Parkinson's diagnosis inspires competitive rower

Portland athlete sets sights on 2020 Paralympic Games in Tokyo

At 43 years of age and an accomplished rower who has coached the sport professionally for more than a decade, Todd Vogt relished spending his summer mornings gliding across the water. The last place he expected to be in the summer of 2018 was sitting in an exam room at Oregon Health & Science University. Yet he had an inkling since the spring that something wasn’t right: the weakness in his left arm, a small but persistent tremor, the inexplicable fatigue.

The diagnosis from OHSU neurologist Ron Pfeiffer, M.D., hit him like a splash of cold water: early-onset Parkinson’s disease.

“When I got Parkinson’s, it opened up a whole new world because it allowed me to compete in this whole new realm,” he said.

Competitive exercise also may help manage his condition. Parkinson’s affects about 1.5 million people in the United States alone, with symptoms including tremor, muscle stiffness, slow movement, and coordination and balance problems. Scientists have yet to pinpoint a cause, and therefore treatment and prevention of the disease has remained elusive.

However, a growing body of research suggests that exercise improves clinical outcomes for people with Parkinson’s.

Vogt recently became involved with the Brian Grant Foundation, started by the former Portland Trail Blazer who was diagnosed with Parkinson’s at age 36. The organization emphasizes exercise, nutrition and a supportive network to manage symptoms and maintain overall health.

Vogt, who continues to coach rowing at Station L Rowing Club in Portland, said he definitely feels better after a hard exercise. Even though he says he sometimes feels like a car stuck in third gear, he’s committed to pushing himself on the water to keep his symptoms stable.

“I used to pride myself on my ability to push myself really hard,” he said. “I can still do it, but not quite to my old level.”

Pfeiffer, a professor of neurology in the OHSU School of Medicine, said Vogt is an outlier among his patients, both in terms of his age and in his Olympic aspirations. (Only about 10% of Parkinson’s patients are diagnosed with early onset, usually defined as younger than 40.)

“If he can inspire other patients, both young and old, to do more – that they can do things that they may not have expected to do – then he serves as an inspiration,” Pfeiffer said.
Pain in Parkinson’s disease

Jennifer Nichols, M.D. — Specialist at Northwestern Medical Center Central Dupage, IL
OHSU Movement Disorders Fellow, 2017–2019

Pain is a common symptom in Parkinson’s disease. It is thought that up to 85 percent (in some studies) of Parkinson’s patients have pain, but unfortunately up to 50 percent of these patients go untreated as it is generally underreported. Pain can even predate motor symptoms (stiffness, rigidity and tremor) in up to 40 percent of patients. Recognizing and treating pain is important as it can lead to disability and diminished quality of life.

Pain processing is overall very complex and involves systems that carry information from the periphery (skin) to the brain, central processing systems in the brain, and systems that modulate the effects of both of these other systems. In Parkinson’s disease, all aspects of pain processing can be abnormal. Even in patients who do not report subjective pain, studies have found abnormalities including lower pain threshold and lower pain tolerance. On neuroimaging of the brain, irregularities in the central processing systems have also been captured. When patients report they do experience pain, all these abnormalities are even more prominent.

The most common locations of pain include the shoulders, limbs, trunk and sometimes neck. About 5 percent of patients have uncommon pain syndromes involving the head, face, throat, skin.

About 25 percent of patients report that they have more than one type of pain. Risk factors include difficult-to-control motor symptoms, advanced disease, prominent stiffness/rigidity and female gender.

Pain is responsive to Sinemet and/or pain is significantly related to advanced disease, prominent stiffness/rigidity and female gender.

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The most common locations of pain include the shoulders, limbs, trunk and sometimes neck. About 5 percent of patients have uncommon pain syndromes involving the head, face, throat, abdomen/stomach, pelvis, rectum and genitalia. Pain is more likely on the side of the body more affected by motor symptoms. To help characterize and treat pain, neurologists try and separate pain complaints into different categories. These include muscle/bone pain (aching, cramping, pressure, stabbing, sharp), dystonia-related pain (forceful muscle contractions resulting in sustained abnormal postures) and neuropathic pain (burning, tingling and other uncomfortable sensations such as feeling water or insects on the skin).

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Non-Motor Symptoms

Pain is often an underreported symptom of Parkinson’s disease, which can be effectively treated with a combination approach of medications, possible other procedures and exercise/rehabilitation. If you have Parkinson’s disease and are experiencing pain, you should bring this up with your neurologist as there are tools and treatments to help you feel better.

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Please visit our video library for presentations by Dr. Nichols and physical therapist, Jennifer Wilhelm, DPT, for more information on treating pain in Parkinson’s disease at https://tinyurl.com/pco-videos
Welcome our newest team members:

**Lee Neilson, M.D. — Fellow**

Lee Neilson originally comes from Minneapolis, Minnesota. He attended Emory University where he obtained a B.S. in Neuroscience and Behavioral Biology. He then attended Case Western Reserve University for his medical degree. He stayed at University Hospitals/Case Western for his neurology residency and was unanimously selected as chief resident, in which he served with distinction. He concurrently completed a certificate in medical education from the CWRU Weatherhead School of Management. He is currently a movement disorders fellow at OHSU and the Portland VA Medical Center where he is continuing to further his interest in medical education and in novel biomarkers for Parkinson’s disease progression.

**Marion Dale, M.D. — New faculty**

Dr. Dale grew up in South Carolina and attended medical school at the Medical University of South Carolina. After a neurology residency at the University of Maryland, she completed a movement disorders fellowship at OHSU and the Portland VA Medical Center. She is pleased to rejoin the OHSU Parkinson Center and Movement Disorders team. Dr. Dale has a particular interest in atypical parkinsonism and progressive supranuclear palsy (PSP). Her research seeks to understand the causes of balance dysfunction in PSP and to use noninvasive neuromodulation techniques for symptom control in movement disorders.

**Lauren Talman, M.D. — New faculty**

Dr. Talman grew up in Iowa City, IA where she attended the University of Iowa for medical school. She later completed her Neurology residency at the University of Virginia followed by a Movement Disorders fellowship at Boston University Medical Center. She joined the Neurology faculty at OHSU in September. Though she follows patients with a variety of movement disorders, she has a special interest in Huntington’s disease. She plans to create a dedicated Huntington’s clinic at OHSU with the goal of providing multi-disciplinary care to this patient population.

Research in Parkinson’s disease has also been productive at OHSU. One highlight is the work of Vivek Unni, M.D., Ph.D., demonstrating that the chief component of the Lewy body — alpha-synuclein — may play a role in DNA repair. In July 2019, Dr. Unni published a paper suggesting that the deposition of damaged alpha-synuclein as “Lewy bodies” in brain cells in Parkinson’s disease may kill the cells by pulling “good” alpha-synuclein away from the DNA, causing the brain cells to die because of DNA damage. This is already a highly cited paper for Parkinson’s-specific education. This tele-education program is currently recruiting primary care team participants in rural areas and will be held in the first quarter of next year.

The clinical, research and education missions are all thriving and evolving at OHSU as we approach the end of 2019. Thanks again to our many supporters who receive this newsletter, and best wishes for the New Year.

The OHSU Parkinson Center is a national leader in Parkinson’s disease (PD) research, and is involved in many studies that are fully recruited and others that are being planned. For more information, contact Susan Bonner at 503-418-4387 or at bonnesu@ohsu.edu

We have hired two new neurologists. Lauren Talman, M.D., completed a movement disorders fellowship in Boston in July 2019 and joined our faculty in September. Dr. Talman provides comprehensive care for movement disorders patients and has a special interest in Huntington’s disease. Marion Dale, M.D., who completed her movement disorders fellowship at OHSU a few years ago, returned to OHSU in September to resume clinical practice here while developing a research program for a Parkinson-plus syndrome called progressive supranuclear palsy. The next most recent member of our clinical faculty, Delaram Safarpour, M.D., was named one of “Portland’s Best Doctors” in 2019 by Portland Monthly, and she has assumed some new leadership responsibilities in the Deep Brain Stimulation program while also launching a study of gastrointestinal function and motor fluctuations in Parkinson’s. The Parkinson Center now has eight active faculty neurologists and three postdoctoral fellow neurologists as well as three emeritus neurologist faculty helping to train the fellows. The center has maintained its “Center of Excellence” status, contributing to the recognition of OHSU as one of the top 50 neurology/neurosurgery programs in the U.S., according to U.S. News & World Report.

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Thinking, memory, and cognition

Have you been diagnosed with Alzheimer’s disease, mild cognitive impairment, another type of dementia, OR are healthy and would like to participate in research?

Purpose: The purpose of this study is to see if genes and biomarkers in the blood and cerebrospinal fluid (CSF) can help detect Alzheimer’s disease (AD) at an earlier stage. Researchers would like to learn more about specific types of genes and biomarkers in blood and CSF to help understand the biology of AD. If a gene or genes that cause AD can be found, the diagnosis and treatment of AD may be improved.

Participation Requirements: In order to participate in the study you must be a healthy control (no neurological diagnosis), or have a diagnosis of AD, Parkinson’s disease, frontotemporal dementia, or dementia with Lewy Bodies. You must be age 55–80 years old, have a study partner who will attend study visits with you, be in general good health, not be taking warfarin or other blood thinners, and have no lower back problems or surgeries. This study involves collection of blood from a vein, and a lumbar puncture (spinal tap) for collection of CSF. All visits will be in-person. There are two study visits over approximately 1 month. Eligible participants will receive study-related evaluations at no cost. Participants will be compensated for their time and transportation for the lumbar puncture visit. For more information please contact Jean Allen at allenjea@ohsu.edu eIRB #18119

Pacific Northwest UDALL Center (PUNAU): clinical core and sample collection

Dr. Joseph Quinn is conducting this research study to examine the changes in thinking and memory of Parkinson’s disease patients over the course of the disease to determine the role genetics plays in cognitive impairment in Parkinson’s disease. You must have a diagnosis of Parkinson’s disease to participate in this study or be willing to participate as a healthy control.

This is a long-term study, your participation would last 5 years or more. The study involves collecting blood, urine, and a lumbar puncture (spinal tap) at each visit. In between visits at the VAPORHCS you will have a telephone interview with your study doctor at no cost. You will undergo tests of thinking and memory, have a neurological exam, fill out questionnaires, and have a blood draw of about four tablespoons. Each visit will last for about three to four hours. For the first visit, you have the option to undergo a lumbar puncture. A lumbar puncture is a procedure in which a special needle is inserted into your lower back to remove cerebrospinal fluid (CSF) for testing. You may not benefit from participating in this study. You may not personally benefit from participating in this study.

In order to participate in the study you must have been diagnosed with mild cognitive impairment or Parkinson’s disease dementia. Participants will be randomized (like the flip of a coin) to receive either the study drug or placebo via an intravenous (IV) infusion through a vein in your arm. Further details will be provided at the screening visit. All eligible participants will receive study-related evaluations, laboratory tests, and the study drug at no cost. Participants will be compensated for their time and transportation. For more information please contact Brenna Lobb, Research Coordinator, at 503-220-8262 extension 58171 or by mail at 3710 SW US Veterans Rd, P3-PADRECC, Portland, Oregon 97239.

Dyskinesia ( involuntary movements)

STAT-PD: Preventing Levodopa induced dyskinesia in Parkinson’s disease with HMG-Coa reductase inhibitors (OHSU eIRB #17302; MIRB #3849)

Dr. Kathryn Chung is conducting a research study looking at movements in Parkinson’s disease (PD). Almost all PD patients will develop involuntary movements overtime with treatment of levodopa. This study involves two visits. The first visit, a screening visit, will happen at the VA Portland Health Care System and last about one hour. During this visit you will complete some screening questionnaires, answer some questions about your Parkinson’s disease and have a physical examination. The second visit will happen at Oregon Health & Science University and will last 2 to 9 hours depending on your levodopa cycle. You will arrive in the morning at 08:00 am and in an “OFF” state. You will eat breakfast. You will undergo various measures of your Parkinsonism, movement, cognition, and quality of life questions. For more information please contact Brenna Lobb, Research Coordinator, at 503-220-8262 extension 58171 or by mail at 3710 SW US Veterans Rd, P3-PADRECC, Portland, Oregon 97239.

Blood Pressure in PD

Clinical characteristics of Parkinson’s disease subjects with severe hypertension during motor offs

Dr. Kathryn Chung is conducting a research study looking at blood pressure changes in Parkinson’s disease (PD). This study involves two visits with one at-home monitoring period of a couple of days in-between the visits. The first visit, a screening visit, will happen at the VA Portland Health Care System and last about one hour. During this visit, you will complete some questionnaires, answer some questions about your Parkinson’s disease and have a physical examination. You may not personally benefit from participating in this study. However, by service as a subject, you may help us learn how to benefit patients in the future. For more information on how to participate, please contact Brenna Lobb, Research Coordinator, at 503-220-8262 extension 58171 or by mail at 3710 SW US Veterans Rd, P3-PADRECC, Portland, Oregon 97239.
For those taking Carbidopa/Levodopa
Have you been diagnosed with Parkinson’s disease and currently take carbidopa/levodopa?

Purpose: The purpose of the study is to learn if a person’s response to levodopa is affected by problems with the digestive system. We are hoping to find out if a delayed or lack of response to some or all daily doses of levodopa can be due to changes in how long it takes the medication to move through the digestive system.

Participation Requirements: In order to participate in the study you must have been diagnosed with PD, be age 50–89, currently take carbidopa/levodopa (Sinemet), and be able to swallow a large capsule similar to the size of a fish oil capsule. You must not have had prior gut surgery, bowel disease, implanted medical devices (such as cardiac device, gastric stimulator, insulin pump, or deep brain stimulator (DBS)), or have a diagnosis of diabetes. You must be able to refrain from using medications like aspirin, ibuprofen (Advil, or naproxen (Aleve) for one week.

Participation Details: Study participation lasts about two weeks and involves four visits to OHSU. During the study, participants will be asked to swallow one SmartPill, under the supervision of the study investigator. The SmartPill is an FDA-approved single-use capsule that travels through the GI tract and wirelessly transmits data about your GI tract to a receiver worn on a belt clip. You need to keep the receiver within three feet of your body for five days following ingestion of the SmartPill. You will be asked to return the receiver after seven days. The SmartPill will be passed naturally by your body, and you will not be asked to return the pill. Eligible participants will receive study-related evaluations at no cost. For more information please contact Jean Allen at jeana@ohsu.edu or 503-494-7235. eIRB #20012

For those who receive care at the OHSU Parkinson Center Clinic
The Parkinson Foundation has launched a Patient Registry at all NPF centers of excellence, which includes OHSU. The purpose of the Registry is to collect data on individuals with Parkinson’s disease (PD) to better understand the illness and the effects of various treatments. The ultimate goal is to improve the care of people who have PD. This study was started in 2009 and has been reopened for recruitment. Data will be gathered once a year at a follow-up visit in our clinic, and will consist of a 10–15 minute consultation and a questionnaire. For more information please contact the study’s coordinator Audrey Anderson at 503-947-7245 or anderaud@ohsu.edu for more information. (OHSU eIRB #5508)

Other conditions: Huntington’s disease
Measuring Cortisol Levels in Persons with Parkinson’s (PD) [CORT-PD] (OHSU eIRB #15183)
Dr. Amie Hilger is conducting a research study looking at cortisol levels in Parkinson’s disease (PD), Huntington’s disease (HD), and in healthy controls. Cortisol is a hormone that is normally released in response to events and circumstances such as waking up in the morning, exercising, and stress. We are recruiting Parkinson’s disease patients, Huntington’s disease patients, and healthy controls. To be a healthy control, you must not have a neurological disorder. Both groups must be willing to give saliva samples. This study will last for approximately 1 week. There are two option paths for participation. Option 1 has three (3) days of saliva collection at home and one visit to the Portland VA (VA Portland Health Care System). Option 2 has two visits to the Portland VA. Visit one will last approximately 30 minutes and include questionnaires of mood and quality of life. For PD and HD participants, a disease specific exam will be performed. You will collect your saliva, complete some diaries, and wear some sensors for three days at home. You will return to the Portland VA for a visit that lasts about five minutes to return the sensors, diaries, and saliva. The visit will last approximately 30 minutes and include questionnaires of mood and quality of life. You will be compensated $25.00 for participation in this study. We will reimburse car-alternative travel expenses up to $50.00 round trip. This is a research study and not for treatment or diagnosis of PD or HD. You may not benefit from participating in this study. However, by serving as a subject, you may help us learn how to benefit patients in the future. For more information on how to participate, please contact Brenna Lobb, Research Coordinator, at 503-220-8262 extension 51871 or by mail at 3710 SW US Veterans Road, P3-PADRECC, Portland, Oregon 97239.

For those without Parkinson’s disease (healthy controls)
Have you been diagnosed with Alzheimer’s disease, mild cognitive impairment, another type of dementia, OR are healthy and would like to participate in research?

Purpose: The purpose of this study is to see if genes and biomarkers in the blood and cerebrospinal fluid (CSF) can help detect Alzheimer’s disease (AD) at an earlier stage. Researchers would like to learn more about specific types of genes and biomarkers in blood and CSF to help understand the biology of AD. If a gene or genes that cause AD can be found, the diagnosis and treatment of AD may be improved.

Participation Requirements: In order to participate in the study you must be a healthy control (no neurological diagnosis), or have a diagnosis of AD, Parkinson’s disease, fronto-temporal dementia, or dementia with Lewy Bodies. You must be age 55–80 years old, have a study partner who will attend study visits with you, be in general good health, not be taking warfarin or other blood thinners, and have no lower back problems and/or surgeries. This study involves collection of blood from a vein in your arm, and collection of CSF through a lumbar puncture (spinal tap). There are two study visits over approximately 1 month. Eligible participants will receive study-related evaluations at no cost. Participants will be compensated for their time and transportation for the lumbar puncture visit. For more information please contact Jean Allen at allenjea@ohsu.edu eIRB # 81193

Handling the holidays with Lewy body dementia
Melissa J. Armstrong, M.D., MSc., LBDA Research Center of Excellence, University of Florida (Gainesville) Fixel Center for Neurological Disorders at UF Health

The holidays can be joyful and stressful especially if you deal with Parkinson’s disease or a parkinsonian plus syndrome. Couple the confusion of dementia, and the individual and their caregiver can be overcome. In fact, Dr. Armstrong’s recommendations can be helpful for us all.

1. Celebrate in familiar places. It is easy for people with dementia to become confused in new places. It is often best to have family visit the person with LBD. Keeping a familiar home environment makes gatherings easier.

If you need to travel, try to pick a familiar destination. Limit the number of new situations (e.g. airports). Make use of opportunities for travelers with illnesses, such as wheelchairs and pre-boarding. Tiny airport bathrooms are hard for people with Parkinson’s-like movement problems. Use bathrooms in advance, use family bathrooms when feasible, and consider disposable undergarments as a safety measure. Request assistance from airport staff if you need to use the bathroom and the person with LBD is not able to join you in the bathroom; this will minimize the likelihood of the person walking away and getting lost. Make sure medications are in a carry-on bag.

If you’re hosting, consider whether family should stay with you. It can be helpful for visitors to stay at a nearby hotel or rental. This allows the person with LBD to have a place to retreat from visiting crowds. Visiting family should pick in so that caregivers aren’t overburdened.

2. Prepare visiting family members. If family members haven’t seen the person with LBD recently, let them know the changes that have occurred. Make sure visitors have realistic expectations. Even with advance discussions, family can be surprised or upset about changes since their last visit. Be honest with family members about the difficult emotions they may experience when they see the person with LBD and what has changed.

3. Keep a schedule. Having a daily routine is important for people with LBD. Keeping to this schedule even during the holidays can be helpful. Often mornings are the best time of day for people with LBD. Plan family activities for those best times. Make sure the person with LBD gets breaks during the day for naps or time alone. Plan activities for other family members during these times. Avoid evening celebrations.

4. Involve the person with dementia. Plan activities that the person with LBD can do. People with dementia often connect with music — have a family sing-along. Decorating cookies is an easy activity to do seated. Have grandchildren play musical instruments or read a favorite Christmas book aloud. Look at old photographs. Ask the person with LBD to share a favorite holiday memory.

5. Expect a post-gathering letdown. People with LBD can sometimes rally themselves for big events or family gatherings. Afterwards, though, they may be more fatigued or more confused than usual.

The holidays are a great time to make special memories. Thoughtful planning can help make family celebrations a success.

Dr. Armstrong’s article is shared with her permission and that of the Lewy Body Dementia Association.

It’s the most wonderful time of the year… But it may take some extra planning and new ways of celebrating, if you live with someone with memory and thinking problems (dementia). Traveling, large family gatherings, and long days of celebration can be particularly challenging for people with Lewy body dementia (LBD). Here are some ideas for making the holidays easier.

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Annual Options & Opportunities Symposium reaches 35 years and counting!

More than 350 people with PD and their family caregivers participated in a full day of presentations, resources and meeting new friends at our 35th annual symposium this fall. Tackling the tough challenges of advancing PD was the focus of the day, with presentations on a team approach to motor fluctuations, dyskinesia, and learning more about psychosis in PD. Kimberly Berg, owner of Rebel Fit Club and Rock Steady boxing trainer, energized the crowd with a drumming break. Twelve members of her Rose City Rebels Dance group also entertained the group, impressing all with their performance. If you weren’t able to attend, visit our video library at the end of the year to view the presentations online at www.ohsubrain.com/pco.

We would like to thank Boston Scientific and Amneal for their generous sponsorship of our patient programs.

Upcoming OHSU events

January–June 2020

Newly Diagnosed PD Education Session — Monthly
Each month the OHSU Parkinson Center offers a three-hour session for people recently diagnosed with PD and their spouses or family members. Participants may ask any and all questions of a PD specialist and long-time patient and caregiver, $20/person; refreshments served.

Dates: Jan. 9, Feb. 13, Apr. 9, May 14, Jun. 11.
Registration online at http://tinyurl.com/NewParkinson or call 503-494-9054 with questions.

Essential Tools for Mid-Stage PD Series 2020
Key issues encountered by people with PD and their loved ones during the middle stages of the disease will be presented throughout the year. In a two-hour program, topics will be presented by experts with time for audience interaction. Upcoming dates: More information and registration will be available in late December.

Dates: Jan 23, Mar. 5.
For registration and details: https://tinyurl.com/eetools2020.

CarePartner Connections
Saturday, May 16, 2020 — Lake Oswego, Ore.
The annual OHSU Parkinson Center Caregiver event where caregivers will have the opportunity to come together, gather new information, and enjoy the support of one another. It is also an opportunity for us to celebrate family caregivers with special acknowledgement of their sacrifices for their loved ones. At 2020 Caregiver Connections, we will join the Parkinson’s Foundation Caregiver Summit live for world renowned speaker presentations for the first time—uniting caregivers nationwide. Registration will open in February 2020.

In the Parkinson’s community

Parkinson’s Resources of Oregon (PRO)
Serving the PD community through education, support and advocacy. PRO has numerous ongoing educational events. Call 800-426-6806 or visit their website at www.parkinsonsresources.org for more information.

Educate.Inspire.Empower.
Saturday, May 9, 2020
Salem Convention Center, Salem, OR
Parkinson’s Resources’ annual Parkinson’s disease education conference features leaders in the field of treatment and care as key presenters discussing a variety of topics of interest to people with PD, care partners and professionals.

Celebrate Hope
Friday, April 24, 2020 – Portland, OR
PRO’s annual Celebrate Hope gala and auction will commemorate 40 years of specialized support and services in the Parkinson’s community. Friends and supporters invited to join the festive evening. Details at progala.org.

Brian Grant Foundation (BGF)
Helping people with PD live active, fulfilling lives through wellness and community. BGF has produced a PD exercise video you can follow in your own home featuring our own OHSU physical therapist, Jenny Wilhelm.

Check it out at www.briangrant.org.

Shake It Till We Make It Gala
Friday, May 15, Portland Art Museum
Join the Brian Grant Foundation in commemorating 10 years of helping people with PD live active, fulfilling lives through wellness and community.

For more information about the gala and upcoming 2020 events, visit briangrant.org.

PADRECC
The Veteran Administration Parkinson’s Disease Research, Education and Clinical Center (PADRECC) Serving our veterans with PD though research, education and care. Visit parkinsons.va.gov/northwest for more information on upcoming events and to watch the My Parkinson’s Story Videos online. This series of videos features real veterans telling their Parkinson’s stories with commentary provided by VA medical providers.

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