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American Parkinson Disease Association

APDA Greater St. Louis Chapter

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OUR 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 research.

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YOU Can Make a Difference!

Ambassadors for Increasing Awareness of Parkinson Disease and Resources



Deborah Guyer, M.A., Executive Director, St. Louis Chapter

You, too, can make a difference. Each and every one of you reading this newsletter can make a difference. Are you up to the challenge? It doesn't even require writing a check (although we never turn those away); you don't have to be wealthy, but you can still make a huge difference. Let me share some stories about people making a difference.

There is never a donation too small. We have a loyal Blue Ball, Pennsylvania, donor, Char Ann, who sends a \$1 bill hidden within newspaper coupons she clips every week and sometimes twice a week. Monetary donations of any size are gladly accepted and always appreciated, no matter how many zeros precede the decimal point.

Mark, an individual who has Parkinson disease, is an artist. His artwork is displayed on consignment at various studios around town, and he donates the proceeds of his sales to APDA as his way of contributing to our mission. Another artist and individual with Parkinson's, Celeste, renders drawings of fellow residents at her nursing facility and sends in their donations to APDA.

We have featured many individuals and families who have hosted their own local fundraisers as Optimism Events. The Vermillion family held a fish fry and bean bag toss for family and friends in their rural community, raising \$1,551 for DBS research. Friends of Joe, a musician who had Parkinson disease, held a benefit in honor of their fellow musician who played in various bands spanning a 40-year period. Tommy from Columbia, Missouri, memorialized his dad who had Parkinson's by fundraising and hosting a tractor pull. We feature these Optimism Events in every newsletter, and there are three more to read about in this issue.

More and more families are requesting tributes to honor birthdays, anniversaries, and holidays for individuals who don't need another gift but are thrilled to be notified of a tribute made in their name. Memorial trib-

utes are often requested in lieu of flowers by families suffering a loss—families paying it forward, paying it back for services and care they have received over the years. One family wrote about their recently deceased loved one, "She courageously battled Parkinson disease for 18 years, and she was greatly supported by the patient programs provided by the St. Louis Chapter of the American Parkinson Disease Association," raising awareness and funds for APDA simultaneously. We also receive a number of memorial tributes from families and friends of individuals who were never connected to our Chapter of the APDA. It always saddens me that we missed an opportunity to be connected and to help someone who may have been struggling to live with this disease, unaware of the million-and-a-half other individuals who have Parkinson's in this country.

One man asked his church to include information about Parkinson disease in its bulletin, including information on how to contact the Greater St. Louis APDA for resources. Now many other members of the church will benefit from having this information at their fingertips. Also, there are individuals we are connected to who return

continued on next page

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Disclaimer: The information and reference material contained herein concerning research being done in the field of Parkinson disease and answers to readers' questions are solely for the information of the reader. It should not be used for treatment purposes, rather for discussion with the patient's own physician.

YOU Can Make a Difference! *continued from front page*

to their internist and neurologist, showing them the welcome packet of information that we send out to newly diagnosed individuals and family members. We will gladly supply doctors with this information for their waiting rooms so all of their patients have access to Parkinson literature and the St. Louis APDA!

Awareness is the key to funding and finding a cure for this devastating disease. We hope you will consider planned giving. Including a gift as part of your estate plan can be a meaningful and impactful way to leave a legacy. We are deeply grateful for the gifts you have already given and continue to give in support of our work. You can have an even greater impact on changing the course of Parkinson disease. If you are interested

in exploring ways to leave a lasting legacy through your will, living trust, annuity, or retirement plan, please let us know, as we have professionals on our board that can help you consider your options, big or small.

We're counting on your generosity and creativity. You are not alone. According to the research findings conducted by Dr. Allison Willis in 2009, there are over 132,000 newly-diagnosed cases of Parkinson's in this country every year. My friend, Pam Quinn, recently offered this thought: "Awareness of Parkinson's leads to compassion; compassion leads to giving; giving leads to research; and research will lead to a cure." You CAN make a difference — let's start now! ■

Coming to Terms with Parkinson Disease

Thomas Teichmann, Pastor, Messiah Lutheran Church, Amherst, NH



It's been more than ten years since I was diagnosed with Parkinson disease. It was devastating, and I told no one except my spouse. After five years of leading a covert life, I came to a point where I could finally admit PD's existence in my life—to myself, as well as to those around me. A big part of that initial denial and subsequent recognition of the condition was an ongoing inner dialog concerning the spiritual dimension of chronic illness. The questions of "why" and "why me" and the search for meaning in a life dramatically altered by a disease I did not cause, challenged my spirituality.

You may shy away from your spiritual self. Although you may not consider yourself to be "religious," there is a spiritual part of you. A part that seeks meaning in life; a part that recognizes you can discover order even in a chaotic world; a part that hopes, even when there seems to be no hope. You are a spiritual being. And just as "use it or lose it" is your slogan for both physical and cognitive training—so, too, your spirit can be exercised, nourished, and used to promote the wellness of the whole body.

I began to see my relationship with this condition as "living with Parkinson's." Accent on the with. Accepting its presence as a part of my life—then stretching its limitations, adapting

to its progression, and not allowing it to define my life—provided a means through which I could interact with others in a world that is largely uninformed about PD. Living with Parkinson's is integrating the hard reality of the disease into the ever-changing story that I, and all of us, tell about ourselves. It becomes a thread that runs through our lives.

The wise use of an ever-evolving vanguard of Parkinson's medications, joined with taking care of oneself through diet, exercise, and supplements, makes up the familiar physical routine of "living with." Staying connected to the world, treating depression, and actively engaging the brain in exercises designed to promote healthy cognition, all work towards the mental goals of living with Parkinson's.

I would venture this—somewhere along the line you are going to accept this Parkinson's as yours. Unique to you, neither good nor bad—it just is—like a hand... an eye... a birthmark. PD is like a visitor who stays in your guest room and eats every meal with you and has no thought of leaving. But he is not a foreign intruder. He was always there. It is like your hair going gray. Something to manage, adjust to, admit to, negotiate with, subjugate at times, but always acknowledge. ■

This article first appeared in "Parkinson's Companion," Spring 2015. Portions of Tom's original article are reprinted with permission of the author and Diane L. Sherman, PhD, Editor and Coordinator of the Parkinson Information & Referral Center at Dartmouth-Hitchcock.

DUOPA – A New Levodopa Delivery System to Treat Motor Fluctuations

Paul Kotzbauer MD, PhD, Associate Professor of Neurology, Washington University School of Medicine

The US Food and Drug Administration (FDA) recently approved a new delivery system for carbidopa/levodopa, the most commonly used drug for managing the symptoms of Parkinson disease (PD). This new approach uses a pump to deliver a carbidopa/levodopa suspension (Duopa) to the small intestine, and aims to overcome issues such as variable absorption and short half-life that lead to fluctuations in PD symptoms when carbidopa/levodopa is taken in tablet form. The Duopa system is designed to provide more consistent and steady dopamine levels, which is difficult to achieve with oral medications as the disease progresses.

The motor symptoms of PD (tremor, rigidity, difficulty with walking and mobility) typically respond very well to carbidopa/levodopa, also known by its brand name Sinemet. The production of dopamine in the brain gradually declines in PD, and levodopa is helpful because it increases dopamine production, which is essential for the proper function of brain circuits that control movement. The carbidopa component has no effect on symptoms but is included to prevent side effects such as nausea caused by levodopa.

Levodopa typically produces clear improvement in symptoms, but over time many people develop fluctuations in their response to levodopa. They fluctuate between the “on” state, during which levodopa works well to minimize PD symptoms, and the “off” state, during which PD symptoms re-emerge. These “motor fluctuations” are caused by the rise and fall of drug levels that occur each time tablets are taken by mouth. They are likely related to a decline in the ability of the brain to store the levodopa delivered by each dose. Some people also develop dyskinesias or involuntary movements, which are typically triggered when the peak levodopa level is higher than optimal after a dose of medication.

When people with PD develop difficulty with either “wearing off” or dyskinesias,

symptoms can sometimes remain well controlled by adjusting medication doses to keep levodopa levels in the optimal range or by adding other medications that work in combination with levodopa. However, as time goes on, “off” periods and dyskinesias often become more problematic despite attempts to optimize medication.

Deep brain stimulation surgery is a current treatment option that can improve motor fluctuations, but an additional option to directly address the fluctuations in levodopa levels is now available with Duopa. Carbidopa/levodopa has been formulated into a gel (carbidopa-levodopa enteral suspension) that is delivered directly to the small intestine by a pump. A tube, known as a percutaneous endoscopic gastro-jejunostomy or PEG-J tube, is inserted through the skin of the abdomen into the small intestine. A programmable pump is connected to the tube to continuously deliver the medication to the small intestine, the place where it is normally absorbed. This bypasses the unpredictable time required for tablets taken by mouth to move from the stomach to the small intestine. The pump can be programmed to deliver the gel at a rate that is optimized for each individual, an improvement over the irregular delivery that occurs with tablets. The risks of the surgical procedure required to insert the tube and the need to carry the pump are potential drawbacks, but the pump can be carried in a number of ways including attaching it to a belt or shoulder strap.

Clinical studies of the Duopa system were recently completed in the United States (US). The Movement Disorders Center at Washington University School of Medicine was one of multiple sites involved in these clinical studies of Duopa. Studies were also previously conducted in Europe, where it is approved and marketed under the brand name Duodopa. Results of the recent US studies indicate that the Duopa system maintains relatively steady levels of levodopa in the bloodstream.

They also demonstrated that conversion from carbidopa/levodopa tablets to the Duopa system resulted in a significant reduction in “off” time and a significant increase in “on” time without bothersome dyskinesias, in people with PD who were experiencing motor fluctuations. The FDA approved the Duopa system for use in the US based on these studies.

Placement of the PEG-J tube is performed by a GI specialist, using endoscopy to guide the placement of the tube in the correct position in the small intestine. The tube enters the stomach through a small incision made in the abdomen and extends through the stomach into the initial portion of the small intestine. The procedure to place the Duopa tube is the same approach that is commonly used to place a feeding tube in individuals who develop difficulty swallowing from conditions such as a stroke. There are risks related to complications of the procedure such as infection. Other potential drawbacks over time are problems such as blockage or displacement of the tube, which require placement of a new tube.

A Movement Disorders Specialist oversees the initiation of Duopa following placement of the PEG-J tube. The Duopa system needs to be carefully measured to deliver levodopa at the optimal rate for each individual. This is accomplished by observing the individual’s response to Duopa as the settings on the pump are gradually adjusted over several days in order to program the pump for optimal Duopa delivery. Adjustments can be made as needed to improve control of symptoms over time. Those who are interested in whether Duopa is an appropriate option to address problems with motor fluctuations should discuss it with their neurologist. The Movement Disorders Center at Washington University will offer consultations to those interested in further evaluation and advice regarding whether Duopa would be an appropriate choice for treatment of their PD symptoms. ■

On Your Mark – Get Set – GO! St. Louis Marathon & Family Fitness Weekend

With 135 APDA team members participating in the walking or running events in St. Louis on April 11 and 12, our APDA Greater St. Louis chapter topped the chart of participating charities in both number of participants and monies raised for the organization for the second consecutive year. Through individual and business sponsorships, over \$55,000 was raised to support Parkinson research and the APDA Information & Referral Centers across the nation in our second year with GO! St. Louis. This Parkinson disease research includes new therapies that will increase quality of life for many individuals with Parkinson disease. Scientists across the world are hard at work trying to find a therapy to slow or stop the disease progression. Special recognition is given gratefully to committee member Gail Glenn, who exceeded her first year personal goal by raising \$12,500. Gail made sure that friends knew of her passion and the importance of raising funds for promising Parkinson research. She wanted everyone to know that real progress is being made toward a new generation of Parkinson treatments and a cure. Gail realized how much help she needed in order to reach her personal and our shared goals. As a result of the generosity of friends and family of all of our



team members, over 600 separate donations were received. A large tent at the Saturday 5K run/walk event helped raise awareness about the APDA and Parkinson disease,

and APDA staff were all on hand to answer questions as part of the April Awareness Campaign “30 Days, 30 Ways to Make a Difference.”

We regret that we are only able to list gifts of \$50 or more which were received by April 1, 2015. Please refer to a complete listing which is available on our website. Our gratitude is extended to members of the walk/run committee who have given their hearts and “sole” (pun intended!) to make this event a resounding success. For participants, we hope you enjoyed the weekend and plan to join us again in 2016! For a complete viewing of the photos captured during the weekend, visit our website at www.stlapda.org.



St. Peters Exercise Class



Shellie Fidell, Gail Glenn, Jill Indovino, Ronnie Brockman

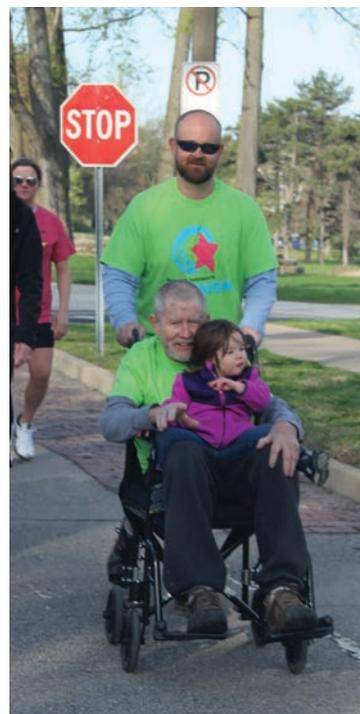
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Determining What Types of Care You Need



Stacey Barton, MSW, LCSW, Medical Social Worker, Washington University School of Medicine

As a social worker, one of the most common requests I receive is for help getting additional care needs met. People often know there is help “out there” but really have no idea what types, how to access it, or how it is paid for. At a recent APDA workshop, I co-presented on this topic with Lori Zimmerman of Elder Link St. Louis. In this article, I will recap the presentation and provide you with information you need to make a determination about how to get help, what type of help to get, and set some expectations on how it will be funded.

This article will address in-home care such as home health and private duty, adult day care, and residential care options such as independent living, assisted living/RCF and nursing homes/skilled nursing facilities. In addition, hospice will also be discussed very briefly.

IN-HOME CARE

The first place people often want to begin is looking at care they can receive to allow them to stay at home. Many people use the term “home health” generically, but it is important to realize that this term may not actually reflect the needs you have. I will use the term “home health” to refer to temporary health services provided in the home for an illness or injury, typically covered by medical insurance. I distinguish this from “private duty” which is not covered by medical insurance, does not require a skilled service (i.e., professional nurse, physical therapist, occupational therapist, etc.) and can continue for as long as you want this service.

Home Health is in-home care with a goal in mind. It is meant to treat an illness or injury in order to get better and regain independence. Patients must be homebound; otherwise, they are expected to receive these services through outpatient clinics. Care is intermittent and temporary only and is typically covered by Medicare Part A or Part B. Medicare Advantage Plans also provide this coverage but will have specific providers from which the patient must choose. For people with original Medicare, they pay none of the cost of home health care services and 20% of the cost of medical equipment unless they have a supplemental insurance that will pick up these costs. There is no limit to the number of annual visits, but they won't go on forever. A home visit is about an hour and the patient typically only receives services for a few weeks.

Home health requires a doctor's order and the patient must be under a doctor's care. The doctor must certify that the patient

needs one or more of the following:

- Intermittent skilled nursing care (but not just blood draws) e.g., wound care, IV therapy, nutrition therapy, injections
- Rehab services: physical, speech or occupational therapies

The condition must be expected to improve in a reasonable, predictable period of time or require a skilled therapist to create or assist with a maintenance program. Once a patient qualifies for nursing or therapy services, s/he may also qualify for social work services, intermittent home health aide, medical supplies, and medical equipment.

Home health is NOT 24-hour a day care (or even extended hours of care), home delivered meals, homemaker, custodial or personal care. This is where private duty comes in.

Private Duty typically consists of personal care and homemaker services. It is not covered by medical insurance such as Medicare or commercial insurance. Some people may be able to receive a few hours of this care through Medicaid if they meet specific criteria, which include being impoverished and otherwise requiring nursing home care. These services may also be covered through VA benefits and are usually covered in long-term care insurance policies if the person meets the requirements of their policy.



Private duty is rather expensive. Although there is a lot of variability, the average is about \$20 per hour through an agency, and many agencies require a four hour minimum. People can save money by hiring someone privately, but there are caveats to be aware of if you choose to go that route. That is probably an article in itself, but in general the advantages of hiring an agency are that they assume responsibility for screening, hiring and firing staff, providing liability insurance, training the staff, and administering the taxes. In addition, you will be assured that there are backup staff available if your primary caregiver is ill, or on vacation or if their car breaks down. They can also alter the staffing if the skill set required to care for the patient changes. Finally, for individuals with long-term care coverage for private duty, you may be required to use a licensed agency for the care. There are some advantages of hiring a private aide outside of an agency. Primarily the benefit is one of cost. There may also be greater consistency of having just one worker, you may have more choice in who provides the care and there may be flexibility in scheduling such as not having a minimum number of hours.

ADULT DAY CARE

This is one of the most overlooked resources available. Adult Day Care (ADC) is a safe and therapeutic place for a person with a disability or dementia to go during the day to receive care, social engagement, and oversight and then return to their homes in the afternoon or evening. Most ADCs are open 10-12 hours per day, 5 days a week and some offer regular or occasional Saturdays. Full and half-day options are available at most centers. The cost is quite reasonable with an average of about \$75 for a full day of care. The costs are covered through private pay, Medicaid, long-term care insurance and VA benefits. Some ADC centers offer scholarships or sliding scale.

ADC provides a lot of care for the cost. Included in the care at most centers are meals, personal care, activities and medication administration. Some centers also offer transportation, rehabilitation services, beauty salon, podiatry, and more.

RESIDENTIAL CARE

Sometimes remaining at home is no longer an option. There are several types of residential care, and many of these terms are used loosely and generically. When talking to providers, friends, and medical professionals be sure to clarify that you are all talking about the same things. I will use the terms residential care facility (RCF), assisted living (AL), nursing home (NH), and skilled nursing facility (SNF).

First, let's not overlook independent living. There are a number of campuses that provide housing for people who are older or disabled that are independent. These are often apartment, villa or cottage-like homes that include upkeep of the outside facilities and basic housekeeping. Many offer some meals, scheduled activities and transportation. Additional services, such as medication administration and personal care, may be available but at the same cost as private duty care as described above. Independent living is private pay and may include a refundable or partially refundable admission fee.

Assisted living is probably the term social workers hear used most loosely. For our

purposes, we will consider AL facilities as well as RCFs together. In addition to RCF and AL, you may also hear the terms Supportive Living Community or Board and Care Home used in this category of care. There are slightly different licensing rules for AL and RCF, but in general these are facilities that provide protective oversight 24 hours a day 7 days a week plus meals. Many, but not all, will provide medication administration. It is important to know when looking at AL/RCF what you are getting because of the variation in services provided. Additional services may be provided a la carte, and this can add up quickly if you need a lot of care. Payment is typically private pay although long-term care insurance occasionally will cover this level of care and the VA may partially pay in some instances. For lower-income people, there may be access to a small state grant of \$292 per month, but this is only occasionally used because it often is not enough to bridge the cost gap. The average national cost in a residential care facility is around \$24,000 per year or about \$65 per day.

Nursing homes and skilled nursing facilities are familiar to most of us, but even then there is often some confusion about what these consist of and how they are paid for. These are also terms often used interchangeably, but some people may distinguish the two, and some facilities offer both within their own building. For clarity, I will consider NHs as facilities that provide custodial care to patients with significant care needs due to illness or age. I will define SNFs as facilities that provide 24-hour care also, but typically this is in a rehabilitation setting where patients are recovering from an illness or injury and are attempting to maximize their potential so they can return home or return to a NH bed for ongoing custodial care. Many NHs offer SNF services in a wing of the facility.

For people undergoing rehabilitation or nursing care in a SNF (pronounced "sniff"), they will receive 24-hour care by skilled nurse and/or rehabilitation services. This care requires a doctor's order and is often covered by medical insurance such as Medicare. This is where the confusion often comes in. Patients know

that Medicare covers SNF care, and they mistakenly think this means that all NH care is paid for by insurance. This is not correct. Medicare will cover SNF care in very specific situations for a very limited period of time. As you might imagine, there are a lot of government rules managing this coverage, but in general, SNF coverage is available to people who require skilled care beyond their hospitalization and have had at least three midnights in the hospital under inpatient status. This is key, as observation status doesn't count, and patients often don't know what status they are admitted under – so if you are in the hospital, ask! Patients no longer have to show continual improvement and rehab potential to stay under this care, but that doesn't mean that Medicare will cover it for long. At best, Medicare covers the first 20 days of SNF care in full and then there are 80 more days of care available, but Medicare covers only a portion of this expensive care. If you have a Medicare supplement, then your portion is typi-

continued on page 10

ADDITIONAL RESOURCES

- **Adult Day Care in St. Louis** (Courtesy of the Alzheimer's Association) www.alz.org/stl/documents/stlreportadc.pdf
- **Adult Day Care, Licensed** (MO Dept of Health and Senior Services) health.mo.gov/seniors/nursinghomes/pdf/ADC-licensed.pdf
- **Family Caregiver Alliance** www.caregiver.org
- **Medicare and Home Health Care** www.medicare.gov/Pubs/pdf/10969.pdf
- **Medicare Compare**
- **Home Health–** www.medicare.gov/homehealthcompare
- **Nursing Home –** www.medicare.gov/nursinghomecompare/search.html
- **Veteran's Aid –** www.veteranaid.org
- **Understanding Long-Term Care Insurance** longtermcare.gov/the-basics/
- **VOYCE** (Long-term care ombudsman) – check quality of nursing homes in St. Louis www.voycestl.org
- **Show Me Long-Term Care** www.dhss.mo.gov/showmelongtermcare

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Determining What Types of Care You Need *continued from page 7*

cally covered through the gap insurance. Bottom line, at most, SNF lasts for 100 days, but the extensive regulations governing this level of care mean it is not a good planning tool for covering the cost of residential care.

Like SNF, NH care covers personal care, laundry, meals, medication administration, activities and all the basic needs of life, 24 hours per day, seven days per week. Care is meant to be personalized through a Care Plan, but the care is never one on one. Rehabilitation services are available, but unlike SNF not included in the daily rate (they are usually billed to Medicare separately). For NH care, there are a number of payor sources including private pay, VA benefits, Medicaid (MO HealthNet), and long-term care insurance. NH costs are on the rise, and the current national cost is about \$64,000 per year for a NH

(about \$175 per day). Rates are even higher for a private room.

HOSPICE

Hospice care deserves an article of its own, but is included here since it can be a way to obtain additional care. Hospice is intermittent care provided to people who are approaching the end of their life, defined as an expected prognosis of six months. There are no crystal balls, though, so anyone who is late in the stages of PD might consider asking their physicians about hospice care. Hospice care can be provided wherever anyone lives – in the home or in residential settings. There are very specific admission criteria for hospice care, but once enrolled people typically receive nursing visits and nurse aide visits a couple of times per week each, social work and chaplain support, and volunteer help,

and many of your medications and equipment needs will be paid for by hospice. Hospice covers occasional respite and may cover continuous care in periods of crisis, but in general the home visits are about an hour in length, several days per week. In addition, there is 24-hour on-call support and unscheduled visits can occur if there is a need. Medical insurance almost always covers the cost of hospice care in full.

We are fortunate in our area to have a lot of resources available for people who need additional help managing day-to-day life. By learning your options, evaluating your resources, and asking the right questions, hopefully, you will utilize the right level of care at the right time and increase quality of life for the person with PD and their families while allowing people to remain as independent as possible for as long as possible. ■

Hi-VOLT™ 4 PD

Hi-VOLT™ 4 PD is an audio CD containing 27 minutes of guided voice practice, developed by speech-language pathologist, Mary Spremulli, MA, CCC-SLP. The CD contains words, phrases, and sentences, all designed to help users access breath support and feel the effort it takes to achieve or maintain adequate voice loudness.

The accompanying Hi-VOLT™ voice-on-light is a voice-activated bracelet. It has been calibrated so that when the user speaks loud enough to activate the light, they will be loud enough for others to hear them. “In therapy with my own patients,” Spremulli says, “I give only one cue: speak loud enough to activate the light.” The bracelet can be worn like a watch or placed in front of the user. Just like a speedometer on your car provides feedback, the Hi-VOLT™ voice-on-light provides feedback, helping users stay loud enough for everyday conversation.

The battery life on the Voice-on-Light is 30 continuous hours of static and active engagement in the ‘ON’ position. Based on one hour/day of use, the bracelet should provide 30 days of use before needing to be replaced. Many persons have expressed a desire to use the device throughout the day, so, the manufacturer is currently investigating options for a longer lasting or easily replaceable battery.

Portable Digital Voice Amplifier

A portable voice amplifier can be a great tool for those instances when it feels harder to use your voice. Mobility devices, like canes and walkers, help you move more safely and independently, so why not have a voice amplifier available as a “vocality” tool? Amplifiers are used routinely by teachers and public speakers as a way of reducing vocal strain. A person with a weak voice from Parkinson’s or related diagnosis might enjoy using an amplifier for social gatherings or other settings where you just want your voice to be heard. This amplifier is dispensed with a headset microphone and long-lasting rechargeable battery.



You may obtain further information about these new devices/tools at their website: www.voiceaerobicsdvd.com

Both devices, in addition to other helpful amplifiers and loudness monitors, are available for demonstration in the APDA Resource Center in Chesterfield.

Vibrating Watch

Stop in at the Resource Center and view a sample of Vibra-Lite wrist watches. They have large, easy to read displays, and easy, user-friendly prompts assist in setting. Unique to this medication reminder is that you may select vibration, audible or both as options. There are multiple daily alarm settings, with a countdown timer with auto repeat option and option of alert reminders before zero. www.vibrallite.com



Liftware Spoon

Liftware is a stabilizing handle and a selection of utensil attachments that include a soup spoon, everyday spoon, and fork designed to help people with hand tremor eat more easily. It works best for those with mild to moderate tremor. This adaptive device automatically stabilizes so the attached utensil shakes 70% less than your hand. It enables you to worry less about spilling and focus more on enjoying your meal. Liftware automatically turns on the moment both parts are connected, and temporarily “goes to sleep” when not in use.



New Prescription Medication Co-Pay Program

The Patient Access Network Foundation recently established a co-pay program for individuals with Parkinson’s. Co-pay programs provide direct financial assistance to qualified patients, assisting them with prescription drug co-payments their



insurance requires relative to their diagnosis.

TO QUALIFY:

- Patients must have either Medicare or a commercial insurance, and
- Not have income in excess of 500% above the federal poverty line.

Co-pays for all drugs prescribed for the treatment of Parkinson disease are eligible with a maximum yearly reimbursement of \$16,500.

Patients, their clinicians or their pharmacy can register for the program at the Patient Access Network Foundation by phone at (866.316.7263) or through the PAN Web site (www.PANfoundation.org) by answering a few questions. Individuals will know immediately if they are eligible for this new co-pay program.

PillPack – Pharmacy Simplified

People with Parkinson disease often have a large number of medications to manage. Sorting medications can be difficult and time consuming. PillPack, a new kind of pharmacy, simplifies the process of managing medications.

- Medications come organized in individual packs organized by date and time.
- Your PillPack is delivered to your door every 2 weeks.
- The service comes with proactive refill management. Pharmacists manage your refills, so you’ll never run out.
- Pharmacists are available 24 hours a day to answer your questions via phone or email.
- Packs can include prescribed and over-the-counter medications and multivitamins.



There is no charge for PillPack beyond your standard 30-day co-pays. PillPack accepts most major insurance plans, including forms of Medicare Part D. There are no shipping, handling, or extra fees associated with switching to PillPack.

To learn more about PillPack or to enroll, visit the website at www.pillpack.com or call, 1.855.745.5725.

Prescription Assistance Programs Directory

Modified from Salt Lake City, Utah, Information and Referral Center Summer/Fall 2009 Parkinson's News.

The programs below offer financial assistance toward the cost of prescription medications. Most of these organizations work on the patient's behalf with the drug companies, and may charge a small fee for their service.

Extra help with prescription drug costs

You must be enrolled in a Medicare Prescription Drug Plan.

www.ssa.gov/prescriptionhelp
1.800.772.1213

Patient Advocate Foundation – Co-Pay Relief

Helps with co-pay cost for patients with insurance. Limited to specific diseases.

www.copays.org • 1.866.512.3861

Needy Meds

An information resource to help people who can't afford to pay for their medications.

www.needy meds.org • 1.800.503.6897

Rx Assist

Provides a comprehensive listing of pharmaceutical company Patient Assistance Programs.

www.rxassist.org • 401.729.3284

Partnership for Prescription Assistance

Provides assistance for low-income uninsured patients to get free or nearly free prescription medicines through existing Patient Assistance Programs.

www.pparx.org • 1.888.477.2669

Rx Outreach

A low-cost, mail-order prescription generic drug program for lower income families.

www.rxoutreach.com • 1.800.769.3880

Rx Help

A prescription assistance company that helps qualified patients access and remain in a pharmaceutical Prescription Assistance Program.

www.rxhelp4u.com • 1.866.960.9497

Rx Hope

A web based assistance program to help patients access pharmaceutical Prescription Assistance Programs.

www.rxhope.com • 1.877.267.0517



Optimism Dresses Down

Paramount Mortgage Company recently sent a check in the amount of \$352 to our chapter. They have a casual day every Friday, and in order to participate in casual day, each employee contributes a dollar in the monthly charity as chosen by their Employee of the Month. Receiving this contribution has been beneficial to the services and programs we provide at APDA. Perhaps you could encourage your employer to offer such a program.



Optimism Trivia Night

You may recall the St. Louis Esprit Softball girls. Every year, since 2012, these young girls have held a Trivia Night in February, honoring "His Honor" former Mayor Marty Rudloff, and this year that event made \$500 more than in the previous years, raising \$1,700 in February for patient services. The efforts of these young people have resulted in \$4,800 for patient services in our community—way to go St. Louis Esprit Softball members. You hit another one out of the park!



Optimism Gives Back

For the second year in a row, Scottrade and its associates participated in a program named Giving Back Together. The program allowed associates to donate a designated amount of money from their paycheck each month to a group of charities, with an additional match from their employer, Scottrade. In two years, Scottrade and its associates have generously provided close to \$9,000. How wonderful to work for an employer who encourages philanthropy among its employees that the company matches. Please check with your employer as you may be able to double your gifts simply by completing paperwork requesting a matching gift.



APDA Partnership Will Provide Social Work Services

As of March 1, APDA Greater St. Louis Chapter is funding a pilot effort to offer social work services to its members.

This pilot is very limited in scope but will offer 16 hours a month of social work to people with Parkinson disease and/or their family members. The initial pilot is funded from March 1- August 31, 2015, and may be renewed in subsequent fiscal years.

The social worker, Stacey Barton, MSW, LCSW, works for the Movement Disorders Center in the Department of Neurology at Washington University School of Medicine. These new social work services are not limited to patients receiving care there.

The social worker can assist with concerns such as connection to local resources, transportation, equipment, continuum of care (adult day programs, nursing homes, assisted living, etc.), education on how to select facilities, education about and assistance with understanding insurance (especially selection of Medicare Part D plans), and prescription assistance referrals and education.

Because of the limited scope of the program, requests for referral will have to be prioritized upon receipt.

For more information or for a referral to the social worker, please call the APDA office at 314.362.3299.



Missouri Support Group Calendar

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, check our website, www.stlapda.org, or call the APDA Information & Referral Center or the facilitator. Information that has changed since the last **LiNK** appears in **bold**.

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	2:00 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 Nancy Rapp	636.532.6504 636.537.3761
Chesterfield	St. Louis	For Caregivers Only APDA Community Resource Center 1415 Elbridge Payne, Suite 150	2nd Monday	10:30 AM	Dee Jay Hubbard	314.362.3299
Columbia	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Patsy & David Dalton	573.356.6036 573.434.4569
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	Joe Vernon	314.614.0182
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	314.306.4516
Festus/ Crystal City	Jefferson	Disability Resource Association 130 Brandon Wallace Way	3rd Tuesday	1:00 PM	Penny Roth Sara Dee	636.931.7696 x129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Nancy Robb	314.869.5296
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Wednesday	3:00 PM	Jennifer Urich, PT David Urich	573.632.5440 573.796.2395
Joplin	Jasper	Byers United Methodist Church 1730 S. Byers, Gymnasium	Every Monday	3:00 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 x56765
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 & David Dalton	573.356.6036 573.434.4569
Poplar Bluff	Butler	Poplar Bluff Regional Medical Center 3100 Oak Grove Rd. Ground Floor Education Room 3	2nd Monday	6:00 PM	Charles Hibler register with Beryl or Dana	573.785.6222 855.444.7276 573.776.9355
Rolla	Phelps	Phelps County Regional Medical Center, Pulaski Room, 1000 W. 10th St.	4th Thursday	2:30 PM	Sarah Robinson	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
Springfield	Greene	Mercy Hospital 1235 E. Cherokee	2nd Thursday	2:00 PM	Randi Newsom, RN, BSN	417.820.3157



continued from previous page

Missouri Support Group Calendar

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
St. Peters	St. Charles	Spencer Road Library 427 Spencer Rd., Room 259	1st Tuesday	1:00 PM	Sherrie Rieves Ann Ritter, RN	636.926.3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem. Hospital Education Conf. Room, Hwy. 61 & 32	2nd Wednesday	10:00 AM	Jean Griffard, RN	573.543.2162
Trenton	Grundy	Royal Inn 1410 E. 9th Street	1st Thursday	10:00 AM	Novy & Mary Ellen Foland Gloria Koon	660.357.2283 660.485.6558
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
Webster Groves	St. Louis	Laclede Groves 723 S. Laclede Station Rd.	3rd Wednesday	3:00 PM	Dina Spies	314.446.2594



Illinois Support Group Calendar

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, check our website, www.stlapda.org, or call the APDA Information & Referral Center or the facilitator. Information that has changed since the last LiNK appears in **bold**.

CITY	COUNTY	MEETING SITE	DAY OF MEETING	TIME	LEADER(S)	PHONE
Alton	Madison	Senior Services Plus 2603 N. Rodgers Ave.	2nd Tuesday	9:30 AM	Kim Campbell	618.465.3298 x146
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
Centralia	Washington	Heritage Woods of Centralia 2049 E. McCord St.	2nd Wednesday	2:00 PM	Dennis Krupp Betty Evans Helena Quaid	618.545.6597 618.533.0224 618.493.6064
Champaign	Champaign	Savoy United Methodist Church 3002 W. Old Church Road	Every Monday	10:00 AM	Charles Rohn Chuck Arbuckle	217.549.6167 217.586.3100
Decatur	Macon	Westminster Presbyterian Church 1360 West Main Street	3rd Thursday	1:30 PM	John Kileen	217.620.8702
Glen Carbon	Madison	The Senior Community Center 157 N. Main St.	3rd Wednesday	10:30 AM	Nancy Goodson Rich Rogier Jeanette Kowalski	618.670.7707 618.288.3297 618.288.9843
Greenville	Bond	Bond County Sr. Center 1001 E. Harris Ave.	4th Monday	10:30 AM	Anna Oestreich	618.664.1465
Greenville	Bond	Bond County Sr. Center Baumberger Comm. Rm. CAREGIVERS ONLY	4th Friday	1:00 PM	Anna Oestreich	618.664.1465
Jacksonville	Morgan	Passavant Area Hospital 1600 W. Walnut—Meeting Room 2	1st Wednesday March-December	6:00 PM	Karen Ladd	217.377.4973
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
Springfield	Sangamon	St. John's Rehab. @ Fit Club South 3631 S. 6th. Street #C	Odd numbered months: 1,3,5,7,9,11	2:00 PM	Kelly Neumann, PT	217.483.4300

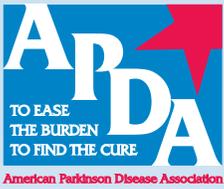


Exercise Classes

The APDA now offers 17 exercise classes that meet weekly. Exercise is essential to managing Parkinson symptoms and slowing the progression of the disease. Our patient services funding comes from donations and is limited, so we encourage those who wish to attend multiple classes to make a \$5 per week donation. This minimal donation helps us defray the cost of the classes which run around \$10 per person to cover the instructors' salaries, room rentals, and equipment. This donation request is on an honor system, and we don't turn anyone away from attending as many classes as they choose. To make a donation for exercise classes, use the blue envelope in your newsletter and note that it is for exercise class. Many people choose to pay quarterly to reduce the number of checks they write each month. Any amount you can contribute is used exclusively for our patient services to keep these programs free or at little cost to our patients.

Our exercise classes meet once a week or otherwise as noted. Information that has changed since the last **LINK** appears in **bold**. Attend one class per week at no charge, or for \$20/month attend as many classes as you want. No RSVPs are required. Check our website, www.stlapda.org, or call to find out any changes since publication.

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 Deslodge Outpatient Center 121 St. Luke's Center Drive Conference Rooms 1 & 2	Monday	10:00 AM	Sarah Farnell, OT	314.205.6934
Chesterfield	St. Louis	Friendship Village 15201 Olive Blvd. Friendship Hall-Door #5	Tuesday	1:30 PM	Jessica Andrews	636.733.0180 x7719
Chesterfield	St. Louis	Parkinson Resource Center 1415 Elbridge Payne, Ste. 150	Monday	1:30 PM	Becky Miller, DPT	314-362-3299
Chesterfield	St. Louis	Tai Chi APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Wednesday or Friday	10:00 AM 11:30 AM	Craig Miller	314.362.3299
Chesterfield	St. Louis	Yoga Maryville University, Walker Hall <i>Reservations Required</i>	Wednesday	6:30 PM	Pradip Ghosh, PT, PhD	314.362.3299
Creve Coeur	St. Louis	Aquatic Exercise Rainbow Village 1240 Dautel Lane	Spring Session April 6 – June 12	1:00 PM Tuesdays	Brenda Neumann	636.896.0999 x21
Creve Coeur	St. Louis	LOUD Crowd Mo. Baptist Medical Center <i>Reservations Required</i>	June 10 & 24 July 8 & 22 Aug. 5 & 19	12:00 PM Wednesdays	LSVT certified SLP clinicians	314.362.3299
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	Tuesday	10:00 AM	Bobby Lautenschleger, PTA	314.355.6100
Joplin	Jasper	United Methodist Church 1730 Byers Ave.	Monday	2:15 PM	Nancy Dunaway	417.623.5560
Kirkwood	St. Louis	RehabCare 439 S. Kirkwood Rd., Ste.200 Park in rear	Thursday	1:00 PM	Brandon Takacs	618.971.5477
Ladue	St. Louis	Tremble Clefs Singing Salem United Methodist 1200 S. Lindbergh Blvd. Lower Level Choir Room	Saturday	1:30 PM	Linda McNair	314.362.3299
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	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 6 – June 12 Summer Session July 6 – Sept. 11	1:45 PM Thursdays	Brenda Neumann	636.896.0999 x21
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	Monday	4:00 PM	Alice Hammel, RN	573.964.6534
Greenville, IL	Bond	Bond County Sr. Center 1001 E. Harris Ave.	Wednesday	10:30 AM	Anna Oestreich	618.664.1465



Help us manage our expenses by letting us know when you move, if you want to be removed from the mailing list, or if you'd rather receive an electronic version. Just call **314.362.3299** or email guyerd@neuro.wustl.edu to let us know! Thank you in advance for helping us spend our resources wisely!

**Washington University School of Medicine
American Parkinson Disease Association**
Campus Box 8111
660 S. Euclid Ave.
St. Louis, MO 63110

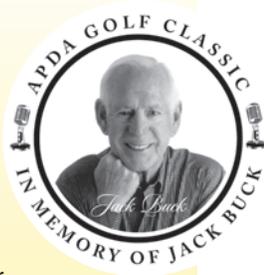
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SAVE THE DATES

MAY 18, 2015

17th Annual APDA Memorial Golf Tournament Honoring the Memory of Jack Buck at Algonquin Golf Club, 340 N. Berry Rd., St. Louis, MO –Reservations required for golf and dinner only option. Honorary Chair-John Mozeliak, Senior VP and General Manager, St. Louis Cardinals.



JULY 25, 2015

Annual Mid-Missouri Patient/Care Partner Conference on Parkinson Disease held in Columbia, MO, at the Holiday Inn Executive Center. Registration will take place 8:30-9:00 a.m., and the conference will be from 9:00 a.m.-12:30 p.m. Speakers will include Bokwan Jun, MD, Neuro-Ophthalmology; James Roller, MD, dermatology; Thorkild Norregaard, MD, functional neurosurgery; Irving Asher, MD, movement disorders neurology; and Patsy Dalton, Support Group Coordinator. Attendance is free.

AUGUST 15, 2015

Hull of a Race, Hull, IL
10th year for this annual event, which began under the direction of Quincy, IL APDA Parkinson Support Group facilitator and continues as a tribute to Marilyn White, beloved former teacher who has Parkinson disease. Both 5k and 10k race courses are certified. Hull of a Race uses a professional timer and chips for more accurate timing. The race is the kickoff for the Hull picnic—featuring a fried chicken dinner that same night.

You can register online, by mail or the morning of the race. Registration opens at 7 a.m. Visit the website, www.hullofarace.com for more details.

Loud Crowd Loud Crowd Loud Crowd Loud Crowd

We are happy to announce that the **LOUD CROWD** is returning for the summer months. If you are an LSVT graduate, or wish to have an opportunity to practice your speech at an acceptable loudness level, you are invited to join the **LOUD CROWD** group which will meet at **Missouri Baptist Medical Center on June 10 and 24, July 8 and 22, and August 5 and 19**. This group is led by certified and trained LSVT instructors, and the class is limited to 10-12 participants.

It will be held in the Missouri Baptist new outpatient rehabilitation center, located on the main hospital campus, 3015 N. Ballas in Creve Coeur. Participants may valet their cars at the front door and walk straight in. The outpatient clinic is located just down the main corridor on the right side of the hall.

Reservations are required and will be taken on a first-come, first-serve basis, so **call the APDA Center at 314.362.3299** to reserve a spot for this special group!

Tremble Clefs Sings Broadway Tunes

Tremble Clefs, under the direction of music therapist extraordinaire Linda McNair, performed in the chapel of Salem Methodist church on Sunday, March 29. They entertained 50 guests “Whistling a Happy Tune” “On the Street Where You Live” among other Broadway favorites. We hope you will consider joining the group, which meets on Saturdays from 1:30-2:45 p.m. at Salem Methodist on Lindbergh at Highway 40/64. Their calendar for rehearsals in April and May is posted on our website.

Please let us know if you would like to improve your voice and speech while enjoying the socialization provided by this group choir.