ALS CHALLENGE:
No cure for devastating disease

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findings of genetic markers and alterations. This takes research one step closer to finding a treatment or cure. The funds have also allowed the association to increase its multitude of support programs.

"Nationally, two people in 100,000 are diagnosed with Amyotrophic Lateral Sclerosis," explained Carmen Hull of Sisters, who was diagnosed with the disease a year ago. "In our tri-county area, there are 25 people with this disease, at least four of them here in Sisters."

The low numbers of people affected accounts for some of the "back-burner" attitude in research over many decades. Research is costly, and pharmaceutical companies don't want to invest in drugs that may have a low impact in sales and profit.

But, for families of ALS patients and for those diagnosed, this disease is far from low-impact. The drive and popular exposure to the disease by the Ice Bucket Challenge has changed the attitude of research. The ALS Association supports groups for both the patient and the caregiver, usually a spouse or family member, who have also benefited from the funding surge.

Both the Hulls are very grateful for the support groups and what they offer. Allen Hull, Carmen's spouse, attends both the patient and caregiver support groups.

"It is interesting," he noted, "to watch people (in the public) get quiet when ALS is discussed." When asked why he thought this happens, he said he believes there is fear in not having the ability to know if you could be diagnosed with this disease. Along with that, fear comes from lack of knowledge. Hull paused before he added, "The stark reality is that there is no cure."

Carmen displays a lower leg brace that came from the association's "Loaner Closet," a collection of devices left by past ALS patients to be shared with others who can benefit from their use.

"I am not riding my bicycle at this time," Carmen said, "but I hope to get back to that, and that wouldn't be an option without the brace."

She is considering a three-wheeler bike, admitting that there is some consternation about falling from the two-wheeler she has been riding for most of the year.

The monthly group meetings allow time for shared tears from members whose lives can never recoup many losses, to share ideas and support through listening, and freely sharing feelings they may be unwilling to express to friends and families.

"This is a disease of tears," said Allen, and the couple acknowledged that there are plenty of those, but there is laughter in the fellowship, too.

At the monthly discussions and lunch, the groups also develop ways to create patient involvement in their communities. Education is primary. Joining groups of people with other forms of disability is another action that is encouraged as a means of more exposure.

This is a disease of disability, so there is much to share with anyone else with a handicap. The groups feel regenerated in planning and implementing new projects. People go home feeling emotionally better.

The association's desire to relieve caregivers by providing professional caregivers at no cost to the family has been elevated over the last year by the fundraising success. As a long-term goal, the association hopes to establish this service to all ALS families.

Local ALS coordinator, Betsy Paige, schedules occupational, speech, and physical therapy appointments for Central Oregon patients and provides mental and emotional support. She works with an MD and a pulmonologist to evaluate and set protocols of therapy for each individual patient. Her funding comes directly from the ALS Association at the state and national level.

PHOTO BY BONNIE MALONE

Hull Hustlers are recruiting for the ALS Walk in Bend.

On September 12, the Central Oregon Walk to Defeat ALS is another opportunity to assist in this cause. It will begin at Riverbend Park at noon. Carmen lights up when she reports that the goal of the Central Oregon ALS Walk in 2014 was a grandiose $80,000. Instead, the event raised $115,000 — a result of the Ice Bucket publicity.

"Our team, the Hull Hustlers, had 50 walkers," she said proudly, as Allen displayed their sign for this year. "This program at the church and the Walk for ALS is about bringing more attention to our community about this disease."

They would welcome anyone who wants to be a Hull Hustler or join any other team to sign up. To join the Walk to Defeat ALS, visit www.walk@alsa-or.org.

ALS Day at Shepherd of the Hills Lutheran Church will begin at 10 a.m. After Aubrey McCauley speaks, the Ice Bucket Challenge will begin around 11 a.m. The church recommends wearing appropriate clothing for the "dousing," and, if available, bring a bucket. There is no need to register for either event at the church.

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