

KIDS TAKING ACTION TO HELP END PARKINSON'S DISEASE - PART 1

The future rests in our youth. With a new PD diagnosis every 9 minutes, young people throughout the United States are impacted every day by this disease. It could be a grandparent, parent, friend of the family or a neighbor but what is extraordinary is that kids are stepping up to the plate to make a difference. APDA is proud to present this two part series highlighting the efforts of kids who have directed their energy to help Ease the Burden – Find the Cure for Parkinson's disease. Whether it is by organizing a bowling tournament, baking and selling cupcakes or donating their own money, they all have the same thing in common...they care.

OUR MISSION

AS THE COUNTRY'S LARGEST GRASSROOTS PARKINSON'S DISEASE ORGANIZATION, THE AMERICAN PARKINSON DISEASE ASSOCIATION (APDA) IMPROVES THE LIVES OF PEOPLE WITH PARKINSON'S DISEASE AND THEIR FAMILIES FROM COAST TO COAST WITH PATIENT/CAREGIVER SUPPORT; EDUCATION AND POSITIVE LIFESTYLE PROGRAMS; AWARENESS, SOCIAL AND FUNDRAISING EVENTS; AND SCIENTIFIC RESEARCH FUNDING AT ALL LEVELS. THROUGH A NATIONAL NETWORK OF CHAPTERS, INFORMATION & REFERRAL CENTERS, SUPPORT GROUPS, AND CENTERS FOR ADVANCED RESEARCH, APDA DELIVERS HELP FOR TODAY AND HOPE FOR TOMORROW.

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HIGH SCHOOL SENIOR PROJECT RAISES AWARENESS AND FUNDS TO PAY TRIBUTE TO A SPECIAL MAN.

As his senior project for high school, Brandon Eckles held a bowling tournament called, *Pins for Parkinson's* and raised \$1,880! Brandon's grandfather was an avid bowler before Parkinson's took its toll on his life. 18-year old Brandon who lives in Rhode Island, used social media to plan and gain support for the event both locally and across his social network. "I saw firsthand the debilitating effects of Parkinson's disease and decided to use my senior project as a way to bring awareness and to raise money for programs and research and to pay tribute to a great man," said Brandon.

Brandon presented his donation to the APDA Rhode Island Chapter Young Onset Support Group at their monthly meeting. In return the group surprised Brandon. Thanks to an anonymous donor's matching gift, Brandon's \$1,880 donation became... almost \$3,000! Brandon plans to attend and play basketball at Springfield College in Massachusetts this fall.



Along with Mary Ellen Thibodeau, Executive Director of the Rhode Island chapter, Brandon presents his donation from "Pins for Parkinson's" to support PD.

SINCE THE AGE OF FOUR, YOUNGEST VOLUNTEER MAKES A DIFFERENCE.

12-year old Savannah Boyen hailing from Texas has been a dedicated volunteer for the APDA San Antonio Chapter for 8 years. She began volunteering at the age of four. At monthly support group meetings Savannah can be found greeting folks, setting up snacks and serving coffee to members just the way they like it. She is also known for doling out hugs.



Savannah Boyen – all smiles as she supports PD with her big heart!

Savannah's creative ways to raise spirits and funds range from baking cupcakes, to attending the San Antonio Chapter Annual Symposium's Silent Auction, to making duct tape flower pens that raise funds at the Chapter's annual Optimism Walk. But perhaps most touching of all, is Savannah's generosity in giving her own money directly to support the cause.

Savannah is also an advocate for raising awareness. She recruited two of her friends who joined her at the Chapter's

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ASK THE EXPERT

DR. HARRISON C. WALKER, MD, ASSISTANT PROFESSOR, DEPARTMENT OF NEUROLOGY, THE UNIVERSITY OF ALABAMA AT BIRMINGHAM

Q: Treatment for superficial wound infection in DBS surgery, can it be treated medically without removing intracranial leads?

If the infection is confined to the outer layer of the skin (an infected stitch, for example), it will often resolve with antibiotic medications. If the hardware under the skin is infected, the infected hardware must be removed, which may or not require removal of the intracranial leads. If the battery under the collar bone is infected, often the electrode in the brain can be spared. If there is inflammation and

redness along the wire itself beneath the skin, the intracranial leads usually have to be removed.

Q: Does DBS surgery lower your cognitive ability? Does DBS surgery cause speech difficulties?

Multiple studies show that DBS surgery is safe cognitively. DBS is associated with mild decreases in executive function and verbal fluency versus patients who remain



Dr. Harrison C. Walker

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DEEP BRAIN STIMULATION FOR PARKINSON'S DISEASE. IS IT FOR YOU?

RITESH A. RAMDHANI, MD ASSISTANT PROFESSOR OF NEUROLOGY AND NEUROSURGERY
ICAHN SCHOOL OF MEDICINE AT MOUNT SINAI

Parkinson's Disease (PD) affects 1-2% of all adults over the age of 60 years with the cardinal features of asymmetric tremor, stiffness, and slowness along with gait problems. Caused by the degeneration of dopamine secreting neurons, it is not unusual for patients who have had Parkinson's disease for a number of years to be on a regimen of medications including carbidopa/levodopa and dopamine agonists to treat the motor complications of the disease. But as the disease progresses, not only does the amount of medication a patient takes increase, but motor fluctuations and severe dyskinesias can develop at the expense of mobility.

Deep Brain Stimulation (DBS) is a viable therapy that effectively treats many of the motor symptoms of Parkinson's disease. It works by delivering electrical pulses through an electrode implanted into a specific region of the brain. Though the exact therapeutic mechanism is unclear, it does not cure the disease nor inflict damage to brain tissue. When compared to best medical therapy,

Parkinson's patients with DBS are more mobile, have a better quality of life, and spend their days with longer 'on' time. It alleviates tremor, motor fluctuations, and dyskinesias as well as improves limb rigidity and slowness. In addition, based on the brain target chosen, reduction in medication is possible.

This DBS electrode is implanted by a skilled neurosurgeon in the operating room, who utilizes high-resolution brain imaging techniques and neurophysiology during the surgery. The electrode is then attached to an external wire that is tunneled below the skin and connected to a pulse generator placed under the clavicle. An external programmer is used to adjust the distribution and intensity of the current through the pulse generator, allowing a neurologist to tailor it to each patient's needs.

Who should think about DBS? Patients with a diminishing quality of life due to progression of their disease that is potentially complicated by adverse effects from medications.

The most suitable candidates for DBS must have: idiopathic PD and not atypical variants (e.g. progressive supranuclear palsy, multi-system atrophy, corticobasal degeneration); medication refractory symptoms such as tremor, motor fluctuations, and/or dyskinesias; a robust response to medication that is greater than 30%; and minimal to no cognitive dysfunction.

Determination of candidacy requires seeing a movement disorder's neurologist who will confirm the diagnosis of PD, evaluate the various symptoms and medication regimen, and conduct standardized testing both on and off medication to calculate medication response. In addition, neuropsychological and neurosurgery consultations are also necessary in the candidacy evaluation.

Though Parkinson's is a degenerative illness, DBS has not only offered further insight into this disease, but serves as an effective therapeutic option for many patients looking to regain their quality of life.

APDA “IN THE NEWS”

APDA SCIENTIFIC ADVISORY BOARD MEMBER, DR. MAHLON DELONG, RECEIVES BREAKTHROUGH PRIZE ON LIFE SCIENCES AND APDA LIFETIME ACHIEVEMENT AWARD

Mahlon DeLong, MD, distinguished member of APDA’s scientific advisory board was one of six recipients of the *2014 Breakthrough Prizes on Life Sciences award* for his work defining the interlocking circuits in the brain that malfunction in Parkinson’s disease. This \$3 million award is the largest given in the sciences and is presented to researchers who have made discoveries that extend human life. The Prize awarded annually since 2013 was founded by internet entrepreneurs including *Mark Zuckerberg, Sergey Brin, Yuri Milner, and Anne Wojcicki.*

At the “Community Conversations with Parkinson’s Disease Researchers” conference hosted in May by Emory-Udall Center of Excellence for Parkinson’s disease Research which is also an APDA Advanced Center for Research, APDA President & CEO, Leslie A. Chambers, presented Dr. DeLong with a special Lifetime Achievement Award to commemorate the Breakthrough Science Award as well as recognize Dr. DeLong for his research discoveries that address the symptoms and progression of PD.



Dr. Mahlon DeLong

APDA’S NATIONAL REHABILITATION RESOURCE CENTER DIRECTOR DR. TERRY ELLIS RECEIVES CHATTANOOGA RESEARCH AWARD



Dr. Terry Ellis

APDA congratulates its Director of the National Rehabilitation Resource Center, Terry Ellis, PhD, PT, NCS, for receiving the **Chattanooga Research**

Award from the American Physical Therapy Association at their June conference. This award honors individuals who publish the best articles on physical therapy research in Physical Therapy. The research article for which Dr. Ellis won the award appeared in the April 2013 issue of Physical Therapy and is titled “Comparative Utility of the BESTest, Mini-BESTest, and Brief-BESTest for Predicting Falls in Individuals with Parkinson Disease.”

In addition to being the APDA’s National Rehabilitation Resource Center Director housed at Boston University, Dr. Ellis is also an Assistant

Professor at Boston University, College of Health & Rehabilitation Sciences in the Department of Physical Therapy & Athletic Training and Director of the Center for Neurorehabilitation at Boston University. Her research focuses on investigating the impact of exercise and rehabilitation on the progression of disability in individuals with Parkinson’s disease. Dr. Ellis has been a leader in defining the importance of physical activity for persons with Parkinson’s disease the understanding that a sedentary lifestyle hastens disability while increasing physical activity is essential to improving physical function and enhancing quality of life.

APDA RANKED #20 BY GENETIC ENGINEERING & BIOTECH NEWS AS ONE OF THE TOP 30 GRANT-GIVING DISEASE FOUNDATIONS: 2014 EDITION.

Each year *Genetic Engineering & Biotech News* ranks nonprofit disease organizations that give grants and other awards (collaborations, fellowships) for research, by the percentage of total revenues spent on those grants and

awards. As National Institute of Health’s (NIH) funding over the last decade has declined some years and stayed flat others, many researchers, particularly new scientists, rely on these nonprofits to help pick up the funding slack. APDA

is proud to be one of the organizations to offer funding to PD researchers conducting high risk/high reward work that can be parlayed into future funding through organizations like the NIH.



KIDS TAKING ACTION TO HELP END PARKINSON'S DISEASE *Continued from page 1*

Optimism Walk in May to help with the event set up (at 6 AM!) and greeted participants as they arrived. Savannah also helped stuff 400 goodie bags that were handed out at the walk.

“Savannah’s warmth and generosity have made a difference in many lives of very special patients and caregivers, always thinking of them first.” says Dianne Johnson, RN and coordinator for the APDA San Antonio I&R Center at The University of Texas HSC. “She is a wonderful role model for young people...to give to others, and make a difference in others’ lives through love, smiles, time and kindness.”

LONG ISLAND TEENAGER CELEBRATES BAR MITZVAH BY HONORING HIS GRANDMOTHER

Long Island resident Ben Borrok celebrated his bar mitzvah by honoring and supporting someone he is very close to – his grandmother, Shelly. Ben formed a team named *Shelly’s Shining Stars* in tribute to his grandmother’s battle with PD. Ben’s team successfully raised \$2,646 to help *Ease the Burden – Find the Cure* for PD.

Shelly’s Stars included Ben, his parents, brother, aunt, uncle, cousins and grandparents who all walked together last October in the Long Island, NY 2013 Optimism Walk - Paws for Parkinson’s. The event was jointly organized by APDA’s I&R Center at NYIT College of Osteopathic Medicine in Nassau County and the I&R Center at St. Catherine of Siena Medical Center in Suffolk County.

SWIMMING FOR PD

The Saluki Swim Club Team in St. Louis recently raised \$4,550 in honor of Cary Bailey –a Young-Onset Parkinson swim mom. Teen swimmers Eleni Robinson (age 16) and Kelsie Walker (age 18) organized a swim-a-thon to honor Cary Bailey whose daughters – Cody (age 18) and Chloe (age 12) - are fellow swim club team members. Eleni designed shirts for the event and her father’s company, J & L Robinson Construction Co., donated them to allow all proceeds from the swim-a-thon to be donated to the Greater St. Louis APDA chapter. Approximately 60 swimmers attended the event, with 40 collecting pledges for their swim.

Swimmers who participated in the swim-a-thon for PD gather for a photo ▼



Ben, his grandmother Shelly, and family gathered for a photo at the Long Island, NY 2013 Optimism Walk - Paws for Parkinson’s. ▲

“LIVING WITH OPTIMISM”

TWO EVENTS YOU WON'T WANT TO MISS.

THE AMERICAN PARKINSON DISEASE ASSOCIATION IS PROUD TO LAUNCH A NATIONWIDE TV AND RADIO PUBLIC SERVICE ANNOUNCEMENT ON SEPTEMBER 12

JOIN US FOR ONE OF TWO EXCLUSIVE PSA SCREENING EVENTS –

LOS ANGELES,
THURSDAY,
SEPTEMBER 11, 2014

AND

NEW YORK,
WEDNESDAY,
SEPTEMBER 17, 2014

TO RECEIVE AN INVITATION OR
LEARN MORE ABOUT THE PSA CALL
800-223-2732



Jim diagnosed at 42



Cecilia diagnosed at 53



Brett diagnosed at 59

AMERICANS LIVING WITH PARKINSON'S GET DANCING WITH OPTIMISM

BALLET MOVEMENT CLASSES FUNDED BY THE APDA SOUTH FLORIDA CHAPTER

BBT4PD is more than a fun acronym it is a dance program that allows people with Parkinson's disease to manage stress, reduce tremors and improve posture and balance while encouraging a positive attitude and sense of accomplishment.



BBT4PD participants during class

The Boca Ballet Theatre in Boca Raton, Florida, offers a wonderful dance course (at no charge!) to those with Parkinson's and their caregivers — people at all levels, abilities and ages can participate.

Boca Ballet Theatre 4 Parkinson's (BBT4PD) began in 2013 as a 6 week trial class funded by the American Parkinson Disease Association South Florida Chapter. President & CEO Leslie A. Chambers and Vice President for Chapter Development & Field Operations, Michelle Harmon McDonald recently had the privilege to participate in a class to witness first-hand the impact of this innovative program. “Kudos goes to the South Florida Chapter for their partnership with the Boca Ballet. As a result of the leadership and fundraising efforts of the chapter board and Executive Director, Gig Gilcrease the chapter has supported this program since 2013 and will continue this support through the 2014-2015 season” said Ms. Chambers.

“This program is quite special, and we believe tremendously beneficial to our students both physically, mentally and emotionally. We could not offer this program without the support of APDA's South Florida Chapter,” explains Cindy Surman, the program director. APDA has long believed in the benefits of dance and is proud to have funded the original research that revealed dancing reduces the symptoms of Parkinson's.

Teachers Cindy and Natalie Parker get the class moving, stretching, and often times laughing! They enjoy the classes just as much as



the participants. It is the highlight of their week! “Our students inspire me with their willingness to try it all!” expresses Cindy. “Everyone works hard, maintains a great sense of humor, and supports one another. I love the class and I love the students. I'm so thankful for the opportunity to be a part of this class. Thank you APDA!”

Gathering at the South Florida Chapter to get look at BBT4PD are (L to R): Andrea Doyle, BBT4PD Assistant; Martha Brown, BBT4PD Accompanist; Beth Ann Krug, BBT4PD Assistant; Gigi Gilcrease, Executive Director APDA South Florida Chapter; Leslie A. Chambers, APDA President & CEO; Michelle Harman McDonald, VP of Chapter Development & Field Operations; Cindy Surman, BBT4PD Program Director; Natalie Parker, BBT4PD Program Director.

UCLA RESEARCHERS IDENTIFY ANOTHER GENE THAT MAY PROVIDE A TARGET FOR DRUGS THAT COULD ONE DAY PREVENT OR EVEN CURE PARKINSON'S DISEASE

In the past decade, scientists have identified a handful of genes, when mutated, cause Parkinson's disease and a team of UCLA researchers has identified another gene involved in the neurological disorder that may provide a target for drugs that could one day prevent or even cure this debilitating illness.

This study was carried out in the laboratory of Dr. Ming Guo, Professor of Neurology, Pharmacology, and a practicing neurologist at UCLA School of Medicine. The work was supported by the National Institute of Aging, the National Institute of Neurological Disorders and Stroke (EUREKA award), an Ellison Medical Foundation Senior Scholar Award, the McKnight Neuroscience Foundation, the Klingenstein Foundation, the American Parkinson Disease Association and the Glenn Family Foundation.

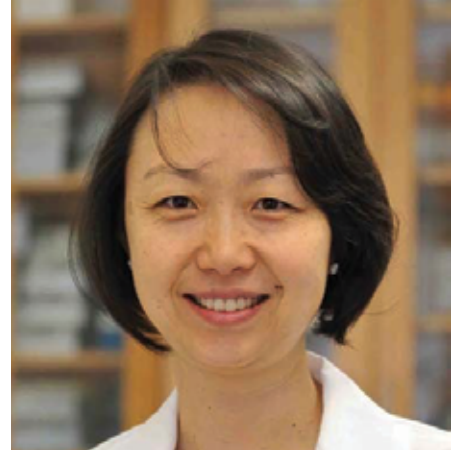
Mutations in PINK1/Parkin lead to inherited Parkinson's disease. Guo was one of the first two teams in the world who discovered that PINK1 and parkin function in the same pathway to regulate mitochondrial integrity and quality. Recently, they identified an important gene known as MUL1 (also known as MULAN or MAPL) that acts in parallel to the PINK1/parkin pathway in regulating mitofusin and compensates for loss of PINK1/parkin.

Dr. Guo's team performed experiments in fruit flies and mice that showed providing an extra amount of MUL1 helps reduce the amount of damage that mutated PINK/Parkin create in mitochondria, and that inhibiting MUL1 in mutant PINK1/Parkin exacerbates the damage to the mitochondria. In addition, Guo and her collaborators found that removing MUL1 from mouse neurons of the Parkin disease model,

in collaboration with Dr. Zuhang Sheng at the National Institute of Health, results in unhealthy mitochondria and degeneration of the neurons.

"We show that MUL1 dosage is key and optimizing its function is crucial for brain health and to ward off Parkinson's disease," said Guo, a tenured Professor and a practicing neurologist at UCLA. "Our work proves that mitochondrial health is of central importance to keep us from suffering from neurodegeneration. Further, finding a drug that can enhance MUL1 function would be of great benefit to patients with Parkinson's disease." Guo and her team plan to work on identifying compounds that could specifically target MUL1, and examine whether mutations in MUL1 exist in some people with inherited forms of Parkinson's.

"This finding is a major advance in Parkinson's disease research and I am so grateful to APDA for supporting our work," Guo said. "Our work has provided important insight in understanding Parkinson's disease, and will be particularly helpful for patients with early onset of the disease. APDA is the only foundation that offers patient help with early onset PD patients. We welcome these patients and researchers to contact us for genetic testing and evaluation. I am very optimistic that we will find a cure for this disease in the near future".



Dr. Ming Guo

ASK THE EXPERT *Continued from page 2*

on medications. Executive function refers to cognitive abilities that are involved in planning, organization, and attention. Verbal fluency tests measure the number of words of a certain category that a patient can generate over a given period of time (usually a minute). DBS surgery occasionally can cause difficulties with speech (dysarthria). This occurs most commonly when brain stimulators have been placed on both sides of the brain. Sometimes these speech problems can be improved by adjusting the settings of the stimulator in clinic or with speech therapy. Progressive cognitive symptoms and speech problems are both associated with advanced PD without DBS, so the disease itself may contribute to these symptoms over time, as well.

Q: *I'm 64 years old, I have PD and was in the final steps at getting DBS, and then my heart failed. I'm getting ready to pursue DBS again, but I need to know does it help with psychosis and cognitive problems? I can live with muscle rigidity, tremor, drooling and fatigue, etc.*

DBS is a therapy for motor symptoms – it typically does not help cognitive problems. One exception to this is when patients are experiencing cognitive or behavioral side effects from their PD medications. In this scenario, DBS can sometimes improve cognitive symptoms because it allows reduction or cessation of medications that cause these side effects.

RESEARCH GRANTS

The American Parkinson Disease Association Scientific Advisory Board is honored to award \$1.2 million for 2014-2015 research funding through the following programs:

- ◆ **Four Post-Doctoral Fellowships** awarded to support recently graduated post-doctoral scientists whose research holds promise to discover into new insights into the psychology, pathophysiology, etiology and treatment of Parkinson's disease.
- ◆ **Seven Research Grants** awarded to investigators affiliated with and performing research at an academic institution in pursuit of the cure for PD.

GRANTS AWARDED IN VARIOUS AREAS OF STUDY

Alpha-synuclein
– a protein abundant in the human brain

- ◆ Peter Ash, Ph.D., Boston University, Boston, MA
- ◆ Cristina Guardia Laguarda, Ph.D., Columbia University, NY, NY
- ◆ Talene Yacoubian, MD, Ph.D., University of Alabama at Birmingham, AL

- ◆ Nebojsa Kezunovic, Ph.D., Icahn School of Medicine at Mount Sinai, NY, NY
- ◆ Khoa Nguyen, Ph.D., Stanford University, Palo Alto, CA
- ◆ Laura Volpicelli-Daley, Ph.D., University of Alabama at Birmingham, AL

LRRK2– Leucine-rich repeat kinase 2. Mutations in this gene are the most common cause for inherited Parkinson disease.

mo•bil•i•ty
(mō-bī lī-tē) n.
– The quality or state of being mobile.

- ◆ Theresa Ellis, Ph.D., Boston University, Boston, MA

Neuroprotection
New approaches to protecting or restoring the brain in PD.

- ◆ Leilei Wang, Ph.D., University of Texas Southwestern Medical Center, Dallas, TX
- ◆ Daniel Lawrence, Ph.D., University of Michigan, Ann Arbor, MI
- ◆ Jinbin Xu, Ph.D., Washington University, St. Louis, MO

mor•tal•i•ty
(mawr-tal-i-tee) n. Studies of how PD affects the lifespan.

- ◆ Samuel A. Frank, MD, Boston University, MA

In addition, APDA will continue funding at **Eight Centers for Advanced Research** located in major academic and medical centers across the country intended to strengthen and help to integrate already existing investigative teams.

- Boston University School of Medicine
- Emory University School of Medicine
- Rutgers Robert Wood Johnson Medical School
- University of Alabama at Birmingham
- UCLA School of Medicine
- University of Pittsburgh
- University of Virginia Medical Center
- Washington University



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OPPORTUNITIES TO SHOP AND SUPPORT APDA...ALL AT THE SAME TIME.

THE AMERICAN PARKINSON DISEASE ASSOCIATION HAS MANY WAYS YOU CAN “SHOP TO SUPPORT APDA”.

Thanks to the generosity of a variety of businesses, APDA raises much needed dollars that help *Ease the Burden – Find the Cure* for PD when you shop with any of the following generous partners -



APDA has partnered with **Luxe Studio** an Oklahoma based jeweler to design and create the exclusive, handcrafted APDA “*Optimism Jewelry Collection.*” **Luxe Studio** generously donates 30% of all net proceeds to APDA. Order online at www.luxestudiollc.com or call 918-928-6458.



APDA has also partnered with **Affinity** stores where shoppers can find more than 1,200 stores offering tremendous discounts, coupons, and cash back, all while giving back to APDA. Visit www.shopapda.org.



Cast Paper Art partnered with APDA to raise funds through an exclusive series of “Hope Ornaments.” This St. Louis-based paper company was founded by a former opera singer-turned-entrepreneur and person with Parkinson’s who wanted to make a difference. The ornaments are made of 100 percent recycled cotton fiber, natural plant material and 12 different species of wildflower seeds. The eco-friendly paper can be planted and it blooms into a perennial garden making a unique gift to memorialize any occasion. \$3 of every \$10 “Hope Ornament” purchase will be donated to APDA. Visit www.castpaperart.com.

eBay Giving Works offers multiple ways to support APDA. With **eBay Giving Works**, you can make APDA your favorite non-profit, browse listings that support APDA, donate 10-100% of your sale to APDA or Give at Checkout every time you make an eBay purchase. Visit www.givingworks.ebay.com.



AmazonSmile operated by Amazon, allows buyers to enjoy the same wide product selection, low prices, and convenient shopping features as Amazon.com but with the added dimension that the AmazonSmile Foundation will make a donation to APDA for purchases made at www.smile.amazon.com.



EDUCATIONAL RESOURCES

APDA’s website www.apdaparkinson.org is the source of many free educational and patient/caregiver support materials. A complete list of booklets, supplements and other publications can be found there. You will also find information on the website to help you connect to an **APDA Information and Referral Center**, **APDA’s National Young Onset Center**, **APDA’s National Resource Center for Rehabilitation**, and **APDA’s National Veterans Center**.