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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.

Providence ALS Center

An ALS Association Certified Center of Excellence in Oregon

The mission of the Providence ALS Center is to provide comprehensive and expert care to people with amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease. ALS is a rapidly progressive and fatal neuromuscular disease. Though it is not yet curable, it is very treatable. There are many things that we do to slow the disease progression, improve quality of life, and help people with ALS (PALS) to continue to find joy in life. Our team is dedicated to supporting PALS and their loved ones from diagnosis to the end of life.

The gold standard for treating PALS is the multidisciplinary clinic model, which is the model that has been used here at Providence for nearly 15 years. Our multidisciplinary clinic meets twice a week and patients generally attend once every three months. Over the course of one afternoon PALS are able to see up to 10 ALS specialists—the ultimate in one stop shopping! They have the opportunity to see a neurologist, pulmonologist, occupational therapist, physical therapist, speech therapist, augmentative and alternative communication specialist (AAC), ALS nurse, ALS social worker, dietician, and palliative care nurse practitioner. We also have a team psychologist and numerous specialty providers we work closely with. It is a long afternoon and snacks are always available for patients—we try to make these healthy but a Kit Kat has been known to sneak in from time to time. Once the patients have seen all of the specialists, the team meets to debrief and to develop an expert, comprehensive, and proactive treatment plan. We truly get to know and appreciate our patients during these discussions.

The Providence ALS Center is an ALS Association Certified Center of Excellence

and meets the highest criteria for providing comprehensive quality care. To qualify as a certified center we are actively involved in ALS research and clinical trials. Clinical trials are an important source of hope for our patients. Since we serve a large population of PALS our center has the opportunity to participate in the most promising clinical trials that are available worldwide.

Our center continues to grow and to offer more and more services to our patients. We have recently developed a program to teach PALS and their caregivers mindfulness and meditation techniques to help with the stresses associated with the disease. We have also developed a unique support system for caregivers of patients with ALS and frontotemporal dementia which is a challenging cognitive impairment that can be associated with ALS. Soon we will be offering telemedicine visits to our patients who are no longer able to leave their homes. As part of our expansion, we are excited to be adding Dr. Nick Olney to the team. He will be co-directing the center along with Dr. Kimberly Goslin, our current director and founder of the center. ■

Team Member Spotlight: Dr. Nick Olney



Dr. Nick Olney, Neurologist

My father was diagnosed with ALS in 2004. Upon hearing the news I promptly bowed out of my job doing bench work in biotech and moved home to become a caregiver. As a caregiver, I assisted my father in doing the physical things he could no longer do. During this time, we had many long discussions. My father was a neurologist and ALS researcher so during this time we talked a lot about medicine, neurology and ALS. I was already thinking of medical school, but these discussions solidified my desire to learn more about the human body, neurology and ALS.

I was accepted into UCSF for medical school. I decided to do an extra year of school as a Pathways to Careers in Clinical and Translation Research (PACCTR) fellow focusing on research. I received a scholarship grant for the Doris Duke Foundation to support my research in the project entitled "Behavior, Physiology and Experience of Pseudobulbar Affect in ALS Patients," which I did at the UCSF Memory and Aging Center (MAC).

This became a rather personal project for me, since as a caregiver I saw the symptoms of pseudobulbar affect (uncontrolled laughing and crying) progress in my father. At the time there were no FDA approved treatments for pseudobulbar affect and I it was an under researched area, so I thought I could make a difference, even as a medical student.

Doing this research I recruited patients from the UCSF ALS center for a behavioral lab session at UC Berkeley. My father ended up being both a participant in the lab session and help analyze the data which ended up in my first publication about the mechanism of pseudobulbar affect in ALS patients. This year also solidified my interest in neurology and ALS research.

After this year, I returned to clinical work to finish medical school. I completed an internship at Highland Hospital in Oakland, CA and then moved to Los Angeles for my residency in neurology at UCLA. Neurology residency was very busy, but I continued to have research interests in ALS and neurodegenerative diseases. I returned to the

MAC at UCSF for a fellowship focused on neurodegenerative disease and dementia with plans to expand the ongoing research in biomarkers and neuroimaging in ALS. I was awarded the AAN ALS fellowship grant to explore a novel spinal cord imaging tech-

"I can attest that the compassionate care at the Portland Providence ALS Center is known beyond the northwest, which is one of the many reasons I am excited to join the team."

nique (Phase Sensitive Inversion Recovery) and neurofilament as potential biomarkers for ALS. During the last half of my 3 year fellowship I was able to focus my clinical efforts on ALS diagnosis, and treatment as I became more and more passionate about providing care for ALS patients.

I am honored to join the Portland Providence ALS Center as co-director. I can attest that the compassionate care at the Portland Providence ALS Center is known beyond the northwest, which is one of the many reasons I am excited to join the team. I look forward to serving the Oregon ALS patient community, while contributing to national research efforts and clinical trials developing treatments for ALS. ■

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 Title: 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

Study Coordinator: Arlena Cummings, CCRP

Study Title: 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

Study Coordinator: Arlena Cummings, CCRP

Study Title: 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

Study Coordinator: Arlena Cummings, CCRP

Study Title: 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

Study Coordinator: Arlena Cummings, CCRP

Study Title: 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

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



It is not hyperbolic to state that ALS is one of the worst things that can happen to someone. Second perhaps only to Alzheimer's disease in the completely

undignified and terrifying way it kills, a diagnosis of ALS is absolutely devastating. It is also not hyperbolic to state that one of the best weapons against the ravages of this disease is the multidisciplinary ALS clinic. I personally cannot imagine going through this disease without my care team. A dedicated team of experts coming together to get the big picture and provide not only treatment, but expectations and support, is a luxury very few people are ever gifted with.

The ALS clinic makes the journey not only better, but perhaps even possible at all.

Scheduling so many appointments with so many separate providers would become a job in itself; a Herculean task when one is already exhausted from just continuing to be alive. One day every three months for a four hour whirlwind tour of health is a tremendous relief of burden, even without considering the travel times. In addition to the vast benefit of freed time and effort, the end-of-day consultation when the whole team comes together to talk about me as a whole and complete person, instead of a series of interesting little snippets, provides for a much better plan of attack. A completely holistic and complete picture of me as a person with ALS, instead of a case file of how ALS is affecting Patient X with regards to diet/respiratory/insert-your-favorite-discipline-here. It is so much better for the patient when doctors talk to each other - who knew?

ALS affects each person differently, and we collectively know so little about it that research on one's own is almost pointless. It's only through the collective care and knowledge of the team at Providence that I've been able to get a grasp on my disease at all. Every question I ask is answered, every minor complaint met with compassion and understanding, and above it all, the concern I'm given is genuine. I've never had such a beautiful working relationship with medical professionals before. The care and compassion of this clinic's providers are one of the greatest tools a person with ALS could ever hope to have; a wonderful consolation prize.

If ALS is a Pandora's box of symptoms and troubles, then the ALS clinic is the remaining hope. I'm wholly grateful for this resource. I literally could not do this without it. ■

Available on our Web site at 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.

Events:

- **Providence ALS Center** is a proud sponsor of the ALS Association Oregon and Southwest Washington Chapter. Join us at local events this Summer and Fall.
- **Ride to Defeat ALS.** Saturday, July 14th 2018. Mt. Angel, OR. For ages 11+. Ride options include 3mi, 25mi, 50mi, Metric Century (62mi), and 75mi routes. \$35 registration fee and \$150 fundraising minimum.
- **Walk to Defeat ALS.** 6 dates and locations in Oregon and Southwest Washington throughout September. Walk with Providence ALS Center in Portland on Sunday, September 23rd 2018. 3mi route starting at the World Trade Center plaza.



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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For the latest in neuroscience news and education, visit brainacademy.providence.org