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INSIGHTS

APDA ADVOCATES GUIDE \$16 MILLION IN US DEPARTMENT OF DEFENSE PARKINSON'S RESEARCH FUNDING



Brett Watterson, who served in the U.S. Air Force and U.S. Space Program, steps up for a second year with PRP.

Each year, the Department of Defense assesses scientific opportunities to advance research through the Department of Defense Parkinson's Research Program (PRP). As part of this program consumer reviewers are asked to represent the collective view of those who are living with Parkinson's disease, including patients, caregivers, and family members. They review applications that aim to better understand Parkinson's disease, halt progression, and extend the quality of life for individuals affected by Parkinson's disease.

APDA was thrilled to be represented on the consumer review panel by Brett Watterson and Thomas L. Zielinski. Brett, from California was nominated for his second year and Tom from Illinois participated for the first time this year. The consumer reviewers are full voting members, along with prominent scientists, at meetings to help determine how the \$16 million appropriated for the program by Congress for Fiscal Year 2016 will be spent on research for Parkinson's disease.

"Just imagine, what a legacy to pass on to the next generation — to usher in a world free of Parkinson's ... and to be part of it, to be able to claim 'I helped make that possible.'"

— Brett Watterson

Brett served in the U.S. Air Force for 26 years and worked his way up to the rank of Colonel after joining the U.S. Space program. He was once again asked to deliver the programs' opening Moment of Silence speech, he reminded the group that: "10% of the 60,000 Americans who will be diagnosed with PD this year will be under 50 years of age ... each with spouses and young children still needing to be cared for, nurtured, and unconditionally loved."

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Strength in optimism. Hope in progress.

Brett further commented on his experience as a consumer reviewer that:

"I take away two strong feelings of both gratitude and hope from my experience as APDA's Consumer Reviewer on the 2016 Parkinson's Research Program. Gratitude because I know that all over the country and the world researchers are on a quest to solve the enigma of Parkinson's. Every one of the researcher's proposals seek to get a step nearer to a comprehensive understanding of this strange disease. Hope, because I know that behind all those research proposals is an army of people, organizations and individuals that are as passionate about finding the answers, as I am hopeful that they shall."

Tom is a former Marine and Firefighter Paramedic who has devoted his life to the service of his country and community. Diagnosed with Parkinson's disease at only 38-years old following the birth of his third son, Tom was faced with a choice: to be defeated by his diagnosis, or to carry on in the Marine tradition to adapt, improvise, and overcome.



Thomas L. Zielinski, a former Marine and Firefighter Paramedic, served on PRP for the first time in 2017.

Tom decided to take action. He has participated in classes, volunteer work, fundraising, and support groups including APDA's Young Onset Program and Veterans with Parkinson's.

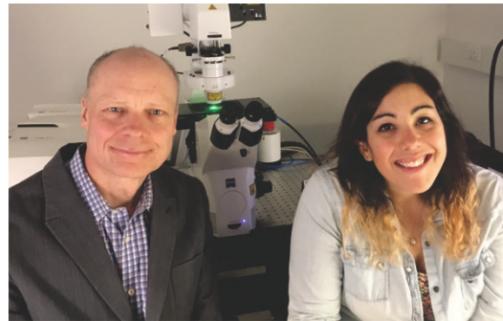
"The biggest thing I had to overcome was my self-image," says Tom. *"I had this persona of a big strong guy. Parkinson's didn't fit that image. Then I started attending a support group and quickly realized... I wasn't alone."*

Tom has a unique and fresh perspective, which draws from his lifetime of experience in serving the United States, as well as representing the Young Onset community.

We are so grateful to have the perspectives of veterans like Tom and Brett representing APDA as part of this important scientific process.

NEW FINDING COULD
RELIEVE DYSKINESIA

We've known for a long time that in Parkinson's disease (PD), brain cells that normally produce dopamine die, causing dopamine levels to decrease. But recently, Andreas H. Kottmann, PhD, with The School of Medicine of City College of New York (CUNY) and his team embarked on an APDA-funded research project and discovered that DA neurons do not only secrete dopamine but also an additional factor called "Sonic Hedgehog" (Shh). Kottmann and his team concluded that both, dopamine and Shh levels must diminish in PD.



Dr. Andreas H. Kottmann, Ph.D., principle investigator on an APDA-funded research project and Lauren Malave, graduate student and lead scientist for dyskinesia in his laboratory.

Unfortunately, a major downside of Levodopa, a common Parkinson's treatment that replenishes dopamine, is that it often causes dyskinesia — a side effect characterized by fragmented or jerking movement of the limbs or torso — also known as Levodopa-induced dyskinesia (LID). Kottman and his team had an idea that just might make a difference for people with LID.

"Discussion with and observance of people with this side effect helped to guide our thinking and reasoning," says Dr. Kottmann. These discussions sparked a thought for the team, *"Could this finding on Shh have implications for patients coping with LID?"*

Kottmann wondered if the reason behind LID could be that Shh levels were left unaltered, while dopamine levels were replenished by Levodopa. This led his team to hypothesize that LID could be counteracted by boosting the levels of both dopamine and Shh.

In the study they conducted in mice, they confirmed that when Shh was reduced, the subjects experienced stronger LID, and more importantly, they discovered that the converse was true: stimulating the activity of "Smoothed", the receptor of Shh, resulted in milder dyskinesia.

Dr. Kottmann is hopeful that this finding will prove successful when extended to human trials, so that patients can be relieved of dyskinesia. *"There is no doubt that inhibition of LID will improve the quality of life for people with Parkinson's disease,"* he says.

Dr. Kottmann has a message for donors like you who made this APDA-funded study possible:

Thank you so much for helping to fund research projects like these that have real potential to lead to better treatments. Because of you, we can make strides in improving the quality of life for people impacted by Parkinson's.

Learn more about APDA-funded research projects at apdaparkinson.org/apdafundedresearch.

What's happening at



Optimism Walks are Approaching

Make a difference — join an Optimism Walk near you! This is a great opportunity for friends, families and individuals to rally together in the fight against Parkinson's disease. Optimism Walks are being held in 14 locations across the country between April and October. To find cities and dates, visit apdaparkinson.org/optimism-walks.



Tune in for a Webinar

APDA often schedules webinars that anyone can listen to, with topics including treatments, management of symptoms, and how to improve quality of life. We welcome you to join us for *Spotlight on Motor Fluctuations* with Dr. Lisa Shulman on May 11! Or, you can always watch an archived webcast later at apdaparkinson.org/webinar.



Read the Latest PD Publications

In her column in the *New York Times*, Jane Brody writes about the importance of exercise for people with Parkinson's disease. Be sure to read her article "Exercise Can Be a Boon to People With Parkinson's Disease," which explains some of the ways that physical activity can ease symptoms of PD and slow its progression. Catch up on more relevant articles and publications through apdaparkinson.org.



A message from
President and CEO,
Leslie A. Chambers

Dear Friend,

Parkinson's Disease Awareness Month is upon us! Throughout the month of April, we remain committed to elevating public awareness of Parkinson's disease (PD) and ramping up our efforts to spread hope and optimism across America!

April is undoubtedly an important and energizing time for our community. And for the American Parkinson Disease Association, PD awareness is a critical issue that we work to address all year-round.

The American Parkinson Disease Association stands apart in our ability to empower those impacted by PD today so that they can live life to the fullest. Instead of letting this disease knock us off course, we will band together to fight it — and each of us will become stronger through this journey.

We are grateful to have friends like you by our side, who are so essential to this foundation of support. With you, we are going farther than ever before to spread awareness and to uplift the PD community through our programs and services.

This Parkinson's Disease Awareness Month, let's celebrate those living with PD who find sources of strength and support through APDA. And let's show the rest of the world what it really means to live the best life possible in spite of a PD diagnosis.

Sincerely,

Leslie A. Chambers
President and CEO
American Parkinson Disease Association

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APDA PUBLISHES MANUAL FOR VETERANS WITH PD

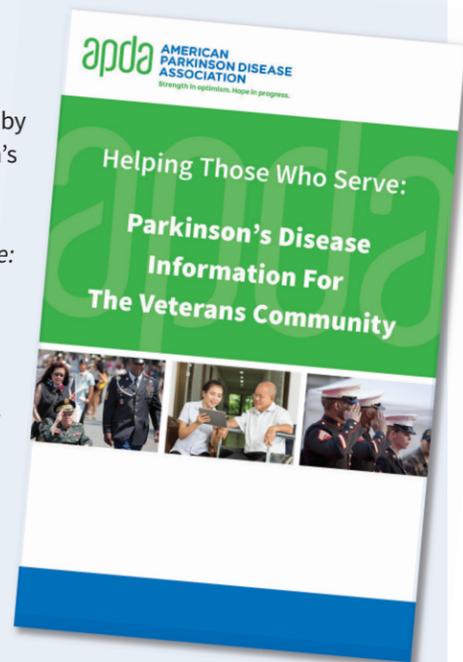
In an effort to address the unique issues faced by veterans with Parkinson's disease, APDA recently published a guide called *Helping Those Who Serve: Parkinson's Disease Information for the Veterans Community*.

This informative manual covers everything from the basics of understanding Parkinson's disease to finding care through the Veterans Health Administration.

APDA is proud to have this opportunity to give care and support for the United States veterans who have selflessly served our country.

We provide critical information and resources to guide them through the process of this disease, as well as platforms for veterans to connect with one another.

You can view the guide for yourself at apdaparkinson.org/VAManual, or pass it on to a veteran you know who is living with Parkinson's disease.



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DISCOVERING THE BENEFITS OF EXERCISE



Maureen Chamberlain never could have predicted that golf would one day become an important part of her life.

She was skeptical when her doctor first recommended it in order to help ease her symptoms of Parkinson's disease. But her doctor insisted, explaining that golf would utilize her hands, arms and legs,

and would help to integrate both sides of her body.

Maureen was surprised to discover the unexpected benefits of the practice, and that it has even become an enjoyable pastime.

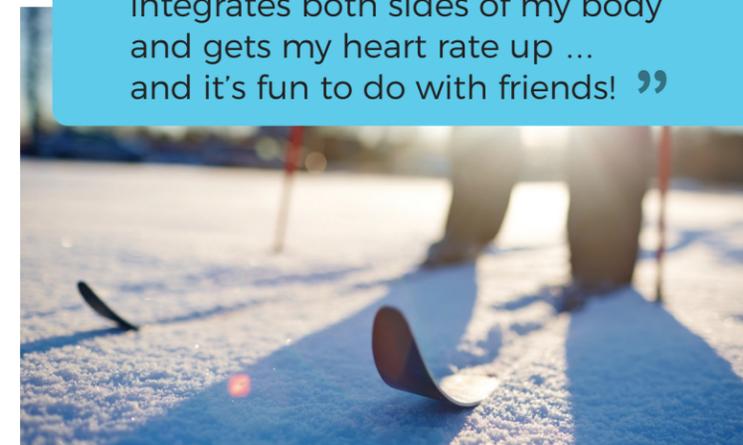
"My husband and I learned to play golf together and we have a good time," she says. "It really is a great sport."

Maureen and many others have found that golf helps by focusing on balance, expanding the range of motion, and connecting different parts of the body. It can even be a positive mental exercise because of the concentration required, and offers an opportunity to walk long distances over the course of a game.

This inspired Maureen to try new exercises that were recommended by her doctors, including cross-country skiing.

Flexibility exercises, aerobic activity and resistance training have all

"I was a downhill skier all my life, but I tried cross-country. It integrates both sides of my body and gets my heart rate up ... and it's fun to do with friends!"



been shown to help people with Parkinson's. These practices can ease symptoms by improving balance, flexibility and motor coordination, and might even help slow the progression of the disease.

People like Maureen are discovering the benefits of physical activity every day! To learn more about wellness through exercise for people with Parkinson's disease, visit apdaparkinson.org/BeActive.

PD TRAINING PREPARES FIRST RESPONDERS



When first responders are called to the scene of an emergency, there is no time to waste. These police officers, firefighters and emergency medical service providers have to be equipped with vital knowledge to act swiftly and deliver people to safety.

As anyone who is impacted by Parkinson's may know, there are a unique set of considerations that must be taken into account to ensure that people with Parkinson's are given the proper care. That's why APDA partnered with the Office of Continuing Professional Education (OCPE) at Rutgers University.

Together, we have created a web-based, user-friendly program to help first responders recognize the symptoms and needs of those with Parkinson's disease, enabling them to provide the best care possible.

The online training program is a 1-2 hour course with instructional videos intended to provide overall education and protocols for interacting with a person who shows signs of Parkinson's. And since every decision counts in an emergency, sharing this resource with first responders could save lives.

"An EMT treating someone who has undergone deep brain stimulation must understand the implications of the device; otherwise the person's life could be at stake."

— Allan Bleich

We're grateful for the opportunity to work with Allan Bleich, a retired police officer and President of the APDA New Jersey Chapter who led this important effort. We would also like to thank those who served as expert consultants to this project, including Dr. Lawrence Golbe, Cathi A. Thomas, and Laura Lieb.

If you'd like to learn how to help someone with Parkinson's in an emergency, visit apdaparkinson.org/firstresponders to access our free training program.