

Finding a hero at the Ice Bucket Challenge

By Dani Palmer
Cannon Beach Gazette

Last year, the ALS Association Ice Bucket Challenge went viral, raising \$115 million globally for research. Locals like Susan Simon, whose son has ALS, are trying to keep that challenge going.

Amyotrophic lateral sclerosis is a progressive neurological disease affecting the nerve cells in the brain and spinal cord. Symptoms include muscle weakness and difficulty swallowing. Approximately 20,000 Americans have the disease at any given time.

Adam Simon, 42, was diagnosed in 2008 and put in a medical ward at the Air Force base in San Antonio. He had served in the Gulf War and retired as a staff sergeant a year after being diagnosed. In 2012, he moved in with his mother in Cannon Beach.

Adam was only given two to five years to live. It's been seven.

"Sometimes in life you never have a hero," Susan said. "Adam is my hero."

She noted that those diagnosed under the age of 40 often display a slower rate of progression. Adam is unsteady and falls often, but can still walk with a walker and gets out, Susan said. He goes swimming and does other activities with caregiver Daniel Stowers.

Stowers was an army combat medic for six years in Afghanistan and recruited by Suzanne Evans, Adam's other caregiver also served in Afghanistan as a medic with the Oregon Army National Guard.

Susan said she saw a bracelet soldiers wear to remember fallen comrades on Stowers' wrist and told him about the job after learning he'd also been a medic.

Evans was "pretty messed up" after departing the military, finding it difficult to even leave home. She said she felt blessed to receive the job with the Simon family as it was a safe place to do what

she loves. "The cherry on the cake is that it's another brother in arms," she said.

She cooks, cleans, takes Adam to Portland every three months for medical appointments and does physical therapy with him.

"I'm just there as somebody he can count on," she said. "Anything you take for granted is harder for him."

Stowers said he's learned more about ALS through his work with Adam and educates others.

"Adam's awesome," he said. "He's very quiet, but he's one of those people who says more without saying anything."

Researchers are still studying the correlation, but military veterans are twice as likely to be diagnosed with ALS than the general population, according to the ALS Association.

In 2014, \$77 million of the \$115 million raised through the Ice Bucket Challenge went toward research, \$23 million toward patient and community services and \$10 million to public and professional education.

There is no cure for ALS yet, only palliative care providing relief from symptoms.

"This death is not for sissies," Susan said. "It's like a big train engine is coming toward you and you can't get off the track."

Along with her Ice Bucket Challenge, Susan, an artist at White Bird Gallery, presented a \$500 donation to the ALS Association.

via the sale of her paintings.

Those who receive the Ice Bucket Challenge are encouraged to record themselves dumping a bucket of ice water over their heads, to challenge at least three more people and donate to the ALS Association. Susan extended the invitation to the Ice Bucket Challenge to members of American Legion Post 168.

More information can be found at www.alsa.org/fight-als/ice-bucket-challenge.



DANI PALMER/CANNON BEACH GAZETTE

Military veterans Suzanne Evans, left, and Daniel Stowers pour water on Susan Simon, left, and Andy Kerr for the ALS Association's Ice Bucket Challenge. Susan's son, Adam, a retired staff sergeant from the U.S. Air Force, has ALS.

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