Volume 2, Issue 2
Spring 2005

Parkinson's Wellness Connections

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Tri-state Parkinson's Wellness Chapter of Ohio, Kentucky and Indiana

Tell us what you think of our new newsletter!

- Call us at (513) 948-1100
- Toll free 800-840-2732
- Email us at info@parkinsonswellness.org
- Visit our website at www.parkinsonswellness.org

TPWC, Bacchanalian Society Team Up To Fight Parkinson's

Please join us Thursday, May 12 from 7 pm-10 pm for a Spring Wine Tasting. Our featured wine will be merlot.

The event will be located at the beautiful Old Saint George Spiritual Center at 42 Calhoun in Clifton and will feature plenty of wine, a raffle and silent auction and even some live music!

Three cheers and a toast for the Bacchanalian Society, the organization helping us host this event. The Bacchanalian Society is a non-profit organization that was founded three years ago by three 30-year old businessmen new to Cincinnati as a way to create a social gathering for people to meet outside of work. Todd Fisher, Ashley Hess and Kevin Ghessemian put together a wine tasting and formed the Bacchanalian Society, named for the god of wine.

Their first event drew 60 people and they quickly realized this could be a powerful tool to encourage volunteerism and help charities raise funds. The event quickly grew to 300 people, with the last event drawing 750!

The kind of altruism shown by the Bacchanalian Society has helped charities raise money and recruit volunteers. This sort of help has been especially vital to our organization—many of our volunteers are living with Parkinson's Disease, so an event of this magnitude might otherwise be physically impossible without the help of the Bacchanalian Society.

To register for this event, contact the Tri-state Parkinson's Wellness Chapter at (513) 948-1100.

The Rules of the Game: How the Bacchanilian Society's Wine Tasting Event Will Work

Here's how it works: At each event, a different type of wine is chosen. This time, it's merlot.

Each attendee will bring three bottles of the same merlot. Upon arrival, all three bottles will be given to the hosts, who will wrap two bottles, concealing the identity of the wine. The wrapped bottles will have a number randomly assigned to them and will then be set out for tasting. The third bottle will be left unopened and will not be put out for tasting.

Each person will be given an index card with a space to rate each wrapped bottle of wine. After having a chance to taste all of the bottles of wine, attendees will be asked to rate the bottles on a scale of 1 to 5.

After two hours of tasting, the numbers are tallied and the wine with the highest average score wins. The winner (the one who brings the winning wine) goes home with everyone's third unopened bottle of wine.

"Tapestry" hits a high note for PD

It was a night filled with smiles, fun and some wonderful music. The presentation of Carole King's Tapestry at the Covedale Center for the Performing Arts was a major success for the Tri-State Parkinson's Wellness Chapter. Entertainer Nancy James led singers Shannon Kramer, Spring Star Pillow, Lynn Comstock, Leslie Hitch and pianist Terry LeBolt in an unforgettable evening of song that had folks swaying and singing in their seats, while Rob Reider kept everyone laughing as the evening's master of ceremony.

A sincere thank you to all who helped support this touching Bob Braun Memorial event. A special appreciation for Mary Jo Katona and her Bill Allison fan club of more than 70 people who came out to support us on a very cold night. We'd also like to thank our underwriter, Meijer Stores, and major supporters Strauss & Troy Legal Professional Association, Protivity Independent Risk Consultants and Schwarz Pharma Foundation, as well as donors Larosa's, Kroger Floral (Phil Dammarel), O'Charley's, Skyline, High Tech Signs (Jan and Bob Steiner), TGI Friday's, Paragon Salons and Keebler, as well as Hannah Kuenneke for poster design.

Clean Sweep: A Company with heart

It all started with a dust bunny!

Three years ago, Lee Schaefer and his wife were visiting a friend who was living with Multiple Sclerosis when his wife noticed dust under the furniture and noted, "There are dust bunnies under your couch, and they are having babies." The homeowner laughed, but then explained that MS made it impossible for him to do some of the heavier cleaning in his home, and being on disability made employing a cleaning service financially impossible.

That night the Schaefers pitched in and cleaned the house. Lee, who was then working as a vice president of development for a non-profit, could not get his friend's situation out of his mind. He thought about Matthew 25:40, "What you do for the least of my brothers, you do for me."

This event changed Lee's life. He was inspired to write a business plan for what is now Clean Sweep and quit his job. Clean Sweep is a cleaning company that uses the profits made from contracts with corporate clients to help subsidize cleaning the homes of the disabled.

"Most corporations that have a heart understand what we do and will try to give us work. I use the profits from those jobs to pay for the other jobs. I even hire some individuals with disabilities to work for us," says Schaefer. Some clients even donate funds to help sponsor a person in need of some homemaking assistance.

"We charge about $30 to clean a home," says Schaefer. "If they cannot afford that, we lower our price." Clean Sweep usually spends two to three hours cleaning a home, running errands and even helping balance check books. But that's not all—the carefully selected employees also provide much needed companionship to people who might be homebound and often cut off from vital social situations.

If you would like to hire Clean Sweep for your company, or know someone in need of their help, contact Lee Schaefer at (859) 750-7110.

Get Connected to PD: Featured Website

http://gofree.indigo.ie/~pdpals

Ireland's Young PD Support Group (PALS) website is a must see!

This website is full of information on exercise, nutrition, a question and answer forum with neurologist Timothy Lynch and reports on pharmacological research on PD in Europe. The site is maintained by a young woman living with PD, Ann Kelty.

The PALS Support Group has formally existed since November 1998 and is a branch of the Parkinson's Association of Ireland. It is the brainchild of its Chairman, David Magennis, who has had PD since he was 28.

Because some of the challenges that younger people with PD face are different than those faced by those who are older, meeting and talking to others in similar situations about common problems can help greatly in facing life with PD. This site provides a unique look into life with PD and is a must see for all ages.

If you have a suggestion for a must see website, let us know by emailing us at info@parkinsonswellness.org.

At the other end of the line

If you call the Tri-State Parkinson's Wellness Center with a medical question, there is a good chance you will talk to registered nurse Debbie Mills. As the tri-state APDA Coordinator, she is one of the American Parkinson's Disease Association's 60 coordinators in the United States who are either RNs or Social Workers who also have an expertise in movement disorders.

Debbie also has special nursing certification in Gerontology and a degree in education. When not answering the many calls that come into the Center, Debbie visits support groups, health facilities and community groups to provide educational programs.

You could say Debbie was born to be a PD educator and advocate. Debbie's father had been diagnosed with PD when she was born. She knew at a very young age the importance of having support and accurate information about the disease. "I saw the suffering people with Parkinson's and family members go through, and the incorrect information and assumptions made by the public and health community about Parkinson's patients. I also knew what it was like on the other side of the fence as a family member trying to understand the disease, trying to live with it every day," says Mills.

In 1985, Debbie's personal experiences and desire to be a nurse led her to start caring for patients living with PD in acute care settings and chronic care settings. By 1990, she had become a nurse clinician for the University of Cincinnati Stroke Team, entering in the neurological care arena. In 1994, she had the opportunity to become a neuro-movement disorder nurse clinician and team leader of the Parkinson's Team (one of two known PD teams in the country at that time) at the University of Cincinnati. Debbie worked in the neurology clinic and in neurosurgery under the direction of Dr. Fred Samaha, MD and Dr. Jamal Taha, MD.

Debbie now spends some of her time working with the Tri-State Parkinson's Wellness Chapter at Drake and can be found speaking at area facilities, health centers and support groups. She believes there are no bad questions about PD.

The most frequent calls and concerns from patients and family members include:

- My doctor just diagnosed me, but no one explained what I have. What is Parkinson's?
- Can you help me understand ?
- Will I die from this?
- I have these symptoms, are these PD?
- Should I tell my employer?
- What should I expect when the doctor says there is nothing more they can do?
- The doctor said I have Parkinson's-Plus, MSA, PSP, CBGD, Lewy Body Disease, etc. What does this mean?

While Debbie has a passion for helping people living with PD, she also has dreams of where this driving force will take her. "Hopefully, funding in the Tri-state Parkinson's Wellness Association will help the program expand affording me to visit tri-state PD clinics as an APDA representative on a regular schedule to help teach and consult with the healthcare team as well as their patients," she said.

Mills says that it is vital for practitioners and family members alike to understand that while they may see a Parkinson's patient, they should try to change their thinking, and must first try to see a person who is trying to live the best they can with Parkinson's Disease. In essence, living well with Parkinson's is what she tries to teach everyone.

Mills says, "The important aspect is to look at the whole person and the whole environment of support and dynamics of friends, family, career, etc not just treatments, meds and surgeries. Your loved one is there! The package may have changed, but they are there inside. Don't forget, because they can't smile, they still laugh inside. Because they can't frown, they still hurt inside. Because they can't run, they still enjoy the game. Because they don't speak as fast as they used to, they still have something to say. Families need to remember the love—love comes in all packages!"

Debbie Mills, RN,C will be conducting a free, 3 hour workshop entitled "When the Diagnosis is Parkinson's" Workshop on Saturday, June 11, 2005

For more info or to register, call 513-948-1100

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Team PD Flying-High In The Pig

They are pounding the pavement in Cincinnati for some real life Parkinson's Disease heroes! A team of runners will run and raise funds to fight Parkinson's Disease in the Cincinnati Flying Pig Marathon, Sunday, May 1st. Cyndi Kenyon is one of them.

Cyndi, the marathon veteran, is running in honor of her heroine, Mary Schroeder. "I am running in honor of Mary because she has always been an inspiration to me. She is a coworker of mine and she continues to show strength and energy in our school setting. If she is not volunteering for a school committee, or cooking something delicious for teachers on a staff meeting day, she is on the computer figuring out how to make our job as teachers better," says Kenyon. She adds her fellow school staff is eager to support her run and Mary.

"Running a marathon in her honor is the least I can do. I hope to raise funds for the Tri-State Parkinson's Wellness Chapter in hopes that this money will get us a step closer in dealing with this disease." She hopes this run will be an inspiration for entire families living with PD to get moving to find an effective treatment for PD.

To get involved with the Parkinson's Team for the Flying Pig Marathon, collect sponsorships with the enclosed sponsor sheet or please contact the Tri-State Parkinson's Wellness Chapter at (513) 948-1100.

We Need Your Help!

We're looking for some dedicated volunteers. We currently have a hard working crew that answers phones, provides educational support, plans fundraisers to fight PD and even puts together newsletters like this one. But we need more of us!
We are launching a major push to increase our services and are looking for folks who can help staff our phones, and also people who want to help with, or potentially plan and develop future fundraisers.

Are you a budding journalist? We would be happy to consider any article submissions for future newsletters. We are also interested in technical support under the direction of our IT volunteer. How about speaking or being a greeter at a support group?

In June we plan to have new elections for our board and are hoping to recruit some new people with new ideas and a lot of energy. If you are interested, please call us at (513) 948-1100.