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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.

Palliative Care for patients and families living with ALS

By Rick T. Warren, ANP, BC

Palliative care is specialized medical care for patients and families living with a serious illness. This care focuses on promoting comfort, quality of life, improved communication and informed decision making. Palliative care services are offered early in the course of a serious illness in an effort to help patients and families avoid crisis, access information and remain an active partner in treatment options and decision making. Physical, emotional, social and spiritual concerns of patients and families are some of the issues that we discuss.

At the Providence ALS Center I usually meet with patients and families when they visit the clinic for their second or third appointment. I initially explain palliative care concepts and discuss how we can work together as their condition changes. I want to understand what worries patients and families and what they are struggling with. I also want to know about their support system, how they approach decision making and what helps them cope. I believe that these issues and discussions are just as important as the medical care and therapy that we offer patients. This gives patients and families a voice in shaping their treatment plan and helps us prioritize what they feel is most important.

When someone is first diagnosed with ALS, they often begin to gather information so that they can better understand what they can expect from this illness, what treatment options might be offered and how this ill-

ness may affect their lives and the lives of their family. They may also begin to consider what procedures they may or may not want, particularly as it relates to comfort, quality of life, function and life-extending treatments. We feel strongly that these issues should be discussed with medical providers, including those from palliative care.

These aren't always easy discussions, as we consider problems that may arise as ALS progresses. In palliative care, we encourage discussions about a person's values, changes in healthcare status, treatment options and how these treatments may affect a person's quality of life, comfort and life expectancy. Although these are emotional topics, research indicates that patients and families who receive palliative care support have better access to services, are better able to cope, make better decisions and are more satisfied with their health care.

Although palliative care is available in most areas, it is still a relatively new concept. Services may vary in different health care systems. At the Providence ALS Center, we offer palliative care to all of our patients and families. Some may refuse this care, but it is always available. If you or a loved one has a serious illness, talk to a member of your healthcare team to see if palliative care might be beneficial. Palliative care is covered by most insurance plans, including Medicare, and may provide you and your family with some additional help or support during a difficult time. ■

Team Member Spotlight: Anjelica



Anjelica

What is your role at Providence?

I am a Patient Relations Representative, which means for most of our patients I am the first point of contact with the clinic. I answer most of the incoming phone calls, verify information, provide information to prospective patients, and do a lot of little things to make sure our clinic runs smoothly.

Because I work in the ALS team, my role extends beyond the normal parameters of a PRR. I help schedule patients for ALS Clinics, verify the variety of visits will be covered by insurance, and provide general information for additional services patients may need.

How did you become interested in ALS?

I kind of fell into the role I am in, but I couldn't be happier. I have aspirations to become a social worker for hospice patients, so working with patients with such a diagnosis seemed like a natural fit. Since joining the ALS team at Providence, I have learned so much about ALS and am very excited to be in a position to get lots of hands on experience.

What do you like to do outside of work?

I do very few things of interest outside of work! On my days off, you can usually find me reading or watching movies with my cat and boyfriend. I do have several friends who are musicians, so I go to a lot of concerts on the weekends. I also just bought a new DSLR camera, so I have fun playing around with that at concerts. Find my photos on Instagram at @starfuzzphoto .

Who would you invite to your dream dinner party (alive or dead)?

This was such a hard question to answer! I think it would be really fun to have a conversation with some of my favorite writers, Kahlil Gibran, e.e. cummings, and Raymond Carver. I have read many of their poems, stories, and books. I feel like they have some interesting thoughts on the meaning of life and what it means to be alive, from varying perspectives.

What life experience has taught or changed you the most?

I was a volunteer at a camp for people with special needs in college for a few weeks. I had never had experience like this before – caregiving, personal care assistance, and dietary needs were all very new to me. Previously I never dreamed I could handle a job like this. I needed to have everything under control and changes freaked me out. I always felt a drive to help people so I figured it would be a good experience and an easy way to knock out what counted as a full 4 class credits at PSU.

Going to camp, I had no idea what to expect. But it turned out to be one of the most challenging and rewarding experiences, one that shaped the rest of my career. I had to quickly learn how to provide support to my campers without hindering their independence. I had to learn how to best handle behaviors, the most efficient way to provide personal care, and how to properly respond to medical emergencies without cracking under pressure. I didn't realize how much growing I did during this experience, but I use the skills I learned at camp every day in my job. ■

ALS CLINICAL RESEARCH

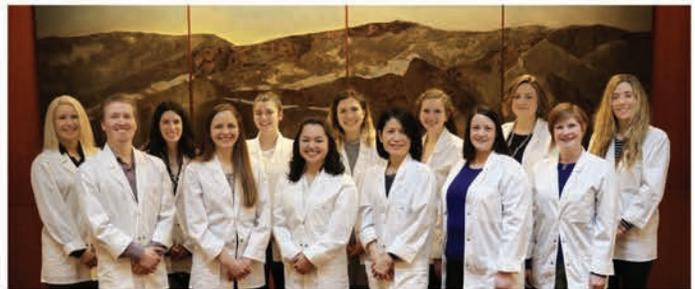
Providence Health & Services

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 Trials

- ◆ A Multicenter, Double Blind, Placebo Controlled Study to Assess the Efficacy and Safety of H.P. Acthar® Gel in the Treatment of Subjects With Amyotrophic Lateral Sclerosis (Sponsor—Mallinckrodt)
- ◆ A single or multiple visit protocol for collection of DNA/RNA/SERUM/PLASMA/CSF in Amyotrophic Lateral Sclerosis and related disorders
- ◆ PENDING: 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

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

Providence ALS Center
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Amyotrophic Lateral Sclerosis Research
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A Patient's Perspective

I'm Jerry and my life is now defined by three letters: ALS. I received my diagnosis in November 2017 and my life has been forever changed.

At first, the journey seemed a bit adventurous. We sold our old house and bought a new one-level house. I stopped working. I started receiving Radicava treatments. I started attending clinic. I visited physical therapists and occupational therapists. We remodeled our new house. There was a lot going on and we were busy. We went on a trip to Ireland. I didn't spend a lot of time thinking about what was happening to me and just got lost in the busyness.

But eventually, these three little letters, ALS, started to sink in. It got hard to walk, and then harder to walk, and then I was unable to walk. I still feel independent, yet I know that I'm not. I can't dress myself. I need help in the bathroom. I need help getting in and out of bed. It takes all I've got just to brush my teeth. It's a struggle especially when I think about my wife and my children. It's

devastating to think about the future when I focus on my family. ALS is truly awful.

Fortunately we have discovered many resources on this path. The ALS Association has been incredibly helpful along with the Providence ALS clinic. We are so thankful for the love and care we receive from all the dedicated professionals helping us. We are not alone.

Recently, we had an opportunity to fight back. We had the opportunity to travel to Washington D.C., and advocate for people living with ALS. We lobbied our Senate and congressional delegations to increase funding for ALS research and to fight back against competitive bidding procedures that would limit non-invasive ventilators. It was good to tell my story and put my face in front of legislative delegations. We were listened to, and it was great to have an opportunity to fight this disease in such a tangible way.

As my disease progresses I have decided to no longer focus on what I can't do and start

focusing on what I can do. With my family I focus on today and not tomorrow. I'm still sad at times, but I strive to be optimistic. I'm still real. I understand my circumstances. I strive to be positive and look for ways to help others. I work hard to encourage when I can. I smile and laugh when I can. It's a mindset based on gratitude. Gratitude that is forged by the love and friendship of so many wonderful people that have stood with us during this difficult time. We are grateful for the thousands of hours of volunteer labor that these people have provided. We can't help but have a changed perspective as we focus on all that's been done for us by others. We are truly thankful.

I keep fighting every way I can. I connect with others, advocate against this disease, rally friends and do everything I can to make sure this disease doesn't defeat me. I always say I have ALS but that doesn't mean ALS has me.

I'm thankful and blessed, and I will keep fighting. ■

ALS FAMILY CAREGIVER BOOTCAMP

WHAT IT IS: A 4-hour family caregiver training with ALS expert therapists and therapy students from local colleges. Trainings will cover common ALS caregiving needs World Trade Center plaza.

TOPICS COVERED:

- Hoyer lift transfers
- Feeding tubes
- Bathroom transfers
- Heimlich Manuever (both in and out of a wheelchair)
- Fall Recovery
- Swallow Adaptations
- Respiratory equipment
- Feeding Equipment
- Other common caregiving tasks

TO REGISTER: Please email lauren.brown3@providence.org
Please provide desired bootcamp date, name and contact information

NOVEMBER 23RD

LOCATION:
PPMC – Social Room
4805 NE Glisan St
Portland, OR 97213

TIME:
1 pm – 5 pm

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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