



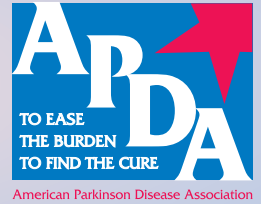
American Parkinson Disease Association  
 Georgia Chapter and  
 The Information and Referral Center  
 at Emory University  
 P.O. Box 49416  
 Atlanta, GA 30359

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# Parkinson's @ Us

## Newsletter

Winter/Spring 2009



A Publication of the American Parkinson Disease Association Information and Referral Center at Emory University and the Georgia Chapter.

## Botulinum Toxin Use In Parkinsonism

By Alan Freeman, MD

Botulinum toxin (BTX) has been successfully used for hyperkinetic movement disorders for over twenty years. Botulinum neurotoxin is produced by the anaerobic bacillus *Clostridium botulinum*. There are seven botulinum serotypes labeled A-G. Two forms of BTX, A and B have been approved for clinical use. BTX A is available worldwide as Botox (Allergan), in Europe and elsewhere as Dysport (Ipsen) and in Germany as Xeomin (Merz pharma). Botox is the only form of BTX-A currently available in the US, although the other two forms may be available for therapeutic use next year. A single formulation of BTX-B is available worldwide in the US as Myobloc and in Europe as NeuroBloc (Solstice). BTX types C and F have been used in humans, but only on an experimental basis. The US Food and Drug Administration (FDA) has approved Botox for the treatment of blepharospasm (forced eyelid contractions), cranial nerve seven disorders (hemifacial spasm), cervical dystonia (involuntary neck spasm), and hyperhidrosis (sweating). Myobloc has been approved for the treatment of cervical dystonia.

BTX has many other uses, but none have currently been approved by the FDA. Some of these include spasticity, headache, sialorrhea (drooling), tremor, overactive bladder, limb dystonia, and tics.

BTX works by inhibiting acetylcholine release at the neuromuscular junction and salivary/sweat glands. This causes temporary paralysis of the muscles and a decrease in secretion of the glands. The duration of effect varies, but is usually 10-20 weeks (for involuntary movements and excess salivation).

Doses of BTX are dispensed in units. The units of each form

of BTX are not clinically equivalent; therefore the different formulations are not interchangeable. In addition, each formulation has different diffusion and side effect profiles.

Botulinum toxins may be used in idiopathic Parkinson's disease (PD) as well as atypical parkinsonian syndromes. [i.e. progressive supranuclear palsy (PSP)]. Patients who develop blepharospasm, either from the primary illness or medications, can be successfully treated with BTX. Patients typically are injected with small doses of toxin approximately every three months.

Drooling can be a major problem with advanced PD. Both Botox and Myobloc have been successfully used in this condition. Myobloc may have an advantage, as a side effect of Myobloc seen with cervical dystonia is dry mouth. We were recently involved in a Myobloc sialorrhea study for PD, and preliminary results look very promising.

Botulinum toxin can also be used in cervical dystonia as may be seen in patients with PSP. BTX has been used with some measure of benefit in limb dystonia with PD and parkinsonian syndromes. This includes the "dystonic clenched fist" in the upper extremity and foot inversion or toe flexion/extension in the lower extremities.

Botulinum toxin has been successfully used in the field of movement disorders for the past two decades. Many new uses are currently being investigated, but remain off label. Once the FDA approves a new use for BTX, it will be much easier to get reimbursement from Medicare and insurance companies. Hopefully, there will be new approved uses in the near future (spasticity, sialorrhea).

### MARK YOUR CALENDAR!

The next Educational Meetings are located at Clairmont Oaks in Decatur, GA

**February 21, 2009**

Motor Fluctuations in PD by Dr. Jorge Juncos

**March 21, 2009**

Life Changes = Legal Changes:  
 Overview of Estate Planning, VA Benefits Planning, and Life Care Planning  
 by Victoria Collier, P.C. Elderlaw attorney

**April 18, 2009**

Ask the MD by Dr. Marsha Smith

**May 16, 2009**

Nutrition in PD by Judy Tormey

\*\*\*\*\*No meetings in June or July\*\*\*\*\*

Educational meetings will start at 10:30am. Please come prepared with your questions.

#### OTHER EVENTS:

**March 14-16, 2009**

4th Annual golf tournament at Smokerise

**June 27 & 28, 2009**

4th Annual Cycle for Parkinson's at Georgia Gwinnett College



This newsletter made possible by an educational grant from UCB

#### DISCLAIMER

The material in this newsletter is presented solely for the information of the reader. It is not intended for treatment purposes, but rather for discussion with the patient's physician.

# President's Corner

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APDA Georgia Chapter  
P. O. Box 49416  
Atlanta, GA 30359  
404-325-2020  
[www.apdageorgia.org](http://www.apdageorgia.org)

## Emory I & R Center Staff

Jorge L. Juncos, M.D.  
Medical Director  
Mary Louise Weeks  
R.N., B.S.N Coordinator

1841 Clifton Road NE  
Room 504  
Atlanta, GA 30329  
404-728-6552

## Newsletter Staff

Mary Louise Weeks  
R.N., B.S.N  
Editor  
Linda McGinn, R.N.  
Copy Editor

Dear Friends,

Despite the current gloomy economic news, we at the Georgia Chapter of APDA are committed to growing this wonderful organization!

We will continue our support of the existing programs including the CAREGIVER ASSISTANCE programs, the monthly educational meetings, the newsletter, the website, and our ongoing support groups.

In addition, we are looking at adding NEW programs to help people impacted by Parkinson's Disease. More on that in subsequent newsletters. Your input on what programs YOU want to see us support is always welcome.

Of course, this means that we will be busy with our upcoming fundraisers. The next one on the agenda is the annual Smoke Rise Golf Tournament "Driving Parkinson's Away". Please check our website for details on how to participate.

Again, please stay in touch. I welcome your suggestions and comments.

Best wishes,

**Annemarie Schwarzkopf**  
President  
Board of Directors  
APDA Georgia Chapter  
[www.apdageorgia.org](http://www.apdageorgia.org)

You are cordially invited to attend the

### Michael J Fox Foundation RESEARCH ROUNDTABLE

Monday, February 09, 2009

6:00 to 8:00 PM  
(5:30 PM Registration/Meet-and-Greet begins)

**Hyatt Regency Atlanta**  
Hong Kong / Cairo Room  
265 Peachtree Street, NE, Atlanta, GA 30303  
(404) 577-1234

Reservations are complimentary, however, seating is limited. Light refreshments will be served.

To RSVP, email [events@michaeljfox.org](mailto:events@michaeljfox.org), or call (212) 509-0995 ext. 225.

The scammer will most likely keep trying to convince his intended victim, so it's best to hang up after delivering the comeback line.

Practice these comebacks with your loved one. Also, have your loved one tell telemarketers to take his or her name off their call list. If the telemarketers don't, they're breaking the law. Sign up for the National Do Not Call Registry. As a last resort, get your loved one an unlisted phone number.

Fraudulent telemarketers may also use a senior's forgetfulness against them. The scammer may tell her target she's with a well-known charity, and the senior has forgotten to send a heck for a pledge.

"Most telemarketers can tell when they've got an older person by the voice or inflection of the voice and they will take advantage of it," Wright says.

### Mail Fraud

As a caregiver, you also can help monitor your loved ones' mail for potential fraud. Look for stacks of unsolicited mail with various offers for money or prizes. Encourage your loved one to throw that kind of mail straight into the recycle bin. Also, see if your loved one has received packages of cheap costume jewelry or other "gifts." Offer to help balance their checkbooks, and look for any unusual large withdrawals or checks written to companies you've never heard of. Check credit card statements for any unauthorized charges. If you suspect mail fraud, contact the Postal Inspection Service in your city. Go to [www.usps.com/ncsc/locators/find-is.html](http://www.usps.com/ncsc/locators/find-is.html) and type in your zip code for contact information of the nearest office.

### Home Repair Fraud

Another prevalent scam against seniors is for home repairs. For example, someone shows up at the door claiming to have been re-roofing a neighbor's house. The scammer will say that while he was up on that nearby roof, he noticed the senior's home has some shingles loose. He may even climb up a ladder and pull off some perfectly good shingles as "proof." When the senior hires him to fix the roof, the scammer demands payment in advance, makes a lot of noise pretending to fix the roof, leaves for lunch and never comes back.

Scammers also may pose as a utility worker, saying they need to check the phone line inside the house, and then stealing personal information once inside. Or they may simply politely ask to use the bathroom, while an accomplice sneaks in and steals something.

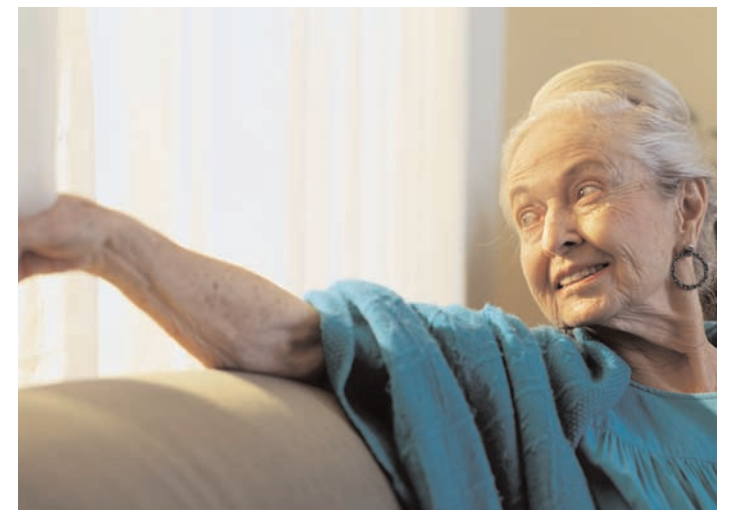
### Fighting back

Educating seniors about the different types of fraud and how to fight back can go a long way toward thwarting scammers. The Illinois Attorney General's Office has an innovative program called Senior Sleuths. It trains senior citizens to educate other seniors how to avoid all kinds of fraud. AG staffers teach older citizens how to file complaints with the state's Consumer Fraud Bureau, and how to monitor telemarketing calls and door-to-door solicitations. Senior Sleuths also receive a resource manual with information on various types of scams, how to check a company's background before sending money, and how to file a complaint.

The NCPC's Wright says fraud for all age groups is under-reported, partly because the victim is embarrassed. Many seniors are afraid of losing their independence, so they won't tell their loved ones if they were defrauded, because they don't want them to take their checkbook away.

Oftentimes, fraud happens because of a basic human emotion—loneliness. "There used to be somebody sitting across the table in a chair and they're not anymore; there's a void," Wright explains. "And, in many cases, who's filling that void is a telemarketer."

### Article Provided by a Place for Mom



# Fraud and Seniors

Seniors can make easy targets for fraud, whether it's for unbelievable investment returns or fraudulent sweepstakes prizes. Fraud on seniors can happen by phone, mail, in person, or, less commonly, the Internet (because seniors are online in smaller numbers). It can happen to wealthy seniors, and those of limited means. According to the Federal Trade Commission, studies show con artists are more likely to target senior citizens than other age groups because they believe seniors are more susceptible to such scams. The FTC reports that fraudulent telemarketers direct from 56 to 80 percent of their calls at seniors.

"Seniors are available because they tend to be retired, they're home, they answer their phones and read their mail. So, some of the offers that come in aren't necessarily more attractive to seniors, but they have the time to read it," Jim Wright, managing director of programs at the National Crime Prevention Council, explains.

"There's still the prevailing idea that seniors grew up in a more polite time when they thought it was rude to hang up on someone," he adds, "and there is the issue of being alone or lonely, so they're more likely to talk to strangers."

According to the NCPC, seniors age 60 and over are targets of 49 percent of telemarketing scams involving medical care services and products, 41 percent involving sweepstakes and prizes, and 40 percent involving magazine sales. The NCPC estimates that each victim of a sweepstakes scheme lost an average of \$7,000.

## Phone Fraud

Wright explains that fraudulent telemarketers use five basic techniques:

- Scarcity: The senior has been identified as the grand prizewinner, but if she doesn't accept the prize immediately (and pay that "handling charge") the runner-up will get the prize instead.
- Hype: The telemarketer screams and hollers about how excited he is the senior has won.
- Authority: The telemarketer passes the phone to his "boss," so his target will know the offer is "legitimate."
- Phantom Fixation: The prize is too good to pass up, and the targeted senior becomes fixated on it.

- Reciprocity: The telemarketer explains that she won't receive her commission unless the senior accepts the prize and pays the handling fee. When the senior protests that he doesn't have enough money to pay the fee, the scammer asks how much he can afford, and says she'll accept that smaller amount, just because she's so happy the senior has won the prize.

Wright says fraudsters will change from one persuasion tactic to another if necessary. "The theory is the longer we're on the phone, we're going to do business, legitimate or otherwise," he says.

The NCPC (with Crime Dog McGruff as its spokesdog) has put together a short guide to fraud protection for seniors. The guide features five ways to make unwanted telemarketers go away. Tape it by your loved one's phone and he or she will always have a polite—but firm—comeback for unscrupulous come-ons. (Of course, the best way to get rid of someone you don't want to talk to is to simply hang up.)

**Tip #1:** Never give personal information, such as bank account or social security numbers, to anyone over the phone, unless you initiated the call and know you've reached the right agency.

**Comeback:** "I don't give out personal information over the phone. I'll contact the company directly."

**Tip #2:** Don't believe it if the caller tells you to send money to cover the "handling charge" or to pay taxes.

**Comeback:** "I shouldn't have to pay for something that's free."

**Tip #3:** "Limited time offers" shouldn't require you to make a decision on the spot.

**Comeback:** "I'll think about it and call you back. What's your number?"

**Tip #4:** Be suspicious of anyone who tells you not to discuss the offer with someone else.

**Comeback:** "I'll discuss it with my family and friends and get back to you."

**Tip #5:** If you don't understand all the verbal details, ask for it in writing.

**Comeback:** "I can't make a decision until I receive written information."

# Driving Parkinson's Away

**MARCH 15 & 16, 2009**

Smoke Rise Golf & Country Club  
4900 Chedworth Drive, Stone Mountain, GA

The 2009 event will be held at the Smoke Rise Golf and Country Club located at 4900 Chedworth Drive, Stone Mountain, GA. The weekend begins on Saturday night, March 14th with a Dinner/Live Auction and then golf foursomes playing on Sunday & Monday, March 15th and 16th. We are seeking businesses and individuals who are interested in partnering with us by providing sponsorship dollars, in-kind sponsorships, event promotion, and teams of four to play in the tournament.

Last year's sponsors included StreetBlimps, Inc., Boardworks Outdoor Advertising Co., Wilkins Media Company, Park Springs, LLC/Peachtree Hills, Brasfield & Gorrie, LLC, Bank of North Georgia, Merrill Lynch, Georgia Power, Metro Media Technologies, Olympus Media, Kroger, Chick-fil-A, Teva Neuroscience, Coca Cola, Tee Time Enterprises, Inc., Mark & Pat Soltys, Smoke Rise Bottle Shop, Manry & Heston, Hooters, AT&T Telecom Pioneers (Lenox Life Member Club), Atlanta Home Care Partners, Inc., Smoke Rise Bottle Shoppe, and Tom Jumper Chevrolet. The entire event was a huge success and raised more than \$75,000.00.

For additional information, please visit our website at [www.apdageorgia.org](http://www.apdageorgia.org) and click on the tournament icon on the home page or call Kathy Edwards at 404-325-2020.



The Georgia Chapter of APDA presented "An Enchanted Evening at Glenridge Hall" on November 1, 2008. Attendees enjoyed an elegant evening in the historic grandeur of Glenridge Hall, a beautiful 1929 home sited on 47 acres of grounds and gardens in Sandy Springs, GA. Guests sampled selections from some of the top chefs in our community, paired with complementary cocktails, coffee and desserts.

The proceeds from this event will help us continue providing services and programs for the Parkinson's communities across the State of Georgia and support research to determine the cause and find the cure for this devastating disease.

A special thanks to the following sponsors: Glenridge Hall, Belmont Village, Wildfire Restaurant, Chef Rob's Caribbean Café, Slope's BBQ of Sandy Springs, Persepolis, Old Milton Beverage, Mood Lounge, Pop's Wine & Spirits, Chequers, Trader Joe's, Cabot Cheese, Sarah Care Adult Day Care, Tom Schulte, D & F Photography and Marc Matullo with Parties 2 Go.

Thanks to the gala committee for an awesome job in putting this event together.

# Care to Share Through Parkinson's Support Groups

by Peggy Willocks

Several years ago, I received a call from the rehab facility where our Parkinson's support group meets. The lady gave me a name of a person who "needed to be contacted" and had shown an interest in joining the group. I took the number and forgot about it for a day or so. As I started making plans for our annual picnic, I saw the sticky note on my roster of members and decided to give "Bobby" a call. I'm so glad I didn't pass up this opportunity.

A child answered; then there was a lengthy pause before speaking to my intended party. Bobby's voice was weak and nervous-sounding. After a few of the "formalities" of informing him when our support group met, membership, programs, etc., we got to the meat of the conversation.

With labored speech and slurring his words, Bobby shared his story. At 27, he was diagnosed with Parkinson's, and he was now only 38. He had been through experimental DBS (deep brain stimulation) in a clinical trial at Emory and was still having difficulty with tremors and dyskinesia. He was also in the midst of a divorce and an ugly custody battle.

"Bobby!" I lamented, "Are you telling me you've been enduring this battle all alone?" He then shared how he had become somewhat of a "recluse" since his diagnosis. For 11 years, Bobby had been trying to manage his life with severe tremors plus all the other PD symptoms, was disabled and having financial difficulties, and was now fighting the losing battle of divorce . . . all of this alone! What's so sad is that Bobby lived within only 10 miles of my home. After swallowing the lump in my throat, I shared with him some internet sites for information and support. Then I invited him to our picnic and exchanged e-mail addresses. My heart melted as he told his story - one that needed to be shared immediately after his diagnosis, not 11 years later.

I recall attending my first support group meeting at this same facility and not liking what I saw. Some attendees were like me - their Parkinson's symptoms were often hidden - you had to observe the person for a while to see that arm that didn't swing, that foot that slightly dragged, or that hand tremor. I watched one couple out of the corner of my eye. The lady was in a wheelchair, and her husband had to help her with the simple refreshment menu of cookies and punch. And there was the tall guy who flailed his arms and head when he talked, and remember thinking how awkward he looked.

I have to be honest in telling you that my first meeting and the second one were nearly a year apart. Maybe I thought by staying away from people with Parkinson's, I wouldn't get worse. By the end of that year, however, I realized that I couldn't do this Parkinson's thing on my own. It wasn't what took place at the actual meetings that helped me through the day - although the speakers and programs were very informative - it was the networking outside of the meetings. There was comfort in knowing that I could call Judy or Linda about the new medication the neurologist had suggested, or that I could help someone fill out their long-term disability papers. We were all fighting life's usual battles with a disadvantage; we were also living with a chronic illness that had no cure.

I was an elementary school principal and in the limelight of the community's eyes. My symptoms, diagnosis, and battle with Parkinson's were followed by many from the onset of symptoms, to the diagnosis, to the disability retirement I had to take four years later. As I hung up the phone and immediately sent a follow-up e-mail to Bobby, I had to wonder how many other Parkinson's "victims" were out there floundering like a fish on dry land, just waiting for someone to throw them back into the water of life? How many were becoming a "recluse" like Bobby had described? How many would have benefitted emotionally from being able to share their battles about job security, raising children, weathering relationship changes? Or how many could have improved their quality of life by knowing about a diversity of treatment options? I shuddered to think. Although I was thankful that I had opened this door of opportunity to help someone like Bobby struggling with Parkinson's, I still shed a tear of remorse for not finding about it earlier.

*Peggy lives in Northeast Tennessee with her husband, 3 grown children, and 3 grandchildren. She has been diagnosed with Parkinson's for 14 years, and in 2000 was a participant in a clinical trial requiring experimental surgery at Emory. Still active with her local support group, she is also an advocate, writing articles, and speaking across the country. She is the TN State Coordinator and a Board member of the Parkinson's Action Network, and a charter member of the Parkinson Pipeline Project, a grassroots group affiliated with the Parkinson's Disease Foundation who are dedicated to speeding up the drug and treatment approval process.*

# IRA Charitable Rollover Extended

Congress has extended the IRA charitable rollover as part of the Emergency Economic Stabilization Act of 2008 allowing older Americans to make a gift directly from their IRAs to a charity such as APDA without the withdrawal being taxed as income.

**The tax-free donation must meet the following criteria:**

- The gift is made in 2008 or 2009
- The IRA holder is age 70½ or older
- The gift totals \$100,000 or less each year
- The charity is a 501c3 organization
- The withdrawal goes directly from the IRA to the charity

This information is not intended to serve as legal or tax advice, and APDA suggests those wishing to donate, consult their tax adviser or attorney.



## Two New Dosage Strengths of Stalevo® Approved in the U.S. Provide Greater Dosing Flexibility for People with Parkinson's Disease

On October 28, 2008 – Novartis Pharmaceuticals Corporation announced the launch of two new FDA-approved dosage strengths of Stalevo® (carbidopa, levodopa and entacapone), which is indicated for certain people with Parkinson's disease who experience end-of-dose "wearing off". The approval of Stalevo 75 and 125 tablets (18.75 mg carbidopa, 75 mg levodopa, 200 mg entacapone and 31.25 mg carbidopa, 125 mg levodopa, 200 mg entacapone, respectively) provides physicians with options that may enable more customized approaches to treating people with Parkinson's disease in the U.S. Now available in pharmacies, these new dosage strengths complement the already existing Stalevo 50, 100, 150 and 200 tablets, which may also help lessen the burden of managing multiple medications among people with Parkinson's disease and their caregivers.

Stalevo simplifies treatment because it combines the most widely-used agent for treating Parkinson's disease, levodopa, with the enzyme inhibitors carbidopa and entacapone, to

provide greater and more sustained levels of levodopa in the blood. When patients start taking carbidopa/levodopa, they may experience benefits in terms of symptom control, but over time, those benefits may last for increasingly shorter periods of time, which is known as "wearing off". As the therapy wears off, patients find that their symptoms begin to re-emerge prior to their next scheduled dose, which may impact their motor functions and daily activities. Stalevo significantly improves the ability of patients with "wearing off" to control body movements and perform daily activities, compared to traditional levodopa therapy.

Please contact your healthcare provider for further information or visit [www.novartis.com](http://www.novartis.com).

