

Parkinson's & Us

A Publication of APDA I & R Center and Georgia Chapter

Summer 2013



Are you familiar with PAN?

The Parkinson's Action Network or PAN is the voice of Parkinson's on numerous public policy issues affecting people with Parkinson's and their families. The Washington, D.C. – based non-profit organization continues to be the leading voice for patient advocacy. Through educating the public and government leaders on better policies for research and an improved quality of life for people living with Parkinson's, PAN partners with other Parkinson's organizations to make a difference.

At the recent "Community Conversations with Emory PD Researchers" event, we were pleased to have Amy Comstock Rick, Chief Executive Officer of PAN as the keynote speaker. Ms. Rick with PAN's Board

of Directors helps lead the organization as the unified voice advocating for better treatments and a cure for PD. They have established a strong national grassroots advocacy program that works to bring much-needed awareness to the public and lawmakers about the effects of PD. According to Ms. Rick, PAN continues to work on National Institute of Health (NIH) funding and research, Parkinson's-specific programs at the Department of Defense and Veteran's Affairs, FDA drug approval issues and HHS programs (Medicare and Social Security). They also continue the struggle to achieve research freedom for stem cell research.

Ms. Rick briefly discussed several key findings from two recent stud-

ies in the journal *Movement Disorders*. According to the studies, the economic burden of Parkinson's disease in the U. S. is \$14.4 billion a year and that by the year 2040, the PD population will more than double. She emphasized the importance of increased research funding not cuts as proposed by the NIH. To read more on the key findings that Mrs. Rick discussed, go to www.pdf.org/communitynews.

For more information regarding PAN and the important public policy work they do, go to www.parkinsonsaction.org. In Georgia, the PAN advocates are: Paul Cordella, Director, 706-754-6662, cholta@aol.com and Connie Ray, 706-291-7250, connie.ray0628@att.net.

News from PAN

Dear Parkinson Action Network readers –

In June, PAN launched **PAN: Policy, Advocacy, News**, a new informational tool and news service. Each Friday, this e-resource will bring you the latest on PAN activities in D.C., updates from our grassroots network, and all of the relevant news articles that you are used to seeing in your inbox as "News from PAN."

PAN: Policy, Advocacy, News replaces "News from PAN," as well as our monthly e-newsletter, and will regularly communicate our ongoing work and progress on key issues, as well as provide you with opportunities to stay engaged. We look forward to your feedback as we roll out **PAN: Policy, Advocacy, News**.



Executive Board Members

Eric Burkard, CLTC

President

Cheryl Richards-Mann

Secretary

Ed Nichols

Treasurer

Jorge L. Juncos, M.D.

Medical Director

Barbara Mooney

Administrative Manager

Lynn Ross, LMSW

Information & Referral

Center Coordinator

Susan Palmer

Accounting

Ken Alfiero

Member at Large

Katie Beshara

Member At Large

Mary Lynn Billman

Member At Large

Annemarie Schwarzkopf

Member At Large

APDA Georgia Chapter

P.O. Box 49416

Atlanta, GA 30359

404-325-2020

www.apdageorgia.org

President's Corner



Dear Friends,

It was nice to see many of you on Saturday, June 1st at the 3rd annual "Community Conversations with Emory Parkinson's Disease Researchers", sponsored by the Morris K. Udall Center at Emory and supported by APDA Georgia Chapter and other organizations. If you were not able to attend, I hope you will consider coming next year. It is a truly outstanding educational event, attended by people from all over, and it is free. One of the big "takeaways" for me was learning about the work of the Parkinson's Action Network (PAN) in Washington. Be sure to read the enclosed article on PAN.

We have some fun events coming up, and we hope you can get involved.

On July 4th, yours truly ran his 8th Peachtree Road Race and his 3rd supporting the APDA Georgia Chapter. It was an exciting opportunity to represent our organization and connect with others who are running to raise awareness about our mission.

On Saturday, July 6 from 4:30 – 6:30 pm, we hosted a Wine Tasting event in Alpharetta at Vino100, complete with appetizers, live music and a nice door prize. A special thanks to those who were able to attend and even some of our Emory notables were there to extend support.

Speaking of notables, just around the corner is Dr. Jorge Juncos' annual "Parkinson's Update" on Saturday, August 17 from 10:30 am – 12:00 pm at Clairmont Oaks in Decatur, so please mark your calendar for this popular educational meeting.

As a treatment for Parkinson's, *EXERCISE* undoubtedly has the best cost/benefit ratio of any treatment, and in this regard we will be working diligently to help set up and support as many exercises classes as possible. They will be specially tailored for PWPD and may also include Tai Chi and Tango. Your generous dollars will help fund these valuable benefits.

Thank you again for your support, and I look forward to seeing you soon!

Best regards,
Eric Burkard

It is here!

We are pleased to announce the release of our newly designed website, with a fresh new look and user-friendly navigation, updated with the latest information about our programs and services. The site's homepage welcomes

you with a clean uncluttered design and scrolling images with featured content focused on our mission to provide you with the most accurate information in the field of Parkinson's disease. We hope that you will enjoy

browsing the new site and that it will be yet another tool for strengthening our mission to ease the burden to find a cure.

Visit www.apdageorgia.org to see the new site.

Developments in Parkinson's Disease

Nearly 50 residents and guests in the Somerby of Alpharetta retirement community turned out to hear Dr. Jorge Juncos, Emory Associate Professor of Neurology and Georgia APDA Medical Director.

Dr. Juncos presented information about the latest research and clinical care for Parkinson's disease. If you want to learn more information about research and clinical trials, please contact Becky McMurray 404-728-6427.



Jorge Juncos, M.D. at Somerby

EXERCISE CLASSES FOR PEOPLE WITH PARKINSON'S

In Smyrna

- What:** The class consists primarily of standing activity and is designed for people who have walking and balance impairments, but who do not require assistance with mobility.
- When:** Tuesdays, 12:00-1:00
- Where:** Aline Wolfe Adult Recreation Center, 884 Church Street, Smyrna
- Cost:** \$4/class + Wolfe Center Membership (\$20 yearly for residents, \$50/yearly for non-residents)
- Contact:** Diane Yelich, (678) 631-5541

In Douglasville

- What:** The Parkinson's-friendly class will be combined with the Silver Sneakers "Classic" exercise class. Exercises include strengthening, stretching and are adapted for all levels. Exercises can be done standing or seated.
- When:** Monday & Wednesdays, 11:30 -12:15 pm
- Where:** Woodie Fite Senior Center
1000 Simeon Springs Court, Douglasville
- How to register:** In-person at the Woodie Fite Senior Center or call 678-626-5630
- Cost:** \$20/month
- Contact:** Karen Flagg at 770-598-0644

In Roswell

- What:** This class, which will address the unique concerns of PD, is moderate to high intensity and will accommodate people with gait and/or balance impairments.
- When:** Friday 10:30 – 11:30 am
- Where:** Roswell Adult Recreation Center
830 Grimes Bridge Road, Roswell
- How to register:** www.roswellgov.com (class 40024-01); or in-person at the Roswell Adult Recreation Center; or call 770-641-3705
- Cost:** \$40 for 11 weeks for Roswell residents; \$60 for non-residents
- Contact:** Dave Jones 770-552-0982 H or 404-808-0618 C

Support Group Spotlight

Dear Friends,

The Lake Country Shakers is a Parkinson's support group based at St. Paul's United Methodist Church in Gainesville, Georgia. It is one of the oldest groups of its kind in the Atlanta Area. Founded by Marie and Bob Bridges, the Lake Country Shakers recently celebrated 20 years of Parkinson's Support with a luncheon at the Smith House in Dahlonega, Georgia. This event was held in conjunction with Parkinson

Awareness Month 2013. The group currently boasts a membership of more than 60 members that includes Parkinson's patients, care-partners as well as sons and daughters.

The support group meets twice a month on the first and third Thursday of each month. In earlier years, the group sponsored overnight and 2 day trips to St. Mary's at St. Simons Island, Chattanooga and Montgomery, Alabama. Since the membership has matured the group has reduced trips to only one day excursions to the cherry blossoms festival in Macon, Georgia and other nearby attractions.

The purpose of the group is to provide information and support, as needed or requested. Although membership has aged over the years, our group composition ranges from individuals diagnosed over 20 years ago to those diagnosed in recent months.. As a result, we have a wide range of experiences to share in this unplanned journey. The geographic area of our support and fellowship extends East of I-75 in Flowery Branch, Gainesville, and Cumming, North to the Carolina borders all the way to Helen in the West. Dean and David Poole are now facilitating the group and we want to thank David for sending the article and picture of the Lake Country Shakers. Everyone is welcome to visit and share their knowledge and experiences. We look forward to being of service to you.

Best regards,

The Lake Country Shakers

Dates to Remember

What: Dinner at Huntcliff Summit Independent Senior Living, 8592 Roswell Rd, Atlanta, GA 30350

Followed by a presentation on the "Latest Advances in Parkinson's Disease Research"

When: Tuesday, August 20, 2013 at **6:30 p.m.** with Stewart Factor, DO of Emory University

Cost: \$40.00 per person pay online or by mail: APDA Georgia Chapter, PO Box 49416, Atlanta, GA 30359

What: Southeastern Parkinson Disease Conference (SPDC)

When: August 9 - 11, 2013, Sheraton Gateway Hotel, 1900 Sullivan Rd., Atlanta, GA 30337

Register: To register for the conference visit <http://spdc.bravesites.com/>

Emory Udall Center Presents Community Conversations

The clinicians, faculty, staff and volunteers at the Emory Udall Center of Excellence for Parkinson's Disease wish to extend a heartfelt thank you to each participant who attended our Annual Community Conversations event in June. The meeting was a huge success because of your commitment to foster education, awareness

and outreach to eradicate Parkinson's disease. This annual event allows patients and families to discuss current findings and developments in Parkinson's disease research with Emory scientists. Attendees had the opportunity to participate in three of the 18 discussions groups with 8-10 people in each small group. Discussion topics ranged from "Nutritional strategies to combat neurodegenerative disease to Surgical Treatments in Parkinson's Disease." In this unique setting, small groups learn firsthand about research, care and treatment. To learn more about the Emory Udall Center visit www.udall.emory.edu.



Thomas Wichmann, MD at Community Conversations

Customized Medical Bracelet for Parkinson's

The Care Medical Bracelet is an easy-to-use medical bracelet that allows you to create a personal health record to have with you at all times.

The bracelet has been proven to be lifesaving in an emergency situation, allowing first responders instant access to medication lists, allergies, doctors and emergency contacts and much more.

The bracelet can be edited from any computer, MAC or PC. No internet access is required, as the program works directly from the bracelet and saves information to the bracelet.

And now there is a customized version for Persons with Parkinson's or other Movement Disorders that includes an alert of a movement disorder, specific information on Deep

Brain Stimulation (DBS) and Ventriculooperitoneal Shunt (VPS) and a Medications page which has a list of safe and contra-indicated medications.

In support of the APDA Georgia Chapter, GC Publishers, LLC, the maker of the Care Medical History Bracelet is offering this bracelet at the discounted price of \$27.99 (retail is \$29.99) plus shipping and handling. Additionally, for each bracelet ordered, GC Publishers, LLC will donate \$5.00 to the APDA Georgia Chapter.

To order this bracelet, visit www.medicalhistorybracelet.com and enter code "APDAGeorgia" upon checkout.

For more information or to order by phone, please contact: Julie Bruce, Vice President of Sales at (480) 353-7560 or email Julie@gcpublishers.com.



2013 Skyline Gala in Atlantic Station, October 12, 2013

Don't miss APDA's annual Skyline Gala on October 12th which will be a "Casino Royale" high atop 201 17th Street in Atlantic Station complete with some Atlanta notables, over a dozen Gaming Tables, Music, heavy Hors d'oeuvres, Open Bar, Food Action Stations, Raffle Prizes, Silent Auction (some of our best selling trips

will be auctioned) and one of the best skyline views of downtown Atlanta. Plenty of tables and seating will also be available. Black Tie is optional, but if black tie is not your thing, do come "dressed to kill". We will have a special prize for the best James Bond (any) and "Bond Girl" (any).

To purchase your tickets, visit our website www.apdageorgia.org and go to "Upcoming Events". Tickets are \$100 per person. If you'd like to make it a night on the town, consider staying at the elegant TWELVE Hotel (one block away) that night. For hotel reservations, call 404-961-1212 and ask for the "APDA" special rate of \$159/night. Your support at this Gala event will allow us to maintain and expand important local initiatives to "ease the burden" of people with Parkinson's and their families in Georgia. See you soon!

American Parkinson Disease Association, Georgia Chapter

Skyline Gala



Wilkins Parkinson's Foundation 6th Annual Fundraiser



Don't miss the Wilkins Parkinson's Foundation (WPF) sixth-annual Polo for Parkinson's fundraiser at Chukkar Farm and Polo Club on Sunday, September 29th! We're making some exciting changes to the event this year, and be sure to visit www.wilkins-pf.org for updates. Hope to see you in September!

Donations made to the APDA Georgia Chapter

Donations:

John and Judith Anderson
Aon Foundation
Dan and Merrie Boone
Matthew Bullock
Harry Burnett
Mary Cahill
John Carmichael
Robert & Judi Crutchfield
Ms. Sylvia Dieges
Joseph & Annie Dimon III
Jim & Claydene Dunlap
Tom & Kathy Edwards
Dick & Agnes Fritz
Marvin & Fran Galarza
Cindy Gibbs
Michael Hagearty, D.D.S.
Christopher Hall
Glenda Hardee
Dr. James Hodnett, MD
Home Depot Match Program
Wayne & Patsy Huey
Robert and Barbara Hunter
Miles P. Hurley
Mr. & Mrs. Allen Ivey
Betty Jacobson
Michael James
Gregory & Cindy Kindred
Joseph & Gayle Lesser
Joel and Janet Levy
Louise Lopushinsky
Eugene Lorenz
Jim Mason
Joan McCall
Everett J. & Donna McCubrey, Jr.
Sara McGarity
Barbara and Joseph Means
Lawrence & Veronica Miller, Jr.
Bill & Bettye Millsaps, Jr.
Elijah & Ena Moore
Rory Owen Murphy
Bruce Nelson
Lee & Laura Oakley
Paul and Jacqueline Odom
George & Jo Ann Olsen
Charlotte Parsons
J. H. & Sue Passman
Don & Marilu Pehrson

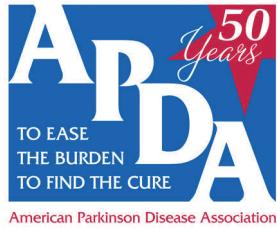
William & Faye Pender
Bill & Susan Posey
Kelly & Jean Price
William & Sally Radford
Joe and Janice Ransbotham
Daniel & Alice Roseman
Marcia Rosenberg
Jeff Schade
Michele Siverson
Mark & Patricia Soltys
Jerry & Janice Spyke
Al & Merna Stein
Deborah Stone
Terry & Margaret Stent
Rev. Karl Suhr
Suntrust United Way Campaign
Carl Swearingen
Michael Swomley
Karen Thompson
Stanley & Ruth Thorson
Heather Tillis
Truist , Altruism Connected
A.S. Turner & Sons, Inc.
Hazel Tyson
Allan & Joan Walker
Kerry & Genelle Wilkes
Bill and Jean Witcher
Stuart Witham
Donn & Sherry Wright
Royal Yates

Linwood R. Gatlin
First Baptist Church Magna Sunday School
Melvin, Rooks & Howell, PC
Keith BradyWade and Linda Gatlin
Teresa Grubbs
Glenda Dunn
James Turner
Larry and Lisa Saxon
Courtney Restivo
Willard E. Jones
David and Ann Patterson
David Menard
Joan Menard
Carol Vess
James and Diane Snell
Lou Doerrie
Ward Bondurant
Jim Keith
Marcia Rosenberg
Spencer Ladd
Gary and Sam Alexander
Edgar C. Lighthiser
Bob and Ann Rawsthorne
Dorothy Sprecher
Arthur Parsons
Charlotte Parsons
Andrew Purcell
Sydney L. Smith
Charles Rafshoon
Robert and Shelley Antin
Lawrence Rafshoon
KLG, LLC
Ruth Smith
Bonnie Beerman
Arleen Kolko
Muriel Steinberg
Janet Sunshine
Marcia Rosenberg
Ben Upchurch
Jim Rundorff

In memory of:

Joan Ashley
Mary Newell Cobb
Elva Smith Harris Burns
Melanie Key
Betty Cone
Marvin and Elaine Mangham
John Cook
Patricia Falconer
Christlena Lawton
Gary and Joan Harless
Ed Dery
Chuck Esposito
Donnie Diamond
Marcia Rosenberg
Randy Feinberg
Marcia Rosenberg

As a 501(c)(3) not-for-profit organization, the Georgia Chapter of APDA serves Parkinson's communities throughout Georgia with the generous support of your individual and corporate donations. **Gifts can be given by mail, phone, or on-line:**
Georgia Chapter APDA
P. O. Box 49416
Atlanta, GA 30359
Phone: (404) 325-2020
Online: www.apdageorgia.org/donations.php



American Parkinson Disease Association
Information & Referral Center
1841 Clifton Road
Atlanta, GA 30329

MARK YOUR CALENDAR!

Educational Meetings are held at Clairmont Oaks
441 Clairmont Avenue, Decatur, GA 30030

August 17, 2013
Jorge Juncos, M.D. "PD Research Update 2013-2014"

September 18, 2013
Patricia Creel, P.T. and Dave Jones "Exercise and PD"

October 19, 2013
TBA by Virendra Ranadive, M.D.

November 16, 2013
Roza Adamcyzk, M.D. "Managing PD Symptoms"

For directions or questions, please call the APDA Helpline at 404-728-6552

No meeting in December