



# SALT LAKE CITY



Friday, February 26, 2016  
Salt Lake City, Utah

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## SPECIAL NOTES

**Emergency:** If you or someone around you requires emergency or first aid assistance, please contact a staff member or volunteer. The building is equipped with AED's, located in the lobby at the front desk and in the Sheraton fitness room.

**Volunteers:** Need a helping hand? Volunteers can be identified by a black shirt with a colorful bike on the back – feel free to ask them questions throughout the day.

**Name Badges:** Thank you for wearing your badge as it allows you access to all sessions, indicates your lunch order and is a great way to connect with others who may live in or nearby your town!

**Evaluation:** We'd love to hear from you! The blue survey in your program bag is intended for your feedback on the event. Drop off completed surveys in blue bins or hand them to staff and volunteers.

**Online:** Today's presentations are available at our website:  
<http://www.DavisPhinneyFoundation.org/VS-SLC>

**Food:** Lunch is served to you at your tables, and coffee/tea is available during the morning in the Exhibit Hall. You can also find free snacks in your program bag, courtesy of Boulder Brands®. Starbucks and the 5<sup>th</sup> Street Grill in the Sheraton Salt Lake City Hotel offer snacks and drinks for purchase.

A special thanks to Boulder Brands® for donating your complimentary snack.



## THE VICTORY SUMMIT AGENDA

- 8:30 – 9:30**      **Pre-Event Session: Parkinson's 101**  
*Denise Skuster, MD, Intermountain Healthcare*
- 8:30 – 9:55**      **Visit Exhibit Hall**  
*Exhibit hall open from 8:30 – 2:30*
- 10:00 – 10:20**      **Welcome & Opening Remarks**  
*Polly Dawkins, Davis Phinney Foundation (Boulder, CO)*
- 10:20 – 10:30**      **Moments of Victory®**  
*Davis Phinney, Founder, Davis Phinney Foundation (Boulder, CO)*
- 10:30 – 10:40**      **LSVT LOUD®: Movement Break**  
*Becky Boyack, M.Ed, CCC-SLP, Cornerstone Healthcare*  
*Richard Vinson, MSPT, Cornerstone Healthcare*
- 10:40 – 11:10**      **Not Just the Shakes: Cognition & Non-motor Symptoms**  
*Aaron Haug, MD, Blue Sky Neurology (Denver, CO)*
- 11:10 – 11:35**      **Coffee & Connection Break**  
*Browse exhibitors and meet other attendees*
- 11:35 – 11:45**      **Boxing & Parkinson's: Movement Break**  
*Lee Dibble, PT, PhD, ATC,*  
*University of Utah Department of Physical Therapy*
- 11:45 – 12:10**      **10 Commandments of Living Well**  
*Susan Imke, FNP, GNC-P, Kane Hall Berry (Bedford, TX)*
- 12:10 – 1:00**      **Lunch - Delivered directly to tables – Exhibit Hall open**
- 1:00 – 1:05**      **Local Inspirations**  
*Honoring members of your local Parkinson's community*
- 1:05 – 1:35**      **Exercising For the Rest of Your Life**  
*Matt Ford, PT, PhD, Samford University (Birmingham, AL)*
- 1:35 – 1:40**      **Pay It Forward**
- 1:40 – 2:05**      **Live Your Best**  
*Tim Hague, Sr., Canada's Amazing Race Winner*  
*(Winnipeg, Manitoba, Canada)*

**2:05 – 2:25**

**Break**

*Transition to the Track 1 Breakout Session of your choice*

**2:25 – 3:05**

**Track 1 Breakout Session** (descriptions on pages 5-6)

Ballroom.....**Panel Discussion: DBS & Surgical Therapies**  
*Elena James, MD, Salt Lake Regional Medical Center, IASIS Healthcare, Physicians Group of Utah*  
*Paul House, MD, University of Utah Health Care*  
*Steve Welling, Parkinson's Advocate*  
*Suzanne Peterson, Parkinson's Advocate*

Room 1.....**Navigating Depression & Anxiety**  
*Martin Freimer, MD, University of Utah Health Care, Salt Lake Regional Hospital*

Room 2.....**Reclaiming Intimacy & Relationships**  
*Susan Imke, FNP, GNC-P, Kane Hall Berry*

Room 3.....**Maximize Your Mobility: Fall Prevention**  
*Reuben Jessop, DPT, NCS, Northern Utah Rehabilitation Hospital*

**3:05 – 3:20**

**Break**

*Transition to the Track 2 Breakout Session of your choice*

**3:20 – 4:00**

**Track 2 Breakout Sessions** (descriptions on pages 6-7)

Ballroom.....**Medication Management & Strategies**  
*Lauren Schrock, MD, University of Utah Health Care*

Room 1.....**How to Tame Your Bladder**  
*Jim Ballard, PT, DPT, GCS, University of Utah Rehab Wellness Clinic*

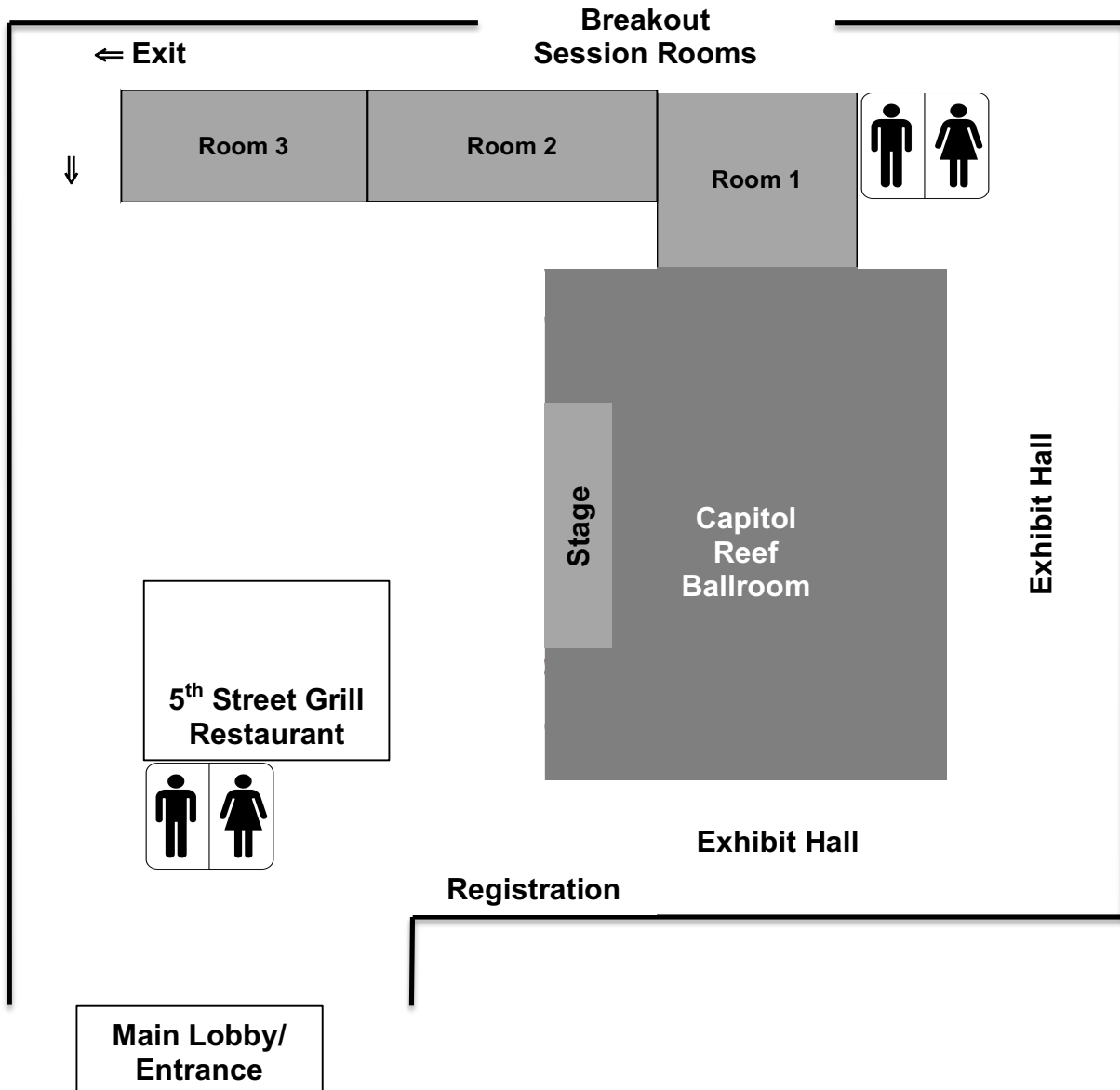
Room 2.....**Strategies for the Care Team: Living Well**  
*Connie Carpenter-Phinney, member of Davis Phinney Foundation Board of Directors*

**4:00**

**Head Home!**

*Make your commitment to live well today with Parkinson's!*

## SHERATON SALT LAKE CITY HOTEL CONFERENCE CENTER



## MOVEMENT BREAK DESCRIPTIONS

See pages 9-14 for speaker biographies

### LSVT LOUD®

LSVT LOUD® is a speech treatment for individuals with Parkinson's disease and other neurological conditions. It improves vocal loudness by stimulating the muscles of the voice box (larynx) and speech mechanism through a systematic hierarchy of exercises.

Focused on a single goal – “speak LOUD!” – the treatment improves respiratory, laryngeal and articulatory function to maximize speech intelligibility. The treatment does not train people for shouting or yelling; rather, LSVT LOUD uses loudness training to bring the voice to an improved, healthy vocal loudness with no strain.

### Boxing & Parkinson's

Boxing is just one of the many types of exercise that has been shown to improve quality of life for people with Parkinson's through building strength and flexibility. Rigorous exercise emphasizing motor movement, balance and hand-eye coordination has been shown to positively impact range of motion. Exercise has also been shown to be neuro-protective, meaning it slows the progression of Parkinson's.

The University of Utah Physical Therapy Department has partnered with the University of Utah Boxing Club in coaching a Parkinson's specific boxing class. A typical class starts with a warm up and conditioning session then moves into the boxing portion. Participants have two minute rounds with an active rest between rounds. Each participant has one volunteer who guards them for safety and one boxing coach who provides feedback on their boxing technique.

**More information about the local Boxing & Parkinson's class can be found in the “Local Resources” section of the program book on page 31.**



## BREAKOUT SESSION DESCRIPTIONS

See pages 9-14 for speaker biographies

### **Pre-Event Session: Parkinson's 101**

*Denise Skuster, MD*

**Capitol Reef Ballroom**

**8:30-9:30am**

A diagnosis of Parkinson's disease can feel overwhelming and confusing. To learn more about what to expect, strategies for coping and resources available in your area, join the morning pre-event session, Parkinson's 101. Discussion will include:

- What is Parkinson's?
- Motor symptoms of Parkinson's to expect
- Non-motor symptoms of Parkinson's to expect
- Parkinson's treatment options overview

Directly following this session, attendees are encouraged to visit the Exhibit Hall, located in the foyer outside of the Ballroom.

### **Panel Discussion: DBS & Surgical Therapies**

*Elena James, MD; Paul House, MD; Steve Welling, Suzanne Peterson*

**Capitol Reef Ballroom**

**Track 1**

You may have heard of surgical therapies for Parkinson's such as deep brain stimulation therapy (DBS) or enteral suspension, but you might not be sure what they are, who it is for or when to consider it. Come learn from a panel of experts in the field and individuals who have undergone the procedure themselves. Discussion will include:

- Description of DBS therapy and enteral suspension
- Potential benefits and risk factors of each
- Who qualifies as a good candidate and when to consider the therapies
- Perspectives from panelists who have experienced DBS therapy

This interactive panel discussion will feature 20 minutes of moderated discussion between panelists and 20 minutes of audience questions. *Please feel free write a question down on the index cards on the table.* A volunteer will collect them throughout the panel discussion. Questions from the audience will be reviewed and posed to the speakers by the moderator during the second half of the session.

### **Navigating Depression & Anxiety**

*Martin Freimer, MD*

**Room 1**

**Track 1**

Living with Parkinson's often includes changes in mood – including depression. Addressing these issues head-on may feel overwhelming and oftentimes shame can play a role in ignoring the symptoms of significant changes in mood. Take the next step in living well by learning how to manage mood changes with Parkinson's disease. Discussion will include:

- Defining depression and mood
- Interpreting the warning signs and symptoms of significant mood changes
- Practical coping and strategies
- When and how to ask for help

The audience will have the opportunity to ask follow up questions during the final 10 minutes of the presentation.

## **Reclaiming Intimacy & Relationships**

**Room 2**

*Susan Imke, FNP, GNC-P*

**Track 1**

It's time to recognize that Parkinson's and intimacy are not mutually exclusive. Learn about the positive impact of renewing intimacy in relationships in the context of a movement disorder. This session will include discussion of:

- Unique challenges of intimacy with PD
- Benefits of intimacy
- Tips to increase intimacy
- Importance of honest communication in personal relationship

The audience will have the opportunity to ask follow up questions during the final 10 minutes of the presentation.

## **Maximize Your Mobility: Fall Prevention**

**Room 3**

*Reuben Jessop, DPT, NCS*

**Track 1**

Falling, fear of falling, freezing and shuffling are common mobility challenges in Parkinson's. Learn how to proactively reduce the frequencies of falls and address freezing/shuffling. This session will include discussion of:

- Beneficial environmental changes
- Benefits of exercise in fall reduction
- Demonstrations of fall prevention exercises
- Demonstrations of freezing and shuffling exercises
- Adaptive equipment information

The audience will have the opportunity to ask follow up questions during the final 10 minutes of the presentation.

## **Medication Management & Strategies**

**Capitol Reef Ballroom**

*Lauren Schrock, MD*

**Track 2**

As many people living with Parkinson's can attest, keeping track of medications and timing them correctly can vastly improve your quality of life. In this session, learn what you can do right now to more comfortably manage your Parkinson's medications. This session will include discussion of:

- Maximizing benefits of Parkinson's medications
- Interactions between common Parkinson's medications
- Side effects of common Parkinson's medications
- Optimal intake strategies of common Parkinson's medications

The audience will have the opportunity to ask follow up questions during the final 10 minutes of the presentation.



## How to Tame Your Bladder

*Jim Ballard, PT, DPT, GCS*

**Room 1**

**Track 2**

Urinary dysfunction is a common and often irritating symptom of Parkinson's disease. The most common urinary symptoms experienced are the need to urinate frequently and a sense of urinary urgency. Learn about how these symptoms can be addressed and managed. This session will include discussion of:

- Incontinence and other common symptoms
- Medications to reduce bladder over-activity
- Physical therapy and exercise to reduce symptoms
- When and how to talk with your doctor

The audience will have the opportunity to ask follow up questions during the final 10 minutes of the presentation.

## Strategies for the Care Team: Living Well\*

*Connie Carpenter-Phinney, MS*

**Room 2**

**Track 2**

The role of a care partner is ever-evolving. Learn about navigating the world of the care partner in a positive way through self-care. Care partners, spouses and family members are all encouraged to attend this session. Discussion will include:

- Importance of self-care
- Significance of social engagement
- Strategies for navigating this role
- Practical tips for taking care of your own well-being
- When and how to ask for help

The audience will have the opportunity to ask follow up questions during the final 10 minutes of the presentation.

***\*This session is for care partners. People with Parkinson's are encouraged to visit a different session. If assistance is wanted, volunteers will be outside of Room 2 to accompany people with Parkinson's.***

Presentation PowerPoints given at The Victory Summit in Salt Lake City will be available on the Davis Phinney Foundation event webpage at:  
<http://www.davisphinneyfoundation.org/VS-SLC>

## LOCAL INSPIRATIONS

At each Victory Summit symposium, the Davis Phinney Foundation recognizes people in the Parkinson's community who are determined to celebrate the Moments of Victory® in their lives. These individuals are proof positive that people with Parkinson's and care partners can live rich, full lives – sometimes even opening up new opportunities and experiencing joys they had never imagined possible before a diagnosis.

### It is the Davis Phinney Foundation's privilege to honor:

**Bill Binger** of Salt Lake City, UT

In recognition of his beautiful poetry and sharing his creativity with the Parkinson's community.

**Liz Covington** of Orem, UT

In recognition of serving as a mentor to the newly diagnosed and always taking time to answer any questions.

**Randy Covington** of Orem, UT

In recognition of his tireless support and commitment to those in need in his Parkinson's community.

**Arvin Fackrell** of Willard, UT

In recognition of his hard work in leading a support group, always bringing in great speakers and living an active lifestyle.

**Dale George** of Davis County, UT

In recognition of his dedication to create the first Parkinson's support group in Davis County and an eagerness to help the families of those with Parkinson's.

**Dave Healy** of Kaysville, UT

In recognition of his constant engagement in the Parkinson's

community and his endless love and support to his family.

**Brian Moss** of Salt Lake City, UT

In recognition of his "never give up" attitude, his commitment to staying physically fit and living an active lifestyle.

**Eileen Rencher** of North Salt Lake, UT

In recognition of her activism in the Parkinson's community and endless commitment.

**Barton Taylor** of Draper, UT

In recognition of helping those with young onset Parkinson's and being a support system to those who need it.

**Steve Welling** of Utah County, UT

In recognition of pioneering a new music genre called "Movement Disorder Rock" and for his always positive attitude.

**Catherine Zobell** of Fountain Green, UT

In recognition of never giving up hope, always having a smile on her face and for always being a true optimist.

## SPEAKER BIOGRAPHIES

*(In Alphabetical Order)*

### **D. James (Jim) Ballard, PT, DPT, GCS**

Jim Ballard has been a faculty member in the Department of Physical Therapy at the University of Utah since 2004. He is an Assistant Clinical Professor and the Clinical Director of the University Rehabilitation and Wellness Clinic. In the entry level physical therapy curriculum he teaches management in geriatrics, men's and women's health and wellness and assists in teaching vestibular rehabilitation.

Dr. Ballard is a board certified clinical specialist in geriatric physical therapy. His chief clinical interests are Parkinson's disease rehabilitation, balance training, vestibular rehabilitation and male and female pelvic floor muscle rehabilitation. He is a member of the Deep Brain Stimulation (DBS) Team at the University of Utah Health Sciences Center. In this capacity, Dr. Ballard assesses the motor effects of levodopa in individuals with Parkinson's disease before DBS surgery. He also performs assessments for individuals with essential tremor and dystonia prior to DBS surgery.

### **Becky Boyack, M.Ed, CCC-SLP**

Becky Boyack is a Speech Therapist with Cornerstone Home Health. Ms. Boyack has a bachelor's degree in Speech and Hearing Science from the University of Utah and a master's degree in Communication Disorders from Utah State University. As a speech therapist, she provides therapy in the areas of cognition, speech, language, articulation, verbal expression, auditory comprehension, writing, reading and voice. Ms. Boyack is an LSVT (Lee Silverman Voice Treatment) Certified Clinician. LSVT is a voice therapy used by speech therapists to help patients with Parkinson's disease increase the vocal loudness in order to support their independent and effective communication with caregivers, doctors, family and friends.

### **Connie Carpenter-Phinney, MS**

Connie Carpenter is an entrepreneur, author, artist, life-long athlete and is extremely passionate about her work as a member of the Board of Directors for the Davis Phinney Foundation. She particularly enjoys sharing her experiences through the written word and as an eloquent and humorous public speaker.

Connie has a masters of science in exercise science from the University of Colorado and completed her undergraduate work at the University of California – Berkeley. She has two adult children, Taylor and Kelsey, with her husband, Davis Phinney.

## **Polly Dawkins, MBA**

Polly Dawkins brings 25 years of for-profit and non-profit experience to her position as the Executive Director of the Davis Phinney Foundation. That experience includes transforming a struggling UK-based engineering organization into a multi-million dollar venture and, closer to home, leading a local fundraising chapter of an international literacy organization.

Polly's track record managing organizations responsibly and with transparency dovetails with her humanitarian worldview. She is committed to making wise use of the Davis Phinney Foundation's resources, enabling it to extend its reach while staying true to its mission. Polly holds a masters in business administration in international business from Thunderbird School of Global Management and a bachelor's degree in international studies from Earlham College.

## **Lee Dibble, PT, PhD, ATC**

Lee Dibble is an Associate Professor within the Department of Physical Therapy at the University of Utah. For the past 15 years, Dr. Dibble had directed the University Rehabilitation and Wellness Clinic, a clinic that delivers preventative and traditional rehabilitation care for persons with chronic neurologic disease including but not limited to persons with Parkinsonism. In addition, he co-directs both the Motion Capture Core Facility and the Skeletal Muscle Exercise Research Facility.

Dr. Dibble's current research examines mobility, postural control and gaze stability in persons with degenerative neurologic diseases such as Parkinson disease and Multiple Sclerosis. As a component of this research, he and his colleagues study the effects of physical activity and exercise on the progression of disability in Parkinson's. Dr. Dibble has authored numerous scientific publications and garnered grant support for his research from the National Institutes of Health, the US Army and disease specific non-profit foundations. He lectures nationally and internationally on topics related to rehabilitation and Parkinson's disease.

## **Matt Ford, PT, PhD**

Matt Ford is an Associate Professor and Chair of the Department of Physical Therapy in the College of Health Sciences at Samford University in Birmingham, AL. He holds a bachelor of science in Physical Therapy from Quinnipiac University, a master's in Motor Learning from Teachers College, Columbia University and a doctoral degree in Motor Behavior from Pennsylvania State University. He previously held faculty positions in the Departments of Physical Therapy at the University of Alabama at Birmingham (UAB) and Saint Francis University.

Dr. Ford has spent the past 10 years working with persons with Parkinson's in both a research and service capacity in collaboration with the Department of Neurology – UAB, Center for Exercise Medicine – UAB, Lakeshore Foundation, Neuromuscular Rehab and Balance Center at Southeast Alabama Medical Center, the Parkinson's Association of Alabama and the Davis Phinney Foundation. Dr. Ford is a regular speaker at The Victory Summit symposia on the subject of "Exercising for the Rest of Your Life" and is featured on the Davis Phinney Foundation's "Parkinson's Exercise Essentials" DVD. He resides in Alabama with his wife, Kim, and their sons, Dylan and Jack.

## **Martin Freimer, MD**

Martin Freimer is an Assistant Clinical Professor in the Department of Psychiatry and also holds adjunct appointments in Neurology and the Division of Geriatrics in the Department of Medicine at the University of Utah. Dr. Freimer completed his clinical and research training at the University of Iowa. Subsequent to his training he was on faculty at Yale University and the University of Nebraska.

Dr. Freimer has practiced Geriatric Psychiatry for twenty years and has consulted at numerous long term care facilities. He is board certified in Psychiatry and also has the added qualification of Geriatric Psychiatry. He is currently the Medical Director of Geriatric Psychiatry at Salt Lake Regional Hospital.

## **Tim Hague, Sr.**

Tim Hague, Sr. is a Professional Speaker, Parkinson's Advocate and Registered Nurse. He was diagnosed with Young Onset Parkinson's Disease at the early age of 46 and of the many side effects that accompany this disease the most thrilling was its influence on getting him on The Amazing Race Canada! Tim and his son Tim Jr. were not only selected but went on to win Season #1 of this award winning reality television show. Tim travels across North America and internationally sharing his story of strength and courage.

Drawing on his experience as the Winner of Season #1 of The Amazing Race Canada, Tim weaves a story of failure and success that moves his audience. You will be lost in the wonder of storytelling as he recounts his adventures from the race. He will take you on a very personal journey through his diagnosis of Parkinson's disease. You will experience a sense of loss that comes from this diagnosis, but more importantly the hope and the determination to persevere. [www.TimSr.ca](http://www.TimSr.ca)

## **Aaron Haug, MD**

Aaron Haug is a Neurologist and Movement Disorder Specialist practicing in Denver, Colorado at Blue Sky Neurology. He received his medical degree from the University of Kansas. Dr. Haug completed his internship in Internal Medicine and residency in Neurology at the University of Colorado, including a year as chief resident. He went on to complete his fellowship in Movement Disorders at the University of Colorado. He holds board certification from the American Board of Psychiatry and Neurology and joined Blue Sky Neurology in 2012.

Dr. Haug is interested in medical and surgical treatments for the motor and non-motor symptoms of Parkinson disease. He is involved in patient education through a variety of advocacy groups including the Parkinson Association of the Rockies. Outside the office, he likes to spend time with his wife, run, ski, and follow Kansas Jayhawks basketball.

## **Paul House, MD**

Paul House is a Neurosurgeon and Assistant Professor with the University of Utah Department of Neurological Surgery. He received his medical degree from Washington University and completed his fellowship with the University of California – San Francisco.

Dr. House specializes in surgical treatment of people who suffer from epilepsy, movement disorders (including tremor, Parkinson's disease, and dystonia), trigeminal neuralgia and brain tumors. His research interests include improving the "decoding" of movement information from the brain, understanding epileptic activity across several orders of scale and designing new devices to provide communication with the brain.

## **Susan Imke, FNP, GNP-C**

Susan Imke is a practicing Nurse Practitioner with Kane Hall Berry Neurology in Bedford, Texas and holds ANCC certification as a Gerontological Nurse Practitioner and Texas licensure as a Family Nurse Practitioner. She has a bachelor of science degree in Nursing from the West Texas A&M University and a master of science degree from the University of North Texas.

Mrs. Imke serves on the faculty of the National Parkinson Foundation's Interdisciplinary Team Training Program and on the advisory board for the Parkinson Alliance in Princeton, NJ. She has authored numerous publications for families living with movement disorders and dementia. She is a well known speaker to audiences of health professionals as well as family caregivers on topics related to neurology of aging and living with chronic illness. Mrs. Imke's primary clinical interests include Parkinson's disease, dementia, stroke and chronic pain.

## **Elena James, MD**

Elena James is a board certified Adult Neurologist practicing in Salt Lake City since 1996. She attended medical school at the University of Texas Medical Branch in Galveston, Texas, graduating in 1991. Dr. James then did her internship in Internal Medicine at the same institution, and completed her adult neurology residency in 1995. She did a research fellowship with Dr. Bill Willis in neuroscience concentrating on spinal cord pathways involved with visceral pain.

Before medical school, Dr. James was a research associate with a focus on gastrointestinal peptides and their role in specific gastrointestinal cancers, she has 30 publications. Dr. James has been practicing Adult Neurology in Salt Lake City for 20 years and has a special interest in movement disorder specifically Parkinson's Disease. She programs many people with Parkinson's that have received deep brain stimulation therapy. Dr. James sits on the Pharmaceutical and Therapeutic Committee for PEHP, is on the Critical Care Committee at Salt Lake Regional Medical Center, and is on the Board of Directors for a non-profit organization, Lost Coin Zen.



## Reuben Jessop, DPT, NCS

Reuben Jessop is the Chief Operating Officer and the Director of Therapy Operations at Northern Utah Rehabilitation Hospital. He is passionate about working with individuals suffering from neurological conditions. Advanced training in Parkinson's disease, stroke, traumatic brain injury, spinal cord injury and multiple sclerosis equip him to serve patients with proficiency and compassion. Dr. Jessop earned a doctorate in physical therapy and a neuro-clinical specialty certification from the University of Utah. He received advanced training in hospital administration through Ernest Health's Leadership Training Program.

Dr. Jessop is active in the community, teaching continuing education courses on Parkinson's disease and locomotor training both locally and throughout Ernest Health. He currently serves as president of the Utah Chapter of the American Parkinson Disease Association and sits on various advisory boards.

## Davis Phinney

Davis Phinney was fresh off of a successful professional cycling career where he won an Olympic bronze medal in 1984, and was part of the first American team to race in the Tour de France when he was diagnosed with Parkinson's disease. He founded the Davis Phinney Foundation in 2004 with the pioneering vision of helping those living with Parkinson's to take action to improve their quality of life through education, inspiration, resources and effective self-care. Ten years later, thanks to the work of the Davis Phinney Foundation, hundreds of thousands of people with Parkinson's, their health care professionals, care partners and communities have dramatically changed the way they approach living with and treating individuals with Parkinson's.

Davis' perseverance, coupled with his infectious positive attitude and dedication, inspire the work of the Davis Phinney Foundation and have earned him the reputation as a tireless advocate and mentor for others living with Parkinson's. In spring of 2015, he was honored at the White House as a Champion of Change because of his work and pioneering vision to share education, inspiration and effective self-care strategies so that those living with Parkinson's can take action to improve their quality of life.

## Lauren Schrock, MD

Lauren E. Schrock is the Medical Director of the University of Utah Deep Brain Stimulation (DBS) Program and the Interim Chief of the Division of Movement Disorders and Sleep Medicine in the University of Utah Department of Neurology. She received her medical degree from the University of Iowa College of Medicine and completed her fellowship in Movement Disorders and DBS at the University of California – San Francisco.

Dr. Schrock is a highly experienced neurologist with DBS having managed upward of 800 DBS patients. She speaks nationally on DBS for the treatment of movement disorders and is a member of the Annual DBS Think Tank conference. She is an investigator on several ongoing clinical research studies involving novel DBS devices and computational modelling-assisted DBS programming platforms, and welcomes inquiries for people interested in learning more about participating in clinical research.

## **Denise Skuster, MD**

Denise Skuster is a Neurologist with Intermountain Healthcare Salt Lake Clinic. Dr. Skuster is a 1989 graduate of the University of Iowa College of Medicine and completed her neurology residency training at the University of Utah and is a Diplomate of the American Board of Psychiatry and Neurology. Her professional organizations include the American Academy of Neurology, American Headache Society and Movement Disorders Society.

Dr. Skuster has been practicing neurology at the Intermountain Salt Lake Clinic since 1993. Her special interests include providing care for people with headache disorders, Parkinson's disease and Multiple Sclerosis.

## **Richard Vinson, MSPT**

Richard Vinson is the owner and Director of Therapy and Marketing at Cornerstone Healthcare in Murray, UT. Mr. Vinson received a bachelor's degree in Sports Medicine at Brigham Young University and a master's degree in Physical Therapy at the University of Alabama at Birmingham. He has been a therapist for 30 years and worked in a variety of settings including hospital, skilled nursing, rehabilitation, outpatient and home health.

Mr. Vinson is also the owner and President of Hidden Cove Physical Therapy outpatient practice. He currently serves on the Fall Coalition of Utah with the Utah Health Department and is actively involved in the community with the prevention of falls through evidence based programs of "Stepping On" and "Otago." He is certified in LSVT BIG® in the treatment of Parkinson's disease. Mr. Vinson is a member of the American Physical Therapy Association and the geriatric and private practice sections.

## **Steve Welling**

Steve Welling holds a master's degree in Electrical and Computer Engineering from Brigham Young University. Steve was diagnosed at age 35 with young onset Parkinson's disease and has since received deep brain stimulation therapy. After 15 years of experience in the engineering field, he now works as a free-lance guitarist, composing, recording and performing various types of music projects. Steve claims to be pioneering a new genre called "Movement Disorder Rock." He often says, "Parkinson's disease is not the end of the song, but more like a change in key." To learn more about his music visit his website [www.inGig.com/MDRock](http://www.inGig.com/MDRock).



## PARKINSON'S GLOSSARY

A guide for the terms you may hear throughout the day and wonder "What is that?"

Brought to you by the  
**World Parkinson Coalition**

**Agonists:** A chemical or drug that can activate a neurotransmitter receptor. Dopamine agonists, such as pramipexole, ropinirole, bromocriptine and apomorphine, are used in the treatment of PD.

**Alpha-synuclein:** A protein normally present in nerve terminals (neurons). Present in high concentrations in Lewy bodies. A genetic mutation in this protein is the basis for a rare, inherited form of PD. Alpha-synuclein also accumulates in multiple system atrophy and in Lewy Body Disease. Alpha-synuclein appears to play a key role in the development of PD.

**Amygdala:** An almond-shaped nucleus located deep in the brain's medial temporal lobe in animals. It is involved in fear and anxiety responses, in particular in the formation of memories involving emotion.

**Ataxia:** Inability to coordinate voluntary muscle movements; unsteady movements and staggering gait.

**Autonomic Nervous System (ANS):** Part of the peripheral nervous system, consisting of sympathetic and parasympathetic nerves that control involuntary actions, in particular the heart, smooth muscle (such as bladder and blood vessels) and glands.

**Basal ganglia:** Clusters of neurons that include the caudate nucleus, putamen, globus pallidus and substantia nigra which are located deep in the brain and play an important role in movement. Cell death in the substantia nigra contributes to Parkinsonian signs.

**Biomarker:** An early indicator that a person may have a disease, such as Parkinson's. A biomarker, if present, could indicate that the person has a disease before symptoms of that disease appear. Biomarkers could be a chemical, clinical, physiologic or imaging finding.

**Bradykinesia:** Literally, means slowness of movement. It is commonly used synonymously with akinesia and hypokinesia. Bradykinesia is a clinical hallmark of Parkinsonism.

**Brain stem:** The part of the brain between the cerebral hemispheres and the spinal cord. The three parts of the brain stem are the medulla oblongata, pons, and midbrain. The brain stem is a vital structure that is a passageway between the brain and spinal cord, and it contains neurons involved in sleep and wakefulness. The substantia nigra, which is damaged in Parkinson's, is located in the midbrain of the brain stem.

**Carbidopa: (C-DOPA)** A drug given with levodopa. Carbidopa blocks the enzyme dopa decarboxylase, thereby preventing levodopa from being metabolized to dopamine. Because carbidopa does not penetrate the blood brain barrier, it only blocks levodopa metabolism in the peripheral tissues and not in the brain, thereby reducing side effects but increasing the effectiveness of levodopa.

**Cerebellum:** Part of the hind brain; controls smooth movements. When damaged, it results in ataxia.

**CNS:** abbreviation of Central Nervous System, which consists of the brain, brain stem and spinal cord.

**Clinical trials:** Research studies utilizing human volunteers. Observational trials do not test drugs or treatments, as researchers instead observe and monitor participants' health. Interventional trials test the safety and effectiveness of a treatment.

**Cognition:** Mental processes including attention, remembering, producing and understanding language, solving problems and making decisions.

**Deep Brain Stimulation (DBS):** A surgical treatment that involves the implantation of a medical device (electrical stimulator) that acts as a brain pacemaker sending electrical impulses to the specific area in which the electrode was inserted. In Parkinson's patients the device is typically inserted in either the subthalamic nucleus or the globus pallidus, less often in the thalamus or pedunculopontine nucleus, depending upon the specific problem.

**Dementia:** A decline in cognitive function due to damage or disease in the brain beyond what might be expected from normal aging. Areas particularly affected include memory, attention, judgment, language, planning and problem solving.

**Alzheimer's disease dementia:** The most common form of dementia, typically presents with difficulty in remembering names and events. May also initially include apathy and depression, and later impaired judgment, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking. Associated with abnormal deposits of the protein fragment beta-amyloid (plaques) and twisted strands of the protein tau (tangles) as well as brain nerve cell damage and death.

**Dementia with Lewy bodies (DLB):** Similar, but not identical, symptoms as in Alzheimer's dementia. DLB commonly has a greater occurrence of sleep disturbances, well-formed visual hallucinations, and muscle rigidity. Associated with aggregation of alpha-synuclein in the cerebral cortex. Lewy bodies are also a pathologic hallmark in Parkinson's disease. The relationship of DLB and PD remains to be resolved.

**Parkinson's dementia:** Presents similarly to Alzheimer's dementia or dementia with Lewy bodies, but is typically preceded by clinical Parkinson's disease. Associated with alpha-synuclein aggregates that are more likely begin in the brain stem, including the substantia nigra.

**Dopamine:** A small chemical molecule that is one of the brain's neurotransmitters. It is found particularly in cells within the substantia nigra. These cells project to the striatum in the basal ganglia. Deficiency of dopamine causes symptoms of Parkinsonism.

**Dopamine agonist:** A compound that activates dopamine receptors, other than dopamine. Examples include, bromocriptine mesylate (Parlodel), pergolide (Permax), pramipexole (Mirapex), ropinirole hydrochloride (Requip), piribedil, cabergoline, apomorphine (Apokyn), rotigotine (Neupro patch) and lisuride. These act like dopamine, but are not actually dopamine. They can be used in both the early and late stages of Parkinson's disease. They are the second most powerful type of anti-Parkinson medication after levodopa. They can cause side effects such as sleepiness, sleep attacks, ankle swelling, hallucinations and impulse control problems, more commonly than levodopa does.

**Dysarthria:** Impaired speech function.

**Dyskinesia:** Abnormal involuntary movements; hyperkinesia. A common side-effect of levodopa medication. (*See: Hyperkinesia*)

**Dystonia:** Abnormal involuntary movements, often associated with pain and cramping of the muscles.. A common effect associated with when PD medications start to wear off and dopamine levels dip below a specific level.

**Dysphagia:** Difficulty in swallowing.

**Essential Tremor:** Nervous system disorder causing rhythmic shaking. Occurs most often in the hands. Can be misdiagnosed as Parkinson's.

**Festination:** An involuntary quickening of the gait; the acceleration of gait noted in Parkinsonism and similar disorders, literally means "chasing the center of gravity".

**Freezing of gait:** A brief pause or marked reduction of forward progression of the feet despite the intention to walk.

**Gene therapy:** The insertion of genes into an individual's cells and tissues to treat hereditary diseases where deleterious mutant alleles can be replaced with functional ones. The genes are usually placed within a non-pathogenic virus, which serves as the vector to penetrate the cells. Gene therapy can also be used to correct non-genetic deficiencies such as the loss of dopamine in Parkinson's, to modify the function of a group of cells (e.g. convert an excitatory structure to one that is inhibitory) or to provide a source of growth factors.

**Genotype:** The collection of genetic material in an organism that gives rise to its characteristics.

**Handwriting:** (*See: Micrographia*)

**Hyperkinesia:** An abnormal increase in movement and/or muscle activity. Synonymous with dyskinesia. (*See: Dyskinesia*)

**Idiopathic:** Arising from an unknown cause.

**Levodopa (L-DOPA):** A chemical that is the precursor to dopamine. It can pass through the blood-brain barrier (whereas dopamine cannot). Once it has entered the central nervous system, L-dopa is converted into dopamine by aromatic L-amino acid decarboxylase (DOPA decarboxylase/DDC). L-DOPA is also converted into dopamine within the peripheral nervous system, but this is usually blocked by employing peripherally-active dopa decarboxylase inhibitors.

**Lewy bodies:** Abnormal clumps of protein that develop inside nerve cells. They are the pathological hallmark of Parkinson's, and found in everyone with the PD.

**Magnetic resonance imaging (MRI):** A noninvasive medical imaging technique to visualize detailed internal structure and limited function of the body. MRI provides much greater contrast between the different soft tissues of the body than computed tomography (CT), making it especially useful in neurological (brain), musculoskeletal, cardiovascular and oncological (cancer- related) imaging.

**Motor skills:** The degree of control or coordination provided by brain control of the skeletal muscles.

**Motor symptoms:** Symptoms that involve movement, coordination, physical tasks or mobility. These include, among others: resting tremor, bradykinesia, rigidity, postural instability, freezing, micrographia, mask-like expression, unwanted accelerations, stooped posture, dystonia, impaired motor dexterity and coordination, speech problems, difficulty swallowing, muscle cramping, and drooling of saliva. (*Related: Non-Motor Symptoms*)

**Micrographia:** The impairment of a fine motor skill, manifesting mainly as a progressive reduction in size of writing. Handwriting may decrease in size across a single line or as each line gets added with continued writing in a paragraph. A clinical feature commonly associated with PD.

**Multiple System Atrophy (MSA):** A less common degenerative neurological disorder that causes symptoms similar to Parkinson's disease but with more widespread damage to the central nervous system. Other systems involved besides the basal ganglia include the cerebellum and autonomic systems.

**Neuromodulator:** A chemical substance other than a neurotransmitter, released by a neuron at a synapse and either enhances or dampens their activities.

**Neuroprotection:** Mechanisms within the nervous system that would protect neurons from dying due to a degenerative disease or from other types of injury.

**Neurotransmitter:** A chemical messenger in the nervous system that permits communication between two neuronal cells, normally across a synapse. The neurotransmitter is released from the nerve terminals on the axons. Examples of neurotransmitters include dopamine, acetylcholine, adrenaline, noradrenaline, serotonin, glutamate, and GABA.



**Non-motor symptoms:** Symptoms that do not involve movement, coordination, physical tasks or mobility, including loss of sense of smell, constipation, sleep disorders or disturbances, mood disorders, orthostatic hypotension, bladder problems, sexual problems, excessive saliva, weight loss or gain, vision and dental problems, fatigue, depression, fear and anxiety, skin problems, and cognitive issues. (*Related: motor symptoms*)

**On and Off:** The clinical states of PD while being treated with levodopa, which commonly causes clinical fluctuations after a few years of treatment. The “on” state is when the PD symptoms and signs are reduced by levodopa. The “off” state is when the benefit has been reduced or lost. The most common type of “off” is wearing-off, due to the levodopa’s benefit not lasting more than 4 hours after a dose. Sudden and unpredictable “off” states can also occur, but are less common. “Off” states usually will respond to another dose of levodopa. Clinical fluctuations are considered a complication of levodopa therapy.

**Parkinson-plus syndromes:** A group of neurodegenerative diseases featuring the classical features of Parkinsonism (rigidity, akinesia/bradykinesia, postural instability and less commonly tremor) with additional features that distinguish them from typical Parkinson’s disease. Parkinson-plus syndromes include multiple system atrophy (MSA), progressive supranuclear palsy (PSP), and corticobasal degeneration (CBD).

**Parkinsonism:** A group of neurological diseases whose features include slowness and paucity of spontaneous movement (bradykinesia), rest tremors, rigidity of the muscles, loss of postural reflexes, flexed posture and freezing of gait.

**Parkinsonian gait:** With bradykinesia, gait is slow, short paced and with a tendency to shuffle, associated with decreased arm swing. Freezing of gait can also occur in Parkinsonism.

**Placebo:** A simulated or inert form of treatment without known proven benefit on a symptom or a disease. Placebos are employed in controlled clinical trials along with the active drug being tested. The difference in responses between the two drugs is considered the true effect of the active drug. Surgical trials can also utilize a placebo arm in which sham or simulated surgery is performed in the control group.

**REM (rapid eye movement) sleep behavior disorder (RBD):** A sleep disorder that involves movement and abnormal behavior during the sleep phase with rapid eye movements – the stage of sleep in which dreaming occurs. In normal sleep, muscles are paralyzed during dreaming, except for the eye movements. In RBD, muscles are not paralyzed so that the dreamer acts out his or her dreams. RBD is common in people with Parkinson’s disease or MSA.

**Restless leg syndrome (RLS):** A neurological disorder characterized by unpleasant sensations in the legs, like the feeling of ants crawling underneath the skin. These sensations usually occur in the late evening and during sleep. Walking around relieves the sensation, hence the term “restless legs.” RLS interferes with sleep and is common in people with PD. Medications, such as dopamine agonists, levodopa and opioids, can be effective treatments.

**Serotonin:** A neurotransmitter that regulates mood, appetite, and sleep. It also has some cognitive functions, including memory and learning. The serotonin-containing neurons are in the brain stem. Serotonin is reduced in PD.

**Sleep apnea:** A sleep disorder characterized by abnormal pauses in breathing or instances of abnormally low breathing during sleep.

**Shuffling gait:** Refers to short, slow steps, with feet close to the ground or dragging along the ground. This gait is often seen in people with advanced Parkinson's disease. (See: *Freezing of gait and Parkinsonian gait*)

**Synapse:** The narrow space between two neurons (axon to dendrite) or between a neuron and a muscle. Axons release neurotransmitters at the nerve terminal. The neurotransmitter crosses the synapse to activate or a receptor on the dendrite.

**YOPD:** The abbreviation for Young Onset Parkinson's Disease, which is defined as a diagnosis under the age of 50.



**Register Now!**  
**September 20-23, 2016**

**Learn more about the 4<sup>th</sup> World Parkinson Congress at [www.WPC2016.org](http://www.WPC2016.org)**

## THE VICTORY SUMMIT EXHIBITORS

Visit the Exhibit Hall outside of the General Session ballroom from 8:30am until 2:30pm to explore both local and national Parkinson's resources.

**AbbVie**

North Chicago, IL  
[www.AbbVie.com](http://www.AbbVie.com)

**AbbVie Patient Advocate**

[www.PDAdvocates.com](http://www.PDAdvocates.com)

**Acorda**

Ardsley, NY  
[www.Acorda.com](http://www.Acorda.com)

**Age Performance**

Salt Lake City, UT  
[www.AgePerfromance.com](http://www.AgePerfromance.com)

**Cornerstone Home  
Health & Hospice**

Midvale, UT  
[www.CornerHH.com](http://www.CornerHH.com)

**Davis Phinney Foundation**

Boulder, CO  
[www.DavisPhinneyFoundation.org](http://www.DavisPhinneyFoundation.org)

**GE Healthcare Life Sciences  
Core Imaging**

Marlborough, MA  
[www.GEHealthcare.com](http://www.GEHealthcare.com)

**IASIS Healthcare Neuroscience &  
Rehabilitation Specialists**

Salt Lake City, UT  
[www.NeuroscienceRehab.com](http://www.NeuroscienceRehab.com)

**Intermountain Neurosciences  
Institute at Intermountain Medical**

Murray, UT  
[www.IntermountainMedCenter.org/Neurosciences](http://www.IntermountainMedCenter.org/Neurosciences)

**LSVT Global, Inc.**

Tucson, AZ  
[www.LSVTGlobal.com](http://www.LSVTGlobal.com)

**Lundbeck**

Deerfield, IL  
[www.Lundbeck.com/US](http://www.Lundbeck.com/US)

**Medtronic**

Minneapolis, MN  
[www.MedtronicDBS.com](http://www.MedtronicDBS.com)

**Northern Utah Rehabilitation  
Hospital**

South Ogden, UT  
[www.ErnestHealth.com](http://www.ErnestHealth.com)

**Salt Lake Regional Medical Center**

Salt Lake City, UT  
[www.SaltLakeRegional.com](http://www.SaltLakeRegional.com)





## THE VICTORY SUMMIT EXHIBITORS CONTINUED

Visit the Exhibit Hall outside of the General Session ballroom from 8:30am until 2:30pm to explore both local and national Parkinson's resources!

**University Health Care-  
Department of Neurology**  
Salt Lake City, UT  
[www.Medicine.Utah.edu/Neurology](http://www.Medicine.Utah.edu/Neurology)

**US WorldMeds**  
Louisville, KY  
[www.USWorldMeds.com](http://www.USWorldMeds.com)

**Teva Neuroscience**  
Marion, IA  
[www.TevaUSA.com](http://www.TevaUSA.com)

**FURTHER,  
TOGETHER**

At Medtronic, we're changing what it means to live with chronic disease. We're creating innovative therapies that help patients get back to enjoying some of the things in life they thought they had lost forever. Seeing our work improve lives is a powerful motivator. The more we do, the more we're driven to push the boundaries of medical technology.

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## THE VICTORY SUMMIT CORPORATE FUNDERS

Today's Victory Summit is made possible by our National Corporate Funders, through whose investments into the Davis Phinney Foundation programs allow attendees to participate free of charge.

### **AbbVie**

AbbVie is a global, research-based biopharmaceutical company focusing on supporting the patient journey through the continuum of care to improve health outcomes. By listening and responding to patients' needs, AbbVie develops better products to help people improve their lives. [www.AbbVie.com](http://www.AbbVie.com)



### **Acadia Pharmaceuticals**

ACADIA Pharmaceuticals Inc. is a biopharmaceutical company focused on the development and commercialization of innovative medicines to address unmet medical needs in neurological and related central nervous system disorders. [www.Acadia-Pharm.com](http://www.Acadia-Pharm.com)



### **Acorda**

Acorda is focused on developing therapies that restore function and improve the lives of people with neurological disorders, including novel treatments addressing multiple sclerosis, Parkinson's disease, post-stroke walking deficits, epilepsy and migraine. [www.Acorda.com](http://www.Acorda.com)



### **Cynapsus**

Cynapsus is a specialty central nervous system pharmaceutical company developing and preparing to commercialize a Phase 3, fast-acting, easy-to-use, sublingual thin film for the on-demand turning ON of debilitating OFF episodes associated with Parkinson's disease. [www.Cynapsus.ca](http://www.Cynapsus.ca)



### **GE Healthcare Life Science and Imaging**

GE Healthcare provides transformational medical technologies and services to meet the demand for increased access, enhanced quality and more affordable healthcare around the world. From medical imaging, software & IT, patient monitoring and diagnostics to drug discovery, biopharmaceutical manufacturing technologies and performance improvement solutions, GE Healthcare helps medical professionals deliver great healthcare to their patients. [www.GEHealthcare.com](http://www.GEHealthcare.com)



### LSVT Global

LSVT Global trains speech, physical and occupational therapists in the evidence-based treatments, LSVT LOUD and LSVT BIG to improve communication, mobility, and function in people with Parkinson disease. LSVT Global has trained over 20,000 clinicians from 69 countries and offers free webinars, symposiums and exercise support tools to patients globally.

[www.LSVTGlobal.com](http://www.LSVTGlobal.com)



### Lundbeck

Lundbeck is a pharmaceutical company focused entirely on brain disorders, including PD, which is a core area of Lundbeck's research efforts. Its employees annually participate in hundreds of PD-related events, and proudly support the Davis Phinney Foundation.

[www.Lundbeck.com/US](http://www.Lundbeck.com/US)



### Medtronic

At Medtronic, we're changing what it means to live with chronic disease. We're creating innovative therapies that help patients get back to enjoying some of the things in life they thought they had lost forever. To learn more, visit

[www.MedtronicDBS.com](http://www.MedtronicDBS.com)



**Medtronic**

### Teva Neurosciences

Teva is working every day to make quality healthcare accessible. As a manufacturer of specialty and generic pharmaceuticals, Teva provides both new and innovative therapies and greater access to affordable medicines.

[www.TevaUSA.com](http://www.TevaUSA.com)



### US WorldMeds

At US WorldMeds, we hold a fundamental belief that our science has the potential to improve the lives of Parkinson's patients. Our pipeline of development projects, along with our currently available PD treatment, reflects our resolve to bring innovative solutions to Parkinson's patients.

[www.USWorldMeds.com](http://www.USWorldMeds.com)



## THE VICTORY SUMMIT PARTNERS & SUPPORTERS

Thank you to our local Event Partners and Community Supporters, who provided insight into the local community, initiated connections and cultivated a collaborative environment where The Victory Summit could thrive. Partners and Supporters worked together to help make this regional event a robust, information-filled day!

### EVENT PARTNERS

#### Cornerstone Healthcare

Cornerstone Home Health & Hospice is a privately-owned and operated provider of health care services with an expert staff ready to take on the role as guardians of your health. We established our company to address the diverse health care needs of our clients all over Midvale and the surrounding communities in our Utah service areas.

[www.CornerHH.com](http://www.CornerHH.com)



#### Intermountain Neurosciences Institute

The Intermountain Neurosciences Institute at Intermountain Medical Center offers comprehensive care for conditions related to the brain, spine, and nervous system. Our team-based approach includes experts from many disciplines working together to provide the most appropriate care and treatment for each patient.

[www.IntermountainMedCenter.org/Neurosciences](http://www.IntermountainMedCenter.org/Neurosciences)



#### Northern Utah Rehabilitation Hospital

At Northern Utah Rehabilitation Hospital, we provide specialized inpatient and outpatient rehabilitative services to our patients, serving South Ogden and surrounding areas. We see patients who often are recovering from disabilities caused by injuries, illnesses, or chronic medical conditions.

[www.NURH.Ernesthealth.com](http://www.NURH.Ernesthealth.com)



### **Salt Lake Regional Medical Center**

For more than a century, Salt Lake Regional Medical Center has provided high quality healthcare for residents of the Salt Lake Valley. Conveniently located near the heart of the city, this historic acute care hospital remains one of the most trusted medical centers in all of Utah. Today you will find advanced medical staff focused on providing patients with leading-edge care and comfort.

**[www.SaltLakeRegional.com](http://www.SaltLakeRegional.com)**

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**MEDICAL CENTER**

In Partnership With Physician Owners

### **University Health Care- Department of Neurology**

The Department of Neurology at the University of Utah is committed to the conquest of neurological disease through specialized patient care, innovative research and the education of tomorrow's physicians. Our department provides comprehensive primary and tertiary neurologic care, as well as both inpatient and outpatient neurologic consultation.

**[www.Medicine.Utah.edu/Neurology](http://www.Medicine.Utah.edu/Neurology)**



**University Health Care**

Department of Neurology

## **COMMUNITY SUPPORTERS**

### **Age Performance**

Age Performance clients receive a customized program designed to meet their specific needs. Physical activity programs that address special needs for those individuals with chronic disease including stroke, arthritis, cancer, depression, Parkinson's disease, osteoporosis, diabetes, and dementia are also available.

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### **IASIS Healthcare-**

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## LOCAL PARKINSON'S RESOURCES

Below is a collection of resources specific to the Parkinson's community in Salt Lake City and the surrounding areas, including support groups, exercise programs and wellness classes. Resources are categorized by type.

### Support Groups

#### **Brigham City**

4<sup>th</sup> Friday of each month, 4pm  
Brigham City Hospital Cafeteria  
950 South 500 West  
Brigham City, UT 84302  
Contact: Rebecca Starks  
(801) 585-2354  
[Rebecca.starks@hsc.utah.edu](mailto:Rebecca.starks@hsc.utah.edu)

#### **The Betty Rutledge Cache Valley Parkinson Support Group**

2<sup>nd</sup> Monday of each month, 10am  
Logan Steak House  
2427 N Main St  
Logan, UT 84341  
Contact: Carol Stinner  
(435) 752-2658  
[cams631@yahoo.com](mailto:cams631@yahoo.com)

#### **Davis County**

1<sup>st</sup> Wednesday of each month, 6pm  
North Davis Senior Activity Center  
42 S State St  
Clearfield, UT 84015  
Contact: Dale George  
(801) 451-6238  
[dalegeorge6268@msn.com](mailto:dalegeorge6268@msn.com)

#### **Heber City**

1<sup>st</sup> Monday of each month, 1pm  
Heber City Senior Center  
465 East 1200 South  
Heber City, UT 84032  
Contact: Penelope Peterson  
(435) 657-0114

#### **PSP/MSA/CBD -Information Night**

Meets Quarterly in May, August,  
November, and February  
2nd Monday, 6 pm  
Imaging & Neurosciences Center  
729 Arapeen Dr  
Salt Lake City, UT 84108  
Contact: Rebecca Starks  
(801) 585-2352  
[Rebecca.starks@hsc.utah.edu](mailto:Rebecca.starks@hsc.utah.edu)

#### **Salt Lake City**

3<sup>rd</sup> Thursday of each month, 6pm  
Imaging & Neurosciences Center  
729 Arapeen Dr  
Salt Lake City, UT 84108  
Contact: Claudine Saxton  
(801) 292-2188  
[claudine\\_saxton@hotmail.com](mailto:claudine_saxton@hotmail.com)

#### **Sandy**

2<sup>nd</sup> Thursday of each month, 2pm  
Sandy Senior Center  
9310 South 1300 East  
Sandy, UT 84094  
Contact: Mike Ogden  
[mike.ogden@valeohh.com](mailto:mike.ogden@valeohh.com)

#### **St. George**

3<sup>rd</sup> Wednesday of each month, 10am  
St. George Senior Center  
245 North 200 West St  
St. George, UT 84770  
Contact: Pat Sapio  
(435) 688-4123  
[patrick.sapio@intermountainmail.org](mailto:patrick.sapio@intermountainmail.org)

### **Tooele**

3<sup>rd</sup> Friday of each month, 1pm  
Tooele Applied Technology College  
(TATC)  
88 South Tooele Blvd  
Tooele, UT 84074  
Contact: Barbara Royal  
(801) 656-9673  
[barbcroyal55@hotmail.com](mailto:barbcroyal55@hotmail.com)

### **Utah County**

3<sup>rd</sup> Thursday of each month, 6 pm  
Utah Valley Specialty Hospital  
306 West Riverbend Ln  
Orem, UT 84604  
Contact: Randy and Liz Covington  
(801) 225-9099  
[bettycoed@gmail.com](mailto:bettycoed@gmail.com)

### **West Jordan**

4<sup>th</sup> Thursday of each month, 6pm  
Copper Ridge Health Care  
3706 West 9000 South  
West Jordan, UT 84088  
Contact: Diane Hagen  
(801) 232-9242  
[dhagen@ensigngroup.net](mailto:dhagen@ensigngroup.net)

### **Young Onset**

2<sup>nd</sup> Thursday of each month, 7pm  
Ameritech College Building  
12257 South Business Park Dr  
Suite 200  
Draper, UT 84020  
Contact: Vicki Rathunde  
(801) 913-6156  
[vicrath@icloud.com](mailto:vicrath@icloud.com)

## **Care Partner Support Groups**

### **PD Caregivers – Bountiful**

1<sup>st</sup> Wednesday at 2pm  
460 West 2600 South  
Bountiful, UT 84010  
Contact: Brock VanZweden  
(801) 336-7228

### **PD Caregivers – Salt Lake City**

2<sup>nd</sup> Monday at 2pm  
Imaging and Neurosciences  
729 Arapeen Drive  
Salt Lake City, UT 84108

Contact: Janette Reber, RN, BSN  
(801) 505-5349

### **PD Caregivers – Salt Lake City**

3<sup>rd</sup> Thursday at 2:30pm  
Moreau Auditorium  
1002 East South Temple  
Salt Lake City, UT 84102  
Contact: Rebecca Starks  
(801) 585-2354  
[Rebecca.starks@hsc.utah.edu](mailto:Rebecca.starks@hsc.utah.edu)



## Exercise and Wellness Classes

### **Parkinson's Wellness (Exercise)**

#### **Program Salt Lake City**

University of Utah College of Health  
Tuesday and Thursdays

10am – 3pm

The University Rehabilitation  
and Wellness Clinic

520 Wakara Way

Salt Lake City, UT 84109

Contact: (801) 226-8880

### **Parkinson's Boxing Class**

University of Utah College of Health  
Thursdays 2pm

The University Rehabilitation  
and Wellness Clinic

520 Wakara Way

Salt Lake City, UT 84109

Contact: Amy Powell-Versteeg  
(801) 585-7341

### **Parkinson's Wellness (Exercise)**

#### **Program Provo**

Monday, Wednesday, Friday

8:30am-9:30am and 11:30am-12:30pm

Utah Valley Specialty Hospital

306 West River Bend Ln

Provo, UT 94604

Contact: Matt Harmer  
(801) 226-8880

### **Yoga for Parkinson's**

Tuesday 7:30-8:30am, Friday 4-5pm

Utah Valley Specialty Hospital

306 West River Bend Ln

Provo, UT 94604

Contact: Matt Harmer  
(801) 226-8880

### **Parkinson's Wellness (Exercise)**

#### **Program Ogden**

Stewart Rehabilitation at McKay- Dee  
Hospital

Wednesday and Friday

Contact: (801) 387-2080 to register.

\$50 for two months of assisted exercise,  
physician referral required, physical  
therapy evaluation required prior to  
participation.

### **Tai Chi for Parkinson's**

(every 8 weeks)

Holladay Healthcare Center

4782 Holladay Blvd

Salt Lake City, Utah 84117

Contact: (801) 277-7002

### **Dance for PD®- Salt Lake City**

Tuesdays, 9am – 10am

Beverly Taylor Sorenson Arts and  
Education Building

AWFK Auditorium first floor

1721 Campus Center Dr

Salt Lake City, UT 84112

Parking available adjacent to the building.

Contact: Juan Carlos Claudio  
(801) 581-3223

[j.c.claudio@utah.edu](mailto:j.c.claudio@utah.edu)

### **Parkinson's Performance**

Tuesdays and Thursdays, 11am

Age Performance

1291 South 1100 East, Suite 202

Salt Lake City, UT 84105

\$160 for 8 classes

Contact: Paul Holbrook  
(801) 467-6554

## Local Clinical Trials

### Enroll-HD

This is an observational, open-ended, prospective, multi-national, multi-center study without experimental treatment. Any member of an HD family, including spouses, can participate. Individuals cannot learn genetic status through this study.

Contact: Matthew Halverson  
(801) 587-8581  
[matthew.halverson@hsc.utah.edu](mailto:matthew.halverson@hsc.utah.edu)

### Tissue Repository of Neurodegenerative Diseases

This study is designed to obtain DNA (one-time blood draw) and family pedigree (optional) from all patients and family members to be used for future research on neurodegenerative disorders including Parkinson's disease, atypical parkinsonism, dementia, ataxia, chorea, essential tremor, ALS and others. For more information about Ataxia research publications, please visit

<http://pulstlab.genetics.utah.edu/>

Contact: Linh Huynh  
(801) 581-4847 (lab), (801) 339-9212 (pager)  
[lhuyh@genetics.utah.edu](mailto:lhuyh@genetics.utah.edu)

### Implantable Neurostimulator for the Treatment of Parkinson's Disease

This study is designed to evaluate the safety and effectiveness of new implantable deep brain stimulation (DBS) system for bilateral stimulation of the subthalamic nucleus in adults with advanced, levodopa responsive, bilateral. Parkinson's disease not adequately controlled with medication.

Contact: Meagan Joy Johnson  
(801) 581-7978  
[meagan.joy.johnson@hsc.utah.edu](mailto:meagan.joy.johnson@hsc.utah.edu)

### Coming Soon:

### Tolerability, Safety and Activity of SRX246 in Irritable subjects with HD

This study is designed to assess the tolerability and safety of SRX246 in irritable Subjects with early symptomatic HD over a period of 12 weeks compared to placebo.

Contact: Paola Wall  
(801) 581-4543  
[paola.wall@hsc.utah.edu](mailto:paola.wall@hsc.utah.edu)

### SURE-PD3

A randomized, double-blind, placebo-controlled trial of urate-elevating inosine treatment to slow clinical decline in early Parkinson's disease. This study is designed to determine whether oral inosine dosed to moderately elevate serum urate over 2 years slows clinical decline in early PD, and to determine safety and tolerability of urate elevating inosine treatment.

Contact: Matthew Halverson  
(801) 587-8581  
[matthew.halverson@hsc.utah.edu](mailto:matthew.halverson@hsc.utah.edu)

## Idaho Resources

### **Boise- Plantation Place Assisted Living**

3<sup>rd</sup> Wednesday of each month, 2pm  
3921 W Kessinger Ln  
Boise, ID 83703  
Contact: Betty Boone  
(208) 336-7137  
Mary Jo Campbell  
(208) 286-9901  
[maryjoinidaho@hotmail.com](mailto:maryjoinidaho@hotmail.com)

### **Meridian- Title One Title & Escrow**

2<sup>nd</sup> Saturday of each month, 12:45pm  
Eldorado Business Center  
1940 S Bonito Way #109  
Meridian, ID 83642  
Contact: Holly Marsh  
(208) 891-7977  
[hjmarsh@gmail.com](mailto:hjmarsh@gmail.com)  
Contact: Lisa Bain  
(208) 880-3608  
[parkinsonsadvocate@gmail.com](mailto:parkinsonsadvocate@gmail.com)

### **Pocatello Support Group**

1<sup>st</sup> Wednesday of the month, 10am  
Marshall Public Library  
113 S. Garfield Ave  
Pocatello, ID 83204  
Contact: Joyce Muhlestein  
[joymuhl@msn.com](mailto:joymuhl@msn.com)

### **Twin Falls Exercise Class**

Tuesdays & Thursdays, 12:30pm - 1:30pm  
St. Lukes Elk Rehab Center  
775 Pole Line Road W  
Twin Falls, ID  
Contact: Kristina Mills  
(253) 845-7566

### **Meridian- Meadow Lake Village Retirement Community**

1<sup>st</sup> Tuesday of each month, 2pm  
4037 E Clocktower Ln  
Meridian, ID 83642  
Contact: Becky Dallum  
(208) 888-2277  
[bmd@touchmark.com](mailto:bmd@touchmark.com)

### **Nampa- Clearwater House**

2<sup>nd</sup> Thursday of each month, 3pm  
715 W Comstock Ave  
Nampa, ID 83651  
Contact: Terry Savino  
(208) 407-2544  
[terrysavino@multicareinc.com](mailto:terrysavino@multicareinc.com)

Presentation PowerPoints given at The Victory Summit in Salt Lake City will be available on the Davis Phinney Foundation event webpage at:  
<http://www.davisphinneyfoundation.org/VS-SLC>

## ADDITIONAL PARKINSON'S RESOURCES

### **Catrike**

Designs, makes and markets a recumbent trike for the United States.

[www.Catrike.com](http://www.Catrike.com)

### **Lift Labs**

LiftWare cancels tremor to bring back the joy in mealtime. Stabilize your hand tremor with this special tremor-cancelling device. Other adaptive utilities include Lift Stride and Life Pulse. [www.LiftLabsDesign.com](http://www.LiftLabsDesign.com)

### **MagnaReady**

Magnetically infused shirts make getting dressed quick and painless. Specifically manufactured for people with Parkinson's and other disabilities. [www.MagnaReady.com](http://www.MagnaReady.com)

### **Melvin Weinstein Parkinson's Foundation**

Purchases equipment and supplies necessary for people living with Parkinson's to sustain a safe and healthy environment and preserve their self-esteem and dignity. Currently responding to funding requests. [www.MWPF.org](http://www.MWPF.org)

### **The Michael J. Fox Foundation**

Dedicated to finding a cure for Parkinson's disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today. [www.MichaelJFox.org](http://www.MichaelJFox.org)

### **Muhammad Ali Parkinson Center**

Located in Phoenix, this is one of the most comprehensive Parkinson treatment centers in the world. Coordinating patient care, physical therapy, speech therapy, occupational therapy, pharmaceutical and surgical care, research, and patient education and outreach. [www.BarrowNeuro.org](http://www.BarrowNeuro.org)

### **National Parkinson Foundation's Recursos en Español**

Varios recursos en español

[www.Parkinson.org/Espanol](http://www.Parkinson.org/Espanol)

(800) 473-4636

### **Parkinson's Action Network**

The unified voice of the Parkinson's community advocating for better treatments and a cure. Educates the public and government leaders on better policies for research and an improved quality of life for people with Parkinson's. [www.ParkinsonsAction.org](http://www.ParkinsonsAction.org)

### **Parkinson Disease Foundation**

National Parkinson's organization that funds scientific research to find the causes of and a cure for Parkinson's. Also offers educational programs and support services for people with Parkinson's and their loved ones. [www.PDF.org](http://www.PDF.org)

### **Parkinson's Voice Initiative**

Aims to record 10,000 voices across the world, collecting enough recordings to address the need for a test for Parkinson's disease. Voices of people with and without Parkinson's are needed. [www.ParkinsonsVoice.org](http://www.ParkinsonsVoice.org)

### **Pill Pack**

A full service pharmacy that delivers pre-sorted and labeled medications to your door every two weeks. [www.pillpack.com](http://www.pillpack.com)

### **PWR! Parkinson Wellness Recovery**

PWR! teaches health professionals the latest research-based exercise techniques to target the specific motor and non-motor symptoms of PD. It is about early intervention, enrichment, education and empowerment of those living with Parkinson disease with exercise as a first line of defense. [www.PWR4Life.org](http://www.PWR4Life.org)

### **Social Security Disability Help**

SSDI and SSI are the two largest federal assistance programs that offer financial support to people with disabilities. Learn about benefits, applications and assistance online. [www.SSA.gov](http://www.SSA.gov)

### **SpeechVive**

Detects when the person with Parkinson's is speaking (using an accelerometer built into the earpiece), wherein the device plays a background sound into the user's ear. The background sound is a natural clue that elicits louder and clearer speech through an involuntary reflex. [www.SpeechVive.com](http://www.SpeechVive.com)

### **Stravida Velcro Belts**

Enable users of any ages, capabilities and symptoms to independently and fashionably dress themselves, thanks to the Velcro fastener. Belts look like traditional belts – no one can tell you are wearing a Stravida belt but you! [www.Stravida.com](http://www.Stravida.com)



**Lundbeck** 

Lundbeck is a pharmaceutical company committed to improving the lives of people living with brain disorders, including Parkinson's disease.

We're actively engaged at 100+ Parkinson's events each year, and are deeply invested in Parkinson's research.

**Stop by the Lundbeck table to learn more about us, or visit [www.LundbeckUS.com](http://www.LundbeckUS.com).**

UBR-D-00317



## THIS IS PARKINSON'S



"This is Parkinson's" is a photography exhibit by Norwegian photographer and person with Parkinson's, Anders M. Leines. The exhibit displays images of people with early-onset Parkinson's disease and strives to challenge the stereotypical image of Parkinson's. The exhibit shares stories and images of people with Parkinson's and works to inspire through real stories from real people with Parkinson's in their daily lives.

**Be sure to check out "This Is Parkinson's" throughout the hallways today!**



*Teva  
for your  
whole life*

**T**eva is working every day to make quality healthcare accessible.

As a manufacturer of specialty and generic pharmaceuticals, Teva provides both new and innovative therapies and greater access to affordable medicines.

For more information, please visit [tevausa.com](http://tevausa.com).

**TEVA**

## NOTES

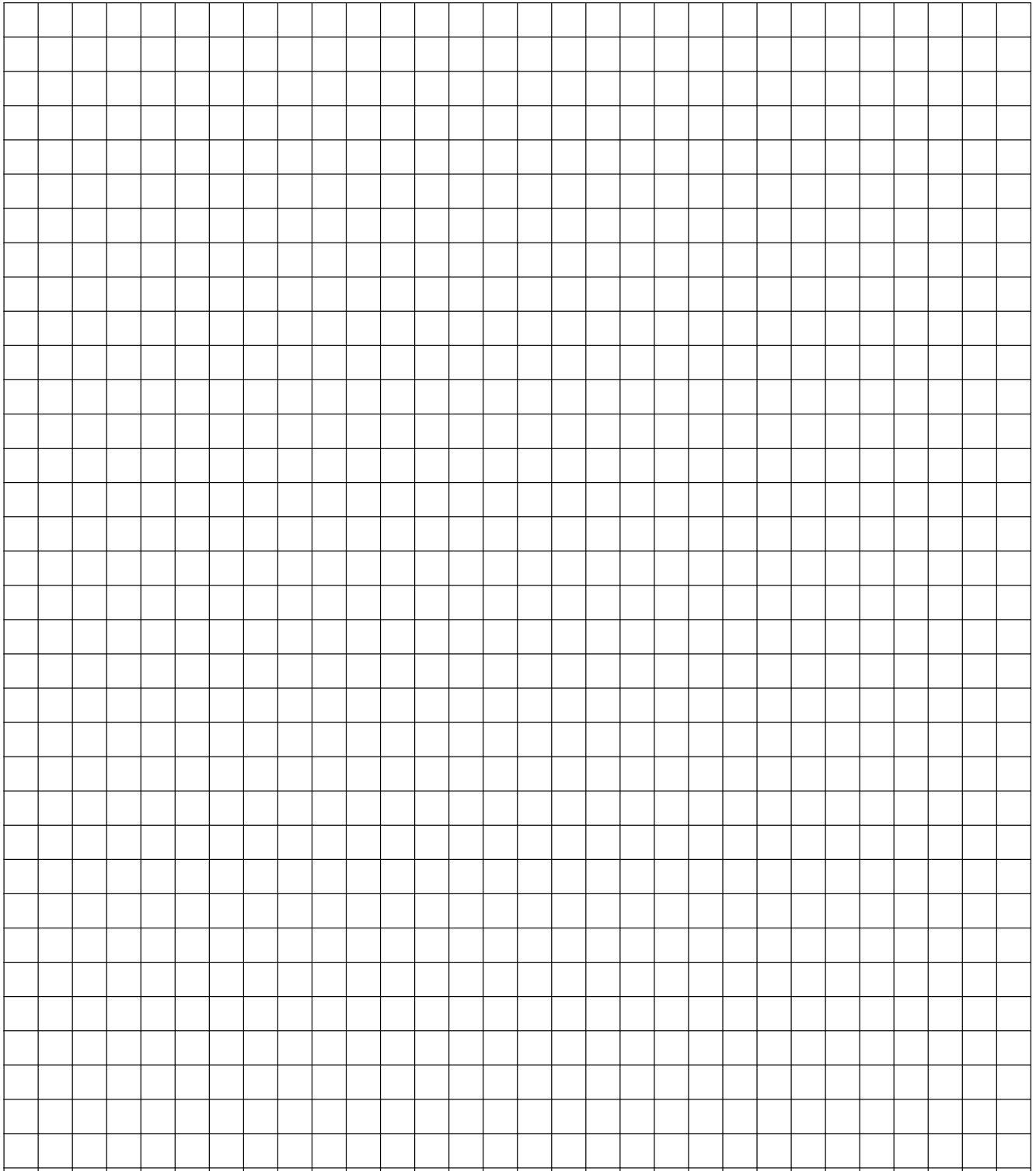
Some people with Parkinson's indicate that **using graph paper helps with micrographia** (small handwriting). Try it out here and see if it helps you, too!

This image shows a full page of blank graph paper. The grid consists of small, equal-sized squares formed by thin black lines. There are no margins, text, or other markings on the page.



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## Who is **THE DAVIS PHINNEY FOUNDATION**?

The Davis Phinney Foundation is a US-based, international non-governmental organization whose mission is to help people living with Parkinson's to live well today. While it's critical to find a cure, we feel strongly that people living with Parkinson's need information, inspiration and tools that motivate them to take action to improve their quality of life right now.

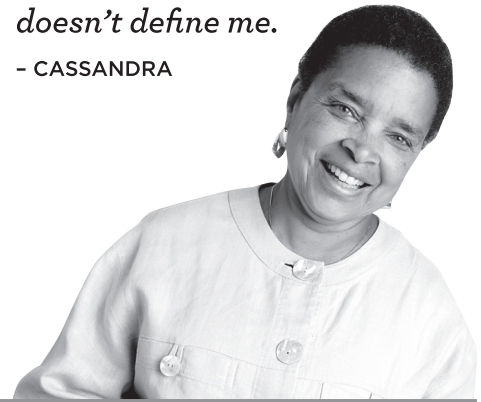
We fund innovative, early-stage research to discover therapies and enable people with Parkinson's to thrive. We build communities and connections across the country and around the world. We call on our Tribe to fight hard, to live fully and to make every victory count.

We believe in the power of positive change, grounded in science. When people with Parkinson's make living well a priority, they undergo a transformation.

Inertia gives way to determination. I can't becomes I can.  
Hope becomes real.

*I would stuff my hands in  
my pockets to hide it.  
But there's nothing  
to hide. This disease  
doesn't define me.*

- CASSANDRA



## Information, Inspiration & Tools for **LIVING WELL TODAY**

### **EVERY VICTORY COUNTS®** Self-Care Manual

Each person's journey with Parkinson's is unique. Not everyone will experience the same symptoms in the same way. With so many variables, the key to living well with Parkinson's is a strong foundation of knowledge that paves the way for self-advocacy, self-efficacy and promotes a treatment plan that reflects the needs of the individual. The *Every Victory Counts®* manual, available in soft cover or e-reader format, provides a comprehensive road map for personalized care and coping strategies. More than 20 worksheets and self-assessments enable readers to pinpoint needs and take appropriate action.

### **LIVING WELL CHALLENGE™** Educational Webinar

Everyone living with Parkinson's should have access to timely information to help them make informed choices about their own care. The Living Well Challenge™ webinar transcends geography and other barriers to bring presentations by nationally and internationally recognized clinicians and researchers to people living with Parkinson's, on demand, wherever they may be. New videos are added bi-monthly and are available on the Davis Phinney Foundation website, Vimeo and YouTube channels.

### **PARKINSON'S EXERCISE ESSENTIALS**

Developed by the Davis Phinney Foundation, this first-of-its kind video provides a range of workouts that can be modified for any level of fitness, from beginner to advanced, and can be performed at home, in a fitness center or out in the community. More than an "exercise along" video, this program goes significantly further in providing a prescription for customizing and safely progressing exercise activities over a period of years in order to stay motivated and derive the greatest benefit and enjoyment from workouts. Available on DVD or as an HD download.

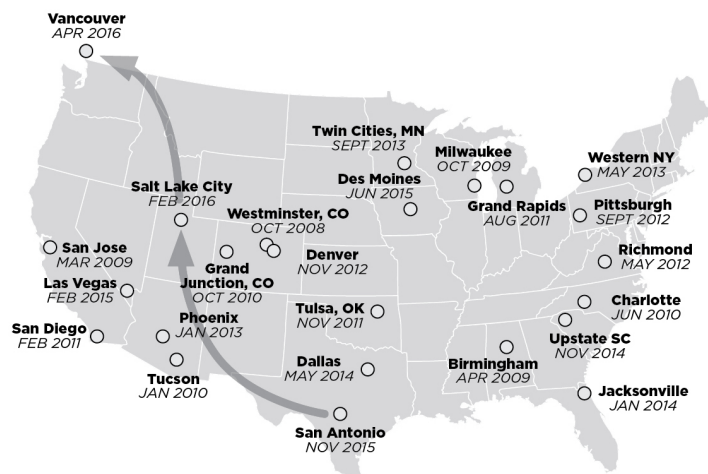
Visit [www.davisphinneyfoundation.org](http://www.davisphinneyfoundation.org) to learn more about these resources.

## Who is THE DAVIS PHINNEY FOUNDATION?

### How Have You Been INSPIRED TODAY?

We hope that the day you're spending with us at *The Victory Summit* event today is a day you won't soon forget. We challenge you to turn this one great day into something lasting. Use today's inspiration to create momentum, to regain momentum. Rather than let the day become a memory, why not ask yourself: "What is my take away? What did I hear that struck a chord, that made me want to do things differently?"

Maybe there was a piece of advice you heard, a coping strategy you learned about or an activity you tried that especially resonated with you or your loved one. Whatever it was, we hope that you walk out of *The Victory Summit* event feeling connected to others living with Parkinson's, motivated and armed with the information and resources you need to create your personal action plan for living well today and every day.



### PAY IT FORWARD to Vancouver

Attendees at *The Victory Summit* in San Antonio this past November paid it forward to help bring *The Victory Summit* to you! Thanks in part to their donations, you experienced this day of education and inspiration at no cost!

Without them, today's event could not be successful. And, without you, we can't make uplifting, innovative events like this one possible in the future. Help us bring *The Victory Summit* symposium to Vancouver on April 30, 2016 so that more people with Parkinson's can share in the experience you are having today.

100% of your Pay it Forward donation will help the Davis Phinney Foundation reach more people who are living with Parkinson's.

Please complete your Pay it Forward card today, so that hundreds in Vancouver can raise their arms in victory at the end of the day, inspired to take action to live their best life today.

## GENERAL SESSION ACTION STEPS

These are the action steps identified by the General Session speakers as ways  
YOU can take control of living well today.

### Exercising for the Rest of My Life

- Develop a NEW culture/habit
- You may have the “YETS,” but all the more reason to exercise
- Find a qualified TEAM of health care professionals
- Put exercise to MUSIC, use technology
- Have FUN

### Not Just the Shakes: Cognition & Non-motor Symptoms

- Commit to exercise – go for a walk, find a class, join a gym, get a treadmill
- Keep an updated medication list in your wallet or purse
- Connect with your Parkinson's community
- Recognize at least one non-motor symptom to discuss with your doctor

### 10 Commandments of Living Well

- |  |  |
|--|--|
| <ul style="list-style-type: none"> <li>➤ Thou shalt not take doctors too seriously</li> <li>➤ Thou shalt pace thyself</li> <li>➤ Thou shalt not fall</li> <li>➤ Thou shalt speak in a loud voice</li> <li>➤ Thou shalt drink water religiously</li> <li>➤ Thou shalt not drive if friends are terrified to drive with you</li> </ul> | <ul style="list-style-type: none"> <li>➤ Thou shalt sleep by night and nap by day</li> <li>➤ Thou shalt check in with your mood</li> <li>➤ Thou shalt love thy family as thyself</li> <li>➤ Thou shalt cultivate a good sense of humor</li> <li>➤ Thou shalt hope without ceasing</li> <li>➤ Thou shalt adapt to a new normal</li> </ul> |
|--|--|

### Celebrating Moments of Victory

- Strengthen ties to your community
- Find your inner strength; pledge to make tomorrow better than today
- Commit to some form of exercise; a little is better than none
- Look for examples of people who can serve as role models: let their successes provide you with hope and optimism
- Tap into local resources to help you reach your goals



## THANK YOU TO OUR EVENT PARTNERS.



## THANK YOU TO OUR COMMUNITY SUPPORTERS.



THANK YOU TO OUR CORPORATE FUNDERS.

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