# Fourth Annual

# Onondaga County Conference

# Living An Active Life with Parkinson's Disease

## Thursday, October 13, 2016

**Drumlins Country Club**

**800 Nottingham Road**

**Syracuse, New York 13224**

This **Education Guide** is Provided Through the Generosity of Lamacchia Honda

HONDA Lamacchia Honda Since 1934

## Onondaga County Office for Aging

# Finding Your Way With Parkinson's Disease

**Approximately 60,000 people are diagnosed with Parkinson's Disease every year. As with any diagnosis, understanding your disease is key to successfully maintaining the meaningful activities of your daily life.**

**Join other patients and families, dealing with Parkinson's Disease, for informational presentations at one of two locations:**

**Where:** The Hearth at Greenpoint

150 Old Liverpool Road, Liverpool

**When:** First Monday of each month, 12:30 - 2:00 pm

~ Or ~

**Where:** Brookdale Summerfield

100 Summerfield Village Lane, Onondaga Hill, off Velasko Rd.

**When:** Second Tuesday of each month, 4:00 - 5:30 pm

**For information or to sign-up, call Cynthia at:**
**(315) 435-2362 ext.4993, or email at cstevenson@ongov.net**

## Marlene F. Reinmann Conference Chair

# Conference Schedule

7:30 **Exhibitor Check In**

8:15 to 8:45 **Guest Check In & Community Resources Preview**

8:15 to 8:45 **Coffee Hour for Recently Diagnosed Persons**
**Cynthia Stevenson**, Director Caregiver Services
Onondaga County Office for Aging

8:45 to 9:00 **Welcome**
**Susan M. Kennedy**, Host
WCNY-TV PBS "Cycle of Life"

**Peter J. Headd**, Executive Director
Onondaga County Office for Aging

**Cynthia Woods**, Executive Director
Upstate University's OASIS and HealthLink

9:00 to 9:45 **Movement and Physical Activity in Parkinson's Disease**
**Pages 12 - 33**
**Carol Sames**, Director, Vitality Fitness Program at
Upstate Institute for Human Performance

9:45 to 10:30 **Universal Design - Building Your Future**
**Pages 34 - 45**
**Scott McClurg**, President & Co-Owner
McClurg Remodeling & Construction Services

10:30 to 11:00 **Community Resources Education - Exhibitors**

# Conference Schedule Continued

11:00 to 12:00 **Medical Treatments: Discover Medtronic DBS Therapy for Parkinson's Disease**
**Pages 46 - 56**
**Andrew M. Wensel**, MD, Neurosurgeon
University of Rochester Medical Center, Rochester, NY

12:00 to 12:45 **Pascale's Plated Lunch & Community Resources Education**

12:45 to 1:30 **The Science and Practice of LSVT LOUD & BIG Programs**
**Pages 57 - 83**
**Lisa Halpin**, MS, CCC-SLP
**Julie Lombardi**, PT, DPT
The Centers at St. Camillus

1:30 to 1:45 **Live a Little Easier**
**Pages 84 - 94**
**Kevin Gagnon**, Store Operations Manager, DME (Durable Medical Equipment) Specialist
Brewerton and Village Pharmacy
**Marlene F. Reinmann**, Senior Care Professional

1:45 to 2:15 **Parkinson's Dance: Moving Through Possibilities**
**Tumay Tunar, PhD and the Parkinson's Dance Group**
Syracuse University and Parkinson's Dance

2:15 to 2:30 **Closing Remarks**

# Host - Susan M. Kennedy

**Susan M. Kennedy** is the Host and award winning producer of the WCNY-TV PBS program, "Cycle of Health." She is responsible for researching topics, scheduling interviews, assisting in field reporting and anchoring programs featuring stories of compassion and hope from people seeking to improve their health. She has been with the program since 2013.

From 2008 through 2010, Ms. Kennedy was the founding producer and on-air host for the "Tempo Public Square" series on WLVT-TV PBS in Bethlehem, PA. She was responsible for researching current events, scheduling on-set interviews, guiding field reporting and anchoring smart and lively programs devoted to a single public policy subject. Susan was the host of 32 weekly shows on topics including social security, health care, state budget challenges, consumer spending, teen troubles and social media.

Ms. Kennedy worked previously as an anchor, producer, reporter, news writer and media strategist for WPBN-WTOM-TV NBC in Traverse City, MI, WWTV-WWUP-TV CBS in Cadillac, MI, WQAD-TV CBS in Moline, IL and WMAQ-TV NBC in Chicago, IL.

Susan received her Bachelor of Journalism from the University of Missouri, Columbia, School of Journalism.

# Speakers of the Day

**Kevin Gagnon** is the store operations manager of the Brewerton & Village Pharmacy. He is also their DME Specialist and Consultant. He has been with Brewerton Pharmacy for over twenty years.

**Lisa Halpin**, M.S.,CCC-SLP graduated Summa Cum Laude from State University of New York College at Cortland with a Bachelor of Science in Speech & Language Disabilities; and obtained a Master of Science in Communication Science & Disorders from East Carolina University in Greenville, NC.

She is licensed in New York State to practice Speech-Language Pathology, and holds a Certificate of Clinical Competence from the American Speech-Language-Hearing Association (ASHA). Lisa has experience working with all populations from birth to adult, including Early Intervention and preschool & school age children in both the home and public school settings.

She has been working with the adult population as a medical speech language pathologist at The Centers at St. Camillus for the past 4 years as part of the team in the short-term rehabilitation unit.

Lisa belongs to the Central New York Speech Language Hearing Association & participates in continuing education for the medical speech language pathologist on a regular basis. She attained her certification in Lee Silverman Voice Therapy (LSVT LOUD), a therapeutic, research based treatment of voice for people with Parkinson's Disease (PD), in February of 2015.

She currently works with people with PD in both the inpatient and outpatient populations.

# Speakers of the Day

**Julie Lombardi**, PT, DPT has practiced as a licensed physical therapist in the outpatient center at the Centers at St. Camillus in Syracuse, NY for 8 years.

She obtained her doctorate in physical therapy from Upstate Medical University in 2008. Julie has a special interest in working with patients with vestibular and other neurological conditions. She obtained her certification of competency in vestibular rehabilitation in 2012 through the Emory University and APTA sponsored annual competency based course. Since that time she has continued to attend advanced vestibular rehabilitation courses.

Her interest in treating patients with Parkinson's Disease began as a student in PT school where she started "Smooth Moves," a dance class for people with PD. She has had the opportunity to attend local PD support groups and lecture on the topic of exercise for PD. In May 2014 she attained her certification in LSVT BIG, a therapeutic approach for people with PD.

**Scott F. McClurg** is president and owner of McClurg Remodeling & Construction Services which he started in 1969 in Marcellus, NY. Challenged by the need to remodel his parent's home to accommodate his father's disabilities resulting from a chronic disease, he dedicated his company to "Universal Design". He has Certifications from the National Association of Home Builders as Graduate Builder, Aging in Place Specialist and Green Professional. In addition, he is Lead Safety Certified by the Environmental Protection Agency RRP.

Most recently he was honored by The Centers of St. Camillus for his "dedication to giving back to our community" in recognition for outstanding service as a Trustee.

Scott's goal is to construct or remodel space to meet the needs of all people even as their conditions change along life's journey. As he says, "Think of Universal Design as a home for a lifetime."

# Speakers of the Day

**Marlene F. Reinmann** is a senior care professional with a strong background in senior housing, marketing and event planning. She has been our chairperson for the "Living an Active Life with Parkinson's Disease" conference for the past 4 years.

Before retiring her professional position to begin a family, Marlene was the Director of Marketing and Sales and Director of Recreation at Summerfield Retirement Community in Syracuse for 11 years. In this role she provided guidance to families as they navigated local and regional elder care services and recognized how a supportive local community enhances the lives of seniors and their families.

Throughout her career she has frequently partnered with community agencies to provide educational opportunities to the public. By bringing together and collaborating with other professionals in her field, local businesses and community residents Marlene enjoys implementing diverse program opportunities and special events which enhance the lives of local seniors

**Carol A. Sames**, PhD earned her PhD in "Teaching & Leadership/Exercise Physiology" at Syracuse University. She currently is Associate Professor & Director of the Vitality Fitness Program in the College of Health Professions at Upstate Medical University, Syracuse, NY.

Carol uses her academic background in physiology and exercise science to research and develop programs for wellness and healthy aging. One highly regarded program is the Vitality Fitness Program at the Institute for Human Performance. She is a frequent lecturer in the central New York area and has published widely in her field.

This is her second appearance as a speaker at the "Living An Active Life With Parkinson Disease" annual conference. Carol's philosophy is reflected in the title of a class she presented at Upstate HealthLink, "Better Than Any Pill: Using Movement to Maintain Your Health with Parkinson Disease".

# Speakers of the Day

**Tumay Tunur** holds a Ph.D. in Cell and Molecular Biology from Tulane University, New Orleans, LA. She worked as a Postdoctoral Research associate in the Psychology Department at the University of Illinois, and in the Biology Department at Syracuse University. Her main research focus has been on effects of ovarian steroids on learning and memory. She has worked with rodents studying object and context memory, spatial navigation, and learning strategies. Currently, she holds a position as a Teaching Postdoctoral Fellow in the Exercise Science Department at Syracuse University. Tumay Tunur has taught numerous courses in biology, neuroscience, and kinesiology.

An accomplished dancer, she uses her skills to teach both the young and the elderly, with a special focus on people with Parkinson's disease. Currently, Tunur combines her research interests with her dance expertise by leading the Moving Through Possibilities program, which aims to engage the community in movement and promote healthy aging. She collaborates with the Mark Morris Dance Group (MMDG), the founding company for the world-renowned Dance for Parkinson's Disease program, in research projects. This year, Tunur received the Orange Circle Award for her program and the Tolley Award for her research collaboration with MMDG.

**Andrew M. Wensel**, MD is Assistant Professor of Surgery/Neurosurgery at the University of Rochester Strong Memorial Hospital, Rochester, New York.

He earned both his undergraduate degree in biology and his Doctor of Medicine at Case Western Reserve University. Dr. Wensel is board certified by the American Board of Neurological Surgery.

In 2009 and 2012, he had supplemental training in Deep Brain Stimulation at the University of Buffalo, University of Florida and University of Pennsylvania.

He has published and lectured frequently on pain, spinal and brain disorders and Deep Brain Stimulation.

# Parkinson's Support and Education Groups

## Jefferson County

### Chaumont Group

Every Tuesday at 11:00 a.m.

All Saints Church, Chaumont, NY

Exercise, pot luck lunch, speaker or activity, art class

Thursdays - T'ai Chi in Watertown

For information contact: Richard Guga at 315-771-6606

Sister Ann Hogan at 315-649-2717

### North Country Coalition for Parkinson Disease and Movement Disorders

"Success Is Touching One Person's Life Today - Improving It For Tomorrow"

Second Wednesday of each month at 1 o'clock

St. Andrew's Parish Center, Sackets Harbor, NY

For information contact:

Norman Hunneyman at 315-646-3446
North Country Coalition for Parkinson Disease
and Movement Disorders
PO Box 572, Sackets Harbor, NY 13685
www.northcountryparkinson.org

## Madison County

### Parkinson's/MSA Support Group of Madison County

Fourth Tuesday of each month from 12:30 - 3:00 p.m.
Jim Marshall Farms Foundation, Inc.,
1978 New Boston Road, Chittenango, NY

For information contact: 315-655-3796 or 315-687-9014

# Parkinson's Support and Education Groups

## Monroe County

**National Parkinson Foundation Greater Rochester**

PO Box 23204, Rochester, NY 14692

For information contact: 585-234-5455, 800-327-4545

800-437-4636 Helpline

## Oneida County

**Central New York Parkinson Support Group, Inc.**

Third Tuesday of each month at 12:30 p.m. - meet and greet

1 - 3:00 p.m. - program/speaker

Presbyterian Home

4290 Middlesettlement Road, New Hartford, NY 13413

For information contact: Presbyterian Home at 315-797-7500

**Onondaga County -** See inside front cover.

## National Parkinson's Disease Foundations

**National Parkinson Foundation**

www.parkinson.org 800-327-4545

**Michael J. Fox Foundation for Parkinson Research**

www.michaelfox.org

800-708-7644

**Davis Phinney Foundation**

www.davisphinneyfoundation.org

866-358-0285

# A Gracious Thank You to Our 2016 Community Supporters

## At Home Independent Living

Non-Medical Companion, Homemaking Service & Escorted Transportation to Medical Appointments.
315-579-4663 Ext. 105
Mike Massurin, Director of Client & Dementia Services

## Caring Transitions of Syracuse

A solutions company. They assist their clients with sorting and organizing, move management and estate liquidation. They manage every aspect of the transition process in an organized and compassionate way.
315-401-7633
Jennifer Novak, Managing Owner

## Franciscan Companies

Home & Community based care including Lifeline, licensed home care, medication dispensers and durable medical equipment. 315-458-3600
Stacey Gingrich

## Inspire Care of CNY

The region's leading expert in Aging Life Care providing experienced Aging Life Care Management and private home physical therapy. They identify and engage local, cost effective resources in order to tailor a care plan for each individual's circumstances. They work for you and with you, making "Aging Well" a priority. 315-447-3164
Becky Auyer, Owner Care Manager

## Brewerton Pharmacy

Prescription services, specialized compounding and a complete line of home medical equipment.
315-676-4441
Kevin Gagnon
Operations Manager

**Brewerton Pharmacy**
315-676-4441
**Village Pharmacy Central Square**
315-668-2659
**Village Pharmacy North Syracuse**
315-458-0500

## The Centers at St. Camillus

Home & Community based care including home care, social & medical model day programs. Inpatient or Outpatient Rehabilitation and Skilled Nursing Community.
315-703-0822, 315-703-0732
Michael Connor, Debbie Christiansen

## McHarrie Life Senior Community

Is a continuum of care that offers independent, assisted living, memory care and skilled nursing health & rehabilitation.
315-638-2521
Maggie Reap, Administrator
Assisted Living McHarrie Pointe

# A Gracious Thank You to Our 2016 Community Supporters

## Hearth Managed Senior Living Communities

The Hearth on James
Independent & Enriched Living
315-422-2173
Alescia Porceng

**The Hearth at Greenpoint**
Independent & Enriched Living
315-453-7911
Nate Nosel & Lisa Jackson

**Keepsake Village at Greenpoint**
Memory Care
315-451-4567
Lisa Merrill

## Loretto

Home & Community based programs including the PACE Program and medical day programs. Independent & Assisted Living and Skilled Nursing Communities in Syracuse & Auburn.
315-251-2662 ext. 3100
Katy Nappi

## Jarmel Physical Therapy PLLC

Susan Jarmel , Physical Therapist, provides neurorehabilitation for chronic diseases, soft tissue pain treatment and other rehabilitation programs for cancer, fall prevention, geriatrics and amputees.
315-314-7834 Susan Jarmel

## OASIS Upstate Medical University CDSMP Program - Chronic Disease Self Management Program

The purpose of the Chronic Disease Self-Management Program Workshop is to enhance one's skills and ability to manage his or health and maintain an active and fulfilling lifestyle. Participants are invited to bring a family member, friend and/or caretaker. The program is FREE and available for anyone living in Onondaga County.
315-464-1746 Sally Terek

## Rock Steady Boxing

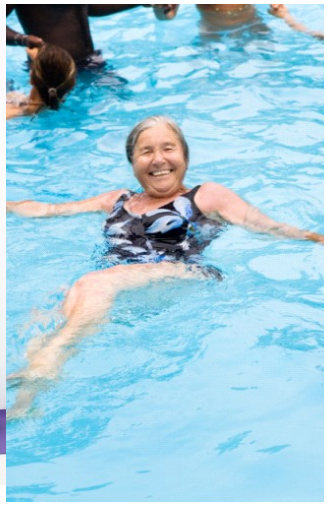
Is a first-of-its-kind fitness program dedicated to improving the quality of life of people diagnosed with Parkinson's disease. Patients at all levels of symptom progression are seeing improved motor function as a result of intense non-contact, boxing style exercise. Rock Steady Boxing CNY has joined the fight against Parkinson's disease right here in the Syracuse area. 315-622-2332
Jeanette Riley, Coach

## Senior Home Care Solutions & Alzheimer's Solutions

Specializing in Non-Medical home care for seniors.
315-247-6741
Sheila Ohstrom

# Movement and Physical Activity in Parkinson's Disease

Carol Sames


# Movement & Physical Activity In Parkinson's Disease

CAROL SAMES PHD, UPSTATE MEDICAL UNIVERSITY
DEPARTMENT OF PHYSICAL THERAPY EDUCATION & *VITALITY* FITNESS PROGRAM

## Outline

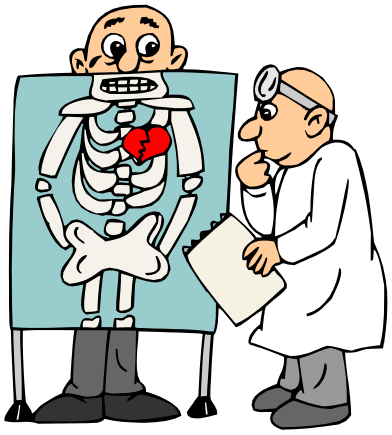
- **1. Benefits of Regular Physical Activity**
- **2. Sedentary Behavior & Impact on Health**
- **3. Current Research on Parkinson's Disease & Physical Activity**
- **4. Nuts & Bolts of Physical Activity**
- **5. FITT Principle of Physical Activity**
- **6. Physical Activity Demonstration**
- **7. Community Resources**

## Benefits of Regular Physical Activity

- **Higher activity levels are associated with lower death rates from:**
- **1. heart disease**
- **2. all cardiovascular disease**
- **3. colon & breast cancer**
- **4. type II diabetes.**

## Benefits of Regular Physical Activity

- **More activity with less fatigue**
- **Less shortness of breath**
- **Heart & Lungs work better**
- **Improved circulation to hands & feet**
- **Decreased risk of osteoporosis**
- **Decreased anxiety & depression**
- **Improved feelings of self-worth**
- **Improved performance of work, recreational and life activities**
- **Improved Quality of LIFE !!!**



## Benefits of Regular Physical Activity

- **Increase Weight Loss**
- **Long-Term Maintenance of Weight Loss**
- **Increase muscle strength-you need muscle to MOVE!**
- **Increase flexibility**
- **Reduces risk of falls and fractures**
- **Lower risk for developing vascular dementia.**
- **WOW! That's a lot of benefits!**

## Sedentary Behavior & Impact on Health

## Risks Associated With A Sedentary Lifestyle

- **A sedentary lifestyle is an INDEPENDENT RISK factor for cardiovascular disease.**
- **Abnormal glucose metabolism**
- **Weight gain leading to obesity**
- **Increased risk of cardiovascular death**
- **Premature death**
- **Women >30 years old, sedentary lifestyle has been demonstrated to be a stronger Risk Factor for Cardiovascular Disease then smoking.**

## The Bottom Line……

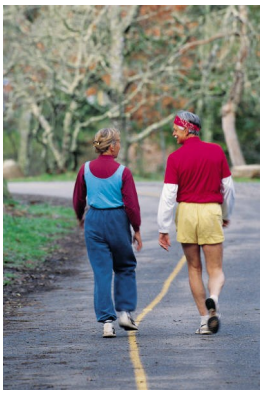
- **The bad news----Individuals are engaged in TOO MUCH SEDENTARY ACTIVITY and it is contributing to poor health.**
- **The good news---even small breaks in activity behavior can reverse negative metabolic outcomes.**
- **The bad news---Physical activity does not guarantee protection if individuals are engaged in long periods of sedentary activity.**

## The Bottom Line…..

**•Our bodies were designed for movement--inactivity causes physiological problems that become worse with time.**

**•A sedentary lifestyle is associated with decreased physical function & adverse health outcomes.**

**•An activity program can be started at any age, with any body type or presence of disease.**



## Research on Physical Activity & Parkinson's Disease

- Reynolds et al. (2016). Review—aerobic & strength training demonstrated improvement in motor function, mood, cognition and sleep especially in early stages of disease with minimal side effects & adverse effects.
- Murray et al (2014). Systematic review—aerobic, strength training & dance demonstrated improvement in cognitive function—optimal type, amount, duration unclear.

## Research on Physical Activity & Parkinson's Disease

- Allen et al. (2011). Meta-analysis found exercise (walking, treadmill, tai chi, dance) improved) & motor training improved performance on balance related activities.
- Goodwin et al. (2008). Meta-analysis found exercise improved physical functioning, quality of life, leg strength, balance and walking distance & speed.

## Can Physical Activity Be Beneficial In Parkinson's Disease?

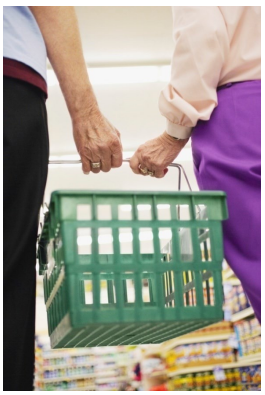
- **YES IT CAN! Limited long term research but short term studies have demonstrated improvements in balance, gait, strength, physical function, cognitive function, and quality of life.**
- **The main goal of activity is to delay disability, prevent secondary complications, and improve quality of life.**
- **Four key health outcomes of an activity program include: gait (walking), transfers, balance, and joint mobility and muscle power (strength) to improve function.**

## Nuts & Bolts of Physical Activity

- **Must be individualized based on movement symptoms, functional abilities, physical fitness, secondary diagnoses, and medications.**
- **One size does not fit all!**

## Nuts & Bolts of Physical Activity

- **Individualized movement considerations:**
- **Is movement speed slowed?**
- **Difficulty starting movement?**
- **Episodes of "freezing" movement?**
- **Difficulty with balance or posture/falls?**
- **Wriggling/writhing movements?**
- **Tremor?**
- **Muscle stiffness/rigidity?**
- **Is Physical Therapy Needed Before Independent Physical Activity?**



## Nuts & Bolts of Physical Activity

- **Individualized non movement considerations:**
- **Sleep difficulty**
- **Fatigue**
- **Depression, lack of motivation, anxiety**
- **Difficulty with memory/concentration**
- **GI difficulty**
- **Urinary difficulty**
- **Additional diagnoses**

## Nuts & Bolts of Physical Activity

- **Develop an activity plan.**
- **PLAN FOR SUCCESS.**
- **Keep an activity journal- include type of activity, duration, time of day, perceived effort, adaptations, problems, pain that persists 2 hours after activity.**
- **Set Short & Long-term goals.**
- **Reward yourself for goal achievement.**

## Nuts & Bolts of Physical Activity

- **START SLOWLY-especially if you have been inactive.**
- **Be creative—activity is all around you.**
- **Be flexible—after all, this is CNY and weather changes quickly. *Some activity is always better than no activity.***
- **Be patient.**
- **Consistency is the key to success.**


## FITT Principle of Physical Activity

- **Frequency**
- **Intensity**
- **Time**
- **Type of Activity**
- **Guidelines developed by the American College of Sports Medicine.**

# FITT Principle—Aerobic Activity

- **Frequency—3 to 5 days/week**
- **Intensity—fairly light to somewhat hard.**
- **Time—150 minutes/week; aim for 30 minutes per session BUT can break into smaller segments.**
- **Type—continuous, large muscle group activities such as walking, dancing, activities of daily living, swimming, water activities, yoga.**

# FITT Principle—Type of Aerobic Activity

- **Aerobic (continuous) Activity: selection is dependent on PD clinical symptoms, functional ability/limitations, and any additional diagnoses.**
- **Traditional & Non Traditional Activities.**
- **BE CREATIVE!**

## FITT Principle—Resistance (Strength) Activity

- **Frequency-- 2-3 days/week.**
- **Intensity—fairly light to somewhat hard.**
- **Time-- 1-2 sets repeating each exercise 8-12 times.**
- **Type—machines, hand weights, body weight, stability ball, therabands, weighted balls, functional activity.**

## FITT Principle—Type of Resistance (Strength) Activity

- **Resistance (strength) Muscles of trunk & hip to prevent faulty posture; all major muscles of leg to maintain mobility; upper extremity to prevent frozen shoulder.**
- **Can be done in a chair or standing using body weight.**
- **Emphasize proper form, no breath holding, pain free range of motion and safety.**

## FITT Principle—Flexibility (Range of Motion) Activity

- **Frequency-- 1-7 days/week.**
- **Intensity-- full extension, flexion, rotation, or stretch to the point of slight discomfort.**
- **Time-- major muscle groups holding stretch for 10-30 seconds.**
- **Type—Slow static stretch for all major muscle groups.**

## FITT Principle—Type of Flexibility (Range of Motion) Activity

- **Flexibility Activity: Slow static stretch (no bouncing) for all major muscle groups for all severity stages of PD.**
- **Spinal mobility & neck flexibility should be emphasized as correlated with posture, gait, balance & activities of daily living.**

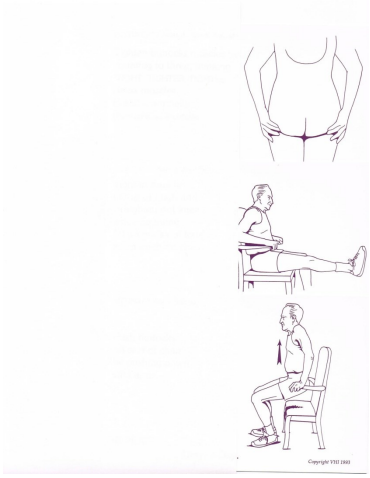
# FITT Principle—Balance Activity

- **Frequency—3 days/week.**
- **Intensity—challenging but safe.**
- **Time-- 4-5 exercises (standing & moving).**
- **Type—stepping & reaching in all directions, stepping up & down, obstacles, standing & sitting, tai chi, dancing.**

# General Exercises to Improve Flexibility & Strength

- **Knee Extension/Flexion**
- **Toe/Heel Raises/Circle**
- **Lower Leg Stretch--Stand**
- **Hamstring Stretch--Sitting**
- **March in Place—Sit/Stand**
- **Hip Out/Together—Sitting**
- **Hip Pendulum--Stand**
- **Draw In (10x10sec) & Butt Squeeze (10x10sec)**
- **Sit to Stand--Sitting**
- **Wall Squats--Standing**
- **Wall Push Up—Standing**
- **Chair Push Up--Sitting**
- **Seated Sit-ups—Sitting**
- **Curl Ups—floor/bed**
- **Front/Side Lunges—Standing**

# Exercise Pictures



- **Butt Squeeze--strength**
- **Knee Extension/Flexion-strength**
- **Chair Push Up--strength**

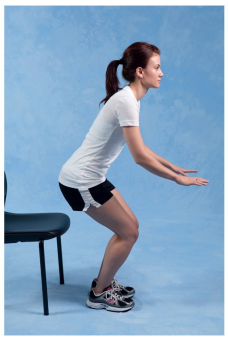
# Exercise Pictures

**Lower Leg Stretch--flexibility**

**Hamstring Stretches-flexibility**

# Exercise Pictures

**Sit To Stand—strength & balance**



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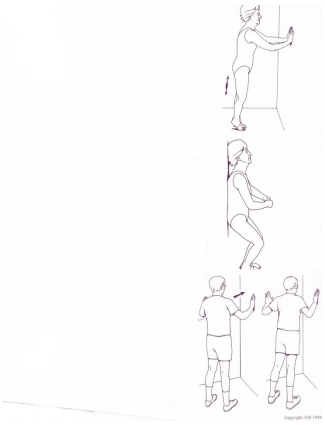
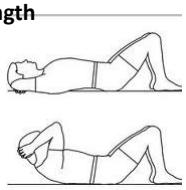
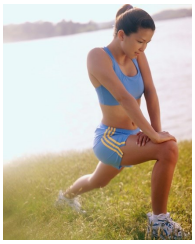
**Toe Raises, Wall Squats & Wall Push Ups—strength & balance**



# Exercise Pictures

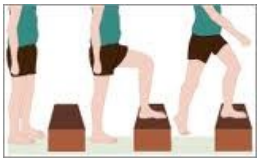
**Crunches (cross arms over chest)—core strength**





**Lunges—strength & balance**

**Leg Raises--strength**



**Step Ups—strength & balance**

## How Do I Become More Active?

- 1. **What are you currently doing? Identify your starting point and your limitations.**
- **2. Identify your barriers to activity.**
- **3. Make activity a PRIORITY.**
- **4. Make activity FUN—yes FUN ☺**
- **5. Make activity interesting—what do you enjoy, what would you like to do?**
- **6. Set goals that are specific, realistic & important to you.**
- **7. Make activity part of your regular routine—yard work, household activity, taking the stairs, walking the dog, strength training or stretching during commercials. Be Creative!**

## Special Considerations

- **Outcome of activity training varies significantly by individual due to symptoms and complexity of disease.**
- **Safety during activity is imperative. Select activities with safety in mind—look at the environment & equipment.**
- **Medications can further alter HR, BP and also can cause headaches, blurred vision, dry mouth.**

## Special Considerations

- **If cognitive changes are present, help and support may be needed.**
- **Avoid multi-tasking when starting an activity program.**
- **Complete 1 activity before starting another activity.**

## Special Considerations

- **If long-term use of Levodopa, is there evidence of "end of dose wearing off" or predictable/unpredictable "off time".**
- **If so, be active around these times.**

# Community Resources

- **If you find it difficult to be active on your own or you are looking for a specialized, individualized exercise program, the *Vitality* Fitness Program may be for you.**

## *Vitality* Fitness Program—Upstate Medical University

- **Located at the Institute for Human Performance**
- **Land & Aquatic Programs**
- **Initial Assessment Completed**
- **Staffed by Exercise Physiologists**
- **Individualized program depending on limitations, medical history, functional ability, occupational and personal goals.**
- **Various class times from 8:15A-4:30P on Monday, Wednesday, and Friday.**
- **Call 464-9992 for additional information.**

# Community & Online Resources

- **YMCA—multiple sites in Onondaga County—indoor track, pool, aerobic equipment, Active Older Adult Programming.**
- **http://www.syracuse.ymca.org/programs/healthy-living/fitness/active-older-adults.html**
- **Davis Phinney Foundation—Parkinson's Exercise Essentials Download Video**
- **http://www.davisphinneyfoundation.org/living-pd/dvd/**
- **Michael J Fox Foundation—Exercise Podcasts**
- **https://www.michaeljfox.org/understanding-parkinsons/living-with-pd/topic.php?exercise&navid=exercise**
- **Syracuse Parks & Recreation—Senior Fitness Programming**
  **http://www.syracuse.ny.us/parks/FitnessAndWellness.html**

# The Bottom Line

- **KEEP MOVING**-you will feel the physical, emotional and quality of life benefits of being active.
- **Parkinson's Disease isn't a reason to sit on the sidelines**-whatever your level of ability, you can be active.
- **YES YOU CAN!**

# References


- ACSM's Guidelines for Exercise Testing & Prescription (9th Edition). 2013. Wolters Kluwer/Lippincott, Williams & Wilkins. ISBN-13: 978-1-60913-605-5
- ACSM's Resource Manual for Guidelines for Exercise Testing & Prescription (7th Edition). 2014. Wolters Kluwer/Lippincott, Williams & Wilkins. ISBN-13: 978-1-60913-956-8
- McArdle, Katch & Katch. Exercise Physiology: Nutrition, Energy, and Human Performance (8th Edition). 2015. Wolters Kluwer/Lippincott, Williams & Wilkins. ISBN-13: 978-1-4511-9155-4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- Allen et al. Balance & Falls in Parkinson's Disease: A Meta-analysis of the Effect of Exercise and Motor Training. *Movement Disorders,* 26(9), 2011, pp. 1605-1615.
- Goodwin et al. The Effectiveness of Exercise Interventions for People with Parkinson's Disease: A Systematic Review and Meta-Analysis. *Movement Disorders*, 23(5), 2008, pp.631-640.

# References


- Murray et al. The Effects of Exercise on Cognition in Parkinson's Disease: A Systematic Review. *Translational Neurodegeneration*, 2014, 3(5).
- Reynolds et al. The Therapeutic Potential of Exercise to Improve Mood, Cognition, and Sleep in Parkinson's Disease. *Movement Disorders,* 2016, 31(1), pp. 23-38.

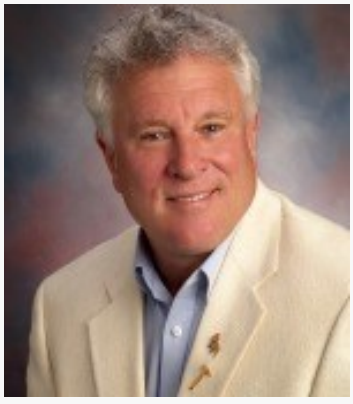
# Universal Design
# Building Your Future

Scott McClurg

McClurg

Universal Design-building for your future

## THE MCCLURG TEAM



Scott F. McClurg
President, McClurg Remodeling & Construction

*"**39 years strong!** We pride ourselves on trust, quality and integrity. We believe in our process and it has proven successful for our customers and our team."*
-Scott F. McClurg

## GOING ON 40 YEARS STRONG!

- *Professional Remodeler* magazine has placed McClurg on its list of ***America's Top Remodelers***. McClurg is ranked 108 nationally and number one in Upstate New York.
- *REMODELING* magazine has named McClurg the **58th largest full service remodeling company in the U.S.** and the largest in Upstate New York.
- *Angie's List* awarded McClurg the Super Service Award and a **consistent "A" rating**.
- *Guild Quality* awarded McClurg with the Guildmaster Award for six consecutive years and in 2015, awarded McClurg with twenty consecutive GREAT reviews.
- *National Association of Home Builders* awarded McClurg with the Council Award for Demonstrating Remodeling Excellence (CADRE) in the Service Project category.

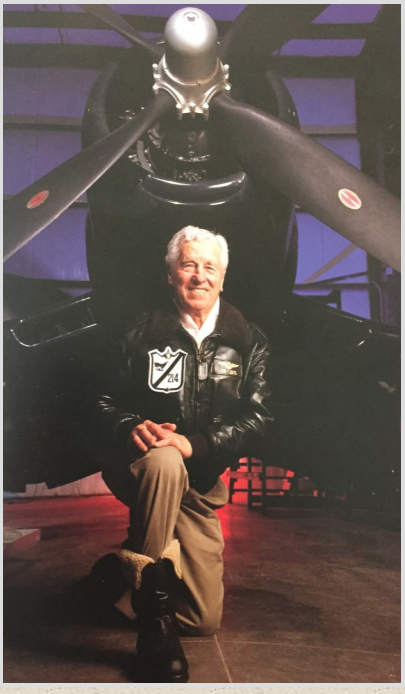
## WHAT IS UNIVERSAL DESIGN?

***"Universal Design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design." ---NAHB-***

Think of a Universal Design home as a "home for a lifetime."

## A GROWING INDUSTRY

- Did you know there are more than ***50 million*** adults in the US living with a disability? Nearly ***20%*** of the population.
- Baby Boomers-77 million strong (28 percent of the population)



Universal Design
& my Father

## UNIVERSAL DESIGN- NOT JUST BATHROOMS

- **Throughout the Home**
- No-step or level entryways
- Doorways 32-to-36 inches wide
- Hallways 36-to-42 inches wide
- More and open floor space
- Level thresholds
- Lever handles on doors
- Rocker light switches
- Electrical outlets placed 25 inches above the floor
- Slip-resistant flooring
- Casement windows
- Good lighting
- Adjustable closet rods and shelves

## UNIVERSAL DESIGN

## UNIVERSAL DESIGN

## UNIVERSAL DESIGN-EX. THRESHOLD

McClurg

## UNIVERSAL DESIGN FEATURES

- Residential elevator to enable access to all levels of a home

McClurg

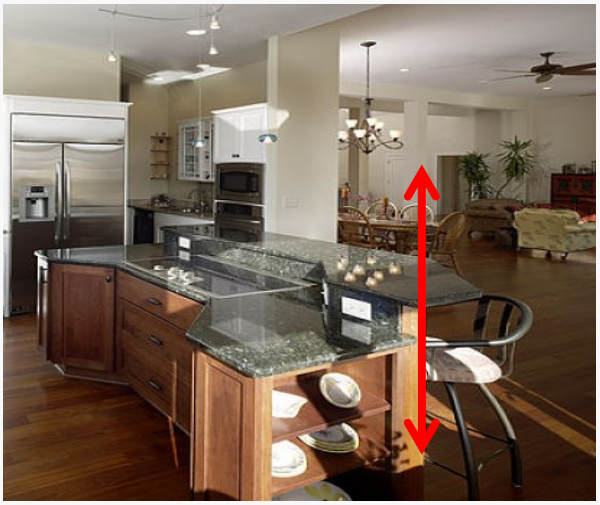
## UNIVERSAL DESIGN "APPLIANCES"

- Stoves and cooktops with front controls are user-friendly.
- Microwave ovens installed under a counter.
- Dishwasher drawers that can be raised from the floor for easy loading.
- Refrigerators with a freezer drawer and side-by-side doors are more accessible.
- Ovens with side opening doors are accommodating for wheelchair users.

## UNIVERSAL DESIGN FEATURES

Hardware and cabinet drawers

## UNIVERSAL DESIGN FEATURES



Multi-height counters

Rounded corners

Lower counter height

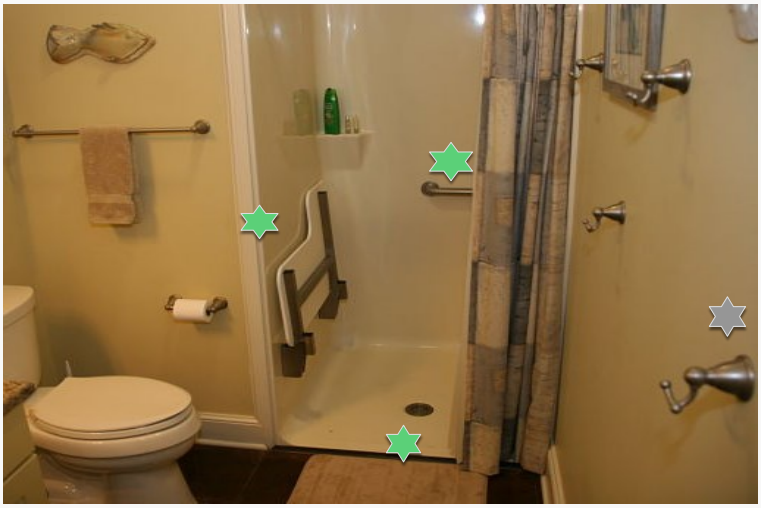
Custom Shelving

Accessible cooktop Controls

## UNIVERSAL DESIGN FEATURES

Gas stovetop with front access controls. On the right side of the cabinet panel below the stovetop are controls for the vent downdraft. The recessed cabinetry provides easy wheelchair access and is an interesting architectural feature.

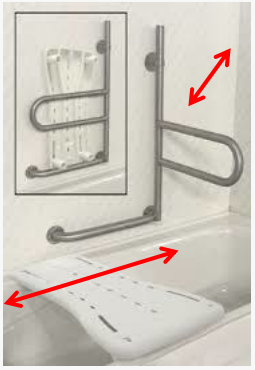
## UNIVERSAL DESIGN FEATURES BATHROOM OPTIONS



## "TRENDY" UNIVERSAL DESIGN FEATURES




## "TRENDY" UNIVERSAL DESIGN FEATURES

Adjustable Grab Bars & Moveable seat

McClurg

## BATHROOM

ZERO THRESHOLD

36" DOORWAYS

SHOWER SEAT

GRAB BARS

FULLY ACCESSIBLE

## UNIVERSAL DESIGN CONSIDERATIONS

LIGHTING OPTIONS

RAISED ELECTRICAL

NON SLIP FLOORING

WIDE FLAT EXTERIOR PATHS

EXITS & ENTRANCES

HANDRAILS

RAMPS

LEVEL THRESHOLDS

## HOW TO CHOOSE A CONTRACTOR

- Trust- "Keys to your home"
- Insurance
- Permits
- References
- Repeat and Referral business
- History- Do your Home work

# Medical Treatments: Discover Medtronic DBS Therapy for Parkinson's Disease

Andrew M. Wensel


Discover Medtronic DBS Therapy for Parkinson's Disease
Medtronic
ACHIEVE DAILY VICTORIES
Iris C.
Benefiting from DBS Therapy since 2008


Medtronic DBS Therapy
• What is Medtronic DBS Therapy (deep brain stimulation)?
• How does DBS Therapy work?
• Is DBS Therapy proven?
• When is it time to be evaluated for Medtronic DBS Therapy?
• What are the benefits and risks associated with DBS Therapy?
• How can DBS Therapy help me achieve daily victories?
• What can I expect from the surgical procedure?
• Is DBS Therapy covered by insurance?
Perry C.
Benefiting from DBS Therapy since 2007

## What is Medtronic DBS Therapy?

- FDA approved treatment that delivers electrical stimulation to very specific areas in the brain using a surgically implanted medical device (similar to a pacemaker)
- **More than 140,000 patients have chosen Medtronic DBS to manage their movement disorder symptoms**

Wanda M.
Benefiting from DBS Therapy since 2004

## How does DBS Therapy work?

- Pacemaker-like device sends mild electrical signals to an area in the brain that controls movement
- These signals block some of the brain messages that cause disabling motor symptoms
- As a result, you may experience better control over your body movements, making it easier to perform everyday tasks

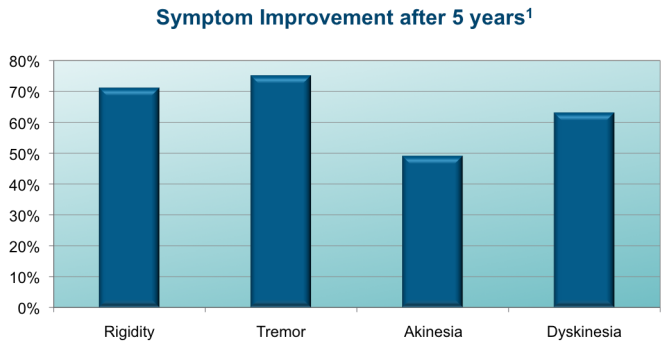
## Is DBS Therapy proven?

Yes!

- With more than 2,000 original publications[1] Medtronic DBS Therapy continues to be the fastest growing treatment option for individuals with movement disorders.
  - It's proven to improve motor function in Parkinson's disease patients
  - It's reported to offer sustained benefit; Medtronic DBS Therapy has been reported to maintain motor symptom improvement in PD patients even after 5 years[2]

1. PubMed Electronic Database of the National Library of Medicine, www.pubmed.gov. Literature search for original clinical studies published between 1993 and May 2009.
2. Krack P, Batir A, Van Blercom N, et al. Five-year follow-up of bilateral stimulation of the subthalamic nucleus in advanced Parkinson's disease. *N Engl J Med.* 2003; 349(20):1925-1934.

## Medtronic DBS Benefits Reported to Last More Than 5 Years




1. Krack P, Batir A, Van Blercam N, et al. Five-year follow-up of bilateral stimulation of the subthalamic nucleus in advanced Parkinson's disease. *N Engl J Med*. 2003;349:1925-1934.

## More Than a Decade of DBS Effectiveness

**1987**
Prof. Alim Benabid, MD, a neurosurgeon, and his team in Grenoble, France implant a Medtronic Itrel® device to control disabling tremor and begin the first systemic study of thalamic stimulation.

**1992**
Start of Medtronic-sponsored European multicenter clinical study of thalamic stimulation for tremor.

**1995**
Thalamic brain stimulation therapy for essential tremor and Parkinson's disease available in Europe, Canada, and Australia.

**1997**
US Food and Drug Administration (FDA) approval for essential tremor and tremor in Parkinson's disease.

**2001**
Efficacy and safety information for DBS Therapy for Parkinson's Disease published in the first of a series of landmark articles in the *New England Journal of Medicine*.[1]

**2002**
FDA approval for advanced Parkinson's disease motor symptoms.

**2003**
Medtronic DBS Therapy receives HDE* approval from US FDA and CE mark in Europe for managing symptoms of primary dystonia.

Long-term benefits and safety of Medtronic DBS Therapy for Parkinson's Disease reported.[2]

**2006**
Medtronic DBS Therapy and medication reported to be more effective than the best medical therapy alone.[3]

**2009**
First rechargeable DBS device, Activa RC.

Medtronic Reclaim® DBS Therapy for obsessive-compulsive disorder (OCD) receives HDE* approval from US FDA.

**2010**
More than 80,000 patients worldwide receiving Medtronic DBS Therapy for a variety of movement disorders.

1. The Deep-Brain Stimulation for Parkinson's Disease Study Group. Deep-brain stimulation of the subthalamicnucleus or the pars interna of the globuspallidusin Parkinson's disease. *N EnglJ Med.September 2001;345(13):956-963.*
2. KrackP, Batir A, Van blercom N, et al. Five-year follow-up of bi-lateral stimulation of the subthalamic nucleus in advanced Parkinson's disease. *N Engl J Med*. 2003; 349: 1925-1933.
3. Deuschl G, Schade-Brittinger C, Krack P, et al. A randomized trial of deep-brain stimulation for Parkinson's disease. *N Engl J Med*. 2006; 355(9): 896-908.

*Approved as a Humanitarian Use Device in the US. The effectiveness of this device for the treatment of dystonia and OCD has not been established.

## When is it time to be evaluated for Medtronic DBS?

- When you have difficulty controlling your movements despite having tried several drug combinations

or

- When you are no longer satisfied with the effects of your current medications

*"At night I had to button my shirt buttons and tie my tie in preparation for the morning because my meds didn't kick in before I needed to be dressed."*

Perry C.
Benefiting from DBS Therapy since 2007

## Discover your Window of Opportunity for Medtronic DBS Therapy

- Window opens when PD medications begin to lose effectiveness
- Window closes when PD symptoms no longer respond to medication

**Window for Medtronic DBS Evaluation**

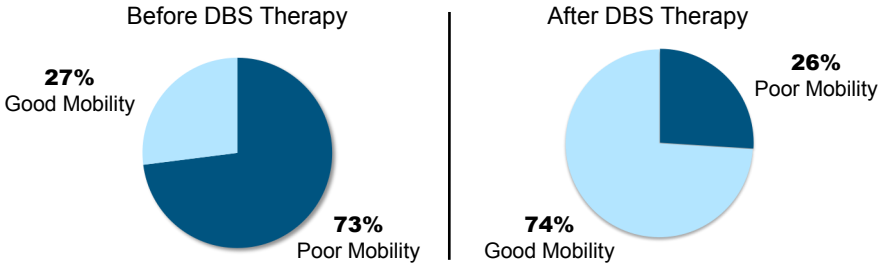
| | Not Yet Ready | Window Open | Window Closed |
|---|---|---|---|
| Drug Classes Used | 1-2 | **3-5** | Variable |
| Daily levodopa Doses | Few | **Frequent** | Variable |
| Complications Despite Medications | No | **"Off" time dyskinesia** | Poor "best on" dementia |
| Possible DBS Candidacy | No | **Yes** | No |
| Diary Recommended | Yes | **Yes** | No |

## What are the benefits associated with Medtronic DBS Therapy for PD?

Medtronic DBS Therapy can reduce several motor symptoms associated with PD:

- Rigidity (muscle stiffness)
- Bradykinesia/akinesia (lack of movement or slowness)
- Tremor (shaking)

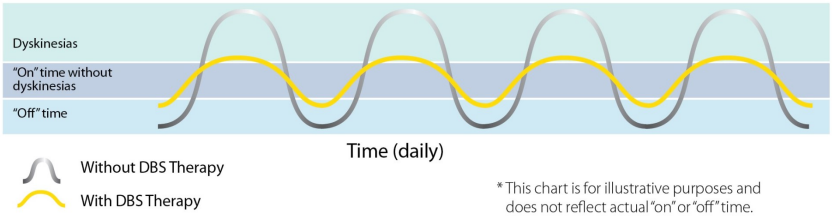
## Medtronic DBS Therapy Plus Medication for PD Increases "On" Time Without Dyskinesia[1]




Good mobility: "On" time without dyskinesia
Poor mobility: "Off " time and "on" time with dyskinesia

1. The Deep-Brain Stimulation for Parkinson's Disease Study Group. Deep-brain stimulation of the subthalamic nucleus or the pars interna of the globus pallidus in Parkinson's disease. *N Engl J Med.* 2001;345:956-963.

## DBS Therapy with Medications Provides an Additional 5.1 Hours of "On" Time to Smooth Out Motor Function Throughout the Day[1]




1. Activa Therapy Clinical Summary, 2009.

Compared to Medications alone, Medtronic DBS Therapy used in combination with medication has been found to reduce several symptoms of PD and some drug side effects.

| Medications Alone | Medtronic DBS Therapy + Medications |
|---|---|
| 0 hours of additional "on" time[1] | Average 5.1 hours additional "on" time without troubling dyskinesias* |
| Unpredictable motor fluctuations | More predictable motor fluctuations |
| Dyskinesias and nonmotor side effects | Medication reduction may lead to fewer drug-induced side effects |

1 Activa Clinical Summary, 2009.
* Mean results; DBS is adjunctive to medications

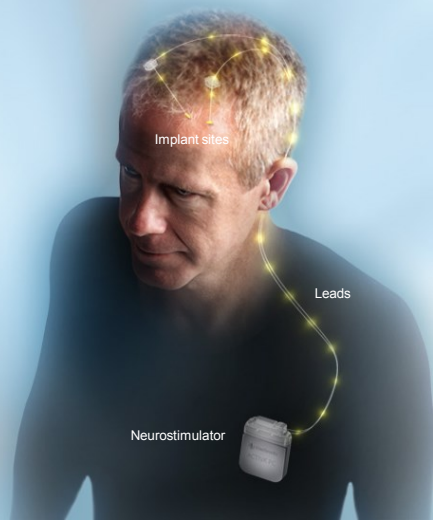
## What are the risks associated with DBS Therapy?

- **There are some risks to consider with DBS Therapy, as is the case with any other brain surgery. Please be sure to discuss the possible surgical complications and side effects with your doctor.**
- **Risks of brain surgery may include serious complications such as coma, bleeding inside the brain, seizures and infection. Some of these may be fatal.**
- **Possible device complications include infection, problems with lead/extension connector positioning, parts wearing through the skin, or an interruption in therapy because of mechanical or electrical problems. Any of these situations may require additional surgery or cause your symptoms to return.**
- **Some side effects associated with the stimulation may include worsening of tremor or speech and language impairments. Typically, these side effects are not permanent and can be resolved by adjusting stimulation parameters. Depression, suicidal thoughts, and suicide, have also been reported. Occurrence of "fall" has been observed in patients with Parkinson's disease.**

## What can I expect from the surgical procedure?

Receiving Medtronic DBS Therapy typically involves the following steps:

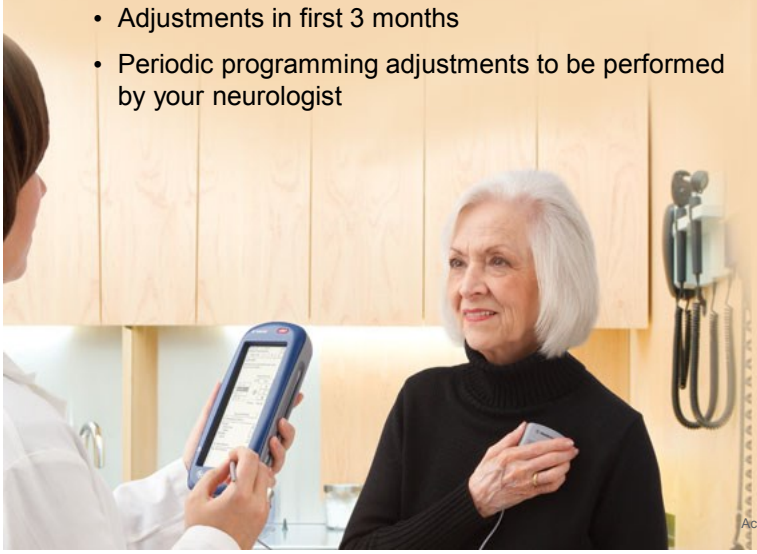
- Brain Imaging
- Brain Mapping
- DBS Lead Placement
- Neurostimulator Placement
- Therapy Activation




Actual patient not pictured.

## What can I expect after the surgical procedure?

- First programming 2 to 4 weeks after surgery
- Adjustments in first 3 months
- Periodic programming adjustments to be performed by your neurologist



Actual patient not pictured

## Is Medtronic DBS Therapy covered by insurance?

- Approved by Medicare
- Private insurance:
  - Preauthorization from your insurance company may be required
  - Your costs will vary by benefit plan

## What are my next steps?

You May Benefit from Medtronic DBS Therapy if:

•you have tried several drug combinations, and

•you are still having difficulty controlling your movements,
e.g."off" time with shaking, stiffness, slowness/lack of movement, or troubling dyskinesias.

*"I used to paint quite a bit and then I had to stop. After my surgery, I painted each of my doctors a picture"*

Wanda M.
Benefiting from Medtronic DBS Therapy since 2004

## Brief Summary Disclosure

**Medtronic DBS Therapy for Parkinson's Disease, Tremor and Dystonia: Patients should always discuss the potential risks and benefits with a physician.**

**Indications: Medtronic DBS Therapy for Parkinson's Disease: Bilateral stimulation of the internal globus pallidus (GPi) or the subthalamic nucleus (STN) using Medtronic DBS Therapy for Parkinson's Disease is indicated for adjunctive therapy in reducing some of the symptoms of advanced, levodopa-responsive Parkinson's disease that are not adequately controlled with medication.**

**Medtronic DBS Therapy for Tremor: Unilateral thalamic stimulation using Medtronic DBS Therapy for Tremor is indicated for the suppression of tremor in the upper extremity. The system is intended for use in patients who are diagnosed with Essential Tremor or Parkinsonian tremor not adequately controlled by medications and where the tremor constitutes a significant functional disability. The safety or effectiveness of this therapy has not been established for bilateral stimulation.**

**Medtronic DBS Therapy for Dystonia: Unilateral or bilateral stimulation of the internal globus pallidus (GPi) or the subthalamic nucleus (STN) using Medtronic DBS Therapy for Dystonia is indicated as an aid in the management of chronic, intractable (drug refractory) primary dystonia, including generalized and segmental dystonia, hemidystonia, and cervical dystonia (torticollis), for individuals 7 years of age and older.**

**Contraindications: Contraindications include patients who will be exposed to MRI using a full body radio-frequency (RF) coil or a head transmit coil that extends over the chest area, patients who are unable to properly operate the neurostimulator, or for Parkinson's disease and Essential Tremor, patients for whom test stimulation is unsuccessful. Also, diathermy (e.g., shortwave diathermy, microwave diathermy or therapeutic ultrasound diathermy) is contraindicated because diathermy's energy can be transferred through the implanted system (or any of the separate implanted components), which can cause tissue damage and can result in severe injury or death. Diathermy can damage parts of the neurostimulation system.**

**Warnings/ Precautions/Adverse Events: There is a potential risk of tissue damage using stimulation parameter settings of high amplitudes and wide pulse widths. Extreme care should be used with lead implantation in patients with a heightened risk of intracranial hemorrhage. Do not place the lead-extension connector in the soft tissues of the neck. Placement in this location has been associated with an increased incidence of lead fracture. Theft detectors and security screening devices may cause stimulation to switch ON or OFF, and may cause some patients to experience a momentary increase in perceived stimulation. Although some MRI procedures can be performed safely with an implanted DBS System, clinicians should carefully weigh the decision to use MRI in patients with an implanted DBS System. MRI can cause induced voltages in the neurostimulator and/or lead possibly causing uncomfortable, jolting, or shocking levels of stimulation. MRI image quality may be reduced for patients who require the neurostimulator to control tremor, because the tremor may return when the neurostimulator is turned off.**

**Severe burns could result if the neurostimulator case is ruptured or pierced. The DBS System may be affected by or adversely affect medical equipment such as cardiac pacemakers or therapies, cardioverter/ defibrillators, external defibrillators, ultrasonic equipment, electrocautery, or radiation therapy. Safety and effectiveness has not been established for patients with neurological disease other than Parkinson's disease or Essential Tremor, previous surgical ablation procedures, dementia, coagulopathies, or moderate to severe depression; or for patients who are pregnant, under 18 years, over 75 years of age (Parkinson's Control Therapy) or over 80 years of age (Tremor Control Therapy). For patients with Dystonia, age of implant is suggested to be that at which brain growth is approximately 90% complete or above. Depression, suicidal ideations and suicide have been reported in patients receiving Medtronic DBS Therapy for Movement Disorders, although no direct cause and effect relationship has been established.**

**Additionally, the abrupt cessation of stimulation for any reason should be avoided as it may cause a return of disease symptoms. In some cases, symptoms may return with an intensity greater than was experienced prior to system implant ("rebound" effect). Adverse events related to the therapy, device, or procedure can include: stimulation not effective, cognitive disorders, pain, dyskinesia, dystonia, speech disorders including dysarthria, infection, paresthesia, intracranial hemorrhage, electromagnetic interference, cardiovascular events, visual disturbances, sensory disturbances, device migration, paresis/asthenia, abnormal gait, incoordination, headaches, lead repositioning, thinking abnormal, device explant, hemiplegia, lead fracture, seizures, respiratory events, and shocking or jolting stimulation.**

**Humanitarian Device (Dystonia): Authorized by Federal Law for the use as an aid in the management of chronic, intractable (drug refractory) primary dystonia, including generalized and segmental dystonia, hemidystonia, and cervical dystonia (torticollis), for individuals 7 years of age and older. The effectiveness of this device for this use has not been demonstrated. USA Rx only Rev 0910**

## Brief Summary Disclosure

**Reclaim™ Deep Brain Stimulation Therapy for Obsessive-Compulsive Disorder: Product labeling must be reviewed prior to use for detailed disclosure of risks. Indications: The Medtronic Reclaim DBS Therapy is indicated for bilateral stimulation of the anterior limb of the internal capsule, AIC, as an adjunct to medications and as an alternative to anterior capsulotomy for treatment of chronic, severe, treatment-resistant obsessive-compulsive disorder (OCD) in adult patients who have failed at least three selective serotonin reuptake inhibitors (SSRIs).**

**Contraindications: Contraindications include patients who will be exposed to MRI using a full body radio-frequency (RF) coil or a head transmit coil that extends over the chest area, and for patients who are unable to properly operate the neurostimulator. Also, diathermy (e.g., shortwave diathermy, microwave diathermy or therapeutic ultrasound diathermy) is contraindicated because diathermy's energy can be transferred through the implanted system (or any of the separate implanted components), which can cause tissue damage and can result in severe injury or death. Diathermy can damage parts of the neurostimulation system. Transcranial Magnetic Stimulation (TMS) is contraindicated for patients with an implanted DBS System.**

**Warnings/precautions/adverse events:**

**Electroconvulsive Therapy (ECT) – The safety of ECT in patients who have an implanted deep brain stimulation (DBS) system has not been established. Induced electrical currents may interfere with the intended stimulation or damage the neurostimulation system components resulting in loss of therapeutic effect, clinically significant undesirable stimulation effects, additional surgery for system explantation and replacement, or neurological injury.**

**There is a potential risk of tissue damage using stimulation parameter settings of high amplitudes and wide pulse widths. Extreme care should be used with lead implantation in patients with a heightened risk of intracranial hemorrhage. Do not place the lead-extension connector in the soft tissues of the neck. Placement in this location has been associated with an increased incidence of lead fracture. Theft detectors and security screening devices may cause stimulation to switch ON or OFF, and may cause some patients to experience a momentary increase in perceived stimulation. Severe burns could result if the neurostimulator case is ruptured or pierced. The safety of somatic psychiatric therapies using equipment that generates electromagnetic interference (e.g., vagus nerve stimulation) has not been established. The Reclaim DBS System may be affected by or adversely affect medical equipment such as cardiac pacemakers or therapies, cardioverter/ defibrillators, external defibrillators, ultrasonic equipment, electrocautery, or radiation therapy. Patients should be monitored for at least 30 minutes after a programming session, for side effects, including: autonomic effects (e.g., facial flushing, facial muscle contractions, or increased heart rate), hypomania, increased disease symptoms, sensations such as tingling, smell, or taste. In addition, during treatment, patients should be monitored closely for increased depression, anxiety, suicidality, and worsening of obsessive-compulsive symptoms. The safety and probable benefit of this therapy has not been established for patients with: Tourette's syndrome, OCD with a subclassification of hoarding, previous surgical ablation (e.g., capsulotomy), dementia, coagulopathies or who are on anticoagulant therapy, neurological disorders, and other serious medical illness including cardiovascular disease, renal or hepatic failure, and diabetes mellitus. In addition, the safety and probable benefit has not been established for these patients: those whose diagnosis of OCD is documented to be less than 5 years duration or whose YBOCS score is less then 30, who have not completed a minimum of 3 adequate trials of first and/or second line medications with augmentation, who have not attempted to complete an adequate trial of cognitive behavior therapy (CBT), who are pregnant, under the age of 18 years, and who do not have comorbid depression and anxiety. Physicians should carefully consider the potential risks of implanting the Reclaim DBS System in patients with comorbid psychiatric disorders (e.g., bipolar, body dysmorphic, psychotic) as the Reclaim DBS System may aggravate the symptoms. Additionally, the abrupt cessation of stimulation for any reason should be avoided as it may cause a return or worsening (i.e., "rebound" effect) of disease symptoms. Serious adverse events related to the therapy, device, or procedure can include: suicidality/increased depression, increased OCD/fluctuating results, intracranial hemorrhage, lead/extension failure, aggression/violent behavior, accident proneness, irritability, death, hypomania, infection, pyelonephritis, and post-operative seizure. Adverse events related to the therapy, device, or procedure can include: coma, paralysis, pain or discomfort at incision/implant sites, general post-op discomfort, GI symptom (post op), increased anxiety, insomnia, cognitive disturbance (clouding), induced muscle contraction, restlessness, stimulation induced paresthesia, device migration, shocking or jolting stimulation, induced sensation of taste/smell, weight gain, increased fatigue, upper respiratory infection, headaches, dizziness, dry mouth, itching at surgical site(s), nausea, sedation, and weight loss.**

**Humanitarian Device: Authorized by Federal (U.S.A) law for use as an adjunct to medications and as alternative to anterior capsulotomy for treatment of chronic, severe, treatment-resistant obsessive-compulsive disorder (OCD) in adult patients who have failed at least three selective serotonin reuptake inhibitors (SSRIs). The effectiveness of this device for this use has not been demonstrated. USA Rx Only Rev 1009**

# The Science and Practice of LSVT LOUD & BIG Programs

Lisa Halpin
Julie Lombardi

# The Science and Practice of LSVT LOUD®:

## Speech treatment for Parkinson disease

•**Lisa Halpin MS, CCC-SLP**

•**The Centers at St. Camillus**

Supported, in part by research grants:
R01 DC01150, R21 RFA-NS-02-006, R21 DC006078, R21 NS043711

# Objectives of Presentation

•Explain advances in neuroscience and impact on the field of rehabilitation

•Discuss development and data on an efficacious speech treatment LSVT LOUD

•Briefly describe development and key aspects of limb motor treatment LSVT BIG

•Outline future directions and alternative modes of treatment delivery using technology

# It is a "Stunning Time" to be in rehabilitation today

Basic science evidence for the value of exercise in PD (classically drugs, surgery, today…)

Identified key principles of exercise that drive activity-dependent neural plasticity

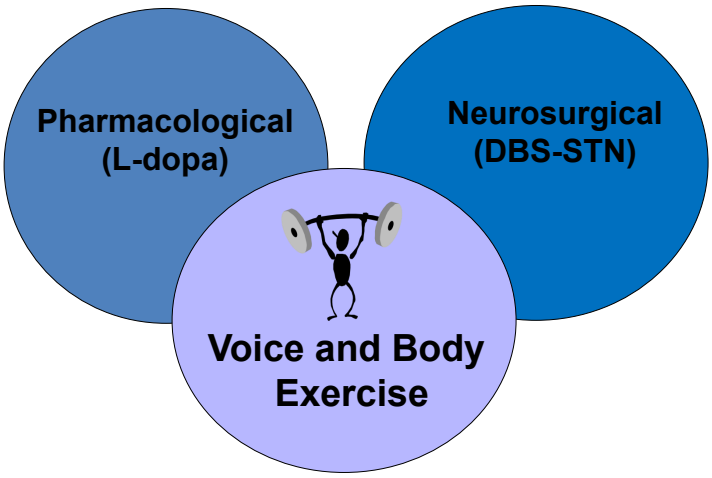
Demonstrated that exercise can improve brain functioning (neural plasticity) and may slow disease progression

**Exercise is Medicine!**

Kliem & Jones, 2008; Ludlow et al, 2008

# Legitimate Therapeutic Options

To provide symptomatic relief; improve function




Zigmond et al, 2009

## Video Example:

59 year old female
2.5 years post-diagnosis
On-meds pre and post video

Pre/post LSVT LOUD
(Lee Silverman Voice Treatment)
Intensive physical exercise of speech mechanism

Video "Short Shirley"

## 1. Background and development

- **Critical need for**
- **Speech treatment in PD**

**"If only we could hear and understand her"**

**Family of Mrs. Lee Silverman 1987**

# BACKGROUND ON LSVT 1987

"Lee Silverman Center
for Parkinson's"
Scottsdale, Arizona
Carolyn Mead Bonitati
M.A., CCC-SP

6 Million people
with PD worldwide

**89% have a speech or voice problem**
**(Logemann et al.,1978)**

**4% receive traditional speech therapy** **(Hartelius & Swenson, 1994; Oxtoby, 1982)**

# Consensus 1990:
# Speech treatment
## (articulation and rate at low dosage)
# does not work

**(Sarno, 1968; Allan, 1970; Green,1980; Aronson, 1990;**

**Weiner & Singer, 1989)**

Surgical and Pharmacological Treatment doesn't improve speech in PD

**Pharmacological: L-Dopa, dopamine agonists**

**Surgical: Fetal Cell Transplant,**
**Deep Brain Stimulation (DBS)**

**Informal survey 25-60% speech worse after DBS (PA)**

**Medical interventions effective on limbs, unestablished effects on speech**

**(Leanderson, Meyerson, Persson, 1971; Solomon & Hixon, 1993; Larson, Ramig & Scherer, 1994; Larson, Ramig & Johnson, 1994; Freed et al., 1992; Goberman, 2005; Trail et al., 2005; Pinto et al., 2004; Sapir et al., in press; Krack et al., 2003; Wang et al., 2003; Rousseaux et al., 2000)**

## Creating a treatment that works

- **A journey from discovery through efficacy**
- **LSVT LOUD: The fundamentals of therapy**
- **LSVT LOUD Outcomes: Efficacy data**

# Speech Characteristics in PD

Reduced loudness
Hoarse voice quality
Monotone
Imprecise articulation
Vocal tremor
(Darley et al, 1969a; 1969b; 1975; Logemann et al, 1978)

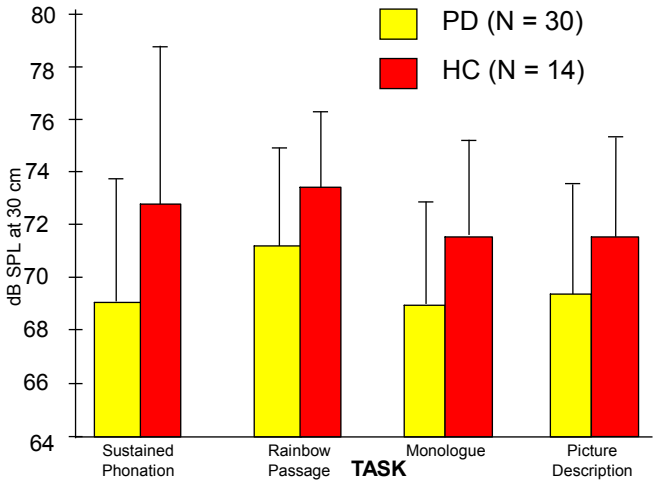
Some patients report volume, hoarse voice or monotone as the first PD symptom
(Aronson, 1990)

(perceived as bored, disinterested, apathetic)

Mean vocal SPL for subjects with PD and HC

**PD are 2-4 dB less than HC across tasks**

(Fox and Ramig , 1997)




**PD less likely to participate in conversations or have confidence in voice**

**PD=30, HC=14 (Fox and Ramig, 1997)**

# Does this speech problem matter?

- **"if I have no voice, I have no life"**
- **-Natalie**
- **"No one listens to me anymore"**
- **-Shirley**
- **"… people with PD live for years frustrated by communication impairment, withdrawal, social isolation and embarrassment "**
- **(Miller et al., 2006)**

## 20+ year journey from invention to scale-up

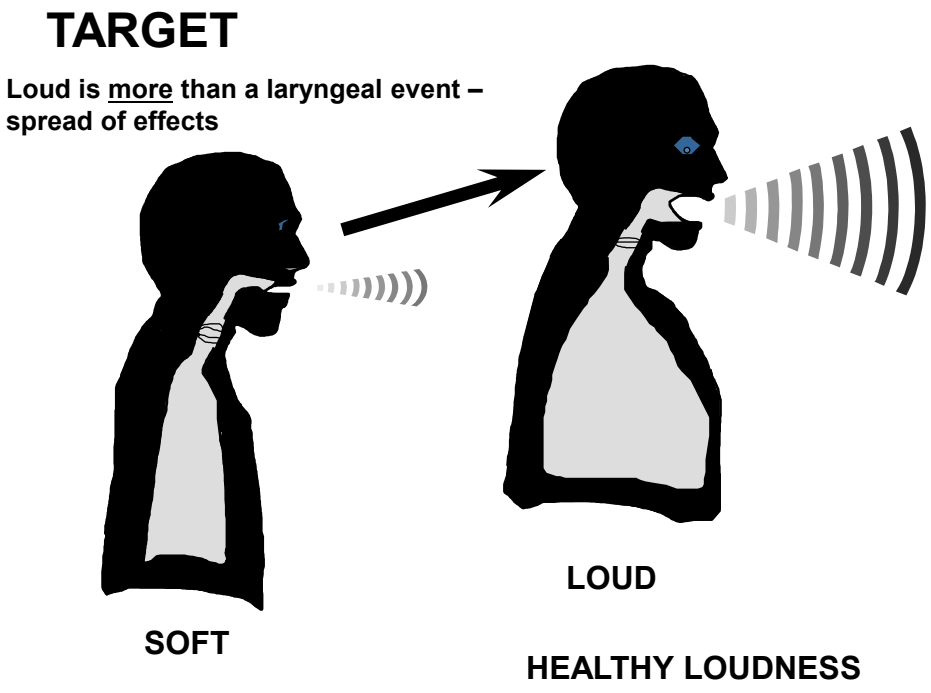
Over 8 million dollars in NIH funding

Phase I, II
- 1987-89: Initial invention; Pilot data (Scottsdale)
- 1989-91: Office of Education OE-NIDRR

Phase III
- 1991-94: OE-NIDRR
- 1990-95: NIH funded RCT Efficacy
- 1995-00: NIH funded EMG, Kinematics
- 2002-07: NIH funded RCT Spread of effects
- 2007-12: NIH funded RCT, imaging

Phase IV, V
- 2001-02: Coleman Institute (PDA; LSVTC)
- 2002-04: NIH and Michael J FOX Foundation (R21)
- 2002-04: Coleman Institute (VT; LSVTVT)
- 2004-06: NIH LSVTVT (R21)
- 2004 : Coleman Institute (LSVT Down Syndrome)
- 2004-07: LSVT–Dissemination
- 2006: Technology-enhanced Clinician Training (SBIR)

# LSVT LOUD


TARGET
Loud is more than a laryngeal event – spread of effects
SOFT
LOUD
HEALTHY LOUDNESS

## MODE

Intensive High effort

**Intensive dosage and within sessions**

High effort

Repetitions
Force/resistance
Accuracy
Fatigue

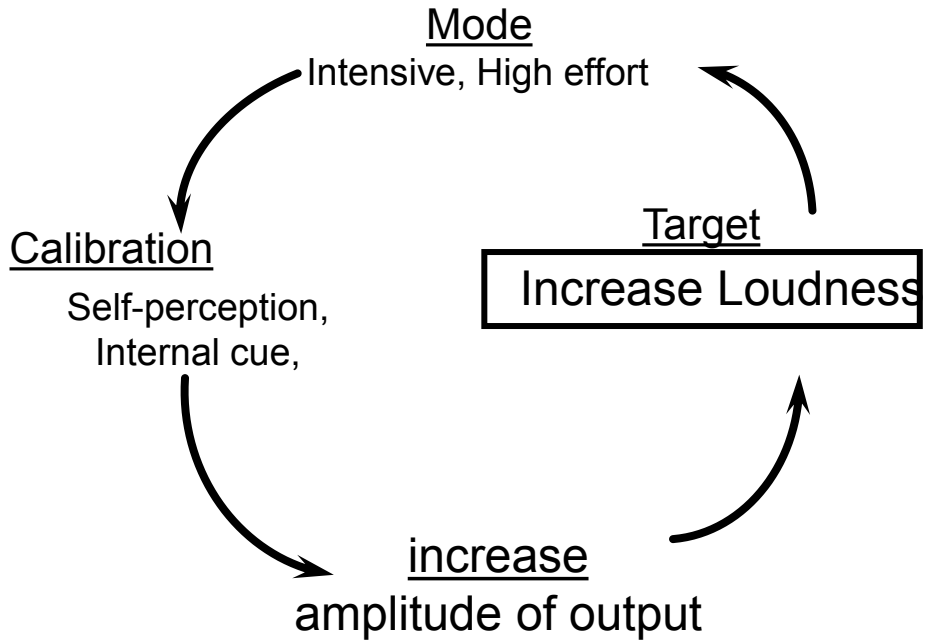
What do data say?
Intensive practice is important for maximal plasticity
(Kliem & Jones, 2008)

## CALIBRATION

MISMATCH between on-line perception of output and how others perceive it

"I'm not too soft"
"I can't speak like this, I am shouting!!"

**Fox et al, 2002; Sapir et al, 2011**



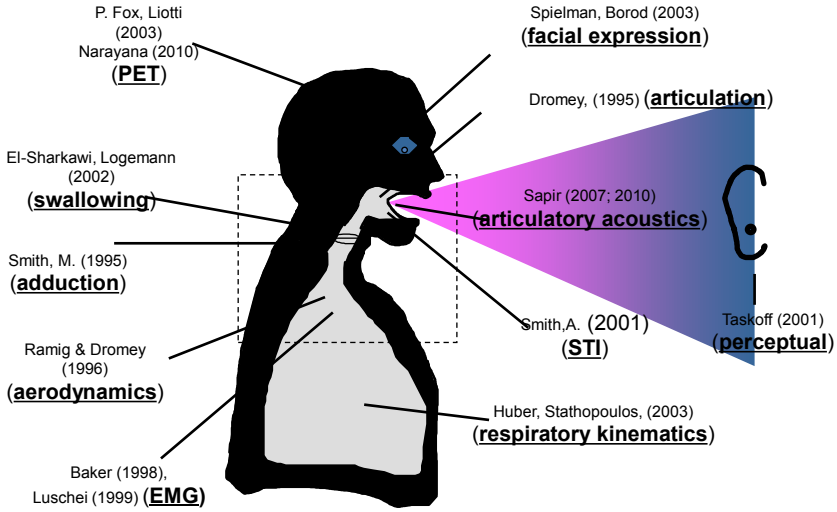

# LSVT LOUD Outcomes

- **Efficacy data**

## Advances in Clinical Efficacy

(Ramig et al, 1995; 1996; 2001a; 2001b; Goetz, 2003)

## Cross-system effects, Neural changes

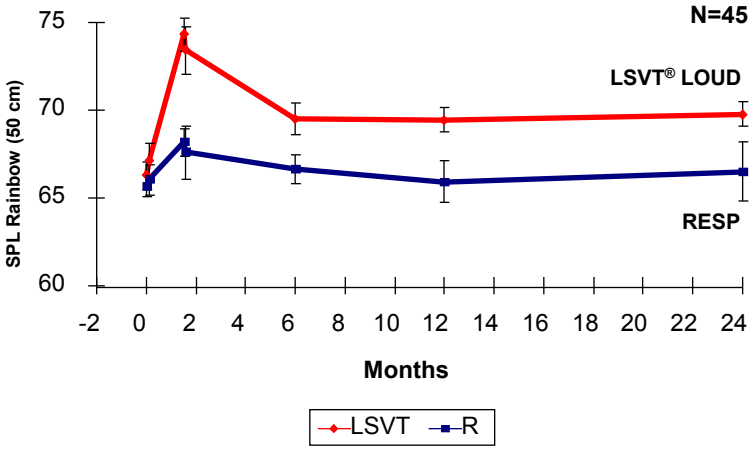



## Long-term follow-up?
## CONVENTIONAL WISDOM

"Changes in treatment room disappear on the way to the parking lot"

(Allan, 1970; Sarno, 1968)

**Ramig et al., 2001; J Neurol, Neurosurgery, Psychiatry**
**Level 1 Evidence Goetz,2003**




Blinded, no med change
Same time med

## 2. Unexpected outcomes:

## System-wide spread & Insight into Basic mechanism

- **Articulation** **Swallow**
- **Rate** **Face**
- **Speech Motor Stability** **PET**

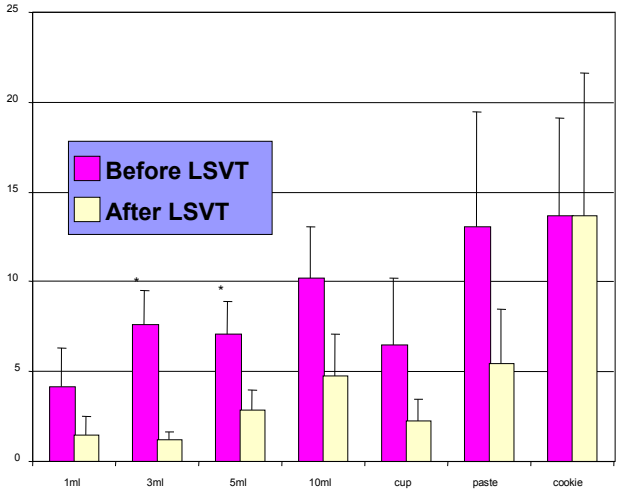
- (Spielman, et al. 2002; El-Sharkawi, 2002; Spielman et al., 2003; Kleinow et al., 2001; Liotti et al., 2003)

## SWALLOWING PRE POST LSVT® LOUD

**Approximate oral residue percentage (ORES)**

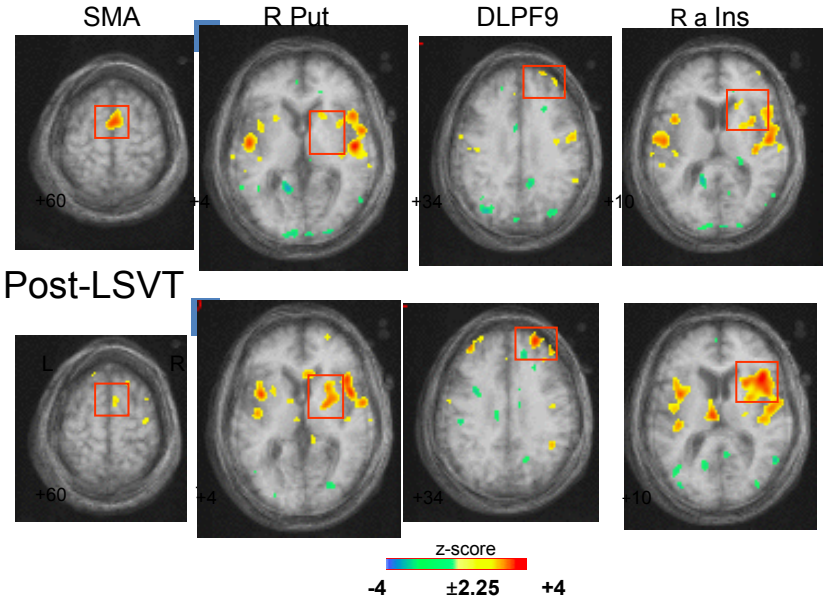
***=p<0.05**

- **El-Sharkawi**
- **et al (2002)**




## Phonation Task - PD N=5

Liotti et al, 2003; Neurology



- **To a patient……major life impact**

- **"My voice is alive again"**
- **"I can talk to my grandchildren!"**
- **"I feel like my old self"**
- **"I am confident I can communicate!"**

## What are the LSVT LOUD exercises?

**Daily tasks**

First half of treatment session
Rescale amplitude of motor output through CORE Loud

**Sustained "ah" (minimum15 reps)**
**High/Low "ah" (minimum15 reps)**
**Functional phrases (minimum 50 reps)**

**Hierarchical speech tasks**

Second half of session
Train amplitude from CORE exercises into in context specific and variable speaking activities

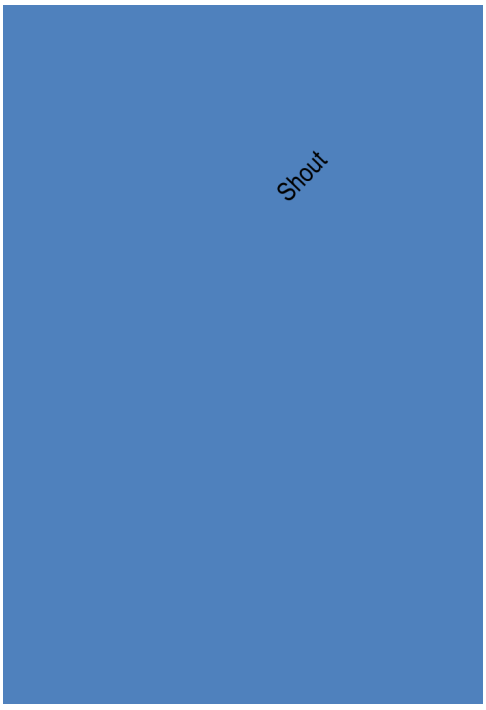
**Week 1 – words, phrases**
**Week 2 – sentences**
**Week 3 – reading**
**Week 4 - conversation**

Shorter, simple

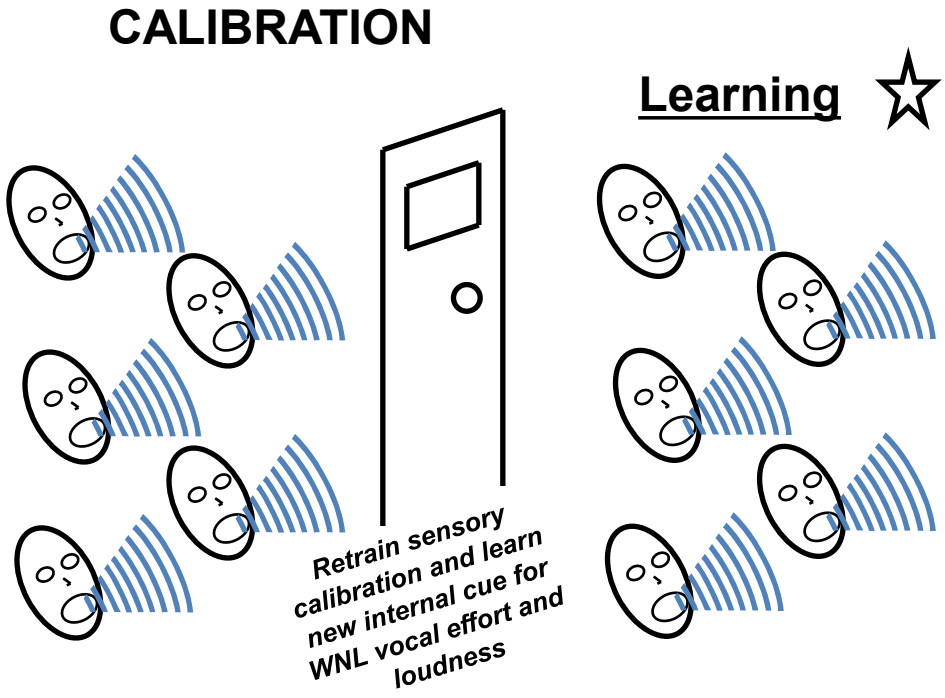
Longer, more complex

# Speech Hierarchy

Week 1 – words/phrases
short/simple conversation –
bridge gap to conversation
Week 2 – sentences/reading
short/simple conversation
Week 3 – reading/conversation
Week 4 – conversation



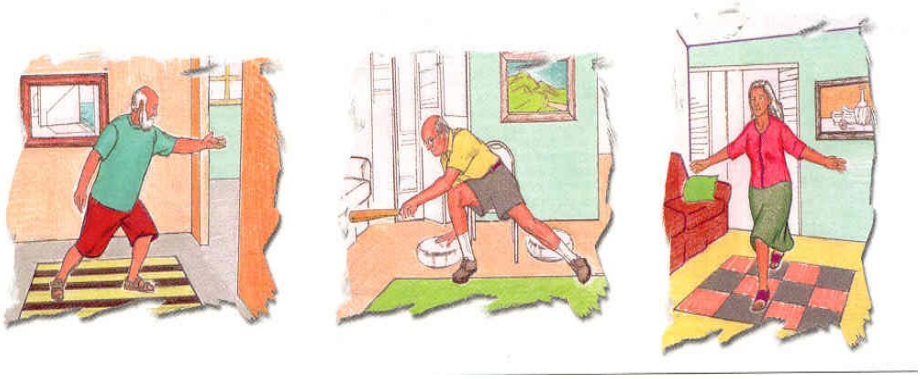
***If you don't feel like you are talking "too loud" you are not talking loud enough!!***



# 3. Fundamentals of treatment generalize to:

- **Other systems (limb motor)**

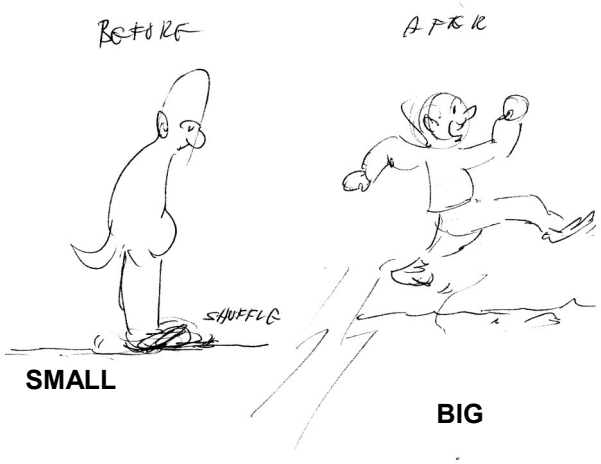
**LSVT LOUD®** ➡ **LSVT BIG ®**



(Ebersbach et al, 2010; Farley & Koshland, 2005; Fox, et al., 2012)

# *TARGET*

**<u>BIG (Large amplitude whole body movement)</u>**
**Single Target - Triggers Activation across motor systems**




# *MODE*

- <u>Delivery</u>
  - Certified LSVT BIG Physical/Occupational Therapist
    - 1:1 intervention
- <u>Time of Practice</u>
  - 4 consecutive days per week for 4 weeks
  - 16 sessions in one month
  - 60 minute sessions
  - Daily carryover assignments (30 days/entire month)
  - Daily homework (30 days/entire month)

## *CALIBRATION*

MISMATCH between on-line perception of output and how others perceive it

*"I had no idea how small my world had become"*

*"I can't move like this, people will think I am crazy!!"*

## Patient case: Bernie

- 71 year-old, diagnosed with Parkinson's disease in 1994
- Reason for referral: slowness and difficulty walking, history of falls, freezing
- Optimized on PD medications
- Hoehn & Yahr 3

# LSVT Walk BIG

## Case Study Outcomes:

| | PRE | POST |
|---|---|---|
| • Falls | 1-2/month | 0/month |
| • Assistive device | Cane | None |
| • Gait Velocity m/s | 0.35 m/s | 1.17 |
| • % of age matched norm | 29.6 % | 100% |
| • Endurance | 730 ft | 1200 ft |

To improve his walking
To go to the movies
To play with his grandchildren
To go out to dinner with friends and family

**Comparing Exercise in Parkinson's Disease — The Berlin BIG Study** (2010, Movement Disorders)

Georg Ebersbach,* Almut Ebersbach, Daniela Edler, Olaf Kaufhold, Matthias Kusch, Andreas Kupsch, and Jo¨rg Wissel[3]

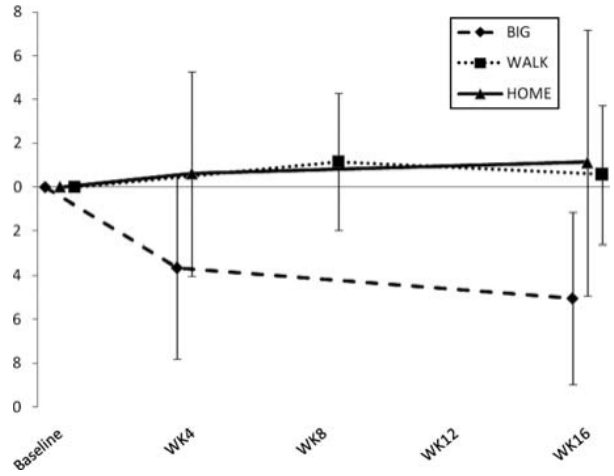
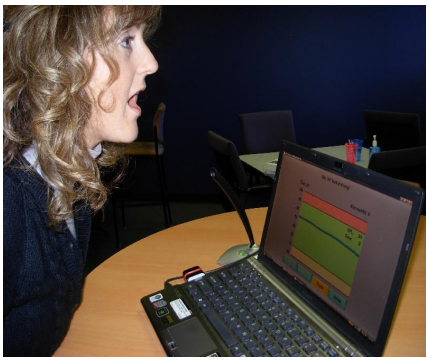



FIG. 2. UPDRS motor score (blinded rating), mean change from baseline (vertical bars 5 standard deviations). Change between baseline and follow up at week 16 was superior in BIG (interrupted line) compared to WALK (dotted line) and HOME (solid line), P <0.001. ANCOVA did not disclose significant differences between in intermediate and final assessments.

# Future Directions

- LSVT Programs and Technology (telepractice and software programs)



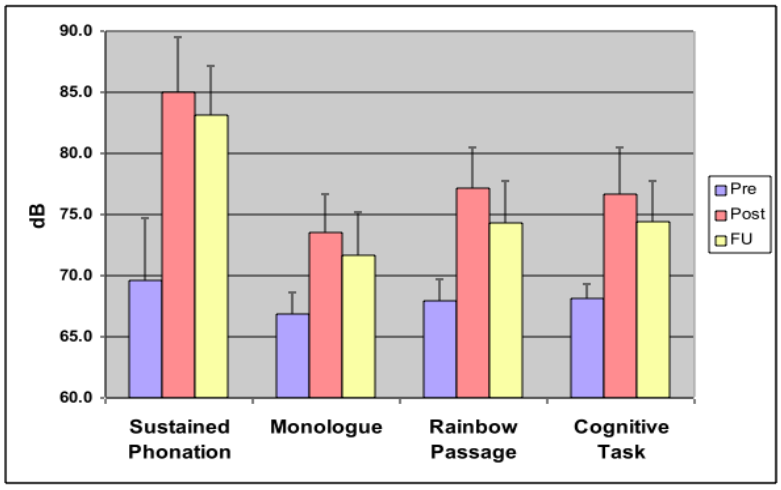
**LSVT eLOUD** **LSVT Companion**

Telepractice

**Funded by: NIH-NIDCD & Michael J. Fox Foundation**

**www.LSVTGlobal.com**

## Pre, Post, 6 month dB SPL ($p < 0.001$)




**Changes consistent with those reported in previously published data (Halpern et al., 2012)**

# Summary


•Advances in neuroscience have provided evidence supporting the positive impact of exercise-based protocols in people with PD

•LSVT Programs have been developed and studied over the past 20 years

•LSVT LOUD has well established efficacy and is considered Level 1 evidence for speech treatment in PD

•LSVT BIG is one type of physical therapy program that has potential to offer improvements in movement and quality of life for people with PD

•Technology will assist with accessibility


# How to get started with LSVT LOUD and LSVT BIG

Ask your doctor for a referral and a prescription for a speech or physical/occupational therapy **evaluation** and **treatment**

Visit www.lsvtglobal.com to find an LSVT LOUD or LSVT BIG Certified Clinician in your area (as per video demonstration)

DVDs available to introduce you to voice exercises used in LSVT LOUD and movement exercises used in LSVT BIG: www.lsvtglobal.com/products or www.amazon.com/shops/LSVTGlobal

*"If my possessions were taken from me with one exception, I would choose to keep the power of communication, for by it I would soon regain all the rest"*

*Daniel Webster*

# For More Information

info@lsvtglobal.com
www.lsvtglobal.com

# Live a Little Easier

Kevin Gagnon,
Marlene F. Reinmann

# Live a Little Easier

Equipment

Games

Smartphone Applications

## Consult a Professional

- There is an vast selection of equipment available now to help individuals overcome obstacles limiting their daily activities. You may find them on the internet, in catalogs and in many stores. It is important to remember that just because something looks as though it may be helpful, it may not be the most appropriate "tool" for your situation.
- Consider having a thorough assessment by an occupational or physical therapist to ensure the right equipment is selected for your personal needs and strengths. Consider visiting a local durable medical equipment retailer to personally try and review equipment and to discuss your personal needs.
- A specialist can help make sure equipment is properly installed and can provide training on how to safely use the equipment. Purchase and installation of grab bars and poles should be based on your personal strengths and the structure of your home.

- The following is not an endorsement of any of the products or websites.
- We want to encourage you to explore the recourses available to help you live each day a little easier by talking with professionals, using the internet and visiting local retailers.
- Take advantage of community education and support groups to meet friends who are also dealing with similar issues and can share what they have found and what is working for them.

# Medication Reminders

**Medcenter 31 day with alarm**


**Dispill Program – Brewerton Pharmacy**

# Writing

**Pen Again**

**Steady Write**

# Computer

There are many different options for computer keyboards that can make typing easier. Key guards allow one to rest their hands right on top of the keyboard and access keys by placing their fingers through each hole. This reduces typing mistakes and provides a great place to rest when fatigue sets in. Computer programs such as Steady Mouse or optional equipment such as a Roller Mouse are also available.

**Keyboard guards**

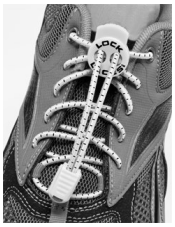
**Large Keyboards**

**Roller Mouse**

# Clothing and Shoes

**Button & Zipper Tool**

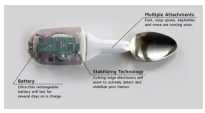
**Elastic Lock Shoe Laces**



There are many websites that offer clothing with adaptive closures such as Velcro. You can search "adaptive clothing."

# Silverware & Cups

**Liftware**



**Weighted Silverware**

**Cup with Lid & Straw**

**Lift Labs** (San Francisco, CA) has developed patented spoon technology that stabilizes tremors from Parkinson's Disease to allow patients to enjoy their meals again. According to Lift Labs website: "The Liftware Spoon is the most practical and effective spoon for people living with Essential Tremor, Parkinson's, or other disorders. With Liftware, the spoon is kept steady using our innovative Active Cancellation of Tremor technology." There are local resources where you can try Liftware before you buy it. Liftware is successful in 2 out of 5 cases, it doesn't respond as well to weak tremors and does not work if you try to use your finger to stabilize it.

# Chair Lifts & Chair Canes

Lift chairs can help with the difficulty of standing up from a seated position by bringing your "butt above your knees" which is the key to standing up with more ease.

# Bedroom

**Pull Strap**

**Rail Assists**

# Bathroom

**Grab Bars**

**Pole Assists**

Grab bars don't have to be ugly! But they do need to be installed properly. Remember to consult your PT or OT for appropriate placement depending on your personal strengths and have a professional install them for your safety. An improperly installed grab bar is more dangerous than helpful.

# Bathroom

**Hand Held Shower Wand**

**Long Handled Scrubbers**

# Vehicle

**Handy Bar**

**Swivel Seat**

**Belt Extender**

# Fun & Games

**Make sure to build in time to enjoy the activities you love and don't forget to keep trying new activities!**

# Fun & Games

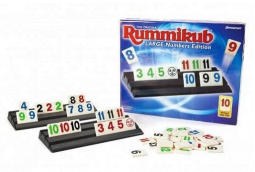
**Card Holders and Card Shufflers**

Use the internet to search for games that many retailers do not stock in store but have available online. Check out Walmart, Target, Kohls, Amazon, LLBean and Bed, Bath & Beyond

# Fun & Games

**Large Scrabble**

**Large Rummikub**




**Magnetic Dominoes**

**Shut The Box**

# On the Horizon

- Path Finder is a shoe that projects laser lines to trigger walking and prevent 'freezing of gait' (FoG), a common symptom of Parkinson's disease. The laser cues are activated by pressure observed when the wearer touches down on the ground. In this way, the standing foot projects a line for the opposite foot, i.e. the left foot will project for the right foot to take a step forward and vice versa. It is believed that the visual cues are able to trigger gait by focusing the attention of the wearer.
- We are currently at prototyping stage and have developed a partnership with an academic institute in The Netherlands, Radboud University, with whom we will conduct patient testing.
- Our initial results are very encouraging, so there is a great potential for the product to benefit users. This will increase quality of life and reduce the risk of falling, impacting both users and their families. Following successful user trials, we will seek regulatory approvals to establish Path Finder as a medical device, so that it can be recommended by healthcare professionals. We aim to have it on the market in approximately two years.
- View this full article at – "Parkinson's Life" January 2016

# Smartphone Application

- Lift Labs has also developed an app to help Parkinson's patients to walk called Lift Stride. The app allows patients to adjust the cadence of a beat to just above their walking speed. Patients can dabble with the settings till they find a pace that works right. The app is said to work best with a Bluetooth headset.

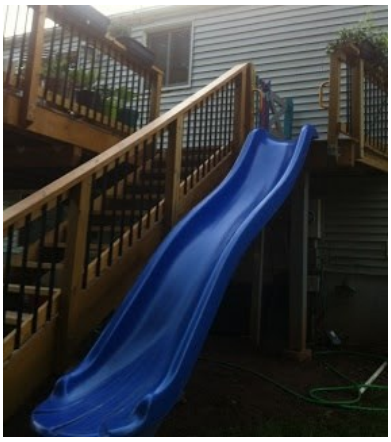
- With almost half of the US owning a Smartphone (and quickly growing), we thought there had to be an elegant solution that we could offer. So, we came up with Lift Stride – a free Smartphone app for Parkinson's disease (available for Iphone and android). Our app is very simple. All you have to do is turn it on, adjust the cadence to just above your walking speed. You can play around with the setting until you find a pace that works right. The app works best with a Bluetooth headset (which is very discreet and does not look like a medical aid). We are keeping the app free (with zero ads). Our hope is that it will help spread awareness of our company, our talent, and our exciting upcoming products.

- View this full article at socalmds.com March 26, 2013 search "lift stride Parkinson's "

# Smartphone & IPads

- Search "Best Apps for Parkinson's Disease"
- By using the microphone button on an Ipad keyboard your words will be typed in as you speak
- Create Shortcuts for phone numbers with "Parkinson's EasyCall"
- Use apps such as "ShopShop" to create a permanent shopping list to access repeatedly
- Utilize YouTube or your Ipad to have books read aloud to you

# Be Innovative



Or at least keep your sense of humor! Obstacles are a part of life whether you are 2 or 72. Utilize the resources in your community, family and on the internet to help find ways to attain your goals.

# Parkinson's Dance: Moving Through Possibilities

Tumay Tunar &
The Parkinson's Dance Group

# Notes

# Thank You For Attending!

# PARKINSON'S DANCE

## *MOVING THROUGH POSSIBILITIES*

*For those with Parkinson's & their Caregivers, Friends & Family*

# *Free dance class!*

EVERY **Thursday from 1:45 to 3:00 p.m.**
at the **Dance Theater of Syracuse**
117 Harvard Place Syracuse, NY (Near Westcott St.)

Contact: Tumay Tunur (504) 570-0752
ParkinsonsDance@yahoo.com

Visit our website at: http://parkinsonsdance.weebly.com

ongov.net

DANCE THEATER OF SYRACUSE

SYRACUSE UNIVERSITY SCHOOL OF EDUCATION

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