



American Parkinson Disease Association

# Parkinson Pathfinder

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

Spring 2005

## APDA of Washington State Parkinson's DVD Soon to be Launched

*Michael G. Shanahan, APDA Board Member and STHH Committee Co-Chair*



*Mike Shanahan, co-chair of the APDA's STHH Committee and the driving force behind its creation.*

For the last two years members of the Washington Chapter of the American Parkinson Disease Association (APDA) have been working to produce a DVD for newly diagnosed Parkinsonians. Later this spring copies of the DVD will be made available to APDA members via the various I&R centers throughout the United States. Those who have labored in this vineyard are

looking forward to the release. Playing a prominent leadership role in producing the audiovisual document was vm:creative of Seattle Washington.

The following is a short executive summary that will give the reader a clear view of an exciting use of technology that was primarily developed in behalf of newly diagnosed PD patients. However, it is also of benefit to those who have had the disease for a significant period of time. This enterprise has been well received by all those who have had exposure to it. We look forward to its release with great enthusiasm.

### Managing Parkinson's:

#### STRAIGHT TALK & HONEST HOPE

In the last several years a number of high profile people have raised the level of awareness surrounding Parkinson's Disease (PD). Principal among them are Pope John Paul II, Muhammad Ali, The Reverend Billy Graham, Janet Reno and Michael J. Fox. Research of this disease that afflicts 1.5 million Americans with another 3 million displaying PD symptoms, is receiving major media focus because many in the medical community believe a cure or major breakthroughs are at hand.

#### Easing The Burden

The Washington Chapter of the American Parkinson Disease Association (APDA) is concentrating its efforts on the phrase "Easing the Burden" which makes up one half of the association mission. Managing Parkinson's -Straight Talk

and Honest Hope (STHH) has two major goals. The first is to promote candid information sharing among patients, their healthcare professionals and lay support providers. The second goal is to demonstrate the utility of user-friendly technology others can replicate for managing a variety of chronic diseases. With growing numbers of Early Onset Parkinson's persons filling the "ranks," the need for honest, hopeful dialogue coupled to personal health maintenance strategies is becoming critical. Joining the Washington APDA Chapter in this enterprise are leaders from the Northwest Parkinson's Foundation.

Compared with many other infirmities, there are not a great number of clinicians specializing in treatment of PD patients. This is particularly true in the less populated areas of rural and even suburban America. Managing the challenge of first diagnosis with its high levels of depression (50%) argues convincingly for outreach initiatives to bolster individual hope, coupled to what can be best described as a large pool of printed information about PD. However, what is missing is the personal hope-strengthening advice and "high touch" encouragement that can be shared with recently diagnosed patients and their families through a comprehensive digital video disc (DVD).

#### Information Age Technology

The Washington APDA Chapter is working with vm:creative of Seattle, Washington to produce such a DVD that will provide personal accounts of experiences, common feelings that affect most Parkinsonians and successful

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**Information & Referral Center**

UW Dept. of Neurology

Box 356465

Seattle, WA 98195

Phone: (206) 543-5369

1-888-400-2732

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

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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.

**News from your Washington State APDA****April is Parkinson's Disease Awareness Month**

April 11<sup>th</sup> marks the birthday of Dr. James Parkinson, who first recognized the disease now named for him. You can help to promote awareness about PD by participating in April Parkinson Disease Awareness Month events, and/or making a special effort to disseminate PD information within your community. On page 5 you will find an invitation to the 3<sup>rd</sup> annual "Rockin' for a Reason" event, coinciding with PD Awareness Month. If you would like any literature or posters to help disseminate information about Parkinson's Disease, please contact us at the the APDA I&R Center, at the contact information listed on the left. *There's a lot of work to be done to raise PD awareness.....please join us in this huge effort!*

**Calling all Young Onset Parkinson People!**

In response to a growing need to develop more effective support to the Young Onset Parkinson's community, the Washington State APDA Chapter and I&R Center are planning a focus on YOPD programming and events for their 2005 program year. There are many ideas afloat, including a YOPD event. In order to gather feedback from a larger group of people affected by PD at a younger age, a group of support group members has developed a survey that you will find inserted in this newsletter. If you are a person with YOPD, please help in this effort to identify YOPD needs and interests by completing the survey. Others can help by passing the survey on to persons with YOPD that you know or encounter. Our thanks to the survey developers for their efforts.

**Support Group News**

- The **PD Young at H.E.A.R.T. Group**, under the leadership of Steve Bohannan of Bainbridge Island, has developed a website which is open to anyone who wishes to "check in". The site, [www.pdyoungatheartsupportgroup.org](http://www.pdyoungatheartsupportgroup.org) contains information about the group's meetings and projects, along with other items of interest to persons affected by PD. The group itself meets monthly on the 1<sup>st</sup> Monday (see page 7 for details and contact information). Kudos to Steve and the group on this wonderful resource, which will be a real asset to our region!
- The new **Snohomish County Young Onset Parkinson Support Group** was organized by Karen Painter, and has had its first two meetings. The group meets monthly on 3<sup>rd</sup> Saturdays at 2pm at Providence Hospital Colby Campus in Everett. The group is also developing an online network. For further information, contact Karen at 425-327-9401 or at [kpainter62@aol.com](mailto:kpainter62@aol.com). We are pleased to have another group added to the roster!

**Upcoming Events**

- **Save the Date!! The 21<sup>st</sup> Annual APDA Parkinson's Symposium** will be held at the Shoreline Conference Center on Saturday, October 8<sup>th</sup>. See future issues of the Pathfinder, or the WA State APDA website for details [www.waparkinsons.org](http://www.waparkinsons.org)
- Due to the success of last year's research fundraising efforts, APDA will be once again inviting individuals and "teams" to host events for the **2005 Build a Benefit Campaign for PD Research**. Need ideas? Would you like to organize your own community mini-walkathon? We can help! Look for details later this spring here and online.

## Ask The PD Specialist



### Parkinson's and Your Bones—Both Need Special Care

Kathrynne Holden, MS, RD

**Q:** I have just heard that osteoporosis is a factor in PD. If so, is this true for men as well as women? My husband has PD, and I am concerned.

**A:** First, the bad news. Studies have shown that both men and women who have PD are at risk for bone thinning, osteoporosis, falls, and fractures. Compared to age-matched control groups, those with PD have lower serum levels of vitamin D, greater degree of bone thinning, and greater incidence of bone fractures. And still another study finds that people with PD have more difficulty with rehabilitation following a hip fracture than those who don't have PD. This, too, is true for men as well as for women.

Several years ago, I conducted a pilot study of 24 people with PD. The objective was to find out if the calcium, magnesium, and vitamins D and K in their daily diet was sufficient to help prevent bone loss. The results?

- Only one person met the daily requirements for calcium and vitamin D.

- Few were getting much weight-bearing exercise, which strengthens bones.

- Few got regular exposure to sunlight, a source of vitamin D.

If these findings are true for most folks with PD, it may mean that depleted diet, along with lack of sunshine and weight-bearing exercise, are a large part of the reason for the higher rate of bone thinning. Bone health is of special concern, because people with PD may have balance problems, postural instability, dizziness, freezing of gait or orthostatic hypotension. All of these can increase the likelihood of falls, and if the bones are weak, the risk for fracture is greater.

Now, the good news. Bone thinning and fractures are usually preventable, beginning with diet. Adults age 50 years need daily:

- 1200 mg of calcium

- 420 mg of magnesium (men) and  
320 mg magnesium (women)

- 10 mcg (400 IU) vitamin D

- 120 mcg vitamin K (men) and 90 mcg vitamin K (women).

The best and most readily absorbed sources of these nutrients are foods. Magnesium is found in whole grains, nuts, vegetables and fruits, although processed foods have often lost much of their magnesium content.

Dark green leafy vegetables, such as spinach and broccoli, and plant oils are excellent sources of vitamin K (and often of magnesium as well.) Milk is a very good source of both calcium and vitamin D. However, a few people who use levodopa find that the protein in milk can block the absorption of levodopa, longer than other proteins. For those who are milk-protein sensitive, orange juice that is fortified with calcium and vitamin D is a good choice. Fortified soy and rice milk substitutes are also good alternatives.

It's also a good idea to take a daily multivitamin. Unless you are anemic, choose one that contains little or no iron, such as One-A-Day 50 Plus, or Centrum Silver or a generic version of these. That will supply vitamins D and K, along with bone-building trace minerals. You may still need a calcium supplement or calcium-fortified foods. If you don't like swallowing more pills, these supplements can be crushed and taken with some applesauce, for easier swallowing.

Finally, try to get outdoors on sunny days. Just an hour a week can boost your vitamin D levels. And, walk as much as possible – weight-bearing exercise strengthens the bones of the legs, hips, and spine.

I encourage people with PD of all ages to talk with a registered dietitian (RD). The RD can help you plan the foods, fortified foods and/or supplements you need for bone health. And I also recommend that both men and women with PD ask your physician to conduct a Dexascan (bone scan) or other test to determine whether any bone thinning exists.

*Ms. Holden is a registered dietitian specializing in Parkinson's disease. She has authored "Eat Well, Stay Well with Parkinson's Disease," "Cook Well, Stay Well with Parkinson's Disease," and "Parkinson's Disease and Constipation;" see [www.nutritionucanlivewith.com](http://www.nutritionucanlivewith.com) or call 877-565-2665. She moderates the e-mail forum Ask the Parkinson Dietitian, [www.parkinson.org](http://www.parkinson.org), Online Forums.*

### KEEP MOVING!!

Laurel Beck, a physical therapist who is also on the APDA Board, emphasizes that weight bearing activities are important to minimize bone loss. These activities can take many forms, but the basic idea is to create a gentle stress through the bones. Walking is generally a great way to create the mild work load through the hips. Arm exercises can be helpful in creating more of a load through the shoulders and spine. She cautions that if you have any medical concerns or questions, you should check with a medical professional before starting a new exercise regime.

Suggestions for a variety of exercises are contained in the APDA Booklet *Be Active!* which is available for free through the APDA Information and Referral Center. (*see contact on page 2*)

## New Treatment for Parkinson's Disease with Dementia *James B. Leverenz, M.D.,*

It has become increasingly clear that many older individuals with Parkinson's disease (PD) can develop dementia (a loss of cognitive/thinking skills from a previously higher level that impairs a person's ability to perform normal functions). Evidence to date suggests that people with PD and dementia do not have coincidental Alzheimer's disease, but in fact have a complication of PD. A variety of terms have been used to describe this PD complication including PD with dementia, Lewy body dementia, and diffuse Lewy body disease (this writer prefers to use the term PD with dementia in patients where the PD precedes the cognitive problems). To date, there have been very limited formal treatment trials for this complication of PD.

In December of 2004 Emre and colleagues published, in the *New England Journal of Medicine*, a large treatment study of PD with dementia (541 participants) using a drug normally used for the treatment of Alzheimer's disease. The drug, rivastigmine (brand name Exelon), blocks the breakdown of a chemical used by brain cells to communicate (acetylcholine) and thus increases its levels. We know from studies in the brains of PD patients who have died that this chemical is significantly reduced in many brain regions. The study compared rivastigmine to placebo (sugar pill), and neither the PD subjects nor the investigators knew which one (a "double blind" study). The study found that PD subjects on

rivastigmine performed significantly better on cognitive testing of memory and other thinking functions and in terms of behavior problems than those taking the placebo. The rivastigmine group did have a larger number of subjects that complained of gastrointestinal symptoms (nausea and vomiting) and increased tremor. The latter complication appeared to be minor, since the evaluating doctors did not detect increased tremor on formal evaluation.

In the paper the authors note that the effects were modest. A similar impression was given in the editorial also published in the same issue of the journal. This writer is encouraged by the attempts to develop treatments for PD with dementia and the effects of this treatment on both cognition and behavior. Many physicians will likely now be using rivastigmine, and similar drugs such as donepezil (Aricept) and galantamine (Reminyl), for this PD patients with dementia and related behavioral problems.

*Dr Leverenz is an Associate Professor in the UW departments of Neurology and Psychiatry as well as a Neurologist at Seattle VA, and an investigator at the VA Parkinson's Disease and Mental Illness Centers and UW Alzheimer's Disease Center.*

*For information about Parkinson's research being conducted by Dr Leverenz, please call 206-277-4631 or 800-329-8387, ext. 64631.*

### *Continued from page 1.* **DVD Soon to be Launched**

initiatives that have improved patients' quality of life. This aspect can best be described as a one-way intervention and support group meeting. Because of its audiovisual capability, families and close friends can share the DVD viewing experience together in a more meaningful way. In most cases this can be in the supportive environment of their own homes.

A number of the STHH "team" have shared their confusion and sense of isolation following diagnosis. Even though there are support groups and resource centers available, few want to start off by going public as there are a number of issues to be faced, not the least of which is "telling the boss." With a FAQ approach, this product can help tens of thousands touched by PD. In its final form the DVD will contain links to a wide range of Internet sites and sources of information. The immediate goal is to include multiple types of information into one single and easily operated tool. At some future date down loading from a maintained web site will be possible.

#### Production and Distribution

What is envisioned is the sharing of the DVDs with neurologists, internists, general practitioners or anyone related to the diagnosis and treatment of PD. The American Parkinson Disease Association has over 60 Information and Resource Centers which are available to the 50,000 new patients annually. They can be the distribution paths to many thousands of these newly diagnosed patients.

STHH will be copyright protected, but plans are in place

to allow for copies to be made so long as the copying organization is a 501c3 charity recognized by the Internal Revenue Service, and that it be copied in a prescribed manner.

#### Ecumenical Spirit

Joining the APDA in this DVD production effort have been selected Parkinson's persons, their spouses and families, representatives from the Northwest Parkinson's Foundation, neurology faculty from the University of Washington Medical Center and Oxford University, healthcare providers and other appropriate contributors. Dr. C. Everett Koop, Former Surgeon General of The US Public Health Service has dedicated his personal support for this project by delivering recorded keynote remarks on campus at Dartmouth University.

To professionals in medicine and the pharmaceutical industry, the necessary time in bringing a new product to market can easily be a decade. A decade to a Parkinson's patient might well be life ending. With HOPE as the underlying goal, Managing Parkinson's –Straight Talk and Honest Hope has a positive mission that may have far reaching benefits not yet recognized.

*The DVD is in the final stages of production and should be available for distribution after May 1<sup>st</sup>. Donations to help with distribution costs can be made to WA Chapter, APDA. Please designate for "STHH". DVD orders will be accepted at the APDA I & R Center at the University of Washington (see Page 2 for contact information).*



## Washington State Parkinson Support Groups

### Eastern Washington

#### \*Okanogin

Valley Care Nursing Home

Contact Sandra Johnson

509.826.0491

Meets 3rd Thursday, 1pm

#### Wenatchee

Wenatchee Senior Center

Contact Estella Lenhart

509.667.0844

Meets 3rd Monday, 1:00pm

#### Richland

Richland Lutheran Church

Contact: Neurological Center

509.943.8455

Meets 3<sup>rd</sup> 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

yopdwc@hotmail.com

Meets 2nd and 4th Wednesday, 7 pm

#### Burlington

Homeplace Care Center

Contact Nancy Gentry

360.755.1493

Meets 2nd Tuesday, 2pm

#### Mill Creek

Merril Gardens

Contact: Bob Detmer

425-316-3958

Meets 2<sup>nd</sup> Tuesday, 7pm

#### \*North Whidbey Island

Oak Harbor Senior Center

Contact J.C. King

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 3<sup>rd</sup> 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: Hazel Forbes, 360.403.8896

Meets 4th Saturday, 2pm

**Caregiver Group**

Contact: Bill Coy, 425-338-3136

Meets 2<sup>nd</sup> 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, 2pm

#### \*Federal Way

Federal Way Library

Contact Brenda Vizzini, 253.839.9793

Meets 3rd Monday, 2pm

#### Edmonds

South County Senior Center

Contact: Merrie Kay Sharar

425.774.5555

Meets 4th Tuesday, 3pm

#### 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 res06h12@gte.net

Anne Guthrie 206.543-5369

Meets 3<sup>rd</sup> Wednesday, 7 pm

#### North Seattle/Shoreline

Shoreline Senior Center

Contact Scott Tieson

206. 365-1536

Meets 3rd Tuesday, 3pm

#### Mercer Island

Mercer View Community Center

Contact Carin Mack, 206.230.0166

Meets 1<sup>st</sup> and 3<sup>rd</sup> Tuesdays, 2-3:30 pm

#### \*West Seattle

Admiral Congregational Church

Contact Anne Guthrie 206.543-5369

Meets 3rd Thursday, 1:30 pm

#### Seattle Well Spouse Group

Greenwood Activity Center

Contact: Carin Mack or

socialwkr@earthlink.net

Meets 3rd Monday, 4 pm

#### \*Seattle Caregivers Group

University Congregational Church

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

#### Seattle VA Puget Sound

Restricted to Veterans

Contact Lois Osborn, 253.835.3144 or

Romay Franks, 206.277.4560

Meets monthly

Before joining a group,  
please contact the Group  
Leader to confirm  
location and schedule

\*Denotes APDA Affiliation

## Parkinson's Notes: Updates and Upcoming Events

- **“Ask the Experts about Parkinson's Disease: A Panel Discussion”**, a presentation by Booth Gardner Parkinson's Care Center will be held Thursday March 24, 2004, 12-2:30 pm. At the Evergreen Hospital and Medical Center in the Education Classrooms (TAN Area) Please call 425-899-3000 to register and for directions.
- **Volunteer Opportunity:** Join an advisory board to a coalition of people and organizations working with people with a variety of disabilities! Help us develop a **Wellness and Community Center** for non-elderly people with disabilities in King County. For more information, contact Alan Wittenberg at the MS Association, 206-633-2606.
- The New Jersey APDA Information and Referral Center at Robert Wood Johnson University Hospital has designed a **2005 calendar featuring NJ artists who have Parkinson's disease**. Entitled “The Art of Living: Living Well With Parkinson's Disease”, each page features one of a range of artworks: photography, paintings, drawings, quilting and needle point. Calendars can be ordered for \$10 each through the APDA I&R Center, Education Department, Robert Wood Johnson University Hospital One RWJ Place, Box 2601, New Brunswick, NJ 08903-2601. (732) 745-7520-Parkinson's Center line or via Elizabeth.schaaf@rwjuh.edu
- **“Challenges in Caregiving: Giving Care, Taking Care”**, an annual caregiver training conference, will offer practical caregiving skills, strategies and resources through workshops and exhibits. Monday June 6, Tukwila Community Center. Pre-registration is required and space is limited. Call for a full brochure and registration form at (800) 422-3263 or (360) 725-2544
- A **Health Fair** will be held on Friday, April 29<sup>th</sup> at the **South County Senior Center** in Edmonds, WA. The event will run from 9:30 am to 1:00 pm and admission is free. For information, call the Center at (425) 774-5555.
- **Research Volunteers Needed** Researchers at the University of Washington are trying to better understand why people with Parkinson's disease have difficulty switching between actions and maintaining an action over time. If you would like to learn more about the study, please call Kristie Spencer, Ph.D., Department of Speech and Hearing Sciences, at 206-543-7980 or email kas@u.washington.edu
- **Live Music and Auction Benefit for YOPD!** On Sunday May 15, from 1-5 pm, this family-friendly event at the Main Street Bar and Grill in Ferndale, WA will raise funds for programs dedicated to persons with Young Onset PD. Advance tickets are \$5.00 and can be obtained through contact with Susie at (360) 384-4634 or yopdwc@hotmail.com

University of Washington  
Department of Neurology  
Box 356465  
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!*



Your invitation to **Rockin' for a Reason** is enclosed. Join us in celebrating April as Parkinson's Disease Awareness Month!