his friends who battle the disease without access to specialized care.

“I will not rest until the ALS residence is an option for people with ALS across the country,” he wrote on Facebook.

Amyotrophic lateral sclerosis is a neurodegenerative disease that affects nerve cells in the brain and the spinal cord. About 5,600 people are diagnosed with ALS each year in the United States.

Life expectancy for those with the disease averages two to five years.

The fund-raising campaign, spreading rapidly across social media, has been highly successful. In the past two weeks, the national office of The ALS Association has received \$2.3 million in donations, compared with \$25,000 during the same span last year.

With local chapters included, the nonprofit has received \$4 million, compared with \$1.1 million last year.

Residents of the center in Chelsea watched with delight as the staff accepted their dousings Tuesday. Bonnie Berthiaume, who has multiple sclerosis, said she loved how seemingly everyone was taking the ice bucket challenge. Her whole family had done it, even her 2-year-old grandson, she said.

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PHOTOS



Photos of ice bucket challenge

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“I wish we could get everyone to do it,” she said. “It should have happened a long time ago.”

Barbara Tracey, a retired teacher who was diagnosed with the neuromuscular disease PLS last October, said she welcomed the outpouring of support. “It’s unbelievable,” she said. “It’s like magic.”

Joelle Smith, who directs an annual walk to raise money for health care facilities run by the Chelsea Jewish Foundation, said the campaign has raised awareness about the disease, and she hopes the higher profile will lead to breakthroughs against it.

“Before this, ALS wasn’t a household name,” she said.