

IN THIS ISSUE:

Farewell Interview:
Dr. Kim Goslin
p. 2

ALS Clinical Research
p. 3

Living with ALS
p. 4



TeleALS in the Times of Coronavirus

The spread of coronavirus has changed the world and the way we practice medicine. Prior to COVID-19, telehealth was primarily being used by stroke clinicians for acute stroke assessment and was not part of routine care for outpatient neurology or ALS.

The Providence ALS Center received a quality improvement project grant from PIPA (Portland InterHospital Physicians Association) to pilot telehealth, knowing already this was important to our population of patients. The project was designed to provide access for people with ALS that had long commutes or other barriers that made coming to clinic challenging. Upon the arrival of COVID-19 and recommendations of social distancing, people with ALS were one of the first groups to be offered unrestricted telemedicine visits with ALS neurologists. After this conversion, the next goal was to focus on the ALS multidisciplinary clinic in order to keep the team dynamic intact while adhering to social distancing. There were many considerations to balance beyond the technology, and things were moving fast to adapt.

The local ALS Association organized meetings between the ALS centers in the Portland area to exchange notes and identify things that were working and things that were not. The Providence ALS RN team piloted many different permutations so that people with ALS could continue to receive care via telemedicine. The clinic now has a triage system to identify those with urgent needs for in person care and to find others where telemedicine is a more suitable option. On multidisciplinary clinic days, we can now accommodate 6 people with ALS seeing specialists onsite or offsite via telemedicine. There continues to be a learning curve for everyone involved in telemedicine. Our work with ALS families has proven how resilient and adaptable they are, and the telemedicine experience is no exception. Many people with ALS are helping us trial these new approaches and expressing appreciation of the ability to stay engaged with the clinic and the ALS team. ■

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.

Farewell Interview with Dr. Kim Goslin



Dr. Kim Goslin

This Fall, Providence ALS Center will say a fond farewell to our founder and co-medical director, Dr. Kim Goslin. We wish her a joyful retirement, and know she will always be a part of this community. Here is our parting interview with her:

Any fun plans for retirement?

My husband and I recently moved out to the country and bought a farm. Now we have 5 goats, 8 chickens, a dog, a cat and two Icelandic horses. We plan on trekking with the horses all over the country and doing competitive endurance training. We also love to travel, sail, climb, hike and ski. Of course, I will also stay involved with Providence and the ALS community.

How has ALS Care changed since you began this work?

I started working in this field over 20 years ago when there was very little that could be done to help people with ALS. This area has burgeoned with new options for treatment including the Multidisciplinary Clinic approach to care that we have at Providence, two medications to slow progression and non-invasive assisted ventilation. Every year, there are many more exciting trials for promising therapies for ALS. There is very genuine hope for a more effective treatment in the future.

How has the team/multidisciplinary approach at Providence ALS Center made a difference?

I believe that this team approach has been fundamental for improving the quality of life and life expectancy of many people with ALS. Patients and their loved ones come to a clinic every three months and see up to 10 different ALS specialists in one afternoon and in one office. It's a one-stop shopping approach with many talented, expert, proactive and compassionate team members. From a personal point of view, there has been so much joy for me in collaborating with such caring and compassionate team members. It has been a constant source of inspiration, and I feel so lucky to have had this team.

If you could host a dinner party with anyone, who would the guests be?

The main person that I have always wished to meet is the Buddha. His teachings on compassion have been a motivation for me throughout my career.

What have you learned from the ALS families you've worked with through the years?

People with ALS and their families are my heroes and the reason that I have loved the work I do. Through them, I have learned the depth of compassion and resilience and strength that human beings can have, even under difficult circumstances. ■

ALS CLINICAL RESEARCH

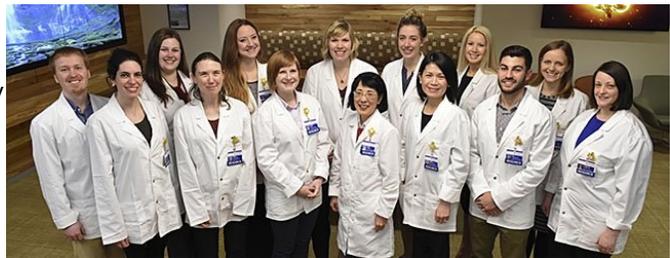
Providence Health & Services

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 2017

Currently Enrolling Trials

- ◆ A single or multiple visit protocol for collection of DNA/RNA/SERUM/PLASMA/CSF in Amyotrophic Lateral Sclerosis and related disorders
- ◆ A Study to Evaluate the Efficacy, Safety, Tolerability, Pharmacokinetics, and Pharmacodynamics of BIIB067 Administered to Adult Subjects with ALS and Confirmed Superoxide Dismutase 1 Mutation
- ◆ Therapy in ALS to determine if Memantine at 20 mg twice daily when in conjunction with Riluzole, can slow progression and potentially improve neuropsychiatric changes, as well as determine if serum biomarkers can be used both as diagnostic and prognostic markers

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

Providence ALS Center
 5050 NE Hoyt St Suite 315,
 Portland, OR 97213

Amyotrophic Lateral Sclerosis Research
 Arlena Cummings, BS, CCRP
arlena.cummings@providence.org
 503.962.1171

Living with ALS



The day after they married on May 31, 1980, Dave and Laurie Clarke headed west to work in the wilderness in Idaho for the US Forest Service. They also spent four years living and working in the bottom of Hell's Canyon, six miles from the end of the road, year-round with no electricity! One thing led to another, and they ended up in Sandy, Oregon with Dave becoming a Captain with Gresham Fire Department and Laurie as an academic advisor at Mt. Hood Community College. Lots of child-centered activities followed along with hiking, skiing, and cycling. After the kids, Annie and Dale, were out of school, Dave joined Portland Mountain Rescue (PMR) and worked tirelessly at learning and training. He became a president of the organization and then went on to be on the board of the Mountain Rescue Association (MRA) and the president there. While there, he was voted to be a delegate to ICAR, the International Commission for Alpine Rescue. At the same time, Laurie joined PMR and worked on background projects, and continued to volunteer for the MRA as the editor of its quarterly online publication. Also, Dave was quite active with glacier cave exploration and research done on Mt. Hood, Mount St. Helens and Mt. Rainier.

All of these life experiences taught them hands on skills: how to work on a team, how to manage while on your own, and most importantly, they learned how to be resourceful. Little did they know this would be tested when Dave's diagnosis of ALS arrived in June of 2018. Remodeling the house for accessibility, giving up climbing and skiing and his beloved bicycles (which were replaced by a recumbent tricycle, and by woodworking), learning to ask for help from friends and family, adjusting to changing physical needs all came with a learning curve. So now, though a hard part of this diagnosis has been coping with loss and grief, Dave's attitude has saved the day. He stays positive and does what he has always done—taking an explorers attitude and putting his shoulder into it.

Dave and Laurie have raised money to contribute to the ALSA in Oregon and SW Washington through the Ride to Defeat ALS and the Ski to Defeat ALS. They are humbled and grateful for the help they have received from the wonderful staff at the Providence Brain and Spine Institute and the ALSA. This journey would be rough and lonely without them. ■



Top photo: Dave and Laurie at Kirkwood Bar Historic Ranch on the Snake River, Idaho where they worked when first married. Photo by L. Kusleika, 1980. **Middle photo:** Dave working on building cribs; and making accessibility adjustments in his wood shop. Photo by Laurie Clarke, 2020. **Bottom left photo:** Dave riding in the 2020 Ride to Defeat ALS. Photo by Laurie Clarke, 2020. **Bottom right photo:** Born during a worldwide pandemic, twin grandsons, David and Ethan have their Grampa to lean on. Photo by Laurie Clarke, 2020.

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

5050 Northeast Hoyt St., Suite 315
Portland, OR 97213
503-215-8580