Racial and Geographic Variation in Parkinson’s Disease

Allison Wright Willis, M.D.

Parkinson disease is a common neurodegenerative disease of the elderly with no known cause. My research seeks to identify demographic and environmental factors which may influence who develops PD and who does not. Previously, we did not know how common PD was in the United States, nor did we have extensive data on which people are more likely to develop the disease. Using Medicare data, which is utilized by 98% of Americans over the age of 65, we were able to determine Parkinson disease rates in the United States by race and region of residence. Below are the highlights from my recently published article in the journal Neuro-epidemiology (A. W. Willis et al, Neuro-epidemiology 2010; 34:143-151).

We found that Parkinson disease affects approximately 1.6% of the U.S. population over the age of 65, with about 480,000 people living with the disease at any time. Approximately 130,000 people are newly diagnosed each year. Men are slightly more likely to have the disease, with a male: female ratio of 1.55 (155 men have the disease for every 100 women). PD rates increase with age. White men have a much higher rate of Parkinson disease, up to double that seen in Blacks or Asians. Asian women seem to have the lowest rate of PD in the United States. Geographically, Parkinson disease rates are highest in the Midwest and Northeast regions of our country, where the rates of new and existing cases of Parkinson disease are two to ten times greater than that in the West and South.

There are several interesting theories suggested by this recent study. The finding that Whites have substantially higher rates of Parkinson disease may mean that Blacks and Asians are somehow less susceptible to PD, perhaps due to a protective genetic factor or, to decreased exposure to key environmental factors.
environmental factors. The finding that PD is more common in the Midwest and Northeast supports previous research which suggests that nonhereditary PD may be associated with environmental factors (some of which may be pesticides or metals). These areas of the country are hubs of agriculture and industry, and future studies may be able to identify specific environmental factors which raise or lower PD risk.

Reprinted with permission by Allison Wright Willis, M.D. and Debbie Guyer, St. Louis APDA I&R Coordinator. This article appeared in the February 2010 issue of “The LINK.”

Notes from Marie Saint-Hilaire, MD, FRCPC, Medical Director APDA Center at Boston University Medical Campus

This study by Dr. Willis is a very important study because it utilizes a very large pool of data, the Medicare Data Set. This is the first time a study representing a very large population has been done in the United States. It has been done in other countries that have a public health system but are not as racially diverse as the US.

This study confirms an observation that has been made repeatedly, that Parkinson’s disease (PD) affects more Caucasians than African Americans. For example, although the population served by Boston Medical Center is very diverse, the great majority of Parkinson’s patients we see in our center are Caucasian. This suggests that certain genetic factors play a role in PD.

On the other hand, the finding that PD is more prevalent in the Northeast and Midwest suggests that environmental factors also play a role.

Therefore, this supports the hypothesis that PD most likely results from a complex interaction between environment and genetics.

We thank Dr. Willis and her colleagues for their excellent, ongoing research in Parkinson’s disease.
Greetings from the MA Chapter President

The Massachusetts Chapter of the American Parkinson Disease Association has continued to be a strong provider of services to the Parkinson’s disease community, and this year is no exception. Despite a weak economy and increasing pressure on non-profit organizations, the all volunteer MA Chapter has been busy following our mission – “To Ease the Burden – To Find the Cure”.

The following are just a few examples of how the APDA MA Chapter and I & R Center support you in several ways. We:

- Organize and present numerous Parkinson education programs and informational sessions across the state – All of these programs are well-attended.

- Work closely with the country’s first APDA National Resource Center for Rehabilitation at Boston University College of Health and Rehabilitation Sciences: Sargent College - The MA Chapter financially supports half of the grant for this program; the national APDA office supports the other half.

- Distribute over 5,100 pieces of literature annually; mail 9,400 newsletters; and send weekly email updates to 1,000 subscribers.

- Operate a telephone help line Monday – Friday: 9:00 AM -5:00 PM.

- Provide information, guidance, and support to 47 PD support groups across the state

While we have had many successes, we have many challenges ahead as well. The following are some of the important issues that we intend to focus on in the near future:

- Develop a better understanding of our client base and their needs recognizing geographic location – This will help us deliver the precise services needed to those in greatest need at the right time and place.

- Assemble a larger volunteer base – The MA Chapter continues to grow and in order to provide more services and support we will build on our small, dedicated group of volunteers with new individuals, talents, and expertise.

As always, we are open to your comments and suggestions. How can we best help you in your fight against PD? What programs do you wish were more readily available in your community?

The APDA MA Chapter would not be successful if it weren’t for the generous support of volunteers, donors, support group leaders, and dedicated community participants; we are extremely grateful. I look forward to my second year as Chapter President and continuing our work with the Massachusetts PD community. If you have any questions/comments or would like to get involved with the Chapter, please contact me at Lyczmanenko@gmail.com or (617) 638-8466. Thank you for your support

Volodymyr Lyczmanenko

Above (left - right): Debbie Case and Allyson Gormley, LICSW
Research Opportunities

The APDA Massachusetts Chapter and Information and Referral Center is pleased to provide you with basic information on research studies ongoing at various movement disorder centers. Although the APDA has not individually reviewed or specifically endorsed each study posted here, each has been reviewed and approved by the Institutional Review Board at its respective medical center. For further information on any study posted here, please utilize the specific contact information provided with the description of the actual study in which you are interested. As always, consult your physician to discuss the individual benefits and risks of each study prior to participating. To increase your awareness of ongoing research and clinical trials visit www.pdtrials.org, www.clinicaltrials.gov, or www.pdpipeline.org.

Study on the Health of Caregivers to Relatives with Parkinson’s Disease

Participants needed for study on the health of caregivers to relatives with Parkinson’s Disease and other related movement disorders

If you are providing care for a relative with Parkinson’s Disease and you are 60 years or older, you may be eligible to participate in a study on how caregiving affects your health. This study will involve 4 yearly face-to-face interviews, conducted by trained interviewers at the General Clinical Research Center at BUMC in Boston’s South End. You will be asked questions about your physical and emotional health, and about the person for whom you provide care. In addition, you will be asked to give blood and urine samples. This study is funded by the National Institute of Health.

The first interview is expected to take 2 hours. It will take place in the early morning. You will be reimbursed up to $40 for your time, and your parking costs will be paid. You can bring your care recipient to the interview where someone will stay with him or her during your interview.

If you are interested in participating in this study, please call (617) 638-7736.

STEADY PD (Safety, Tolerability, and Efficacy Assessment of Dynacirc® CR for PD)

The Parkinson Study Group (PSG), under the direction of Tanya Simuni, MD (Northwestern University), and Kevin Biglan, MD, MPH (University of Rochester), is conducting a multi-center, randomized, double-blind, placebo-controlled study of isradipine CR (Dynacirc® CR) in individuals with early Parkinson disease (PD). The purpose of the study is to assess the general safety and tolerability of isradipine CR, to determine effective dosage of isradipine CR and obtain pilot data on the potential effect of isradipine on slowing the progression of PD. Approximately 18 research centers across North America will enroll up to 100 subjects for 12 months each.

Isradipine CR is a medication that is approved for the treatment of high blood pressure by the Food and Drug Administration Agency (FDA), but not for the treatment of PD. Isradipine CR has been shown to have a neuroprotective effect in preclinical models of parkinsonism (poster Simuni, et al).

This study is being conducted under a research grant award from the Michael J. Fox Foundation (MJFF) and the Dixon Foundation.

For more information please contact Boston University Parkinson’s Disease and Movement Disorder Center at 617-638-7737.
SURE-PD (Safety and Ability to Elevate Urate in Early Parkinson’s Disease)

SURE-PD (Safety and Ability to Elevate Urate in Early Parkinson’s Disease), a new clinical study, has begun enrollment at sites across the United States. The study’s main goal is to determine whether inosine (a potential brain protectant) can safely increase the body’s levels of urate, a natural antioxidant in humans. Based on previous research findings that Parkinson’s disease tends to progress more slowly in people who have higher urate levels. Michael A. Schwartzchild, MD, PhD and his colleagues in the Parkinson Study Group hope that the results of SURE-PD will set the stage for future investigation into whether inosine can slow the progression of Parkinson’s disease.

If you are a recently diagnosed Parkinson’s disease patient not yet on medication, you may be eligible to participate in the SURE-PD study. If you are interested in participating or would like more information, call the Parkinson Study Group at 888-887-3771. Additional information can be found on the following websites: www.ltparkinson-study-group.org, www.clinicaltrials.gov, and www.pdtrials.org.

Dr. Schwartzchild of Massachusetts General Hospital and Alberto Ascherio, MD of the Harvard School of Public Health lead the Sure-PD research study.

Community Resources

The APDA National Resource Center for Rehabilitation

To help people who have Parkinson's disease (PD) access information on exercise recommendations, the American Parkinson Disease Association (APDA) and Boston University have established the country's first National Resource Center for Rehabilitation. The center's toll-free "helpline" telephone number is 1-888-606-1688. Callers are able to speak with a licensed physical therapist who can answer questions about exercise, provide information about programs in the caller's area, and provide educational materials. For more information, call the line or visit the website below.

(888) 606-1688 - www.bu.edu/neurorehab/resource-center

Information for Veterans

The Department of Veterans Affairs reports new disability eligibility for veterans who served in Vietnam from 1962 to 1975 and those who were exposed to herbicides outside of Vietnam. For more information, visit the website below.

www.publichealth.va.gov/exposures/agentorange/benefits.asp
Golf Tournaments Raise Money for PD!

The 3rd Annual DOPA Golf Tournament

The Annual DOPA Golf Tournament was once again a success. On Sunday, August 7th, more than 80 golfers joined to support Parkinson’s disease and founder, Bob Tullis Jr. $14,500 was donated to the APDA MA Chapter, which brings a total of $40,000 from three years of DOPA tournament play. The community couldn't be more thankful.

The weather was ideal and everyone had a great time. All the attendees and volunteers enjoyed an amazing raffle, silent auction, live auction, and magnificent lunch. In addition, tournament founder Bob Tullis never leaves anyone out and there is always a chance to walk away with something, whether it be a prize or a trophy.

We thank all of the volunteers, sponsors, and supporters for helping make this event such a success and so much fun!

Above (left-right): Robert Tullis Sr., Tim Tullis, Sue Tullis, and Timothy Tullis Jr.

1st Annual Shawn Thornton's Putt's and Punches for Parkinson's Golf Tournament

The Boston Bruins Foundation and host Shawn Thornton (pictured below) held the 1st Annual Shawn Thornton's Putt's and Punches for Parkinson's Golf Tournament on Monday, August 9, 2010 at the Ferncroft Country Club in Middleton, MA. Thornton very generously chose to support the American Parkinson Disease Association in the fight against Parkinson's disease.

We thank him and the Bruins Foundation for their excellent work and generous support!

(Photo from the Salem News:www.salemnews.com)

Melick, Porter and Shea LLP Golf Tournament

Boston Law firm Melick, Porter and Shea LLP held its annual Golf Tournament for employees and clients on Thursday, June 24th. Every year they make a donation to a charity on behalf of the firm and clients. This year, they made a generous $5,000 donation to APDA Massachusetts.

Below (left-right): Bob Powers, Kate Boucher, Volodymyr Lyczmanenko, Cathi Thomas, and Rick Shea
Community News

Ken Bernstein receives the APDA MA Chapter Community Lifetime Achievement Award

The American Parkinson Disease Association (APDA) MA Chapter has recently recognized Ken Bernstein for his long-term volunteer support and advocacy on behalf of the Parkinson Community. APDA Chapter President Volodymyr Lyczmanenko presented the Community Lifetime Achievement Award in recognition of Ken’s important work at this year’s 24th Annual APDA MA Chapter Walkathon held at the Reebok International Headquarters in June.

APDA Information and Referral Center Nurse Coordinator, Cathi Thomas, has worked with Ken for over twenty years. She notes Ken’s many accomplishments, such as establishing the first Young Onset PD Support Group in Massachusetts, editing the newsletter "The Young and the Restless", and developing one of the first PD Web Internet sites. Thomas states, “Ken volunteers and supports the Parkinson community in many ways, whether it is sharing information on PD with a young scientist or providing strategies to a person recently diagnosed with Parkinson’s to better cope. Ken’s efforts have significantly raised the level of awareness and care in Massachusetts.”

APDA Board Member Donna Leitao receives special recognition from the APDA MA Chapter

The American Parkinson Disease Association Massachusetts Chapter honored one of their outstanding board members, Donna Leitao by presenting her the Volunteer of the Year Award at the 24th Annual APDA MA Chapter Parkinson’s Walkathon. Chapter President Volodymyr Lyczmanenko presented Donna with this well deserved award. Donna has been an outstanding volunteer for the past five years. She was a key member in creating the Annual DOPA Golf Tournament. She has introduced social networking to help increase awareness of Parkinson support in Massachusetts and has enlisted hundreds of volunteers to participate in APDA events. Donna currently serves as an active member of the MA Chapter Board as a Member-at-Large.
On Sunday, June 6, 2010 volunteers, walkers, supporters, and vendors joined together for the 24th Annual American Parkinson Disease Association Massachusetts Chapter Parkinson’s Walkathon. The weather tested walkers’ dedication this year, but they were determined and ready to walk rain or shine. The thunderstorms held out and the event was once again a huge success. Hundreds of participants across generations and 57 teams worked endlessly to raise over $100,000 for Parkinson’s disease research. Matt Siegel from KISS 108 FM’s Matty in the Morning once again donated his time as the event emcee while the KISS 108 street team shared games and prizes. Cory Brett offered his photography services to the chapter by taking group pictures of the teams and candid shots of the entire event (All of the photos on pages 8-10 are provided by Cory Brett Photography). There was pizza, ice cream, Italian ice, and even handmade, fresh cannoli for everyone to enjoy.

The APDA MA Chapter was honored to present the Community Lifetime Achievement Award to Ken Bernstein and the Volunteer of the Year Award to Donna Leitao. Both Ken and Donna have demonstrated tremendous support to the community and advocacy for Parkinson’s disease for many years.

We would like to thank all of our volunteers, team captains, and sponsors for supporting the MA Chapter this year. Our volunteers are the backbone of this event. From driving across the state for supplies and meetings, arriving bright and early on a Sunday morning to set up the stage, and supporting all of the attendees, they are always there to lend a helping hand. To continue the volunteers’ efforts, it is the team captain who brings the walkathon to life. Not only do they organize their team, but they support their teammates through the fundraising effort and inspire us all. Many of the teams create their own t-shirts to show their spirit which provide much appreciated splashes of color across the track.

The sponsors and vendors are also crucial members of the Walkathon team. They bring the day together as a full family event and provide opportunity for the fundraising efforts by our participants to go straight to Parkinson’s disease research projects approved by the APDA Scientific Advisory Board.

And last, but certainly not least, we

Continued on next page
would like to thank all of our donors. Whether it be through financial support, gifts-in-kind, or donations of time and efforts, words cannot express how grateful the MA Chapter is for all the generosity and kindness the community continues to share. It is through efforts such as this that the APDA continues in its mission – “To Ease the Burden – To Find the Cure”.

*We look forward to seeing you all again next year!!*
Walkathon Acknowledgements

SPONSORS:
Alfredo Aiello Italian Foods
Boston Medical Center
Boston University
Braintree Rehab Hospital
Collaborative Consulting
Costco Wholesale
Coyne Healthcare
Gentiva
Greater Medford VNA
Junk Pick-Up - Canton
KISS 108FM
- Matty in the Morning
Owens Corning
Por-Shun Dairy
- The Corduck Family
Spaulding Rehabilitation
Spirited Movement
TEVA Neuroscience

VOLUNTEERS:
Event Coordinator: Deb Case
Publicity Co-Coordinators:
Cindy Bittker, Kris Stapleton
Raffle Coordinator:
Meg McAuliffe
Photographer: Cory Brett

Alex Deal
Alex Yan
Allyson & Cameron Gormley
Beth Hagan
Bob & Laurie Jo Tullis
Cameron Boyce
Cathi & Marty Thomas
Chris Saba
Corduck Family
Denise Myers and Family
Denyse Turpin
Donna Leitao & Family
Janet & Joel Brown
Jeanne Vautour
Karen Finnell
Keith Ciccone
Kim Creem
Laura Bridges
Laurie Pant
Melissa Diggin
Mike & Gail Achin
Nancy Fine
Paul & Elaine Proulx
Rachel Burns
Ray, Lauren, & Lilly James
Rick Mirkin
Tricia Keck
Wendy Greene
Volodymyr Lyczmanenko

GIFTS-IN-KIND:
Alex Deal
Alfred Aiello & Family
Bernie & Phyl’s Furniture
Boston Beer Company
Boston Celtics
Boston College
Boston Red Sox
Brockton Rox
Cathi Thomas
Cory Brett Photography
Denyse Turpin
Dunkin Donuts - Quantum
Edaville USA
Franklin Park Zoo
Isabella Stewart Gardner Museum
JFK Library & Museum
JP Licks
Kevin Maguire
Laurie Jo Tullis
Legal Seafoods
Margarita’s Restaurant
New England Aquarium
New England Patriots
New England Revolution
Ocean Spray
Prana Yoga
Plymouth Plantation
Salem Witch Museum
Shiseido
Six Flags
Sugar Cone Norwood
Veryfine/Sunny Delight
Water Wizz

TEAMS:
Barbie's Dolls
Boston University Neurology
Canton Lions
Carole's Crusaders
Charlie's Crew
Cronin Crew
Dempsey Family
DOPA Schmopa
Ed's Striders
Grammy's Team
G'Squared
Hamel Ten Pins
Jack's Pack
Jigg's Team
Jim Blankenship Friends & Family
Just Because
Ken's Krew
Ma's Bit-O-Honeys
MOFOCA
Papa Flash
Papa's Angels
Papa's Posse
Papa's Progeny
Patsy's Posse
Pearson
Pop's Caddies
President's Team
Rich's Team
Robbins' Raiders
Rota-Rooters
Sandy's Angels
Seven Sisters
Sheldon's Squad
Sheri's Angels
Sinai Sashayers
Stevie's Wonders
Struble Striders
Team Backman
Teab Bob
Team Buddy
Team DominAchin Over PD
Team Glenn
Team Herb
Team Jerry Silver
Team MacLennan
Team Nonno
Team Norton
Team O'Reilly
Team Timitly
Team Whitmore
The Balboni Bombers
The Evans Family
The Movers & Shakers
The Toby Champs
Vinny's Voyagers
Weiss Walkers

* Please let us know if we have left your name off of this list, we will correct it immediately.
Thank you.
Community Health Charities

The APDA MA Chapter is pleased to announce its affiliation, as an associate member, with Community Health Charities of New England.

The mission of Community Health Charities of New England is to raise funds for, and increase awareness of, its member charities through workplace giving campaigns. These member charities, all of which are nationally recognized health agencies, offer vital resources and services including education, treatment, outreach and research in communities throughout New England.

If your workplace participates in the Community Health Charities giving campaign, you can designate the APDA MA Chapter as recipient of your donation. To learn more call the I & R Center at 800-651-8466 or visit www.chcofne.org

Discounted, Gently Used, and Donated Medical Equipment

At the APDA I&R Center we receive several phone calls about where someone could get gently used or donated medical items in their community. There are programs and organizations that have discounted, gently used, or donated medical items, some of which have never been used. Look below to find suggestions on whom to contact and where to look. Also note that some assistive devices require an evaluation or recommendation from a rehabilitation specialist such as physical or occupational therapist. These specialists evaluate if assistive devices are appropriate for you. Rehabilitation specialists also ensure that you can use them safely and that they are properly fit for your height and weight.

Please let us know if you have items in good condition you would like to donate. We will put you in touch with a grateful recipient.

Resources for equipment include:

Your local Senior Center or Council on Aging
To locate your community COA visit: www.disabilityinfo.org/mnip/db/tacr/OfficeByAgency.aspx?id=6

Your Local Independent Living Center
To locate the center nearest you visit: www.disabilityinfo.org/mnip/db/tacr/OfficeByAgency.aspx?id=12

Quincy Helping Hands
(617) 328-0102

Scituate Etrusco Associates, Inc.
(781) 545-4411

Wheelchair Recycler - Marlborough
(508) 460-6328
www.wheelchair-recycler.org

AT Exchange in New England
MassMATCH's free AT device exchange program. To buy donate, or sell used AT, call the toll free MassMATCH INFO-line at (866) 682-9955 (voice) and (617) 204-3815 (TDD) or visit the website. www.getatstuff.org

Masons - Malden
(781) 322-1052
The Mason Warehouse is only open on Saturdays from 9am to 12am. There is no delivery available. Call for directions and information.

Please let us know if you know of any additional resources. We will gladly add them to this list. Thank you.
Below are Parkinson’s disease support groups in Massachusetts by community. Please contact the support group leader(s) for more information on the support group nearest you.

<table>
<thead>
<tr>
<th>Community</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amherst/Hadley</td>
<td>Ruth Allis - (413) 584-2192 <a href="mailto:rallis@microbio.umass.edu">rallis@microbio.umass.edu</a></td>
</tr>
<tr>
<td>Andover</td>
<td>Kristine Arakelian (978) 623-8321 <a href="mailto:karakelian@andoverma.gov">karakelian@andoverma.gov</a></td>
</tr>
<tr>
<td>Attleboro</td>
<td>Frances Anderson (508) 695-6569 <a href="mailto:frances_anderson@verizon.net">frances_anderson@verizon.net</a></td>
</tr>
<tr>
<td>Barnstable</td>
<td>Joyce Ginouves (508) 420-0252</td>
</tr>
<tr>
<td>Bedford</td>
<td>Wendy Aronson (781) 275-6825 <a href="mailto:wsatr@aol.com">wsatr@aol.com</a></td>
</tr>
<tr>
<td>Beverly</td>
<td>Ray James, RN, BS (617) 638-7745 <a href="mailto:rcjames@bu.edu">rcjames@bu.edu</a></td>
</tr>
<tr>
<td>Boston</td>
<td>Deep Brain Stimulation - Keith J. Ciccone, BS, LPN - (617) 638-7749 - <a href="mailto:keith.ciccone@bmc.org">keith.ciccone@bmc.org</a></td>
</tr>
<tr>
<td></td>
<td>Melissa Diggin, GNP (617) 638-7630 - <a href="mailto:melissa.diggin@bmc.org">melissa.diggin@bmc.org</a></td>
</tr>
<tr>
<td></td>
<td>Gardner - Carl Billington (978) 632-9682 <a href="mailto:karter@tiac.net">karter@tiac.net</a> marybeth_kumph@lsw (978) 630-6436</td>
</tr>
<tr>
<td></td>
<td>Greenfield - Ruth Allis (413) 584-2192 <a href="mailto:rallis@microbio.umass.edu">rallis@microbio.umass.edu</a></td>
</tr>
<tr>
<td></td>
<td>Hingham - Leslie Vickers, RN, MS - (617) 750-2275 <a href="mailto:Vickers.Leslie@yahoo.com">Vickers.Leslie@yahoo.com</a></td>
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<tr>
<td></td>
<td>Lexington - Arthur Sotak (781) 862-7071 uno-us@junocom</td>
</tr>
<tr>
<td>Medford</td>
<td>Marie Knasas, RN, BSN, MBA (781) 396-2633 ext. 202 <a href="mailto:mknasas@gmva.com">mknasas@gmva.com</a></td>
</tr>
<tr>
<td>Martha’s Vineyard</td>
<td>W. Tisbury - Ken Beebe (508) 693-3497 <a href="mailto:kenb44@aol.com">kenb44@aol.com</a></td>
</tr>
<tr>
<td>Peabody</td>
<td>Council on Aging - Diane Durkee - (978) 532-0712 <a href="mailto:siddia2@live.com">siddia2@live.com</a></td>
</tr>
<tr>
<td>Plymouth</td>
<td>David Banks - (781) 871-0555 <a href="mailto:banks.dave@gmail.com">banks.dave@gmail.com</a></td>
</tr>
<tr>
<td>Quincy</td>
<td>Debbie Case (617) 638-8466 <a href="mailto:dcase@bu.edu">dcase@bu.edu</a></td>
</tr>
<tr>
<td>South Weymouth</td>
<td>Joseph Rota - (781) 545-3195 <a href="mailto:rotas@comcast.net">rotas@comcast.net</a></td>
</tr>
<tr>
<td>Springfield</td>
<td>Bobbie Levin (413) 536-1895 <a href="mailto:joyce.dupont@nesinai.org">joyce.dupont@nesinai.org</a></td>
</tr>
<tr>
<td>Stoughton</td>
<td>Deb Ribak, LSW (781) 297-1375 - <a href="mailto:dri-bak@nesinai.org">dri-bak@nesinai.org</a></td>
</tr>
<tr>
<td>Wakefield</td>
<td>Howard Porter (781) 245-7299</td>
</tr>
<tr>
<td>Waltham</td>
<td>Nancy Mazonson, MS, OTR/L (781) 693-5069 <a href="mailto:nmazonson@jfcbsboston.org">nmazonson@jfcbsboston.org</a></td>
</tr>
<tr>
<td>Williamstown</td>
<td>Robert Morrow (413) 458-8522</td>
</tr>
<tr>
<td>Worcester</td>
<td>Elizabeth Austin, PsyD - (508) 856-2409 <a href="mailto:austine@ummhc.org">austine@ummhc.org</a></td>
</tr>
</tbody>
</table>
## Caregiver Support Groups

The following support groups are designed for family caregivers. The Stoughton group is intended for caregivers of individuals with LBD and the Newton group is for family and friends of individuals with Young Onset Parkinson’s disease.

<table>
<thead>
<tr>
<th>Town</th>
<th>Contact/Group Information</th>
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<tbody>
<tr>
<td><strong>Hingham</strong></td>
<td>Leslie Vickers, RN, MS&lt;br&gt;(617) 750-2275&lt;br&gt;<a href="mailto:Vickers.Leslie@yahoo.com">Vickers.Leslie@yahoo.com</a></td>
</tr>
<tr>
<td><strong>Stoughton</strong></td>
<td>Lewy Body Dementia (LBD)&lt;br&gt;Kristin Orr - 617-650-0717&lt;br&gt;<a href="mailto:SouthshoreLBD@gmail.com">SouthshoreLBD@gmail.com</a></td>
</tr>
<tr>
<td><strong>Newton</strong></td>
<td>Young Onset Caring&lt;br&gt;Family &amp; Friends&lt;br&gt;Allyson Litos Gormley, LICSW&lt;br&gt;(617) 638-7747&lt;br&gt;<a href="mailto:Allyson.Gormley@bmc.org">Allyson.Gormley@bmc.org</a></td>
</tr>
<tr>
<td><strong>Winchester</strong></td>
<td>Diane Saparoff&lt;br&gt;(781) 721-7136&lt;br&gt;<a href="mailto:coasocialworker@yahoo.com">coasocialworker@yahoo.com</a></td>
</tr>
<tr>
<td><strong>Martha’s Vineyard</strong></td>
<td>W. Tisbury&lt;br&gt;Ellen Reynolds, MSW&lt;br&gt;(508) 693-2896</td>
</tr>
</tbody>
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### Young Onset PD Support Groups

Allyson Gormley is the contact/facilitator for both young onset Parkinson’s disease support groups.

<table>
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<th>Town</th>
<th>Contact/Group Information</th>
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<tbody>
<tr>
<td><strong>Boston</strong></td>
<td>Younger Young Onset&lt;br&gt;Allyson Litos Gormley, LICSW&lt;br&gt;(617) 638-7747&lt;br&gt;<a href="mailto:Allyson.Gormley@bmc.org">Allyson.Gormley@bmc.org</a></td>
</tr>
<tr>
<td><strong>Newton</strong></td>
<td>Young Onset Baby Boomers&lt;br&gt;<a href="mailto:Allyson.Gormley@bmc.org">Allyson.Gormley@bmc.org</a></td>
</tr>
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</table>

### Parkinson’s Plus Support Groups

The following support groups are intended for individuals affected by the Parkinson’s related conditions LBD (Lewy Body Dementia), MSA (Multiple System Atrophy), PSP (Progressive Supranuclear Palsy), and/or CBD (Corticobasal Degeneration). Individuals are also invited to participate in any support group on the general list found on the previous page.

<table>
<thead>
<tr>
<th>Town</th>
<th>Contact/Group Information</th>
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</thead>
<tbody>
<tr>
<td><strong>Boston</strong></td>
<td>Jamaica Plain - LBD&lt;br&gt;Victoria Ruff - (617) 710-0136&lt;br&gt;<a href="mailto:octoryrose@yahoo.com">octoryrose@yahoo.com</a></td>
</tr>
<tr>
<td><strong>Boston</strong></td>
<td>MSA&lt;br&gt;Melissa Diggin, GNP - (617) 638-7704&lt;br&gt;<a href="mailto:melissa.diggin@bmc.org">melissa.diggin@bmc.org</a></td>
</tr>
<tr>
<td><strong>Burlington</strong></td>
<td>LBD, MSA, PSP, CBD&lt;br&gt;Ann Aversa - (617) 872-8356&lt;br&gt;<a href="mailto:bappsg@comcast.net">bappsg@comcast.net</a></td>
</tr>
<tr>
<td><strong>Braintree</strong></td>
<td>LBD, MSA, PSP, CBD&lt;br&gt;Allyson Litos Gormley, LICSW&lt;br&gt;(617) 638-7747&lt;br&gt;<a href="mailto:Allyson.Gormley@bmc.org">Allyson.Gormley@bmc.org</a></td>
</tr>
<tr>
<td><strong>Stoughton</strong></td>
<td>LBD Caregivers&lt;br&gt;Kristin Orr (617) 650-0717&lt;br&gt;<a href="mailto:SouthShoreLBD@gmail.com">SouthShoreLBD@gmail.com</a></td>
</tr>
</tbody>
</table>

Above (left-right): Peggy Roaf, Cathi Thomas, and Angela Pangakis

Peggy & Angela have recently stepped down as leaders of the Beverly Parkinson Support Group. This summer we celebrated their twenty years of service.
Moving in the Spirit: Care for Caregivers Retreat
Saturday, October 23, 2010

The Spirited Movement Foundation, in collaboration with APDA MA, will have a retreat for caregivers of individuals with Parkinson’s disease, Dystonia, Tremor and other movement disorder conditions.

The program will be held at Glastonbury Abbey, one of the most beautiful retreat centers in New England. The Abbey’s grounds feature a spacious, light filled, accessible retreat center, a labyrinth, bookstore, chapel, outdoor sculpture and more.

The retreat will be facilitated by Lindsay McGrath, M.Div., an interfaith chaplain and director of the Spirited Movement Foundation.

For more information, contact Lindsay McGrath at lindsay@spiritedmovement.org or (781) 385-9401.

Glastonbury Abbey
16 Hull Street
Hingham, MA
# Calendar of Events - Save the Date

| Sunday & Monday,  
| September 12 & 13, 2010 | APDA New England Regional Young Onset Parkinson's Retreat  
| This two-day retreat is designed for young individuals with Parkinson's disease and their family members, to offer activities that will provide an opportunity to learn, share, relax, and have fun. Registration is required. For information, please call the APDA Vermont Chapter at (888) 763-3366.  
| Lake Morey Resort  
| 1 Clubhouse Road - Fairlee, VT 05045 |

| Wednesday, October 6, 13, & 20, 2010  
| 6-8:00pm | A Good Start Program  
| For individuals recently diagnosed with Parkinson’s and their families. Contact the APDA I & R Center at (617) 638-8466. Registration is required  
| Boston University College of Health & Rehabilitation Sciences: Sargent College |

| Sunday & Monday,  
| November 7 & 8, 2010 | APDA New England Regional Biennial Sturbridge Symposium  
| The Sturbridge Host Hotel  
| 366 Main Street - Sturbridge, MA 01566  
| Additional information will be posted soon on our website. |

## Become a member of the MA Chapter of the APDA

Fill out the registration form and mail it to  
APDA MA Chapter, 72 East Concord St, C3, Boston, MA 02118

Name ___________________________________________ Date ________________

Address ___________________________________________________________________________

City _______________________________ State ___________ Zip _______________

Email _______________________________ Telephone ____________________________

Membership Fee: $10 per individual, $15 per family
The APDA MA Chapter wants to keep you informed. To keep mailing costs down and distribution up, we are encouraging everyone who uses email addresses to add them to our online mailing list.

If you or a family member uses email, please send your address to us at information@apdama.org and we will gladly add you to the list. The APDA Information & Referral Center sends out weekly announcements regarding community events and news. Please keep in touch!