

MOVING FORWARD TOGETHER



You don't want to miss the 5th annual APDA Optimism Walk on **Saturday, October 9** at Logan University in Chesterfield, Missouri.

This is a wonderful opportunity to be part of a nationwide movement to mobilize and inspire people to help put an end to Parkinson disease. Proceeds from the event will help us provide programs, services and research in alignment with our mission of every day providing the support, education and research that will help everyone impacted by Parkinson disease live life to the fullest.

"There is strength in numbers and when we see friends and families come together at the Optimism Walk, year after year, we are reminded of how important that strength can be," says Cathy Krane, Executive Director. "We hope to see all of our friends and family on October 9 as we come together for the first time in over a year!" There are approximately one million people living with PD in the United States, with more being diagnosed every day. By raising funds and awareness, each and every participant in the Optimism Walk is helping to make a difference for those living with the disease today.

Sign up today on our website www.apdaparkinson.org/greaterstlouis or call 636.778.3377. If you are unable to join us in person, create a virtual team by asking friends, family and neighbors to join your fundraising efforts.

Lace up your sneakers and step up to help us put an end to Parkinson disease!





APDA Turns 60!

Our Research Highlights

The year 2021 marks the 60th Anniversary of APDA, which was founded in 1961. This milestone has given us the chance to look back at our accomplishments over the past 60 years and reflect on what we have achieved – and also what we have yet to achieve. One of the key pillars of APDA’s mission is the support of research designed to unlock the mysteries of Parkinson’s and ultimately put an end to this disease. APDA has been a funding partner in many major Parkinson’s disease (PD) scientific breakthroughs, investing more than \$51 million in research since its inception.

Today, we will look at two of these major PD scientific breakthroughs that are part of APDA’s legacy.

Supporting the work of George C. Cotzias, MD

In 1957, Dr. Arvid Carlsson demonstrated that dopamine was a neurotransmitter, or brain chemical, that was important in movement. After these observations, doctors tried to treat people with PD with levodopa, a precursor of dopamine, that unlike dopamine was able to cross the blood brain barrier. These efforts were not successful, mostly because people could not tolerate the doses of levodopa required to improve movement. Doctors may have given up at that point if not for the crucial work of Dr. George C. Cotzias, who gave people small doses of levodopa every two hours, building up to the doses that were beneficial for movement. In this way, Dr. Cotzias demonstrated that levodopa was an effective and feasible treatment for Parkinson’s disease.

Dr. Cotzias worked on many crucial elements of levodopa treatment. In this paper shown below, he made the critical observation of what is now called the levodopa “protein effect”, that in some people, diets high in protein can interfere with levodopa absorption and decrease the efficacy of the medication.

Although levodopa remains the most effective treatment for Parkinson’s, research scientists have

built upon the discoveries of Dr. Cotzias to devise a whole variety of new ways to deliver levodopa to the brains of people with PD.

APDA is proud to have supported the pioneering work of Dr. Cotzias, and in 1979, APDA’s George C. Cotzias Memorial Fellowship was created in his memory. This award supports a promising physician-scientist over a three-year period, allowing for early-career development in research and patient care of PD. It has been awarded to 30 individuals since it was established, six of whom became department heads (or higher) at major academic medical centers.

George C. Cotzias Fellowship Recipients

Here are the accomplishments of just a few of the past recipients of the George C. Cotzias Memorial Fellowship. (The year is which they won the Cotzias Fellowship is in parenthesis next to their name):

Dr. David Eidelberg (1995) – is the Susan and Leonard Feinstein Professor of Neurology and Neuroscience and has served as director of the Center for Neurosciences at the Feinstein Institutes for Medical Research in Manhasset, NY since its founding in 2001. His research focuses on characterizing the brain networks in PD and related disorders using imaging techniques, such as PET scanning and functional MRI.

Dr. David Standaert (1996) – is the John N Whitaker Professor and Chair of Neurology at University of Alabama School of Medicine at Birmingham. His research focuses on understanding the molecular causes of PD including the role of inflammation in the development of PD. Dr. Standaert serves as the Chairman of APDA’s Scientific Advisory Board.

Dr. Talene Yacoubian (2007) is an Associate Professor of Neurology at University of Alabama School of Medicine at Birmingham. Her research focuses on understanding the mechanisms that contribute to development of PD including the mechanisms by which abnormal alpha-synuclein propagates in the brain.

Dr. Vivek Unni (2016) is an Associate Professor of Neurology at Oregon Health & Science University in Portland, OR. His research focuses on understanding the role of alpha-synuclein in the development of PD using advanced imaging techniques in the live mouse brain.

Discovery of alpha-synuclein

APDA also played a pivotal role in another major breakthrough in our understanding of PD – the discovery of alpha-synuclein as a key factor in development of Parkinson's.

Up until the late 1980s, PD was understood to be caused mostly by environmental factors and not faulty genes. Dr. Roger Duvoisin was one of the earliest chairmen of APDA's Scientific Advisory Board (SAB), and a prolific PD researcher. At the time, he worked at Robert Wood Johnson School of Medicine in New Jersey, which was, and continues to be, an APDA Center for Advanced Research. Duvoisin was a firm believer that genetics were not significant in the development of PD and in the 1980's, he was involved in epidemiologic studies which attempted to show that genetic factors did not play a major role in the development of PD.

What changed this thinking and led to a revolution in PD research that continues today, was the discovery in 1990 of the Contursi family, a large family in Italy who had, what appeared to be, autosomal dominant PD, which meant that PD was found generation after generation, and children with a parent with PD had a 50% chance of developing the disease.

Dr. Lawrence Golbe, also at Robert Wood Johnson School of Medicine, spearheaded this effort, partially funded by APDA, to study this family.

By 1997, researchers including Golbe and Duvoisin discovered that the family harbored a mutation in alpha-synuclein, now known to be the fundamental component of the Lewy body, the pathologic hallmark of Parkinson's.

It is hard to overstate how important this discovery was in our understanding of PD. Since 1997, a tremendous amount has been learned about alpha-synuclein and its role in PD. This knowledge has been transformed into potential therapies for PD and today, multiple clinical trials are focused on manipulating alpha-synuclein

pathology to treat PD and hopefully slow down the disease.

APDA continues to fund cutting edge research to help advance our understanding of PD and help bring us closer to more effective treatments, and eventually, a cure. Learn about what we are currently funding at apdaparkinson.org/research.

Tips and Takeaways

- APDA has been a funding partner in many major Parkinson's disease (PD) scientific breakthroughs since its inception in 1961.
- APDA helped fund work that led to the use of levodopa for treating PD and for identifying alpha-synuclein as a key molecular player in the pathogenesis of PD.
- APDA continues to fund some of the brightest minds in PD research – awarding grants every year to fund promising research projects that have met the stringent criteria of our Scientific Advisory Board.
- To join us in our research efforts, please consider donating to APDA.

DR. REBECCA GILBERT
APDA Vice President and Chief Scientific Officer

Dr. Gilbert received her MD degree at Weill Medical College of Cornell University in New York and her PhD in Cell Biology and Genetics at the Weill Graduate School of Medical Sciences. She then pursued Neurology Residency training as well as Movement Disorders Fellowship training at Columbia Presbyterian Medical Center. Prior to coming to APDA, she was an Associate Professor of Neurology at NYU Langone Medical Center. In this role, she saw movement disorder patients, initiated and directed the NYU Movement Disorders Fellowship, participated in clinical trials and other research initiatives for PD and lectured widely on the disease.

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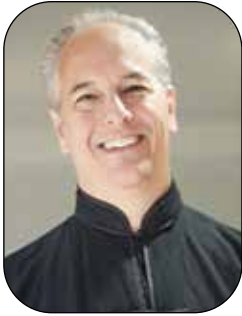
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CRAIG MILLER | TAI CHI



Craig Miller has been a student of tai chi for over 16 years. He has been teaching tai chi for 10 years. Craig personally practices and teaches meditation, qi gong - including Shibashi style, push-hands and the Chen, Yang and Sun styles of tai chi.

He is trained in fall prevention, holds first aid and CPR certifications and is a member of the Show Me Falls Free Missouri Coalition (SMFFMO).

While taking his Mom to a tai chi class, thinking it would help her with her Parkinson's disease, Craig discovered his own passion for this practice which fuses both martial arts and meditation. He started feeling the health benefits almost immediately for himself. He first noticed better balance, improved health and was sleeping better at night. Craig's Mom also noticed an improvement in her Parkinson's symptoms. Craig practiced tai chi with his Mother, until her passing in 2014.

Craig has a fondness in his heart for people with Parkinson's and other chronic diseases. He has trained with several well-know instructors and Masters including Dr. Paul Lam. Craig is a senior trainer in Dr. Lam's organization, one of only fifty two in the country and two in Missouri

Prior to the COVID pandemic Craig was teaching tai chi, qigong and meditation, including classes for the St. Louis Chapter of the APDA, to fourteen different classes in 8 different locations, totaling over one hundred and fifty students a week! People of all age groups can enjoy Craig's classes.

Craig is also very active in his community. He routinely gives talks and demonstrations on tai chi related to Parkinson's Disease and also fall prevention. He does presentations about tai chi

to local elementary and middle schools (usually in association with the Chinese New Year). He has also spoke about the benefits of tai chi at a local Acoustic Neuroma Support Group and a state wide traumatic brain injury conference. Craig organized six world tai chi day events, complete with food and tai chi demonstrations.

Craig is married and has two daughters. He enjoys reading, weather, barbecuing, canoeing and camping. He lives in South County (Lindbergh School District for you lifelong St. Louis people) and his goal in life is to make Puka Dogs.

Contact:
www.taichistl.com
craigm@taishistl.com
314 280 7500 (cell)





Building Your Abilities



A series of short, focused videos

Check out our new Building Your Abilities video series. Each video is around 10 minutes long and focuses on common challenge areas. Use one, two, or all 10 to fit your specific need.

Go to <https://www.apdaparkinson.org/community/st-louis/resources-support-stl/exercise-classes/building-your-abilities/> to see all 10 videos. Keep coming back to see new videos which will be added soon.

- Getting up from your Chair
- Head to Toe Warmup
- Increase your Flexibility
- Exercising Your Voice
- 5 Functional Exercises for Daily Activities
- Range of Motion
- Cognitive Challenges
- 3 Exercises to Improve your Coordination
- 5 Balance Exercises to do at your Kitchen Counter
- Hand Exercises

MAKE A DIFFERENCE TODAY and SAVE ON TAXES!



You Can Support APDA Greater St. Louis Chapter with Stock Gifts and/or IRA Designations

Stock Gifts: Did you know APDA accepts gifts of publicly traded securities? So, you can gift stock to APDA, rather than selling it and donating the proceeds. By doing this, you may receive the federal and state charitable deduction and avoid paying capital gains tax. Both you and APDA benefit!

IRA Designations: If you are 70½ years old and older, you can give any amount (up to a maximum of \$100,000) per year from your IRA directly to a qualified charity such as the APDA without having to pay income taxes on the money. Gifts of any value \$100,000 or less are eligible for this benefit and you can feel good knowing that you are making a difference at APDA. This popular gift option is commonly called the IRA charitable rollover, but you may also see it referred to as a qualified charitable distribution, or QCD for short. Since the gift doesn't count as income, it can reduce your annual income level. This may help lower your Medicare premiums and decrease the amount of Social Security that is subject to tax.

An Easy Way to Get Started

Call the ADPA office today at **636-778-3377**. In under 10 minutes, you can give to APDA Greater St. Louis Chapter from your IRA.



ADVOCATING FOR YOUR MEDICATION NEEDS



*by Hedva Barenholtz Levy,
PharmD, BCPS, BCGP
July 21, 2021*

It has never been more important to advocate for yourself or your family member regarding the

safe use of medications. Especially with Parkinson's Disease (PD), where the wrong medication can worsen symptoms or interact with one of your PD medications, it is critical that caregivers be aware of your PD diagnosis and specific medication regimen.

As we emerge from stay-at-home orders from the COVID-19 pandemic and start taking on more activity than we might have been used to in the past 18 months, it is important to plan ahead for the worst-case scenario, while still anticipating that the best will happen. This means making sure your medication list is up to date and includes the time(s) when each medication must be taken. It also can be helpful to include the symptoms that you experience when your medications are

delayed. This will help caregivers understand the importance of your medications and what happens if your medication schedule is thrown off. Especially if you are admitted to the hospital or a care facility, delays in obtaining medications can be avoided when you are able to provide to the pharmacy your complete and accurate medication list. Be sure it contains the name of each of your medications—including details like “CR” or “XL,” for example—as well as the strength (how many “mg”) and when you take it. This can avert delays of several hours in getting your medications.

We are fortunate in St. Louis that our chapter of the APDA has put together a resource to help you advocate for your medication needs when working with different caregivers or when admitted to the emergency department, hospital, or a rehabilitation setting. **It is called “Time Matters” and is available as a download from the APDA website.** This resource was created to help patients avoid the dangerous situations that can arise when hospital and care facility staff do not understand the risks of a missing or late dose of your PD medication.

Some of the tools found in the Time Matters binder are:

- Checklists to identify your symptoms and activities you need assistance with
- A page to list all medications, times given and purpose
- Suggestions for how to avoid problems if admitted to a hospital or other care facility
- Important drug interactions

Drug interactions are a particular concern because of the often-delicate balance between drug effectiveness, toxicity, and lack of effectiveness. There are two general categories of interactions:

1. Interactions between medications and PD, in which a drug can worsen motor symptoms as a result of a direct effect on motor function; and
2. Interactions in which other drugs interact with Parkinson's drugs to make them either less effective or more toxic.

Nonprescription medications deserve special attention because they are freely accessible and can be used without the knowledge of your healthcare team. Nonprescription products, including dietary supplements, have the potential to interact with other medications. It is always important to verify with your pharmacist that you are taking a combination that is safe.

Finally, the role of advocating for yourself cannot be overstated. Do not assume that healthcare professionals or caregivers understand the unique medication-related issues with PD. Never hesitate to ask questions or double check with your Parkinson's specialist before medication changes are made. Be assertive so that your care needs are addressed. Institutions have standard administration schedules for giving medications to patients. However, patient care comes first, and you need to speak up if the facility is not accommodating your medication needs. When necessary, elevate your concerns to the head nurse, talk to the pharmacist at the facility, or contact your Parkinson's doctor.

Anticipate the best, but prepare for the worst. Planning ahead by having your medication and symptom information ready to go can make all the difference to your health and well-being.



Double Your Donation to Fund Important Parkinson's Research

The James and Alison Bates Charitable Foundation has made a \$50,000 Challenge Grant for research. Your donation will be doubled between now and the end of the year by this generous gift. Donate to research now and make twice the difference. Email Melissa Skrivan at mskrivan@apdaparkinson.org for more information.

LIVE STREAM EXERCISE CLASS SCHEDULE

Please visit: bit.ly/APDAYoutube for exercise classes.

DAY	TIME	CLASS	LEVEL	INSTRUCTOR
MONDAY	10:00am	Strength & Cardio	Level 2	Marina Clements
MONDAY	1:00pm	Interval Training	Level 2	Jen Berger
TUESDAY	1:00pm	Seated Exercise	Level 1	Michelle Valenti
WEDNESDAY	1:00pm	Interval Training	Level 2	Michelle Valenti
THURSDAY	1:00pm	Seated Exercise	Level 1	Jen Berger
FRIDAY	10:00am	Tai Chi	Level 1	Craig Miller
FRIDAY	11:15am	Tai Chi	Level 2	Craig Miller

ZOOM EXERCISE CLASS SCHEDULE

Please contact Teri at APDA for zoom link. 636) 778-3377 or apdastlouis@apdaparkinson.org.

DAY	TIME	CLASS	LEVEL	INSTRUCTOR
TUESDAY	9:00am	Seated Exercise	Level 1	Jen Berger
TUESDAY	10:00am	Strength & Cardio	Level 2	Jen Berger
THURSDAY	10:00am	Strength & Cardio	Level 2	Vicki Frazier
FRIDAY	10:00am	Strength & Cardio	Level 2	Michelle Valenti
FRIDAY	11:00am	Seated Exercise	Level 1	Vicki Frazier
FRIDAY	11:00am	Seated Exercise	Level 1	Michelle Valenti

YOPD VIRTUAL SUPPORT GROUP

DAY	TIME	LEADER
Every Thursday	6:00pm	Karen Frank & Mike Mylenbusch

SUPPORT GROUP SCHEDULE

For more information, please call 636.778.3377 or email apdastlouis@apdaparkinson.org.

MISSOURI SUPPORT GROUPS

LOCATION	DAY	TIME	LEADER	RETURN TO IN-PERSON
Ballwin	4th Tuesday	2:30pm	Chaplain Carla Schmidt	July 27 1 Meramec Bluffs Dr. - Veterans Rm.
Cape Girardeau	1st Monday	6:00pm	Desma Reno & Jayanti Ray	August 2
Carthage	Last Tuesday	2:00pm	Tericia Mixon	July 27 Fair Acres Family YMCA
Chesterfield Caregivers	2nd Monday	10:30am	Lynda Wiens & Jay Bender	July 12 Salem United Methodist Church
Chesterfield	1st & 3rd Tuesday	11:00am	Carrie Burgraff	VIRTUAL
Kirkwood	4th Tuesday	6:30pm	Terri Hosto	TBD
South County	4th Wednesday	10:30am	Caitlin Jones	July 28 Tesson Heights Cedarhurst
Ste. Genevieve	2nd Wednesday	10:00am	Teddy Ross	July 14 Ste. Genevieve Co. Community Center
St. Louis Caregivers	3rd Monday	1:00pm	Kathy Schroeder	TBD
St. Peters	1st Tuesday	1:00pm	Jodi Peterson	August 3 Spencer Road Library #243
Washington	2nd Monday	6:00pm	Carol Weber	July 12th Washington Public Library

ILLINOIS SUPPORT GROUPS

LOCATION	DAY	TIME	LEADER	RETURN TO IN-PERSON
Belleville	TBD	TBD	Jodi Gardner	TBD Belleville Health & Sports Center
Carbondale	1st Wednesday	1:00pm	Gayla Lockwood	VIRTUAL
Champaign	Monday	10:00am	Carol Clark	July 12 Savoy United Methodist Church
Decatur	3rd Thursday	1:30pm	John Kileen	July 22 Westminister Presbyterian Church
Edwardsville	1st Tuesday	2:00pm	Pam Pinegar	July 2 Drost Park
Highland	4th Tuesday	2:00pm	Kayla Deerhake	September 28 HSHS St. Joeseph's Hospital
Quincy	2nd Saturday	10:00am	Terri & Dave May	July 2 Quincy Public Library
Jacksonville	1st Wednesday	1:00pm	Jim & Fran Ringle	TBD Passavant Area Hospital



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THANK YOU!!

The APDA Golf Classic, held on June 21, helped raise over \$100,000, to support local programs and services for our Parkinson's community.

Thank you to our amazing sponsors who helped make this day possible! We encourage you to express your thanks when supporting their businesses and recognize their outstanding contributions to our community.

James and Alison Bates Foundation



**Scott Lentin
Fund**



APDA St. Louis Chapter receives \$13,000 from Pedaling 4 Parkinson's!

Pedaling 4 Parkinson's had another successful ride in June, raising **\$13,000** to help find a cure for Parkinson's. The ride took place in Aviston, Illinois and had participants from as far as North Carolina and Chicago who took part virtually.

APDA Community Resource Center

1415 Elbridge Payne Rd, Ste 150 | Chesterfield, MO 63017
Hours: 8:00 a.m. - 4:00 p.m. M-F
636.778.3377

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