

BEYOND THE DOCTOR'S VISIT: TAKING PARKINSON'S CARE TO THE NEXT LEVEL

"Game Changing." That's how Robin Kornhaber, Senior Vice President, National Programs and Partnerships at the American Parkinson Disease Association (APDA), describes APDA Information and Referral (I&R) Centers.

APDA I&R Centers are institutions across the country where APDA supports either a full or part time staff person within their movement disorder center, creating a direct connection between all of the resources of APDA and individual patients visiting providers in their own communities.

Filling a gap

Most people who see a Parkinson's disease (PD) movement disorder specialist see them twice a year for about 20 minutes at a time. It can be hard to cover everything – from symptoms, medications, and treatment options to social and emotional support, exercise, and the needs of care partners – in that space of time. Having an APDA I&R Coordinator within their institution creates more services and programs for people who are coming to see neurologists at those clinics.

In other words, the support doesn't end when the doctor's appointment ends.

Clinical expertise just for you

"The advantage of having an APDA I&R Coordinator is that individual (who has a clinical background in health care and usually in Parkinson's disease) can then take the baton and spend time with the patient to help them understand



I&R Coordinators connect PD patients and their care partners with support groups and other resources.

their disease, to provide them with resources," Kornhaber says.

This is especially important because PD is such an individualized disease. Rarely do two people experience the exact same symptoms in the same way.



I&R Coordinators help PD patients find ways to stay active and exercise, which are important for managing PD symptoms.

A unique resource for the PD community

APDA I&R Centers are exclusively offered by APDA and made possible by the generosity of supporters like you. Together we're transforming the standard of care for people living with PD, wherever they are on their journey.

As APDA I&R Coordinators build relationships with patients, they become a consistent presence that patients can rely on and go to, to get the information they need along the disease continuum.

"It's essential to have somebody who supports you," Kornhaber explains, "but more than that, really understands and knows what's going on with your medication, with your treatments, with all the things that you need to keep you well as a Parkinson's person."

"We have found the services of the APDA I&R Coordinator extremely valuable...it has been a vital social connection to other people who understand the challenges of living well with PD."

– Joan and Ross Collard

***Announcing a new APDA I&R Center:
Pacific Neuroscience Institute Foundation in Los Angeles, CA!***



A message from
President & CEO,
Leslie A. Chambers

Dear Friend,

As the pace of life picks up this fall season, I hope you know how grateful we are for your support of the American Parkinson Disease Association (APDA). Every day, people with Parkinson's disease (PD) are living life to the fullest, thanks to you. In this issue of APDA Insights, I'm pleased to give you an in-depth look at our Information and Referral Centers, which are raising the bar for how health care providers connect with PD patients. Thank you for making this type of amazing work possible. I hope we can count on your continued support.

Sincerely,

Leslie A. Chambers
President & CEO
American Parkinson Disease Association

APDA GATHERS WITH GLOBAL PD COMMUNITY

Every three years, the Parkinson's community — researchers, organizers, advocates, and people living with PD — gather for the World Parkinson's Congress (WPC). This forum brings together people from around the world who are passionately invested in defeating PD. This year's event (the 5th since the Congress began in 2006), drawing 2,777 attendees from 60 countries, took place in Kyoto, Japan from June 4-7, 2019. APDA was excited to be a part of it.

Cutting-Edge Research

A big part of WPC involves sharing the latest in PD research. Experts from around the world shared their research results and insights on many topics including:

- Personalized medicine for PD
- Advances in stem cell therapy for PD
- Discovering new genetic contributors to PD
- Wearable devices to monitor PD
- New exercise approaches to optimize PD symptoms



Rosa Peña presents her APDA poster at WPC

APDA was among the experts sharing our knowledge. Our staff members presented informative posters highlighting the success of our PRESS™ program, about educating medical students about PD and more.

NEW PROGRAM OFFERS CREATIVE OUTLET, IMPROVES PD SYMPTOMS

Coloring outside the lines of traditional PD therapies

An innovative new program offers a host of benefits for people with Parkinson's who have challenges in visual perception and spatial relations, affecting their ability to move through the world. Most current PD treatment regimens don't focus on this significant non-motor symptom, and there's a lot to learn about how things like art therapy might improve it.

That's why APDA is so excited to be piloting a new program called **Connecting Through Art**. This program, sponsored by Acorda Therapeutics, is designed to help people living with PD bring art into their lives and socialize with others. The first activity for this pilot program will be an art class, facilitated through The Art Cart's **Smile Through Art™** workshop, allowing people with PD to express their feelings, emotions, and concerns through painting and drawing.

Some people with PD experience an increase in creativity even while they are dealing with challenges to their visuospatial ability, possibly related to their medications. Art therapy could give them an outlet while also improving things like hand dexterity, mood, and quality of life. We hope and expect to see more research shedding light on the benefits of art therapy in the coming years.

For now, we know that people with PD can find happiness, satisfaction, and camaraderie in artistic expression. We are currently in the process of organizing classes for **Connecting Through Art** in 15 locations this year. If you are interested in learning more, contact Heather Gray at hgray@apdaparkinson.org or **718-981-8491**.



Why should you care about a conference on the other side of the world?

At WPC, doctors and researchers from all over the globe discussed trends in research, advancements in care, problems still to solve. Patients got to hear firsthand about the work being done to help understand this disease. It was an incredible sharing of ideas and a collective energy that can only help move things forward for the PD community.

We returned home more committed than ever to our mission.



Our team representing APDA in Japan

RESEARCH UPDATES



Members of the APDA Scientific Advisory Board (SAB)

In September, APDA announced funding for cutting-edge research projects for the 2019-2020 academic year totaling \$1.7 million.

These grants, along with others that were submitted, were reviewed earlier this year by APDA's Scientific Advisory Board (SAB). The annual SAB meeting is also a time to hear updates on previously-funded research. David Standaert, MD, PhD, University of Alabama at Birmingham, presented an update on his APDA-funded, pioneering work on the role of brain inflammation in the development and progression of PD. Joel S. Perlmutter, MD, Washington University School of Medicine, updated the SAB on his team's APDA-funded research focusing on imaging biomarkers for PD.

This critical research is only possible due to the generosity of APDA's supporters. We are excited about the new research we are funding and the potential outcomes that may help people living with PD. Detailed information about APDA funding can be found at www.apdaparkinson.org/research

CLINICAL TRIAL ANNOUNCEMENT

An Experimental, One-Time Gene Therapy For Parkinson's Disease

If your response to Parkinson's disease medications has become unpredictable or isn't what it used to be, this clinical study may be an option that you should discuss with your doctor. The RESTORE-1 Clinical Study is evaluating an experimental, one-time gene therapy approach to see if it may help improve motor function.

Who may be eligible to participate:

- 40 to 75 years of age
- Diagnosed with Parkinson's disease for at least four years
- Have noticed your motor symptoms are unpredictable despite medication

Additional study eligibility requirements and restrictions apply.

To learn more visit RESTORE1Study.com

A NEW WAY TO HAVE A LASTING IMPACT



What will your legacy be?

One of the most powerful ways to ensure continued education, support, and research for people living with PD for years to come is through a gift in your estate plan. Creating a will can feel like a daunting task, but APDA has partnered with FreeWill to provide you with a free and easy way to write your legally-valid will. We encourage you to check this important to-do off of your list and consider including a gift to APDA to help ensure people with PD can live life to the fullest. If you are planning to speak to a lawyer about your will, this tool can help document your wishes beforehand, making the conversation easy and efficient. Visit www.freewill.com/APDAParkinson to get started.

Provide support and optimism with retirement assets

Are you 70½ or older? You can make a qualified charitable distribution of up to \$100,000 to satisfy the required minimum distribution from your IRA. To benefit in 2019, act by December 1. APDA has provided a free online tool to simplify the paperwork. You don't pay taxes on your IRA withdrawal, which means the IRA charitable distribution is tax-free. You won't however be eligible for an income tax charitable deduction for the gift. Visit www.freewill.com/qcd/apdaparkinson to get started.

FREEWILL 

Ask the

DOCTOR Q&A

with
Dr. Rebecca Gilbert



Q. How much control does a person with Parkinson's have over his/her symptoms?

A. One of the key observations with movement in PD, which can be baffling for onlookers, is that *automatic* movements are affected. When a person with PD *concentrates* on their movements they are often able to make them more normal-appearing than when they allow the automatic portion of their brain to take over. Therefore, one strategy for improving movement in PD, is to perform movements correctly in a conscious way so that the automatic part of the brain can relearn how to do things. Physical and occupational therapy can be helpful in this regard.

Q. My mother has PD as well as depression. Sometimes I also feel that she is not as cognitively sharp as she was. What can I do to help her?

A. It is very common for people with PD to also suffer from depression and it can be very disabling. The good news is that it can often be successfully treated. You should speak with your mother's neurologist about treatment options for depression.

As for her cognitive difficulties –depression can cause what is known as “pseudodementia”. That is, she may appear to be having more cognitive difficulties when she is depressed. Therefore, if she is treated for depression, she may improve. PD can cause cognitive difficulty independently however it would be hard to assess for this when your mother is actively depressed.

Please visit www.apdaparkinson.org/publications to see our publications about *Depression and Parkinson's Disease* and *Cognitive Changes in Parkinson's Disease* for additional information.

Published quarterly 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, Patrick McDermott
Chairman of the Scientific Advisory Board, David G. Standaert, MD, PhD
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.

What's Happening at APDA?



Inspiration in Iowa

Education and inspiration were in full force at the annual APDA Iowa Parkinson's Disease Symposium in Des Moines this past June. Keynote speaker (and APDA PSA cast member!) Allison Toepperwein motivated more than 700 attendees with her personal story of determination and optimism.

Golfing in St. Louis

Our Greater St. Louis Chapter hosted a sold-out golf tournament in May – the 21st Annual APDA Gold Classic in Memory of Jack Buck. In addition to 18 holes, guests enjoyed dinner, a live auction, and a special talk with St. Louis Cardinals President of Baseball Operations John Mozeliak and local radio sports commentator Tom Ackerman! More than \$210,000 was raised!

East Coast/West Coast Walking Strong!

Two APDA Optimism Walks – on opposite sides of the country – had fantastic turnouts this spring. The APDA Northwest Optimism Walk had their strongest results ever with more than 700 participants and raising more than \$170,000! APDA's Massachusetts Chapter also hosted a successful Walk with more than 450 attendees and \$185,000 raised. A big thank you to all who participated and donated.

Spring Symposium Success

APDA's Minnesota Chapter hosted a successful educational symposium in April that received rave reviews from attendees. The program of expert speakers resonated with the audience, with feedback including: “It helped a lot to understand what to expect in years to come,” and “I had a renewed sense of hope for helpful research and the future.”