



American Parkinson Disease Association

# Parkinson Pathfinder

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

Winter 2006-2007

## Raising the Flag for Parkinson’s

*Over view by Ann Zylstra*

This was the APDA’s 22<sup>nd</sup> annual educational conference. This year’s event was special and unique for many different reasons. We joined together this year, with the Northwest Parkinson’s Foundation, to offer a bigger event than ever before. A record attendance; 650 individuals, enjoyed the variety of professional presentations which offered positive outlooks and treatment strategies for those suffering with Parkinson’s disease. About 40 % of the audience was patients with Parkinson’s, 20-30% caregivers and the rest were physicians, researchers, therapists and other healthcare providers.

The conference was commenced with a joint presentation by the current and past 3 governors of the state of Washington. Governor Christine Gregoire gave a positive message of hope for a cure. She discussed the establishment of the Life Sciences Discovery Fund that was indicative of Washington’s State commitment of support for research; to find a cure for progressive diseases such as Parkinson’s disease.

Past governor Gary Lock, was unable to attend as planned, but sent a heart felt letter talking of his mother’s struggle with Parkinson’s disease.

Dan Evans, whose brother has Parkinson’s, talked about the importance of quality care for those living the disease. He and Booth Gardner worked together on the NWPF board to help launch the Booth Gardner Parkinson’s Care Center at Evergreen Hospital. “We came from different sides of the political aisle” he stated; “but good ideas are not preceded by a R or a D”.

When Booth Gardner was introduced he was preceded by his 16 year old grandson, Jack Nettleton. Jack spoke of his interactions with his grandfather and how the disease was

slowing his grandfather down. Booth Gardner shared his newest treatment, the deep brain stimulation, including removal of his shirt to show his wires and pace generator in his chest. He encouraged people to offer help to others when it is obvious someone is struggling with a task.

After the governors there were 2 more morning Plenary sessions, one by Dr. Monique Giroux of the Cleveland Clinic in Ohio, and another by Dr Dave Heydrick. Dr. Giroux spoke of the treatment options for Parkinson’s and Dr. Heydrick spoke of his Parkinson’s Pyramid™ which he designed to empower patients to live well with Parkinson’s.

The afternoon gave the audiences choices of 3 different breakout groups. The afternoon speakers included Dr. Giroux, and Dr. Heydrick answering questions from the morning talks. Dr. Alida Griffith spoke with a group about couples and relationships. Dr. Jim Leverenz and Dr. Cyrus Zabetian discussed current research going on in Washington and the established Parkinson’s Registry. The registry consists of voluntarily provided personal health information that would enable them to be more easily selected for voluntary clinical trails.

Other presenters included Ann Zylstra PT (How Parkinson’s affects Gait and Balance), Kay Ballen OTR/L (Driving with Parkinson’s), John Gibson, DSW (Care partnering), Dr. Jeff Shaw (Cognitive aspects of Parkinson’s), and Sierra Farris, PA (DBS surgery).

The response to the symposium was very positive. Those who attended understood the problems with parking and room sizes that are inherent with any meeting of this size. To view video segments from the conference go to the Washington Chapter website, [www.waparkinsons.org](http://www.waparkinsons.org).

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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

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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****Executive Directors Report, Winter 2006**

First of all I would like to wish everyone a very Happy Holiday Season, and please remember to send a small donation in the enclosed envelope at this time of Giving.

We had a wonderful Conference, and 650 people attended this event on November 18<sup>th</sup>. Governor's Gregorie, Evans, and Gardner all attended, and all make very compassionate speeches to our audience. This was the 1<sup>st</sup> year that we collaborated with Northwest Parkinson's Foundation, and it was indeed a great success.

Our PD Teens Support Group is now up and running, and we will be holding our 1<sup>st</sup> Event on December 20<sup>th</sup>, which will be a ski trip to Snoqualmie. If you need further information on this please feel free to contact Karen Gorrin who is our PD Teen Facilitator.

Our best wishes for a speedy recovery go out to Anne Gurthrie, our Information and Referral Coordinator, who has been in hospital. We hope to see you back in the office very soon.

The Awards this year for Excellence in Leadership and Service were awarded to Ann Zylstra and Peggy Newsom, for their outstanding work and dedication to the Washington Chapter of the APDA.

Please mark your calendars for our Annual Auction/Dinner on April 21<sup>st</sup>, 2007 at St Demetrios Church Hall, Seattle. Save the Date cards will be going out after the Holidays.

**Have fun while exercising your voice!***By Richard Price**First Hill Seattle PD Support Group participant*

Parkinson patients here's an option to strengthen your voice modulation while staying active. And the answer is KARAOKE! Spend 30 minutes or more each day singing your favorite songs and if you can...dance along with your singing! Don't worry about how you sound or if you have the talent for this...Just Do It...Do It...Do It!

Double or triple your fun by getting your partner, family members, friends, and neighbors to join you. Whenever possible be sure to get young people

involved as they will most certainly energize your sessions and increase immensely the entertainment level. After experimenting at a friend's home for the past few months I've decided to purchase (for Christmas) a Karaoke player for my home and plan to make this a regular part of my day. I know, I know....I'm not quitting my day job...just yet!!! If this sounds like something you'd like to discuss further or if you have questions feel free to contact me via APDA. Now go get started and have a Good Time!!! Who knows maybe we'll see each other on "American Idol"!!!



**Happy Holidays to You & Your Family  
from the board and staff at  
American Parkinson's  
Washington State Chapter**



## Washington Parkinson's Disease Registry

One of the greatest obstacles facing researchers in Parkinson's disease (PD) today is finding adequate numbers of patients to participate in research studies. This often leads to substantial delays in getting research projects started and frustrates patients who are eager to participate but do not find out about the studies until it is too late. To address this problem, the APDA is partnering with the Northwest Parkinson's Foundation, Northwest Collaborative Care, and local researchers to create the Washington Parkinson's Disease Registry. Patients who choose to participate in the Registry will receive information about studies for which they are eligible on a regular basis and in a timely fashion. These studies might include research on new drugs or other therapies, genetic and environmental risk factors for PD, or new methods for early diagnosis and tracking disease progression. The Registry will create a network of physicians, scientists, and patients from across the state who will work together to accelerate progress on studies that will be critical in better understanding and treating PD. It will also serve to raise awareness about PD both in the community and among health care professionals.

The Registry will be co-directed by Drs. James Leverenz and Cyrus Zabetian at the Seattle Veterans Medical Center and the University of Washington. The anticipated launch date will be in the spring of 2007. We will provide an update on how the Registry is progressing and let you know how you can participate in this exciting project in the next edition of the Pathfinder!

## Elderly Can Take Steps To Prevent Falls

By Jose Loera, M.D., University of Texas

Although many seniors may fear catching a cold at the grocery store or being involved in a fender bender, one of the biggest preventable dangers to people over age 65 exists within their own homes - accidental falls. More than one quarter of seniors experience at least one fall per year. Commonly, both the number of falls and severity of injuries increase with age. Injuries from falls account for a large percentage of hospital admissions in seniors and can potentially cause severe trauma, such as hip or other bone fractures, and head injuries. Three of the most common causes of falls in the elderly living independently are:

1. **Accidents**
2. **Poor balance or weakness when walking, resulting from arthritis, side effects of medications, alcohol, pain, and/or seizures**
3. **Declining hearing and vision**

As one ages, the body may experience a loss of muscle mass and slowing nerve responses. These changes may make it difficult for a person to avoid a fall since the ability to detect and react to potential obstacles may be diminished.

## *Learn to Appreciate the Ordinary*

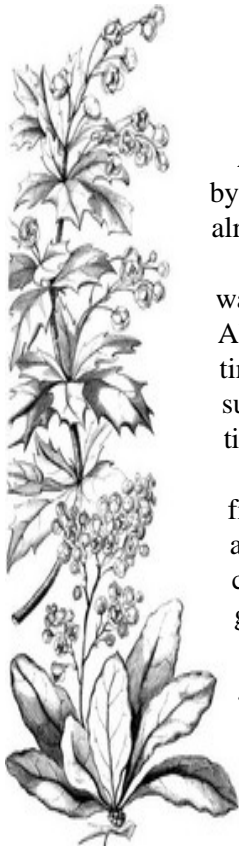
Author Mitch Albom says that for his book *For One More Day*, he became fascinated by how people answer this question: If they could spend one more day with a loved one already departed, how would they spend it? What would they do?

Albom says in a piece for *Parade*, that what he found time and again was that people wanted to spend an ordinary day doing ordinary things with the people they had loved. Almost everyone, he says, wanted to tell the person that they loved him or her one more time. Some said they wanted to do the habitual things they always did with the person, such as head to the racetrack, or eat in a favorite hamburger joint and talk about old times.

One son wished that he could share knowledge that would have relieved his father from guilt over an incident where the father threw a snowball and accidentally blinded another son. Later, after the father's death, the family learned that the son had a condition that had predisposed him to this happening. He wanted to give his father the gift of lifting his burden.

One man longed for a moment with his son who died in a car accident. He wanted to go for a walk with him in the woods that had been their getaway.

Albom says asking people about this scenario, helped him understand what we yearn for. Often, he says, it's not something exotic or far away. It's about connection. And realizing that a normal day is something we should all treasure, he says.



## Choice Advisory Services

CHOICE Advisory Services is a referral agency whose purpose is to help families and older adults grapple with the realities of aging. CHOICE has helped thousands of families make an informed decision to either help a loved one remain at home with in-home care support or make a transition to a senior retirement or care community. The agency also helps people downsize to less complex living arrangements in a condominium or single-story, low maintenance home.

Developed in 1993, CHOICE offers the assistance of over thirty knowledgeable representatives serving the greater Puget Sound area. Services are offered in any Washington State county that touches the Puget Sound. Assistance is also offered through offices Oregon and Southern California.

There is no charge for the assistance of a CHOICE Advisor. The guidance CHOICE offers is made possible by funding from the senior housing and care providers. These providers value the work CHOICE does in meeting with people and helping define their options. The agency also does all it can to help ease the stress of this transitional time by helping to arrange the various services that will facilitate a smooth move to a new living environment.

To qualify for CHOICE's assistance, a person must be able to pay privately for services for six or more months. CHOICE also provides real estate and financial services if a person is in

need of assistance with selling a home; or if financial assistance is needed to structure a payment plan for services. CHOICE also helps individuals apply and qualify for state and veteran's assistance, when necessary or applicable.

People at CHOICE take the time to discuss a person's specific options and to explain the services available in their community. Their work involves continuous visits and interactions with the care or service providers; but their true value comes from their interactions with the families who access their services. CHOICE continues the relationship with its clients even after the move is completed. This way the CHOICE advisor is aware of which communities are best able to serve the individual needs of people with mobility, memory loss or personal care concerns.

Les Ostermeier, founder of CHOICE says, "We're fortunate to have so many options and services available in our community, but knowing which of these options are the right matches for people can be a complex issue. By working with CHOICE, people get the focused and helpful guidance they need. We're not a placement agency – we're an information and referral agency – founded on the principal of helping people find what they're seeking or what they need."

CHOICE can be reached seven days a week from 8:30AM to 8:30PM, 365 days a year.

## SAVE THE DATE!!!!!!

*The American Parkinson's Disease Association*  
*Washington Chapter's*  
**FIFTH ANNUAL**  
**DINNER**  
**AND AUCTION**

Please mark your calendars Now! The Date is Saturday, April 21, 2007

St. Demetrios Church, Seattle, Washington

for our Annual Dinner and Auction

Early Reservations can be made

Cost: Tables of 8 - \$475      Single Tickets - \$65.00

For Tickets and Information please contact Evelynne Davis at 425 443-8269

E-Mail: [evedavis@gmail.com](mailto:evedavis@gmail.com)

## Letter From the President

By Ann Zylstra

Another exciting year is coming quickly to a close. On behalf of Suzanne Cameron and myself, thank you again for your wonderful support to the APDA. This year had so many wonderful successful events, but none of it would be possible without all of you!

This year began (or last year ended) with the hiring of our executive director, Evelynne Davis. She is so energetic and efficient that time has truly flown.

The auction this year had the best turn out it's ever seen. Our theme "The magic of Hope" will continue for years to come. This year's auction raised \$39,000 for use within the state of Washington only. This money is being used for funding of educational events, support groups, medical equipment for those who can not afford it, and for research. We are actively involved with the PDRC (Parkinson's disease research center) and are very excited about the research and the establishment of the registry.

This summer we hosted the first annual retreat for local Parkinson's non-profit organizations. The purpose was to join together to discuss how we can all coordinate our efforts to be more financially responsible and more efficient in striving

to ease the burden of Parkinson's disease. Each group reported their mission and time was spent getting to know how to better work together and share new information.

Our fundraiser for National research was again led and organized by Suzanne Cameron. The theme was Pirates of the APDA which was fabulous and attended by many. This function raised \$28,700 that will be directed nationally toward research, with the request that some of the money be returned to Washington, for the Cameron-Jewel research grant.

Our 22<sup>nd</sup> annual educational conference took place on November 18<sup>th</sup>. We coordinated efforts and financial support this year with the Northwest Parkinson's Foundation to host a much bigger conference than ever before. Current totals are 652 attended. Our goal had been to reach 400 people in the northwest so we are all very pleased with the outcome of the conference.

We have several new faces on the volunteer board of the WAAPDA. If you are interested in volunteering time for the APDA please let Evelyn Davis know at 425-443-8269.

On behalf of myself and Suzanne, and all of our wonderful board of volunteers, Have Happy and Healthy Holidays.



### Inspiration



#### On Strategy. . .

What you can't get out of, get into wholeheartedly. ~ Mignon McLaughlin

#### On Leadership. . .

To be a leader you must feel that you are both everything and nothing: nothing in that you are on this earth for a few years out of billions ~ everything, because you are the center of all activity in your world.

~ Edith Weiner

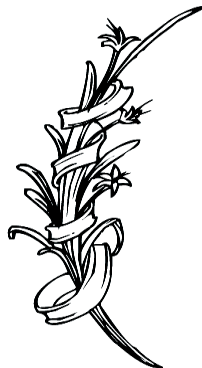
#### On Courage. . .

The ultimate measure of a man is not where he stands in moments of comfort and convenience, but where he stand at times of challenge and controversy.

~ Martin Luther King Jr.

### PD Teens Group Now Forming

The APDA is pleased to announce it's first-ever support and social group exclusively for teens with parents living with Parkinson's Disease. The new group, called "PD Teens" held an information session at this year's Governor's Conference, and was attended by nearly a dozen Seattle-area teens. Those in attendance shared ideas for co-creating a fun, interactive, supportive community. Future activities will likely include a skiing trip, bowling, discussion group, hiking, board game night, and more. PD Teens is facilitated by psychotherapist Karen Gorrin and will include both in-person monthly gatherings and an online message board forum. PD Teens is open to people aged 13-18. For more information contact Karen at 425.920.8008 or email: karen@karengorrin.com.



Donations received September 1, 2006 to November 2006

## Thank you for your Greatly Appreciated Donations!



### Donations

Thomas Timar  
Mr. and Mrs. Otto Gaiser  
Sherry Kasparek  
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Norman and Kathryn Adamson  
Viola Rutherford  
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### Donations for Straight Talk/Honest Hope DVD

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Karen Koger  
Beverly J. Alaraid  
James K. Drury  
Linda Lovell  
Paul Davit

*...and thank you to those who made equally  
important smaller donations*

### In Memory of:

**Marion Vanicelli**  
Priscilla Droge  
**Gerald Seitel**  
Jerry and Grace Lanuti  
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Mr. and Mrs. Richard Marcoux  
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### In Honor of:

#### Susan Wrigley

Mr. and Mrs. Richard Gibson  
**Chris Jewell and Suzanne Cameron**  
Sam and Lisa Howe Verhovek

## APDAppreciation:

*The following corporations are deserving of our sincere thanks for their efforts on behalf of APDA and the Parkinson's community. Please support them in return!*

**Stuart Whitmore of Johnny Pixel Productions** for his ongoing technical support for APDA's website development and multimedia event coverage.

**Paragon Media** whose collaborative spirit has enhanced the distribution of APDA's DVD Managing Parkinson's: Straight Talk and Honest Hope".

## 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!

### Greater Seattle Area

#### General PD Groups

##### Bellevue/Eastside

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

##### \*Bothell

North Shore Senior Center  
Contact Suzie Favaro  
425.486.4564  
Meets 2nd Tuesday, 9:30am

##### \*Federal Way

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

##### Issaquah

Providence Point  
Contact Phil Tompkins  
425-391-6941  
Meets 2nd Monday, 2 pm

##### North Seattle/Shoreline

Shoreline Senior Center  
Contact Scott Tieson  
206-365-1536  
Meets 3rd Tuesday, 3pm

##### Mercer Island

Community Center at Mercer View  
Meets 1st and 3rd Tuesdays, 2 pm  
Contact: Carin Mack 206-230-0166

##### Seattle First Hill

VM Medical Center  
Contact Laurel/Anne  
206.543-5369 (temporary)  
Meets 1st Tuesday 1:30pm

##### West Seattle

Park West Care Center  
Contact Katie Stokely  
206-933-5931  
Meets 3rd Thursday, 1:30 pm

#### Specialty Groups

##### Adult Children of Parents with PD \*NEW\*

Community Center at Mercer View  
Meets 2nd Thursday, 3 pm  
Contact: Carin Mack 206-230-0166

##### Mercer Island PD Carer's Group

Community Center at Mercer View  
Meets 2nd Thursday, 3 pm  
Contact: Carin Mack 206-230-0166

##### PD Teens \*NEW\*

##### (12-18 yr old teens of parents with PD)

Location and Time TBA  
Contact Evie Davis for details  
425-443-8269  
developmentdirectorapda@gmail.com

##### \*Seattle PD Carers Group

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

##### Seattle Well Spouse Group

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

##### Young Onset PD-Seattle

Meets in members homes  
amerson, 206.286.8149  
7pm

##### Young Onset PD-Eastside

Meets in members homes  
Contact Linnae Saari  
425.828.6198 linnaesaari@comcast.net  
Meets Saturday, 10 am

### Western Washington

#### General PD Groups

##### 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 sbhannon@msn.com  
Meets 1st Monday, 1 pm

##### Bellingham

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

##### Bremerton

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

##### Burlington

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

##### Chehalis

Dayspring Baptist Church  
Contact Gwen Moor  
360.858.1206  
Meets 2nd Thursday, 1 pm

##### Des Moines \*NEW\*

Wesley Homes  
Contact Jane Sepede  
206-870-8114

##### \*Everett PD Group

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

##### Longview

Canterbury Inn, 3rd and Hudson  
Contact Barbara Sudar, 360.423.7012  
Meets 3rd Wednesday, 1:30 pm

##### Mill Creek

Merril Gardens  
Contact: Bob Detmer  
425-316-3958  
Meets 2nd Tuesday, 7pm

##### Port Angeles/Sequim

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

##### Puyallup

United Methodist Church  
Contact Jennifer Wrye 253.752.7117  
Meets 3rd Thursday, 1:30pm

##### Olympia \*NEW LOCATION\*

West Woods Assisted Living  
Contact: Karen Williams 360.956.3396  
Meets 3rd Tuesday at 11:00

##### Tacoma

Tacoma Lutheran Home  
Contact Sharon Jung 253.284.4488  
Meets 3rd Friday, 11:30 am

##### Vancouver

SW Washington Medical Center  
Contact Jeanne Laviolette 360.403.8896  
Meets 3rd Saturday, 2pm

#### Specialty Groups

##### Bellingham Young Onset

Fourth Corner Community Church  
Contact Susie Leppala  
Yopdnw@hotmail.com  
Meets 2nd and 4th Wednesday, 7 pm

##### \*Everett Caregiver Group

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

##### Puyallup Caregivers Support Group

United Methodist Church  
Meets 2nd Thursday, 1pm  
Contact Jennifer Wrye 253.752.7117

##### Vashon Island Young Onset

Contact Kate Lanigan, 206.463.3140

##### Young Onset of Snohomish

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

### 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

#### Yakima

Wellness House  
Contact Jaci Rice 509.248.9963  
Meets 2nd Thursday, 1pm

\*Denotes APDA Affiliation

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

## Parkinson's Notes and Resources

### Parkinson's Communication Group

First Wednesday of each month

1-2:30 p.m., \$5 per session

Monthly program for Parkinson's patients to practice working on speaking with increased loudness, in a relaxed, welcoming environment with others who have movement disorders. Group will be hosted by speech pathologist Shirley Glazer, MS, CCC. Coffee and cookies provided.

### Neurological Exercise Group

Beginning Monday January 8, 2007

12:45 - 1:45 pm, \$20 per 4 week session

Gentle stretch and strength exercises for patients affected by Parkinson's disease and other neurological disorders. Four-week sessions.

For more information or to register,  
visit [www.evergreenhealthcare.org](http://www.evergreenhealthcare.org)  
or call 425-899-3000 Monday -Friday 7 am - 7 pm

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

Non Profit Org.  
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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!*

*Season's  
Greetings*