

(continued from pg. 1)



Brett participated in the APDA "Live with Optimism" public awareness campaign that has aired on television and radio since September of 2014. The TV spots have aired more than 60,000 times across the country. We thank Brett for his service to our country and his tremendous example to live each day with optimism.

His participation in the DOD NETPR review process allowed him to explore the array of new medical technologies being discovered across a broad spectrum of disciplines. Today, he continues his career and lifetime training to "never give up."

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Sleep disturbances in PD include frequent awakenings, which can be related to difficulty rolling over in bed, tremor, having to use the bathroom, or other body movements. These movements can be simple twitches and leg jerks, or complex movements related to dream enactment behavior.

When PD patients act out their dreams, they might have a condition called REM sleep behavior disorder (RBD), which affects 30-50% of PD patients. RBD is an active research area because symptoms of RBD can appear several years before the motor symptoms of PD emerge and could therefore identify people who might someday benefit from earlier treatment interventions.

Another common sleep-related problem in PD is daytime sleepiness. This can be so pronounced that it can have a significant impact on safety. Possible causes of daytime sleepiness include brain changes related to PD, nighttime sleep problems such as sleep apnea or leg jerks, or medications.

It is very important to discuss any of these sleep issues with your physician because many of them can lead to injury to yourself or your bed-partner. Further, these conditions can be effectively treated with medications or other interventions, or simply by adjusting medication timing.

One of the most effective ways to improve sleep is to make sure that you use good sleep hygiene. This includes keeping a consistent bedtime schedule every day, as well as avoiding TV, electronics, or reading in bed. Sleep relaxation techniques such as meditation and progressive muscle relaxation can also help you fall to sleep more easily.

For more information about research opportunities in the UAB Division of Movement Disorders, contact 205-934-0683.



Nicolas with his grandfather, Frank, and sister

## What's Happening at APDA

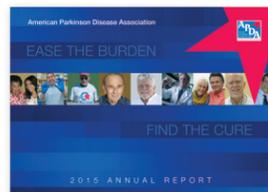
### A high school senior honors his grandfather's legacy.

Nicolas Hoffman lost his grandfather Frank Tangorra to Parkinson's disease in 2013. Since then, Nicolas has been paying tribute to a man who meant so much to him. On April 5, Nicolas traveled with APDA to the New York State Capital in Albany to receive a resolution from Governor Andrew M. Cuomo declaring April as Parkinson's Awareness Month. He was joined by his grandmother Louise Tangorra, fellow classmates, APDA Board Members and people living with Parkinson's disease and their care partners. Additionally, on April 23, Nicolas also joined with his teacher Rachael Monaco and a team of 150 dedicated students to participate in the Parkinson's Unity Walk in Central Park.

**NEW Oral Health supplement is available!** APDA recently released a supplement called *Oral Health in Parkinson's Disease*. To download the supplement, please visit [apdaparkinson.org/publications](http://apdaparkinson.org/publications).



**We recently released our 2015 Annual Report.** Thanks to the generosity of people like you, we accomplished so much in the past year. In 2015, APDA provided more than 900 support groups to 60,000 individuals with Parkinson's and their care partners. On the research side, we invested \$1.3 million to support four Post-Doctoral Fellowships, eight Research grants to junior investigators, three Summer Student Fellows and eight APDA Centers for Advanced Research. Download the full 2015 Annual Report at [apdaparkinson.org/Annual Report](http://apdaparkinson.org/Annual Report).



### Educational supplements are now available in Spanish

APDA recently collaborated with volunteer, Jose Ricardo López Castellanos, MD, to translate a variety of supplements for patients who speak Spanish which include: *Como Vivir Bien con la Enfermedad de Parkinson, La Fatiga, and Constipación*.

To read all of our supplements, please visit [apdaparkinson.org/publications](http://apdaparkinson.org/publications).



# INSIGHTS

SUMMER 2016 NEWSLETTER

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President & CEO Leslie A. Chambers

American Parkinson Disease Association is exempt from federal income taxes under Section 501(c)(3) of the Internal Revenue Code.

## APDA advocate provides critical consumer voice in research funding

This year, Congress provided \$1 billion to support 27 specific disease programs funding high impact, high risk and high gain projects. One of these programs is the Department of Defense (DOD) Neurotoxin Exposure Treatment Parkinson's Research (NETPR).

The vision of the DOD NETPR is to slow the progression of, prevent, and cure Parkinson's disease (PD) in order to lessen the personal and societal impact of the disorder.

Consumer reviewers who have military experience and are living with PD or family members/caregivers of a person living with PD are nominated to participate in the grant review process each year.

APDA was pleased to nominate Brett Watterson from California to participate as a consumer reviewer for the program and were thrilled when he was selected to be a part of this important grant review process that took place in Virginia in March.

*"I believe that active research efforts, combined with grassroots support and outreach, position people with PD to be on the cutting edge of advancement and give us all hope for the future,"* stated Brett when he learned that he was chosen to serve on the review board.

As part of the two-day program, Brett was chosen to lead the moment of silence that kicked off the sessions. He took that opportunity to pay tribute to the 10 million people across the globe living today with PD.

*"I recognize that my story is only one of many. Every nine minutes there is a new diagnosis of PD. Over the next two days, we will focus our energy on this important work and during that*



The crew of STS-62A space shuttle. Front row (l to r): Guy Gardner, Mike Mullane, Jerry Ross, and Dale Gardner. Back row (l to r): Pete Aldridge, Jr, Robert Crippen, and Brett Watterson

*time, we must think about the 288 new people who will be diagnosed with PD,"* said Brett in his remarks.

After serving 26 years in the U.S. Air Force, Brett joined the U.S. Space program. While there, he achieved the rank of Colonel, worked in NASA's Jet Propulsion Lab as well as for The Aerospace Corporation, and was the Payload Specialist on the STS-62A space shuttle mission. That mission was unfortunately cancelled following the tragic Challenger loss in 1986.

From the earliest days of his career, he was trained to "never give up."

But nothing could have prepared Brett for his Parkinson's diagnosis at age 59. While the diagnosis changed his life, he chose to concentrate on becoming as healthy as possible by staying active through aqua-aerobics, Tai Chi, yoga, weight training, and cardiovascular activities.

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To learn about the many ways you can support APDA, please call (800) 223-2732 or visit [www.apdaparkinson.org/ways-to-donate](http://www.apdaparkinson.org/ways-to-donate).

For more information, visit our website at [www.apdaparkinson.org](http://www.apdaparkinson.org), or call (800) 223-2732. To make a donation online, visit [www.apdaparkinson.org/SummerInsights](http://www.apdaparkinson.org/SummerInsights).



A message from  
President and CEO,  
Leslie A. Chambers

Dear Friends,

Summer is finally here! For those of us living in the Northeast, we made it through the winter! But no matter where you're from, let's celebrate summertime and the good weather to come.

Being active is so important to our physical and mental wellbeing. That's why this edition of *APDA Insights* includes information about our new exercise booklet called *Be Active and Beyond*.

Daily exercise for people with Parkinson's disease is now recognized as a vital part of their treatment plan. Throughout the country, APDA Chapters and Information & Referral Centers offer exercise classes including: stretching, yoga, Tai Chi, boxing, rowing, tango and many more.

Through APDA's National Rehabilitation Center for people with Parkinson's disease, we continue to provide support, information and referrals to local experts and programs to encourage everyone with Parkinson's to develop a fitness regimen.

What better time to start exercising than the summer. There are so many activities you can do outside – and wearing a Fitbit or exercise tracking device is an exciting way to see your progress. We encourage you to reach out to your local APDA chapter to learn about the exercise programs available to you.

Sincerely,

Leslie A. Chambers  
President and CEO  
American Parkinson Disease Association

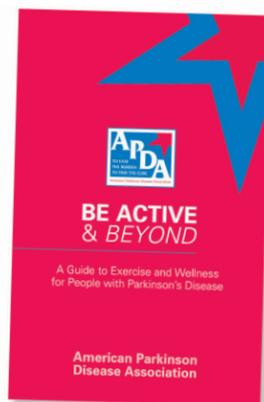
## Be Active and Beyond

Terry Ellis, PhD, PT, NCS

We are proud to announce the release of our new exercise booklet, *Be Active and Beyond*. The goal of this manual is to help you optimize wellbeing through exercise. This booklet has been updated to reflect a surge in the evidence revealing the essential role that exercise plays in improving day-to-day function and quality of life for people with Parkinson's disease.

*Be Active and Beyond* contains some exciting new features including:

1. A summary of how research informs exercise recommendations in Parkinson's disease
2. Tips to overcome barriers to exercise to help you get started
3. National Exercise Guidelines including the types and dose of exercise recommended
4. Clear, easy-to-see photos of people with Parkinson's disease performing the exercises
5. Clear and concise instructions on how to perform and progress the exercises
6. The exercises are presented with three levels so that all exercisers, from the novice exerciser to the lifelong fitness buff, can be appropriately challenged



Engaging in exercise over the long term is an important part of the treatment of Parkinson's disease. Although exercise is important at all stages, we recommend starting as early as possible. Consulting with a physical therapist can also help to make sure your exercise program is individualized to meet your specific needs.

We hope that *Be Active and Beyond* launches you into an exercise program that you enjoy and that helps you live life to the fullest! To download *Be Active and Beyond* please visit [apdaparkinson.org/BeActive](http://apdaparkinson.org/BeActive).

If you have any questions about exercise, please contact our APDA National Rehabilitation Center at **1-888-606-1688** or [rehab@bu.edu](mailto:rehab@bu.edu).

## Medically qualifying for disability benefits with Parkinson's disease

Deanna Power, Director of Community Outreach, Social Security Disability Help, Boston, MA



If you have been diagnosed with Parkinson's disease, you may be concerned about continuing to work and make a living for yourself and your family. Because Parkinson's is a progressive disease, you may find work more challenging as time goes on. Fortunately, there is help available for you. The Social Security Administration (SSA) offers financial benefits for people with Parkinson's who are no longer able to earn income due to the disease.

### Parkinson's disease and the Blue Book

Whenever the SSA receives an application for disability benefits, they will compare your medical records and test results to their own guide known as the Blue Book. The Blue Book lists hundreds of conditions that are potentially disabling, as well as the test results or symptoms you'll need to be approved for benefits.

Parkinson's disease is listed under Section 11.06 of the SSA's Blue Book — Parkinsonian syndrome. To qualify under this listing, you will need to show that you experience at least one of the following symptoms in two extremities:

- Rigidity
- Slowness of movement
- Tremors

### These symptoms need to be severe enough to affect one of the following:

- Your ability to perform dexterous movements, such as typing on a computer
- Your ability to walk
- Your ability to stand upright

Keep in mind that even if you experience one of the qualifying factors, a disability examiner does have the right to deny your claim. It's unlikely, but possible. This could happen if your Parkinson's affects your ability to walk or stand, but you have a desk job. A disability examiner may argue that you don't need to walk to keep your job and earn income, so you should not qualify for benefits.

This is why it is vitally important to submit as much medical evidence as possible when applying for benefits. Write down the name of every single doctor who's familiar with your condition, as well as every hospital where you've received treatment.

If you are planning on applying for Social Security disability benefits with Parkinson's disease, you can either apply entirely online through the SSA's website, or call the SSA toll free at 1-800-772-1213 to schedule an appointment at your local office.

What if you don't meet the SSA's medical guidelines? You can still qualify for disability benefits through what's known as a Residual Functional Capacity (RFC) evaluation. **To learn more, read part two of this article at [apdaparkinson.org/socialsecurity](http://apdaparkinson.org/socialsecurity).**

## Coping with sleep problems caused by Parkinson's disease

Amy Willis Amara, MD, PhD



Physicians and researchers who study Parkinson's disease (PD) are becoming increasingly aware of the non-motor symptoms that affect patients with PD. One particularly common non-motor symptom is sleep dysfunction, which can have a significant negative impact on quality of life for patients and their family members.

Sleep issues have become an active area of research. At the University of Alabama at Birmingham, my lab is investigating the effects of exercise on sleep and daytime alertness in PD. In this study, patients are randomized to receive exercise or a sleep hygiene intervention and evaluated with overnight sleep studies and other measures. We know that exercise can improve motor symptoms in PD, but want to find out if it improves sleep as well. We are also studying a home-based computer game intervention to determine if this improves safety related to daytime sleepiness. In this study, we are measuring safety with a virtual reality street-crossing task.

(continues on back)