



LINKED TOGETHER

THE PARKINSON ASSOCIATION OF MINNESOTA NEWSLETTER

APRIL IS
**Parkinson's Disease
 Awareness Month.**
See article page 2.

Mark Your 2009 Calendar

SPRING MEMBERSHIP SOIREE

Date: Thursday, April 23
 Time: 6:00 pm
 The Crown Plaza
 St. Paul Riverfront Hotel



TWIN CITIES WALK FOR PD

Date: Saturday, May 2
 Registration: 9:30am
 Wolfe Park in St. Louis Park



PD DAY AT THE DOME

Date: Sunday, July 12
 Game time: 1:10pm
 Twins vs Chicago White Sox

7th ANNUAL GOLF TOURNAMENT

Date: Monday, July 27
 Registration: 11:00 am
 Minnesota Valley
 Country Club

an affiliate of



National Parkinson Foundation, Inc.

Join Bert and Gayle Blyleven at the 2009 Twin Cities Walk for Parkinson's Disease

Join Bert and Gayle Blyleven and more than 600 walkers to raise funds that support those with Parkinson's disease. The Walk for PD is the major fundraising event sponsored by the Parkinson Association of Minnesota. And thanks to all of the wonderful participants in 2008, more than \$54,000 was raised! Help us raise even more this year; it's easy as 1-2-3:

1. Plan to attend the Twin Cities Walk for PD on the morning of Saturday, May 2.
2. Start collecting donations. Ask your friends, neighbors, and co-workers to sponsor your participation in the walk. Collect donations and turn in on the day of the walk.
3. Bring your family and friends to Wolfe Park, 3700 Monterey Drive, St. Louis Park, on May 2. Registration tables open at 9:30am, the starting ceremony is at 10am, and the prize ceremony will be at 11:30am.

Make checks payable to Parkinson Association of Minnesota (PAM).

For additional information about the Walk or to register online, visit the PAM website at: www.parkinsonmn.org



Please see "Walk for PD Family Challenge" on page 3.

2009 Spring Membership Soiree

We hope you have called in your RSVP and you plan to join us for an evening of free food, wine and entertainment on Thursday, April 23. The event is FREE to PAM members and those wishing to join PAM for a donation of only \$25 per household.

TIME

- 6:00pm Social
- 6:15pm Dinner and entertainment by Opus Ensembles
- 7:15pm Medical Update
 Dr. Martha Nance
 Drawing for 'Wall of Wine'

PLACE

Crowne Plaza St. Paul Riverfront Hotel
 RSVP by April 14 to Jill at 763-545-1272 or info@parkinsonmn.org

WALL OF WINE: Bring a bottle of wine to be included in the "Wall of Wine" chance drawing.

PD Day at the Dome

Join the Parkinson Association of Minnesota, K2 Logistics and Strategic Warehousing for the second annual Parkinson's Day at the Dome. The event is Sunday, July 12, with a 1:10 game between the Minnesota Twins and the Chicago White Sox. Tickets are \$20 each (a \$2 savings). Buy your tickets at the May 2 Walk, online at parkinsonmn.org or through the mail. Please note the money is for Twins tickets and let us know if handicapped accessible or low row number seats are needed. Be sure to make Circle Me Bert signs so we get noticed!

Respite Care Grants

Thanks to the fundraising efforts of the annual PAM Golf Tournament and your generous support, PAM is awarding \$500 grants for eligible respite care. Examples of services that the grant may fund include day programs, home care agencies, assisted living facilities and nursing homes offering respite care, and adult foster homes.

Here's a summary of the guidelines:

1. The person with Parkinson's (or other related movement disorder) must not be eligible for funding under the Medical Assistance/Medicaid, EW, ACG, CADI or other county programs.
2. The respite care may be provided either in or out of the home:
 - Respite that takes place out of the home must be provided in a facility or location approved by the local county social service agency. When respite care is provided in a non-MA certified facility or setting, the facility must meet state licensure standards.
 - In-home respite care providers must be agencies that meet the state qualifications for registered or licensed home care. In situations where the person receiving care requires medical attention while receiving respite, the caregivers must be under the supervision of a registered nurse.
3. The PAM Respite Program will pay up to \$500 per client for respite care during our fiscal year (June 1 to May 31), or until funds are depleted, whichever comes first.
4. Verification of diagnosis of Parkinson's disease or other related movement disorder is required to be considered for the respite care grant.
5. Respite providers will be paid directly by submitting invoices to Parkinson Association of Minnesota.

For a grant application:
call 763-545-1272

or

log onto www.parkinsonmn.org

Applications are kept confidential.

7th Annual PAM Golf Tournament

The 2009 PAM Golf Tournament is scheduled for July 27, 2009, at the Minnesota Valley Country Club in Bloomington, Minnesota.

Why Golf? Because 100 percent of this year's proceeds, plus all matching funds, will be contributed to the PAM Respite Care Grant Program.

Price: \$200 per player (includes greens fees, cart, contests, driving range, lunch, dinner & gifts)

TOURNAMENT SCHEDULE:

Women's Golf Clinic 10:00 am
Registration & Lunch 11:00am
Shotgun Start 12:30pm
Dinner & Awards..... 6:00pm

FORMAT: Four-Player Scramble

For additional information on golfing, sponsoring, matching respite funds or prize donations, please call Jill at 763-545-1272 or email us at info@parkinsonmn.org. Registration is limited to the first 100 golfers.

TOURNAMENT SPONSORS:

PLATINUM: The Westrum Family, In Memory of Maxine Westrum

GOLD: Maser & Amundson, P.A.

SILVER: Right at Home- In Home Care & Assistance

Walk for PD Family Challenge

For several years the Walk has included the "Family Challenge" in an effort to get families of those with PD involved in the event. It has been successful; the Family with Most Participants has grown from a group of 24 to the winning group with more than 60 participants. Wonderful prize baskets will be awarded for the following categories:

- **Most Money**—family or individual that raises the most money from sponsors
- **Most Participants**—family with the most participants at the Walk
- **Greatest Distance Traveled**—family or individual that traveled the farthest to attend the Walk
- **Oldest Participant**
- **Youngest Participant**
- **Most Unique Sign**—let the creative juices flow! Create a fabulous, creative, interesting sign. No limits on size or materials. Messages can be about Parkinson's, someone you love with the disease, your walk team, a slogan... think of the possibilities!

NOTE: "Most Unique" sign replaces Most Creative T-shirt Contest.

Parkinson's Action Network 15th Annual Policy Forum

Despite the tough economy, more than 300 Parkinson's disease advocates—most of them patients—gathered in Washington, DC in mid-March to get updates on the latest news in research and treatment options, and to visit Capitol Hill. Jackie Hunt Christensen, vice-president of the Parkinson Association of Minnesota (PAM) board and state coordinator for the Parkinson's Action Network (PAN), was one of a delegation of about a dozen Minnesotans who attended.

One of the highlights of the meeting was a town hall-style meeting with the heads of the six national PD organizations. Joel Gerstel of the American Parkinson Disease Association; Katie Hood of the Michael J. Fox Foundation; Joyce Oberdorf of the National Parkinson Foundation; Amy Rick of the Parkinson's Action Network; Robin Elliott of the Parkinson's Disease Foundation; and Carol Walton of the Parkinson Alliance responded to questions from the audience for nearly 90 minutes. Many questions centered on the number of organizations. Panel members talked about unique areas that their organizations cover, but they did concede that there is some duplication, but also needs that are going unmet.

Another highlight was the convergence of all of the PD advocates upon Capitol Hill. There were more than 280 different appointments for advocates to meet with their respective members of Congress. The Minnesota attendees met

with staff from the Representatives from all eight Congressional districts and from lone Senator Amy Klobuchar's office.

PAN has identified two primary legislative requests for Congressional action:

- 1) Support \$55 million in funding for the Department of Defense's Neurotoxin Exposure Treatment Parkinson's Research (NETPR) program; and
- 2) Co-sponsor and support the National Multiple Sclerosis and Parkinson's Disease Registries Act.

The NETPR program funds research into possible environmental links to PD, such as chemical exposure, head trauma, stress and other conditions that are experienced by military personnel. These circumstances are also very relevant to many Parkinson's patients in the general population.

The National MS and Parkinson's Disease Registries Act would provide \$5 million annually for five years to create two separate databases that, for the first time ever, would track cases of Parkinson's and multiple sclerosis (MS). Information from these databases would be used to generate statistics based on actual data, rather than the fairly arbitrary estimates that are used now.

To learn more about PAN's legislative requests, go to their website, www.parkinsonsaction.org. To watch portions of the 2009 PAN Forum, visit <http://www.parkinsonsaction.org/2009-Forum-Webcast.html>. You must register, but it is free and instructions are posted on the aforementioned website.

April PD Awareness Campaign

If you are stuck in traffic in the Twin Cities metro area any time from April 7 to May 7, take a look at that bus ahead of you. There is a good chance that the placard on the tail of the bus will say "Every 9 minutes, another person is diagnosed with Parkinson's. You are not alone. www.parkinsonmn.org."

Or if you live in greater Minnesota and happen to be at a multiplex theater in Duluth, Mankato, Moorhead, Rochester, Willmar or Waite Park/St. Cloud, watch for a similar ad onscreen before the movie starts.

These two advertising methods are the Parkinson Association of Minnesota's 2009 efforts to raise awareness and funds for "Parkinson's Awareness Month." "We hope that these ads will resonate with someone who is newly diagnosed, or has a family member with PD," said PAM vice-president Jackie Hunt Christensen. "We want them to know that there is help available right here in Minnesota."

Let us know what you think about the ad campaign by sending an email to info@parkinsonmn.org or dropping us a note at 2205 Zealand Ave. N., Golden Valley, 55427. We are open to other outreach ideas.

Because of the Respite Care Program...a Dream Realized

Thank-you! Thank-you!!

Your Respite program allowed me to pull off a dream I have had for two years. My mother is the primary caretaker of my father. As her health began to deteriorate I knew it was now or never. A dear friend of mine told me about applying for your grant, I was so excited to get the letter saying it went through! My dream was to set up a date at a B&B for my mother and her four sisters, ages 82-72.

I would hazard a guess these gals haven't had a sleep-over since the first one left the farm to get married in 1946. They were so excited! It took forever just to get them into the house, as they were stopping every few feet to talk! My three sisters and I made a beautiful dinner, then we sat back, watched and learned. I have never been able to say my ears hurt until that day! Trying to follow different conversations going on at the same time, and collect all the information being offered up, no matter how far fetched, or elaborate it had gotten over the years. All of our stomachs and faces hurt from laughing. They are still talking about it after several months have passed.

I feel very blessed to have had your help in granting my mother and these wonderful aunties of mine a day they will remember forever. Please continue your efforts in aiding families caring for their loved ones with Parkinson's, it is truly a great deed.

*Sincerely,
Margaret M*

2008-2009 PAM BOARD

Paul Blom, President
Jackie Christensen, Vice President
Joan Gardner
Barb Green, Secretary
Jerry Kissell, Treasurer
Kris Maser
Eileen Smith
Stacy Williams

Jill Brezinski, Administrative Assistant

Special Thanks to:

Newsletter Staff.....Jill Brezinski

Barb Green

Eileen Smith

Jackie Hunt-Christensen



PAM Membership

- Membership is open to anyone wishing to promote Parkinson's disease awareness.
- Annual memberships are \$25.00 per household.
- Memberships received after September 1 apply to the next calendar year.
- All local funds are used for research, education, and support activities for the Parkinson's community in our state.

To join the Parkinson Association of MN, simply send us a note with your name, address, phone number, and check for \$25.00 made out to: Parkinson Association of MN. Send this and any other correspondence to:

Parkinson Association of MN
2205 Zealand Avenue North
Golden Valley MN 55427

NPF Website

The National Parkinson Foundation website includes many helpful and interesting topics to explore and participate in. Options include: Discussion Corner, Ask The Doctor, Ask The Speech Clinician, Ask The Dietician, Ask The Surgeon, Caregivers Forum, Open Forum, and Young Onset Forum.

You can email a question to any of the health professionals and you can participate in online conversations with others that are living with Parkinson's disease. It is a very useful tool and well worth a look. The website address is: parkinson.org

Email: info@parkinsonmn.org

Website: www.Parkinsonmn.org

The Parkinson Association of Minnesota, a nonprofit, voluntary alliance, is dedicated to improving the lives of those affected by Parkinson's disease, through fundraising, community building, advocacy and increasing public awareness.

Parkinson Association of MN
2205 Zealand Avenue North
Golden Valley MN 55427

