

# Parkinson Voice Enhancing Lives, Connecting Communities

## **Stress & Parkinson's**

By Monique Giroux, MD, Movement & Neuroperformance Center

Stress can impact symptoms of Parkinson's disease. It is not uncommon for the first symptoms of Parkinson's disease to emerge at the time of a significant life stress or for stress to worsen symptoms such as tremor, dystonia, dyskinesia or freezing of gait. Stress can also worsen non-motor symptoms such as pain, depression, anxiety, sleep and digestion. Most importantly, stress can have a long-term impact that may influence your emotional outlook, motivation, sense of hopefulness, ability to problem solve, see the positive, your lifestyle choices and resiliency to overcome obstacles in life.

How stress influences Parkinson's disease is not clear but evidence points to compensatory changes in brain and neurologic activity, cellular health and the physiologic influences of chronic stress on emotions and body function.

#### **Neurologic Control of Stress**

Your nervous system is constantly adapting and changing as it responds and reacts to your environment, activities, thoughts and emotions. When dealing with a stressful situation, these physiologic changes help your body deal physically, emotionally



and cognitively. When stress is short-lived, these changes are necessary and adaptive. However

when stress is prolonged these physiologic changes can threaten your health.

The neurologic control of stress is a complex one, involving specific regions of the brain and the autonomic nervous system. Every awake moment of every day is filled with a cascade of emotional, cognitive and physical experiences which are registered by this complex network of neurons. A situation representing a potential threat can serve as a control switch to preferentially engage one branch of the autonomic nervous system.

These branches are defined by their action. The key to health is a balance of these systems:

- 1. Sympathetic nervous system engages the fight or flight response.
- 2. Parasympathetic system engages the relaxation response.

Continued on page 2

### **Colorado Gives Day** 24 Hours to Give Where You Live

Mark your calendars for Tuesday, December 8th as a reminder to support our community through Colorado's Annual Day of Online Giving! Each year Coloradoans come together to raise millions of dollars for nonprofits like ours and with your support we can reach our goal of raising \$30,000 in just 24 hours!

This unique opportunity allows you to give to your favorite, approved Colorado Gives Day charities through the Colorado Gives website, *www.ColoradoGives.org*. When you give online any time on December 8th - the Colorado Gives Day partners, Community First Foundation and First Bank, will cover all credit card and processing fees. Additionally, the value of your donation will be increased by the one million dollar incentive fund, provided by these partners.

#### Worried you'll forget?

Preschedule your gift today! All charges will be processed on December 8th to "give where you live!"



Mrs. Shaky

Paws Top 10

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Duopa Therapy How Can You Give Today?

### Stress & Parkinson's from page 1



The fight or flight stress response is an adaptive response that increases your breathing, heart rate, blood pressure, level of alertness and muscle tension to allow your body to function at a heightened level of performance during a time of perceived threat. The relaxation response balances the sympathetic system reducing blood pressure, heart rate, breathing and muscle tension allowing your body to return to a restorative and rejuvenated state.

This dual system of neurologic control works well for acute stress allowing mind and body to take action during times of stress or threat, and to rest once the threat or stressful event is resolved. Problems arise when we experience chronic stress. Chronic stress shifts the natural balance toward an overactive sympathetic response with fewer times of recovery.

Modern life brings many stressors with busy jobs, traffic, increasing demands, unmet expectations, financial insecurities, multitasking, worrying about the future and even loneliness. Living with a chronic disease adds to this stress. If left unchecked, an overactive sympathetic nervous system leads to a sustained increase in stress hormones especially one called cortisol. Chronic stress and elevated cortisol levels can cause anxiety, fatigue, depression, sleep problems, muscle pain (especially in the back, shoulders and neck), weight problems, ulcers, high blood pressure and heart disease.

#### Stress and Parkinson's disease

Stress can worsen movement and non-motor symptoms of Parkinson's disease. It is unknown if stress plays a direct role in the neurodegeneration seen with Parkinson's disease; research suggests that this may be the case. Research linking stress to Parkinson's disease or brain health includes:

- Cortisol stress hormones are elevated in people with Parkinson's disease compared to age matched individuals without Parkinson's disease.
- Chronic stress causes brain atrophy in crucial areas of the brain important for learning, movement and emotional reasoning.
- Telomeres (protective caps at the ends of genes that influence cell health, aging and even cell death) are reduced with stress.
- In animal models of Parkinson's, stress blocks the protective effect of exercise.

#### **Reduce the Impact of Stress on Your Health**

You cannot remove all stress from life but you can change how you react to stress. Stress is a part of life. Research suggests that it is not simply the presence of stress in one's life that can influence disease but more importantly how you deal with the stress. Understanding what causes excessive stress in your life, and how your body reacts to stress, is an important first step. You may notice that your Parkinson's symptoms feel better when you are relaxed, enjoying a particular activity or on vacation. This is the parasympathetic system at work!

Relaxation techniques help you balance sympathetic and adrenal overdrive by increasing the parasympathetic or relaxation response. Mind-body techniques include: cognitivebehavioral therapy, therapeutic yoga, tai chi, meditation, breathwork, guided imagery, hypnosis or gratitude exercises (such as journaling and social support). Utilizing techniques like these help you gain control over the moment, reduce the impact of stress, increase your emotional and physical resiliency and help you see positive solutions to your problems. Relaxation techniques influence the autonomic nervous system to reduce the sympathetic fight or flight response and engage the parasympathetic or relaxation response.

The holiday season is upon us and with that comes added stress. Try using the above techniques to reduce your stress.

#### <u>Resource</u>

*Optimal Health with Parkinson's A Guide to Integrating Lifestyle, Alternative and Conventional Medicine,* Dr. Monique Giroux.

This comprehensive text, to be released in November, is the first book to be published in the emerging and important field of Integrative Medicine and Parkinson's disease.

You can learn more about this book and get helpful worksheets on stress management and brain health at www.DrGiroux.com.

### Save the Date for the 14th Annual Vitality Walk Two Sites • 2,000 Steps • One Unforgettable Experience!



Sunday, June 5th 2016 | 9:00am

Wash Park, Denver | Sandstone Ranch, Longmont | Choose to Snooze Walk the Walk that Connects Community and Enhances Lives. Walk the Vitality Walk!



## **Care Partner Support Groups**

Contact the Parkinson Association of the Rockies at (303) 830-1839 | Info@ParkinsonRockies.org for contact information for support group leaders.

#### BROOMFIELD Friday after the 1st Tuesday of every OTHER month 10:30am Broomfield Community Center 280 Spader Way

COLORADO SPRINGS **3rd Friday • 1:30pm** Care & Share Building 2605 Preamble Pt. DENVER 4th Wednesday • 6:30pm (Nov. and Dec. meets on 3rd Wednesday) Scheitler Recreation Center

5031 W. 46th Ave.

#### ENGLEWOOD MSA/PSP/CBD 4th Friday • 10:00am Johnson Adult Day Center 3444 S. Emerson St.

LAKEWOOD **3rd Friday • 12:00pm** InnovAge Cody Center 8405 W. Alameda Ave.

#### LONGMONT

**1st Tuesday • 11:30am** Perkins Restaurant 2051 Main St. STEAMBOAT SPRINGS **3rd Thursday • 4:00pm** Contact the Parkinson Association

#### We care about Care Partners!

We're here to help, contact Cari Friedman, LCSW at (303) 861-1810 or CFriedman@ParkinsonRockies.org for tips for the care partner and respite care resources.

## **Parkinson Association Classes**

The Parkinson Association is pleased to offer the following exercise classes. A liability waiver from your doctor is required. There is a fee associated with most of the classes. *Not all classes meet every week*.

For more information, please call (303) 830-1839 or email Info@ParkinsonRockies.org.

#### Power Punch for Parkinson's Non-Contact Boxing

Wednesdays • 10:00 - 11:15am Denver Red Shield 2915 High St., Denver

#### Saturdays

9:15 - 10:30am 10:30 - 11:45am Denver Red Shield 2915 High St., Denver

**Saturdays** • 8:00 - 9:00am The Corner Boxing Club 5500 Central Ave. #115, Boulder

\*More classes coming soon to Fort Collins & Colorado Springs

#### Singing & Voice Classes Tremble Clefs

Wednesdays • 11:00 - 12:00pm Valmont Community Church 3262 61st St., Boulder

#### **Good Vibrations**

**Thursdays** • 1:00 - 2:00pm LifeCare Center of Aurora 14101 E. Evans Ave., Aurora

#### LOUD for LIFE

**Mondays** • Afternoons Our Father Lutheran Church 6335 S. Holly St., Rm. 300, Centennial Participants need to have previously received LSVT LOUD. For more information, contact (303) 534-0324

#### Yoga for Parkinson's

**Mondays** • 1:40 -2:40pm University of Colorado, Stapleton Clinic 3055 Roslyn St., 1st Floor, Denver

Tuesdays • 9:30 - 10:30am Littleton YMCA 11 W. Dry Creek Ct., Littleton

#### Wednesdays

11:00 - 12:00pm 12:30 - 1:45pm Scheitler Recreation Center 5031 W. 46th Ave., Denver

**Thursdays** • 11:00am Yoga Center of Steamboat 701 Yampa Ave., Steamboat Springs

#### **B.E.A.T. High Intensity**

**Tuesdays •** 9:30 - 10:30am Fitness in the City 1212 Delaware St., Denver

**Thursdays** • 4:00 - 5:00pm 5700 W. 25th Ave, Edgewater

#### Rhythm and Grace Dance for PD<sup>®</sup> Mondays • 12:00 - 1:15pm Colorado Ballet 1075 Santa Fe Dr., Denver

#### PAR for the Course Exercise Balance & Strength Classes

*Higher Intensity:* for individuals early in the diagnosis of Parkinson's disease *Low Intensity:* for individuals who need assistance with mobility

#### **Tuesdays**

11:30am - 12:30pm, Higher Intensity 12:30 - 1:30pm, Low Intensity Schlessman YMCA 3901 E. Yale Ave., Denver

Wednesdays • 2:00 - 3:00pm Southwest YMCA 5181 W. Kenyon Ave., Denver

Wednesdays • 1:30 - 2:45pm United Methodist Church 36 Oak St., Steamboat Springs

**Thursdays** • 12:00 - 1:00pm Schlessman YMCA 3901 E. Yale Ave., Denver

Fridays • 9:00 - 10:15am United Methodist Church 36 Oak St., Steamboat Springs



# **Support Groups**

For Care Partner specific Support Groups, please visit page 3.

For Support Groups in Wyoming & Nebraska, please visit *www.ParkinsonRockies.org*. For more information on Support Groups and contact information for support group leaders, please call (303) 830-1839

#### ALAMOSA

**3rd Wednesday • 4:00pm** The Bridge 3407 Carroll St.

#### ARVADA

**3rd Thursday • 1:00pm** Community Recreation Center of Apex 6842 Wadsworth Blvd.

#### AURORA

**2nd Tuesday • 1:00pm** Life Care Center of Aurora 14101 E. Evans Ave.

#### BOULDER

**3rd Tuesday • 10:00am** East Boulder Senior Center 5660 Sioux Dr.

#### BRUSH

Quarterly Meetings Contact the Parkinson Association Eben Ezer Lutheran Care Center 122 Hospital Rd.

#### BROOMFIELD

**1st Tuesday • 10:10am** Broomfield Community Center 280 Spader Way

#### **BUENA VISTA**

**1st Saturday of ODD months 10:00am** 127 Hill St.

#### CEDAREDGE

2nd & 4th Wednesday • 9:30am Cedaredge Assembly of God 1596 SW 9th St.

#### CENTENNIAL

**Young Onset Group** Contact the Parkinson Association

**2nd Thursday • 10:30am** Holly Creek Fellowship Hall 5500 E. Peakview Ave.

#### **CHERRY HILLS VILLAGE**

Deep Brain Stimulation 2nd Friday • 1:00pm Bethany Lutheran Church 4500 E. Hampden Ave., Great Hall

#### **COLORADO SPRINGS**

**2nd Saturday • 10:00am** First Presbyterian Church 105 N. Weber St.

#### CORTEZ

**3rd Monday • 10:30am** Trinity Lutheran Church 208 N. Dolores Rd.

#### DENVER

Recently Diagnosed (1-3 years) 3rd Tuesday • 11:30am Christ Episcopal Church 2950 S. University Blvd., Barnes Hall

**2nd Thursday • 6:30pm** Bethany Lutheran Church 4500 E. Hampden Ave., Room 315

**4th Saturday • 9:30am** Jack A. Vickers Boys and Girls Club 3333 Holly St.

DURANGO 3rd Thursday • 1:00pm First United Methodist Church 2917 Aspen Dr.

#### **EAGLE VALLEY**

**4th Thursday • 5:00pm** Trinity Church of Edwards 90 Lariat Loop

ENGLEWOOD MSA/PSP/CBD Support Group 2nd Friday • 10:00am Johnson Adult Day Center 3444 S. Emerson St.

#### **ESTES PARK**

**3rd Tuesday • 2:00pm** US Bank Building 363 E. Elkhorn Ave.

#### EVERGREEN/CONIFER/ MORRISON 1st Friday • 1:00pm

Contact the Parkinson Association

#### FORT COLLINS

**1st Wednesday • 10:30am** Ft. Collins Senior Center 1200 Raintree Dr.

#### **GRAND JUNCTION**

**1st Wednesday • 3:30pm** First Christian Church 1326 N. 1st St.

#### GREELEY

**4th Thursday • 10:00am** Hope Pool & Physical Therapy Center 2780 28th Ave.

#### HIGHLANDS RANCH

**4th Tuesday • 10:00am** Highlands Ranch Library 9292 Ridgeline Blvd.

**3rd Friday • 10:00am** Wind Crest Community 3235 Mill Vista Rd.

#### LAFAYETTE

**4th Tuesday • 2:30pm** Exempla Good Samaritan Medical Center 200 Exempla Cir. (Check desk for room)

#### LAKEWOOD 4th Wednesday • 3:30pm Atria Inn at Lakewood

555 S. Pierce St.

#### LITTLETON

Last Wednesday • 10:00am Morning Star Senior Living 5344 S. Kipling Pkwy.

#### LONGMONT 2nd Wednesday • 10:00am

Longs Peak United Methodist Church 1421 Elmhurst Dr.

**1st Monday after the 2nd Wednesday • 6:00pm** Longmont Senior Center 910 Longs Peak Ave.

#### LOUISVILLE

Last Tuesday • 2:00pm Balfour Retirement Community 1855 Plaza Dr., Wellshire Center

#### LOVELAND

MSA/PSP/CBD 2nd Friday • 1:00pm Northern Colorado Rehab Hospital 4401 Union St.

#### MONTROSE

Last Monday • 2:00pm Montrose Memorial Hospital 800 S. Third St., Acute Rehab Unit

#### PARKER

**2nd Tuesday • 10:00am** Life Care Center of Stonegate 15720 Garden Plaza Dr.

#### **PUEBLO**

2nd Tuesday • 11:15am YMCA Campus 3200 E. Spaulding Ave., Community Room

#### SALIDA

1st Saturday of EVEN months 10:00am 205 G St.

#### STEAMBOAT SPRINGS

**2nd Monday • 5:00pm** Casey's Pond 2855 Owl Hoot Trail

#### **SUMMIT COUNTY**

**3rd Friday • 10:00am** Contact the Parkinson Association

#### WESTMINSTER

**1st Monday • 1:15pm** Covenant Village Retirement Community 9153 Yarrow St., Evergreen Room

#### WHEAT RIDGE

**3rd Wednesday (Sept-May) • 10:00am** Applewood Baptist Church 11200 W. 32nd Ave.

#### **WOODLAND PARK**

**3rd Saturday • 10:00am** Woodland Park Library 218 E. Midland Ave., 3rd floor, Board Rm.

# Party for Parkinson's - Party in the Gallery



On Thursday, October 15th, a perfectly crisp fall evening, our community came together to Party in the Gallery at the Artwork Network in the Denver Art District.

During the cocktail and social hour event guests tried their luck spinning the artist pallet at Win-a-Wine and attempted to guess the correct number of paint chips or colored pencils at Give-a-Guess. They also purchased vintage art postcards for prizes at Pick-a-Palooza. Guests enjoyed music from the live band and showed a bit of whimsy in the Photo Booth; all while sipping CherryTini's, the event's signature drink.

Following this, the guests feasted on a delicious cherry and festively fall themed dinner and desserts; then played Heads & Tails for a chance to win an iPad Air2 and placed their bids

during the Live Auction. The final auction item of the evening was "Cherries Jubilee", the event's signature art piece, which was painted and donated by Sally Prindonoff West. Sally also shared her journey of living with Parkinson's and how she is just one of the many faces of Parkinson's. She talked about living courageously and how, for her, creativity and painting helps her to focus in a more positive direction, rather than focusing on the challenges she now faces.

Sally shared, "Even though life's not always a bowl full of cherries and challenges are tough, it's important to be arateful for the cherries we have and celebrate each day to its fullest! My life has evolved in the last nine years (with Parkinson's), but the important point is that the Parkinson Association of the Rockies has been there to support me every step of the way as I have met new challenges. They are truly my lifelines in lending me a helping hand!"

We also took time to celebrate our accomplishments, which are only made possible due to the generosity of our supporters. The party concluded with quests helping to paint the future of the Parkinson Association; ensuring the Association continually adds to its pallet of programs and services to enrich and enhance our Parkinson's community.

We are overwhelmed by the generosity of event guests, you exceeded our expectations and we are deeply grateful for the brush strokes you've added to fill our canvas of future programs and services. Thank you to all our guests, volunteers and sponsors for making this lively celebration possible!

### **Special Thanks to Our Party Sponsors!**

**Celebration Sponsors** 















# Join Us for the Next Party!

### PARTY FOR PARKINSON'S - PARTY WITH A HOUSE (What house? The Gingerbread House!)

Welcome the holiday season and spread some cheer by joining us for a one-of-a-kind competition for the best decorated gingerbread house. Your participation in this event also generates critical community awareness of Parkinson's disease. Event participants will be provided with a pre-built gingerbread house, frosting and candy decorations. Everyone is also encouraged to add some flair to their house with personal decorations!

**\$25/House to Participate** Houses can be decorated by individuals or as a group



#### WHEN & WHERE

Saturdays in November & December | 9:00 - 10:30am November 14th | Denver November 21st | Aurora & Lakewood December 12th | Broomfield & Littleton

Space is Limited-REGISTER TODAY! More Info & Registration: www.ParkinsonRockies.org/HouseParty (303) 830-1839

Presented By: JACKSON USbank Hosted By: OLD CHICAGO

Sponsored By:

Party Partners: Carbon8, Denver Center for the Performing Arts, HighPointe Assisted Living & Memory Care, HomeWatch CareGivers, Yogurtland



Sponsorship Opportunities Available Contact Kari Buchanan at (303) 830-1839 or KBuchanan@ParkinsonRockies.org

### **Donations in Memory**

Virginia Allen Charla Bloom **Colleen Dugan** Elva F. Dugan Deb Dyer Jeanne Heimbuck Jack B.R. Holland **Gary Bass** Jim Anthony Jeralyn Mohr Mike Spencer Jerry Bullock **Dan & Deena Buffington** Melanie Christenson Larry & Ruth Dolezal Grace Dugan Zeta Graham Jean A. Greene Wesley Hodgson Mary Kilkenny Tom Lindsey Jeffrey Miller Warren Miller John Realph Suzanne C. Romero **Ronald Wilson** American Legion Aux., #54 Break Throughs Inc. Maurice Chevalier Deborah Wagner **Ethel Clarkson** Jeanne Dowe Sue Feinaold Jennifer & Lane Feingold

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#### Your thoughtfulness helps the Parkinson Association continue to provide services and support. The following gifts were received between July 1, 2015 – October 31, 2015

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## e<sup>3</sup> Conference: educate • empower • energize



On October 9th, at the Denver Marriot Tech Center, over 400 individuals attended the Parkinson Association's 3rd Annual e3 conference to be educated, empowered and energized through a number of topics that ranged from exercise to care partner collaboration. We were overwhelmed by the positive responses we received from attendees, "What an enjoyable day! We met so many lovely people and left with a lot of information!"

From the evaluations, we found that participants walked away with a deeper understanding of Parkinson's disease and its many symptoms. They also came away with specific tools to live vibrant and healthy lives with Parkinson's.

They were educated, "I learned that I need to stop saying, I can't!"

They were empowered, "So empowering to have such outstanding speakers and wonderful support for the Parkinson's community!"

We are deeply grateful to our e3 presenters, who donated their time and knowledge to provide our community with helpful tips and tricks for thriving with Parkinson's. The success of this conference is due in great part to the e3 Committee members; for the many hours they dedicated to creating a powerful conference. Thank you also to the day-of volunteers who ensured the conference ran smoothly.

#### Special Thanks to e3 Conference Sponsors and Exhibitors:





Abbvie, Abby Senior Care, Accessible Systems, Colorado Neurological Institute, Davis Phinney Foundation, GoldLeaf HomeCare, Homewatch Caregivers, InnovAge, Life Care Center of America, Littleton Adventist Hospital, LSVT Global, Lundbeck, Medtronic, More Than Motion, Partners in Parkinson's, Pedaling for Parkinson's, Rosemark, Senior Path, The Denver Hospice, Touching Hearts at Home, UCB, University of Colorado Hospital, Qualicare **06** 

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# Duopa:

### A New Therapeutic Alternative for Patients with Advanced Parkinson's Disease

#### By Rajeev Kumar, MD & Victoria Segro, MSN C-ANP

As Parkinson's disease becomes advanced, wearing off of the clinical effect of medications between doses occurs and patients develop excessive involuntary movements (dyskinesia). Until now, the main option for patients who had substantial disability from these motor complications, despite optimal medical therapy, has been deep brain stimulation (DBS) surgery which can markedly reduce the severity and duration of wearing off and dyskinesias.

A recently approved alternative for such patients is Duopa therapy. This requires implantation of a tube into the small intestine via the stomach during an outpatient surgery. The pump is programmed by a neurologist, typically over 3-4 days, to deliver an optimal dose of a gel formulation of levodopa/ carbidopa continuously through the tube. The pump is started each morning by the patient upon awakening (or by care partners before the patient awakens) and usually the patient has a good effect within 30 minutes. The continuous infusion markedly improves wearing off and dyskinesia by eliminating the peaks and troughs which occur with oral medications. The long-term efficacy of Duopa therapy is fairly comparable to DBS. The pump and medication cassette is approximately 8″x4″x2″. Patients wear a holster or fanny pack during the day to hold the device. Patients disconnect the pump at bedtime. Most patients can discontinue their other Parkinson's disease medications, although some patients may take an oral dose of levodopa at bedtime.

The most common side effects of Duopa therapy include infection or pain from the surgical procedure or mechanical problems such as dislodging, kinking or clogging of the tube. Side effects of the levodopa/carbidopa gel are the same as oral levodopa/carbidopa (Sinemet). In contrast, side effects of DBS include a 1-2% risk of brain hemorrhage (stroke) with permanent disability or death, suboptimal placement of the electrodes in the brain target, potential worsening of cognition especially in patients with pre-existing cognitive impairment or dementia, worsening of verbal fluency and/or speech and infection or breakage of the implanted hardware. DBS is a fully internal system while Duopa patients wear an external pump. Unlike the DBS hardware, removing the tube is a relatively simple procedure for patients who wish to discontinue Duopa therapy.

Either therapy may be appropriate for many patients who may choose which one they prefer based on the different risks and lifestyle issues (with having an external or internal device). However, Duopa therapy is likely a lower risk option for the more than 50% of Parkinson's disease patients who eventually develop dementia, which can often be worsened by DBS.



# **News from Northern Colorado**

#### By Tom Hubner, Longmont Support Group Leader

There has been a lot of exciting news coming out of the Parkinson's support groups in northern Colorado. This past year support groups from Estes Park to Westminster gathered to brainstorm and work on several projects in their communities to better serve those with Parkinson's in northern Colorado. Below are some of the noteworthy accomplishments these groups have made in a short time.

Estes Park is celebrating their four-year anniversary supporting Parkinson's patients in the area, while Fort Collins has started to work with the local hospital developing a Patient's Advocacy Progam. Some of the care partners in Greeley, who have lost their partner, continue to gather in an informal setting.

The Cheyenne support group is gaining momentum after receiving a PCORI grant to gather information on the Parkinson's community in Wyoming. This information will be used as a pilot to better serve other communities throughout Wyoming. This group is also currently working to broaden their reach into outlying communities.

The Westminster support group has started to explore the use of webinars to introduce education on various topics. Along with expanding education, the group has developed a Parkinson's disease library. They also have an exercise class that they hold twice a week. In addition to their meetings and exercise classes, they've started a six-week art class for people with Parkinson's.

Westminster isn't the only group utilizing the web, the Boulder support group is currently in the process of developing guidelines for an online message board, which will allow members of the group to have open discussions on Parkinson's topics.

Longmont has just concluded a very successful awareness program. For the second year, support group members participated in the farmer's market to discuss information and distribute brochures to the community. People were encouraged to sign up for the support group's newsletter and join the meeting. The new Brunch Bunch meets on the fourth Wednesday of every month at 9:30am at Leenie's Cafe (800 S. Hover Rd). This is a social meeting, without an agenda, to enjoy the company of others.

Support groups are vital to connecting communities and improving the lives of those living with Parkinson's and their care partners. Thank you to the groups in northern Colorado for their active involvement.

## **Palliative Care Clinical Research**

#### By Benzi Kluger, MD & Kirk Hall, Person with Parkinson's

A new clinical research study titled "Does outpatient palliative care improve patient-centered outcomes in Parkinson's disease?" has begun at the University of Colorado Hospital Anschutz Campus and is actively seeking interested individuals over the age of 40 that have been diagnosed with Parkinson's disease and their care partners. Dr. Benzi Kluger is the principal investigator for the study which is being funded by the Patient-Centered Outcomes Research Institute (PCORI) and will take place over a period of three years.

Many people are confused by the term "palliative care". It is a treatment approach focused on improving quality of life by relieving suffering in the areas of physical symptoms (such as pain), psychiatric symptoms (such as depression), psychosocial issues and spiritual needs for persons with Parkinson's disease, care partners, and families at all stages of Parkinson's disease. This study plans to learn more about the effect of palliative care on patients with Parkinson's disease and their care partners.

#### Participant Requirements and Information:

- Complete a battery of questionnaires every three months for one year. These questionnaires will ask the persons with Parkinson's and/or care partners about their quality of life, disease symptoms, healthcare and overall well-being. This battery will take up to two hours.
- In addition to the standard care provided by a primary care physician and neurologist, half of participants will visit a palliative care team every three months for one year.
- The remaining half (chosen randomly) is the control group and will receive standard care provided by a primary care physician (PCP) and neurologist only. If you do not have a PCP or neurologist, assistance will be provided to find either or both.
- If there is an urgent need for palliative care services, you will not be accepted for the study, but you will have the option to make an appointment with the palliative care team at University of Colorado Hospital.
- By participating in the study, you will help determine whether there is a quantifiable benefit for individuals who receive support from a Parkinson's
  disease palliative care support team, which includes a palliative care physician, nurse, social worker and spiritual/emotional counselor. If it is
  shown that there is a benefit, this will help pave the way for more of these kinds of services.

Consistent with the "patient-centered" nature of the study, Dr. Kluger is working with a patient advisory committee organized by Kirk Hall. This committee has been involved in the study design and questionnaire reviews; and will provide input and feedback regarding the study implementation and analysis of the outcomes. The committee recently participated in a Parkinson's Disease Palliative Care Conference in Denver funded by the Parkinson Disease Foundation and attended by palliative care experts from the U.S., Canada, England, Ireland and Australia.

If you would like to register for this study or receive additional information, please call Etta Abaca at (303)724-4718.

## **Overcoming Challenges as a Team**

#### By Karen Hubner, Care Partner & Longmont Care Partner Support Group Leader

Knowing what all Care Partners go through, I want to thank every Care Partner for their love, care and support given each and every day to their partners with Parkinson's. As I have often read, both the patient and partner have Parkinson's, but in very different ways and with different symptoms.

I have been a wife, mother, grandmother, teacher, former patient and now have an unwanted job as a Care Partner for my husband Tom. This is a career none of us have asked for. This job is not always rewarding but it is a part of our life. Knowing this, we all have a choice. Should we feel sorry for ourselves or should we get out of our chairs and fight. This means a positive fight not just for us but, also including our partner, as a team. Tom and I do not wake each morning and say Tom has Parkinson's. We wake and thank the Lord for another day, make plans and then work on those plans; which include moving and exercising. If we could only think of it like the quote by Dr. Seuss.

"I've learned there are troubles. Of more than one kind. Some come from ahead. And some come from behind. But, I've bought a big bat. I'm ALL ready you see. Now my troubles are going to have troubles with me!" - Dr. Seuss

I read Susan Hamburger's Caregivers Column on www.myparkinsons.org and she has some wonderful positive insights. She says, "There are various ways to deal with Parkinson's and, believe it or not, we have and can make a choice as to which way we go."

> Susan has another thought worth considering: "Control what you say to yourself, and you control your mind. Control your mind and you control your thoughts. Control your thoughts and you control the way you feel. Control the way you feel and you control the way you act. Control the way you act and you control the way you live."

> Lastly, give yourself credit for all you do. YOU are doing YOUR (not anyone else's) best! Life is 10% what happens to you and 90% how you react. Improving your self-esteem and gaining control of YOU is the beginning. You have been chosen to be a Care Partner so show the world the "big bat" you carry.

Tom and I are trying to have the most positive attitude we can. No "poor me" is allowed. Parkinson's could be considered a game to be played, knowing that sometimes we win and sometimes we do not.

Create time for you. Focus on the humorous side of daily caregiving, laughter is therapeutic. Be patient with yourself and in honor of all you do, buy yourself some flowers, you are definitely worth it!

## **How Can You Give Today?**

#### By Cheryl Siefert, MNM, Executive Director, Parkinson Association of the Rockies

#### **Supporting Parkinson's Services**

Parkinson's disease is an expensive disease. The combined direct and indirect cost of Parkinson's is estimated to be nearly \$25 billion per year in the United States alone. The annual burden of non-medical costs is estimated to be \$10,000 per person living with Parkinson's.

The Parkinson Association of the Rockies provides programs and services which have a meaningful impact on the quality of life for those living with Parkinson's. How do we fund those services? Through your generosity and the many ways you give.

Check out ways to give and maximize your contribution:

#### Let Your Fingers Do the Shopping

Thank you to those who shop online at Smile. Amazon.com and designated the Parkinson Association of the Rockies as your preferred charity. For every dollar spent on accredited purchases Amazon donated 0.5% to the Parkinson Association of the Rockies.

I am a fan of online shopping for the holiday season. Amazon has taken the stress out of shopping by eliminating the mall crawl and the fight for a close parking space on a cold winter day. If you are an Amazon shopper, donate each time you make a purchase. It's easy — all you need to do is go to www.Smile.Amazon.com. Sign in with your regular Amazon account or set up a new account. Designate the Parkinson Association of the Rockies as your preferred charity and shop until you drop! Amazon will take care of the rest.

#### Giving to the Future of the Parkinson Association of the Rockies!

Make a legacy gift. A legacy is any amount of bequest in a will or even the naming of the Parkinson Association of the Rockies as the beneficiary of a life insurance policy. You can leave a designated amount or a percent of your estate to the Parkinson Association. Same with life insurance. You can name the Association as the sole beneficiary or a co-beneficiary. Please let us know if you have named the Association in your will or as an insurance beneficiary. We want to extend our thanks and sincere gratitude for your interest and passion in helping others.

#### **Double Down - Corporate Matching Programs**

The company you work for may have a policy of matching your charitable donations. Check with your Human Resources Department to see if your donation is eligible to be matched. If so, let us know. We would gladly complete the company's form to apply for the matching gift.



## **Creatively Enhancing Lives in Our Community**

We are deeply grateful to our friends who generously host events for the Parkinson Association. We are fortunate to have a multitude of organizations, companies, clubs, individuals and restaurants which devoted their time to create unique events this year. These events raise significant awareness of Parkinson's disease while also generating critical funding for the Association's programs and services.

In 2015, over \$75,000 was raised to enhance the lives of individuals, living in our community, who are impacted by Parkinson's. We are in awe of our community for choosing to stand beside us and put their personal passions, creativity and resources to work to make a difference!

#### 2015 Community Hosted Awareness & Fundraising Events

- Land Title Guarantee Company's Holiday Card: December January
- Air Academy High School Fundraiser: Fébruary 15
- ICON Gala Awards Charity Partner: March 6
- All-Out Multi-Sports Spring Fever 5K, 10K, Half Marathon: March 22
- Gabby Gourmet in Memory of Mark Miller: April 1
- Put a Sting on Parkinson's with the DCPA: April 3
- REFIT: Dancing to Make a Difference: April 11
- Going Mongolian for Parkinson's at bd's Mongolian Grill: April 15
- Pitching in for Parkinson's with the Colorado Rockies: April 21
- Henry Prescott's Cycle Sea to Sea for PD: May June
- Cardel Homes' Pushups for Parkinson's: May June

- Julia West's Colfax4Parkinson's: May 16-17
- Xactly Corporation Summer Picnic: June
- Gary Bass Memorial Golf Tournament: July 25
- Lisa Graznak's Mojito Party: August
- Team Up with Tea Friends: August 13
- LenderLive Shared Services Dress Down for Charity: August 15
- Redneck Ride for Parkinson's in Estes Park & Loveland: August 23
- Colorado Courage 5K in Denver: August 29
- Colorado Rockies Player's Favorite Things Online Auction: September 3-6
- Imperial Court of the Rocky Mtn. Empire Drag Show: September 12
- Facing Fears for Parkinson's Shark Diving: September 15

# Mrs. Shaky Paws Top 10 Tips for Care Partners

### By Linda Hall, Care Partner

#### 1. Live in the moment

- Learn from the past, plan for tomorrow, but live for today.
- Don't put off those activities that you have talked about doing "some day".
- Make time for fun.
- Kirk has written an article on this subject on his blog which can be accessed at http://bitly/1MwsBrG.

#### 2. Communicate

- It is crucial to keep the lines of communication open. Tell each other what you are thinking and feeling.
- Share the things you are worried about and problem solve together. Express your love for each other frequently.
- Catch each other doing little things that provide an opportunity to express appreciation.

#### 3. Learn

- Learn as much as you can about Parkinson's disease and related issues.
- Stay engaged by participating in support groups and seminars.
- Participate in clinical research trials with your partner in order to help yourselves as well as others.
- Understand and accept that Parkinson's disease is a moving target and that your partner's evolving condition/needs, as well as your own, will require flexibility and adaptation.

#### 4. Advocate for your partner and yourself

- Accompany your partner to all medical appointments in order to provide first-hand information about what your partner is experiencing, as well a "second set of ears".
- Since it is typical for your partner to have executive function problems, take notes on important details.
- Ask questions, voice thoughts/ideas and ask for clarification of anything that is unclear.

#### 5. Take care of yourself

- Ask for help. Solicit assistance as needed from family members and/or friends.
- Make time for yourself. Stay engaged with your passions.
- Attend to your personal wellness.

#### 6. Faith

- Our belief that we will be equipped to deal with whatever happens is extremely comforting to us. Staying committed to that idea over time requires faith.
- Faith provides an opportunity to "let go" of fear about the future over which we have no control, and
  focus on the things we can control.
- Read the same article listed under #1 if you haven't already.

#### 7. Patience

- Parkinson's disease mood swings and/or cognitive problems can be very hard on relationships. No matter how good your communication, it is
  likely that your partner will sometimes act or react in ways that are "not tactful". Try very hard not to take these things personally. At a later time,
  communicate about what happened.
- Don't let an individual episode create a rift between you.
- Talk with your Movement Disorder Specialist (MDS) or doctor about any ongoing concerns.

#### 8. Balance

- Your "Parkinson's disease life" takes place in the context of your "overall" life. It will be beneficial to both of you to keep the two integrated and balanced as much as possible.
- Based on your knowledge of your partner, you can experiment with different strategies to encourage exercise, keep them engaged mentally and socially, discourage driving and more. Keep your doctor in the loop and ask for suggestions.
- Care partner/Persons with Parkinson's breakout sessions in support group meetings are a good opportunity to share concerns and get suggestions.

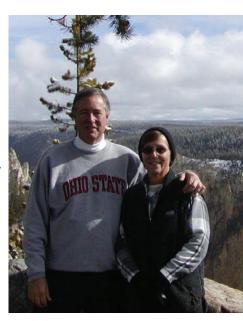
#### 9. Be prepared to make tough choices

- Despite your best efforts, there may be a time when you are no longer able to cope with your partner at home by yourself. Explore options (preferably with your partner) such as assisted living, residential facilities or in-home care/services so that you can make an informed decision if and when the time comes.
- Do not "suffer in silence" or feel compelled to "go down with the ship". Talk to your doctor, support group friends and family members as necessary.

#### 10. Perspective

- Continue to find the joy in your lives and the love in your relationship.
- Celebrate the small victories.
- Be happy whenever possible.
- Do NOT let Parkinson's disease own you!

Linda is a retired social worker, care partner of Kirk Hall, author and Parkinson's advocate. Initially reluctant to accept her husband's diagnosis, Linda has become very knowledgeable regarding Parkinson's. She is an active participant with Kirk in Denver area support groups and the Parkinson Association of the Rockies. Linda is engaged in an ongoing "balancing act" between her six grandchildren, her love of exercise and competitive tennis, involvement in the Parkinson's community, church and Kirk's evolving needs and activities.



# Mission

### Committed to enhancing lives and connecting communities.

The Parkinson Association of the Rockies supports, strengthens and empowers the Parkinson's community in Colorado. We do this through educating, promoting research, creating awareness, serving as an advocate and providing support services for the Parkinson's community.

### **Connect with us...**



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www.ParkinsonRockies.org Info@ParkinsonRockies.org



Join us for the 2nd Annual Ski for Parkinson's - a premier Nordic Ski & Snowshoe event to raise awareness of Parkinson's disease, as well as critical funding to directly support those living with Parkinson's in the Yampa Valley communities. All proceeds benefit the Parkinson Association of the Rockies Yampa Valley Parkinson's Support Network's (YVPSN) programs and services.

#### Saturday, January 23, 2016

Lessons available at 9:30am, 10:30am or 11:30am | Lunch available at 11:30am, 12:30pm or 1:30pm Haymaker Ski Touring Center | 34855 East US Highway 40, Steamboat Springs Ski for Parkinson's Registration Fee: \$75/person | Lunch Only: \$50/person Admission Includes: All-day (Cross Country Ski, Skate Ski or Snowshoe) Trail Pass, Nordic Cross Country Ski Lesson, Discounted Rate for Nordic Ski or Snowshoe Rental Equipment, Delicious Buffet Lunch & More!

For More Info & to Register: www.ParkinsonRockies.org/Ski4PD

#### SPONSORSHIP OPPORTUNITIES AVAILABLE

Contact Sheri Steiner, YVPSN 2016 Ski For Parkinson's Marketing Coordinator, for more info: sherilu1@gmail.com | 970-846-0166



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