

Parkinson Pathfinder

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

Fall 2003

Walking for Parkinson's Research

On Saturday, September 13 the 2003 Washington APDA Walkathon was held in Marymoor Park after a week of clouds parted for another of this season's abundant sunny days. All of the enjoyable event elements that the crowd of registered walkers, friends and family members gathered anticipated were duly offered by the hardworking planning committee led by co-chairs Suzanne Cameron and Sue Skelton: 20 brimming raffle baskets, fun new Walkathon t-shirts (this year joined by tote bags as an option), refreshments of every sort, lively music, relaxing massages, warm up exercise and a sociable amble along the park's delightful paths.

Walkers were led off by the Issaquah High School ROTC Color Guard, which included Dan Murray Baker son of a committee member. This year a few new activities highlighted the mission of the day: supporting research for the treatment and ultimate cure of Parkinson's Disease. Dr Cyrus Zabetian and his research aid Ms Luke Wander were on hand to explain their current study which hopes to discover the specific genes that either increase risk of developing PD, or modify the risk of developing certain symptoms associated with PD (see related article on page 3). They encouraged people to join the study and met with those interested.

A large banner was unfurled by Judi Baker, Washington representative to PAN (the Parkinson's Action Network, a national advocacy group), who invited people to add their thanks and encouragement to researchers and their supporters at two of the largest national centers of activity- The Michael J Fox Foundation and the Muhammad Ali Parkinson Research Center. The APDA I&R Center display of materials had a table of educational materials for children to help them understand the amazing workings of the human brain. We are pleased to see that despite our area's difficult economy, as of press time, participants have helped APDA come close to the \$50,000 raised last year for national research funding. This year's top individual fundraiser was once again Suzanne Cameron, followed by Jeanne Keiffer, Debbie Harrington and Susan Geisler (in a tie with Suzanne Geiger who deferred). The top fundraising team was the Sandra Evans team. Thanks to all who contributed through donation of money, time and effort. *continued on page 4*



APDA Executive Director Pat Noonan welcomes Walkathon 2003 participants



Walkathon Co-chairs Suzanne Cameron (left) and Sue Skelton (right) announced 22 raffle winner baskets.



I & R Center Coordinator Anne Guthrie at the Kids Education and Fun Booth

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 www.waparkinsons.org.

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 Ali Samii, MD

APDA Center Coordinator
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APDA WA State Chapter

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Board Address:
 P.O. Box 75169
 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.

News from your Washington State APDA

Longtime Parkinson's Advocate and Board Member Harry Benton will be missed



Harry Benton passed away in Tacoma on September 12, 2003, on the eve of APDA's annual Walkathon- an event he enthusiastically supported for many years. APDA of Washington was saddened to hear the news and wishes to express both gratitude for his years of leadership and efforts, and condolences to his wife Joy and his extended family.

Maria Linde, in her capacity as long-serving Information and Referral Center Coordinator and Board Member, worked closely with Mr. Benton and recalled this gentleman with the following tribute:

Harry Benton was an APDA Chapter President from 1985-1997 and remained on the board until his death. He was recognized by National APDA as an outstanding leader and as such was chosen to be a regional representative for APDA. Under his leadership, the Chapter sponsored the annual Walk-A-Thon for research and Harry was always the first one on the job and the last to leave. Harry was a true professional, always loyal, modest and kind. He was a consensus builder and a positive thinker; a true American hero. He will be sorely missed by his many friends.

In recognition of Harry's dedication, a leadership award was established in his name that is bestowed upon an individual each year at the annual APDA Symposium. This year's award ceremony will be even more significant to all as it will honor his many lifetime contributions as well.

A Big Band Benefit for Washington APDA

APDA of Washington was thrilled when it was informed that it was the charity selected to benefit from the proceeds of a dance held by the Weatherly Inn for Assisted Care in Tacoma. The dance, billed a "1940's USO Dance" was held Saturday September 27th at the Inn on North Highland Parkway. Clothing of the era was the dress of choice and the dance floor was hopping to music of many styles- Big Band, Swing and Latin- all provided by the live music of the Johnny Lewis Band. Along with entertainment, the evening featured a fine catered buffet and beverages.



Sincere thanks go to the residents and management of the Weatherly Inn for helping fund the programs and services of Washington APDA through such a fun-filled event!

Board Member Changes

APDA of Washington is pleased to welcome as new Executive Board members Ann Zylstra, Physical Therapist at Booth Gardner Parkinson's Care Center; Laurel Campbell, Physical Therapist and PD Support Group Leader at Virginia Mason Medical Center; and Janice Jaworski of United Way of King County. Board member Lise Ellner has announced her need to step down due to family needs. We thank her for her involvement as a Board member.

Medical and Research News

Local Parkinson's Research Study Seeks Participants

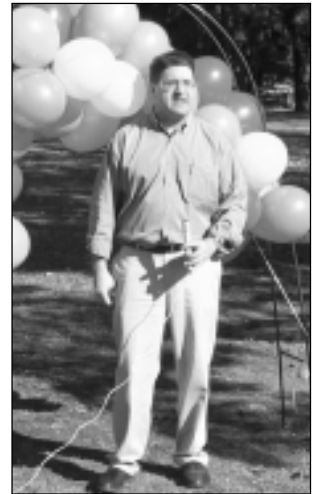
Dr. Cyrus Zabetian recently met with APDA Executive Director Pat Noonan and others to discuss his current PD research and ways the Washington Chapter and the PD community might support it. As a result of their conversation, Dr. Zabetian participated in the 2003 APDA Walkathon and spoke to those gathered about the focus of his group's study and the significance of public support through participation and fundraising. He is one of several PD researchers who have begun to network as a result of meetings initiated by APDA.

In describing his research, Dr. Zabetian provided the following summary:

An individual's risk of developing Parkinson's disease (PD) is determined by a complex interaction between environmental and genetic factors. Identifying these factors will be critical in developing more effective strategies of early diagnosis, prevention, and treatment of PD. Our group is conducting a research study based at the Seattle VA and University of Washington Medical Centers to discover specific genes that wither increase susceptibility to PD or modify the risk of

developing certain symptoms associated with PD. We are seeking both patients with PD and individuals without PD (normal controls) to participate. The study requires a brief assessment of family and medical history, followed by a small blood draw. For further information please contact our research office at (206) 277-4594.

As Washington APDA continues to join the National organization's fundraising efforts to support research to "Find the Cure" for Parkinson's, it will also seek ways to support the dedicated work of local researchers. We hope you will join us in this effort.



Dr. Cyrus Zabetian explained his PD research study at the recent APDA Walkathon for research funding

New Parkinson's Medication Now Available

On September 16 Novartis Pharmaceuticals Corporation announced that a new treatment for Parkinson's disease, Stalevo™ (carbidopa, levodopa and entacapone) tablets, is now available in U.S. pharmacies. Indicated for patients with signs and symptoms of end-of-dose "wearing off," this enhanced levodopa therapy is reported to significantly improve Parkinson's disease patients' ability to control body movements and the ability to perform basic functions such as walking and dressing versus previously available forms of levodopa. Stalevo is the first new treatment for Parkinson's disease in three years, and the first new form of levodopa in more than a decade.

"Levodopa is the most effective drug for treating the symptoms of Parkinson's disease," said C. Warren Olanow, MD, chairman and professor of Neurology at the Mount Sinai School of Medicine in New York. "With Stalevo, we can enhance the effects of levodopa and more effectively treat problems such as end-of-dose 'wearing off' that complicate the long-term use of regular levodopa and limit its utility. Stalevo thus represents an important advance in our ability to treat Parkinson's disease patients."

A recent Harris Interactive survey found that 55 percent of Parkinson's disease patients on an older form of levodopa cited "wearing off" of their medication as the biggest treatment challenge they face. In addition, 92 percent of physicians surveyed said that the re-emergence of Parkinson's disease symptoms due to "wearing off" was a significant

concern about levodopa, with nearly half citing "wearing off" as the one biggest challenge. The survey was conducted in partnership with the National Parkinson Foundation (NPF). **About Stalevo:** Stalevo is a new form of levodopa therapy that targets end-of-dose "wearing off" by combining levodopa, the most widely used agent for treating Parkinson's disease, with carbidopa and entacapone. While carbidopa reduces the side effects of levodopa, entacapone extends its benefits, permitting Parkinson's disease patients to have an improved ability to perform everyday tasks, as well as a reduction in symptoms associated with the disease. Stalevo simplifies treatment for many patients by providing three medications in one tablet, which reduces the number of tablets that patients need to take daily.

The most common side effects of Stalevo therapy are dopaminergic in nature (e.g. dyskinesia, nausea). These side effects may be manageable with alteration in the drug dosing schedule. Other common side effects include diarrhea, hyperkinesias, urine discoloration, hypokinesia, abdominal pain, dizziness, constipation, fatigue, pain and hallucinations. For full prescribing information, visit www.stalevo.com or call 1-866-STALEVO (866-782-5386).

Stalevo was approved by the U.S. Food and Drug Administration (FDA) in June 2003 and is marketed by Novartis Pharmaceuticals Corporation and manufactured by Orion Pharma.

continued from page 1

Walking for Parkinson's Research



PD advocates Dennis Wright and Judy Baker invite signatures on the Researcher Appreciation Banner

Special recognition goes to:

Planning committee members: Marilyn Gustafson (registration table), Jeanne Keiffer (refreshments), Emily Hollyday (donor acknowledgements), Alisa Malloch (park liaison, set-up), and all around contributors Terri Kolar, Maria Linde, Suzanne Geiger, Celia Grether, Pat Noonan, Anne Guthrie and Judi Baker.

Event Volunteers: members of Omicron Master Chapter, Beta Sigma Phi, Tami Horuchi, Dennis Clancy, Chris Jewell and a crew of students including Sam and Pat Jewell and Sam Ryan. Also busily at work were masseuse Denise Paterson and Exercise Leader Debby Hanson.

Corporate donors of goods and services: Jim Carey of CKA Graphics (tee shirts and bags), Kaye Smith Company (banner material) and many food vendors: QFC-Roosevelt Way NE, Encore Sales and Marketing, Summit Brokerage, Inc., Schwan's Foodservice, Stemilt Fresh Fruit, Morton & Associates, and C&C Brokers. Krispy Kreme supplied donuts for the early morning set up crew and hats for all.

Musicians: The Sammamish Eastlake Jazz Band, and The Potbelly Boys.

Thank you to all who joined us at Marymoor, or in other ways contributed to this year's Walkathon. Your help in raising funds fuels research to solve the remaining mysteries of Parkinson's Disease.

Volunteer Opportunities

As a volunteer-based organization, APDA always has need for additional helping hands to assist in carrying out its various programs.

Contact Anne at the Information and Referral Center at 206-543-5369 or by email: apda@u.washington.edu for details of any of the volunteer opportunities listed here.

Thank you!!

Current Needs:

Driver Needed to assist with the delivery of literature to support groups in the North Seattle area. Royale Landy is a participant in the Shoreline Support Group who has developed a Literature Table of Parkinson's information. She has a continually expanding collection of books, newspaper and magazine articles, information on and from websites, video tapes, educational bulletins and various Parkinson's publications. Royale is in need of a driver who can also help set up her display at least once per month.

Coming to the November 1st Symposium? We have need of volunteers to assist with registration, as guides and to be available at the luncheon amongst other things. You will be assured attendance to sessions as well.

Washington APDA Needs Your Continuing Support

How can I Help?

Your contributions make possible such things as:

- * The ongoing services of the Information & Referral Service
- * The free distribution of the Pathfinder Newsletter
- * Support Group Leader Assistance and Training
- * Continuing Education on PD for Health Care Professionals
- * Research for treatment and a cure for PD
- * A variety of outreach activities that ease the burden for those impacted by Parkinson's Disease

What can I do?

- * Make a personal contribution
- * Make a donation on behalf of friends of family instead of purchasing a gift, or as a tribute
- * Ask family and friends to make donations to APDA instead of buying you a gift
- * Remember the APDA in your will or trust

Remember, donations designated to "The Washington State Chapter APDA" will be used exclusively here in the state of Washington in order to provide services and support to our PD community.

Thank you for thinking of us as we strive to provide support to you!

APDAppreciation

The following corporations are deserving of our sincere thanks for their efforts on behalf of APDA and the Parkinson's community:

Safeway stores for selecting us as the Charity of Choice for July 2003 raising over \$41,000 for APDA chapters in Washington, Idaho, Alaska and Montana.

Thanks to all of you who contributed your change at the check out counter.

Great Clips in Washington for selecting the Washington Chapter as the beneficiary of their Great Needs, Great Deeds Campaign for **October 18-24 2003**.

Boehringer Ingelheim, manufacturers of PD medications, for providing funding for a continuing education program for neurologists, featuring one of our co-medical directors, Dr. Ali Samii.

Cut your Hair to Show You Care
**Come to the Great Clips
Clip-A-Thon October 18~24
to benefit Parkinson's**

Everyone knows a haircut will make you look good, but this one will make you feel good, too! Great Clips salons are hosting a Clip-A-Thon the week of October 18-24 to benefit the Washington State Chapter of the APDA. The money raised will be used to support those impacted by Parkinson's Disease in Washington State.

Puget Sound PD Housing Alliance (PuSH for PD) Seeks Your Input

PD advocates in the Seattle area have been organizing to address the housing support needs of the PD community. To better know what people's concerns and interests might

be, they are seeking input on a PD Residential Care Survey. Please consider their information and send in the form below or contact Wendy at:(206) 354-7872 (evenings).

We are an ad-hoc group within the PD community conducting a survey to determine the need for residential care among persons in the advanced stages of Parkinson's disease. We feel that the specialized care required by PD patients necessitates a dedicated residential facility with a program of comprehensive care. While the survey is not officially sponsored by the Washington State APDA, the chapter is notifying the PD community of its availability.

**Do you or someone close to you suffer from Parkinson's Disease?
If so, are you interested in a group-assisted living situation for persons with PD either
on a respite care basis? or on a permanent, full-time basis?**

If the answer to both questions is yes, your input is needed!
Please detach and mail in the slip below and we will mail you a copy of our residential care survey with a stamped, addressed return envelope. Your answers will be held in strictest confidence. Thank you!

PuSH for PD committee members:
Wendy Holman - Maria Linde - Carin Mack - Dennis Wright - Carey Christensen

Yes, please send me a copy of the PD residential care survey.

Name _____

Address _____

City _____ Zipcode _____

Phone _____ email _____

Return by mail to: Wendy Holman, 10544 41st Place NE, Seattle, WA 98125

Washington State Parkinson Support Groups

Eastern Washington

*Okanogan

Valley Care Nursing Home
Contact Sandra Johnson
509.826.0491
Meets 3rd Tuesday, 10:30 am

Wenatchee

Wenatchee Senior Center
Contact Dawn Kelly
509.884.6602
Meets 3rd Monday, 1:30pm

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, Polly Maxwell
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

Hearing and Speech Center
Contact Ruth or Blanche
509.576.9392
Meets 4th Saturday, 2pm

Western Washington

Puyallup

United Methodist Church
Contact Anita Graham
253.435.8532
General Support Group
Meets 3rd Thursday, 1:30pm
+Caregivers Support Group
Meets 2nd Thursday, 1pm

South Sound Young Onset - Tacoma

Group Health Specialty Center
Contact Robert & Kathy Swanson
253.848.5484
Meets 2nd Wednesday, 7pm

Anacortes

Island Hospital
Contact Pat Grady
360.299.3150
Meets 2nd Friday, 2pm

Bainbridge Island

Winslow Manor Apts
Contact Laura Steimmann
206.855.9321
Meets 4th Wednesday, 10:30am

Bellingham

Parkway Chateau
Contact Debra Ivanovich
360.724.3382
Meets 2nd Monday, 2pm

Burlington

Homeplace Care Center
Contact Nancy Gentry
360.755.1493
Meets 2nd Tuesday, 2pm

Chehalis

Dayspring Baptist Church
Contact Parkinson's Resources of Oregon
800.426.6806
Meets 2nd Thursday, 1:00 pm

Mill Creek

Merril Gardens
Contact Bob Detmer
425.316.3958
Meets 2nd Tuesday, 7pm

*North Whidbey Island

Oak Harbor Senior Center
Contact J.C. Kline
360.675.7695
Meets 1st Tuesday, 1:30pm

Vashon Island

The Lutheran Church
Contact Robin Stover
206.463.5173
Meets 1st Thursday, 10:30am

Port Angeles/Sequim

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

Bremerton

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

*Shelton

Alpine Way Retirement Apts
Contact Jacques Davis
360.426.2600
Meets 4th Tuesday, 1:30pm

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 Jane Hiebert
360.574-9168
Meets 3rd Saturday, 2pm

Greater Seattle Area

*Everett

Providence General Medical Center
Contact: Hazel Forbes
425.261.2000
Meets 4th Saturday, 2pm

+Everett Caregiver Group

Providence General Hospital
Contact: Bill Coy
425-338-3136
Meets 2nd Monday 2-4pm

*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 Rosemary O'Dell
253.839.1970
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 3rd Wednesday, 7 pm

North Seattle/Shoreline

Shoreline & Lake Forest Park 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 1st and 3rd Tuesdays, 2-3:30 pm

*West Seattle

Admiral Congregational Church
Contact Anne Guthrie 206.543.5369
Meets 3rd Thursday 1pm

+Adult Children

Elderhealth NW - Northgate
Contact Wendy Holman
206.365.7872
Meets 2nd Wednesday, 7:00pm

* + Seattle Caregivers Group

University Congregational Church
Contact Carin Mack
206.230.0166
Meets 2nd Thursday 3pm

+Caregivers - Eastside

Mercer View Community Center
Contact Carin Mack
206.230.0166
Meets 2nd Tuesday 2pm

Seattle First Hill

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

* Denotes APDA Affiliation

+ Denotes Specialty Group

Short Takes and Upcoming Parkinson's Events

On Thursday, October 30 from 3:30pm to 6pm, the Booth Gardner Parkinson's Care Center is holding a seminar on "Advances in Medical Treatment for Parkinson's Disease and Other Movement Disorders". Speakers will include Dr. Anthony Mosley, Dr Alida Griffith and Dr Berta Leis all on staff at the Center located at Evergreen Medical Center in Kirkland. To register for this free event, call (425) 899-3000.

Telehealth Broadcasts Monthly Educational Meetings

Thanks to the efforts of the Parkinson's Regional Center of Spokane, people in many areas of Eastern Washington can "attend" monthly educational meetings without having to travel to Spokane. A network of area hospitals are making their facilities available for persons to view and interact with live broadcasts of presentations on PD. If you live in one of the areas listed below, contact the site directly to ask the coordinator about the particular broadcast. Educational meetings are typically scheduled the 3rd Monday of each month from 2-4 pm. Call Polly Maxwell at PRC for details at (509) 473-6740 or check their new website at www.spokaneparkinsons.com

City and Site Locations:

Chelan-Chelan Community Hospital
 Chewelah-St Joseph's Hospital
 Clarkston-Tri State Memorial Hospital
 Colfax-Whitman Hospital & Med Ctr.
 Colville-Mt. Carmel Hospital
 Davenport-Lincoln Hospital
 Dayton-Dayton General Hospital

Deer Park- Deer Park Hospital
 Ephrata-Columbia Basin Hospital
 Grand Coulee-Coulee Community Hosp
 Ione-Selkirk Community Hospital
 Moses Lake-Samaritan Healthcare
 Newport-Newport Community Hosp.
 Odessa- Odessa Memorial Healthcare

Omak-Mid Valley Hospital
 Othello-Othello County Memorial Hosp.
 Pomeroy-Garfield Cty Memorial Hosp.
 Pullman-Pullman Memorial Hospital
 Republic- Ferry County Memorial
 Sunnyside-Sunnyside Community Hosp.
 Walla Walla- St. Mary Medical Center

University of Washington
 Department of Neurology
 Box 356465
 Seattle, WA 98195
 Attention: Anne, APDA

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Address Service Requested: 63-2949

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!*

**Register Now for APDA's annual symposium -
 Mind, Motion & Hope, Saturday, November 1 at Shoreline Center**
Great Clips Clipathon for APDA October 18-24