Parkinson's & Us

A Publication of APDA I & R Center and Georgia Chapter
Summer 2012

Let the Patient Beware

By Stewart A. Factor, D.O. Professor of Neurology
Emory University School of Medicine

The unfortunate undisputable truth about Parkinson's disease (PD) is that there is currently no cure. There are a number of treatments to hold the symptoms at bay, but nothing that stops it from progressing. Because of this, patients and their loved ones can be victimized in ways beyond the misfortune of the devastating disease.

A PD patient I knew well for 10 years who was asked to my office by his son, who asked that I speak to a physician. The "doctor," however was not a physician, but a scam artist selling naturopathic remedies (I learned about him later from a variety of websites). He made incredibly outrageous claims without ever laying eyes on the patient, including one that "Parkinson's disease is simple", and that he could cure it in "three weeks" with his remedies. He denigrated university professors claiming he had cured people previously diagnosed with Alzheimer's disease, which he said was generally a nutritional deficiency.

The patient's son had purchased nearly $700 of products, which were nothing more than vitamins and minerals that could be purchased elsewhere for a fraction of the cost. When the son reviewed the list with the man, he was told he needed to purchase more. There is, unfortunately, no shortage of fraudulent treatments made available to the public. Among the "cures" are:

-Easily available over-the-counter vitamins and minerals in the guise of scientific-sounding names.

-Expensive infusion therapies with glutathione, chelators, growth factors, amino acid cocktails and various forms of nutrients.

-Bogus stem cell therapies, whereby stem cells are removed from fatty tissue and given in intravenous infusions or injections on the lower spine or back of the neck (the procedure has no proven benefit and the FDA has not approved it).

The most obvious reason people fall for these scams is a sense of desperation in knowing one has an incurable, progressive disabling disease. Second, well-intentioned family members indiscriminately suggest websites, publication ads and articles promoting various treatments and cures, and popular media reports of news-breaking "medical discoveries." Current medicine is by no means perfect, but physicians provide the FDA-approved treatments that have been studies in a systematic scientific manner with results published in peer-reviewed periodicals. Naturopathic organizations are not held to the same scrutiny and use testimonials from individuals who may be paid by the company. Alternative therapies for the most part are considered medically harmless, and a patient having the time, money and desire will decide independently whether to use them.

But are they harmless? Is it harmless to scam chronically ill patients and drain them of resources that could be used to hire a private physical therapist to sustain or regain strength and independence?

When these treatments fail, patients usually do not come forward because of their embarrassment at being duped. Patients should feel comfortable to ask their physicians when faced with outrageous claims about alternative therapies until these therapies are subject to the same scrutiny level that FDA-approved drug therapies.

From APDA News Winter 2012

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President's Corner

Dear Friends,

It is a hot summer here in Georgia and at the Georgia Chapter of the American Parkinson Disease Association! I hardly know where to start….

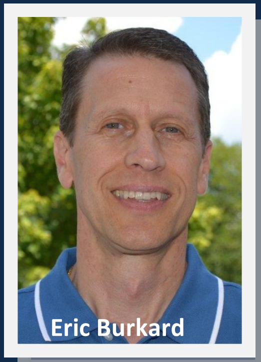
First of all, our annual Gala was amazing this year. I hope you were able to attend. The venue for the event was the sky deck of Nelson Mullins (law firm) in Atlantic Station, and we were blessed with a starry night to view the Atlanta skyline. We were also blessed with our star master of ceremonies, Monica Pearson from WSB-TV, who donated her time and talent to make our Gala a fun and successful event. Our other "celebrities" included Elvis, Marilyn Monroe and Donald Trumpett, who added their own brand of humor to animate the crowd; all in all, a great time for everyone.

Our golf tournament was held again at Smoke Rise Country Club in Stone Mountain and continues the tradition that we started many years ago when Bill Pender and his friends had the idea to hold the fundraiser there. No rain this year but plenty of fun.

This year APDA participated in the Peachtree Road Race: our own Eric Burkard ran the race for us and collected some nice sponsorships along the way. Friend of APDA, Triff Cook, also ran for us and added some funds to our coffers. Next year we plan to recruit a bigger contingent of runners, walkers and supporters, so dust off the old cowbells and cheer the runners on next year!

We still have several great fundraising events ahead of us this year including our Mallorca, Spain Raffle (buy your ticket now at www.apdageorgia.org!) and the Dinner at Agatha's Mystery Theater on October 21st, along with our monthly educational meetings arranged by our I & R Center.

Finally, looking down the road, I would like to let you know that I plan to step down as your President in January and allow our vigorous new Vice President, Eric Burkard, to take over the Chapter reins. Of course I will still remain active and on the board – I have really enjoyed my time with you so far – since November 2006!



Eric Burkard

Thanks for all you do,

Annemarie Schwarzkopf

Purchase your tickets today!

Mallorca, Spain Adventure!

Escape to Palma de Mallorca! Each ticket grants you a chance for a once in a lifetime vacation to this Mediterranean playground! Your trip includes a two week apartment rental with accommodations for up to 4 people & an airfare voucher for $2,500.

Price $50.00 per ticket.

Only 300 will be sold.

All proceeds benefit APDA Georgia Chapter.

APDA
TO EASE
THE BURDEN
TO FIND THE CURE
American Parkinson Disease Association

Dates are subject to availability. For more details please visit www.apdageorgia.org

2012 Skyline Gala

The 2012 Skyline Gala, overlooking the Atlanta skyline and an amazing spring sunset, was held at the sky deck of the Nelson Mullins building. Featured this year was Atlanta's own, Monica Pearson of WSB-TV as Master of Ceremonies in one of her final events before retirement. Her enthusiasm and giving spirit made this an event not to be forgotten. The event was one of the Chapter's best yet with a capacity crowd. The silent auction was an especially noteworthy event featuring works of art, vacation homes and autographed merchandise from such notables as Bruce Springsteen and Muhammad Ali.


APDA GA Chapter Board members

L-R Mary Lynn Billman, Barbara Mooney, Cheryl Richards-Mann, Annemarie Schwarzkopf, and Eric Burkard

AGATHA'S
A TASTE OF MYSTERY

161 Peachtree Center Ave., Atlanta, GA 30303

Join us for a night of fun and laughter at

Agatha's!

Sunday, October 21, 2012

Doors open at 5:30 p.m.

Dinner and Show begin at 6:00 p.m.

Tickets $65 per person

As always at Agatha's, the audience participates in the action in the comic murder mystery.

Each night, the entire audience has a chance to die laughing between 5 courses of dinner including hor d'oeuvres, a choice of entree' and a glass of wine.

A limited number of tickets are available.

Reserve tickets online www.apdageorgia.org

Mail your check to:

APDA Georgia Chapter
PO Box 49416
Atlanta, GA 30359

Neupro® Patch Ready for U.S. Comeback

April 3, 2012 -An announcement from pharmaceutical company UCB, maker of Neupro® (Rotogotine Transdermal System), was sure to be welcome news to people with Parkinson's disease (PD). Neupro, an extended-release dopamine agonist in the form of a skin patch, was approved again in the U.S. It was initially approved by the U.S. Food and Drug Administration (FDA) in 2007, but due to a manufacturing problem, it was withdrawn from the market in April 2008. After UCB solved the problem, the FDA has again approved the patch and it is expected to be on the market in July. Neupro, in patch-form, will be able to maintain as constant a level of drug as possible throughout the day. It is prescribed for patients with PD in the early–stage not receiving concomitant levodopa therapy and patients in the advanced-stage that are taking concomitant levodopa. It is also approved to treat restless leg syndrome (RLS), an uncontrollable urge to move one's legs at rest.

By Alan Freeman, MD

Conversations with Emory Researchers a Huge Success

For the past two years, the APDA I & R Center has joined with the APDA Advanced Center for Parkinson Research and the Emory-Udall Parkinson's Disease Research Center to bring together researchers and the PD community for discussions regarding where the latest research on PD is now and where it is going in the future. Through "roundtable" discussions, patients with PD and their families have been able to ask the researchers involved in the lab and those in the clinic any questions they have regarding the PD clinical trials and studies now at Emory. In non-technical language, the researchers explained the "why" and "how" of the many studies that we have and explained how important it is for the patients and their families to participate.

This past May, over 100 participants were joined by 16 researchers in an informal setting to listen and ask questions about PD research. Volunteers from the APDA Chapter Board were involved as "ambassadors" helping the attendees find the sessions they were interested in and keeping the stop watch on the researchers. Each one spoke to three different groups and kept to a strict schedule. After the sessions, lunch was served and everyone had an opportunity to meet and discuss what they had learned.

From the feedback we received, patients and families were encouraged to learn that much is being done to "ease the burden – find the cure" for people with PD. The roundtable is on the calendar again for 2013, and we look forward to even greater participation next year.

APDA Georgia Programs

Currently we have 19 active support groups all over the state with one new one starting later this month in metro Atlanta. The Chapter also funds a "Caregiver Time Out Program" administered by the Alzheimer's Association. The program allows the caregiver a much needed "time out" to take care of personal needs. It specifically benefits families of limited resources who are caring for individuals who have both Parkinson's and dementia. We chose the Alzheimer's Association as administrators of this program for their experience, their organization and their broad reach throughout the state. Currently, we are evaluating the funding of a day respite program in metro Atlanta that will benefit people with Parkinson's and their families, and we hope to make this a reality soon. The Chapter also has assisted in the startup of exercise classes designed especially for people with Parkinson's. They meet at local assisted living facilities and day care facilities throughout metro Atlanta.

The Chapter has also been very active in promoting and facilitating participation in a new clinical trial by Emory researcher, Madeleine Hackney, PhD studying the beneficial effects of Tango dancing for people with Parkinson's. The classes have been very popular and fill up quickly.

Announcing New APDA Nat'l President & CEO

July 16, 2012 - I am happy to announce that the board of directors has unanimously selected Leslie Chambers as APDA's new president & CEO to replace Joel Gerstel who announced his retirement last year. Joel served American's with Parkinson's disease for more than 25 years, as a board member before his staff appointment and we look forward to him continuing his association.

Leslie will begin her duties August 1, 2012. Leslie brings successful experience in the field of national not-for-profit administration and fund-raising as well as a strong track record of executive leadership and successful execution of aggressive, strategic organizational goals. Until recently, she has been the Easter Seals Coastal Fairfield County Executive Director of Advancement.

Joel Miele Sr., PE

Tips for Working with an Individual Who Has Parkinson's Disease

Susan Gulas R.N., M.S.N.

- Always give PD medications on time at regularly scheduled intervals. Be consistent. Many people need to take their medication one half to one hour before meals or two hours after meals to get the best benefit from the medication. Follow the doctor's orders strictly about timing medication around meals.
- Keep track of which PD symptoms appear, and how soon they reappear after each dose of medicine, so this can be reported to the doctor. This information is an important tool for the doctor to adjust the medicines to best manage the disease.
- Do not assume that a Parkinson's patient is being uncooperative or not listening to you, if they are slow to follow instructions or to start an activity. This slowness of the thought process and action is part of the disease.
- Parkinson's patients may not be consistent in their ability. They may be able to do a lot of activities when their medication is working, and they are "on", but may not be able to do the very same things when their medication is not working, and they are "off".
- Plan all the important activities (eating, outings, and social events) for when the patient is "on" and their medication is controlling their symptoms.
- If the medication is not working and the patient becomes stuck or "freezes", here are some options to try:
    - ◊ Shift weight from side to side and say, "1, 2, 3 go".
    - ◊ March in place and say "left-right, left-right, let's go, and left-right".
    - ◊ Lightly touch their hand or arm and say, "Come with me".
    - ◊ Take the person by the arms as though you are going to dance, and ask them to dance with you across the room to the chair.
- The stress of living with Parkinson's disease can cause depression. Discuss any changes in the patient's function, personality, and attitudes with the doctor. Help for depression is available through medications, exercise, remaining physically active, counseling, and support.
- Use chairs that have armrests. Scoot to the edge of the chair; move feet directly under the hips; lean forward; bringing nose over knees; push up and forward.
- Turning in bed can be difficult. Rotate the head in the desired direction then reach with the arm and then the leg. This maintains rotation throughout the trunk. If turning continues to be difficult, try satin sheets, silk pajamas, or a rope tied to the foot board or side rail.
- Remember that living with Parkinson's disease can feel a lot like you are moving through a jar of molasses. It is hard to get started and hard to keep moving.

Support Groups

Support groups offer patients and their families help with day-to-day issues, provide a forum for gathering information about PD, and serve as a place to make new friends who share similar problems. For a list of Support Group locations, visit our website at www.apdageorgia.org or call 404-728-6552. If you are in an area that doesn't have a group at this time, call Lynn Ross, at 404-728-6552 to discuss how to get one started.

Donations made to the APDA Georgia Chapter

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Atlanta, GA 30329

MARK YOUR CALENDAR!

The Educational Meetings are held at Clairmont Oaks

441 Clairmont Avenue, Decatur, GA 30030

August 18, 2012

“Autonomic Disturbances and PD” by Thomas Wichmann, M.D.

September 15, 2012

“PD Update 2012-2013” by Jorge Juncos, M.D.

October 20, 2012

“Hospice 101” by Embracing Hospice staff

November 17, 2012

“Ask the Social Worker” by Lynn Ross, LMSW

No meeting in December

NATIONAL PARKINSON FOUNDATION Georgia

Make Plans to Attend!!!

National Parkinson Foundation/Georgia

Presents

7th Annual

Southeastern Parkinson Disease Conference

October 12 – 14, 2012
Sheraton Gateway Hotel
1900 Sullivan Road, Atlanta, GA

Focus this year is on
Movement and Complimentary Therapies

The Conference will begin on
Friday, October 12th with a
"Meet & Greet" reception from 6:30 to 9:00 pm

Main Conference will begin at 8:00 am
on Saturday, October 13th
Will include sessions by Medical Professionals and
"Patient Experts"

Topics include:
Family Issues, Treatment Options, Non-Motor

Aspects and Clinical Trial Participation

Plus many more!

Special Track for Care Partners

To register, visit: www.gaparkinsons.org

NATIONAL PARKINSON FOUNDATION | Georgia

Topics include:

Family Issues, Treatment Options, Non-Motor

Aspects and Clinical Trial Participation

Plus many more!

Special Track for Care Partners

Full Conference Registration is only $79.00 per person before September 15th

$99.00 per person after September 15th

Go to www.gaparkinsons.org to register

Hotel Reservations can be made online at www.starwoodhotels.com or

by calling 770-997-1100

Ask for "Parkinson's Conference" Rate of $85.00

To register, visit: www.gaparkinsons.org