

## IN THIS ISSUE:

**Team Member Spotlight:  
Lauren Brown**  
p. 2

**Currently Enrolling Trials**  
p. 3

**A Patient's Perspective**  
p. 4

**News & Events**  
p. 4

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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.

## Caregiver TIPS

During my time as a caregiver, for my father with ALS, we found it was helpful to set up things to look forward to on a monthly basis. Often times this was day long road trips, wheelchair accessible fire roads for hikes, planned visits with friends from out of town or local wheelchair accessible events. We also found out that many "sold out shows" would actually have very nice wheelchair accessible seats that were not available to the public. Although each new venue was a potential challenge we looked forward to the adventure. With "the wheelchair pass" we got amazing seats (sometimes front row) to see: Tom Petty, Bon Jovi, James Taylor, Arcade Fire, Built to spill, and Stephen Kellogg and the Sixers, to name a few of our most memorable events together. My dad enjoyed music and outdoors so being outside and going to music shows worked well for him to keep morale high. Having something to focus on helped on the days that were hard and to have something to look forward to.

~Nick Olney, MD – ALS Neurologist &  
Co-Director of Providence ALS Center

It's like a phone recording: eat your vegetables, get more sleep, exercise, take time to get away, breathe deeply, be financially responsible, and de-clutter your life. Self-care lists like this can sometimes be inspiring at the start of a new year, but later on when life happens? Not so much! The good news is you can break most things down into very small portions and still experience significant benefit. So challenge yourself to take five minutes and savor the moment. Go outside and take a deep breath of fresh air. Have you smelled the rain lately? Find some-

thing new to share, and then laugh about it with a friend till your eyeballs pop out. Enjoy some dark chocolate and a piece of dried fruit instead of cake. Pause when you experience a sweet kindness. Appreciate the moments and know that the positive steps you are taking will add up over time!

~Nancy Hoke, RN, BSN –  
ALS Clinical Nurse Coordinator

I talked to a friend yesterday who said that she is asking herself several times every day "is there is simpler way to do this?" She went on to say that any time she noticed extra drama or stress in her life she looks for a simpler way to approach the task at hand.

I am trying to be increasingly present on a moment to moment basis. Even with simple things, like washing the dishes, I try to pay attention to what I'm doing and not multitasking or thinking about the 11 other things I should be doing.

I also find meditation helpful. There are many free apps you can load on your cell phone like 10% Happier and Headspace. Even 1-2 minutes of "quiet" can be very refreshing.

Exercise is also a huge stress relief for me. Anytime, anywhere, any way I can get. Even a walk around the block helps to recharge my batteries.

Lastly, I like to smile at people. I don't know why but I find it very uplifting when I smile at someone, especially if they look grumpy, and they return my smile.

~Rick Warren, APRN, ACHPN –  
Hospice and Palliative Care Nurse Practitioner

...continued on page 2

## Team Member Spotlight: Lauren Brown



Lauren Brown, ALS Nurse Coordinator with her family

### What is your role at Providence?

I am an ALS Nurse Coordinator. We coordinate the clinics and follow-ups for patients. We also coordinate care across multiple specialties for our patients to hopefully streamline their healthcare to the best of our ability!

### How did you become interested in ALS?

My dad was diagnosed with ALS when I was in middle school. We lived in a very rural town with extremely limited resources available to us. The closest ALS center was 8+ hours away. It was an eye-opening experience to see the lack of knowledge of ALS and the lack of access to resources in our little town. It inspired me

to raise awareness about ALS but even more so to help patients with ALS access resources and get the help they need.

Throughout college, I was always interested in ALS and potentially working with ALS patients in the future. However, I didn't really think I would get an opportunity so early in my career. Thankfully I did and I absolutely love working at the Providence ALS Center.

### What do you like to do outside of work?

My husband and I are total gamer nerds. Currently, we are dedicated to Fortnite. However, we also play board games and Mario games with our daughter. Mario 64 is still one of the best games ever made.

Other than gaming, I enjoy shopping, baking and crafting. Oh and of course, Netflix.

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

This is probably sappy, but I would invite my dad. I think that he would be excited to see the progress of ALS research and my involvement with ALS. Also, he would be ecstatic that the Cubs finally won a world series in 2016.

### What life experience has taught or changed you the most?

Caring for my father after his diagnosis changed everything for me. I had no experience in healthcare. My family is filled with teachers, lawyers and accountants who do not deal with medicine or caregiving. Taking care of my father gave me the experience to realize that caring for people is exactly what I want and need to do with my life. I can't say that I enjoyed every aspect of the care, but I made a difference for him. Offering compassion, hope and my fighting spirit (that is the lawyer in me!), I get to ease the way for our patients during what is likely the most difficult time in their life. ■

### Caregiver TIPS, continued from page 1

Accept help. Even Superman needs a rest every once in a while. It can be hard to accept help and even harder to ask for help. But the time that you can gain by getting a nice nap, bath or shopping trip done can do wonders for your stress! It can be surprising how many people in your life are wanting to help but don't know how to offer.

~Lauren Brown, RN, MSN –  
ALS Nurse Coordinator ■

## ALS CLINICAL STUDIES

Providence ALS Center's research department strives to be a national leader in clinical trials, while also creating a space of hope for people living with ALS and their loved ones. Patients are offered a wide array of treatment options, including the latest research studies and clinical trials that will shape the future of ALS care and bring the ALS community closer to a cure.

### Currently enrolling trials at Providence ALS Center

#### **STUDY 1 | 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 Pharmaceuticals  
Principal Investigator: Kimberly Goslin M.D., Ph.D.  
Study Coordinator: Arlena Cummings, CCRP

#### **STUDY 2 | A Phase 2, Multi-Center, Double-Blind, Randomized, Dose-Ranging, Placebo-Controlled Study to Evaluate the Efficacy, Safety and Tolerability of CK-2127107 in Patients With Amyotrophic Lateral Sclerosis (ALS)**

Sponsor: Cytokinetics  
Principal Investigator: Kimberly Goslin M.D., Ph.D.  
Study Coordinator: Arlena Cummings, CCRP

#### **STUDY 3 | A Randomized, Double-Blind, Controlled, Parallel Group Study to Evaluate the Efficacy and Safety of FLX-787-ODT for Treatment of Muscle Cramps in Adult Subjects with Motor Neuron Disease**

Sponsor: FLEXPharma  
Principal Investigator: Kimberly Goslin, M.D., Ph.D.  
Study Coordinator: Arlena Cummings, CCRP

#### **STUDY 4 | A single or multiple visit protocol for collection of DNA/RNA/SERUM/PLASMA/CSF in Amyotrophic Lateral Sclerosis and related disorders**

Sponsor: PrecisionMed  
Principal Investigator: Kimberly Goslin M.D., Ph.D.  
Study Coordinator: Arlena Cummings, CCRP

#### **STUDY 5 | A Randomized, double-blind, placebo-controlled, parallel group, multi-center study examining the effects of oral Levosimendan (ODM-109) on respiratory function in patients with ALS**

Sponsor: Orion  
Principal Investigator: Kimberly Goslin M.D., Ph.D.  
Study Coordinator: Arlena Cummings, CCRP

#### **STUDY 6 | A Phase 3, Randomized, Placebo-Controlled Trial of Arimoclomol in Amyotrophic Lateral Sclerosis**

Sponsor: Orphazyme  
Principle Investigator: Kimberly Goslin, M.D., Ph.D.  
Study Coordinator: Arlena Cummings, CCRP

### Additional Clinical Trial Resources

- **ClinicalTrials.gov** is a database of privately and publically funded clinical studies conducted around the world. Our ALS trials will be listed on this site for your reference
- **Providence Brain and Spine Institute Clinical Research Site** provides a brief description of our research department as well as offers patients a list of all PBSI enrolling trials as well as a referral form to contact a study coordinator, <https://oregon.providence.org/our-services/c/clinical-trials-brain>
- **Research and Clinical Trials at Providence** website provides access to clinical trials offered at all of our Providence locations, <https://research.providence.org>

### What do our patients say about participating in clinical trials?

*"I feel like I'm part of a larger community and hope my involvement will possibly help myself and others in the future."*

*"It gives me a sense of control over the disease at a time when there are so many aspects of my life where I'm losing control."*

*"I want to help find ways to slow disease progression and be a part of the research to help others."*

*"I trust Dr. Goslin's judgment [on the importance of trials] and want to contribute to research as long as possible."*

*Everyone who participates in a trial makes a difference. I would like my experience to aid in expediting the research to find a cure."*

## A Patient's Perspective

My name is Jill and I have ALS. It's been a year since I received my "definitive" diagnosis and I'm still a little in shock.

The bad news is that I have ALS. The good news is that it will progress slower than average. In the beginning the slowness of the disease didn't mean much to me...but now after living with it for a year, I'm grateful...grateful that I have time.

I'm an independent person with a wonderfully supportive and caring husband. I have a lovely family and good friends. But with all this love and care, this is still hard. It is especially hard on my ego, my pride, my work ethic to have to ask for help or watch others do what

I used to do. I'm the one who wants to help others not have it the other way around. I'm not good at standing on the sidelines.

I find it interesting how my perspective has changed over the past year. When first diagnosed I had a sense that my life was over...that I'll never experience happiness and joy again. I felt sorry for myself. But over time I have come to realize that there are still many opportunities open to me. I just have to give myself permission to focus on what I have and what I can do and not on my losses.

Part of my perspective comes from all the love and care I receive from those

around me...my husband in particular whose one day at a time and we'll get through this attitude means the world to me. And part comes from the ALS Program at Providence. I'm not exactly sure how the staff does this, but they almost make this all seem normal...no reason to panic...they help me find solutions to obstacles. They don't give me hope that I can be cured or fixed but they do provide hope and encouragement that with their skills and knowledge and compassion combined with my desire to make the most out of my life, I will have the best quality of life possible and continue to experience joy, love and serenity. ■

### Available on our Web site at [providence.org](http://providence.org):

- **Provider directory:** Get contact information for the entire care team at Providence ALS Center.
- **Upcoming events:** Providence offers educational events throughout the year. Check our online calendar to view upcoming topics.
- **Clinical trials:** Find out about multiple clinical trials for investigational treatments for ALS, as well as other clinical trials available through Providence.
- **Support groups:** Get details on support groups in Oregon.



For the latest in neuroscience news and education, visit [brainacademy.providence.org](http://brainacademy.providence.org)

### Events:

- **Providence ALS Center** is a proud sponsor of the ALS Association Oregon and Southwest Washington Chapter. Join Providence at local ALS Association events in the coming months. Questions? Call the local ALS Association office at 503-238-5559.
- **Ski to Defeat ALS:** Saturday, March 9th 2019. Mt. Hood Meadows Ski Resort. Adaptive skiing and family-friendly fun. Registration fee and fundraising minimum apply for all participants aged 11+.
- **Strike Out ALS Gala:** Saturday, April 27th 2019. Oregon Convention Center.
- **ALS Research Summit:** Saturday, June 15th 2019. Collaborative Life Sciences Building, South Waterfront.



### 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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