



American Parkinson Disease Association

Parkinson Pathfinder

THE NEWSLETTER OF THE AMERICAN PARKINSON DISEASE ASSOCIATION
INFORMATION AND REFERRAL CENTER OF WASHINGTON

Spring 2006

A Bounty of Washington Parkinson's Events in Spring 2006!

April is National Parkinson's Awareness Month ~ a particularly great time to become informed and help spread knowledge about PD to the larger community.

Plenty of opportunities abound in the next few months for you to learn more about Parkinson's treatments and helpful community services and supports, as well as to join in fundraising efforts for ongoing and emerging programs and research. Here are a few of the upcoming events in Washington state.

Date/Time	Location	Description	Contact
March 28 6-7:30 PM	Tacoma, WA St. Joseph Medical Center	<i>Management of PD and Deep Brain Stimulation</i> ~ Patrick Hogan DO, Peter Shin MD, and Sharon Jung, ARNP	Free, registration required, call 1-888-825-3727
March 31 12-3 PM	Kirkland, WA Evergreen Hospital and Medical Center	<i>Weighing the Risks of Driving with Parkinson Disease</i> Presented by Booth Gardner Parkinson's Care Center Free, with box lunches provided.	Call 425-899-3000 to register and for directions
April 8 6 PM	Seattle, WA St. Demetrios Greek Church	<i>Abracadabra ~ The Magic of Hope!</i> Auction Dinner and benefit for Washington State Chapter APDA. See flyer enclosed for details!	See www.waparkinsons.org or call E. Davis, 425-443-8269. RSVP by March 31
April 13 1-5 PM	Kennewick, WA Red Lion Columbia Ctr.	<i>Challenges and Champions: Summit on Parkinson's Disease.</i> Clinical and research experts present latest on PD. Host: Parkinson Center of Oregon at OHSU.	For registration and details, call 503-494-9054 or email pco@ohsu.edu www.ohsu.edu/pco
April 25 6-7 PM	Tacoma, WA LaQuinta Inn	<i>New Hope for Parkinson's and Other Movement Disorders ~ An Introduction to Activa's Deep Brain Stimulation</i> with Patrick Hogan DO, Peter Shin MD	Free, pre-registration is required. Call toll-free 1-877-438-3574
Full Day Event, Monday June 5	Tukwila, WA Tukwila Community Center	<i>Challenges in Caregiving: Giving Care, Taking Care</i> Conference of workshops and exhibitors to provide current, practical skills and resources for caregivers.	Pre-registration req.: 800-422-3263 or 360-725-2544. AARP, Aging and Disability Services Administration, ElderHealth Northwest

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Information & Referral Center**UW Dept. of Neurology**

Box 356465

Seattle, WA 98195

Phone: (206) 543-5369

apda@u.washington.edu

For information packets, literature, or other Parkinson related issues, please contact the Information and Referral Center at the above address or visit our website at

www.waparkinsons.org**Co Medical Directors**

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Seattle, WA 98175-0169

**Please Send Donations
To The Board Address****National APDA**

1-800-223-2732

www.apdaparkinson.org

If you have any comments or suggestions regarding this Newsletter, please contact the I & R Center at (206) 543-5369.

The material in this Newsletter is solely for the information of the reader and should not be used for treatment purposes, but rather for discussion with the patient's own physician. It does not necessarily reflect the opinion of the Seattle APDA I&R Center or that of the Washington State Board.

Chapter News**Chapter Development Director Report**

Hello Everyone

I have now completed my first 90 days with the Washington Chapter of the APDA, and very pleased to report that things are moving along nicely. We have a busy few months to look forward too – APDA in Washington, Montana, Idaho and Alaska were selected by Safeway to be the Charity of Choice for the month of March, so please remember to shop at Safeway's and look for the coin canisters at the check outs, and place all your empty change in them - it all adds up.

April, as you know is Parkinson's Awareness Month, and the Governor of Washington has issued us our Proclamation, and we will be having our Annual Dinner and Auction on April 8th, at St. Demetrius Church Hall in Seattle, where we will have a wonderful evening of Mime, Magic, Great Food and Wine, and raise a large amount of money. April 11th is Parkinson's Day, so try and organize a small event to recognize this day.

We are working towards finding a date in the fall for our Annual Symposium, and will have this information for you in our next newsletter Requests for our DVD are coming in from all over the world, including many from India, where they learnt about us in a local Hindu newspaper and also as far away as New Zealand.

I look forward to seeing many of you at our April Event, and don't forget those coin canisters, have a great few months and thanks for all the tremendous support

Evelynne Davis, Development Director

A Word from the Chapter Presidents

Greetings and Happy New Year! So much is going on with the WA APDA Chapter it is hard to know where to begin. Suzanne and I are continuing to share the President's position for 2006. Our last task for 2005 / first task of 2006 was to facilitate finding and hiring a new Developmental Director. With the help from several board members we recruited and hired an outstanding DD, Evelynne Davis. She began December 1st 2005 and has already met many of our 2006 goals!

Future goals include the hosting of a major Washington State APDA fundraiser. The last 3 years the auction has been held with a dance (with the Diptones playing) but due to many requests, we are organizing a more formal auction this year which will include a sit down dinner, entertainment, and a silent and live auction. We hope to see many of you there! All donations will remain in this state to fund support groups, educational symposiums, and local research. It will be held at St. Demetrius Church on April 8th, 2006. For more information please see the page 5 or check our website at www.waparkinsons.org. If you would like to donate an auction item or purchase tickets please contact Evelyn Davis at 425-443-8269.

We are currently planning our annual fall symposium, news of location and topics will be coming soon. The WA APDA is also looking at crossing the state to help fund/coordinate an educational seminar east of the mountains.

Our locally produced DVD "Straight talk and Honest Hope" has been an international success! We have produced 25,000 copies (of which over 15,000 have been distributed), and we are now discussing producing 25,000 more copies. If you have not yet requested a free copy please refer to our website soon.

World Parkinson Congress 2006: Thanks to support from the WA APDA chapter, and the Booth Gardner Parkinson Center, I (Ann) was able to attend the first ever World Parkinson Congress. This was such a wonderful experience. It was held in Washington DC for 5 days (following the Parkinson Action Network in DC), February 22 through February 26th. The conference offered educational events for people with Parkinson's, caregivers, clinical experts, and scientists who joined together to share the most current information on living with, treating, and finding a cure for

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Keep Moving!

Research Shows Exercise Protects Against Parkinson's

As reported on Pdtrials (www.Pdtrials.org) scientists are finding that exercise might offer a powerful shield against Parkinson's. Recent studies suggest physical activity might help protect neurons in the brain from the ongoing damage of Parkinson's. "I do believe that exercise will slow the progression," says Michael Zigmond, a neurologist at the University of Pittsburgh's Institute for Neurodegenerative Disorders. The findings, based on research first on lab animals and now on humans, suggest lifestyle measures could prevent or control a disease that afflicts an estimated 1 million people in the USA. It's a number that will rise in the coming decades as boomers start to develop the disease, typically after age 50. By the time of actual diagnosis, the disease already has damaged the substantia nigra and other key brain regions. An injury to cells in those regions causes a shortage of a brain chemical called dopamine, which leads to difficulty in controlling movement. Drugs treat the symptoms, but they cannot stop or slow the progression of the disease, yet studies have suggested that a daily jog might do what modern medicine cannot. The evidence on Parkinson's and exercise includes:

- A study in 2005 at the Harvard School of Public Health found that men who said they jogged, played basketball or did some other sweat-breaking activity at least twice a week as young adults reduced their risk of getting Parkinson's later by 60%.

- The Pittsburgh team found that exercise offered rats a powerful shield against a Parkinson's-like disease. These rats were injected with a toxin that kills brain cells, yet they never developed symptoms and had almost no sign of damage to the brain, including to the dopamine-producing neurons. The

study suggested that the benefit comes from the production of chemicals called neurotrophic factors, which seem released through exercise, and then protect brain cells damaged by the Parkinson's disease process. That and other evidence indicates that exercise might help even people who already have the disease.

- Other research suggests physical activity might do the same for humans. In a preliminary study of 19 people, researcher Anthony Delitto at the University of Pittsburgh found that patients who exercised as little as three times a week showed improvements in balance and the ability to perform daily tasks. Those findings need to be verified in larger studies, but exercise, especially if combined with next-generation drugs, might be able to ward off the increasing disability that goes along with the disease.

While not all animal studies have translated well to humans, exercise is not going to hurt you. "If we were talking about a drug, Zigmond says, "I'd say wait. But there are no side effects to working out." The Harvard study indicates regular workouts early in life might help keep the brain free of damage that can lead to Parkinson's. People who are healthy now are advised to build a fitness routine into their daily schedule. Play basketball. Go out for a walk. Swim laps. The advice is much the same for people who have the disease. Experts say running, walking and other activities all help build muscle mass, which is a boon for people who are fighting not just the disease but also the loss of muscle power that comes with old age. Exercise gives people with Parkinson's more strength and balance, Delitto says. Fitter patients are better able to perform daily tasks that can help keep them independent.

Neurologists & Advocacy Groups Seek Opportunities to Collaborate

WAAPDA staff Evie Davis and Anne Guthrie recently participated in a meeting to explore areas of potential collaboration between neurologists and patient advocacy organizations from across our state. The meeting, organized by the newly formed Washington State Neurological Society (WSNS), was a forum to share ideas about effectively and jointly advocating for quality neurological care in Washington State. A representative from The American Association of Neurology (AAN) described the California NeuroAlliance as a possible model for Washington to bolster collaboration on healthcare advocacy. Evie and Anne feel this may be an effective project to advance PD advocacy and will explore this further as discussions continue.



"Motivating Moves" available on Video or DVD

To help you start and keep moving, an exercise program based on the research of a University of Kansas movement analyst is available on DVD or video. The tape, a collaboration of the KU faculty and the Parkinson's Disease Foundation, features a 30-minute seated exercise routine and practical tips for solving daily movement challenges. Exercises are designed to help people with PD better manage their symptoms and improve their breathing, flexibility, sense of balance, facial expressiveness and dynamic movement and vocal range. To order a copy at \$14.95, contact PDF at 1-800-457-6676 or visit www.pdf.org.

Living Well Event Brings Together the MS and PD Community

The new year began with a successful networking and informational event for persons with PD or Multiple Sclerosis (MS) on January 21 in Tukwila. The full day conference was planned by a committee consisting of persons with YOPD, the APDA I&R Center and staff and consumers with the MS Association of King County as a trial collaboration when it became clear that each of the conditions led to many similar life challenges. The day proved to be a good dialog led by a panel which brought together PD professionals and advocates Dr Jeff Shaw, Shirley Abato, Anne Guthrie and Dennis Wright with persons with MS and affiliated professional providers Dr. Mary Pepping, Dave White, Irene Lavergne and Alan Wittenberg. The focus of the panel and break out workshops was on issues affecting quality of life and emotional well-being as well as strategies to effectively cope with these challenges. During lunch a quartet of members of Parkiejam, a locally-based online Parkinson's group demonstrated how

that network helps subscribers "create a new beat to move by. A beat that is flexible enough to change as often as we do". The group of creative souls, musicians and poets co-wrote "PD Blues", whose many poignant, comical and knowing stanzas were recited by host Laura Dean (Port Orchard), Pat Erickson (Shoreline), April Curfman (Portland) and Carol Meenan (Alabama). Written and verbal evaluations of the event were very positive and have inspired future collaborations.



Parkiejammers (l-r) April, Pat and Carol share their creativity and wit.

Written and verbal evaluations of the event were very positive and have inspired future collaborations.

What you can do about ~ finding a voice amplifying gadget

A device originally developed for exercise leaders and tour guides turns out to be an ideal portable gadget to help people with soft voices be heard! One such device, the Califone personal voice amplifier, is small and can be worn on your belt. For your home, consider purchasing a voice amplifying telephone. Both of these items can be seen and ordered through the Active Forever catalog for about \$100. Call 800-377-8033 or view at www.activeforever.com

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Chapter Presidents

Parkinson's disease. I was amazed at the extent of this conference. Specialists from all over the world gathered together to bring hope and education on the most current studies and treatment of the disease. Numerous educational lectures were offered as was the opportunity to participate in the renewal room for exercises and relaxation, and to speak with a variety of exhibitors to discuss medications or other products available to help dealing with the disease.

The National APDA organization was one of the many exhibitors encouraging support for all and I am proud to state the WA produced DVD was offered to one and all! From 6:00 to 7:30 each night "Creativity and Parkinson's" was offered to showcase art from 14 countries throughout the world. Most importantly, it was the first conference that brought those who live the disease together with those who treat or study the disease. To put it mildly the experience was unique and astounding. Many of the U.S. colleges I have worked with over the last decade were present and openly collaborating with other countries and support networks. We

all are in this together! Personally, I hope this is a huge beginning to a united endeavor to find the cure for PD. I am looking forward to applying some of the "pearls of wisdom" I gained at this conference into my clinical practice, and sharing then with my fellow board members to help expand our awareness.

The year passes quickly so keep in mind that we will be encouraging a fund raiser for research, to help find better treatment and eventually a cure for PD. This is typically held in late summer or early fall. News of this will also be coming soon.

We hope to see 2006 be an inspirational year for all. If you are interested in joining the APDA in easing the burden of Parkinson's disease, please do not hesitate to contact us. Volunteers are encouraged and needed to continue with our positive efforts. Sincerely,

Ann Zylstra & Suzanne Cameron,
Co-presidents of the WA Chapter, APDA

Washington State Parkinson Support Groups

APDA serves as a clearinghouse for PD Support Groups. If you know of one not listed, listed in error or would like to see one created. . .please tell the Information and Referral Center via contacts on page 2. Thank You!

Eastern Washington

*Okanogin

Valley Care Nursing Home
Contact Sandra Johnson
509.826.0491

Meets 3rd Thursday, 1pm

Richland

Richland Lutheran Church
Contact: Neurological Center
509.943.8455

Meets 3rd Thursday, 1:15

Spokane

Riverview Retirement Center
Contact Carol Lewis
509.466.0188

Meets 1st Monday, 7pm

Spokane Parkinson's

Educational Group

St Luke's Rehab Institute
Contact Spokane Parkinson's
Regional Center
509.473.6740

3rd Monday, 2-4 pm

Walla Walla

Congregational Church
Contact Darlene Lambert
509.382.4012

Meets 4th Saturday, 6pm

509.473.6740

3rd Monday, 2-4 pm

Yakima

Wellness House
Contact Kristyan
509.248.8539 or
kristyan@senioravenues.com

Meets 2nd Saturday, 1-2pm

Western Washington

Puyallup

United Methodist Church
Contact Jennifer Wrye
253.752.7112

General Support Group
Meets 3rd Thursday, 1:30pm

Caregivers Support Group
Meets 2nd Thursday, 1pm

Tacoma

Tacoma Lutheran Home
Contact Sharon Jung
253.284.4488

Meets 3rd Friday, 11:30 am

Anacortes

Island Hospital
Contact Pat Grady
360.299.3150

Meets 2nd Friday, 2pm

Bainbridge Gardens

P.D. Young at H.E.A.R.T. Group
Contact Steve Bohannon
206.842-1385 sbohann@msn.com

Meets 1st Monday, 1 pm

Bellingham

Parkway Chateau
Contact Debra Ivanovich
360.724.3382

Meets 2nd Monday, 2pm

Bellingham Young Onset

Fourth Corner Community Church
Contact Susie Morrow
360.384.4634
yopdnw@hotmail.com

Meets 2nd and 4th Wednesday, 7 pm

Burlington

Homeplace Care Center
Contact Nancy Gentry
360.755.1493

Meets 2nd Tuesday, 2pm

Des Moines *NEW*

Wesley Homes
Contact Jane Sepede
206-870-8114

Meets 4th Tuesday, 10 am

Mill Creek

Merril Gardens
Contact: Bob Detmer
425-316-3958

Meets 2nd Tuesday, 7pm

*North Whidbey Island

NEW LEADER NEEDED!
Oak Harbor Senior Center
Contact J.C. Klein
360.675.7695

Meets 1st Tuesday, 1:30pm

Vashon Island

General Group
Contact Robin Stover, 206.463.5173
Young Onset Group

Contact Kate Lanigan, 206.463.3140

Port Angeles/Sequim

Sequim Library
Contact Gene Andrews, 360.582.9076
Meets 3rd Wednesday, 1pm

Bremerton

Green Mountain Rehab. Center
Contact Deb Carpenter, 360.373.9119
Meets 1st Tuesday, 1:30pm

Chehalis

Dayspring Baptist Church
Contact Parkinson's Resources/Oregon
800.426.6806

Meets 2nd Tuesday, 2 pm

Longview

Canterbury Park, Broadway and 7th
Contact Don Taylor, 360.636.1375
Meets 3rd Wednesday, 1:30 pm

Olympia

Evergreen Nursing and Rehab Ctr
Parkinson's Education Society
of Puget Sound, 360-491-9700
Meets 3rd Tuesday, 11:30

Vancouver

SW Washington Medical Center
Contact Jeanne Laviolette
360.403.8896

Meets 3rd Saturday, 2pm

*Everett

Providence General Medical Center
General Group
Contact: Leona Burges, 425.338.3136
Meets 4th Saturday, 2pm

Caregiver Group

Contact: Bill Coy, 425-338-3136
Meets 2nd Monday 2-4pm

Young Onset of Snohomish

Contact: Karen Painter, 425.327.9401
kpainter62@aol.com
Meets 3rd Saturday, 2 pm

Greater Seattle Area

*Bothell

North Shore Senior Center
Contact Suzie Favaro
425.486.4564

Meets 2nd Tuesday, 9:30am

Bellevue/Eastside

North Bellevue Senior Center
Contact Carin Mack, 206.230.0166
Meets 4th Tuesday, 2:30pm

*Federal Way

Federal Way Library
Contact Norma Kay Fetz, 253.833.8306
Meets 3rd Monday, 2pm

Edmonds

South County Senior Center
Contact: Merrie Kay Sharar
425.774.5555

Meets 4th Tuesday, 3pm

Issaquah *NEW*

Providence Point
Contact Phil Tompkins
425-391-6941

Meets 2nd Monday, 2 pm

Young Onset-Seattle

Meets in members homes
Contact Suzanne Cameron, 206.286.8149
Meets 2nd Tuesday, 7pm

Young Onset

Parkinson's Eastside Network

Evergreen Medical Center, Kirkland
Contact Mitch Levy TecToc@msn.com
Anne Guthrie 206.543-5369

North Seattle/Shoreline

Shoreline Senior Center
Contact Scott Tieson
206-365-1536

Meets 3rd Tuesday, 3pm

*Mercer Island *CHANGE*

Community Center at Mercer View
General Group
Meets 1st and 3rd Tuesdays, 2 pm

Carer's Group

Meets 2nd Thursday, 3 pm

Contact for both: Carin Mack 206-230-0166

*West Seattle *CHANGE*

Park West Care Center
Contact Katie Stokely
206-933-5931

Meets 3rd Thursday, 1:30 pm

Seattle Well Spouse Group

Greenwood Activity Center
Contact: Carin Mack or
socialwkr@earthlink.net
Meets 1st Monday, 4 pm

*Seattle Carers Group

Hamilton House (University District)
Contact Carin Mack, 206.230.0166
Meets 2nd Tuesday, 1 pm

Seattle First Hill

VM Medical Center
Contact Laurel Beck
206.625.7373 ext.64553
Meets 1st Tuesday 1:30pm

Before joining a group, please contact
the Group Leader to confirm
location & schedule SUPPORT GROUP
LEADERS NEEDED! LET ME HELP YOU
GET STARTED! Contact Anne, see page 2

*Denotes APDA Affiliation

Parkinson's Notes: Updates and Upcoming Events

***New Seattle locations for monthly Parkinson's Telehealth Broadcasts.** In addition to the many Eastern Washington sites, the Spokane-based live, interactive Parkinson's Education broadcasts are now available monthly in two Seattle area hospitals: **Virginia Mason Medical Center Lindeman Pavilion**, 10th floor conference room, call Joanna Glickler at 877-980-7500 for details and in Kirkland at **Evergreen Hospital**, where the contact is Kathy Repp, 206-352-1459. All sessions start at 2:00 PST on the 3rd Monday of each month.

Upcoming topics: 3/20- *An Open Forum on Parkinson's Disease with Dr. Anthony Santiago, MDS*; 4/17 *Limiting Unnecessary Suffering with Parkinson's: Suggestions for Patients and Caregivers with Dr. Jeff Shaw*.

* **The First Year: Parkinson's Disease, An Essential Guide for the Newly Diagnosed by Jackie Hunt Christensen.** The author has spent much of her professional career enhancing awareness of environmental issues. Since developing Parkinson's disease at a young age, she has faced challenges to make a change in the world's view of this condition, which parallels the difficulties she has faced in getting people to notice the environment. Available at major bookstores or through www.marlowepub.com or www.amazon.com.

***British Parkinson's Employment Guide.** With 10,000 people diagnosed each year, 1 of 20 under age 40, issues related to employment are as prevalent in the UK as in the US. A guide to help navigate such issues as discussing your diagnosis, seeking accommodations, and the decision to leave employment has been developed. Although the benefits, resources and laws discussed are not applicable, the experiences discussed may be helpful. It can be downloaded by checking the Young PD/employment section at www.parkinsons.org.uk.

***Montel Williams**, an Emmy-winning syndicated talk show host, author and motivational speaker, has been named the national spokesman of the **Partnership for Prescription Assistance (PPA)**, a patient assistance program clearinghouse launched last April. Since then, the PPA has matched more than 1.2 million Americans to public and private patient assistance programs that may provide them with free or nearly free medicines. The PPA offers a single point of access to more than 475 public and private patient assistance programs, including more than 150 programs offered by pharmaceutical companies. To access the PPA call toll-free, 1-888-477-2669 or see www.pparx.org.

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Seattle, WA 98195
Attention: Anne, APDA

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Is your address correct on this mailing?

Returned and duplicate mailings waste valuable funds needed for Parkinson Research and support. Please submit any address or name corrections to APDA by contacting the I & R Center by phone, mail or email at the contact information listed on page 2.

Please take a minute to do so ~ we will all benefit!



Help Support World Parkinson's Awareness Month and APDA ~ Join us April 8 at Abracadabra The Magic of Hope!



ABRACADABRA
THE MAGIC OF HOPE!

You have been cordially invited to the 4th annual Auction Dinner to benefit the
Washington State Chapter of American Parkinson's Disease Association.
Saturday, April 8th, 2006

The "Magic" begins at
Six O'clock p.m.

Saint Demetrios Greek Church
2100 Boyer Avenue
Seattle, WA 98112

Enjoy a wonderful evening of Mime, Magic, Dinner and Great Auction Items!

Lets Make the "Magic" Happen!

Name.....

Address.....

City.....State.....Zip.....

Phone.....E-Mail.....

Tickets \$350.00 for table of 8
\$45.00 for single tickets

Please make out checks to : WA Chapter, APDA
Address: Washington State Chapter, APDA
PO Box 75169, Seattle, WA 98175-0169

RSVP by March 31st, no tickets sold at door

For further information, contact Evelynne Davis at 425 443 8269
www.waparkinsons.org