New Early Onset Group in Elkridge
By Debora Bergstrom

My way of adjusting to difficult new situations is to learn everything I can. So at 51, when I was diagnosed with Parkinson’s disease (PD), first I fell apart, then I began my search for relevant information and proactive ways to move forward.

I found that I am in the “early onset” subset of people with PD, because my symptoms first appeared in my forties. Early onset PD accounts for about 10-15% of 1.5 million people with PD in the United States. My age difference was apparent the first time I went to a PD support group meeting. I was 15-20 years younger than most attendees! Everyone was kind, welcoming and reassuring; however, my concerns varied from those of the older group.

As I am at a different stage in life than older onset patients; PD presents a host of different challenges for me. Unlike many of the others, I have children at home, aging parents who need care, and jobs and college tuitions to consider. I was financially and emotionally unprepared. I had not considered long term care or employment disability insurance, which upon diagnosis, became unavailable to me. I was between jobs and immediately faced the possibility of losing part or all of my potential income. My husband’s employee health insurance became more critical as our health care costs substantially increased.

As PD is progressive and costly, financial and employment issues make it risky to openly disclose my health circumstances before retirement. Writing this article is a conscious decision on my part to be open about my PD, regardless of the consequences. However, I have my spouse’s income as a buffer. For some it may be too risky to disclose their PD broadly and they are faced with living a double life between those who know and those who do not.

Because of these key life-stage differences between early and late onset PD, it is important to provide support to both groups separately. For example, early onset support groups should be held on evenings or weekends to avoid working hours. Strategies are needed for stressful issues unique to early onset patients like loss of income, dealing with children at home, caring for aging parents, transportation for a working spouse, working with PD, computer software and hardware tools, levels of disclosure and more.

Talk is cheap. I am for doing something. Our doctors, nurses and therapists can only do so much for us. Toward this end, we have started a new early onset group to better define and address these needs. We are meeting about once a month in Elkridge, MD. If you would like to join the discussion on life with early onset PD, come join us.

My email is dfbergstrom@comcast.net
# Parkinson’s Disease Symposium Agenda

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Presenter/Location</th>
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<tbody>
<tr>
<td>8:00 am</td>
<td>Registration</td>
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<tr>
<td>9:00 am</td>
<td>Welcoming Remarks</td>
<td>Dennis Leebel, Leader Sussex County Parkinson’s Group</td>
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<tr>
<td>9:15 am</td>
<td>Deborah Brooks Co-founder</td>
<td>Michael J. Fox Foundation</td>
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<tr>
<td>9:45 am</td>
<td>Medical Progress &amp; Your Health</td>
<td>Paul Fishman, MD, PhD University of Maryland</td>
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<tr>
<td>10:30 am</td>
<td>Break and Exhibits</td>
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<tr>
<td>10:45 am</td>
<td>Exercise &amp; Your Health</td>
<td>Heather Cianci, PT, MS, GCS University of Pennsylvania</td>
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<tr>
<td>11:30 am</td>
<td>Your Mood &amp; Your Health</td>
<td>Amy Colcher, MD University of Pennsylvania</td>
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<tr>
<td>12:15 pm</td>
<td>Lunch, Networking and Exhibits</td>
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<tr>
<td>1:00 pm</td>
<td>Spirituality &amp; Your Health</td>
<td>Patricia Singleton, Staff Chaplain Christiana Care Health Services</td>
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<tr>
<td>1:30 pm</td>
<td>Medications &amp; Your Health</td>
<td>Joseph Savitt, MD, PhD Johns Hopkins University</td>
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<td>2:15 pm</td>
<td>Break and Exhibits</td>
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<td>2:30 pm</td>
<td>Concurrent Sessions</td>
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<td>3:30 pm</td>
<td>Question &amp; Answer Session with Presenters</td>
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<tr>
<td>4:00 pm</td>
<td>Door Prizes Drawn &amp; Program Concludes</td>
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## Concurrent Sessions

**Session A** Caregiving  
Susan Hamburger, Chairman of Board  
Parkinson’s Foundation of the National Capital Area

**Session B** Deep Brain Stimulation Surgery  
Fred Lenz, MD, PhD  
Johns Hopkins University

**Session C** Exercise Options & Your Health  
Ingrid Pretzer-Aboff, RN, PhD  
University of Delaware  
Nintendo Wii, Art Cooley, Leader  
Lower Shore Parkinson’s Group  
Why Dance for Parkinson’s Disease an eight minute video presentation  
Mark Morris Dance Group  
Relaxation and Chair Exercise  
Peter Liberto

**Session D** Apokyn, a Novel Treatment  
Marye Kellermann, RN, CRNP

**Session E** Parkinson’s Action Network  
Hayley Carpenter  
Parkinson’s Action Network
Sydney Keys: A Pacing for Parkinson’s All-star

Last year the day after registration for Pacing for Parkinson’s closed, I got a call that changed our team. Elaine Keys called to ask if it was too late for her daughter to register her team. Sydney Keys, captain of Sydney’s Turtles, is a bright-eyed nine year-old on a mission to fight PD. Don’t let her age fool you; this little girl is making a difference.

Sydney started fundraising in the first grade when her father, Eric, was diagnosed with PD. Her first campaign was a pajama party at school to benefit the Unity Walk, an annual PD fundraiser in New York City. She came up with the idea herself.

Sydney got involved with Pacing for Parkinson’s when her family moved to Maryland. She liked the idea of raising funds for the Johns Hopkins Parkinson’s Disease & Movement Disorder Center because that’s where Eric receives treatment.

Sydney’s Turtles was the number one fundraising team for Pacing for Parkinson’s, raising more than $1,600. Virtually every dollar was raised by Sydney herself!

This year Sydney isn’t just a team captain, she and her family are members of our planning committee. Sydney likes being on the committee “very much.” She is also once again leading Sydney’s Turtles with 12 runners. With so much work and dedication, Sydney Keys is truly a Pacing for Parkinson’s All-star!

If you would like to receive free literature about Parkinson’s disease or other movement disorders please complete this form, cut it out and mail it to our center.

Your Name: ____________________________________________
Street Address: __________________________________________
City, State, Zip: __________________________________________
Phone Number: __________________________________________
Email: __________________________________________________

Please check those items you would like to receive:
Parkinson Digest: Quarterly Newsletter of The Johns Hopkins PDMD Center
List of PD support groups in MD/DC region
Ways To Give brochure
Parkinson’s Disease: What You And Your Family Should Know*

Join Our Mailing List!

Pacing for Parkinson’s at the Baltimore Running Festival is on October 16th.
For more information go to www.active.com/donate/pacingforpd

Parkinson Disease: Caring and Coping*
Importance of Good Nutrition in Parkinson care*
Parkinson Disease: Speech and Swallowing*
Activities of Daily Living: Practical Pointers for Parkinson Disease*
Parkinson Disease: A Guide to Deep Brain Stimulation Therapy*
Essential Tremor literature
Progressive Supranuclear Palsy Literature
Dystonia Literature
Information on Educational Seminars PD 101/201
Information about annual symposium

* Provided through the National Parkinson Foundation

Please mail to the following address:
ATTN: Nurse Educator
The Johns Hopkins PDMD Center
601 North Caroline Street, Suite 5064
Baltimore, MD 21287
Announcements

PD 201: Managing Care
Designed for those with PD for five years or more, this class offers info on motor complications, coping skills, and DBS surgery. September 13, 2010 12:30-4:30pm. Call 410-955-8795 for more info.

Pacing for Parkinson’s
It’s not too late to show your support for the men and women who are participating on October 16, 2010 at the Baltimore Running Festival. Make a donation or become a fundraiser! For more information, please go to www.active.com/donate/pacingforpd

Parkinson’s Disease Symposium
Experts in Parkinson’s disease research, clinical care and psycho-social issues present seminars on a wide range of topics. Designed to educate patients, families and caregivers. November 6, 2010, 9:00am-4:30pm. For questions call 410-955-8795.

Symposium Registration
Cost to register is $25.00 per person, which includes lunch. After October 1, registration will be $50.00. Registration will close November 1. Please list the preferred concurrent session for each guest.

Name:  
Concurrent Session:  
Address:  
Address:  
Phone:  
Email:  

Name:  
Concurrent Session:  

Name:  
Concurrent Session:  

Name:  
Concurrent Session:  

Number attending x $25.00 = total

Please mail check and completed registration form to:

JHU PDMD Center
601 N. Caroline Street, Suite 5064
Baltimore, MD 21287