



# LSVT Global® Public Webinar Series

Title: **Behind the Scenes with Organizations Supporting the Parkinson's Community**

Moderator: Elizabeth Peterson, MA, CCC-SLP

Panelists: Tom Manak and Jackie Gannon, ***Parkinson's Foundation***  
Gabby Dimotsantos, ***Davis Phinney Foundation***  
Andrea Merriam, ***Parkinson & Movement Disorder Alliance***  
Carol Walton, ***Parkinson Alliance and Parkinson's Unity Walk***  
Veronique Enos Kaefer, ***Michael J. Fox Foundation***  
Rebecca Gilbert, MD/PhD, ***American Parkinson Disease Association***

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**Disclosures**

Financial relationships include:  
All panelists were offered  
honorarium for their time and  
expert knowledge of the  
organizations they represent.

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Slide 5

**Information to Report CE Activity**

- This LSVT Global webinar is NOT ASHA or state registered for CEUs for speech, physical and occupational therapy professionals, but it may be used for self-reported CEU credit as a non-registered/non-preapproved CEU activity.
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- Attendance for the full 1.5 hours is required to earn a certificate. No partial credit is offered.



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Slide 6

**Learning Objectives**

Upon conclusion of this webinar, participants will be able to:

- List at least five organizations available to support individuals with Parkinson's disease and those involved in their care.
- Explain the missions of at least five organizations in supporting the Parkinson's community.
- Locate information necessary to utilize the resources these organizations provide.

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Slide 7

**Poll #1. Who is joining us?**

- Person with Parkinson's
- Family member, friend or care partner
- Physical or Occupational Therapist/Assistant (including students)
- Speech Language Pathologist/Assistant (including students)
- Other

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Slide 8

**Tom Manak**  
*Vice Chair, People with Parkinson's Council*  
*Parkinson's Foundation*  
Glen Ellyn, Illinois



Tom Manak spent his entire career in the healthcare industry focusing on strategy, business development, and finance. This included working with senior leadership teams and boards identifying new opportunities and leading retreats. Tom has been a guest lecturer at University of Illinois at Chicago, Northern Illinois University, and Governors State University. He developed an interest in Parkinson's disease when his wife was diagnosed with PD almost 30 years ago. He is her primary care partner.



Tom holds a BS in Business Administration from Marquette University and a MA in Health Care Administration from George Washington University.

He is a volunteer and Board Member for a local Rock Steady Boxing affiliate, assists in Loud Crowd group speech therapy for Parkinson's patients, was on the 2020 Parkinson's Foundation Care Partner Summit committee, recently nominated as Vice Chair of the Parkinson's Foundation People with Parkinson's Council, and is active in his church.

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Slide 9

**Jackie Gannon**  
*Senior Manager, Strategic Initiatives*  
*Parkinson's Foundation*  
New York, New York



Jackie Gannon has been working at the Parkinson's Foundation for three years. In her role, she helped launch the Newly Diagnosed Initiative in 2019, helps oversee the People with Parkinson's Council, and is passionate about reporting data to show the impact of the Parkinson's Foundation work at a local/community level.



She holds a Masters of Public Administration degree from Baruch College as a National Urban Fellow. Jackie has previously worked for Patient-Centered Outcomes Research Institute (PCORI) in Washington, DC, and the International AIDS Vaccine Initiative in New York, and was a Peace Corps Community HIV/AIDS Health Volunteer in Namibia.

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Slide 13

**Understand Parkinson's through Research** 

- Largest-ever clinical study of Parkinson's disease with more than 13k participants (**Parkinson's Outcomes Project**)
- Funding academic and medical institutions dedicated to furthering PD research (**Research Centers**)
- Grants and Fellowship Awards for Researchers
- Mapping the Future of Parkinson's with free genetic testing + counseling (**PDGENERATION**)

*PD GENERATION @ HOME* \*now available in tele-health to reach goal of 15,000 in 4 years

Find more info at [Parkinson.org/research](http://Parkinson.org/research)



**Better Lives. Together.** 13

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Slide 14

**Educate and Empower People with and Affected by PD** 

**PD Health @ Home** - diverse educational events turned virtual, topics ranging from Mindfulness Mondays to Wellness Wednesdays.

**Community Grants** - help fund education, outreach programs that address unmet needs in PD communities. Awarded **172 community-based programs in 2020**.



**Newly Diagnosed: Building a Better Life with PD**  
- closing the gap between a PD diagnosis and essential resources.

**Moving Day** - a movement for change towards more awareness, more funding, and more understanding. **Now virtual for Spring and Fall 2020**

**Better Lives. Together.** 14

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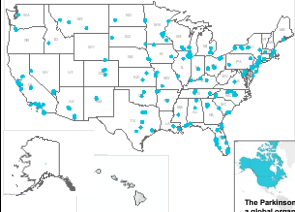
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Slide 15

**Who We Serve and How We Reach Them** 



**Reach Through:**  
Community Grants  
Educational Programs  
Moving Days  
Research Centers  
Local Chapters  
Volunteers

**Partnerships:**  
Centers of Excellence  
Veterans Administration  
AAQP

The Parkinson's Foundation is a global organization

**Better Lives. Together.** 15

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Slide 19

**DAVIS PHINNEY**  
Foundation for Parkinson's  
every victory counts.

**WE HELP PEOPLE WITH PARKINSON'S  
LIVE WELL TODAY.**

We do this by providing **education, tools, resources,**  
**and inspiration** that touch on every aspect of life:  
physical, emotional, intellectual, social, and financial.

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Slide 20

**DAVIS PHINNEY**  
Foundation for Parkinson's  
every victory counts.

**WE HELP PEOPLE WITH  
PARKINSON'S LIVE WELL TODAY.**

 <b>LIVE WELL</b> We share stories and celebrate victories. We are authentic, energetic, and fun.	 <b>INSPIRE ACTION</b> We take an Olympic level approach. We empower positive change and give people hope.	 <b>CONNECT THE COMMUNITY</b> We bring the right resources to the right people. We are collaborative; we are better together.
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Slide 21

**Our Story**

**EVERY VICTORY COUNTS!**

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Slide 34

Andrea Merriam  
Vice President, Community Engagement  
Parkinson & Movement Disorder Alliance  
[andrea@pmdalliance.org](mailto:andrea@pmdalliance.org)  
[www.pmdalliance.org](http://www.pmdalliance.org)



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**PARKINSON ALLIANCE**



Carol J. Walton  
*President & CEO, The Parkinson Alliance*  
*Executive Director, Parkinson's Unity Walk*

Carol's father was diagnosed with Parkinson's disease in 1962 and finding information was a major challenge. Carol's Dad lived in Washington State and she lived in California. Her brother lived in Washington State and they tried to share responsibilities. She attended support groups trying to educate herself and her family about Parkinson's.

In 1994 Carol attended a Parkinson's Action Network Public Policy Forum in Washington, DC. She worked to get the Morris K. Udall Parkinson's Research Act passed in 1997. During that forum she met Margaret and Martin Tuchman. They offered Carol the opportunity to head their new foundation. In 1999 the Tuchmans moved her from California to New Jersey to start The Parkinson Alliance.

Carol is a Board Member of The Parkinson Alliance, Parkinson's Unity, and UPAC—United Parkinson's Advocacy Council of the Michael J. Fox Foundation for Parkinson's Research.



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**PARKINSON ALLIANCE**

LSVT GLOBAL WEBINAR  
SEPTEMBER 16, 2020

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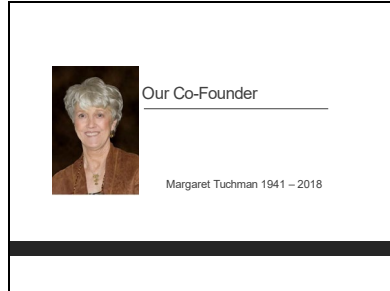
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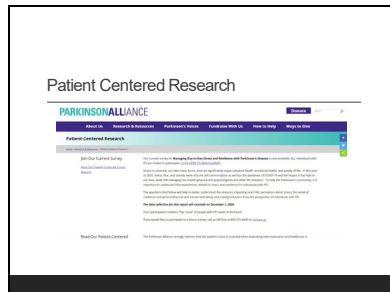
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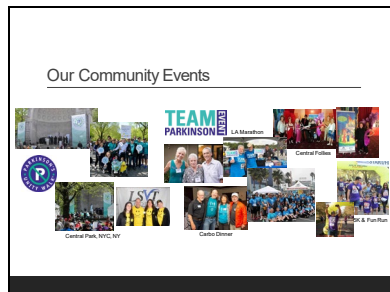
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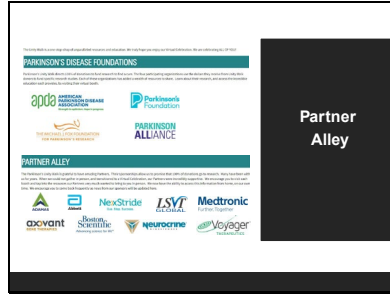
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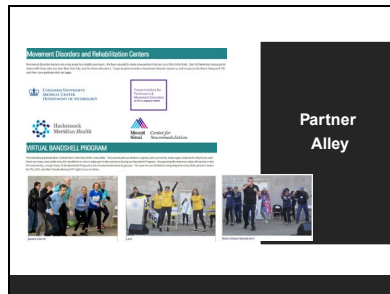
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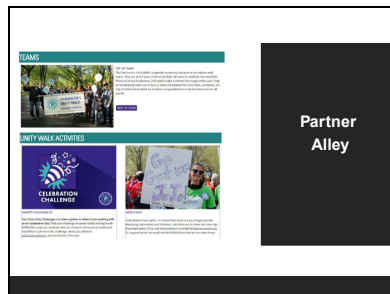
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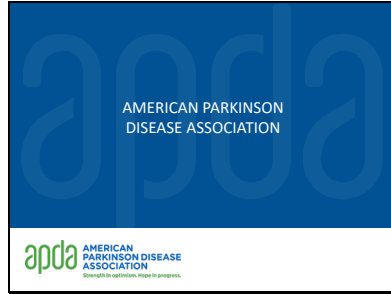
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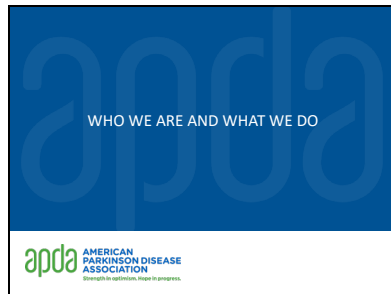
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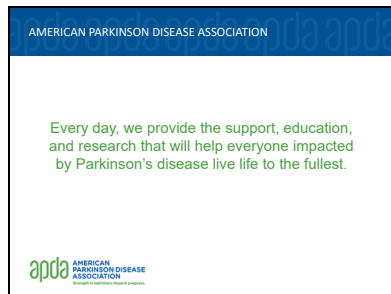
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AMERICAN PARKINSON DISEASE ASSOCIATION

**Local Programs & Services**

- **Information and Referral**
  - I&R Centers
  - 800-223-2732
  - Connections
  - Resources
- **Education & Support**
  - Support groups
  - Symposiums, Educational Events
- **Health & Wellness**
  - Exercise and movement classes
    - Dance, yoga, tai chi, boxing and more
  - Fitness Professionals Training Program



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AMERICAN PARKINSON DISEASE ASSOCIATION

Online programming: education, support and wellness



Midwest Parkinson Congress

Let's Keep Moving with the APDA

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AMERICAN PARKINSON DISEASE ASSOCIATION

**Nationwide Programs & Services**

- Online resources
- Publications
- Webinars



Medications Approved for the Treatment of Parkinson's Disease in the USA

QUESTION & ANSWER

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