

MISSION

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

IN THIS ISSUE

- Charting Your Course.....2
- The Best Exercise for PD.....4
- Potential Serious PD Medication Side Effects and Interactions.....5
- I’m a PD Newbie6
- Nutrition in PD.....7
- Programs Provided by the St. Louis Chapter.....9
- Help Wanted11
- Places to Go, People to See12
- Independent Living Services.....13
- Delay the Disease—Freezing.....13
- Support Groups Calendars 14–15
- Exercise Classes16
- Plan for Your Future and Ours...16
- Tributes & Donations..... 17–19
- Ready, Get Set, Go!19

NEWSLETTER DISCLAIMER
 “The information and reference material contained herein concerning research being done in the field of Parkinson’s 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.”

FINDING THE EXTRAORDINARY IN ORDINARY

Deborah Guyer, Executive Director, Greater St. Louis APDA Chapter

I’ve noticed a United Way poster displayed in several locations around the Medical Center campus this fall. It has a picture of a little girl swinging and the caption reads: “Sometimes typical is amazing.” It made me think about all the typical things we take for granted, like walking, eating, speaking, and breathing. And yet, when you can accomplish the typical acts of maintaining one’s balance, moving about in crowds, getting in and out of a car, and dressing oneself in spite of having Parkinson’s disease, it seems almost amazing!



Our February newsletter, in contrast to our November LiNK which focused on research, will focus on patient services. We want to remind you of the things you and your family can take advantage of, which are provided often at no cost, or at times for a minimal financial shared cost to our members. The Board has approved adding two new facets to our shared cost services: homemaker services for individuals with Parkinson’s disease who may need a little help maintaining their homes and completing activities of daily living (laundry, cooking, cleaning) and transportation assistance for those people with Parkinson’s who no longer drive but need help getting to doctor appointments, the grocery, bank, pharmacy, or even a support group meeting or exercise class.

In addition, for those of you who may be “newly diagnosed,” we continue to offer an individual PD101 session, during which time you and your family can learn about the journey you are about to embark upon as a person diagnosed with Parkinson’s disease in 2012. Education plays such an important role in dealing with this disease. As you will see, our calendar is filled with support group meetings (including

caregivers-only groups, young onset, and DBS), exercise classes (in new locations and new times), aquatic exercise classes, and dance (Tango).

We have tried to be prompt in expressing our gratitude for all the year-end donations received between Thanksgiving and New Year’s. And as the calendar pages have turned to January and now to February, your contributions continue to arrive in all denominations and with such kind notes of thanks for what our services mean to you and your families. On behalf of our Parkinson’s community, beneficiary of your funding of programs and services, critical research, and clinical-scientists,

I want to thank you for your continuous and generous support. I pledged to my mom that I would continue to work hard to “ease the burden and find the cause and cure” for this devastating disease, and with your help, our mission can and will be accomplished. May it be so in 2012! ■

I know that as an adult child of a parent with PD, my parents did not want to burden their children with their problems. Many of you use those exact words when you and I speak on the phone or chat at a meeting. And yet, as an adult child, I would say that I would much prefer to be educated and informed about Parkinson’s disease before a possible crisis arises, or before critical decisions must be made regarding parental care. It is with that thought in mind and in an effort to provide education before a crisis, we’d like to suggest that you share this newsletter with your adult children, or get permission to provide their email address to the St. Louis APDA so that they can also receive our quarterly newsletters. Our lists are NOT shared with anyone, and their names will only be used so that they will receive quarterly newsletters, not solicitations.

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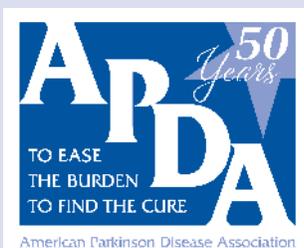
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CHARTING YOUR COURSE WITH PARKINSON'S DISEASE CARE

Kristine Dwyer, LSW, MS and Barbara Churchill, Caregiver

Caring for a loved one with Parkinson's disease at home can be like sailing a ship through uncharted waters. Currents, wind shifts, and changing weather patterns all influence the ship's course on a daily basis. The effects of Parkinson's disease also present an unpredictable course, and caregivers must continually seek solutions and a positive direction for the care they provide.

Barbara has been caring for her husband for over 10 years. He was diagnosed with Parkinson's disease, and she has remained steadfast with his care at home. Through the years, she has been creative in developing practical ideas that save time, require less energy, and reduce stress. Most importantly, employment of these concepts has enabled her to maintain the independence and dignity of her husband.

In the early stages of her husband's disease, Barbara made an appointment for occupational and physical therapy consultations along with a home environment assessment. This decision helped her to begin planning for the physical care and necessary home modifications to support her husband's needs. She offers these additional ideas for caregivers to customize caring procedures as needs arise:

Mobility Aids/Furniture

Wheelchairs—Consider two separate chairs – one to use for indoor mobility and at the kitchen table (can be locked in place) and one to use for outings to the mall or family gatherings.

Walker—The best investment has been a four-wheeled walker with balloon tires, hand brakes, and a padded seat. It glides over the ground and uneven surfaces and was paid for by Medicare and a co-insurance policy.

Recliner—Add a wooden base to the chair to raise the height six to 10

inches. This makes it easier for the care receiver to get in and out of the chair alone. Electric lift chairs are another option and may be partially paid for by Medicare.

Bathroom Safety

Install grab bars in several wall locations and a safety handle on the edge of the bathtub. Be sure to drill the bars into a wall stud for maximum hold and safety.

Remove the toilet seat and place a commode frame with arm rests over the toilet or purchase an elevated toilet seat with raised arms.

For sanitary purposes, keep flushable wet wipes available for use after toileting. Wipes can also be used to clean bathroom fixtures.

Add a non-skid bath mat, a bath bench, and a hand-held shower head to allow the care receiver to assist with their own shower.

For grooming, use an electric razor and an electric toothbrush to encourage self-care.

Incontinence Products

Use incontinent pads and adult briefs in layers as needed for full protection against wetting through clothing.

Clothes or Furniture

Washable sheet protectors and chair pads can be used to save on constant laundering. For full protection, layer several pads on the bed or chair.

Floor Safety

Use a Swiffer-type dry and wet mop on the floors for easier cleaning.

Do not use throw rugs, but if the floor surface is slippery, use a short-napped rug with a rubber backing.

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CHARTING YOUR COURSE

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Personal Safety

Purchase a whistle from a hardware store, tie it onto a long piece of elastic, and place it around the care receiver's neck. This can be used to call for help, especially if the caregiver has a hearing deficit. Place another whistle near the bed or toilet if needed.

Personal Emergency Response System (PERS) or a Lifeline medical alert button can be rented monthly to summon help when the caregiver is out of the home.

Alarm systems can be purchased from medical supply companies and installed at exit doors and on wheelchairs to prevent wandering or falling.

Transfer or restraining belts can be used to keep the care receiver secure in the chair when the caregiver has to leave the room. It can also be used to assist in safely helping the care receiver out of bed or a chair.

Mealtime Options

Canvas aprons can be purchased at craft stores. Cut the ties off and replace with elastic on the top to enable the care receiver to put it on without help. Vinyl or quilted bibs/aprons can also be purchased from medical supply companies. Place the bottom half of the apron underneath the plate for neater mealtimes.

Use cups or glasses with lids and straw holes to prevent spilling. A two-handled cup with a spouted lid can also be kept by the bedside.

If the care receiver has tremors, buy shallow soup bowls and edge guards for plates to keep the food contained.

Purchase utensils with weighted, built-up, or angled handles to help hands remain steady.

Car Ideas

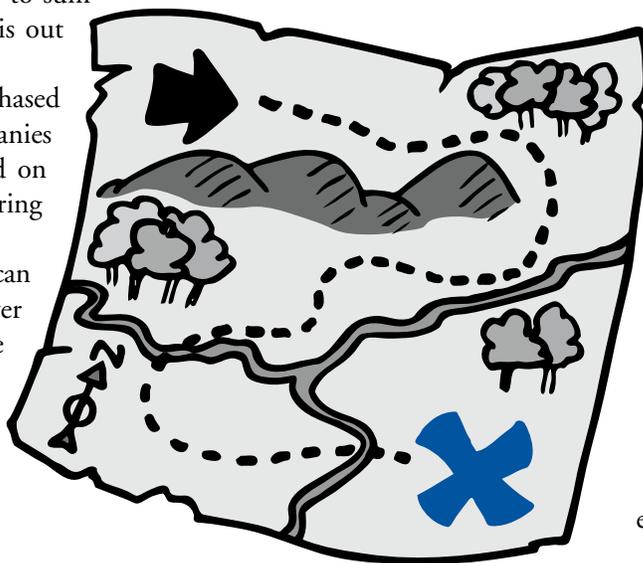
Car seats made of leather are easier to access and to clean.

Consider purchasing a swivel seat cushion to ease car transfers.

Obtain a handicapped vehicle parking permit through the driver's license bureau and have it authorized by the physician. Use the permit at any handicapped parking zone or at any meter in the city.

Pack a car tote bag. Include a package of wet wipes, bibs, a change of clothing, incontinent pads, plastic garbage bags, and water.

Eat in the car and park near a scenic area to enjoy the meal and the view if dining in a restaurant becomes too difficult.



Bedroom Solutions

Consider the need for an electric hospital bed with a trapeze for movement and increased independence. This can be rented monthly through Medicare and a co-insurance policy.

Try nylon or silk pajamas for ease in turning in bed. Use a bed guardrail for safety and support.

Dressing for Success

Velcro Hush Puppy shoes are easier for the care receiver to put on and take off.

Turn a lace-up shoe into a slip-on shoe with elastic shoelaces.

Purchase pull on boots with zippers for winter.

Use a long-handled shoe horn with a spring hinge.

The care receiver will have warmer feet and avoid falling by wearing slipper socks with rubber treads over regular

socks. Thin stockings vs. cushioned sole socks are better on carpeted surfaces.

Sport pants and elastic waistbands ease dressing woes for the caregiver and care receiver.

Visual Cues

Magnifying sheets, magnifying glasses, large wall clocks, talking watches, and natural spectrum lamps help those with impaired vision and encourage independence.

Enriching Activities

Review photo albums and old greeting cards.

Read the comics.

Listen to music and books on tape. Enjoy walks in the park when able.

Create a memory box filled with past treasures or items that encourage reminiscence.

Display things around the home that bring joy such as family photos, children's art work, and holiday decorations. This display also helps with time or seasonal orientation.

Consider attending a Parkinson's disease support group together.

As one can see, revising care procedures and modifying your home can promote successful caregiving. In addition, these ideas will uphold the dignity and independence of the care receiver. Learn from others who have walked in your shoes and set your sails for a new direction in providing care for a loved one living with Parkinson's disease. ■

Kristine Dwyer is a Caregiver Consultant, Licensed Social Worker with Carlton County Public Health in Cloquet, Minnesota and holds a Master's degree in Human Services with a specialization in Gerontology. She is also a past and current caregiver for family members and a parent with PD. Barbara Churchill has been a caregiver throughout her lifetime and is a mother of seven children.

THE BEST EXERCISE FOR PARKINSON'S

Pamela Quinn

What follows is an excerpt from a presentation made by Pamela Quinn at our PD Symposium (PEP) in November of 2011. Quinn is a former professional dancer who has used her extensive movement background to develop therapeutic techniques for Parkinson's, which she has had herself for seventeen years. She teaches classes for Parkinson's patients and has a private practice in New York City. You can learn more about her from her website at pamelaquinn.net.

People ask me all the time: "What is the best exercise for someone with Parkinson's?" I tell them that there are many possible answers to that question. Because of my own background, I am very aware of the benefits that dance can provide. It deals with posture, coordination, balance, presentation of the self, strength, flexibility, dignity, social contact, and physical memory. It embodies the whole notion of conscious movement because dancers move consciously all of the time. It uses music and rhythm as cuing systems, and it activates many different parts of the brain. I can also talk about the benefits of yoga, tai chi, chi gong, bicycling, or Wii games. But over many years of working with people who have Parkinson's, what I've come to realize is this: The best exercise for you is the exercise that you will do.



Does that answer from a movement professional surprise you? It's not that I dismiss the value of the very good research that has been done and continues to be done on exercise for PD. The knowledge we can gain from research is immensely helpful. A recent study by Lisa Shulman at the University of Maryland, for example, determined that non-aerobic exercise for longer periods of time is more beneficial to people with PD than a high intensity workout for a shorter span of time. That's something that could have very practical use for patients and therapists. But the real question for you is: What activity will you realistically be able to sustain? Because the consistency of ongoing physical activity is as significant, or more significant than the particular form exercise takes. So, what will each one of you do? What motivates you to

engage? For those of us dealing with the constrictions of Parkinson's, the adage "use it or lose it" has an added layer of meaning. What will make you take that first step toward physical activity or renew a commitment that you have already made?

Here are some simple tips to help you. These are various; not all may apply to your situation. But one or another may make a difference.

1. **Start small.** Do something you know you can accomplish. Maybe it's just walking to the mailbox once a day; maybe it's going on a treadmill for two minutes! Don't feel that you have to start five times a week with 60 minute sessions. When I'm at a conference about exercise and participants are being told to do x, y and z, I sometimes sense a collective internal sigh. If expressed out loud, the thought would be, "Sure...I'm really going to get up tomorrow and walk for a half hour...and then I'm going to do it all week long! And after that, I'm going to start training for the marathon!" So beware of improbable ambitions. Choose an activity that will give you pleasure, perhaps doing it to your favorite music, and make sure it's something that you can accomplish. We all build on success. Success will give you energy to continue and expand your activity.
2. **Make a commitment to someone else to exercise with them** - your spouse, a friend, or if you are in a position to do so, a professional trainer. If you have a group of friends you can work with, all the better. It can be easy to decide not to do exercise on a given day if you

are the only one whose schedule is affected. But chances are you will be more hesitant to cancel your session with another person. So don't go it alone. There's strength in numbers.

3. **Choose an exercise that you did when you were younger.** The neuromuscular pattern is still there. Have you seen Michael J. Fox on hockey skates? The dyskinesia that is so pronounced when you see him in interviews is totally gone. The body remembers, and we all have physical memories that we can draw on to help us move. Something as simple as bicycling can be a good choice. Even playing catch has something to offer. It's not a cardiovascular workout, but the quick shifts of weight involved in snagging the ball work your balance, and your whole body mobilizes to catch and throw. You are more likely to do something if you enjoy it, and more likely to enjoy it if you can do it!
4. **Exercise at a regular time.** Do you watch the news or a program that you could see while you're on a stationary bike? Or do you listen to books on tape? Make an appointment to listen to a book when you're walking on a treadmill or using an elliptical. The structure of a schedule can give you support.
5. **Go to a movement or exercise class with other PWP.** If there is a class available where you live, it can be a great addition to your routine or even the center of your exercise life. You will make friends. You will go to the class to see them, to exchange ideas, and to move and enjoy one another. Social contact

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THE BEST EXERCISE FOR PD

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is very important for a disease that affects how we're perceived by others and tends to isolate us at home. Getting out and seeing friends and moving together in a nonjudgmental environment is a very good thing.

6. **Use music.** Music is a medication, just as much as the levodopa or pramipexole or any other multisyllabic pharmaceutical you may ingest three times a day. I put on music at home when I am cooking; I listen

to my iPod when I'm walking on the street. And I have a wonderful percussionist named Tiger Benford whose rhythms move everyone in the class I teach. Music is a natural aid to motion and can help you do things you might otherwise think not possible. If you want to walk, jog, skate, or dance, music will propel you.

We all want to gain the benefits exercise has to offer, but we each need a concrete way to get there. The trick is to approach it with sensible goals and recognition

of how you can build encouragement into the process. So in thinking about exercise, avoid the generic. It's essential that your resolutions take into account your individual situation and the multitude of factors that affect it: the timing of your medication, the climate where you live, and particular physical issues that confront you. But whatever your circumstances, there are practical steps to take to make it possible to begin a routine or to enhance the one you already have.

So make that plan. But make it your plan. ■

POTENTIAL SERIOUS PD MEDICATION SIDE EFFECTS AND INTERACTIONS

Created by Indiana Parkinson Center for Care (NPF Center for Care) and modified for your use by Johanna Hartlein, RN, MSN, APN, Clinical Research Coordinator/Nurse Practitioner, Movement Disorder Section, Washington University School of Medicine

Please note that this is not a complete list but does describe many of the PD medications used today and their major side effects as well as medicines that should be avoided or used with caution.

MAO-B Inhibitors: Selegiline (Deprenyl, Eldepryl, Zelapar), Rasagiline (Azilect)

These medicines may cause hallucinations (seeing or hearing things that aren't really there) and lightheadedness (dizziness or fainting, especially upon changing position from lying or sitting to standing). Demerol and Darvocet must never be given with MAO-B inhibitors. If possible, MAO-B inhibitors should be stopped for two weeks prior to surgery. It is imperative that the surgeon/anesthesiologist verify and stipulate this interval. These medications MAY be given with SSRI's safely.

COM-T Inhibitors: Stalevo (carbidopa/levodopa/entacapone), Comtan (Entacapone), Tasmart (Tolcapone)

These medications are given to extend each dose of Sinemet to prevent wearing off between doses. They may

cause diarrhea, nausea, hallucinations, and lightheadedness. Tasmart may cause elevation of liver enzymes and requires frequent blood testing.

Amantadine (Symmetrel)

This medicine is given to control dyskinesia (jerking-like movements which happen commonly when PD patients take carbidopa/levodopa). It may also have a mild anti-Parkinsonian effect. This medicine may cause sleepiness, nausea, lightheadedness, hallucinations, or a harmless discoloration (red splotches) of the skin, commonly of the legs and/or feet.

continued on page 15



We invite you to clip out this information card. Keep it in your wallet for easy reference.



PD Medication Information

Medications NOT TO BE USED by PD patients:

- Haloperidol (Haldol)
- Chlorpromazine (Thorazine)
- Thioridazine (Mellaril)
- Molindone (Moban)
- Perphenazine (Trilafon)
- Perphenazine
- Thiothixene (Navane)
- Flufenazine (Prolixin)
- Risperdal (Risperidone)
- Zyprexa (Olanzapine)
- Geodon (Ziprasidone)
- Abilify (Aripiprazole)
- Promethazine/Phenergan
- Prochlorperazine (Compazine)
- Trimethobenzamide Hydrochloride (Tigan)
- Metoclopramide (Reglan)

Created by Indiana Parkinson Center for Care (NPF Center for Care) and modified for your use by Johanna Hartlein, RN, MSN, APN, Clinical Research Coordinator/Nurse Practitioner, Movement Disorder Section, Washington University School of Medicine

I'M A PD NEWBIE

John Basilico

I am a Parkinson's disease newbie having been diagnosed early last June, a few weeks before my 74th birthday. Several thoughts raced through my mind during the next 24 hours after receiving this diagnosis. The primary thought being that I was not going to allow PD to redefine who and what I am. In addition, I thought there must be something I can do to assist at least one other PD newbie by letting him know he is not alone with his thoughts and feelings. But where do I start? I asked Debbie Guyer, Executive Director of APDA, about writing an article from a PD newbie's prospective, hoping some of my early PD history may be familiar to another newbie. My goal is to give my fellow newly diagnosed patients encouragement and hope as we start our PD journey together. Thanks, Debbie, for your encouragement.

Big Surprise

"Mr. Basilico, you have Parkinson's disease." This pronouncement by a respected neurosurgeon totally surprised my wife and me. You should know that the reason for this appointment was to learn the results of a recent MRI scan on my lower back and whether or not surgery was needed. With this unwanted diagnosis, I became a PD newbie.

During the first few minutes of the appointment, my wife told the doctor of her nearly one year observation of me: stooped upper-body posture, shuffling gait, slower walking pace, and

a sometimes stiff and bent lower right arm. I made the decision to let both know about the dramatic change in my handwriting. Now my wife and I know these are classic symptoms of PD.

Except for the change in my handwriting, I had a logical explanation for



my wife's year-long observations (and the observations of relatives and friends who ask my wife, but not me, what is wrong with John). I was nearly 74 with a chronic lower back problem. Also, my comfortable but loose slippers made it sound like I was shuffling my feet. This

is my story, and I'm sticking to it. After all, some husbands with tenure just know a spouse sometimes will worry needlessly about all kinds of family-related observations. Some husbands just nod at repeated comments about posture, walking gait, and so on and then mentally dismiss them knowing there will probably be a next time. Guilty, I should have listened to my wife. A lesson learned!

It took about 10 minutes for the doctor to make the PD diagnosis. The PD evidence was very compelling. As a bonus, the neurosurgeon recommended back surgery – a medical doubleheader. Needless to say, all this news did not make for a good day. One day later, a neurologist confirmed the PD diagnosis, but by then we were PD "quasi-experts" having done on-line research.

Now What

What is the future for me – and my wife – as PD will affect both of us? We will walk the PD maze arm-in-arm. As said earlier, I will not allow PD to redefine me, but I expect some lifestyle changes in the future. I'm fortunate that I have a caring and loving wife with a nursing background. My attitude towards PD will impact both of us – and I need to always remember this. I confess to one fear about my PD, and that is that any future caregiving activities may be very stressful and confining for my wife.

Let me say a few words about feelings. Today, my primary feeling remains one of surprise, but I know this may change in time. However, my wife has much stronger feelings and we talk about them. I need to improve my listening skills. Whatever the feelings – most are natural and expected – we will deal with them and get help if needed. One thing I do know – I must maintain a positive

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PD Medication Information

Medications TO BE USED WITH CAUTION in PD patients:

- Benzodiazepines: These are medicines sometimes used for anxiety and sleep-like Alprazolam (Xanax), Lorazepam (Ativan), Chlordiazepoxide (Librium), or Clonazepam (Klonopin). At low doses, these are sometimes very successful at treating REM sleep behavior disorder (thrashing around in one's sleep/acting out in one's dreams); however, they must still be used with caution.
- Dextromethorphan (DXM): commonly found in many cough and cold medicines. Many patients use this without any problem but still should use caution.
- Benadryl (Diphenhydramine): commonly found in many cough and cold medicines. Many patients use this without any problem but still should use caution.
- Narcotics: These are medicines used for pain like Hydrocodone, Hydromorphone (Dilaudid), Meperidine (Demerol), Oxycodone (Oxycotin).
- Muscle Relaxers: These are medicines commonly used for pain or for strained muscles and may include Lorcet or Lortab, Percocet, or Darvocet.

These medications can worsen confusion and balance, particularly in elderly PD patients or PD patients with pre-existing thinking problems.



We invite you to clip out this information card. Keep it in your wallet for easy reference.

I'M A PD NEWBIE

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previous page*

attitude about my future life with PD – two people will be dependent on this.

The hallmarks of my personal and professional life have been planning and attention to details. I will continue on this path. I would urge my fellow newbie to plan for the future in areas like estate planning, retirement planning, insurance, and so on. We owe it to our loved ones.

Starting Through the Maze

I've walked through corn field mazes and a huge maze on an English estate. It was fun but often confusing. You start the walk slowly, you take some wrong turns, but persistence wins. So, too, with the PD maze. My wife and I are starting the walk, and I have no doubt together we will survive the maze.

Instead of bread crumbs, I plan to walk through the maze with a map that includes:

- Learning all I can about PD
- Keeping my family and friends close and my wife closer.
- Surrounding myself with an excellent medical team.
- Exercising both my body and my mind.
- Maintaining a positive attitude – the glass is half full.
- Staying grounded in my faith and love of country.

Hopefully, if you are a PD newbie (or even a PD veteran), you will find this article of some value, even if it simply reinforces what you already know. For me, this article has started me on my journey, but no matter the ultimate destination, both my wife and I will get through the maze. Join us and know you are in our prayers. ■

As a result of John's wonderful contribution to this newsletter, we will be featuring a new column called Perspectives, and we'd love for readers to submit ideas or stories to be included from a patient or caregiver perspective for this feature in future newsletters.

UNDERSTANDING NUTRITION IN PARKINSON'S DISEASE

Portions of this article are being used with permission from Jo Bidwell, BS, MEd, editor of The Tulip Messenger, Fall 2011 publication and Coordinator APDA Information and Referral Center in Lubbock, TX and Life in Balance newsletter (Vol. 2, Issue 1, 2010) from Teva Neuroscience, and Michael Rezak, MD, PhD, Medical Director of APDA's National Young Onset Center.

While there is no special diet required for people with Parkinson's disease, eating a well-balanced, nutritious diet is extremely beneficial. With the proper diet, our bodies work more efficiently, we have more energy, and Parkinson's disease medications will work properly. Good nutrition in PD varies for each patient, depending on things such as your age, gender, and other diagnosed medical conditions. The type of medication you're taking for PD and other medical conditions may have an impact on your individual nutritional needs. Poor nutritional status can result in, as well as contribute to, many of the common complaints seen in Parkinson's disease.

There is frequent discussion regarding special dietary needs of a Parkinson's patient. The pendulum has swung from the initial belief that protein should be eliminated from the PD diet completely or at least restricted to only eating protein at night after most medications have been taken for the day to the belief that there is no connection between diet and the effectiveness of medications at the other end. More recently, there has been concern about Azilect (Rasagiline) and certain foods, specifically processed or aged meats, certain cheeses, red wine, beer, and soy products containing tyramine. The current Azilect label says that it can ordinarily be used without dietary restrictions.

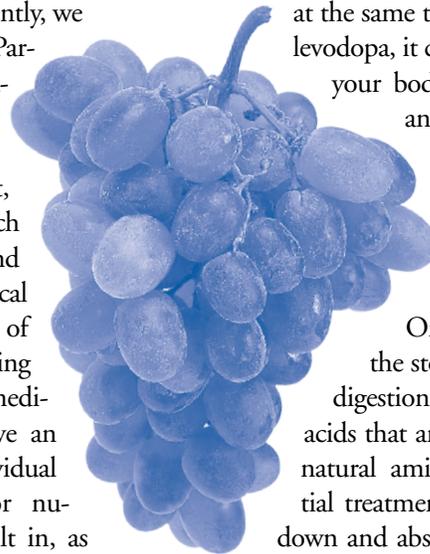
If you are taking levodopa as part of your treatment for PD, keep in mind that the effectiveness of levodopa may be affected

by what kind of food you eat, and when you eat it. Levodopa needs to be absorbed by the body so it can be sent to the bloodstream, and then into the brain. If you eat a meal (especially a high-fat meal) at the same time that you take your levodopa, it can take a long time for your body to absorb the food, and therefore a long time to absorb the levodopa, too. Foods or meals with a large amount of protein can have a similar effect.

Once levodopa arrives in the stomach, it competes for digestion with natural amino acids that are found in foods. The natural amino acids get preferential treatment when being broken down and absorbed by the body. As a result, the medication does not get to the brain as needed, which may result in motor fluctuations and prolonged "off" episodes. A knowledgeable dietetic professional can assist with formulating appropriate diet plans to circumvent protein sensitivity if this is a problem for you.

Timing is critical when taking carbidopa/levodopa. To make sure you get the greatest benefit from your medication, it is recommended that levodopa (Sinemet) be taken on an empty stomach, at least 30-60 minutes before eating a meal. This allows the medication to begin to be broken down and absorbed before other amino acids are introduced. The actual time allowed depends on the individual. Since the entire GI tract is a series of muscles which are controlled by nerves, the GI tract often suffers the effects of bradykinesia (slowness of movement) characteristic of other parts of the PD body. This

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UNDERSTANDING NUTRITION

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slowing of the GI tract not only makes PD patients more inclined to develop constipation, but also slows the digestion and absorption time of medications and foods. If you suffer from serious constipation, then you may want to allow more time between the medication and ingestion of food.

Dieticians recommend that a healthy diet include four to six ounces of protein daily. This can come from complete proteins from animal products or a combination of incomplete proteins from plants (like rice, beans, nuts, etc.). If you become nauseated when taking your medication on an empty stomach, it is suggested that you try eating a couple of saltine crackers or dry bread (low in protein and should not interfere with absorption) or drinking ginger ale or ginger tea (calm your stomach) with your medication. Avoid taking your carbidopa/levodopa with milk, because milk also contains protein. Whole grains such as lentils, corn, soy products, beans and other legumes contain large amounts of natural amino acids and they should also not be consumed at the same time as your medication. As discussed, a diet high in fat can also slow the absorption of your food and consequently your medications. This does not mean that a PD patient should go on a low fat diet, but rather that the amount consumed at the time of your medication be considered (remember that timing of your dose is critical).

Constipation is a serious and common problem in patients with PD at all stages of the disease. Poor hydration, low dietary fiber and decreased exercise, as well as the medications themselves, combine with the decreased neural function of the gut in PD to create the problem. The constipa-

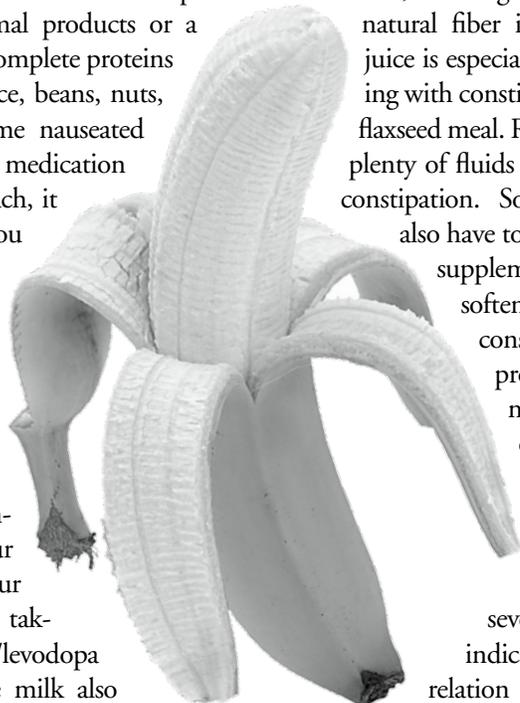
tion can result in a loss of appetite, complaints of bloating, and, if not corrected, can lead to impaction which can be life threatening. Constipation can cause headaches, back pain, fatigue, and overall feeling of sluggishness, and can affect how well nutrients are absorbed. The absolute best treatment is prevention. PD patients should be instructed to increase dietary fiber intake to approximately 25 to 35 grams per day in association with appropriate fluid intake (at least 60-70 oz. of water per day). Consuming whole grains, fruits, and vegetables will provide natural fiber in the diet. Prune juice is especially effective in helping with constipation, as is adding flaxseed meal. Regular exercise and plenty of fluids will also help fight constipation. Some patients may also have to add a natural fiber supplement and/or a stool softener to help. Should constipation remain a problem, your doctor may provide other options.

Two other dietary concerns are of particular interest. First, several studies have indicated a possible correlation between a lack of vitamin D and the onset of Parkinson's. Other studies have indicated that PD patients have a higher than normal prevalence of bone loss which leads to osteoporosis. While there is no definitive evidence that a lack of vitamin D causes Parkinson's, the higher than normal incidence of osteoporosis among the PD community is of concern. Osteoporosis makes patients more vulnerable to falls and fractures. Because patients with PD have a greater risk of falling, you need to make sure you maintain strong, dense bone that won't fracture easily. The absolute best way to obtain vitamin D is sunlight. Some foods are also rich in vitamin D including fish, liver oils, egg yolks, and fortified dairy and grain products. Ingestion of dairy products or food sources fortified with vitamins D and K as well

as calcium are encouraged. Check with your physician before adding vitamin supplements to your medication regimen. Weight bearing exercises are also known to promote bone health.

Secondly, the other dietary concern is a lack of vitamin B12 in PD patients. Several studies have indicated that PD patients lack vitamin B12 which may lead to numerous problems that may complicate Parkinson's. Vitamin B12 deficiencies may cause a lack of appetite and consequent weight loss, numbness, or tingling in the hands and feet which may lead to complete neuropathy, weakness, depression, and a loss of mental acuity including dementia, all of which may complicate similar PD symptoms. Again this concern should be discussed with your physician before large doses of vitamin supplements are consumed, as that may play a role in how well medication is absorbed.

Motor symptoms in PD often result in additional expenditures of energy (e.g. tremor, dyskinesia). This combined with inadequate nutritional intake can affect motor functioning and the overall general health of the patient. Staying on top of your nutritional health as a PD patient may seem complicated, but your doctor or dietetic professional can help you manage your specific needs. To find further information about nutrition in Parkinson's disease, visit the Northwest Parkinson's Foundation website, www.nwpcf.org/wellness/PhysicalHealth, where you can access Nutrition Tips and download these for your home files. At the St. Louis Chapter satellite resource library, books by Kathryn Holden, RD, containing helpful information are available for your perusal, as are articles from newsletters which we have compiled at the Information & Referral Center as well. There are archived webinars at both National Young Onset Center, www.youngparkinsons.org, and on the Parkinson's Disease Foundation website, www.pdf.org under webinars (ExpertBriefing) provided by registered dieticians who supply helpful information regarding nutrition. Don't be afraid to ask for help. ■



PROGRAMS PROVIDED BY THE ST. LOUIS CHAPTER OF THE APDA

One of the *Missions* of our Chapter is to enhance the quality of life for people with Parkinson's disease, their families, and caregivers in our communities throughout Missouri and southern/central Illinois. In the November edition, we discussed research being funded. Now we would like to describe programs offered to enhance the quality of life for persons with PD and their families.

Our *Vision* is to significantly expand services and education programs to better meet the growing needs. As the late cartoonist Charles Schulz said, "Life is like a ten-speed bike. Most of us have gears we never use."

Support Groups

One of the biggest contributions APDA

makes to the PD community is creating a network of volunteer-led support groups. The benefits of peer helping peer are strongly supported by research, including improved knowledge of the disease, improved ability to cope with the disease, lower risk of depression, more positive outlook on life, and increased self-esteem.

The format varies by location, but the goal is always to provide a safe, confidential, welcoming place to come together. Groups offer PD patients and their caregivers the opportunity to exchange thoughts and share concerns and solutions to everyday living.

Groups meet monthly.

David and Patsy Dalton have graciously volunteered to help us become more visible and effective in out-state communities. If you are seeking a support group in your

community, kindly drop us an email or call and let us know, so we can search for the nearest group. If there is a sufficient number of people with Parkinson's in an "un-served" area to warrant a new support group, we are happy to help establish one.

Exercise Classes

Exercise empowers individuals with PD to feel stronger and more in control. Research further supports positive outcomes on personal outlook and mood. The medical literature has shown that medication and surgical intervention alone are not adequate treatment for PD. Exercise, functional training, and education are also integral parts of the management of the disease and its disabilities. As Robert N. Butler, a former

continued on next page

GENERIC WEEKLY SUPPORT GROUP/EXERCISE CALENDAR

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY
WEEK 1	South County Exercise 11:30 AM Joplin Exercise/S.G. 2:00 PM Lake Ozark Exercise 4:00 PM	Florissant Exercise 10:00 AM St. Luke's Exercise 11:00 AM Chesterfield S.G. 10:30 AM St. Peters S.G. 1:00 PM	Carbondale S.G. 1:00 PM McLeansboro S.G. 1:00 PM Clayton Exercise 2:00 PM Tango Dance Class 3:00 PM	Florissant Exercise 10:00 AM Gardenview Chesterfield Exercise 2:30 PM Columbia S.G. 4:00 PM Aquatic Exercise @ Rainbow Village & St. Charles YMCA – weekly sessions (2:00 PM) call for dates of 10 wk.session	Clayton Exercise 2:00 PM
WEEK 2	For Caregivers Only S.G. 11 AM South County Exercise 11:30 AM Alton S.G. 1:00 PM Greenville S.G. 1:00 PM Belleville S.G. 1:30 PM Joplin Exercise/S.G. 2:00 PM Lake Ozark Exercise 4:00 PM	Florissant Exercise 10:00 AM St. Luke's Exercise 11:00 AM St. Peters Exercise 11:00 AM	South County S.G. 10:00 AM Ste. Genevieve S.G. 10:00 AM Ladue S.G. 1:00 PM Clayton Exercise 2:00 PM Tango Dance Class 3:00 PM	Florissant Exercise 10:00 AM Aquatics 2:00 PM Gardenview Chesterfield Exercise 2:30 PM	Clayton Exercise 2:00 PM
WEEK 3	South County Exercise 11:30 AM Joplin Exercise/S.G. 2:00 PM Lake Ozark Exercise 4:00 PM	Florissant Exercise 10:00 AM St. Luke's Exercise 11:00 AM St. Peters Exercise 11:00 AM Festus/Crystal City S.G. 1:00 PM Living & Working with PD (Young-Onset) S.G. 6:30 PM	Glen Carbon S.G. 10:30 AM Clayton Exercise 2:00 PM Jefferson City S.G. 3:00 PM Tango Dance Class 3:00 PM	Florissant Exercise 10:00 AM Lake Ozark S.G. 12:00 PM Quincy S.G. 12:00 PM Pre/Post DBS S.G. 1:00 PM Decatur S.G. 1:30 PM Aquatics 2:00 PM Gardenview Chesterfield Exercise 2:30 PM Rolla S.G. 2:30 PM	Clayton Exercise 2:00 PM
WEEK 4	South County Exercise 11:30 AM Joplin Exercise/S.G. 2:00 PM Lake Ozark Exercise 4:00 PM	Florissant Exercise 10:00 AM St. Luke's Exercise 11:00 AM St. Peters Exercise 11:00 AM Carmi S.G. 1:00 PM Mattoon S.G. (last Tue.) 1:30 PM Meramec Bluffs S.G. 1:30 PM Kirkwood S.G. 7:15 PM	Clayton Exercise 2:00 PM Tango Dance Class 3:00 PM	Florissant Exercise 10:00 AM Florissant S.G. 11:00 AM Springfield, MO S.G. (last Thu.) 11:00 AM Aquatics 2:00 PM Gardenview Chesterfield Exercise 2:30 PM Mount Vernon S.G. 6:30 PM	Webster Groves S.G. (last Friday) 10:30 AM Clayton Exercise 2:00 PM

Cape Girardeau S.G.—call for 2012 dates
Wellness Class—call for 2012 dates
Loud Crowd—call for 2012 dates

PD 101—call to schedule session
Springfield, IL S.G.—3rd Sunday in Jan., Mar., May, July, Sept., & Nov. – 2:00 PM

ST. LOUIS APDA PROGRAMS

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director of the National Institute of Aging once stated, “If exercise could be packed into a pill, it would be the single most widely prescribed and beneficial medicine in the nation.”

Classes focus on exercises and activities to improve function, specifically balance, posture, and functional mobility and are led by trained PT/OT.

Locations:

- The Center of Clayton (Clayton)
- Barnes-Jewish Hospital (St. Peters)
- Gardenview of Chesterfield (West County)
- Garden Villas South (South County)
- St. Luke’s Hospital (Chesterfield)
- Garden Villas North (Florissant)

1-hour class, meets once or twice a week.

Aquatic Classes

In the water, an individual with Parkinson’s can reduce the risk for falling and exercise safely. The buoyancy of the water supports the individual with Parkinson’s while water walking or turning a full circle. Several participants have commented that exercising weekly in the water has increased their ability to walk, turn in a circle, and maintain their balance. One participant commented, “I can walk in the water, but not on land.” She also stated that she did not have to worry about falling while exercising because she was now able to exercise in the water without that worry. The Berg’s Balance Scores concluded that the balance of the participants with Parkinson’s remained the same or improved during the 10 weeks of 60-minute water exercise classes. The participants of the classes have also reported an ability to maintain range of motion in their neck, upper extremities, and lower extremities. The water exercise class motivates participants to keep moving, relax, and have fun improving their psychological well-being.

The St. Louis APDA, ShowMe Aquatics & Fitness, the St. Charles YMCA, and Rainbow Village have collaborated to provide two water exercise classes for individuals with Parkinson’s since the spring of 2008. Classes are led by trained and cer-

tified instructors at pools specifically designed and accessible for our patients. We hope you join us for some fun in the pool!

Locations:

- Rainbow Village
- St. Charles YMCA

1 hour class, meets once a week for 10 sessions, Thursdays 2:00–3:00 pm.

Dance Exercise Classes

Preliminary data gathered from individuals with PD who learned to dance Argentine tango revealed significant improvements in balance, walking, and quality of life.

Wednesdays, 3:00–4:00 pm, at The Center of Clayton.

Social Dance

Dr. Oliver Sacks feels that music is the prosthesis for the injured part of the brain. The pattern, timing, and rhythm involved in music and dance will promote fluidity in movement, speech, thought, and emotions. Creative, social, and fun! Put on your dancing shoes and join us for this fun afternoon!

TBD @ Congregation Shaare Emeth.

PD 101

Designed to impart basic information about Parkinson’s disease, available treatments, and resources in our community. Participants receive printed material, a welcome packet, Parkinson’s Disease for Dummies by Tagliati-Guten-Horne, and an exercise DVD, Delay the Disease, by David Zid.

PD101 is scheduled on an individual basis for persons and family members within two years of a PD diagnosis.

Wellness Courses

The Wellness Course is an education and support group of 12 persons with PD and their care partners who meet once a week for six weeks (two hour sessions). The course is designed to develop skills and confidence for managing the everyday issues that may be challenging when living with PD. The group members choose what topics to discuss each week, with typical past topics being medication management, coping with physical and

emotional changes, home safety, physical fitness, and long-term planning. The overall purpose of the Wellness Course is to enhance the quality of lives of persons with PD and their family members through gaining confidence and skills in managing the consequences of the disease. For the last 10 years, the Wellness Course has been offered through the St. Louis Chapter APDA with participants giving positive feedback and reporting increased personal wellness.

2-hour course, meets once a week for six weeks. Next session will be offered in the spring, in the evenings, or on Saturdays.

Speech Classes

Parkinson’s disease skews the individual’s sensory perception, resulting in a soft voice in 89% of persons with Parkinson’s. Eventually there is a loss of muscle strength and physical endurance to speak at appropriate loudness. These classes incorporate practice and role play situations in conversational speech tasks produced at normal loudness levels in a “safe” environment.

Led by Lee Silverman Voice Treatment (LSVT) trained and certified Speech-Voice Pathologists using the single reminder BE LOUD to bring voices to improved, healthy, and appropriate vocal loudness levels.

1-hour session, meets twice a month for three months.

Speaker Series – Parkinson Education Programs (PEP)

Free speaker series with guest lecturers covering a wide variety of subjects such as Research Updates, The Importance of Exercise, Coping Strategies, Non-motor Aspects of PD, Cognitive Aspects of PD, Deep Brain Stimulation (DBS), LSVT LOUD, and Tips for Caregiving.

2-hour session plus questions & answers, meets quarterly.

For more information on any of the programs described in this article or to register, please contact the St. Louis APDA Information & Referral Center at **314-362-3299**, or visit web site at **www.stlapda.org**. ■

HELP WANTED

TO LEARN MORE ABOUT PARKINSON DISEASE AND THINKING PROBLEMS

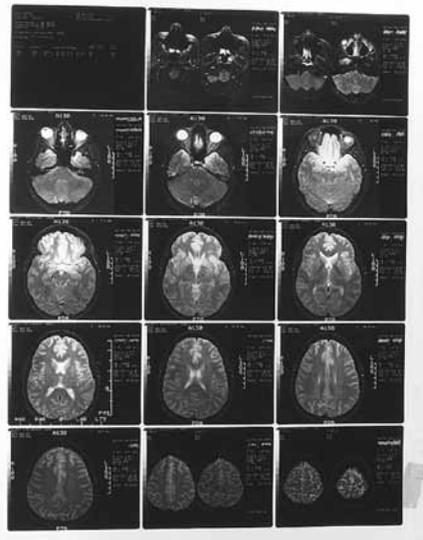
By Joel S. Perlmutter, MD, Director Movement Disorders Section, Washington University School of Medicine

We need your help with a study we are currently undertaking. Based on studies which have been conducted in our lab at Washington University since 2006, I have gratefully received a multi-million dollar grant from the National Institutes of Health (NIH) to fund some very important research into understanding the relationship between thinking problems and PD. Thinking problems are a huge concern and burden to patients with PD, as well as to their family members and caregivers. Not only are thinking problems extremely common in PD, but they are also the leading cause of nursing home placement for patients with PD. Currently, the only “gold standard” way to prove that someone has PD and to prove what sorts of memory and thinking changes someone may have is a test that no one really wants done right now...because that test is to look at someone’s brain under a microscope...which unfortunately means that someone is dead.

Understanding more about how the PD brain works and understanding more about what causes dementia in PD are very important research issues. While it is incredibly valuable to examine patients’ brains after they pass away, that examination unfortunately does not help patients clinically while they are alive and dealing with the stresses related to PD and dementia. We would like to better understand thinking problems in PD. Through understanding of this problem, our goal is to try to determine if we can predict who will go on to develop cognitive deficits so that we can then try to discover ways to stop these problems from worsening or to prevent them from occurring in the first place. Thanks to the incredible participants involved in this study so far, especially those who have given us the

ultimate gift of their brains upon death, we may have discovered a new form of dementia, and this discovery could have important clinical implications both for people with PD and people with Alzheimer’s disease. However, we really need more people involved in the study to draw stronger conclusions. This is why I am asking for your help.

We are looking for people across the PD spectrum including those with no memory and thinking problems, those



with mild memory and thinking problems, and those with very severe memory and thinking problems. We are also looking for “normal” people with no neurological problems, no dementia, and no first-degree blood relative with PD. Participants are required to do the following:

- **Cognitive task evaluation**—two hours. During the time of evaluation, we will also need to talk with a non-demented family member who has known you for a long time to help report on memory. This cognitive evaluation is usually done “off” PD medicines. If you are unable to

tolerate this testing either because of thinking problems or because it would be too difficult to be “off” PD medicines, we can shorten this evaluation to 30 minutes.

- **MRI**—one hour and includes lying in a machine which makes loud sounds and takes pictures of your brain. The MRI is usually done “off” PD medicines. If you cannot tolerate an hour-long MRI either because of claustrophobia or an inability to tolerate being “off” PD medicines, we can shorten this scan to about 20 minutes.
- **PET scan**—is a little over one hour and allows us to see how your brain is functioning. PET scan involves lying on a padded table for an hour with an IV (small straw) in a vein in the arm. This particular PET scan is looking at any possible amyloid protein in participants’ brains. Amyloid is one of the abnormal proteins commonly seen in Alzheimer’s disease.
- **Lumbar puncture (LP)**—involves taking a small amount of fluid from the bottom of your back. We are doing the LP to check for amyloid and other proteins in the cerebrospinal fluid (the fluid that coats the brain and spinal cord) that may be more prevalent in people who currently have or will develop thinking problems. Please note that we numb the back beforehand to minimize any pain. While we encourage everyone to participate in the LP, you will not be excluded from the study if you choose not to do the LP but are willing to do all other parts of the study.

- **Brain donation** at the time of *continued on next page*

HELP WANTED

continued from previous page

your death (hopefully a long way off) which will not impact any funeral arrangements (you may have an open casket), and either I or one of the Movement Disorders doctors at our center will discuss autopsy findings with your family approximately six months after your passing. Keep in mind that brain autopsy is the only 100% sure way to guarantee someone has PD and the only way to diagnose what caused someone's memory and thinking problems. There is no major religion which objects to brain autopsy.

- Yearly or every three years an **in-person memory evaluation** and possible repeat MRIs. For "normal" non-PD subjects and subjects with dementia, follow-up visits are performed every three years. For others with PD, evaluations are performed yearly.

The study pays \$300 for your time and inconvenience. You also receive a free neurological examination, free MRI, free LP, and free PET scan. There is no cost to you or your insurance company to participate. For out-of-town participants, we would be willing to pay for your hotel and meals while you are participating in the study. However, we do not have funds for air travel.

While this study is very involved, it is also pivotal in increasing our understanding and knowledge of both dementia and PD. Research into PD is the only way that we can better understand how PD affects the brain, enabling us to improve the treatments available, and find a cure! Please help us move closer to easing the burden and finding the cure. Thank you for your time and consideration.

For more information about this study, please call my research coordinator, **Johanna Hartlein, Nurse Practitioner**, at (314) 362-0420 or email at johanna@npg.wustl.edu. ■

PLACES TO GO AND PEOPLE TO SEE – ANNOUNCING NEW TRANSPORTATION ASSISTANCE PROGRAM

The APDA Greater St. Louis Chapter Board of Directors has approved a new transportation assistance program which will begin this year for those members who qualify. It is modeled after the Taxi Voucher Program which has been successfully administered by the APDA Chapter in Seattle, WA. Mobility becomes a central issue when our ability to transport ourselves disappears.

in the program. Upon evaluation of your application and receipt of the required paperwork, we will contact you and discuss the amount that has been put into your personal transportation account.

Save your receipts, and submit them to the Center for reimbursement once you have spent at least \$50 in taxi fees. After we receive your receipts, we will mail out a reimbursement check.



But independence doesn't have to end here. There are numerous community and area-wide organizations available for assistance. Whether it's a doctor's visit, grocery shopping, visiting a friend, or participating in a support group or exercise class, a ride may be just a phone call away.

If you have Parkinson's disease and you can no longer drive (either due to PD or the meds you are taking) please contact us at (314) 362-3299, and we will send you an application asking for the following information: (1) a physician's note confirming diagnosis and your need for assistance; (2) a copy of the front page of your most recent tax return OR if you do not file a tax return, a copy of your social security awards letter (which will be shredded upon receipt); (3) a completed application form received from the St. Louis APDA; (4) an annual registration fee of \$25 will be due with the completed application and again annually (September) as long as you continue to participate

There are a limited number of personal transportation accounts available to our Greater St. Louis APDA membership in 2012, so these will be awarded on a first-come, first-serve basis, not to exceed \$300 per year.

We are pleased to be able to provide our PD community door-to-door options for accessible transportation to places they choose to go. So, go ahead and schedule your medical and hair appointments. Make that list of errands. Set up a lunch date. Let our Chapter help you continue to live an independent, connected life. Door-to-door service includes help with steps and packages, heavy doors, and walkers. Please direct any questions you have on this program or request a shared cost application from the Center at (314) 362-3299. A number of community-based programs do provide transportation for no charge or for a voluntary contribution and the Center is happy to provide you with a current list of these possible resources. ■

INDEPENDENT LIVING SERVICES

FOR PEOPLE WITH PD NEEDING IN-HOME ASSISTANCE

This year, the APDA Board has added another enhancement to our shared cost services involving independent living services for people with Parkinson's disease living at home. The aim is to provide you with assistance with those daily activities that aren't as easy for you as they used to be so you may continue to live independently in your own home. The assistance they can provide includes but is not limited to assistance with bathing, dressing, and grooming; running errands, picking up prescriptions, and shopping for groceries; cooking meals and feeding assistance; light home cleaning and laundry; exercising and companionship; and providing medication reminders.

In order for us to determine your eligibility for this program, you must meet the following shared cost requirements: (1) you must have Parkinson's disease; (2) you must not be on Medicaid or receiving

subsidized services from any other agency; (3) you must live in the following geographic areas – St. Louis city and county, St. Charles, Jefferson, and Franklin counties.

If you meet the eligibility requirements that are stated above, please call us at **(314) 362-3299**, and we will send you an application asking for the following information: (1) a physician's note confirming diagnosis and need for assistance; (2) a copy of the front page of your most recent tax return OR if you do not file a tax return, a copy of your social security awards letter (which will be shredded upon receipt); (3) a completed application form received from the St. Louis APDA; (4) an annual registration fee of \$25 will be due with the completed application and again annually (September) as long as you continue to participate in the program.

Once you submit the above documentation, the APDA will evaluate the level of monetary assistance that can be provided. This will be based upon your household income. The St. Louis APDA may cover the entire cost of a program or may cover only a portion of the cost requiring the participant to pay the remainder. If you do not qualify for the APDA Shared Cost Program assistance, but are still in need of these services, please contact the Center. We may be able to arrange reduced pricing for you through one of our preferred providers.

Again, to get started, you must complete a shared cost application and submit the \$25 annual fee along with the front page of your tax return. Your application will be evaluated and the level of assistance provided you for this four hour per week assistance will be determined. A home assistant care provider will be assigned from one of our cooperating agencies. Home care aides allow people to live safely and comfortably where they most want to be – at home. ■

DELAY THE DISEASE – FREEZING

David Zid, BA, ACE, APG Certified Functional Fitness Trainer

Freezing is a problem for many. When you are frozen, your anxiety level goes up because you feel like you need to move. The harder you try, the harder it is to move. Sound familiar? Things that contribute to freezing may be a tight space or crowds, external distraction, and noise. When you are frozen, your mind must think about a new and different movement, then perform that alternate activity and the freezing episode should resolve. For example, when you are frozen in a particular movement, stop that activity and try to perform a completely different task. Then try to return to the original activity at a later time.

Here are some ideas that may help. Good luck, and relax. ■

RELAX YOUR JAW

This may sound funny, but if you relax your jaw, the rest of your body will relax also, allowing you to start moving. Unless there is a bus coming at you, there is no real hurry. If there is a bus coming at you, get out of the way! If you are in line at the bank or grocery store, no one is going to die if you can't move right away. So relax your jaw; this is the first thing you must do before trying any of the following alternate movements.

STEP BACKWARDS

Take a big step backwards or sideways, and then try to step forward with the same foot. Remember to make your first step a big one because the following steps will tend to be large also. If your first step is small, the rest of your steps will tend to be smaller.

STEP OVER AN OBJECT

Find something on the ground—a crack, a dot, a pattern on the carpet, even a piece of gum. Then try stepping over it. Practice this at home using a sock, napkin, or something else that won't put you in danger if you step on it. Practice this over and over at home; then when you are out in public, visualize that napkin or sock and step over it.

TAP THE FLOOR

Try to bend down and attempt to pick up an imaginary object off the floor, or simply tap the floor with a finger. This allows your brain to focus on a completely different activity, thereby allowing you to take a step and “unfreeze.” Remember: Always make your first step a big one.



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**.

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	Call for location	Call for schedule		Desma Reno, RN, MSN	573-651-2939
Chesterfield	St. Louis	APDA Satellite Resource Center 1415 Elbridge Payne, Suite 168	1st Tuesday	10:30 AM	Mary Buck Lynda Wiens	636-532-6504 314-540-2662
Columbia	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Patsy & David Dalton Doris Heuer	573-964-6534 573-434-4569 573-999-2106
Creve Coeur	St. Louis	For Caregivers Only Shaare Emeth 11645 Ladue Rd., Library Conf. Rm.	2nd Monday	11:00 AM	Dee Jay Hubbard, PhD	314-362-3299
Creve Coeur	St. Louis	Young Onset Living and Working With PD Missouri Baptist Medical Center 3015 N. Ballas, Bldg. D, Conf. Rm. 6	3rd Tuesday	6:30 PM	Linda Pevnick, MSW, LCSW, BCD Rich Hofmann	314-362-3299 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	Julie Berthold Paula Simmons 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
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
Webster Groves	St. Louis	Bethesda Institute 8175 Big Bend, Blvd., Suite 210	Last Friday	10:30 AM	Laurel Willis, BSW	314-373-7036
Rolla	Phelps	Rolla Apartments 1101 McCutchen	3rd 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
Springfield	Green	Park Crest Baptist Church 816 W. Republic Road	Last Thursday	11:00 AM	Kay Meyer	417-350-1665
St. Peters	St. Charles	First Baptist Church of Harvester 4075 Hwy. 94 S.	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
St. Louis	St. Louis	Pre/Post-DBS Sunrise on Clayton Senior Living 7920 Clayton Rd.	3rd Thursday	1:00 PM	Steve Balven Stan & Donna Wilensky	314-249-8812 314-997-5114



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
Alton	Madison	Eunice C. Smith Home 1251 College - Downstairs Conf. Rm.	2nd Monday	1:00 PM	Sheryl Paradine	618-463-7334
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
Carmi	White	Phoenix Rehab. & Nursing 615 West Webb St.	4th Tuesday	1:00 PM	Carolyn Chastain	618-382-4932
Decatur	Macon	St. Paul's Lutheran Church 352 W. Wood St.	3rd Thursday	1:30 PM	Cathy Watts	217-428-7716
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 & Bill 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.	3rd Sunday in Jan., Mar., May, July, Sept., & Nov.	2:00 PM	Pam Miller	217-698-0088

PD MEDICATION SIDE EFFECTS & INTERACTIONS

continued from page 5

Dopamine Agonists: Requip (Ropinirole), Mirapex (Pramipexole), Parlodel (Bromocriptine)

These medications confer an anti-Parkinsonian benefit, meaning they treat the motor symptoms of PD, and may cause obsessive-compulsive behavior (shopping, gambling, odd sexual behavior), nausea, sleepiness, lightheadedness, hallucinations, or swelling of the legs or feet.

Carbidopa/Levodopa (Sinemet, Parcopa)

Levodopa turns into dopamine in the brain, replacing the missing dopamine. Carbidopa prevents the levodopa from turning into dopamine before it reaches the brain, where it may cause stomach upset. It is the most commonly used medication to treat motor symptoms of PD. This medication may cause nausea, sleepiness, lightheadedness, hallucinations, and dyskinesia (jerking-like movements).

Atypical Antipsychotics: Seroquel (Quetiapine), Clozapine (Clozaril)

These drugs are utilized to help control hallucinations and delusions (strange thoughts that other people would strongly disagree with, like that someone is spying on you or that your spouse is cheating on you or that the TV is talking to you). These medications may cause lightheadedness and sleepiness. Clozapine must be monitored with frequent blood testing because it may cause a drop in white blood cell counts, the body's infection fighters. ■



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., Aerobics Room	Wednesday & Friday	2:00 PM	Mike Scheller, PTA	314-289-4202
Clayton	St. Louis	Tango Dance Class* The Center of Clayton 50 Gay Avenue	Wednesday	3:00 PM	Gammon Earhart, PhD, PT	314-286-1425
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	2:30 PM	Cathy Clough, COTA	636-537-3333 ext. 204
Creve Coeur	St. Louis	Aquatic Exercise Rainbow Village 1240 Dautel Lane	Thursday Jan.12 – Mar.15	2:00 PM	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 Ste. 117	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.	Thursday Jan.12 – Mar.15	2:00 PM	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

* MUST CALL TO ENROLL

PLAN FOR YOUR FUTURE AND OURS

Because of your generous support, the Greater St. Louis APDA has funded millions of dollars of research and provides wonderful weekly services and programs which you have read about in this newsletter. By arranging a gift in your overall estate and financial plans, you can help ensure that our Chapter can continue to fund critical research being conducted at the Advanced Center for Parkinson's Research at Washington University School of Medicine, one of nine such APDA advanced centers in the nation, while adding programs and services to the communities we serve, which will as they say, ease the burden while researchers find

the cure.

A gift to the Greater St. Louis Chapter of the APDA in your will or revocable trust enables you to support our mission and make a difference in the lives of future generations. We receive calls from you, your attorneys, and financial planners requesting gift language as they prepare legal documents for you. The following language has been reviewed and is deemed a legally acceptable form for including such a bequest:

I, *(name)* of *(city, state, zip)* give, devise, and bequeath to the APDA Chapter of Greater St. Louis located in St. Louis, Missouri, *(written amount or percentage of the estate or description of*

property) to be used for its unrestricted use and purpose (or for the support of a specific fund or program—research at the APDA Advanced Center for Parkinson's Research or patient services funded by the Chapter). Our federal ID number is 13-1962771.

A misconception is that planned giving is only for the "wealthy." The truth is, even people of modest means can make a difference through planned giving. We encourage you to plan for your future and ours. Each of us can make a difference. For further information or questions, please contact the Center at **(314) 362-3299**. ■

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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 special birthday of Courtney Adams
Roselynn Gad

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Pam & Michael Smith

The 70th birthday of Larry Birke
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Don & Diane Donlon
Dale & Norma Plank

In appreciation of Drs. Kevin Black, Joel Perlmutter, Brad Racette, Samer Tabbal, & Allison Willis for their participation in our DVD
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continued on next page

READY, GET SET, GO!

WE'RE TAKIN' IT TO THE STREETS

As many of you recall, the Greater St. Louis APDA Chapter's vision is to expand significantly its patient services and education programs to better meet growing and unmet needs. The Fraternal Order of Eagle's grant we received in 2011 will enable us to achieve our goal of "easing the burden" by furthering education about Parkinson's disease in these underserved markets. Early diagnosed patients who learn about characteristics and treatment options can better manage symptoms and greatly enhance the quality of their own lives. Inadequate access to quality information in rural communities is a special concern. Spot Creative Media and our Chapter have been involved in the filming *Takin' it to the Streets* production since November. The DVD will be divided into chapters to inform medical personnel as well as answer frequently asked questions for patients and families. There will be no charge for this instructional media set, and it will be mailed to 3,500-5,000 underserved locations. In response to community needs, the proposed expansion is both geographical, to underserved out-state areas, as well as vertical,

to encompass physicians, professional caregivers, and senior living facilities throughout the state.

We've completed many of the initial "shoots," and are in the process of creating and reviewing transcripts, choosing sound bites, adding animation, and key visual materials. We have begun the

arduous task of compiling lists of physicians, long-term residential facilities (nursing homes), libraries, rehabilitation centers, and other professionals where state-of-the-art information about Parkinson patient's care and treatment options can best be shared. Public awareness and education play such a vital role in understanding this illness which affects people so uniquely.

If you would like us to share this wonderful 2012 DVD with your doctor, office staff, or staff of the facility in which you reside, please provide us with the name and address, and a complimentary copy of this production will be mailed to them in April. A link to this video will also be available on our website. Our hope is that we can significantly increase the awareness of Parkinson's disease and current treatments through the creation of new knowledge and the training of physicians, professionals, and staff working with our Parkinson's community throughout the state and around the world. ■



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SAVE THESE DATES!

Sun., April 1 **Parkinson Education Program (PEP) *What Is It? What's New? What Can We Do Now?***

Dr. Perlmutter will give a brief review of the clinical manifestations including other parkinsonisms (cousins that look like PD); discuss new understandings of what is really going on in people with PD (causes of PD, changes in different areas of function, it is more than just a movement problem), and new treatments. In each area, Dr. Perlmutter will cover relevant research being conducted.

WEBINARS

The following free educational programs (PD ExpertBriefings) are available online or by phone through the PDF for people with Parkinson's, family members, and health-care professionals. Pre-registration is recommended. PD ExpertBriefings are archived if you miss participating on the scheduled date. Check the PDF website at www.pdf.org/parkinsononline, or info@pdf.org, or call (800) 457-6676 for further information. All sessions meet from 1:00–2:00 pm.

Tue., Jan. 31 **Driving and PD: Balancing Independence and Safety**

Margaret O'Connor, Ph.D., ANPP and Lisa Kapust, LICSW
Beth Israel Deaconess Medical Center, Boston, MA

Tue., Mar. 6 **A Closer Look at Anxiety and Depression in PD**

Laura Marsh, MD, Michael E. DeBakey
Veterans Affairs Medical and Baylor College of Medicine, Houston, TX

Tue., April 17 **Parkinson's Medications: Today and Tomorrow**

Cynthia L. Cornella, MD, FAAN
Rush University Medical Center, Chicago, IL

Tue., June 26 **Understanding the Progression of Parkinson's**

Ronald F. Pfeiffer, MD
University of Tennessee Health Science Center, Memphis, TN

