

PARKINSON'S POLICY FORUM

March 19–21, 2018 · Washington, DC

UNIFIED PARKINSON'S ADVOCACY COUNCIL

The Parkinson's disease (PD) community works together to advance policies that benefit people with Parkinson's, their families and care partners through the Unified Parkinson's Advocacy Council (UPAC). The UPAC comprises representatives from state, regional and national PD organizations to gather field-wide input on priorities and policy matters. UPAC members include:

American Parkinson Disease Association

The American Parkinson Disease Association (APDA) is the largest grassroots network working tirelessly to *provide the support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest*. APDA has a unique nationwide system of Chapters and Information & Referral Centers, delivering education, support, and patient services to Americans with PD each day. Since its founding in 1961, APDA has raised and invested more than \$170 million to provide outstanding patient services and educational programs, elevate public awareness about the disease, and support research designed to unlock the mysteries of PD. Learn more at www.apdaparkinson.org.

Brian Grant Foundation

The Brian Grant Foundation (BGF) provides tools to help improve the well being of people with Parkinson's. BGF's programs focus on exercise and nutrition, to encourage people with Parkinson's to get moving, eat healthy and feel their best. Learn more about BGF's efforts at www.briangrant.org.

Dallas Area Parkinsonism Society

Since 1978, the Dallas Area Parkinsonism Society (DAPS) has served people impacted by Parkinson's disease living in Dallas, Collin, and Tarrant counties by providing free exercise and speech classes, caregiver support groups, and health-related educational meetings. Fueled by our mission to impact and improve the lives of people with Parkinson's disease, DAPS continually explores opportunities to meet our community's needs. Examples of the kinds of programs DAPS offers include traditional strength, flexibility, and stretching exercise classes, Dance for Movement Disorder classes, aquatic exercise classes, non-contact boxing, and cycling. Our newest program Move.Laugh.Connect (MLC), recognizes the value of the physical, emotional, and social dimensions in one's total well-being. You can learn more about DAPS at www.daps.us.

Davis Phinney Foundation

The Davis Phinney Foundation was created in 2004 by Olympic medalist and retired professional cyclist, Davis Phinney, to help people with Parkinson's live well today. As a national leader of quality of life research, the organization's singular focus is to provide programs and resources that offer inspiration, information and tools that enable people living with Parkinson's to take action that can immediately improve their quality of life. Through The Victory Summit® event series, Every Victory Counts® manual, Ambassador program and extensive online content, the organization impacts hundreds of thousands of individuals each year. Learn more at www.davisphinneyfoundation.org.

Hawaii Parkinson Association

The Hawaii Parkinson Association (HPA) is a non-profit organization comprised of volunteers with Parkinson's disease, caregivers, family members, health care professionals, educators and leaders in the business community. HPA's missions are to assist Parkinson's patients, their caregivers and families to live the best life possible; educate patients, caregivers, family, friends, medical professionals and the general public about Parkinson disease; and support ongoing research in finding the cause, treatments and the cure for Parkinson's. Founded in 1996, HPA serves the Parkinson community on the Hawaiian islands of Oahu, Kauai, Maui, and the Big Island. Learn more at www.parkinsonshawaii.org.

Houston Area Parkinson Society

Since 1974, the Houston Area Parkinson Society (HAPS) has offered comprehensive services and innovative programs free of charge to individuals with Parkinson's and their families in the greater Houston area. The organization provides social services, education, support and therapeutic exercise programs to help manage the challenges of this progressive neurodegenerative disease. HAPS remains an independent nonprofit, not a local chapter of a national organization, whose breadth and scope of services fill critical gaps in care. HAPS makes significant community impact through its mission to improve the quality of life for individuals affected by Parkinson's disease through services, education and advocacy. Learn more at www.hapsonline.org.

The Michael J. Fox Foundation for Parkinson's Research

As the world's largest nonprofit funder of Parkinson's research, The Michael J. Fox Foundation (MJFF) is dedicated to finding a cure for the disease and ensuring the development of improved therapies for those living with Parkinson's today. The Foundation pursues its goals through an aggressively funded, highly targeted research program coupled with active global engagement of scientists, Parkinson's patients, business leaders, policymakers, clinical trial participants, donors and volunteers. To date, MJFF has funded more than \$800 million in Parkinson's research. Learn more at www.michaeljfox.org.

Northwest Parkinson's Foundation

Northwest Parkinson's Foundation's (NWPF) mission is to improve the quality of life of people affected by Parkinson's through awareness, education, advocacy, and care. With over 100,000 people living with Parkinson's throughout Washington, Alaska, Montana, Idaho, and Oregon, NWPF seeks to bridge the gap between diagnosis and cure with the best evidence-based programming, to provide high quality, equitable services, and to promote low-cost education of the latest PD research and information. NWPF's goal is to connect those affected by Parkinson's in the Northwest to each other through grassroots, localized support. Learn more at www.nwpf.org.

The Parkinson Alliance

The Parkinson Alliance is the umbrella organization for the **Parkinson's Unity Walk**, the largest single-day community fundraising event, and Team Parkinson. We are dedicated to raising funds for research to end Parkinson's disease, support the development of new therapies and improve the quality of life for those living with the disease. The Parkinson Alliance also directly funds and conducts patient-centered outcomes research in its own right, focusing on both motor and non-motor symptoms, and other aspects of well-being such as resilience and coping skills. Together with the Parkinson's Unity Walk and

Team Parkinson, The Alliance has funded more than \$30 million in research to date. Learn more at www.parkinsonalliance.org and www.unitywalk.org.

Parkinson Association of Alabama

Founded in 1978, the Parkinson Association of Alabama (PAA) is a 501(c)3 nonprofit organization committed to a singular mission: To improve the quality of life for patients, caregivers, and families affected by Parkinson's disease in the State of Alabama. We do this in a variety of ways that include: providing support, distributing information, increasing awareness, amplifying local programs, encouraging collaboration, and supporting research to lead to new and improved treatments for Parkinson's disease that will ultimately lead to a cure. Learn more at www.parkinsonalabama.com.

Parkinson Association of the Rockies

The Parkinson Association of the Rockies connects and empowers people with Parkinson's to thrive. Through support groups, exercise classes and in-home consults with a Licensed Clinical Social Worker, the Association connects people to the community and critical resources. Exercise classes, education, newsletters, and equipment loan services further empower people with Parkinson's to thrive. Advocacy efforts empower, engage and connect people with Parkinson's to use their voice and passion to enhance the care and services available for all people living with this disease. The Association celebrates people with Parkinson's defining their disease rather than letting the disease define their lives. Learn more at www.parkinsonrockies.org.

Parkinson Voice Project

Parkinson Voice Project is the only nonprofit organization in the world solely dedicated to preserving the voices of those with Parkinson's. The organization has developed an effective two-part speech therapy program: SPEAK OUT!® followed by The LOUD Crowd®. Persons diagnosed with Parkinson's or related conditions are invited to receive treatment at Parkinson Voice Project's clinic in Dallas, Texas. The organization also trains speech-language pathologists who want to bring this program to their communities. Parkinson Voice Project's clinic includes an education center where Parkinson's experts present and then video recordings are posted on the organization's website. For more information, visit www.parkinsonvoiceproject.org.

Parkinson's Foundation

The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience, and passion of our global Parkinson's community. We are leaders in ensuring expert Parkinson's disease care; educating and empowering the Parkinson's community; and driving the understanding of Parkinson's through research. As a national organization with a local presence and impact, we bring help and hope to individuals who are living with Parkinson's. Learn more at www.parkinson.org.

Parkinson's Resources of Oregon

Parkinson's Resources of Oregon (PRO) was founded in 1980 when a group of Parkinson's patients organized the first regional support group specific to Parkinson's disease. PRO has since grown and expanded with services now offered from three offices in the Pacific Northwest. We work with the singular focus of improving quality of life for residents living with Parkinson's by balancing hope for the

future with education and services for today. Services include a deep network of Support Groups, ongoing professional and lay Education, Exercise and Wellness classes, Social Work and Counseling, as well as personal support and advocacy. Learn more at www.parkinsonsresources.org.

Power for Parkinson's

Power for Parkinson's is a non-profit organization that provides free weekly exercise, dance, and singing classes for people with Parkinson's and their care partners in Austin, Texas and surrounding communities, as well as globally through our YouTube home video series. Our mission is to engage people with Parkinson's in regular exercise to slow or even reverse the effects of Parkinson's disease, improve their overall sense of well-being, provide opportunities for socialization, and help prevent depression and isolation that often accompanies the disease. Research has shown that exercise is the one thing individuals can do to delay the progression of Parkinson's disease, and we aim to have the most fit group of people with Parkinson's in the country! Learn more at www.powerforparkinsons.org.

Wilkins Parkinson's Foundation

Wilkins Parkinson's Foundation was granted a 501(c)3 charity status in 2010 and is dedicated to accelerating the cure and treatment of Parkinson's disease. Our goal is to increase collaboration from the entire Parkinson's Community and to encourage Patient Participation Activism to emphasize the importance of the Patient Voice. Additional strategies include directing funds to Research, Education and Awareness and advocating for the entire community. Learn more at www.wilkins-pf.org.

Wisconsin Parkinson Association

Wisconsin Parkinson Association provides hope, community, support, and resources to people with Parkinson's and their loved ones. WPA holds educational programs around the state of Wisconsin, and coordinates and assists support groups and exercise groups for people with PD. WPA is an independent 501(c)3 organization that has a big impact on people with PD and their families. For more information visit www.wiparkinson.org.

The Unified Parkinson's Advocacy Council is managed by the public policy department of The Michael J. Fox Foundation. For more information, please contact policy@michaeljfox.org.