LiNK St.Louis APDA

Newsletter of the American Parkinson Disease Association, Greater St. Louis Chapter

Serving the state of Missouri and southern Illinois

APDA
www.stlapda.org

May 2013: Vol. 27, Issue 2

MISSION

Our mission is to enhance the quality of life for people with Parkinson disease, their families, and caregivers in our communities throughout Missouri and southern Illinois, and to provide funding for ongoing Parkinson disease research.

IN THIS ISSUE

NEWSLETTER DISCLAIMER

TELEMEDICINE REPORTEDLY LIMITED IN SCOPE AND AVAILABILITY – *GOT PARKINSON JOURNEY DVD?*

I was reading an article recently on telemedicine and how it can increase the quality of care for people with Parkinson Disease (PD). There were some very interesting statistics I wish to share from this Parkinson Action Network article. Did you know that 42% of people who have PD don't get the specialized care of a neurologist or a movement disorders specialist, and instead see only a general practitioner for their Parkinson-related healthcare needs? Research has shown that patients with PD who receive specialized care are better able to manage their symptoms and the disease. The article concludes that while specialized care isn't something found in every city and town across America, the ability to see a neurologist via everyday technology is a reasonable option. For the Parkinson community, telemedicine has powerful potential in terms of quality of life, better management of symptoms, and the greater general patient well-being of PD patients.

However, current laws limit the availability of telemedicine such that the people who need it most cannot access it. We created *The Parkinson Journey* for our patients, families, and professionals in rural communities in Missouri who have to drive hours to see a movement disorders specialist. Through this DVD, physicians and staff in nursing facilities can expand their knowledge about the diagnosis and treatment of PD. You can have a hand in the quality of your life, better manage your symptoms, and live well simply by delivering this DVD to your general practitioner, family practice physician, or nurse practitioner. We believe you can make a tremendous difference in increasing awareness of current gold standards in the care of PD in the year 2013. You may obtain a free copy for your physicians by calling the Center at **314-362-3299** or emailing **guyerd@neuro.wustl.edu**. Telemedicine may be years away, but this DVD is available now and will help educate those participating in your care to deliver better management of your symptoms. ■

THE PARKINSON JOURNEY

Has your doctor received a complimentary copy of the recently released DVD, *The Parkinson Journey*? Do you want your children to learn about this chronic, progressive disease?

Don't give up your personal copy; let us send one to them.

Call with your physician's name and an address or phone number and a copy will be provided free of charge. Better still, order one for your physician and deliver it in person at your next office visit.

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APDA
TO EASE
THE BURDEN
TO FIND THE CURE

SECRETS, MYTHS, & MISCONCEPTIONS

Melissa J. Nirenberg, MD, PhD, Assistant Professor of Neurology and Neuroscience, and Associate Director of the Parkinson's Disease and Movement Disorders Institute at Weill Cornell Medical College in New York, NY.

This list was first presented by Dr. Nirenberg at a PD ExpertBriefing in 2009. Watch the full seminar online at www.pdf.org/expertbriefings. Adapted from the PDF News & Review, Winter 2010. Reprinted with permission from the Parkinson's Disease Foundation (PDF).

There are many pervasive myths and misconceptions about Parkinson Disease (PD) and its treatment. Below are some tips to help you distinguish between fact and fiction so that you can optimize both your care and your quality of life.

MYTH/MISCONCEPTION

PD only affects movement.

Most people, including some physicians, believe that PD only causes movement-related (motor) symptoms such as tremor, stiffness, and slowness.

REALITY

Many symptoms of PD are unrelated to movement. Non-motor symptoms ("invisible symptoms") of PD are common, and may affect everyday life more than the more obvious movement difficulties. These symptoms may include impaired sense of smell, sleep disorders, cognitive symptoms, constipation, bladder symptoms, sweating, sexual dysfunction, fatigue, pain (particularly in a limb), tingling, lightheadedness, anxiety, and depression.

Secret

Good news: many non-motor symptoms of PD are highly treatable. For this reason, you should write down your invisible symptoms, discuss them with your doctors, and seek treatment.

MYTH/MISCONCEPTION

If someone with PD looks good, then they also feel good.

People will often assume that if someone with PD looks good at one point in time, then they feel well all of the time.

REALITY

PD symptoms fluctuate, and not all of them are visible. Over time, people with PD notice an increasing tendency for their medications to wear off between doses. For this reason, the way they appear at one moment in time may not reflect the way they feel most of the time. Even when someone with PD looks good, they may not feel well because of non-motor symptoms.

Secret

Keeping a symptom diary can help. If your symptoms fluctuate during the day, you should keep track of your pattern of "on" times (when medications work effectively) and "off" times (when medications wear off). This will enable your doctor to optimize your medications and help you to feel more in control of your PD.

MYTH/MISCONCEPTION

You can blame PD for everything.

It is easy for you, and for your doctors, to blame PD every time that you are not feeling well.

REALITY

Certain symptoms should never be attributed to PD. Fever, for example, is not a symptom of PD, and usually indicates an infection. Headache, vision loss, vertigo, loss of sensation, loss of muscle strength, and chest

Continued on next page

SECRETS, MYTHS, & MISCONCEPTIONS

continued from previous page

pain are not symptoms of PD.

Secret

Your doctor should rule out other causes for your symptoms. Sudden-onset symptoms – such as chest pain, shortness of breath, weakness, difficulty with speech, or vertigo – warrant immediate medical attention to rule out an emergency.

MYTH/MISCONCEPTION

PD has spontaneous "exacerbations."

Another common assumption is that PD can "flare up" unexpectedly, but PD does not work this way. Although symptoms may fluctuate throughout the day, the progression of PD is very slow.

REALITY

If PD symptoms worsen over days or weeks, then it is critical to search for an underlying cause. Medication changes, infection, dehydration, sleep deprivation, recent surgery, stress, or other medical problems can worsen PD symptoms. Urinary tract infections (even without bladder symptoms) are a particular common cause.

Secret

Certain medications can worsen PD symptoms. These include antipsychotics, valproic acid (Depakote), lithium, and nausea medications such as prochlorperazine (Compazine), metoclopramide (Reglan), and promethazine (Pherergan). Speak with your neurologist before starting one of these medications to see if there is a better alternative.

MYTH/MISCONCEPTION

Levodopa stops working after five years.

This is perhaps the single most pervasive myth about PD treatment. Many people are reluctant to start taking levodopa because of fear of "using it up." Some physicians also share this "levodopa phobia."

REALITY

Levodopa works for decades. Levodopa does not treat all of the symptoms of PD, but it dramatically helps many of the most disabling motor symptoms.

Secret

Levodopa has been shown to increase lifespan and markedly improve quality of life.

MYTH/MISCONCEPTION

You should wait as long as possible to take the next dose of levodopa.

Many people feel that they should wait until their medication has completely worn off before taking the next dose.

REALITY

Levodopa is most effective when taken on time, just before the previous dose wears off. If you wait too long, then the next dose may never "kick in," and the medication may not work effectively for the rest of the day.

Secret

A medication timer can help. If you are experiencing wearing off of medications, then it is critical to take your doses exactly on time.

MYTH/MISCONCEPTION

Different generic brands of carbidopa/levodopa are usually different colors.

REALITY

The color of carbidopa/levodopa tablets is relatively consistent between brands. If the color of your tablets changes for no apparent reason, then it is important to verify that you are still receiving the correct dosage.

Secret

The most commonly prescribed dosage of carbidopa/levodopa – 25/100 mg immediate-release tablets – is always yellow in color, regardless of the brand. If you are supposed to take this dose, and your pills are not yellow, then an error has occurred.

MYTH/MISCONCEPTION

Your doctor can predict your future.

Many people with PD ask their doctor to predict their prognosis.

REALITY

PD is highly variable from person to person. Even a PD expert has no way of knowing what the future holds for an individual with PD.

Secret

You can help to change your future. You can improve your disease at every stage by ensuring that you stay fit and receive adequate sleep and proper nutrition. Exercise is particularly important for improving mobility, stamina, mood, and quality of life. ■

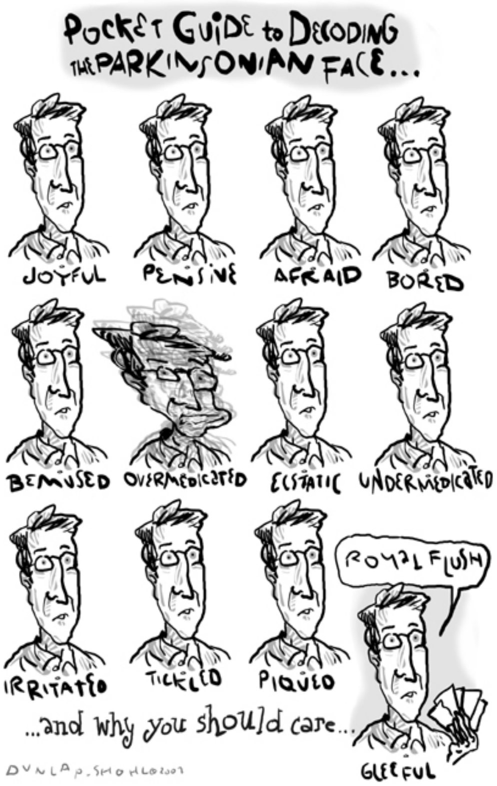
COMMUNICATION-DEPRIVED

Debbie Guyer, MA, Executive Director of the Greater St. Louis Chapter APDA

As many of you know, I spent the first 30 years of my career as a speech-language pathologist (SLP). I evaluated and treated adults who had suffered communication impairments from head injuries, strokes, head and neck cancers, and Parkinson disease. I also had the good fortune of enrolling in the first class of speech-language pathologists ever to be trained and certified in the Lee Silverman Voice Treatment (LSVT) technique.

Susan Levin, Coordinator of the APDA Information & Referral Center and Chapter Advisor for close to 25 years, will confirm that I was hesitant to leave my patients to become Executive Director of the Greater St. Louis APDA. Now I must revisit my roots and discuss the increasing number of communication-deprived Parkinson disease patients. These individuals who experience an inability to be heard or understood too often lead very isolated existences. Much can be done to help reduce the isolation and silence.

1. Include the afflicted person in conversations and discussions in spite of any seeming lack of responsiveness.
2. Engage in a LOUD CROWD group where you are among others also trying to speak with intention and to be heard.
3. Schedule an LSVT evaluation. If you are judged a candidate, engage in the four sessions per week for four consecutive weeks of therapy, but only if you can commit to practice every day for the rest of your life.
4. If you are not a candidate for LSVT, consider using a personal voice amplifier. My friend, Ted Simons, has been busy perfecting the Chattervox he originally designed for a Parkinson relative. The Amplio is another new amplifier that is both discreet and powerful. There are other voice amplifiers, but the Chattervox was specifically designed for a person with PD, and I think the voice quality is superb. (Caution: it will only amplify the signal it is given, so a whisper is only going to result in a louder whisper.)
5. If you are not a candidate for a voice amplifier, what are your options for communication? A simple thumbs up/thumbs down gesture to yes/no question, American Indian (Amerind) signs, self-constructed pages of pictures or words, or use of a more sophisticated augmentative device with gender-specific voice responses to touching or even glancing at the device's screen are available.



Remember that some patient's facial muscles are too weak to express differences of emotion, so expressions of pleasure (smile) or surprise, or concern or displeasure, all look the same.

Please don't sit in silence. This is already such an asocial disease. There is still so much to communicate to one another. ■

THE APDA – GREATER ST. LOUIS CHAPTER

IS JOINING THE NETWORKED AGE!

By this summer we will have a Facebook page and hope to have collected e-mail addresses from the majority of our mailing list that is on the web. Social media and e-mails will give the APDA the opportunity to promote knowledge sharing, provide a platform for communal conversation, and inform our constituents about upcoming speakers, special events, and PD research. Please send your e-mail address to Michelle Brooks at the APDA office (**brooksmi@neuro.wustl.edu**).

MAKING THE RIGHT CHOICE IN CARE

Ann Byrum-Ritter, RN, Nurses & Company

For patients and families struggling to understand and navigate the healthcare system, here is a chart comparing services available in your home that may help you choose the right service and understand the jargon describing various levels of care.

	Home Health	Hospice	Private Services	Adult Day Care
Reason for Services	Joint Replacement, Back Surgery, Wounds, Falls, COPD, Pneumonia	Alzheimer's, Dementia, Cancer, COPD, Renal Failure, End Stage Chronic Illness	Companionship, Meals, Bathing & Personal Care, Safety Concerns, Housekeeper	Dementia, Falls, Caregiver Respite
Criteria	Patient has a skilled need, such as Nursing, PT or OT	Patient chooses to stop invasive treatment for terminal illness	Client has a need for additional assistance to remain independent	Client wants to stay in home but needs a little extra help during the day
Objective	Medical Improvement	Comfortable living and a peaceful end of life	Provide long or short term assistance to keep client comfortable at home	Provide respite for caregiver and interaction for client in a consistent environment
Care Setting	Care provided in home environment	Care can be provided in home, assisted living, or nursing home	Care can be provided in any situation where it is needed	Care is provided in a certified day health care facility
Scope of Services	Limited to skilled needs (PT, OT, Nursing, etc.)	Offers nursing along with extra services such as bereavement & volunteers	Aide to Skilled Care from 1 to 24 hours a day	Nurse, aides and activities director work to provide person centered care
Additional Programs	Falls Program CHF Program Wound Program	Pet Therapy, Journeys Dementia Program Compassionate Touch & Aroma Therapy	Nurse Managed Personalized Care Plan Management	Person Centered Care Music Therapy Pet Therapy
Emergency Care	Nurse on call 24 hours a day, 7 days a week	Nurse on call 24 hours a day, 7 days a week as an alternative to 911	On call staff available for situations that may arise	"Drop in" services may be available during regular business hours
Payment/ Reimbursement	Covered by Medicare, Medicaid and Managed Care	Covered by Medicare, Medicaid and Managed Care	Self-pay, Veterans Affairs, Many Long Term Care policies	Self-pay, Veterans Affairs, Many Long Term Care policies

Useful terminology

Acute Care: providing emergency services and general medical and surgical treatment for acute disorders rather than long-term residential care for chronic illness.

Skilled Care: health care given when you need skilled nursing or rehabilitation staff to manage, observe, and evaluate your care.

Long-Term Care: a variety of services which help meet both the medical and non-medical need of people with a chronic illness or disability who cannot care for themselves for long periods of time.

Long-Term Care Insurance: an insurance product that helps provide for the cost of long-term care beyond a predetermined period. Long-term care insurance covers care generally not covered by health insurance, Medicare, or Medicaid.

Managed Care: a system of health care in which patients agree to visit only certain doctors and hospitals, and in which the cost of treatment is monitored by a managing company.

Medicare: a federal system of health insurance for people over 65 years of age and for certain younger people with disabilities.

Medicaid: a federal system of health insurance for those requiring financial assistance. ■

*More information can be found at **www.NursesandCo.com***

BOTOX INJECTIONS

Morvarid Karimi, MD, Department of Neurology,
Movement Disorders Section, Washington University School of Medicine

Whereas motor and non-motor complaints in PD cover a wide range, our therapeutic arsenal is limited to mainly L-dopa or dopamine agonists, physical therapy, occupational therapy, and speech therapy. However, there are a few indications for use of botulinum toxin injection in PD that are covered by insurance. These include excessive drooling and dystonia. While it is easy to identify excessive drooling, recognizing dystonia can be more challenging. Dystonia can manifest as involuntary inward turning of the foot, neck pulling forward, or be more subtle, as in excessive tightness and/or painful cramps in the neck, arm, or leg, especially as the effect of PD medication wears off. Many times adjustments to the timing and dosage of the medication can provide relief. Nevertheless, if medication fails, injection with botulinum toxin can be considered.

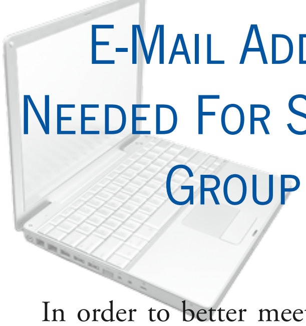
Botulinum toxin injection has been used in medicine since the early 80s. The extremely low concentration of its dosage prevents feared symptoms of botulism. Botulinum toxin blocks the release of a neurotransmitter (chemical messenger) acetylcholine which leads to different effects depending on the injected area: weakening of the muscle, pain, sweat, or saliva reduction. This effect is reversed by regrowth of the nerve endings which release the neurotransmitter. The growth process can take about three months, at the end of which time the effects of botulinum toxin wear off. The relaxation of muscles will reduce cramps or improve the abnormal positioning of the neck or limb. The reduction of the saliva helps with excessive drooling. There are hints that the pain relief is achieved via both muscle relaxation and a direct effect on pain receptors. The procedure is generally well-tolerated and needs to be repeated approximately every three months. The first rounds of injection are usually not as effective; your physician usually tries a lower dosage than may actually be required. Your feedback regarding benefits or potential side effects will assist your physician in modifying injection amounts and patterns. If your PD physician does not perform these injections and decides to refer you to another physician, make sure that the injecting physician is a neurologist. ■

CLINICAL TRIALS

Study volunteers go through considerable trouble and some risk to participate, companies lose money, physicians invest their time, and the Parkinson community as a whole waits impatiently for new developments and a cure. The failure rate of clinical trials is a measure of the immense challenge scientists face in identifying and tracking the mechanisms of diseases, as well as translating these findings into the development of new treatments.

Robin Elliott, Executive Director of the Parkinson's Disease Foundation, suggests that when we do get within sight of tomorrow's cures, we will find ourselves standing on the shoulders of yesterday's failures. So why does the treatment pipeline move so slowly? Finding new drugs to treat Parkinson disease is a bit like looking for a needle in a haystack. We still don't understand what causes the disease. Just because something works on a mouse or monkey doesn't mean that it will work in a human. Parkinson disease may not be just a single disease, but a syndrome. Robin suggests that we need a brain-based version of the global positioning system (GPS) that will tell doctors, using imaging techniques or chemical analysis of blood or spinal fluid, where exactly a person is in his/her Parkinson "journey." And these are things that the research community is working on as we speak.

We will be featuring a column in future newsletters where you can read about various clinical trials you may wish to participate in locally. Just remember the points that Robin Elliott shares as you ponder your involvement. ■



E-MAIL ADDRESSES NEEDED FOR SUPPORT GROUP SURVEY

In order to better meet the needs of Parkinson patients and their families, we are collecting e-mail addresses of current and potential support group members.

If you fit into any of the following categories, please send your e-mail to Michelle Brooks at the APDA office (**brooksmi@neuro.wustl.edu**):

- If you have had DBS surgery
- If you are a young-onset person with PD (still working)
- If you are an adult child of a person with PD

A survey will be sent in the late spring to those providing e-mail addresses. Let your voice be heard! ■

SHAKEN NOT STIRRED BY PD

Mark Whitehead

My Mother once told me, when God shuts a door tight
He opens a window up wide.
And you get to choose
if you will crawl through
and see what is on the other side.
From the song "Closed Doors and Open Windows"
©2012 Single Rose Studio, LLC

I will always remember the day I was diagnosed with Parkinson disease. I was 46 years old with two kids in college, married to my high school sweetheart, and still very much in love. I was doing work I had trained for since junior high and I never dreamed it could end. We had been remodeling our modest home for years and had just installed a hot tub and pool. I was getting ready to take my Shodan (black belt) test in Aikido. Life was good. Then one day I realized I could not stop my right hand from trembling.

To understand my story, it is important to know that Mary and I started our life together with little more than some secondhand furniture, bus passes to get us to work, and lots of love and hope for a brighter future. We had our lean years and we were looking forward to what we called "our time." By the time I saw the neurologist at the first appointment, my entire right side would tremble when I was still, or at least trying to be still. Sleep was difficult and for the first time in my career, I was starting to miss deadlines. The panic it caused sent me back to a local doctor who prescribed a mild sedative. I was also taking pain medicine for the injuries I had sustained during Aikido training. All the elements for a personal and emotional crash were firmly in place. The match that ignited the burn was a prescription for the new dopamine agonist drug. My wife said some time later that she really didn't know me during those months. I was forced to retire and go on disability.

Mary is not one to sit by and watch something go wrong. If I'm a type A personality, she is a type A+. Not happy with how things were going, she started looking for another neurologist, and God (via a good friend) sent us to the office of Dr. Joel Perlmutter. For anyone who has not met Dr. Perlmutter in person, you owe it to yourself to go to one of his lectures or watch one of his videos. What you see is what you get, and more. The "more" is a registered nurse/research assistant named Johanna Hartlein. I wish I were gifted enough to find the words to adequately describe what Johanna means to Mary and me. "Above and beyond" might come close. She is always there for us, even after regular business hours, if we're having a problem or concern with PD medicines or other health issues and need guidance in a hurry.

Dr. Perlmutter reviewed all the medications I was taking and had me stop taking most of them. Parkinson's was now the main focus of my health and everything else was given a lower priority. He put me on Levodopa, "the gold standard" of PD drugs, along with a small amount of the dopamine agonist. Later we would drop the agonist and increase the Levodopa, which is what I take today. Both Mary and I have been recruited into various studies by the Movement Disorders Center, which has helped us feel we are part of the solution and efforts for finding a cure.

Now when my meds are "on," I do a little art, a little engineering, a little guitar playing, and a little writing. Mary and I have created a small company, Single Rose Studio, LLC and I have a new album of 12 original songs, which we wrote together. We have two grown children and three granddaughters. Mary is employed full time at Ameren, and her co-workers have been very thoughtful and supportive since my diagnosis.

I still can't work full time, and I seldom drive and am never alone. I'm able to stay connected to my old vocation due to a progressive-thinking company, Structures, Inc. They installed a computer link in my home office and give me just enough work so that I'm challenged and intellectually engaged, but not enough to get stressed out. I owe them much, and I love them all. However, PD and life in general have taught me the quality of these projects doesn't really matter. What matters is staying in the game as much as you can.

PD is a disease I have. No more, no less. I will not let it define me. Each morning when I wake up, I tell myself today is God's gift to me; what I do with it is my gift to Him. And later when I order my coffee and the waitress asks how I take it, I smile and say, "Same as everything else; shaken not stirred." ■

The American Parkinson Disease Association–
Greater St. Louis Chapter
is Pleased to Announce the

JACK BUCK MEMORIAL PARKINSON GOLF CLASSIC

Monday, May 20, 2013

Algonquin Golf Club
340 North Berry Road
Saint Louis, Missouri
63122

Honorary Chair
John Mozeliak,
GM–St. Louis Cardinals

With your support of this event, we honor the memory of Jack Buck, who also lived with Parkinson Disease, by continuing to seek an end to this devastating disease.

Schedule

10:00 am Registration
11:00 am Lunch Buffet
12:00 pm Shotgun Start
5:00 pm Cocktails,
Q&A with John Mozeliak
6:00 pm Dinner, Raffle, Awards,
Auction

Special Events

Rolex Raffle
BMW Hole-in-One
Diamond Hole-in-One
Q&A with John Mozeliak
Appearance by the
Rams Cheerleaders

Don't Golf?

Come enjoy some of the best cuisine in Missouri from Executive Chef Brian Bernstein

Celebrity Sponsors : Wells Fargo, Benton Homebuilders Community Partnership
Major Sponsors : Carol House Furniture, Brinkmann Constructors, Mark Burkhart, Moneta Group LLC
Golf Cart Sponsors : Barnes-Jewish Hospital, Schumacher Creative
Contest Sponsor : KPMG *Lunch Sponsor* : Steve and Lynn Hurster
Cocktail Sponsors : St. Louis Cardinals, Luxco, For Pete's Sake & Budget Billboards
Hole-in-One Sponsor : Autohaus (BMW 325i) valued at $40,000
Hole-in-One Sponsor : David Kodner Personal Jeweler ($25,000 diamond)
Raffle Sponsor : Simons Jewelers ($10,000 Rolex Watch)

*ALL proceeds from the event will be used by the APDA–Greater St. Louis Chapter to fund research conducted at the Center for Advanced Parkinson Research (WUSM) and to fund patient services in our local communities. *Sponsors as of 4/12/13. Sign up to be a sponsor today!*

"ONLINE" GIVING - MAKE IT EASY ON YOURSELF

Tributes and donations to the Greater St. Louis Chapter of the APDA make up about one third of the organization's annual budget, which funds both Parkinson research and patient services. An easy way to support the APDA on a regular basis is to set up automatic payments through online banking. Those giving online can set up their contributions for as much as they want and when and where they want it to be distributed.

This form of giving has become popular as a way to support Parkinson's and other causes. One APDA Board Member and support group leader reports that "this has been the easiest way to give on a regular basis – an easy, painless way to make a huge impact." For more information or to set up online giving, contact the APDA Parkinson Community Resource Center at 314-362-3299 or **drehere@neuro.wustl.edu**.

MISSOURI SUPPORT GROUP CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

Our Support Groups meet once a month or as noted. Support Group day and time may change periodically. For current updates on support groups and exercise classes, call the APDA Information & Referral Center or the facilitator. Information that has changed since the last **LiNK** appears in **bold face**. *Info subject to change.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Ballwin	St. Louis	Meramec Bluffs Care Center 40 Meramec Trails Dr., Activities Rm.	4th Tuesday	1:30 PM	Gayle Truesdell	636-923-2364
Cape Girardeau	Cape Girardeau	Cape Girardeau Public Library 711 N Clark Street Oscar Hirsch Room	3rd Monday	6:00 PM	Desma Reno, RN, MSN	573-651-2939
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	1st Tuesday	10:30 AM	Mary Buck Lynda Wiens	636-532-6504 314-540-2662
Chesterfield	St. Louis	For Caregivers Only APDA Community Resource Center 1415 Elbridge Payne, Suite 150	2nd Monday	11:00 AM	Dee Jay Hubbard	314-362-3299
Chesterfield	St. Louis	ACOP Support Group APDA Community Resource Center 1415 Elbridge Payne, Suite 150	*Thursday, June 20	6:15 PM	Debbie Guyer Mark Hoemann	314-362-3299 636-278-5197
Columbia	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Patsy & David Dalton Doris Heuer	573-434-4569 573-999-2106
Creve Coeur	St. Louis	**Pre/Post-DBS Group** **Missouri Baptist Medical Center** **3015 N. Ballas, Main Parking Garage** **4th fl. CLI Rm. 419**	**3rd Tuesday**	**6:30 PM**	**Steve Balven** **Joe Vernon**	**314-249-8812** **636-230-8279**
Creve Coeur	St. Louis	**Young Onset** **Living and Working With PD** **Missouri Baptist Medical Center** **3015 N. Ballas, Main Parking Garage,** **4th fl.,CLI Rm. 419**	3rd Tuesday	6:30 PM	**Doug Schroeder** **Rich Hofmann**	314-306-4516 314-369-2624
Festus/Crystal City	Jefferson	Disability Resource Association 420 B S. Truman Blvd.	3rd Tuesday	1:00 PM	Penny Roth	636-931-7696 ext. 129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Melissa McGuire Nancy Robb	314-355-6100 314-869-5296
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Wednesday	3:00 PM	Jennifer Urich, PT	573-632-5440
Joplin	Jasper	The Alliance of Southwest Missouri 2914 East 32nd Street, Suite 102	Mondays	2:00 PM	Nancy Dunaway	417-623-5560
Kansas City	Jackson	VA Medical Center 4801 Linwood Blvd. Hall of Heroes Room	3rd Tuesday	11:00 AM	Jesus Torres Nikki C. Caraveo, RN, BSN, CNRN	816-861-4700 ext.56765
Kirkwood	St. Louis	Kirkwood United Methodist Church 201 W. Adams, Room 201	4th Tuesday	7:15 PM	Terri Hosto, MSW, LCSW	314-286-2418
Ladue	St. Louis	The Gatesworth 1 McKnight Place	2nd Wednesday	1:00 PM	Maureen Neusel, BSW	314-372-2369
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	3rd Thursday	Noon	Patsy Dalton	573-964-6534 573-434-4569
Rolla	Phelps	Rolla Apartments 1101 McCutchen	4th Thursday	2:30 PM	Hayley Wassilak Tyler Kiersz	573-201-7300
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider	314-846-5919

Missouri Support Group Calendar

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City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Springfield	Greene	Park Crest Baptist Church 816 W. Republic Road	Last Thursday	11:00 AM	Kay Meyer	417-350-1665
St. Peters	St. Charles	Spencer Road Library 427 Spencer Road, Room 259	1st Tuesday	1:00 PM	Sherrie Rieves Ann Ritter, RN	636-926-3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem.Hosp. Education Conference Room Hwy. 61 & 32 Intersection	2nd Wednesday	10:00 AM	Jean Griffard, RN	573-543-2162
Washington	Franklin	Washington Public Library 410 Lafayette Avenue	2nd Monday	6:30 PM	Carol Weber	314-713-4820
Webster Groves	St. Louis	Bethesda Institute 8175 Big Bend, Blvd., Suite 210	Last Friday	10:30 AM	Laurel Willis, BSW	314-373-7036
Wentzville	St. Charles	Twin Oaks at Heritage Pointe 228 Savannah Terrace	1st Thursday	1:00 PM	Ann Ritter, RN Sherrie Rieves	636-336-3168 636-542-5400

Exercise Classes

Our Exercise Classes meet once a week or otherwise as noted.
Information that has changed since the last **LiNK** appears in **bold face**.
Attend one class per week at no charge or for $20/month, attend as many classes as you want.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Clayton	St. Louis	The Center of Clayton 50 Gay Ave., Mind/Body Room	Wednesday & Friday	2:00 PM	Mike Scheller, PTA	314-289-4202
Chesterfield	St. Louis	St. Luke's Hospital 232 S. Woods Mill Rd.	Tuesday	11:00 AM	Patty Seeling, PT	314-205-6934
Chesterfield	St. Louis	Gardenview Chesterfield 1025 Chesterfield Pointe Parkway	Thursday	1:00 PM	Brandon Sunderlik Faye Bienstock	618-971-5477 314-917-9983
Chesterfield	St. Louis	Tai Chi APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Wednesday	10:00 AM	Craig Miller	314-362-3299
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Monday	1:00 PM	Susan Mayer, MHSPT	314-362-3299
Creve Coeur	St. Louis	Aquatic Exercise Rainbow Village 1240 Dautel Lane	**Spring session April 8-June 14** **Summer session July 8 - Sept 10**	**1:00 pm Tuesdays** **11:30 AM Tuesdays**	Brenda Neumann	636-896-0999 ext. 21
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	Tuesday & Thursday	10:00 AM	Bobby Lautenschleger, PTA	314-355-6100
Joplin	Jasper	The Alliance of Southwest Missouri 2914 East 32nd Street, Suite 102	Monday	2:00 PM	Nancy Dunaway	417-623-5560
South St. Louis County	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	Monday	11:30 AM	Mike Scheller, PTA	314-289-4202
St. Peters	St. Charles	Barnes-Jewish St. Peters Hospital Healthwise Center 6 Jungermann Circle	Every Tuesday except 1st Tuesday	11:00 AM	Holly Evans, COTA	636-916-9650
St. Peters	St. Charles	Aquatic Exercise St. Charles YMCA 3900 Shady Springs Ln.	**Spring session April 8-June 14** **Summer session July 11-Sept 12**	2:00 PM Thursdays	Brenda Neumann	636-896-0999 ext. 21
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	Monday	4:00 PM	Alice Hammel, RN	573-964-6534

ILLINOIS SUPPORT GROUP CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

Our Support Groups meet once a month or as noted. Support Group day and time may change periodically. For current updates on support groups and exercise classes, call the APDA Information & Referral Center or the facilitator. Information that has changed since the last **LiNK** appears in **bold face**.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Belleville	St. Clair	Southwestern Illinois College (PSOP) 201 N. Church St., Rm 106	2nd Monday	1:30 PM	Jodi Gardner	618-234-4410 x7031
Carbondale	Jackson	Southern IL Healthcare Headquarters University Mall	1st Wednesday	1:00 PM	Bill Hamilton, M.D.	618-549-7507
Decatur	Macon	Westminster Presbyterian Church 1360 West Main Street	3rd Thursday	1:30 PM	Kathy Broaddus	217-820-3096
Glen Carbon	Madison	The Senior Community Center 157 N. Main St.	3rd Wednesday	10:30 AM	Marilynn Kozyak Jeanette Kowalski	618-288-3508 618-288-9843
Greenville	Bond	Greenville Regional Hospital 200 Healthcare Dr. Edu. Dept., Edu. Classroom	2nd Monday	1:00 PM	Alice Wright	618-664-0808 ext. 3703
Mattoon	Coles	First General Baptist Church 708 S. 9th St.	Last Tuesday	1:30 PM	Roy and Kay Johnson	217-268-4428
McLeansboro	Hamilton	Heritage Woods - Fox Meadows 605 S. Marshall Ave., Dining Room	1st Wednesday	1:00 PM	Paula K. Mason	618-643-3868
Mt. Vernon	Jefferson	Greentree of Mt. Vernon 2nd Floor	4th Thursday	6:30 pm	Donna Peacock	618-242-4492
Quincy	Adams	Fellowship Hall of Salem Evangelical Church of Christ 9th & State	3rd Thursday	12:00 PM	Barb Robertson	217-228-9318
Springfield	Sangamon	Christ the King Parish Ctr. 1930 Brentwood Dr. www.parkinsonssupportcentralill.org	3rd Sunday in Jan., Mar., May, July, Sept., & Nov.	2:00 PM	Pam Miller	217-698-0088

LAND VS. WATER EXERCISES - WHY WATER?

Steven J. Bunn, Aquatic Specialist, Strength and Conditioning Professional, US Paralympic Coach

Parkinson disease is a disorder that affects nerve cells in the part of the brain controlling muscle movements. The disease progresses slowly without reducing life expectancy. In fact, people with Parkinson disease can have decades of productive living after being diagnosed. These years can be enhanced and even extended by appropriate exercise and physical activity.

What kind of exercise can you do to increase your neuromuscular function? Central nervous system training involves multi-joint movements that are performed at variable speed and with variable degrees of resistance. Examples of this would include pushing, pulling, stepping, jumping, or lunging. Do these motions in a pool. Buoyancy reduces compression and weight bearing stress on immersed joints, and the hydrostatic pressure of the water can reduce edema (swelling) in the submerged limb.

Do water-specific movements. These are movements that can be performed safely in the water, but considered high-risk in a land-based exercise program. The actual movements will vary from individual to individual based on ability, as well as stage and progression of the disease. An example would be the individual that utilizes a wheelchair on land who is able to participate in a water-walking program due to the increased buoyancy provided by the aquatic environment. Water exercise is aerobically efficient and may provide an ideal cardiovascular conditioning medium for many individuals. Walking and running in water require one-half to one-third the speed of land running or walking to reach the same metabolic intensity. Furthermore, the heart works more efficiently in the water, requiring 10 to 17 beats per minute below land rates. Twenty minutes of water exercise will equate to as much as 60 minutes of land exercise.

As a rehabilitation, fitness, and athletic training professional, I feel that the aquatic environment will continue to be utilized as a component of a client's road to successful outcomes. In the athletic arena or on the road to recovery, the value of water exercise is vital. Contact the Parkinson Resource Center to enroll in our aquatic exercise program provided at no cost to participants by the Greater St. Louis APDA Chapter, 314-362-3299. ■

TRIBUTES & DONATIONS

Tributes are a wonderful way to acknowledge the memory of a beloved person as well as honor those who mean so much to you.
Tribute envelopes can be obtained from the Center 314-362-3299 or made directly on the St. Louis APDA website, www.stlapda.org.

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The 90th birthday of Stanley Hoffman
Sara Lee Fitter

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Debbie Guyer

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Mark Kodner
Steve Hurster

The speedy recovery of Horty Levinson
Allen & Arline Kolons

Joe Marshall
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Larry McIntyre
Diane McIntyre

The 90th birthday of Ellen Nissenbaum
Sara Lee Fitter

The birth of Mr. & Mrs. Harvey Rothschild's great granddaughter
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PD DOES NOT HAVE TO BE THAT PAINFUL

Jonas Bromberg, PsyD, is a clinical health psychologist practicing in Wellesley, MA. He has more than 20 years of experience helping individuals and families cope with and manage chronic illness. Much of his work involves helping people understand their medical conditions, and teaching them skills and strategies to live fuller, healthier lives in spite of their illness.

When most people think about the symptoms of Parkinson disease (PD), they tend to focus on the obvious symptoms that affect movement, such as balance, tremor, involuntary movements, and stiffness. But these are not the only symptoms people with PD experience. Pain is an under-recognized and under-treated symptom of PD, with estimates of the prevalence of pain ranging from 40 to 83 percent. In some people with PD, pain symptoms can be even more disabling than their motor symptoms, and significantly reduce their quality of life. For many people with PD, pain is an important source of distress, yet it is frequently overlooked in clinical treatment in favor of the more obvious motor symptoms of the disorder. In fact, pain is assessed with only a single item on the Unified PD Rating Scale, the most widely-used assessment tool in research and clinical practice.

Chronic pain in PD may be due to direct dysfunction in pain transmitting pathways, or related to motor symptoms such as stiffness, rigidity, dyskinesia, and dystonia. Unfortunately, many of the medications used to treat PD may cause or exacerbate pain. The timing and dosing of medications play an important role in the mechanisms of PD pain.

People with PD pain experience more severe depression than people with non-PD-related chronic pain which negatively impacts functioning. Two-thirds of people with PD have sleep disorders, and research shows that 20 percent of people with PD suffer from restless leg syndrome, a potentially painful condition that causes insomnia (the inability to sleep) and hypersomnia (the inability to stay awake). Sleep deprivation is associated with a decreased pain threshold, muscle aches and stiffness, anxiety, and depression, all of which exacerbate the underlying cause of sleep deprivation in people with PD. Because the relationship between pain, depression, and sleep problems in PD can create a negative cycle, it underscores the importance of both identifying and treating chronic pain.

Interestingly, people with PD pain report their pain to doctors less frequently than people with non-PD pain, and astoundingly only half of those reporting pain received any form of treatment for it. Few patients described their pain symptoms to their provider without being specifically prompted. As a result, approximately half of all PD patients are missing out on potentially helpful pain relief. Many people with PD undergo many unnecessary and expensive workups before the PD is considered as the probable cause of the pain. Unlike other forms of chronic pain that can be relieved by analgesics, pain in PD may not respond effectively to painkillers, making the provision of behavioral strategies an important need.

A comprehensive approach to treating PD requires clinical attention on chronic pain and its psychosocial consequences in addition to motor impairments. To better understand the problem of pain in PD, we conducted a research study with clinical experts, people with PD pain, and family members who served as primary care partners for a person with PD. From our interviews with clinical experts, one of the most frequently cited issues was the relative lack of patient education about chronic pain. All of the experts indicated that patient education is a crucial component of an effective pain management plan. While most providers gave patients resources to learn about pain, a few stated they did not routinely do this, and usually only provided this information when asked for it.

We also asked the experts about the specific treatments they perceived to be most effective for relieving PD pain. The clinical experts emphasized that a combination of therapies and treatments, tailored to the individual, is the best approach for pain relief. Physical movement therapies, massage, and acupuncture were the most cited treatments. Among the participants that could prescribe medication, the most common approach to managing their patient's pain was adjusting the timing and dosing of their PD medications.

Many people with Parkinson's receive treatment from many different providers (primary care doctors, neurologists, nurses, physical therapists, occupational therapists, psychologists, and movement specialists). Because of this, we asked experts to identify who is primarily responsible for managing their patient's pain. Some were not sure, and cited a lack of communication between providers that sometimes exacerbated this problem. Of those that did identify a clear "owner" of the pain problem, most identified physical therapists and occupational therapists as the ones that work most directly in addressing pain problems in people with PD.

Among the experts we interviewed, we learned that a major challenge for doctors is being able to distinguish when pain is caused by another medical problem, and when it may be a non-motor symptom of PD. Experts said this could be especially difficult because the pain symptoms may look like other painful conditions such as a back pain, arthritis, thinning of the bones, or abdominal pain, all of which may be due to the normal process of aging.

From our interviews with people with PD and their care partners, nearly one-third of them did not get any specific kind of treatment for their pain. When we asked what was most helpful in relieving pain, every person we interviewed said that doing some type of exercise or physical activity was the most helpful part of his or her pain treatment plan. This included stretching, yoga, tai chi, walking,

continued on next page

American Parkinson's OPTIMISM EVENTS

These groups with a Parkinson connection recently conducted successful events. We wanted to showcase their efforts to inspire you to consider small ways you can increase awareness and help generate funds to ease the burden and find a cure. Take the challenge and host your own Optimism Event.

Two Optimism events have been held since our February newsletter: a Trivia Night held in honor of Marty Rudloff and a t-shirt sale at a basketball game in honor of Charles Shore.

This second-ever trivia night was sponsored by St. Louis Esprit Softball team. The softball team holds a trivia night each year to raise money for the season. This year they raised $700, bringing the total two-year contribution to a praiseworthy $1900 for the Greater St. Louis APDA, serving the state of Missouri and southern Illinois. You impress us with your dedication and loyalty to Marty.

> **"You cannot do a kindness too soon, for you never know how soon it will be too late."**
>
> **Ralph Waldo Emerson**

Coach Chris Shore from Cassville, MO is so well liked and inspiring that his girls basketball team sold "Make a Difference" t-shirts. The team (as well as their opponents) wore the shirts during practice and held a 50/50 drawing at a recent girls' basketball game in Cassville. They raised $450 toward our cause which will definitely make a difference. Coach Shore plans to make this an annual event. You go, girls! ■

...NOT THAT PAINFUL

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biking, swimming, and aerobics. Twenty-five percent of the people we interviewed attributed improvements in their pain symptoms to adjustments made to their Parkinson medications, and another twenty-five percent reported over-the-counter pain medicines helped reduce their pain. In addition, nearly one-third of the participants told us that using social support (talking with others about their pain) and engaging in pleasurable recreational activities or hobbies were effective for reducing pain.

We asked people whether they communicated with their doctor about their pain. Many people said they did not talk about their pain with the doctors because they did not want to distract them from focusing on their motor symptoms. Some said they felt like they didn't want to bother their doctor with this problem. Nearly half of the people said their physical therapist had been the most helpful in relieving their pain. Whether this was because physical therapists asked more often about pain, or that the treatments provided by physical therapists are especially effective, could not be determined.

So what does all this mean for someone with PD? First, talk with your doctor about your pain. Advocate for yourself. Don't suffer silently and let your pain be overlooked because PD is primarily a movement disorder. By gathering a careful history and doing a thorough physical exam, your doctor will most likely be able to determine the cause of your pain and provide effective treatment. Even if you are not experiencing pain now, ask your doctor which provider on your team will be primarily responsible for helping you manage pain if it does become a problem.

Second, PD does not only affect people physically; it also affects them emotionally. If you are feeling sad, discouraged, or hopeless, talk with your doctor. In many cases, your emotional outlook can make your pain and motor symptoms worse. There are many effective treatments for depression, which can improve both quality of your life and your physical symptoms.

Finally, don't try to live with your pain. Pain is a major source of distress and disability for many people with PD. It is important to let your doctor know if you are in pain, and don't hesitate to ask that your pain symptoms be treated. While the medical world is just beginning to understand the underlying mechanisms and relationship between PD and pain, many effective treatment options exist right now to relieve this serious non-motor symptom. Remember, the best treatment of Parkinson's includes attention to both motor and non-motor symptoms. ■

TRIBUTES & DONATIONS

continued from page 13

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Best Kept Secrets

Did you know you can find past APDA newsletters, fliers for upcoming events, chapters from The Parkinson Journey DVD, information on APDA services and programs, educational materials, and donation information on our website: **www.stlapda.org**? If you have not been there yet, check it out. The website and our Parkinson Community Resource Center (and its staff) are here for you.

GOING GREEN IN 2013

In an effort to help keep the LiNK mailing list current and to protect the environment, please contact the Greater St. Louis office at 314-362-3299 or via email at drehere@neuro.wustl.edu to make any of the following changes to your contact information or mailing preferences:

- Misspelled name
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SAVE THE DATE!

Mon., May 20 **Jack Buck Memorial Golf Tournament benefiting the Greater St. Louis APDA**
Reservations required for golfers as well as for cocktail/dinner-only participants.
Held at Algonquin Golf Club.
More details on page 8 of this newsletter.

Tue., June 4 **Improving Communication in Parkinson Disease: One Voice, Many Listeners**
Angela Roberts-South, MA, CCC-SLP, Ph.D. Candidate, Western University, Ontario, Canada
PD ExpertBriefing register at www.pdf.org

Mon., Oct. 14 **Fashion Show/Luncheon**
at the Sheraton Westport Chalet – reservations required. May request invitations for this event by calling the Center at 314-362-3299.