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A B O U T U S

The **Parkinson's Post** is published by the Northwest Parkinson's Foundation, a 501(c)(3) charitable organization.

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

We welcome comments and inquiries regarding this newsletter and all our activities. Our contact information can be found on the last page of this issue.

We look forward to hearing from you!

Lessons abundant in tai chi practice

By Daniel Loney

It's Friday morning and I meet my fellow tai chi practitioners in the park. As we stand silently among the budding rose bushes and almond trees, I struggle to empty my mind. I feel nervous. Will I be able to get through the form? Will the others notice my trembling hands? Will I lose my balance while doing the kicks?

My tai chi instructor, Arieh Breslow, slowly takes a deep breath, exhales and sinks into his right leg. We all begin to follow as he starts the form.

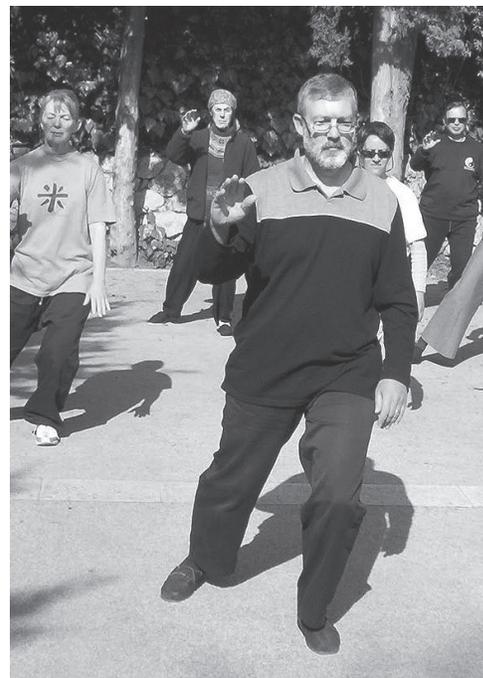
I take a deep breath of the cool Jerusalem air and exhale as I sink, telling myself to relax, relax.

As I progress through the form, I begin to gain confidence in my body. Breathing deeply, sinking, flowing, relaxing, releasing tension, I realize I can still do this. I feel good. I feel *wonderful*.

Starting the form was not always filled with such trepidation. There was a time when I felt completely confident. But Parkinson's disease has changed that.

I first had symptoms of Parkinson's at age 49. My left shoulder wasn't moving easily during warm-up exercises and my left hand wasn't always in the correct position when doing the tai chi form.

At first, I shrugged it off as stiffness. A year later I developed a small tremor in my left hand and my arm didn't swing properly when I walked. It was then that I decided to see a neurologist and was diagnosed with Parkinson's.



Courtesy photo

The author and his tai chi classmates focus while holding a pose.

I knew that if I wanted to maintain a high quality of life, I would need to develop a program for coping with this disease. My doctor prescribed a cocktail of medications for reducing my symptoms, with a myriad of side effects. This prompted me to investigate alternative approaches that would allow me to function as normally as possible.

My medical journey led me into Chinese herbal medicine and Ayurvedic treatments from a doctor in India, pressure-point massage and acupuncture from a Tibetan monk, and yoga lessons.

Although these treatments gave me some relief, I felt that none of them could match the combination of proper medication and tai chi.

Continued on Pages 4 and 5

Exercise to enhance mobility with Parkinson's

By **Lori Newell, MA, CPT, RYT**

If having Parkinson's has left you with limited mobility, there's good news: Regular exercise can help.

Parkinson's brings on many symptoms that can interfere with your ability to get around and perform everyday tasks. You might experience stiffness in the trunk muscles that makes twisting and moving your arms difficult. The muscles in your legs can become tighter, making walking, climbing stairs and getting in and out of a chair more challenging.

Unfortunately, as it becomes more difficult to move, Parkinson's patients often respond by moving less. This lack of movement leads to more stiffness and rigidity, mobility worsens, and a downward cycle begins.

Sticking with a regular exercise program can help lessen the stiffness and, over time, improve your mobility.

A common complaint from people with Parkinson's is difficulty walking. It is not uncommon for those with Parkinson's to walk with quick, short, shuffling steps on the toes, and with arms held stiff. Walking this way puts you out of balance and increases your chances of taking a fall.

Your exercise program should include walking or taking part in a class that gets you moving around the room. When walking, focus on taking long strides that are at least one foot's distance apart.

Make sure you flex your foot and place your heel down first when stepping. This forces you to completely lift your feet and decreases the chance you will drag your toes and trip.

Focus on swinging your arms up to shoulder height when you walk. Aim to walk three to five days per

week for 20 to 30 minutes at a time. Walking correctly may take a lot of concentration at first, but it will become easier with consistent practice.

A regular strength-training routine also goes a long way toward improved mobility. The stronger your muscles are, the more stable you'll be when moving around.

With Parkinson's, getting up from a chair can become difficult. A great exercise to help this is the squat. With a chair behind you, stand up straight with your feet about a shoulder's width apart. The wider apart your feet, the better your balance, so widen your feet if you feel unsteady. As your leg muscles become stronger, move your feet closer together.

Bend your knees, reach your hips back and bring your arms out to the

of motion in the joints. With Parkinson's, it is especially important to focus on stretches that correct posture,

ASK LORI

Got a question about exercise, yoga or meditation? Send it to Lori Newell at info@livingwellyogaandfitness.com or P.O. Box 1057, Montauk, NY 11954. Lori will try to answer one or two questions in each column.



For people with Parkinson's disease, sticking with a regular exercise program can help lessen the stiffness and, over time, improve your mobility.

front for balance, keeping your back straight. Do not round your back or bend too far forward. Go low enough that you come into contact with the chair but do not sit. Then press down into your heels and come back up to standing. Repeat eight to 12 times.

To improve mobility you should do one strength-training exercise for each major muscle group three times a week, taking a day off in between to allow your muscles to recover.

Lastly, a regular stretching routine is essential for maintaining full range

which will reduce your odds of falling.

One great stretch is the corner stretch. Stand facing a corner. Plant your feet a shoulder's width apart and put your palms on the wall level with your shoulders. The wider apart your hands are, the greater the stretch.

Keep your heels on the floor and your hips aligned under your shoulders. Keeping your body in a straight line, lean into the wall until you feel a stretch across your chest. Hold for 30 seconds, then repeat three to five times. Keep your body in a straight line throughout the stretch.

You should do a full-body stretching routine every day you can. Gentle daily stretching can help counteract rigidity, improving flexibility and mobility.

Lori Newell is a certified personal trainer and yoga teacher, as well as author of "The Book of Exercise and Yoga for Those with Parkinson's Disease." The book is available through Living Well Yoga and Fitness (www.livingwellyogaandfitness.com) and costs \$23.95 (price includes shipping and handling). It can be ordered online or by sending a check or money order to P.O. Box 1057, Montauk, NY 11954. Group discounts are available. Newell will donate 30 percent of the cost of each book to the Northwest Parkinson's Foundation when you order directly from her website and mention you read about it in the Parkinson's Post.

Genetic studies give patients, partners a simple way to take part

By Dav'ne Stahley

For those interested in getting involved with Parkinson's research, genetic studies offer one easy and relatively painless way to participate, according to Cyrus Zabetian, M.D., assistant professor of neurology at the University of Washington and a clinician at the Veterans' Administration Puget Sound Health Care System in Seattle.

Zabetian is involved in genetic research into Parkinson's. He heads up the Parkinson's Genetic Research Group, or PaGeR, which is conducting studies to identify the genes associated with Parkinson's and related illnesses.

"In comparison to many other types of research, participating in a genetic study requires only a small time commitment, and it's an easy way for a Parkinson's patient to help in the search for a cure," Zabetian said.

Getting involved in a PaGeR study is simple. It involves a 20- to 30-minute interview with a research coordinator, and a blood draw. One blood sample provides enough DNA to do genetic studies for years, Zabetian said.

Genetic studies need patients with Parkinson's as well as "controls"—people who do *not* have Parkinson's, against whom patients are compared. Many partners of Parkinson's patients take part in research as controls. In fact, between 50 percent and 60 percent of control group subjects are the spouses of patients, Zabetian said.

PaGeR scientists are currently



Cyrus P. Zabetian, M.D.

seeking men over 50 who do not have Parkinson's disease to serve as control group subjects.

They are also interested in people with a close relative with Parkinson's. Just one in 10 people with Parkinson's has a first-degree relative—a sibling, child or parent—with Parkinson's, and the information gathered from first-degree relatives is vital to Parkinson's research, Zabetian said.

If you have Parkinson's and want to participate in a PaGeR study, you must be the patient of a movement disorders specialist at the VA, Virginia Mason or University of Washington medical centers, all in Seattle, or at the Booth Gardner Parkinson's Care Center in Kirkland, WA.

"Genetics studies are only as good as the diagnosis," Zabetian said, explaining why he and his colleagues opted to recruit patients from these four medical facilities, where specialists are using uniform criteria to evaluate and diagnose patients.

To participate in PaGeR research, contact the research team at 206.277.4594 or pgrgroup@u.washington.edu. The website www.depts.washington.edu/pgrgroup is a good place to learn more about PaGeR.

2 studies into medications seek volunteers

The Booth Gardner Parkinson's Care Center in Kirkland, WA, is seeking volunteer participants in two clinical studies.

In one, researchers will examine the efficacy and safety of early vs. delayed Pramipexole treatment in patients with new-onset Parkinson's disease.

The researchers are seeking study participants who have been diagnosed with Parkinson's disease in the past two years, who are between ages 30 and 79, and who are not taking any Parkinson's medication.

There will be 15 visits for this study, 10 at the center and five by telephone. The study will last 15 months.

A second study will assess the Rotigotine transdermal system dose response in individuals with advanced-stage Parkinson's disease.

This study seeks volunteers who have been diagnosed with Parkinson's disease for more than three years. Participants must be taking carbidopa/levodopa and be experiencing approximately three hours of "off" time per day. Participants cannot be taking any dopamine agonist or have had deep-brain stimulation surgery. There will be 10 visits over four months.

Call Teresa Wilson at 425.899.3115 or Cherrie Sia at 425.899.3126 to learn more about participation.

Follow the rules with Parkinson's drugs

By **Stephen M. Setter, PharmD**

People with Parkinson's disease invariably have questions about their medical care, particularly when it comes to medications.

An empathic physician or pharmacist can go a long way toward aiding your understanding. Sharing your experiences with others with Parkinson's also often helps.

Over the years I've established a few important medication rules people with Parkinson's ought to be following.

My No. 1 rule is that all patients should keep an exhaustive, up-to-date list of the prescribed medications, over-the-counter products, vitamins, and herbal supplements they take.

You should share this list with your physicians and pharmacists on every visit. An excellent guide to Parkinson's medications—*Parkinson's Disease: Medications, 3rd Edition*—is available free of charge from the National Parkinson Foundation (800.327.4545 or www.parkinson.org).

Rule No. 2 is that any medication-related questions you have should be posed to your physician or pharmacist. And you should insist on a thorough



Setter

and satisfactory answer.

Rule No. 3: When starting a new medication you should know what side effects to expect. If side effects do arise, find out how to manage them. Don't just stop taking the medication without promptly consulting with your physician or pharmacist.

Rule No. 4 is that you should be working with doctors and pharmacists who understand Parkinson's and are willing to figure out the medications that work most effectively for you.

Many people will slightly modify their medication schedule based on symptoms and situations.

For example, some take an extra dose of medication if they are going out for the evening and need to be more mobile or less anxious. And some will skip a dose if their activity level changes—for example, if they're going for a long car ride.

Never make these decisions alone; always seek guidance from your doctor and pharmacist.

My fifth (though not truly final) rule for this brief article is thus: Always discuss any troubling issues regarding your Parkinson's and your medications with your health-care providers—including symptoms like dizziness, fatigue, anxiety, depression or the worsening of tremor.

While such changes can be related

to the progression of Parkinson's, in some instances they result from medications. Seasoned physicians and pharmacists can often explain why these symptoms arise and offer suggestions to address them.

Sometimes this may take a bit of trial and error. The bottom line is that you must work closely with your health-care providers.

During my last visit to Yakima, I had a wonderful opportunity to visit with a local Parkinson's group.

One gentleman's comments stick in my mind. I asked him for his secret to living so well with Parkinson's. He noted three things: 1) exercise, 2) stress management and 3) V8 juice.

The first two make complete sense to me, but I was puzzled by the third.

It turns out that the salt in V8 juice keeps his blood pressure in the normal range. Without it his blood pressure plummets and he can barely walk due to dizziness and an unsteady gait.

While V8 isn't the answer for everyone, the story illustrates how unique we all are and how simple things can sometimes have a dramatic effect on health and on the ability to live well with Parkinson's.

Stephen M. Setter, PharmD, CDE, CGP, FASCP, is an associate professor of pharmacotherapy at Washington State University in Pullman, WA.

Continued from Page 1

Today, my program is based on three pillars: medication, exercise (with tai chi as the basis) and a low-fat vegetarian diet high in antioxidants to protect and boost my remaining brain cells.

The program is by no means static—I constantly adjust it to my changing condition. Over time, I've noticed the cumulative effects of my regimen. A good tai chi workout seems to be as effective for me as taking a pill and the

results of a session last for hours.

Tai chi is a martial art that uses the mind to control movement. It helps you become aware of your body and the integration of each part with the whole. The slow, deliberate movements of the tai chi form can address many major Parkinson's symptoms:

Preventing falls and developing flexibility—The constant sinking, turning and shifting of weight in tai chi gives a tremendous workout to the legs

and lower body. The constant transition from move to move stretches the hips and groin, strengthening muscles and joints. Each stance ends with roots sunk deep into the ground, while remaining flexible like a tree in the wind.

Balance—In tai chi, proper body alignment is obtained by tucking the chin, raising the back of the neck slightly, and elongating the spine as if it is suspended from the top of the head like a string of pearls. This “string” im-

Ask the Expert is a regular column featuring questions from readers and responses from Parkinson's specialists. Got a question? Email it to questions@nwpf.org or mail it to 400 Mercer Street, Suite 401, Seattle, WA 98109-4641—or just give us a call toll-free at 877.980.7500.

This month's question was posed to **Monique Giroux, M.D.**, medical director at the Booth Gardner Parkinson's Care Center in Kirkland, WA.

I had deep-brain stimulation surgery (DBS) a year ago but my speech is still a problem and getting worse. What can be done to help my speech?

Speech problems in Parkinson's disease tend to begin with vocal softness or reduced volume. Speech can also take on a monotone or "mumbled" quality. Volume may continue to diminish over time, with patients generally unaware they are speaking more and more softly. Word-retrieval problems can further frustrate communication.

Taking your Parkinson's medications on schedule is one important strategy in limiting any speech effects associated with the wearing off of the drugs. But there are other strategies that can help with speech problems.

Physician assistant Sierra Farris, PA-C, a DBS programming specialist at the Booth Gardner Parkinson's Care Center, says speech problems are one of the most common reasons for referral to the center's DBS troubleshooting clinic.

While DBS surgery can improve the same symp-

oms that medications tend to improve, for many people with Parkinson's neither medicine nor surgery dramatically improve speech problems. Speech can worsen over time even after DBS.

That said, any abrupt changes or new speech problems after DBS programming can be side effects of the stimulation. In most cases, an evaluation helps resolve speech-related side effects while maintaining benefit for symptoms that respond to DBS, such as stiffness, tremor, slowness and shuffling.

Speech therapy is an important but often overlooked treatment for declining or sudden changes in speech volume and quality. Clear and loud speech requires a daily routine, but one that is quick and easy, according to Shirley Glazer, MS, CCC-SLP, a speech and language pathologist at the center.

"Speech therapy involves the patient and family and includes simple exercises to perform at home," Glazer said. "The result is louder speech and other improvements to communication."

For DBS patients, Glazer said, it helps to evaluate patients before and after surgery so that any surgery-related changes can be quickly addressed.

It is important to remember that 70 percent of communication is nonverbal. For people with Parkinson's, communication can be further thwarted by a diminishing of facial expressions. This is sometimes referred to as the Parkinson's "mask." Reduced facial expression can mislead family and friends into believing you are uninterested, bored or unhappy.

For some, symptoms are experienced as a sense of tightness around the mouth and lower face. A speech therapist can help by teaching both facial and vocal exercises to reduce the tightness resulting in the "mask" and improve clarity and volume.



Giroux

agery relieves stress on the back muscles, relaxes the shoulders and improves posture and balance.

Rigidity and freezing—It is not unusual for people with Parkinson's to experience rigidity or suddenly become frozen when walking. Concentrating on flowing like a river in the tai chi form produces beautiful, even movements that are thrilling to experience.

Through tai chi, I get a sense of accomplishment and well being, knowing

I can still function relatively well and, in some cases, better than a person with no physical limitations. Tai chi has given me an acute awareness of my body, which parts are not aligned and how to bring them back into the whole of the body so that it functions as one unit. Tai chi has helped me cope with Parkinson's and heightened my enjoyment of life.

I don't know how long my health will hold out. I don't know how long I'll be able to continue with the outward

form of tai chi, but it will always be with me internally.

As for the present, you can find me on Friday mornings in the park among the roses and almond trees, doing tai chi, living fully and enjoying every moment.

Daniel Loney, 57, was born and raised in Corvallis, OR, and moved to Israel 24 years ago. He is an engineer in the computer industry and a volunteer tai chi teacher through the Israel Parkinson Association.



Gifts to the Northwest Parkinson's Foundation support educational programs including our website, email updates, caregiver booklet, newsletter, patient education programs, and annual conference. Donations also fuel outreach and advocacy efforts on behalf of patients and families.

We are privileged so many in the Northwest Parkinson's Foundation family support our mission by giving generously throughout the year in honor or memory of special friends and loved ones.

Thank you, all, for your support.

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Natalie Yaru
Dr. and Mrs. Nicholas Yaru

Libby Zaritsky
Mr. and Mrs. Avrom Zaritsky

Chester Zobrist
Mrs. Margaret Zobrist



There's room for just the new area Parkinson's support groups this issue. You'll find others on our website: www.nwpcf.org

Gig Harbor, WA | 7 to 9 p.m. 2nd Wednesday | Pt. Fosdick fire station | Doug Manuel: 253.858.8741 or manuel@harbornet.com

Lakewood, WA | 1 p.m. 2nd Tuesday | St. Mary's Episcopal Church | Doris Gilmore-Sherwood: 253.582.8421

Renton, WA | 1:30 to 3 p.m. 3rd Wednesday | Merrill Gardens at Renton Centre, 104 Burnett Ave. S | Barbara Shull: als.rentoncentre@gmail.com

Whidbey Island, WA | 1 p.m. 1st Friday | Oak Harbor Senior Center, 51 SE Jerome | Carolyn Hansen: 360.279.1785

Conference featured champions of all stripes

By Dav'ne Stahley

We can't all be Olympic champions, but each of us can be a champion in our own way, whether we have Parkinson's disease, care for someone with Parkinson's, or provide support to the community.

In November, the Northwest Parkinson's Foundation and the Washington Chapter American Parkinson Disease Association presented the second-annual HOPE for Parkinson's Conference in Seattle, a great opportunity to meet champions from the Parkinson's world.

Davis Phinney—former professional cyclist, Olympic medalist, and four-time national champion and stage winner in the Tour de France—kicked off the conference. Phinney, diagnosed with young-onset Parkinson's in 2000, founded the Davis Phinney Foundation, which addresses Parkinson's through research.

Bringing tears to the eyes of many, Phinney shared the ups and downs of an Olympian and patient, offering encouragement and hope.

Nearly 600 Parkinson's patients, care partners, family members and health professionals attended the conference, where they heard from experts on strategies for living well with Parkinson's. Topics covered exercise, depression, treatment options and caregiving.

The Northwest Parkinson's Foundation presented its annual Eyes on the Community award to the Cameron-Jewell family of Seattle for its commitment to the community. Support group leaders, HOPE conference and Team Parkinson's volunteers, and consummate fundraisers for the cure, Suzanne Cameron and Chris Jewell, with their sons Pat and Sam Jewell, are true Parkinson's champions.

The art exhibit featured seven artistic champions who continue to produce superb art despite having Parkinson's. Amazing works by Bill Tozer, Chris Jewell, Mitch Levy, Pamela James, Shirley Cooper, Carol Greene and Rebecca Hudson were enjoyed by all.

Look for details on the 2008 conference in upcoming issues.

TEAM PARKINSON'S

Sign up for Team Parkinson's 2008 at www.nwpcf.org and watch for news about the team in the next issue!



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The Northwest Parkinson's Foundation is a cofounder and partner of the **Booth Gardner Parkinson's Care Center** (13030 121st Way NE, Kirkland, WA 98034). This comprehensive care facility is home to physicians, neuropsychologists, physical and occupational therapists, and speech pathologists, all specialists in working with Parkinson's patients. To make an appointment, call **425.899.3123**.

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Document vital in care situations

Parkinson's Resources of Oregon and the Parkinson Center of Oregon have developed a document to assist patients and medical professionals in optimizing care in Parkinson's. "Critical Information for Caring for the Parkinson's Patient" lets patients document their symptoms and needs and is an educational tool for caregiving staff. Ask that this document be included with the patient's care plan and medical records. You may download it at www.nwpf.org/default.asp?id=51 or call 877.980.7500 to receive a copy by mail.

Friend lends a helping hand

When Dave Payea learned his longtime friend had Parkinson's, he also began to notice the accompanying depression and got his friend to a support group.

To help others with Parkinson's, Payea, president of Senior Safety, a nonprofit in Arlington, WA, will furnish and install one bath grab bar for anyone with Parkinson's—at no charge. There is no obligation to buy anything. This offer is available in most of Western Washington. Call 360.659.8275 to learn more.