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NORTHWEST  
PARKINSON'S  
FOUNDATION

## Couple finds new support, community

BY ALECHA NEWBERN

Patricia and Jim Hoyt have been married for 58 years. They have four children and four grandchildren. Jim boasts that they were high school buddies. Pat smiles coyly at Jim when he tells people about their long life together.

In addition to raising their family, Pat and Jim were world travelers. Pat's favorite location is Rome and Jim's is New Zealand.

Their life experiences have built an unbreakable bond between them. When Pat was diagnosed with Parkinson's in 2000, she and Jim rose to the occasion.

In the early years of the disease they continued their overseas travels and otherwise stayed fully engaged in an active lifestyle. But as the disease progressed they were unable to continue at the same pace. Pat's stability and mobility became more challenged.

She took a number of falls and ultimately found herself relying on a wheelchair to keep her safe and still allow her to get around.

Jim continued to be the primary caregiver for Pat. But as her symptoms



Photo by Stewart Hopkins

**Jim and Patricia Hoyt**

progressed, Jim felt he was no longer able to provide all the support Pat needed, and trying to do so was taking a toll on him.

They decided it was time to find a new home—in an assisted-living community. They wanted to be close to their family and, through a referral from a friend, found the perfect place.

In February 2010, Pat and Jim moved into the Ballard Landmark, a Gencare Lifestyle community situated in a popular Seattle neighborhood.

This move would prove life-altering.

Pat is a lively and determined woman. Shortly after she and Jim settled into their new home, Pat asked her health services

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Our mission is to establish **optimal quality of life** for the Northwest Parkinson's community through **awareness, education, advocacy** and **care**.

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## Hop on the train and don't look back

BY JOHN FASULO

I AM 61 YEARS OLD and was diagnosed with Parkinson's when I was 55. For 23 years, I was a television cameraman in New York City working for CBS, NBC, WOR and CNN. A few months after starting work for CNN, I realized that a change was happening within me. My coordination was off and it took longer me to do things. I became forgetful and my wife noticed that I shuffled my feet when I walked.

I went to a neurologist, who diagnosed Parkinson's. A specialist confirmed the diagnosis. I was put on three Parkinson's drugs that I continue to take daily.

I left the broadcasting business on disability and found myself "retired" at 55. This left me with time to do a lot of the things most people can only do in earnest after age 65. My passion for years had been photography. Now I had the time to spend on projects that for many years were on the back burner.

I am also the father of a 9-year-old, Maya, and have taken on more responsibility for her upbringing now that I'm home.

When I was diagnosed, I was told I would probably go through periods of depression. I'm still waiting. Maybe it's because I'm too busy with my photo projects to be depressed.

As a member of the Center for Railroad Photography and Art, I travel to a conference each year in Lake Forest, Illinois, taking the train from New York to Chicago. My work has been shown at the Steamtown Gallery and as far away as the railway-focused DB Museum in Nuremberg.

In addition, my photography has been featured in numerous railroad publications around the world. This spring, the DB Museum will exhibit a show of my photographs taken in Hof, West Germany, in 1974. These images highlight the Hof Roundhouse and the last division of German railways to still be all steam.

I mentioned keeping busy. I'm usually up at 4 a.m. working on photographs either on the computer or in the darkroom, where I develop my film and, using a Besseler enlarger, print the "old-fashioned way" in photo chemistry.

Depressed? Who has time?

What does all of this have to do with anything? I hope it will help someone else who has Parkinson's and may be feeling down to realize it's not the end of the road. If I've learned one thing, it's to keep busy. Photography is an excellent way to work on your dexterity.



Manual film cameras are best, forcing you to use your hands and your mind. Developing film, which has to be put on a metal reel in the dark, is also a good dexterity exercise.

The key is to keep active and you won't have time to get depressed. Did I mention a 9-year-old daughter? Maya and my wife Cecile play a big part in my life. I plan to be around in eight years when Maya graduates from high school, and to stick around after that to see her graduate from college. If she decides to marry someday, I'd like to be able to walk her down the aisle.

A few final thoughts: Look at life through your own eyes or the lens of a camera or other artistic outlet. One more thing: Don't look back. Yesterday is gone.

The hobo in the film "Polar Express" may have put it best when he said, "Kid, it doesn't matter much where the train is going. What matters is making the decision to hop on board."

*John Fasulo lives in Beacon, New York.*

# Estate planning lets you avoid guardianship

BY DEBORAH L. COCHELIN

**Scenario No. 1.** *A longtime neighborhood resident is diagnosed with Parkinson's disease. He lives alone. He has no one to check on him regularly. Recently, he experienced some bad side effects from medications. They included lightheadedness, cognitive problems, hallucinations and impulsivity control. These conditions mask Parkinson's disease, leading an uninformed bystander to assume that he might lack capacity.*

*Wrongly judging him to be incapacitated, concerned neighbors call Adult Protective Services to report his circumstances. Based on a case manager's assessment, the Attorney General's Office files a petition for guardianship. A guardian ad litem is appointed to represent his best interests. After conducting an investigation, the guardian ad litem files a report with the court recommending the nature and extent of the guardianship and who should be the guardian. A medical examination is required. If he contests the guardianship, he can select his own attorney or have one appointed for him from the court's registry of guardianship attorneys. The attorney's and guardian ad litem's fees are paid from his assets. If he cannot afford an attorney, the court will appoint one for him at county expense. If the matter is not resolved at the guardianship hearing, a trial date is set.*

**Scenario No. 2.** *The spouse managing the family finances is diagnosed with Parkinson's disease. The afflicted family member can no longer write checks or keep track of due dates and mismanages their finances. Refusing to acknowledge Parkinson's disease in a timely manner, it is too late for estate planning. Using the same process as Scenario No. 1, an expensive guardianship is started to preserve the couple's lifelong, and now endangered, assets.*

UNFORTUNATELY, THESE SCENARIOS can happen to people as Parkinson's progresses. The lost ability to speak intelligibly, coupled with diminished ability to write legibly, can lead to communication breakdowns, affecting estate planning.

The good news is that Washington courts favor less restrictive alternatives to guardianships. This provides you with the opportunity to plan to avoid having a court-supervised guardianship imposed upon you. Durable powers of attorney for health care and financial decisions are alternatives to guardianships providing a roadmap with your instructions for someone who can be trusted to take over your personal and financial affairs. Having a power of attorney is far less expensive and private than a guardianship.

A durable power of attorney for healthcare decisions is a document expressly authorizing one or more family members, friends or a professional fiduciary as your agent (attorney-in-fact) to make healthcare and other personal decisions on your behalf if you become unable to do so.

This document allows you to maintain autonomy and privacy by handpicking a trusted friend or family member to act as your informed medical decision maker. A healthcare power of attorney avoids guardianship proceedings if emergency medical treatment is necessary when you have no family member to give consent by designating a single decision maker for you in an emergency situation.

The durable power of attorney for your finances operates in much the same way with many of the same advantages. The distinction is that you are appointing someone to handle all of your financial affairs. Your healthcare attorney-in-fact and your financial power of attorney-in-fact can be the same person.

A healthcare directive, or living will, insures your wishes are carried out so that you can be in charge of your life support decisions before you lose capacity. The Washington Natural Death Act permits you to direct whether life-sustaining treatment should be withdrawn or withheld in the event you are in a terminal condition or permanent unconscious condition. This document can be revoked, regardless of your mental state or competency.

Even if you do not have a living will, healthcare providers are allowed by law to comply with your immediate family's agreement that life-sustaining treatment may be withheld without the appointment of a guardian.

Loss of independence is a significant concern associated with Parkinson's disease. Planning gives you peace of mind. Play it safe and avoid the invasive, costly guardianship process by obtaining these key estate-planning documents. You'll avoid placing your family in a dilemma by making these significant healthcare and financial decisions in advance.

*Deborah L. Cochelin is the principal of Law Office of Deborah*



*L. Cochelin, PLLC, in Seattle. The purpose of this article is to provide information rather than professional advice or legal opinions. Examples are for illustrative purposes only. The author disclaims and shall not be held liable for any losses caused by reliance on the accuracy, reliability or timeliness of such information. No attorney-client privilege has been formed by the reading of this article.*

BY COLLEEN CROWLEY, J.D., CFRE



THE NORTHWEST PARKINSON'S Foundation is moving into its next stage of growth and development. In September we convened a committee to conduct a strategic planning process, and this resulted in a three-year strategic plan that our board

refined in February. The finished product focuses on three strategic areas: organizational, programmatic and operational.

Organizationally, the board reflected on our mission, reaffirming the importance of providing information, education and care to people with Parkinson's. Underlying the significance of providing these services was a desire to expand our reach and connect with many more people throughout Washington, Idaho, Montana, Alaska and Oregon. One way to accomplish this goal will be to broaden our partnerships with other organizations in the region.

Implementation of the plan will begin in earnest over the next few months, as new committees are convened to advise and direct the action steps to be taken. Programmatically, the first year of the plan emphasizes analysis, evaluation, enhancement and coordination of programs and services currently in place. Benchmarks have been identified to evaluate progress, measure success and allocate resources to accomplish results.

Each of you reading this newsletter can help us reach our goals. Tell just one new person about the *Parkinson's Post* and you have helped expand our reach.

We appreciate your participation in furthering the mission of the Northwest Parkinson's Foundation and look forward to keeping you informed of our progress.

## Brother is inspiration for board member

THE NORTHWEST PARKINSON'S Foundation is pleased to welcome **Larry Jacobson**, pictured at right, to its board of directors. Larry has been a member of Team Parkinson's since 2006, when he started riding in the Seattle-to-Portland Bicycle Classic to pay tribute to his brother Michael, left, who was diagnosed with early-onset Parkinson's more than 10 years

ago. Larry is passionate about the opportunity to create and support a strong community network for people with Parkinson's and their families. Joining the board provides Larry a venue for encouraging and educating others about Northwest Parkinson's Foundation programs and services that improve the quality of life for people with Parkinson's. Larry brings a wealth of knowledge and experience from his long career in business that will assist the foundation in its growth.



## Personal connection fuels work

THE NORTHWEST PARKINSON'S Foundation welcomes to its staff **Ruth Egger, M.S.** Ruth joined the organization in February as social services manager. She brings a wide range of experience and knowledge to the position, having worked in the fields of gerontology, exercise and fitness, and social services. In addition to her professional expertise, Ruth has a personal connection to the work—family members with Parkinson's—which has given her a

deep understanding of the challenges of the disease. She looks forward to expanding outreach of the valuable services and programs of the Northwest Parkinson's Foundation. Ruth says the first thing she plans to do is commit herself to a regular exercise routine so she can ride in the Seattle-to-Portland Bicycle Classic with Team Parkinson's... one of these years! Ruth can be reached at [ruth@nwpf.org](mailto:ruth@nwpf.org) or 1.877.980.7500.



## Technology surmounts geographic barriers in Parkinson's patient care

BY LAUREN SEEBERGER, M.D.

THERE ARE FEWER NEUROLOGISTS per capita in the western U.S. than in any other part of the country. The national low is Wyoming, with 1.78 neurologists per 100,000 people. Compare that to Washington, D.C., which has 11 neurologists per 100,000 people.

Correspondingly, there are fewer subspecialists—movement disorders experts—available to treat people with Parkinson's disease.

The majority of people with Parkinson's are treated by their primary care physician. Specialty care improves standards of care and overall Parkinson's symptom management.

Most neurologists tend to be congregated in large cities and at medical centers. There are more than 3,000 counties in the United States, and most do not have a neurologist, let alone a Parkinson's specialist.

As Parkinson's progresses it can be harder and harder to travel to specialty centers, not to mention travel can be expensive if you live far away.

How can we reach out to underserved populations? There has been a great deal of interest among physicians in my field about the use of communications technology in working with people with Parkinson's disease. Parkinson's assessments lend themselves to video conferencing as the assessments are primarily visual.

The first reported use of a two-way link to examine patients with Parkinson's was in the early 1990s. At that time Internet connections were much slower and the resolution of

video images was not as good.

Still, a group of researchers found that, using interactive video conferencing, they could perform a motor rating scale and staging for Parkinson's that was comparable to being in the room with the patient.

In another study, researchers conducted 100 remote exams on 34 patients who were located at a distance from a specialty center. The researchers calculated a savings of \$37,000 in travel and lodging costs for those patients.

Another group of researchers reached out to a rural community using high-speed Internet access and high-clarity video to examine patients who would otherwise not have been able to access specialists. The specialty telemedicine care was compared to their usual care. The patients randomized to telemedicine care had a significant improvement in quality-of-life measures and motor performance. The motor exam administered remotely was deemed reliable and feasible for use in visits with Parkinson's patients.

Telecommunications have improved greatly and no longer pose a barrier to *telemedicine*—the exchange of medical information over a distance. Off-the-shelf computers are equipped with cameras, and high-speed broadband access allows for the rapid transmission of quality images, movement and audio.

The emergence of smart phones with video face-to-face “chat” interfaces further expands the capability of doing remote medicine as there is sometimes cellular service even where there is no Internet service.

Many companies are working on wearable devices that can measure tremor and movement while you do your everyday activities. These devices will someday be able to wirelessly upload information to your computer for access by your doctor in analyzing your motor function.

There are still some barriers to overcome with this type of health care, including reimbursement and coverage issues, regulatory concerns such as physician licensing, and patient privacy.

While technology will never take the place of personal contact with your doctor, it may allow access to specialists in a way that was not possible before.

*Dr. Seeberger is medical director at Idaho Elks Rehabilitation Hospital Movement Disorders Center in Boise.*

## Tapping telehealth?

SOME 70,000 PEOPLE in the five-state region of Washington, Alaska, Idaho, Montana and Oregon have Parkinson's disease. The majority of physicians and other health specialists who care for patients are concentrated in Seattle, Portland and Spokane, leaving people outside these urban centers with limited access to expert resources.

The Northwest Parkinson's Foundation is dedicated to increasing access to the most current and accurate information on treatment and care for patients and families. In partnership with Parkinson's Resource Center in Spokane, we offer a monthly Parkinson's “telehealth” program, a live and interactive broadcast of educational talks presented free of charge in 22 Northwest communities.

A relevant topic is presented by an expert the second Monday of each month, generally from a community hospital. To find a location near you, check our website at [nwpf.org](http://nwpf.org) or call us at 1.877.980.7500.



TRIBUTE GIFTS

**G**IFTS TO THE NORTHWEST Parkinson's Foundation support our educational publications and self-care tools, including this newsletter, weekly email news updates, a content-rich website, patient-education programs and our annual HOPE Conference on Parkinson's.

In addition to sustaining existing programs, your donations support our efforts to develop and implement innovative new programs that respond to the changing needs of the Parkinson's community.

We are privileged that so many in the Northwest Parkinson's Foundation family support our mission by giving generously throughout the year. In each issue we list tribute contributions made in honor or memory of loved ones touched by Parkinson's.

Those wishing to establish a permanent memorial may create a family fund with a minimum donation of \$2,500, either from a single gift or many. New family fund donors are listed below. To learn more, contact Joseph DiChiaro at 1.877.980.7500 or joseph@nwpf.org.

Listed here are tribute gifts received between **December 17, 2010, and February 10, 2011.**

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> CONTINUED FROM PAGE 1

caregiver, Marylyn, "Do you think I will ever walk again?"

Pat wanted to walk, and Marylyn wanted to help. Marylyn put together a walking plan as a first step.

She started Pat out working with a "gait belt"—a device used to help safely transfer people from position to position. They took it one step at a time.

In addition, Pat joined the facility's swimming pool exercise class. In the beginning Pat had to be wheeled to the pool seat lift and lowered into the water. She continued the pool exercises a couple of times a week and progressed.

Today, just eight months after asking that key question, Pat is able to get to the pool with a walker, walk down the pool steps, and navigate the length of the pool several times all on her own.

Pat says she was able to make this transformation through "sheer determination and tremendous support, encouragement and direction" from her water therapy instructor, Peter, and Ballard Landmark's personal trainer, Candace.

Pat and Marylyn now walk together hand in hand—as friends.

---

As Pat's symptoms progressed, Jim felt he was no longer able to provide all the support she needed. Trying to do so was taking a toll on him.

Like many independent and assisted-living residences, Jim and Pat's new home offers many benefits for people with Parkinson's—including opportunities to get to know others.

Jim and Pat are social people—in other words, they like to party! They benefit from the twice-weekly "get acquainted" parties at Landmark. These gatherings are a great opportunity for residents and their guests to enjoy mingling over wine and hors d'oeuvres.

Pat and Jim say they have found a new home that represents "everything we like." It is a community of people who are understanding, personable, gracious, innovative and knowledgeable.

So what's next for Pat? She says she wants to ski again and go sky-diving!

The staff is right there with her, helping her manage her Parkinson's and keep her dreams alive.

*Alecha Newbern is program director at the Northwest Parkinson's Foundation. You can reach her at 1.877.980.7500.*



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## REACHING OUT

### Just diagnosed... now what? Group geared to early-stage PD

DOUG MANUEL IS AN EARLY-STAGE PARKINSON'S PATIENT. He is passionate about managing the disease and not letting the disease manage him. He is determined to let others know that it is possible to manage this chronic illness.



Doug believes that hope for the future creates power in the present, and he wants to tap into that power.

Doug has teamed up with Sharon Jung, a nurse practitioner in Tacoma, Washington. Together, they have planned an informational group for early-stage Parkinson's patients. The group will focus on the particular challenges faced in the early stages of the disease and on how to meet those challenges and remain hopeful.

Sharon and Doug make an experienced team. Sharon has been a Parkinson's support group leader for 10 years. Doug started a support group in Gig Harbor two years ago.

They have consistently seen that patients who are motivated and educated about the disease are managing their disease optimally.

Additionally, patients who learn exercise routines and medication management early on are often able to delay or slow complications of the disease.

The first meeting of the group is scheduled for 6:30 p.m. on March 30 at Forza Coffee, 2209 North Pearl Street in Tacoma. The meeting is free to anyone interested in attending.

If you'd like to learn more about the group, please contact Sharon at [sjung58@gmail.com](mailto:sjung58@gmail.com).

THE NORTHWEST PARKINSON'S FOUNDATION website lists Parkinson's support groups throughout the five-state region. Go to [nwpf.org](http://nwpf.org) and click on the "Care & Support" tab to search for a group near you. Can't find support in your area? Call us toll-free at 1.877.980.7500 and we'll help.