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Providence ALS Center is part of Providence Brain and Spine Institute.

Providence ALS Center is the leading comprehensive care center in Oregon, certified by the ALS Association as a Center of Excellence offering a multidisciplinary approach to ensure ease and excellence. Our program emphasizes treatment, coordinated care, education and early intervention to manage symptoms.

Frontotemporal Dementia

By Kathy Wild, Ph.D. and Nancy Hoke, ALS RN

For years it was thought that frontotemporal dementia (FTD) and ALS were two separate diseases. But we are learning that both carry similar cellular and genetic components. The overlap is a major research question.

Recent studies indicate that up to 50% of ALS patients notice very subtle changes in their thinking, though a much smaller number of patients have serious problems with it. These patients are diagnosed with FTD or other cognitive impairments. With loss of function of neurons in the frontal and temporal lobes, progressive behavior and language changes can occur. This can be seen in thinking, personality, and behavior, and can make problem-solving, decision making and judgment challenging. Hallmark signs can also include emotional blunting, reduced empathy, changes in interpersonal behavior, social withdrawal, and impulsiveness. Quite often, people with FTD have little insight into their own difficulties, and engage in risky behaviors while refusing offers of help or support. In some cases, these changes in thinking and behavior can precede the onset of symptoms of ALS and can be misdiagnosed as psychiatric disorders.

Closest family members and loved ones are typically the first to notice something different, and it can be so subtle that others outside of the home don't even notice. In other cases, FTD symptoms are profound, greatly impacting the lives of those around them. Family members not only have to cope with the physical demands of caregiving, but can be met with resistance and lack of understanding by their loved one.

The Providence ALS FTD Support Group was developed to help caregivers and families. It is led by Kathy Wild, Ph.D., OHSU Psychologist and Associate Professor of Neurology and Psychiatry, who specializes in cognitive impairment and dementia. The meetings are a safe place for caregivers to talk with others who share their challenges, as well as provide emotional support in the face of the daily demands of caregiving. Very practical solutions to problems stemming from difficult behaviors are offered. While it may feel overwhelming to add another "task" to an already overtaxed daily schedule, the recognition and empathy among support group members as they share their experiences seems to reduce burden rather than add to it. This is a difficult journey, one that no one should undertake alone.

Below is information on the Providence ALS FTD Support Group. Families and loved ones are encouraged to contact the Providence ALS team for more information or to be added to the group's private email list.



Where: Providence ALS Center Nursing/ Research Office, Suite 318

When: 2nd Tuesday of every month
5 - 6:30 p.m.



HiketodefateALS.org | May 16, 2020 | Silver Falls State Park



Join us for the inaugural Hike to Defeat ALS on May 16, 2020 at Silver Falls State Park.

Spend a day in nature testing your endurance on a 13.1 or 7.2-mile hike past 10 scenic waterfalls. A 3-mile family friendly, paved hike is also available and suitable for power mobility equipment and strollers. Lunch, rest stops along the routes, entertainment, and more will be provided with your registration.

Visit hiketodefateals.org to learn more and register today!

All participants over the age of 11 are required to raise \$150 or more to support finding treatments and a cure for ALS.

Questions or need help registering? Contact Emily-Rose Wiitala at emilyrose.w@alsolegon.org, 503-238-5559 x105.



The ALS Association Oregon and SW Washington Chapter | 700 NE Multnomah St., Suite 210, Portland, OR 97232

ALS CLINICAL RESEARCH

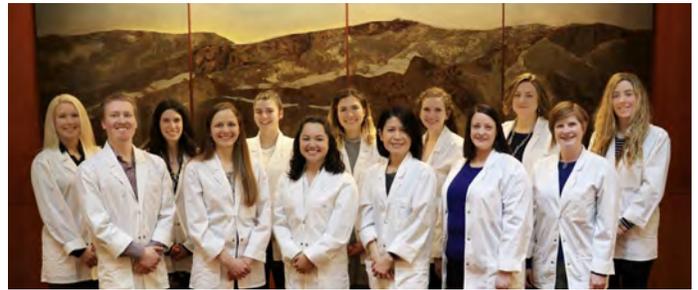
Providence Health & Services

Brain & Spine Institute

ABOUT US

The providers at Providence Brain and Spine Institute are dedicated to finding advanced treatments for neurological conditions. This is done through the involvement in progressive clinical trials, both sponsored and investigator initiated. The patients who choose to take part in clinical trials have access to medications and devices that may improve their health status and quality of life.

- ◆ For more information about Providence Brain and Spine Institute's clinical research department, please visit: <http://oregon.providence.org/our-services/c/clinical-trials-brain/>
- ◆ For more information about ALS Clinical Trials, please visit: <https://clinicaltrials.gov/>
- ◆ For more information about local ALS events and support, please visit: <http://webor.alsa.org>



PBSI Clinical Research Team, March 2019

Currently Enrolling Trial

- ◆ *A phase 3, double blind, placebo-controlled, single ascending dose study to evaluate safety, tolerability, PK and PD of BIIB100 in adult ALS patients with confirmed SOD1.*
DETAILS: Part C: randomized 2:1 100 mg BIIB100 administered intrathecally 8 times over 24 weeks. Only FAST progressing patients with SOD1 mutation may enrol. Open label extension study available upon completion. Must also have SVC >65% and not be using non-invasive ventilation.

Please contact us if you have questions or want additional information regarding research trials

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Team Member Spotlight: Karen



What is your role at Providence?

I am a Speech Language Pathologist.

How did you become interested in ALS?

I have been with the Providence ALS clinic since it began in 2005. I became interested in ALS through my love and expertise in helping people obtain and use Augmentative/Alternative Communication tools. Helping people with ALS is something I am passionate about, as I hope to do anything I can to ease the lives of those who are affected by this disease.

What advice might you share with a caregiver of someone living with ALS?

Take Mr. Rogers's advice and "look for the helpers". Take time to care for yourself as well as your loved one with ALS. There are many people around who really want to help! Take advantage of that.

What do you like to do outside of work?

I mostly enjoy laughing and spending time with my husband and two daughters. Both of my daughters also have had a passion for helping people with ALS since they were little. Each year they look forward to volunteering at the ALS Gala and are expert "Golden Bead" sellers! ■

*Top photo:
Karen and her
family. Right
photo: Karen's
daughters at
the ALS Gala.*



MISSION

As expressions of God's healing love, witnessed through the ministry of Jesus, we are steadfast in serving all, especially those who are poor and vulnerable.

OUR VALUES

Compassion, Dignity, Justice, Excellence, Integrity

PROVIDENCE ALS CENTER

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