Connie Goldman, award-winning public radio producer and author, will speak about her recently published book, The Gifts of Giving: Stories of Hardship, Hope, and Healing. Through personal interviews with 35 male and female caregivers, Ms. Goldman elicited people’s reflections on what they have learned and how being a caregiver has fundamentally changed them. These stories are a powerful testament to the resilience of the human spirit and of the ability of people to overcome incredible adversity. Additional presentations will be given by Julie Carter, ANP, PCO’s Associate Director, who will talk on “The Impact of Parkinson’s Disease on Family Care: A Review of Caregiver Research,” and Vicki Wolff, LCSW, PCO’s Family Care Specialist, who will share tips on “Making Care Transitions.” A small registration fee ($10 per person) will be charged. To register, contact Vicki at 503-418-1661.

Tai Chi: A Healthy Restorative Exercise Program

Tai Chi is an ancient exercise form developed by Taoist physicians/martial artists. Today, some physical therapists are teaching Tai Chi exercises to patients with movement disorders, such as Parkinson’s disease, to prevent falls, improve posture and balance, build strength and enhance relaxation. Tai Chi is a low-impact exercise and has shown to improve overall motor control in people. Classes on Tai Chi have also shown to lead to a decreased fear of falling, and improved self-confidence in movement. Tai Chi is a healthy, restorative exercise program patients can practice effectively at home. (Information gathered from OSU Outpatient Physical Therapy & West End Rehab — Bill Gallagher, M.S.P.T., owner)

Bill Gallagher will be offering a special Tai Chi workshop at OHSU; see events below.

More Than 200 People Attend PCO’s First Rural Symposium

Medford, OR — Reaching out to people with Parkinson’s disease who live in rural communities is a long-term goal of the Parkinson Center of Oregon (PCO). Armed with funding from the National Parkinson Foundation and education grants from private donors and drug companies, the PCO presented “Challenges & Champions: A Southern Oregon Summit on Parkinson’s Disease” on February 16, 2005 at the Rogue Valley Medical Center’s Smullin Health Education Center. Free to the public and healthcare providers alike, over 200 people attended from Eugene to Klamath Falls and every where in between; participants heard a variety of presentations by local and PCO experts. The presentations included “Parkinson’s Disease Management.” Those Symptoms You Didn’t Know Were PD,” “Facing Serious Illness,” and “Secrets to Taking Control of Your Healthcare Team,” as well as a question and answer period with all the presenters. The PCO will host our 2006 regional symposium in eastern Oregon.

Calendar of Events

April 6 - NEWBERG
PCO’s Family Care Specialist, Vicki Wolff, LCSW, will present “Coping with PD” to the Newberg Support Group at 10am.

April 14 - PORTLAND
Caregiver Conference: 5:30-9 p.m. at OHSU’s Vey Conference Center in Doernbecher Children’s Hospital (see above).

April 19 - GRESHAM
PCO’s Nurse Coordinator, Lisa Mann, RN, will present “Secrets to Taking Control of Your Healthcare Team” to the Gresham Support Group at 2pm.

May 11 - PORTLAND
Benefit concert for PCO and PRO by Rob Barteltti and various bands from Portland. More information will be available at www.rbartelti.com and www.ohsu.edu/pro. (See article about Rob inside.)

May 21, 22 - NEWPORT
The Parkinson’s Resources of Oregon’s (PRO) 2nd Annual Education Conference: “Riding the Waves of Parkinson’s Disease” in Newport, Oregon. Please call PRO at (800)-426-6800 to receive more information and a brochure.

August 15 - PORTLAND
OHSU’s Outpatient Rehab team will be sponsoring a Tai Chi workshop from 10-11:30am. Tai Chi is a martial arts based on holistic mind-body-spirit no-impact training. More information will be available at our website -www.ohsu.edu/pro—or by calling 503-494-3153.

September 11 - PORTLAND
The PCO’s 22nd Annual Symposium: “Options & Opportunities” will be held at Portland’s Holladay Inn – Convention Center. Both medical experts and inspirational speakers will present information and practical suggestions for people with Parkinson’s, their families, healthcare professionals, and professional caregivers.

September 25 - PORTLAND
PRO’s “Sole Support for Parkinson’s” Walk along the Willamette River in Downtown Portland. Contact PRO at (800) 426-6806.

February 23-26 - WASHINGTON, DC
World Parkinson Congress, a forum of unprecedented scale for scientists, physicians, people and families with Parkinson’s, Parkinson’s organizations, and government representatives from throughout the world, will convene to review the most current developments in Parkinson’s research, education/training, care, and quality of life issues.

Spring 2006 - PORTLAND
Young Onset Parkinson’s Disease conference. Exact location and date will be announced at a later time.
Dear Vicki...

(PCO’s Family Care Specialist Offers Insight)

What is the best approach to “helping” a parent with Parkinson’s get the help they need? For example, my dad refuses any help even though he vigorously struggles to do basic tasks.

As with anyone facing a progressive disease, there are many complex thoughts and feelings about what it means to need and accept help from others. Some people view dependency as a sign of helplessness, inadequacy, or failure. For others, accepting help is a sign of courage, strength, and an acknowledgment of the reality of Parkinson’s disease.

One of the most important things you can do to help a parent with PD is to try to understand your parent’s perspective by asking questions such as “What is it like for you to live with Parkinson’s disease?” Focus on listening and understanding your parent’s preferences for handling daily activities. This process will help you recognize your parent’s strengths and avoid making assumptions about why he/she refuses help. Second, if you have suggestions that you think he/she is helpful, try to offer them without imposing them. A gentle, but honest approach can be very effective. For example, “Dad, I noticed that you are having a hard time getting dressed. I really want to help, what can I do to make it easier?” Sometimes offering assistance in tasks unrelated to “personal caregiving” may be easier for people to accept (mowing the lawn, grocery shopping, opening the windows). Maintain dignity and respect for the individual. Encourage independence while acknowledging that with Parkinson’s disease tasks that were once easy and automatic are now time consuming and possibly difficult.

If you are dealing with a parent who has a strong sense of denial about the struggles of living with PD, stay focused on the problem and reach out to the person on the level they’re ready to deal with. I find it tremendously more helpful than trying to force someone to face what’s happening. For example, it’s fine to say, “Dad, I’m worried about you – it seems like it’s gotten harder and harder for you and Mom to go places.” That is an open-ended remark and an invitation to your parent to respond. Keep issuing general invitations to talk. I’ve had conversations with the primary caregiver’s need for assistance you can elicit suggestions from the parent with PD. For example, “I am worried that Mom (the primary caregiver) seems more tired. Is there anything you can give her some help, what would you suggest that I do for her?” Have a list of errands or tasks you are prepared to do.

Don’t be surprised or discouraged if you get resistance the first time you bring up this topic. Getting beyond objections isn’t necessarily easy and you might need some guidance on how to proceed. Talk to other family caregivers or professionals that have dealt with this issue. Recognize your loved one’s’ rights to make their own life choices even if you do not agree with the choices they make. If health or safety is at issue, be ready to help or need help in talking about these issues in a family meeting, get a skilled professional to assist you in reaching agreement.

Vicki Wolff, LCSW

GDNF is a neurotrophic factor (in essence, a brain hormone) that supports the survival and function of dopamine neurons. In animal studies, it protects dopamine neurons from toxic damage and restores function in PD.

Now there is much controversy over the interpretation of these results. Is the difference between the pilot study and the double-blind study, because there were small differences in how GDNF was administered in the two studies. The GDNF administration schedule of Parkinson’s disease in humans is problematic (PD).

Because GDNF is a protein, it must be injected into the spinal fluid or into the basal ganglia. A pilot research study conducted at our center has had an improvement in PD patients treated with GDNF.

Ike research with monkeys treated with high doses of GDNF have had an unexplained loss of neurons in the cerebellum.

The scientific community is trying to sort out these various observations, because the promise of better therapy for PD with GDNF is still alive.

By John G. Nutt, M.D.
Dear Vicki...

(PCO's Family Care Specialist Offers Insight)

What is the best approach to “helping” a parent with Parkinson's disease? For example, my dad refuses any help even though he obviously needs it. He says he can do it on his own. What can I do to make it easier? Sometimes offering assistance in tasks unrelated to “personal caregiving” may be easier for people to accept (moving the lawn, grocery shopping, or cleaning the windows). Maintain dignity and respect and for the individual. Encourage independence while acknowledging that Parkinson’s disease tasks that were once easy and automatic are now time consuming and possibly difficult.

As with anything facing a progressive disease, there are many complex thoughts and feelings about what it means to need and accept help from others. Some people view dependency as a sign of helplessness, inadequacy, or failure. For others, accepting help is a sign of courage, strength, and an acknowledgment of the reality of Parkinson’s disease.

One of the most important things you can do to help a parent with PD is to try to understand your parenting strategies and your goals. How does this happen? For example, it’s fine to say, “Dad, I noticed you are having a hard time getting dressed. I really want to help, but what can I do to make it easier?” Sometimes offering assistance in tasks unrelated to “personal caregiving” may be easier for people to accept (moving the lawn, grocery shopping, or cleaning the windows). Maintain dignity and respect for the individual. Encourage independence while acknowledging that Parkinson’s disease tasks that were once easy and automatic are now time consuming and possibly difficult.

If you are dealing with a parent who has a strong sense of denial about the struggles of life with PD, stay focused on the problem and reach out to the person on the level they’re ready to deal with. I find it tremendously more helpful than trying to force someone to face what’s happening. For example, it’s fine to say, “Dad, I’m worried about you – it seems like it’s gotten harder and harder for you and Mom to go places.” That is an open-ended remark and an invitation to your parent to talk. Keep issuing gentle invitations to talk. If you have concerns about the primary caregiver’s need for assistance you can elicit suggestions from the parent with PD. For example, “I am worried that Mom (the primary caregiver) seems more tired. Is there anything you would like me to do to help her, what would you suggest that I do for her?” Have a list of errands or tasks you are prepared to do.

Don’t be surprised or discouraged if you get resistance the first time you bring up this topic. Getting beyond objections isn’t necessarily easy and you might need some guidance on how to proceed. Talk to other family caregivers or professionals that have dealt with this issue. Recognize your loved one’s rights to make their own life choices even if you do not agree with the choices they are making. If health or safety is at issue, or you need help in talking about these issues in a family meeting, get a skilled professional to assist you in reaching agreement.

Vicki Wolff, LCSW

Vicki is the Family Care Specialist at the Parkinson Center of Oregon. The primary focus of this position is to provide emotional support, short-term counseling, community referrals, advocacy, and education to patients and family caregivers.

Gliai Derived Neurotropic Factor (GDNF) and the Treatment of PD

By John C. Natt, M.D.

GDNF is a neurotrophic factor (in essence, a brain hormone) that supports the survival and function of dopamine neurons. In animal studies, it protects dopamine neurons from toxic damage and restores function in models of Parkinson’s disease. Because GDNF is a protein, it must be injected into the spinal fluid or into the basal ganglia. A pilot research study conducted at our center continued GDNF treatment for 36 PD patients and showed a small improvement in PD on only a few measures with GDNF.

Now there is much controversy over the interpretation of these results. Is the difference between the pilot study and the double-blind study, because there were small differences in how GDNF was administered in the two studies? This may suggest that GDNF may be effective in the treatment of Parkinson’s disease. There has been no more complicated because some patients in the studies have developed antibodies against GDNF that could potentially inactivate GDNF treatment by the protein’s body with unknown consequences. Further, research with monkeys treated with high doses of GDNF have had an unexplained loss of neurons in the cerebellum. The scientific community is trying to sort out these various observations, because the promise of better therapy for PD with GDNF is still alive.
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Bill Gallagher will be offering a special Tai Chi workshop at OHSU; see events below.

How Good Is Your Balance?

People with Parkinson’s disease are five times as likely to fall and much more likely to injure themselves in a fall compared with people the same age without Parkinson’s disease. Putting numbers on balance control is something that Dr. Fay Horak does in the balance disorders laboratory at the Neurological Sciences Institute of OHSU. Dr. Horak has been studying how the brain controls balance during standing and walking, and how Parkinson’s disease affects balance.

Dr. Horak, Dr. Patricia Carlson-Kuhta and their colleagues from Italy and Bulgaria have shown that people with Parkinson’s disease can result in poor balance from postural responses that are too weak and joints that are too stiff because muscles on both sides are activated. The ability to quickly change balance responses when the conditions change, such as when holding onto a cane or a walker, also can be affected by Parkinson’s disease. Other aspects of balance control however, such as the ability to use vestibular information in the inner ear and ability to improve with practice, are usually not affected by Parkinson’s disease.

Dr. Horak also works with neurolgists such as Dr. John Nutt and Dr. Penelope Hogarth at OHSU to study how medications and surgery affect balance in people with Parkinson’s disease. They were the first to show that levodopa replacement medication can further impair balance responses to external disturbances. Recently, they found some types of balance are improved, but other types worsened by deep brain stimulation.

Studies have shown that anyone can improve their balance with practice and exercise. If you have a balance problem, you should see a physical therapist who specializes in neurolgical rehabilitation. This specialist can evaluate what type of balance problem you have and provide exercises that are custom-made just for you.

If you don’t have a balance problem, you should prevent or delay balance problems by doing daily balance, strength and flexibility exercises such as tai chi and yoga.

The balance disorders laboratory is supported by grants from the National Institute on Aging. They are always looking for volunteers who have Parkinson’s disease with balance problems as well as volunteers who do not have Parkinson’s disease and have very good balance.

If you are interested in volunteering, call Triana at (503) 418-2602. It’s good to keep your life “in balance.”