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A B O U T U S

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.

We welcome comments and inquiries regarding this newsletter and all our activities. Our contact information can be found on the last page of this newsletter. We look forward to hearing from you!



**NORTHWEST
PARKINSON'S
FOUNDATION**



A Northwest contingent gathers on Feb. 26 between sessions of the World Parkinson Congress in Washington, D.C. Standing, from left, are Wendy Holman, Jeanne Kieffer, Paula Allyn, Bill Bell, and Paul Allyn, all of the Seattle area, and Jacqui and Ed Ewell of Spokane, WA. Seated are Joy Wainwright (left) of Vancouver, B.C., and Carey Christensen of Stanwood, WA.

World Congress meant connections, impact

By Carey Christensen

The World Parkinson Congress that took place in Washington, D.C., from Feb. 22 to 26 was an enormous undertaking, and the statistics were impressive: Over four days, more than 3,000 attendees took part in 127 workshops and symposia given by 281 presenters and viewed 342 scientific posters, 62 exhibits, and art created by 191 Parkinson's patients from 13 countries.

You might imagine the result as a blur of facts and figures—information overload. But I was left instead with indelible memories of specific, important moments. Here are just a few.

The Congress began on Wednesday night with a keynote address by Michael J. Fox. Eager to get a good seat, I arrived early with a couple of good friends. We were lucky to slip through the door just minutes before a guard was posted to keep people away until the official opening. Sitting quietly in the dark, we watched Melanie Maar rehearse the

dance she created in honor of her father, his dyskinesia, tremor and halting gait captured perfectly and poignantly in an artistic and loving portrait. Later in the exhibition hall, Melanie, who also teaches yoga to Parkinson's patients, was eager to talk with us about the creative ways we have learned to move and adapt to the physical challenges of Parkinson's.

Although the workshops were stimulating, the real business occurred in the hallways, cafeterias and lobbies of the D.C. Convention Center. You could stand in one place and an hour later have chatted with five patients, four NIH researchers, three drug reps, two foundation leaders, and a renowned movement disorders specialist. Wendy Holman, the driving force behind the Puget Sound Parkinson's Disease Housing and Care Alliance (see related story, Page 3), casually mentioned to a patient from New York that she had been in email contact with another New

Continued on Page 4

Drug interactions can thwart Parkinson's treatment

By Travis Sonnett, PharmD

Medications benefit us in many ways. But some medications, prescription and over-the-counter, can interfere with those taken for Parkinson's.

Carbidopa/levodopa, otherwise known as Sinemet®, is commonly used to treat Parkinson's disease. Sinemet® works by increasing the amount of dopamine in the brain so as to decrease tremor, stiffness and rigidity. (Sinemet® should not be taken with a high-protein meal because protein may interfere with absorption of the drug—though this

may be more a problem for individuals with severe on/off activity.)

Certain medications, such as phenytoin (Dilantin®) and metoclopramide (Reglan®), may decrease the effectiveness of Sinemet® and exacerbate Parkinson's symptoms. These medications should be used cautiously, if at all, in Parkinson's people. The herb *kava kava* and iron supplements are two over-the-counter agents you should also discuss with your physician before using as they can decrease the effectiveness of Sinemet®.

Mirapex® (pramipexole) and Requip® (ropinirole), known as dopamine agonists, are also commonly used in the treatment of Parkinson's. These two medications work differently from Sinemet®, binding directly to dopamine receptors in the brain and mimicking the effect of dopamine. Dopamine agonists are medications that can be used at all stages of Parkinson's.

Mirapex® and Requip® when used along with some sleeping medications and anxiety treatments, such as Valium® (diazepam), may increase the risk of sedation, drowsiness or the occurrence of sudden "sleep attacks." These sleep attacks have also been observed in patients taking Sinemet® and have been argued to be an effect of Parkinson's itself; however, minimal use of these agents is recommended if you are taking Requip® or Mirapex®.

Anti-nausea agents, such as Compazine® (prochlorperazine) and Phenergan® (promethazine), may aggravate the symptoms of Parkinson's disease. They can interact with most Parkinson's medications and concurrent use should be monitored by a physician.

Selegiline, another medication used in the treatment of Parkinson's, works by blocking an enzyme in the body known as mono-amine-oxidase B (MAO-B). It can interfere with sleep patterns if taken too close to bedtime.

Several medications interact with selegiline, and may cause unwanted side effects in people with Parkinson's. Tricyclic antidepressants such as amitriptyline and desipramine, serotonin reuptake inhibitors (SSRIs) such as Prozac® (fluoxetine) and Zoloft® (sertraline), and antidepressants such as Cymbalta® (duloxetine) and Effexor® (venlafaxine) warrant close monitoring when using selegiline.

Selegiline can often be used safely with the aforementioned medications but potential side effects, such as elevations in blood pressure, require close monitoring.

The pain medication Demerol® (meperidine) should never be used along with selegiline, and the pain reliever Ultram® (tramadol) should be used cautiously.

Antipsychotic agents for treatment of hallucinations may exacerbate the patient's condition, requiring more medication to control Parkinson's symptoms. Medications such as Haldol® (haloperidol), Thorazine® (chlorpromazine), Mellaril® (thioridazine) and Prolixin (flufenazine) are all antipsychotics that could worsen Parkinson's disease.

Currently the drug of choice for treating hallucinations is Seroquel® (quetiapine), as it is considered to have the lowest impact on the symptoms of Parkinson's itself.

Unfortunately there are no medications without side effects and no medications known to be without interactions. Whether with food, other drugs or a health condition, interactions are what we want to avoid in order to achieve the best therapeutic outcomes.

Travis Sonnett is a geriatric resident at Washington State University's College of Pharmacy. For more information regarding medications that could increase the risk of side effects in people with Parkinson's, please email him at tsonnett@wsu.edu.

Drug trial seeks early Parkinson's patients

Virginia Mason Medical Center Department of Neurology in Seattle is recruiting patients with early Parkinson's disease.

Have you recently been diagnosed with Parkinson's disease? You may be eligible to participate in a clinical research study being conducted to determine if an investigational medication (RASAGILINE) slows the progression of Parkinson's. You could be eligible if you:

- ◆ Have been diagnosed with Parkinson's disease within the last year and a half.
- ◆ Are not currently taking any medications for the treatment of your Parkinson's disease.

Qualified participants will receive study medication, study-related office visits, medical examinations and laboratory work at no charge.

For more information, please call Megan Alexander, Clinical Research Coordinator, at 206.223.6835.

Group pushes for Parkinson's home

By Patti Holman

Wendy Holman wanted a place her mother could call home. A Parkinson's-friendly home.

"I kept looking for it," Holman said of the years she spent trying to find residential care for her mother—but the perfect place never materialized.

For the kind of care Holman's mother required, cookie-cutter facilities weren't a fit. She tried independent- and assisted-living facilities, but the routines weren't flexible enough to accommodate her mother's changing Parkinson's symptoms, and the staff weren't able to manage the medications. An adult family home worked for a while, but her mother developed insomnia and began calling Holman during the night.

Holman eventually moved her mother home with her, but that proved challenging. "We really didn't understand what was coming," Holman said of the progressing physical symptoms of Parkinson's and the psychological side-effects—namely, hallucinations—her mother experienced when her medications peaked.

Holman shudders remembering what her family went through. "We were exhausted."

But those experiences educated Holman about Parkinson's, and over time she was able to make changes to more effectively care for her mother.

Emerging from this is Holman's conviction that a good number of patients and families would benefit from a residential facility that truly understands Parkinson's. Unable to find such a place in the Seattle area, Holman is working to start one.

Her new nonprofit organization, the Puget Sound Parkinson's Disease Housing and Care Alliance—or "PuSH for PD"—aims to create an assisted-living facility that cares physically,

medically and emotionally for Parkinson's people.

As PuSH board president, Holman works with board officers Dick Almy, Maria Linde and Peggy Abernathy and board members Bonnie Brian-Caldwell, Jeanne Kieffer and Caren Mack.

Holman and her colleagues envision a residence for up to 20 individuals with moderate to advanced Parkinson's. The layout would be easy to navigate: "No long hallways," she said. It would feature private quarters with bathrooms and kitchenettes as well as social areas and a family kitchen.

Routines would be flexible and activities would take advantage of people's medication "on" times. PuSH also envisions activities—like water therapy and balance and gait therapy—for people with motor symptoms, as well as those targeting mental health.

Staff would be trained to care for patients and would be equipped to help families through transition.

"I began to see that the environment could reduce stress and anxiety if it could provide the types of support the person with Parkinson's really wanted—not what somebody else thought they needed," Holman said.

To Holman's knowledge, there are few such facilities in the nation and none in this region.

The first task PuSH faces is to fund the vision. "We're all volunteers, and we don't have a million dollars sitting in the bank," said Almy, PuSH vice president. "We need a lot of economic support from the Parkinson's community."

Patti Holman is the sister-in-law of PuSH for PD cofounder Wendy Holman. Patti's late mother-in-law (Wendy's mother) lived for 20 years with Parkinson's disease. To learn more about PuSH for PD, email pushforpd@seanet.com or call 206.365.7872.

Online digest an info source for seniors

Seniors Digest is an online magazine for older adults and their families. Sponsored by the Seattle-King County Advisory Council on Aging, it was launched to provide a reliable and trusted way for local seniors to access news and aging-related resources online.

"We are able to provide great information to seniors and caregivers in our community quickly and easily, and the *Digest* encourages older adults to learn computer skills," said Timmie Faghin, Advisory Council member and *Seniors Digest* contributor.

Each monthly issue includes news about events and opportunities of special interest to older adults, their families and caregivers; tips for smart, successful aging and eldercare; fun features to remind us that healthy aging isn't all work and no play; and quick, free access to a wide array of local and national resources for older people and their families.

Email editor@seniorsdigest.org to learn more. Subscribe at www.seniorsdigest.org.

Join the team!

Team Parkinson's is gearing up for an exciting season of fitness, friendship and fund raising. This group of Parkinson's people and their caregivers, friends and family is gearing up for 2006 walking, running and cycling events. With a team goal of raising \$100,000 for Parkinson's programming, members may take part in the athletic event of their choosing.

Details at www.nwpcf.org/bikeride.asp. Questions? Give us a call at 1.877.980.7500 or email info@nwpcf.org.

Music came first, lives on for one patient

By Rick Hermann

My biggest gripe with Parkinson's is that it takes away capabilities I've always considered fundamental to my identity. On the other hand, one of my biggest surprises with this disease is that I can rise above the limitations of my less-ability—at least on occasion.

I've been a guitar player, folk singer, jug band, bluegrass, blues and country musician since I was 11. As teens, my older brother and I used to play a lot of bluegrass, he on the five-string banjo and me on rhythm guitar. The way we learned the complex, fast-paced tunes was to slow our record player to 16 2/3 from the standard 33 1/3 rpms, bringing the tone down an octave and also making the individual notes decipherable. We probably wrecked good Flatt and Scruggs vinyl, to say nothing of the phonograph needle. Mom forgave us, I think.

And indeed, one of the first casualties of my Parkinson's journey (I was diagnosed in 1998 at age 46) was the small-motor skills in my right, my pickin' hand. But I never really considered giving up the guitar. I'm not getting any better at it anymore and I have difficulty learning new music, but I've adjusted to the new normal, which itself changes faces often.

One blessing to come out of all this is that when I had to stop working in 2002 (I had been in book publishing for many years), my peculiar combination of circumstances (lots of free time, little stress) and the increasing rigidity of my right side was encouragement to not focus so much on instrumentalism. I began to write songs and lyrics, something I'd never done before. The results have ranged from pretty-darn-good to "It's still a little rough, honey," my wife's way of saying a song needs another trip through the mill.

I keep my guitar accompaniments simple now, like in my favorite original song based on my meanderings about the neighborhood with our 15-year-old dog, Barney, several times a day. One thing that struck me on these walks was that the only other people outside on weekdays were moms pushing jogging baby-carriages. So the song is titled "Mothers and Babies," and it works great with a minimal amount of guitar.

Parkinson's may have eroded my technical abilities on the guitar, and my fingers may have lost their smooth motion. But I keep playing, even if it's not going well, because the only alternative is *not* to play, which would be a huge loss.

I'm really bad at the old finger-tapping exercise we all perform for our neurologists during appointments. When I attempt the exercise, the fingers on my right hand look and feel incapable of picking my nose let alone my guitar. But I still can pick the guitar, which is the amazing thing, I think it's because the music in me is older than the Parkinson's, and my body knows the tune better than it knows the disease.

Rick Hermann lives in Bellingham, WA, with his wife, Lee.



Continued from Page 1

Yorker regarding a similar housing project. "Oh, I know him! He's having breakfast right over there!" she exclaimed to an astonished Wendy. The connection was made, information exchanged and the project advanced.

Inspiration was always just a conversation away. I joined Clifford and Lorelei Ransom for a drink in the hotel bar, asking a typical ice-breaking question, "How long have you had Parkinson's?" "Sixteen years," was Cliff's answer. "It was tough at first," he continued, "but eventually I realized my life wasn't over. I decided I still could do things, I still could dream. I've always loved photography and always wanted my own business. So Lorelei and I started fresh last year. I now have a studio, and my photos are here on display." We raised our glasses to new beginnings. Clifford Ransom is 75 years old.

The mix of patients and doctors, researchers and clinicians, and art and science at the first-ever World Parkinson Congress was extraordinary. I'm grateful I was able to take part, to listen, laugh and learn with thousands of people gathered together for one reason: to make lives better for those living with Parkinson's disease.

As Michael J. Fox astutely said in his opening remarks, "Translating what we know about disease into cures is all about making connections—working together to lay tracks and never losing sight of the destination. If we do this—and I'm fully confident that we can—we can cure Parkinson's within our lifetime."

The next World Parkinson's Congress will be in Paris in 2009. I hope I'm able to attend—and that a cure, currently beyond the horizon, will be clearly in sight.

Carey Christensen was diagnosed with Parkinson's in 1999 at age 41. She is Washington state coordinator for the Parkinson's Action Network and lives in Stanwood, WA.

'Enriched environment' may boost brain health

By Joanna Glickler

A little exercise more days than not, hobbies, meditation, good nutrition and the company of friends may all add up to a higher quality of life with Parkinson's disease.

This according to Paul David Nussbaum, Ph.D., a neuropsychologist who spoke in February at the World Parkinson Congress in Washington, D.C.

The brain has the capacity for *neurogenesis*—the development of new neuronal cells—Nussbaum said. Exercise, nutrition, socialization, mental stimulation and meditation are all thought to contribute to neurogenesis.

That's good news for people with Parkinson's, he said.

This is because having plentiful neuronal connections—a "brain reserve"—is thought to stave off the onset and progression of brain diseases like Parkinson's and Alzheimer's, Nussbaum said.

He likened the connections among brain cells to trees and their branches. "You want your brain to look like a jungle," he said. "You don't want it to look like a Caribbean island with one palm tree."

He said a brain that looks like a jungle—that is, contains an abundance of synaptic connections—is better protected against brain disease.

Carrying the analogy further, Nussbaum described Parkinson's disease as a "weed whacker."

And when the weed whacker threatens, he said, "Do you want your brain to look like a jungle, or do you want it to look like the Caribbean island with one palm tree?"

"What we've learned about intellectual reserve is that those brains that have tremendous synaptic density fight off these diseases for longer periods of time," he said. "I'm not taking about cure, I'm not talk about

preventing. I'm talking about delaying the onset, which is critically important."

Pursuing "enriched environments"

Nussbaum said the key to neurogenesis at any age is putting oneself in *enriched environments*.

"The brain doesn't know what age it is," he said. "It's just seeking enriched environments."

What's an enriched environment? Nussbaum boiled it down to the combination of five key points. He said all five are backed by studies comprising an emerging area of research into the brain.

Physical activity. Nussbaum said any activity that gets blood circulating to the brain is neuroprotective. He said taking part in exercise programs or simply walking on a regular basis, as well as taking dance lessons and gardening, are all good ways to boost the circulation of blood to the brain.

Nussbaum also counts knitting as a beneficial activity. Like gardening, he said, knitting requires planning ahead and thinking into the future, which is good for the brain.

Trying novel activities is another way to boost brain power. Nussbaum suggested trying to write with the non-dominant hand. He said the fact that this gets easier with practice is evidence of its rewiring effect on the brain.

Nutrition. Nussbaum said foods with omega-3 fatty acids—such as tuna, salmon, herring and walnuts—seem to have a neuroprotective effect. Vitamins E and C, which are powerful antioxidants, also have shown benefit to the brain, he said. He recommended blueberries and red grapes as snacks, and red wine—if permitted by your physician—in moderation.

Nussbaum said it appears that good nutrition has a dosing effect—meaning that the more beneficial foods one eats, the greater the positive effect.

Socialization. Nussbaum cited research suggesting that individuals who isolate or segregate themselves have higher rates of dementia than those who stay well-socialized. Retirement, he said, contributes to isolation.

Nussbaum said retired people and others should work against this by forming hobbies, getting involved with activities outside the home, and spending time with a variety of people.

Mental stimulation. Nussbaum recalled a study that found that playing board games reduces the risk of dementia. He advised doing puzzles with numbers and language. An activity is beneficial as long as it's "complex and novel," he said. "But we tend to fall into the rote and passive (because) it's easy."

Nussbaum also said learning a foreign language is another way to stimulate neuron growth.

Meditation/spirituality. Meditation or any form of spirituality is important "because we go too fast," Nussbaum said. He said meditation and prayer force us to slow down and get away from stress and overstimulation. "We produce a lot of stress when we go too fast. Stress can do damage to the memory system and hippocampus."

Putting it all together

Nussbaum said the meal is the perfect opportunity to create an enriched environment on a regular basis.

His advice? Make a priority of sitting down for meals with family and friends, incorporating neuroprotective choices into menu planning—including that glass of red wine, if you're able. Put on some background music, engage in stimulating conversation, and simply enjoy the pleasure of the enriched environment you've created. Cheers!

Joanna Glickler is Development Director at the Northwest Parkinson's Foundation. Dr. Nussbaum's website can be found at www.paulnussbaum.com.

Agencies give carers a break

By Elaine McGinnis

Primary caregivers often find themselves with less time and energy than they once had for housework, shopping and cooking, as well as for taking part in the hobbies and social activities that are important for us all.

Non-medical home care agencies are designed to help primary caregivers with the activities of caring. Agency staff can do housework and laundry, shop for food, prepare meals, and provide transportation to appointments and errands. Others help with personal care—bathing, hair care, shaving and dressing—as well as administer medications and handle incontinence issues.

People commonly look to home care agencies when a primary caregiver would benefit from time away from caregiving. In such cases, respite care may be for a fixed or indefinite period of time. Agencies are flexible and adjust schedules to meet individual needs. Most agencies can schedule staffing for time periods between two and 24 hours.

To insure consistent staffing, it's a good policy to keep a regular schedule. For example, you may want to schedule a caregiver every Monday, Wednesday and Friday from 1 p.m. to 5 p.m. This gives a staff member time to provide personal care such as a shower or bath as well as to do some housework and cooking, for example. Once a home care staffer has been trained, the primary caregiver need no longer be present.

The benefits of using a home care agency include the following:

- ◆ Caregivers are carefully screened, bonded and insured.
- ◆ Payroll responsibilities are handled by the agency.
- ◆ Replacement caregivers are available on short notice.
- ◆ Caregivers are available 24 hours a day every day, including holidays.

Making arrangements

Before contacting an agency, make sure your household is in agreement about bringing in extra help. The cost for a “private duty” agency (one that receives direct payment from the client) ranges from \$20 to \$25 per hour. Many agencies accept long-term care insurance and can assist with reimbursement from insurance companies.

One way to research home care agencies is to consult *Choice Guide*, which covers the Puget Sound region of Washington State. Call 800.361.0138 for a free copy. Senior Services of King County, WA, has a publication called *Options for Hiring Household Help*. It is available at www.seniorservices.org or by calling 206.448.3110. Information is also available in the Yellow Pages.

For people out of the Puget Sound area, contact your local senior services organization for information about home care agencies in the area.

A general rule of thumb is to call three agencies and make appointments to meet with the representative or social worker of at least two. It is important to compare more than the price. You also need to be sure the agency's management of your situation is compatible with your goals.

Prepare a list of questions in advance of the meeting. Here are some sample questions:

- ◆ What is your hourly rate and minimum number of hours per shift?
- ◆ How often does your agency bill?
- ◆ How do you screen and select your employees?
- ◆ Are your employees Certified Nursing Assistants?
- ◆ What are the qualifications of the person who creates the care plan? (The care plan is an outline of the client's care needs that the caregiver follows.)
- ◆ Is there a charge for the assessment to create the care plan?
- ◆ What are the qualifications of the person who oversees the caregiver?
- ◆ Is the agency a nonprofit organization or a for-profit business?

- ◆ What if the client's needs change and we need more or fewer hours?
- ◆ Can your agency provide live-in or 24-hour staffing if needed?
- ◆ May we meet the prospective caregiver before the individual begins working for us?
- ◆ What happens if the client needs to spend time in a hospital or rehabilitation facility?
- ◆ Are employees bonded and insured?
- ◆ Can I have a different caregiver if the one you choose is unsatisfactory?
- ◆ Can I reach a staff person by telephone 24 hours a day?
- ◆ Is there a charge for social worker or nurse follow-up visits?
- ◆ What are your charges for mileage reimbursement for driving for shopping, errands and appointments.
- ◆ Does your agency charge extra for holiday or weekend shifts?

Is home care right for your family?

If you think home care is a viable option but aren't sure you're ready to make a decision, do some research. Follow the steps above but don't commit right away. Agencies understand the issues that keep a family from taking action—issues like financial concerns or resistance from a prospective client.

Only the primary caregiver and prospective client can know when the time is right to bring in outside help. Choosing to work with an agency is not a permanent commitment and the terms of the arrangement can be altered or cancelled at any time.

Far from being an intrusion into a family's life, caregivers are professionals who perform personal care and homemaker duties and offer welcome companionship. With the proper groundwork before entering into a relationship with an agency, you can reap the rewards of high-quality care.

Elaine McGinnis is with Home Care Associates, a nonprofit division of Jewish Family Services. Home Care Associates (206.861.3193) is based in Seattle, WA, and serves the Puget Sound region.

Those listed here made donations between January 27 and April 25, 2006. *Thank you, friends!* Gifts support educational programming such as our website, our weekly email update, our caregiver booklet, and this newsletter. By giving, you also help fuel our Parkinson's outreach and advocacy efforts on behalf of patients and families. If the work of the Northwest Parkinson's Foundation has made a difference for you or someone you care for, consider making a donation today.

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Administrator

Center hosts education

A Booth Gardner Parkinson's Care Center quarterly educational meeting will take place from noon to 2:30 p.m. Aug. 18.

The free program will be at the Evergreen Hospital and Medical Center Education Classroom (TAN area). Call 425.899.3000 to learn more, register and get directions.

Web lists telehealth topics

More than a dozen, mostly rural communities in the Northwest are connecting to a monthly educational program over the Parkinson's Telehealth Network. They meet at community sites to view the live programming. For a list of topics and to find out if your community is connected, call 1.877.980.7500 or visit

www.nwpf.org/telemedicine.asp.

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The Booth Gardner Parkinson's Care Center is a regional center of excellence in the treatment of Parkinson's disease.

Patients benefit from a team approach to quality of life. The Center's staff includes neurologists; neuropsychologists; physical, occupational and speech therapists; and educators and counselors. All staff specialize in working with Parkinson's patients and their families. Call 425.899.3123 for an appointment.