



# Parkinson's Report

A publication of the American Parkinson Disease Association Massachusetts Chapter and the APDA Information & Referral Center at Boston University Medical Campus.

Fall 2010

## Racial and Geographic Variation in Parkinson's Disease

Allison Wright Willis, M.D.



Dr. Willis is an Assistant Professor of Neurology at Washington University School of Medicine. Her clinical areas of expertise include treat-

ment of adults and children with movement disorders; such as Parkinson disease (PD), dystonia and Tourette Syndrome/tics. Her main area of research is in the environmental epidemiology of PD.

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

Published by the  
American Parkinson  
Disease Association  
Information & Referral  
Center at Boston  
University Medical Campus

72 East Concord St, C3  
Boston, MA 02118  
800-651-8466 or  
617-638-8466  
Fax: 617-638-5354  
[www.apdama.org](http://www.apdama.org)

Editors:  
Cathi A. Thomas MS, RN  
Debra Case

Marie Saint-Hilaire, MD  
Medical Director

This publication is  
supported by the APDA  
Massachusetts Chapter

APDA National Office  
135 Parkinson Avenue  
Staten Island, NY 10305  
800-223-2732  
[www.apdaparkinson.org](http://www.apdaparkinson.org)

This newsletter is intended  
solely to provide you with  
information on Parkinson's  
disease. You should not  
make any changes to treat-  
ment without first discuss-  
ing them with your health-  
care provider.

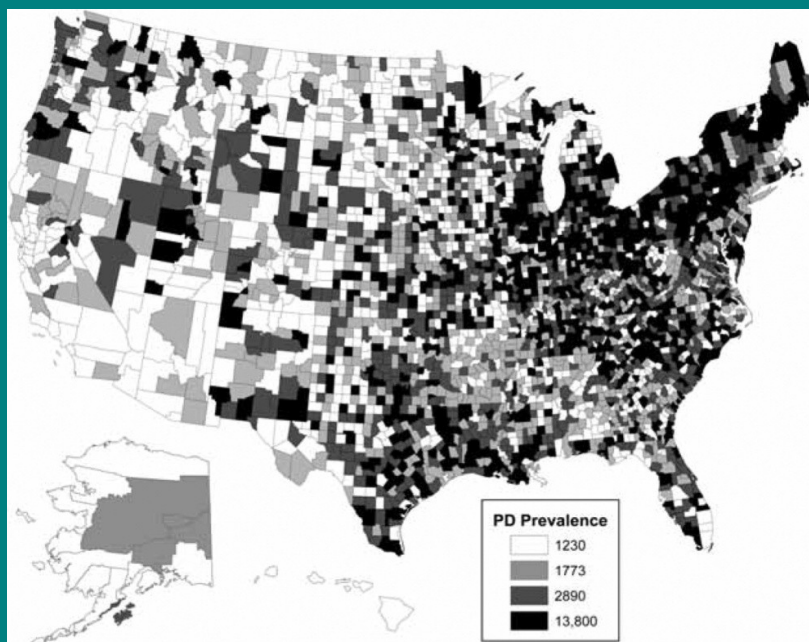
Continued on next page

## Racial and Geographic Variation in Parkinson's Disease Cont.

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."*

Age, race and sex standardized prevalence (per 100,000) of Parkinson Disease among Medicare beneficiaries in the United States (year =2003)



### 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.

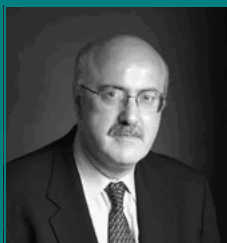
On the other hand, the finding that PD is more prevalent in the Northeast and Midwest suggests that environmental factors also play a role.

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](mailto: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 on-going 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](http://www.pdtrials.org), [www.clinicaltrials.gov](http://www.clinicaltrials.gov), or [www.pdpipeline.org](http://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.parkinson-study-group.org](http://www.parkinson-study-group.org), [www.clinicaltrials.gov](http://www.clinicaltrials.gov), and [www.pdtrials.org](http://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](http://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](http://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,



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

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!

### 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](http://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.

## 24th Annual APDA MA Chapter Parkinson Walkathon

*Debbie Case - 2010 Walk Coordinator*



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 hand-

made, 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



*The Aiello family distributes fresh cannoli to the crowd.*

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

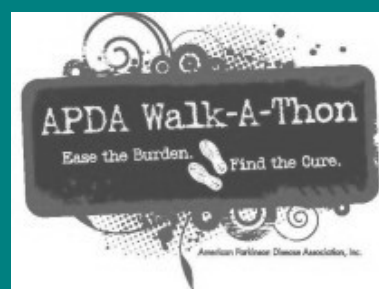


*Continued on next page*



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!!*



Ken's Krew

The Corduck family scoops an endless supply of ice cream and Italian Ice for everyone to enjoy.



Team MacLennan  
(A new addition this 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 Yen  
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 - Squantum  
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 Timilty  
Team Whitmore  
The Balboni Bombers  
The Evans Family  
The Movers & Shakers  
The Toby Champs  
Vinnys Voyagers  
Weiss Walkers

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



*Jack's Pack*

## 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](http://www.chcofne.org)

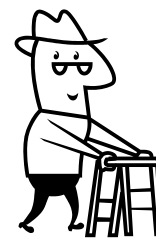


## Discounted, Gently Used, and Donated Medical Equipment

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 physi-

cal 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](http://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](http://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](http://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](http://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.

# Massachusetts Parkinson's Support Groups

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.

## Amherst/Hadley

Ruth Allis - (413) 584-2192  
rallis@microbio.umass.edu

## Andover - Kristine Arakelian

(978) 623-8321  
karakelian@andoverma.gov

## Attleboro - Frances Anderson

(508) 695-6569  
frances\_anderson@verizon.net  
Roy C. Watson  
rcwflowers@verizon.net

## Barnstable - Joyce Ginouves

(508) 420-0252

## Bedford - Wendy Aronson

(781) 275-6825 -  
wsatr@aol.com

## Beverly - Ray James, RN, BS

(617) 638-7745  
rcjames@bu.edu

## Boston

### Deep Brain Stimulation

Keith J. Ciccone, BS, LPN -  
(617) 638-7749 -  
keith.ciccone@bmc.org  
Melissa Diggin, GNP - (617)  
638-7704  
melissa.diggin@bmc.org

## Boston

### Younger Young Onset

Allyson Litos Gormley, LICSW  
- (617) 638-7747 -  
Allyson.Gormley@bmc.org

## Bourne (Cape Cod)

Ellen Weinlich, LCSW - (800)  
696-4047 x3494

## Brookline - Cathi Thomas,

MS, RN - (617) 638-8466  
neurocat@bu.edu

## Concord - Jerry O'Connell

(978) 443-5742  
joconnell@bentley.edu

## Dartmouth - Judy Medeiros

(508) 997-0907 -  
judi0610@yahoo.com

## Falmouth (Cape Cod)

Les Wrigley - (508) 457-5081  
landvwrigley@aol.com

## Framingham - Ann Steacie

(508) 532-5980 x4113  
ams@framinghamma.gov

## Gardner - Carl Billington

(978) 632-9682  
karter@tiac.net  
Marybeth Kumph, LSW  
(978) 630-6436

## Greenfield - Ruth Allis

(413) 584-2192  
rallis@microbio.umass.edu

## Hingham - Leslie Vickers, RN,

MS - (617) 750-2275  
Vickers.Leslie@yahoo.com

## Lexington - Arthur Sotak

(781) 862-7071  
uno-us@juno.com

## Medford

Marie Knasas, RN, BSN, MBA  
(781) 396-2633 ext. 202  
mknasas@gmvna.com

## Martha's Vineyard (W.

Tisbury) - Ken Beebe  
(508) 693-3497  
kenb44@aol.com

## Milton - Leslie Vickers, RN,

MS - (617) 750-2275  
Vickers.Leslie@yahoo.com

## Nantucket

Charlene Chadwick, RN -  
(508) 825-8190  
cchadwick@partners.org

## Newton-Wellesley

Ermes DeMaria  
(781) 444-7446  
ermes@comcast.net

## Newton - Wellesley

### PSGGB

Joel Brown - (978) 887-8544  
Paul Proulx - (978) 685-2240  
paulproulx@comcast.net

## Newton - Young Onset

### Baby Boomers

Allyson Litos Gormley, LICSW  
(617) 638-7747  
Allyson.Gormley@bmc.org

## Orleans (Cape Cod)

Gale Glanville - (508) 255-  
7774  
gpglanville@verizon.net  
Jane McDonald - (508) 240-  
1642 - jimjanemcdonald  
@comcast.net

## Peabody

### Brooksby Village - Susan

Vitiello - (978) 536 7832 -  
Susan.vitiello  
@erickson.com

## Peabody

### Council on Aging - Diane

Durkee - (978) 532-0712  
siddia2@live.com

## Plymouth - David Banks -

(781) 871-0555  
banks.dave@gmail.com

## Quincy - Debbie Case

(617) 638-8466  
dcase@bu.edu

## South Weymouth

Joseph Rota - (781) 545-3195  
rotas@comcast.net

## Springfield - Bobbie Levin

(413) 536-1895  
Joyce Dupont - (413) 323-  
4274  
JdupontB@aol.com

## Stoughton - Deb Ribak, LSW

(781) 297-1375 - dri-  
bak@nesinai.org  
Pat Wilkinson, CSW, LICSW  
pwilkins@nesinai.org

## Wakefield - Howard Porter

(781) 438-0326  
porterart1611@yahoo.com  
Linda McLaughlin  
(781) 245-7299

## Waltham

Nancy Mazonson, MS, OTR/L  
(781) 693-5069  
nmazonson@jfcbsoston.org

## Williamstown

Robert Morrow (413) 458-  
8522  
badotis7@verizon.net  
Pat Goss - (413) 458-9685

## Worcester

Elizabeth Austin, PsyD - (508)  
856-2409  
austine@ummhc.org



## 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.

**Hingham** - *Leslie Vickers, RN, MS*

(617) 750-2275

Vickers.Leslie@yahoo.com

**Stoughton** - *Lewy Body Dementia (LBD)*

*Kristin Orr* - 617-650-0717

SouthshoreLBD@gmail.com

**Newton** - *Young Onset Caring*

*Family & Friends*

*Allyson Litos Gormley, LICSW*

(617) 638-7747

Allyson.Gormley@bmc.org

**Winchester** - *Diane Saparoff*

(781) 721-7136

coasocialworker@yahoo.com

**Martha's Vineyard** - *W. Tisbury*

*Ellen Reynolds, MSW*

(508) 693-2896

## Young Onset PD Support Groups

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

**Boston - Younger Young Onset**

*Allyson Litos Gormley, LICSW*

(617) 638-7747

**Newton - Young Onset Baby Boomers**

Allyson.Gormley@bmc.org

## 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.

**Boston - Jamaica Plain** - LBD

*Victoria Ruff* - (617) 710-0136

octoryrose@yahoo.com

**Boston** - MSA

*Melissa Diggin, GNP* - (617) 638-7704

melissa.diggin@bmc.org

**Burlington** - LBD, MSA, PSP, CBD

*Ann Aversa* - (617) 872-8356

bappsg@comcast.net

**Braintree** - LBD, MSA, PSP, CBD

*Allyson Litos Gormley, LICSW*

(617) 638-7747

Allyson.Gormley@bmc.org

**Stoughton** - LBD Caregivers

*Kristin Orr* (617) 650-0717

SouthShoreLBD@gmail.com



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.

## Resources for Caregivers

### National Alliance for Family Caregiving

4720 Montgomery Lane, 5th Floor  
Bethesda, MD 20814

[www.caregiving.org](http://www.caregiving.org)

### National Family Caregivers Association

10400 Connecticut Avenue, Suite 500  
Kensington, MD 20895-3944  
(800) 896-3650

[www.nfcacares.org](http://www.nfcacares.org)

### Children of Aging Parents

P.O. Box 167  
Richboro, PA 18954  
(800) 227-7294

[www.caps4caregivers.org](http://www.caps4caregivers.org)

### National Family Caregiver Support Program

Administration on Aging  
Washington, D.C. 2021  
(202) 619-0724

[www.aoa.gov/AoARoot/AoA\\_Programs/HC/LTC/Caregiver/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HC/LTC/Caregiver/index.aspx)

### Family Caregiver Alliance

180 Montgomery Street, Suite 1100  
San Francisco, CA 94104  
(800) 445-8106

[www.caregiver.org/caregiver/jsp/home.jsp](http://www.caregiver.org/caregiver/jsp/home.jsp)

### Well Spouse Association

63 West Main Street, Suite H  
Freehold, NJ 07728  
(800) 838-0879

[www.wellspouse.org](http://www.wellspouse.org)

### Today's Caregiver Magazine

3005 Greene Street  
Hollywood, FL 33020

[www.caregiver.com](http://www.caregiver.com)



### Family Caregiving 101

Joint educational effort by NFCA and NAC  
[www.familycaregiving101.org](http://www.familycaregiving101.org)

### Eldercare Locator

(800) 677-1116  
[www.eldercare.gov/Eldercare.NET/Public/Home.aspx](http://www.eldercare.gov/Eldercare.NET/Public/Home.aspx)

## 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](mailto: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

# Please help us update our mailing list!

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!

American Parkinson Disease Association  
Information & Referral Center  
Boston University Medical Campus  
72 East Concord Street - C3  
Boston, MA 02118

(800) 651-8466

NON-PROFIT ORG  
US Postage  
PAID  
Framingham, MA  
Permit 179