



INSIDE:

-NON-MOTOR
FEATURES IN
PARKINSON'S
DISEASE

-A MESSAGE FROM
THE PRESIDENT

-CAROLYN'S JOURNEY
OF OPTIMISM

-ALLAN BLEICH GETS
PARKINSON'S BILL
PASSED IN NEW JERSEY

-ASK THE EXPERT

-KIDS TAKE ACTION

-WHAT'S HAPPENING
AT APDA

Published bi-annually
by the American Parkinson
Disease Association

135 Parkinson Ave.
Staten Island, NY 10305
(800) 223-2732

apda@apdaparkinson.org
www.apdaparkinson.org

Chairman of the
Board of Directors
Fred Greene

Chairman of the
Scientific Advisory Board
David G. Standaert, MD, PhD

President & CEO
Leslie A. Chambers

Understanding non-motor features in Parkinson's disease

By: Michael Rezak, M.D., Ph.D.
Medical Director, APDA Information & Referral Center
Central DuPage Hospital

Treating Parkinson's disease (PD) is no longer a matter of only addressing the well-known motor symptoms of the disease, but also recognizing and aggressively managing the non-motor features, which include difficulties with sleep, mood problems, and dysfunction of the autonomic nervous system.

Sleep Difficulties: It is important to be aware that disruption of normal sleep can have multiple causes and careful evaluation of each patient is required to define the problem and arrive at an appropriate treatment.

Daytime sleepiness is a common presenting complaint and often represents either disruption of normal sleep cycles or may be a side effect of PD medications, particularly the dopamine receptor agonists. **Sleep apnea** (a sleep disorder causing pauses in breathing) is a common cause of daytime sleepiness and can be effectively treated once diagnosed.

Difficulty with sleep initiation and frequent arousals/fragmented sleep may in part be medication related or occurs as a part of PD related symptomatology.

One of the most common sleep disorders occurs during rapid eye movement sleep, called **REM sleep behavior disorder (RBD)**. In RBD, a patient physically acts out their dreams and can potentially injure a bed partner or even themselves if they fall out of bed or strike a wall.

Mood Difficulties: Mood problems associated with PD can be manifested by depression, paranoia, apathy, and anxiety, among others.

In fact, some studies have shown that **up to 80% of PD patients may experience depression** that requires treatment during the course of their illness.

It is important for the person with PD as well as for their families and caregivers to understand that mood changes can be a part of the pathology of PD and symptoms

(continued on pg. 4)

How I became the shaky lady: Carolyn's journey of optimism with young onset Parkinson's disease

Carolyn was a happy, healthy, fun-loving teenager when she first experienced a tremor in her right hand. She thought nothing of it.



By the age of 19, she started dropping things, having persistent headaches, and experiencing bouts of losing consciousness. It was time to see a doctor.

"Some people are just clumsy," one prominent neurologist told her. "I wouldn't worry about it."

So she did just that... for three years.

"I pushed it out of my mind until my body would scream so loudly I couldn't ignore it," says Carolyn.

(continued on pg. 3)



A message from
President and CEO,
Leslie A. Chambers

Dear Friends,

I'm often asked what sets APDA apart from other Parkinson's disease organizations. And I proudly answer: it's our dual focus to *Ease the Burden* — *Find the Cure* for the 1 million individuals and families coping with Parkinson's across the country. But what does that really mean?

It means that we work tirelessly to make sure everyone who is touched by Parkinson's disease has somewhere to turn. Whether you've been recently diagnosed and are searching for answers and need immediate support to help you absorb the difficult news — or maybe, you're a family member of someone battling Parkinson's and you need to connect to others to learn what you can do to best help your loved one.

In short, it means you are not alone. While we pride ourselves in our commitment to providing services like patient and caregiver support groups, vital programs like exercise classes, and educational resources and materials — we also realize that this is half the battle.

Research is critical to finding a cure for Parkinson's disease. Thanks to our generous donors like you, APDA has awarded more than \$1.1 million in new research grants for 2014–2015. We take tremendous pride in our ability to launch the careers of young physicians and scientists dedicated to working on Parkinson's disease as well as help bring promising new investigators into the field, many of whom are in the postdoctoral stages of their careers, and keep them there for the long term. And, we will not stop until we find a cure.

Support. Research. Hope. Optimism. We ground everything we do in these values, including our newly redesigned newsletter, *APDA Insights*. I'm pleased to introduce our inaugural issue and sincerely hope that you walk away with valuable answers and insights that help to guide, comfort and support you during your Parkinson's journey.

Sincerely,

Leslie A. Chambers
President and CEO
American Parkinson Disease Association

Never giving up the fight: Allan Bleich gets first Parkinson's bill passed in New Jersey

"I will not let it defeat me."

These are the determined words of ex-police officer Allan Bleich who was diagnosed with Parkinson's disease at the age of 45. It's been seven years since he first heard those life-changing words.



While Allan battles debilitating symptoms that are often times overwhelming, he refuses to give in to the disease. He made a choice to take a stand to end Parkinson's.

As a motivational speaker and the President of the New Jersey chapter of the American Parkinson Disease Association, Allan has led a statewide effort to increase knowledge of the disease, including pushing for a bill, A-2576 (S-1173), advancing in the Legislature that would create and fund a public awareness campaign.

"I'm not going down without a fight, but I can't do it alone and we need your help," Bleich told legislators during a hearing on the bill.

The NJ Chapter had been working on and off on this bill for more than nine years. When Allan became the chapter President 18 months ago, he took this on as his personal mission. After countless emails, phone calls and meetings — the bill was approved by every committee member on the NJ Senate and Assembly. In December, Governor Chris Christie signed the bill into law.

"The support from our NJ Chapter board members, friends and family, gave me the strength to pursue this endeavor and never give up even while fighting my own battles with Parkinson's disease," says Allan.

The *Parkinson's Disease Public Awareness and Education Act* is now the first bill made into law to promote Parkinson's awareness and education — not only in New Jersey — but in any state in the U.S.

The bill requires the State Department of Health to reach out to the public through local boards of health, doctors and hospitals; provide educational programs to healthcare providers about research findings; and teach judicial staff, police officers, firefighters, and social service and EMS providers how to recognize Parkinson's symptoms and respond to the needs of people with the disease, including through the department website.

To learn more about *The Parkinson's Disease Public Awareness and Education Act*, please visit www.legiscan.com/NJ/text/S1173/2014.



Ask the Expert

Non-motor symptoms and Parkinson's disease:

A Q&A with Dr. Lisa M. Shulman

Medical Director, APDA Information & Referral Center,
University of Maryland School of Medicine

Q: I have no problem falling asleep, but I wake quite a lot during the night and tend to rise early. Is this likely to be from the disease or the medication?



A: The sleep problem that you describe is called sleep fragmentation. There are many contributory factors including anxiety, as well as some of the PD motor symptoms.

It's important to stay active during the day and avoid naps if possible so that you are genuinely tired at bedtime. "Good sleep hygiene" means that you should follow routines including consistent times for dinner and bedtime and avoiding watching TV in the bedroom. Various medications can be helpful including medications indicated for sleep or others that reduce anxiety. Finally, if PD-related immobility is the problem, a bedtime dose of controlled-release carbidopa/levodopa may be helpful.

Q: I am 43 and have been living with Parkinson's disease for 11 years. Over the last year my concentration and memory have gotten a lot poorer. Can you help?

A: Even though Parkinson's is primarily known as a movement disorder, cognitive changes are very common.



Cognitive functions should be tested and followed over time by your neurologist. Mild cognitive impairment (known as MCI) may be treated with cognitive training (for example, novel and stimulating tasks). One helpful strategy might be using alarms

or alerts to recall the need for medication dosing and important appointments.

In terms of medications, the first step is to discontinue medications that are detrimental to cognitive function if at all possible. This includes some drugs used for tremor (known as anticholinergics), sedatives, tranquilizers and narcotics. Finally, when cognitive impairment is more significant, medications used for Alzheimer's disease such as donepezil or rivastigmine are used in Parkinson's disease.

Q: I understand that Parkinson's is known to cause excessive sweating. How do I deal with this extremely antisocial problem?

A: Skin changes including both dry skin and excessive sweating may occur in Parkinson's disease. Excessive sweating is relatively infrequent and there are no specific medications commonly used for this problem. Basic remedies such as avoiding overheating or dressing with warm clothing is intuitive and obvious. Some people experience excessive sweating due to overactivity associated with dyskinesia. Reduction of the severity of dyskinesia will be helpful in this setting.

If you have a question for the expert, please visit www.apdaparkinson.org/ask-the-doctor.



(Carolyn's journey continued from pg. 1)

And at the age of 22, Carolyn was diagnosed with young onset Parkinson's disease. "Devastation does not begin to express what I felt. I was young, vibrant and full of dreams for my future, and now that was all gone. My life was over, or so I thought," says Carolyn.

She decided to reach out to others in the Parkinson's community and found that the American Parkinson Disease Association (APDA) was hosting a conference a few hours from her home.

"After the conference I became very open and wasn't ashamed to admit that my body isn't well. I surrounded myself with people who saw me as a strong, beautiful, capable woman, not a weak, sick, shaky girl," she says.

But, Carolyn didn't just wake up one day and "get over" having Parkinson's disease.

"I found ways to cope, and started a blog at www.theshakylady.com. I used humor, writing, and the love that surrounded me as a crutch, and found my way back to myself," she says.

Carolyn's advice to the newly diagnosed?

Get involved, reach out to people who have been there (there's no reason to feel alone, someone somewhere is feeling what you have felt) learn as much as you can, and allow yourself to feel. I have a rule that I am allowed to feel sad or even bad for myself but never for two days in a row. Always find the positive to come back to.

If you or someone you love has been diagnosed with young onset Parkinson's disease, please call (877) 223-3801 or visit www.youngparkinsons.org.

(Non-motor features in Parkinson's disease continued from pg. 1)

require attention and treatment as much as any other problem in PD.

Appropriate diagnosis and treatment will maximize quality of life. Since depression often has a biochemical basis related to neurotransmitter changes in the brain, medication management can be very effective and should be discussed with your doctor.

PD medications can sometimes be responsible for other psychiatric symptoms such as paranoia, hallucinations, delusions and compulsive behaviors.

Autonomic Nervous System (ANS)

Dysfunction: The Autonomic Nervous System regulates the functions of our internal organs such as the heart, stomach and intestines. ANS dysfunction includes a number of symptoms seen in PD, but that patients may not associate with their disease.

Blood pressure changes - low blood pressure when standing up (orthostatic hypotension) can cause dizziness or lightheadedness and if severe enough, may even result in fainting.

Genitourinary dysfunction - urinary frequency or urgency occurs commonly in PD. If PD related, a “neurogenic” bladder may be responsible (the bladder is smaller and is unable to hold as much urine).

Constipation - Some studies have shown that constipation occurs in up to 70-80% of PD patients. Constipation must be taken seriously, as severe cases can result in serious illness or even death.

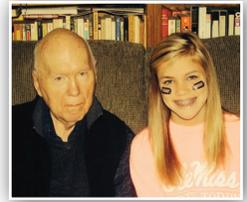
With the many effective treatments we have available today, optimal quality of life can be attained by addressing and managing all of the symptoms that arise from PD.

To read the full article, please visit www.youngparkinsons.org/nonmotor-symptoms.



Kids take action to end Parkinson's

Katlyn: After Katlyn William's grandfather passed away from complications due to Parkinson's, she wanted to do something special to honor her Pop's memory. For her 13th birthday party, Katlyn decided to ask for donations instead of gifts. She raised \$564 and donated every dollar to APDA for research purposes!



Libby: 9-year-old Libby Horton's father has Parkinson's disease. She recently wrote a letter to President Obama regarding fair treatment and equal opportunity for people with PD. The President wrote back and Libby felt like her voice was heard!

Caroline: Caroline Castellone created “Recycle Mania Arcade” an entire arcade made from cardboard boxes. She brought her arcade to APDA's Race, Walk & Roll for Parkinson's in Rhode Island and to the Connecticut Optimism Walk. Caroline's arcade was a tremendous asset and put the “fun” in fundraising for APDA!



WHAT'S HAPPENING AT APDA



- APDA hosted two exclusive screening events of the “Live with Optimism” Public Service Announcement. This exciting new initiative was developed to raise awareness and critical funds that will *Ease the Burden – Find the Cure* for the 1 million Americans living with Parkinson's disease. **To learn more, visit www.apdaoptimism.org.**
- Rhode Island celebrity boxer and reality TV star from the Contender Season IV Richard Gingras promoted APDA during a recent signing by wearing his Optimism t-shirt. Rich and his friend Michael Quaglia started the New England chapter of the Rock Steady Boxing program, which is aimed at helping people with PD.
- The American Parkinson Disease Association Massachusetts Chapter received a generous donation of \$100,000 from the Shawn Thornton Foundation.