Monday, October 11, you will have the opportunity and pleasure of attending the APDA 15th Annual Focus on Fashion—a celebrity fashion show, luncheon, and silent auction held at the Sheraton Westport Chalet. We are indebted to our GOLD level sponsors, The Community Partnership of Benton Homebuilders and Financial Management Partners for their support. Kent Ehrhardt, KMOV Channel 4 meteorologist, will be returning by popular demand, with Victoria Babu, KTRS 550 am news director and anchor morning drive, joining Kent at the podium as co-host. Additional TV and radio personalities and favorite St. Louisans will be on stage serving as celebrity models. You will be entertained by dancers and attractive models, served a scrumptious lunch, and enjoy a little shopping at kiosks and the auction.

We are thrilled to announce that Bill Donius will serve as our Honorary Chairperson this year. Bill is the former Chairman and CEO of Pulaski Bank and Pulaski Financial Corp. in St. Louis, MO and remains a Director and Consultant to the bank. Additionally, he is an active board volunteer in the St. Louis community serving on the board of trustees of multiple civic and charitable organizations including ARCHS, the St. Louis Art Museum, Maryville University, Forest Park Forever, the Barnes-Jewish Hospital Foundation, and several others. He has chaired numerous fundraisers in St. Louis and been recognized for charitable giving. This year’s show will feature fashions for women, men, and children from Paper Dolls, Susan Lynn’s, Marta’s, Vie, Cha, Banana Republic Men, Savvi, Jilly Bean, Alpine Shop, Mister Guy, Petunia, Byrd, and PURE by Jen.

Look for your invitation to arrive in the mail by Labor Day. If you’ve never received an invitation to this charitable event, please call the center and request one! Our Auction Basket Committee promises a return of some of the very popular gift items, along with our annual St. Louis Dinner Buffet (gift certificates to famous and new restaurants) and kiosks featuring items for sale bringing the boutiques to you, the shopper. We look forward to a fun and memorable day celebrating our progress toward finding a cure and supporting those with PD!

For more information, to become a sponsor of this event, to donate an auction item or gift certificate, or to request an invitation, call 314-362-3299.
I am now experiencing pain. Is pain a part of PD? Does it ever go away or just get worse as the disease progresses? What do you recommend taking for the pain?

Pain is not typically part of PD. Usually, the pain patients talk about is related to joints (usually arthritis) or muscles (which can be due to a number of things such as overuse strain, poor conditioning, poor circulation, spinal stenosis, and several metabolic, inflammatory, or primary muscle disorders, etc.). These are not due to PD. There are some patients (a sizable minority) that can get “dysesthesias” (uncomfortable feelings – burning, tingling, crawling, etc.) that can be one of the “non-motor” symptoms of PD. These symptoms must not be confused with other conditions such as Restless Legs Syndrome or a neuropathy. These PD-associated dysesthesias do not just typically go away and may worsen with time. Once it has been determined that other causes are not to blame, it is worth paying attention to how much discomfort is associated with “off time.” Unfortunately, the dysesthesias are not simply an “off time” problem. They may be less for many patients when they are “on.” However, the opposite is not necessarily true. That is, just using usual PD medication to lessen “off time” is certainly helpful for motor function but may not do much for the dysesthesias. Also, it is usually true that traditional “pain medications” do not help much. And, of course, with narcotics there are additional potential problems of diminishing results over time with the same dose, addiction, increased drowsiness, or confusion. These dysesthesias can be very difficult to fully resolve, but I have found that several different medications that are generally useful for “neuropathic pain” are more likely to help. There are a number of these, and the best choice will be an individual one arrived at by you and your physician.

When does PD really start?

This is one of the million dollar questions in PD research. We actually don’t know the answer. From the clinical trial or research perspective, we arbitrarily base the answer on either the occurrence of the first symptom or alternately the date of diagnosis (but we do not really know). The date of diagnosis is, however, biased and largely based on obvious motor symptoms such as tremor, stiffness or slowness. We know that this estimate therefore is grossly inaccurate. In fact, by the time a person with Parkinson’s (PwP) manifests the first symptom (e.g. tremor of the fingers), significant degeneration (i.e. loss of brain cells) of the dopaminergic neurons in the brain has already occurred.

We now know that the loss of sense of smell, constipation, depression, personality changes, sleep problems, and even anxiety may long precede the motor symptoms of PD. The problem with using these symptoms as diagnostic markers, however, is that they commonly occur in the general population, making it very difficult to judge what is part of PD and what is not.

Complicating the picture as to the onset of PD has been the discovery that many patients may have rapid eye movement (REM) sleep disturbances (i.e. when patients attempt to act out their dreams) many years prior to the onset of motor symptoms. Braak and colleagues also have recently proposed that the degeneration in PD actually starts well before dopaminergic cells in the midbrain begin to die.

Can I have a specialty neurologist participate in my care along with a general neurologist/general practitioner?

The best situation for patients is to have both a specialty-trained neurologist (perhaps even at a center of excel-
There are many choices for in-home care. How does one know which in-home care choice is the right choice, and how does one determine if in-home care is the appropriate care choice to begin with? The information below can help in the decision-making process.

Follow the subject titles on the left column and circle appropriate responses for each. Strongly consider the options where more responses fall. Be sure to consider culture, support systems and financial ability when making a decision.

*Used with the author’s permission.*

**Questions for the Doctor continued from previous page**

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**Options for Care at Home—Defined**

Barth Holohan, MSW, MBA, President of Continuum Care for Life

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<table>
<thead>
<tr>
<th>Care Options</th>
<th>Home Care with Monitoring, Possibly Move to a Facility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>Walks and transfers independently.</td>
</tr>
<tr>
<td>Activities of Daily Living</td>
<td>Able to accomplish all without assistance. May need assistance in meals and/or housekeeping.</td>
</tr>
<tr>
<td>Socialization and Recreational Activities</td>
<td>Completely able to socialize and enjoys recreation.</td>
</tr>
</tbody>
</table>
We receive many calls at our clinic inquiring if certain medications are all right to take for people with PD, especially when about to undergo surgical procedures. For that reason, we thought it would be a good idea to give people with PD a list of medicines that need to be completely avoided or at least used with extreme caution. It may be a good idea to cut this page out and keep it in case you or a loved one has an upcoming surgery. Please remember that this does not include any medicines that are not recommended because of drug interactions, just those that should be avoided generally when diagnosed with Parkinson's disease.

**Contraindicated medications for nausea in PD**

Metoclopramide (Reglan), Tri-methobenzamide Hydrochloride (Tigan), or Prochlorperazine (Compazine). These are anti-dopaminergic medicines and can exacerbate or even cause Parkinson motor symptoms. They must be completely avoided. For nausea, instead use Ondanestron (Zofran). If nausea is due to Parkinson medications, extra carbidopa (Lodosyn) or domperidone may also be helpful.

Diphenhydramine (Benadryl, Sudafed, and Tylenol PM) should also be avoided because it can cause confusion and falls. Note: Diphenhydramine is in several over-the-counter medications for allergies, colds, and sleep. Diphenhydramine should be avoided or used with caution.

**For pain in PD**

Narcotics should be avoided as these can worsen balance and cause confusion. Narcotics come in many forms too numerous to list all of them, but a few common ones to avoid or use with caution include Hydrocodone, Hydromorphone (Dilaudid), Meperidine (Demerol), and Oxycodeone (Oxycontin). Narcotics mixed with central analgesics (muscle relaxers) must also be avoided or only used with caution, and a few of those include Hydrocodone with Acetaminophen (Lorcet or Lortab), Oxycodeone with Acetaminophen (Percocet), and Propoxyphene with Acetaminophen (Darvocet). If possible, patients should try to manage pain with Acetaminophen or Ibuprofen. If you must take one of these medications for pain after a surgery, please do so with extreme caution and only for short periods of time.

**For psychosis in PD**

Haloperidol (Haldol), Risperidone (Risperdal), Zyprexa, Aripiprazole (Abilify), or any other typical or atypical neuroleptic medication (with the exclusion of the few listed below). These medications can also cause or exacerbate Parkinson motor symptoms and can cause confusion. They must be completely avoided. Instead, use either quetiapine (Seroquel) or Clozapine (Clozaril). Quetiapine can increase glucose intolerance and does not have proven efficacy compared to placebo in PD. Clozapine has proven efficacy but can cause a drop in white blood cells, so requires frequent blood monitoring.

**For anxiety in PD**

Haloperidol (Haldol), Risperidone (Risperdal), Olanzapine (Zyprexa), Aripiprazole (Abilify), or any other typical or atypical neuroleptic medication (with the exclusion of the few listed below). These medications can also cause or exacerbate Parkinson motor symptoms and can cause confusion. They must be completely avoided. Instead, use either quetiapine (Seroquel) or Clozapine (Clozaril). Quetiapine can increase glucose intolerance and does not have proven efficacy compared to placebo in PD. Clozapine has proven efficacy but
Exercise, Neuroplasticity and Parkinson’s Disease

Mark A. Hirsch, PhD, Carolinas Rehabilitation, Charlotte, North Carolina

Dr. Hirsch’s research has focused on the effect of high-intensity exercise in improving the cardinal signs and symptoms of PD (i.e., postural control, fall prevention).

Exercise and neuroplasticity in persons living with Parkinson’s disease was the theme of a recent paper published in the European Journal of Physical and Rehabilitation Medicine by Mark A. Hirsch, PhD., and Becky G. Farley, PT, PhD. The term “neuroplasticity” can be defined as the brain’s wondrous ability to alter its own structure and function in response to changes in the internal and/or external environment, a process believed to occur in humans throughout life. The authors reviewed animal and human data on high-intensity exercise as it affects the Parkinson’s brain and potential recovery. According to the authors, “Continuous, deficit targeted, intensive training may confer neuroprotection and thereby slow, stop or reverse the progression of the disease or promote neurorestoration through adaptation of compromised signaling pathways” (Hirsch and Farley, 2009, p. 215) and, “Leading a sedentary lifestyle may be pro-degenerative.”

We caught up with Dr. Hirsch at Carolinas Rehabilitation Hospital in Charlotte, North Carolina, where he teaches and conducts research and talked with him about exercise and PD.

What led you to write about exercise, neuroplasticity, and PD?

Mark Hirsch: I got interested in high-intensity exercise (resistance and balance training) and Parkinson’s disease during my time at Florida State University. Back then it was believed that exercise would not improve function in PD and might even be harmful. Recent research suggests that people with Parkinson’s disease (PwP) may be less physically active than individuals with stroke or multiple sclerosis, or even healthy sedentary adults. And in the past few years, we have learned so much about the benefits of exercise for brain health and PD but have conveyed so little of that information to healthcare professionals or patients. So, writing this article was an attempt to remedy that situation. I was inspired by what I learned during a 2008 national conference on physical medicine and rehabilitation, during which we gave a lecture on exercise, neuroplasticity, and PD. At the start of the lecture, we asked the participants, many of whom were physiatrists (physicians specializing in rehabilitation medicine), to raise their hand if they had learned about exercise during their medical training. All participants raised their hands. Then we asked participants to keep their hands raised if they had ever prescribed exercise for their PD patients. About half of the hands remained. Finally, we asked how many participants prescribed exercise because they believed it to have neuroprotective qualities - and not one hand remained raised. That day, we received a great deal of encouragement to write up our lecture for publication.

How important is exercise to PD?

MH: Anyone planning to begin exercise should consult with a healthcare professional (physician, physical therapist). The exercise and PD animal data suggests that individuals with PD should begin exercising the day they are diagnosed. Recently, the American Medical Association launched a new educational initiative they call “Exercise Is Medicine.” The aim of this initiative is to encourage healthcare professionals to talk to their patients about exercise at every office visit and to support patients in making healthy lifestyle choices. Physicians should help their patients find places in the community to exercise. Research suggests that patients value their physicians’ advice, although patients don’t always follow it, and communities may not be offering exercise programs specific to PD, so there is still a disconnect between physicians giving good advice and then patients actually finding places to exercise and sticking with it. In truth, we don’t yet understand what motivates people with PD to begin exercise or the factors that encourage them to keep exercising for a lifetime. But, if healthcare professionals are not talking to their patients about exercise and there are no community programs catering to patients’ individual needs, which may turn out to be the typical situation, we should not be surprised that patients are not as physically active as they could be. It is hoped that our article gives patients and physicians something to talk about!

So if exercise is important, what should people with PD do to get it?

MH: Talk to your doctor or seek the advice of a physical therapist specializing in Parkinson’s care. Many patients in the early stages of Parkinson’s might believe they don’t need exercise and might choose to avoid the subject. These patients may lack awareness that they have deficits because, in the early stages of PD, these can be subtle and difficult to detect and therefore patients may put off going to their doctor; many physicians and therapists are still unaware of neuroplasticity-based exercise principles so they might not be aware that patients at all stages can benefit from exercise and therapy; and the exercises patients may be doing on their own or receiving from PTs may not be as efficacious as they could be. So it is important for patients to be discussing this with their healthcare providers. Patients receiving ineffective treatment may stop exercising altogether, and we know from the animal literature that being sedentary may be pro-degenerative for the Parkinson’s brain. Again, making an appointment with a physician or a PT is one of the most important decisions a patient can make for their overall health and for getting them involved with exercise.
THE POWER OF MUSIC

Beyond the entertainment value, there is growing evidence that listening to music can also help stimulate seemingly lost memories and even help restore some cognitive function. Specialists are prescribing rhythm and melody as a way to treat neurological conditions. In Parkinson’s patients (PwP), whose movements are often characterized by slowness of or difficulty initiating movement (bradykinesias), it is thought that music triggers networks of neurons to translate the beat into organized movement. A study conducted by scientists at Colorado State University’s Center for Research in NeuroRehabilitation and the University of Michigan’s Center for Human Motor Research, asked people with Parkinson’s to walk both with and without music. When walking to music, these PwP could go faster, take bigger steps, and showed better overall balance and control of movement.

The reason rhythm is such a powerful tool is that it permeates the entire brain, engaging a wide variety of functions, including listening, speech and movement. The sound of drumming generates dynamic neuronal connections in all parts of the brain, even where there is damage or impairment. Advances in neuroscience and brain imaging reveal what is happening in the brain as patients listen to music or play instruments. Rhythmic cues can help retrain the brain—the more connections that can be made within the brain, the more integrated our experiences become. We learn “to flow” with the rhythms of life by learning to feel the rhythm of the music. Dr. Concetta Tomaine, executive director of the Institute for Music and Neurologic Function, explains, “Someone who is frozen can immediately release and begin walking. If they have balance problems, they can synchronize their steps with the music, thereby improving their gait and stride.” Muscle bursts and jerky motions, as seen in PwP with involuntary tremor (dyskinesias), can be lessened with slow rhythms, and playing music can also bring impressive results.

Participants in a drumming workshop reported their control of physical movement to be improved after playing the drums. Their motion became more fluid; their tremors lessened considerably. It is with those thoughts in mind that a collaborative effort between the Alzheimer’s Association and the St. Louis Chapter is underway to utilize a technique called memory drumming.

CELEBRATION OF DANCE

On Sunday, June 13, over 50 people attended our annual social dance and moved to the music of a delightful DJ. This dance was sponsored by 1-year APDA Board member and 19-year South Side support group leader, Jack Strosnider. Jack agreed with the DJ who commented, “If only one person comes and has a good time, I am happy.” Well over 50 people came and had a great time and vowed to return for the next dance.

The benefits of dance for people with PD were clearly demonstrated when a gentleman experienced multiple episodes of freezing and a great deal of difficulty walking through the doorway with his walker engaged in swing and ballroom dancing and left the dance floor hand in hand with his partner. When the dance concluded, he walked effortlessly out to the parking lot, without the freezing episodes so characteristic of his ambulation. It was such an amazing and rewarding sight to see and one which clearly reinforces Dr. Gammon Earhart’s research studies on the benefits of dance.

MEMORY DRUMMING

St. Louis Chapter Alzheimer’s Association has graciously invited the St. Louis Chapter Parkinson’s Association to experience this activity together with their members as a collaborative effort. The power of music can be remarkable. It is not uncommon for people with memory loss to respond to old familiar songs. Memory Drumming is a percussion group for people with mild memory loss held on the fourth Monday of the month from 5:30 p.m.-6:30 p.m. The group is held at the Alzheimer’s Association office located at 9370 Olive Blvd, Olivette, MO 63132. These sessions are intended to provide a meaningful and engaging activity for people with early-stage memory loss that combines mental stimulation and socialization. No skills, talent, or past experience with drumming are required. This is an open jam session led by a music therapist, so people are welcome to come when they can. A fee of $5 is charged for each session; 6 sessions for $25. This class is a creative workout for the mind, body, and soul. It offers an opportunity to exercise upper body muscles and the right hemisphere of the brain while working on coordination. Drumming provides an opportunity for people to communicate in ways that words alone cannot express and allows people to move beyond their perceived cognitive and physical limitations.

No registration is needed for Memory Drumming, but feel free to call the Alzheimer’s Association for more information at 314-432-3422 or 1-800-272-3900 and to receive a flyer to attend your first drumming session for FREE!
Fatigue
Joseph H. Friedman, M.D., Movement Disorders Program, Butler Hospital, Department of Neurology, Alpert Medical School of Brown University

Fatigue is a common problem in almost all areas of medicine. It is common in primary care practices, psychiatric populations, and neurology clinics. It is associated with almost every medical and psychiatric problem. However, it wasn’t recognized as being a problem in PD until 1992 (175 years after James Parkinson published his famous treatise on “The Shaking Palsy”). In that year, two studies were published which found that fatigue was the single worst symptom bothering PD patients in about one-third of patients and that one-half of PD patients rated fatigue one of their three worst symptoms, including tremor, stiffness, slowness, walking problems, speech problems, etc. In other words, fatigue was very common and very severe. Several studies from around the world have confirmed this observation in China, Japan, and Europe indicating that this is not a culturally based symptom.

Understanding fatigue has been complicated by our poor understanding of what fatigue is. First of all, fatigue is different than sleepiness. By fatigue we mean lack of energy. Secondly, everyone suffers from fatigue sometime. The question is: When is fatigue a symptom? It is a problem if it interferes with someone’s life. It restricts their activities. A second complication is that there are different types of fatigue: physical fatigue, emotional fatigue, and mental fatigue. In English we used the word “tiredness” to convey both fatigue and sleepiness, although they are different. Fatigue is what we feel after running a marathon, and sleepiness is what we feel when we were up all night. Many PD patients feel fatigue that prevents them from doing things. They can’t go to the movies, go out for a walk, visit old friends, and participate in an exercise program. Some patients don’t suffer from fatigue while they are sitting but can’t perform much because of easy fatigue, that is, they fatigue with little effort.

Why fatigue is common in PD is unknown. What is truly fascinating about it is that it does not correlate with the severity of motor dysfunction. Most patients who are fatigued developed it even before the illness was recognized. In many cases, it was a “pre-motor” or “pre-clinical” feature. In the Elldopa trial, which only enrolled newly diagnosed, very mild, untreated PD patients, one-third suffered from fatigue. With time, fatigue tends to worsen, but most PD patients who didn’t have fatigue early, didn’t develop it later. Fatigue is not related to medications. While it is true that PD patients require more energy to do any motor task than someone without PD (for example, it takes more energy for PD patients to sit still and breathe), nevertheless, an experiment that Dr. Carol Garber and I performed found no significant differences between PD patients with fatigue and those without fatigue during active exercise. We had thought that perhaps PD patients with fatigue were simply less efficient, and therefore required more energy to do tasks.

There have been very few studies of fatigue in PD other than determining how common and severe a problem it is. Only a single study has shown a successful treatment for fatigue in PD, and this used low-dose methylphenidate (Ritalin), a stimulant drug used primarily to treat hyperactive children. Some studies have been performed using modafinil (Provigil), which is used to keep people awake. It does not improve fatigue, which is not surprising since modafinil does not energize people, it simply keeps them from falling asleep.

No one knows how to treat fatigue in PD. I recommend stimulants, like methylphenidate or amphetamines, drugs called “uppers” or “speed” in the US because they “speed” people up, make them more energetic, and even improve mood. However, they have a downside, too, and cannot be taken by people with coronary disease, and they may increase blood pressure.

Fatigue in PD patients may not be due to the PD. Fatigue is common in people with depression, and depression is common in PD. In such cases, treating depression may improve fatigue. Fatigue may, as noted in the beginning of this article, occur in many different disorders, and PD patients can also have other things wrong with them, like anemia, heart failure, lung diseases, or fatigue-inducing medications.

There is hope that other approaches to treating fatigue, like exercise, may be helpful. Exercise has been helpful in cancer patients with fatigue and may work in PD as well.

What should you do if you suffer from fatigue? First of all, make sure there’s no other explanation than the PD. If so, you and your family need to understand that this problem is part of the disease and not a moral failing. Try exercise. Of course, fatigued people complain that they can’t exercise because they’re too tired. They should start with a small amount of exercise, perhaps walking five minutes at a time twice each day, and slowly increase this, perhaps by a minute or two each week, aiming for a single 30-minute walk. If this isn’t helpful, ask your doctor to consider using a stimulant at a low dose. However, there is almost no data to support this approach. It is simply my own approach.
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.

<table>
<thead>
<tr>
<th>City</th>
<th>County</th>
<th>Meeting Site</th>
<th>Day of Meeting</th>
<th>Time</th>
<th>Leader(s)</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cape Girardeau</td>
<td>Cape Girardeau</td>
<td>The Chateau Girardeau 3120 Independence St. St. Francis Med. Ctr. 211 St. Francis Dr. SFMC Cafeteria</td>
<td>Feb. 1, Aug. 2</td>
<td>3:30 PM</td>
<td>Desma Reno, RN, MSN</td>
<td>573-651-2939</td>
</tr>
<tr>
<td>Chesterfield</td>
<td>St. Louis</td>
<td>APDA Satellite Resource Center 1415 Elbridge Payne, Suite 168</td>
<td>1st Tuesday</td>
<td>10:30 AM</td>
<td>Shameem Ahmed, Lynda Wiens</td>
<td>636-579-1134, 636-537-5455</td>
</tr>
<tr>
<td>Columbia</td>
<td>Boone</td>
<td>Lenoir Community Center 1 Hourigan Drive</td>
<td>1st Thursday</td>
<td>4:00 PM</td>
<td>Doris Heuer, Mary Green</td>
<td>573-815-3718</td>
</tr>
<tr>
<td>Festus/Crystal City</td>
<td>Jefferson</td>
<td>Disability Resource Association 420 B S. Truman Blvd.</td>
<td>3rd Tuesday</td>
<td>1:00 PM</td>
<td>Penny Roth</td>
<td>636-931-7696 ext. 129</td>
</tr>
<tr>
<td>Florissant</td>
<td>St. Louis</td>
<td>Garden Villas North 4505 Parker Rd.</td>
<td>4th Thursday</td>
<td>11:00 AM</td>
<td>Julie Berthold, Paula Simmons</td>
<td>314-355-6100</td>
</tr>
<tr>
<td>Jefferson City</td>
<td>Cole</td>
<td>Capital Regional Medical Center SW Campus, Cafeteria</td>
<td>3rd Monday</td>
<td>3:00 PM</td>
<td>Jennifer Urich, PT</td>
<td>573-632-5440</td>
</tr>
<tr>
<td>Joplin</td>
<td>Jasper</td>
<td>St. Johns Regional Medical Ctr. 2931 McClelland</td>
<td>Mondays</td>
<td>1:30 PM</td>
<td>Nancy Dunaway</td>
<td>417-659-6694</td>
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<tr>
<td>Kirkwood</td>
<td>St. Louis</td>
<td>Kirkwood United Methodist 201 W. Adams</td>
<td>1st Monday</td>
<td>7:00 PM</td>
<td>Terri Hosto, MSW, LCSW</td>
<td>314-286-2418</td>
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<tr>
<td>Ladue</td>
<td>St. Louis</td>
<td>The Gatesworth 1 McKnight Place</td>
<td>2nd Wednesday</td>
<td>1:00 PM</td>
<td>Maureen Neusel, BSW</td>
<td>314-372-2369</td>
</tr>
<tr>
<td>Lake Ozark</td>
<td>Camden</td>
<td>Lake Ozark Christian Church 1560 Bagnell Dam Blvd.</td>
<td>3rd Thursday</td>
<td>Noon</td>
<td>Patsy Dalton</td>
<td>573-964-5534</td>
</tr>
<tr>
<td>Oakland/ Webster Groves</td>
<td>St. Louis</td>
<td>Bethesda Institute 8175 Big Bend, Blvd., Suite 210</td>
<td>Last Friday</td>
<td>10:30 AM</td>
<td>Laurel Willis, BSW</td>
<td>314-373-7036</td>
</tr>
<tr>
<td>Rolla</td>
<td>Phelps</td>
<td>Rolla Apartments 1101 McCutchen</td>
<td>4th Thursday</td>
<td>2:30 PM</td>
<td>Hayley Wassilak, Tyler Kiersz</td>
<td>573-201-7300</td>
</tr>
<tr>
<td>Sedalia</td>
<td>Pettis</td>
<td>First Christian Church (Disciples of Christ) 200 South Limit</td>
<td>3rd Monday</td>
<td>4:00 PM</td>
<td>Barbara Schulz</td>
<td>660-826-6039</td>
</tr>
<tr>
<td>South St. Louis</td>
<td>St. Louis</td>
<td>Garden Villas South 13457 Tesson Ferry Rd.</td>
<td>2nd Wednesday</td>
<td>10:00 AM</td>
<td>Jack Strosnider</td>
<td>314-846-5919</td>
</tr>
<tr>
<td>St. Peters</td>
<td>St. Charles</td>
<td>1st Baptist Church of Harvester 4075 Hwy. 94 S.</td>
<td>1st Tuesday</td>
<td>1:00 PM</td>
<td>Ann Ritter, RN</td>
<td>636-926-3722</td>
</tr>
<tr>
<td>St. Louis</td>
<td>St. Louis</td>
<td>Pre/Post-DBS Temple Israel 10675 Ladue Rd.</td>
<td>3rd Thursday</td>
<td>1:00 PM</td>
<td>Steve Balven, Stan Wilensky</td>
<td>314-249-8812, 314-997-5114</td>
</tr>
<tr>
<td>Creve Coeur</td>
<td>St. Louis</td>
<td>Young Onset Living and Working With PD Missouri Baptist Medical Center 3015 N. Ballas, Bldg. D, Conf. Rm. 6</td>
<td>3rd Tuesday</td>
<td>6:30 PM</td>
<td>Jeff Wilsey, Rich Hofmann</td>
<td>314-614-4560, 314-369-2624</td>
</tr>
</tbody>
</table>
Let’s imagine that you have fallen and you are lying on the floor. First, make certain that you are not severely injured or have sustained a bone fracture. Once you are sure that you are safe to move, relax, and take a deep breath; you are safe on the floor. You do not need to get up quickly. Here is the process for moving from the floor. Become familiar with this process, and then practice the following exercises that will make the process easier for you. Don’t hesitate to use a partner for help at first. Good luck.

Getting off the Floor

There are several ways to get up off the floor. Practice both of these techniques; the following exercises will help you get off the floor easier. Initially, roll from your position to a side-lying position with your bottom arm above your head. Bend your knees up and push up onto the elbow that is over your head. Try to get both knees underneath you by turning your hips, using both elbows and hands for support—you should be on “all fours” in a crawling position. From this position:

- **Off the Floor using a Chair**
  Now you can crawl over to a chair to try to help pull yourself up. Grab the edge of the chair with your hands or place elbows on the seat of the chair. Pull your knee up and place one foot flat on the floor. Shift your weight onto your arms on the seat of the chair and bring the other knee up, standing on that foot. Stand up slowly.

- **Off the Floor Unassisted (no chair)**
  Pull one knee up and place that foot flat on the floor. Place both hands on the knee that is raised. Push off the knee as you stand up. Pull one knee up and place that foot flat on the floor. Keeping both hands on the floor, bring the other knee up and place that foot flat on the floor. Now you are in a deep squat position, so just stand up slowly.

For additional exercise ideas, refer to the book and DVD, *Delay the Disease – Exercise and Parkinson’s Disease.*
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.

<table>
<thead>
<tr>
<th>City</th>
<th>County</th>
<th>Meeting Site</th>
<th>Day of Meeting</th>
<th>Time</th>
<th>Leader(s)</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alton</td>
<td>Madison</td>
<td>Eunice C. Smith Home 1251 College - Downstairs Conf. Rm.</td>
<td>2nd Monday</td>
<td>1:00 PM</td>
<td>Sheryl Paradine</td>
<td>618-463-7334</td>
</tr>
<tr>
<td>Belleville</td>
<td>St. Clair</td>
<td>Southwestern Illinois College (PSOP) 201 N. Church St., Rm 106</td>
<td>2nd Monday</td>
<td>1:30 PM</td>
<td>Mary Friedrich Jodi Gardner</td>
<td>618-234-4410 x7031 or 7033</td>
</tr>
<tr>
<td>Carbondale</td>
<td>Jackson</td>
<td>Southern IL Healthcare Headquarters University Mall</td>
<td>1st Wednesday</td>
<td>1:00 PM</td>
<td>Tom Hippenstein</td>
<td>618-684-4282</td>
</tr>
<tr>
<td>Carmi</td>
<td>White</td>
<td>Phoenix Rehab. &amp; Nursing 615 West Webb St.</td>
<td>4th Tuesday</td>
<td>1:00 PM</td>
<td>Carolyn Chastain</td>
<td>618-382-4932</td>
</tr>
<tr>
<td>Decatur</td>
<td>Macon</td>
<td>St. Paul’s Lutheran Church 352 W. Wood St.</td>
<td>3rd Thursday</td>
<td>1:30 PM</td>
<td>Cathy Watts</td>
<td>217-428-7716</td>
</tr>
<tr>
<td>Granite City</td>
<td>Madison</td>
<td>St. Johns United Church of Christ 2901 Nameoki</td>
<td>1st Thursday</td>
<td>1:30 PM Call to verify</td>
<td>Hilda Few Karen Trim</td>
<td>618-797-0527 618-345-3222</td>
</tr>
<tr>
<td>Greenville</td>
<td>Bond</td>
<td>Greenville Regional Hospital 200 Healthcare Dr. Edu. Dept., Edu. Classroom</td>
<td>2nd Monday</td>
<td>1:00 PM</td>
<td>Alice Wright</td>
<td>618-664-0808 ext. 3703</td>
</tr>
<tr>
<td>Matoon</td>
<td>Coles</td>
<td>First General Baptist Church 708 S. 9th St.</td>
<td>Last Tuesday</td>
<td>1:30 PM</td>
<td>Marcia Smith</td>
<td>217-254-4869</td>
</tr>
<tr>
<td>Mt. Vernon</td>
<td>Jefferson</td>
<td>Greentree of Mt. Vernon, 2nd Floor</td>
<td>4th Thursday</td>
<td>6:30 PM</td>
<td>Donna &amp; Bill Peacock</td>
<td>618-242-4492</td>
</tr>
<tr>
<td>Quincy</td>
<td>Adams</td>
<td>Fellowship Hall of Salem Evangelical Church of Christ 9th &amp; State</td>
<td>3rd Thursday</td>
<td>12:00 PM</td>
<td>Barb Robertson</td>
<td>217-228-9318</td>
</tr>
<tr>
<td>Springfield</td>
<td>Sangamon</td>
<td>Christ the King Parish Ctr. 1930 Brentwood Dr.</td>
<td>3rd Sunday in Jan., Mar., May, July, Sept., &amp; Nov.</td>
<td>2:00 PM</td>
<td>Dan Vonberg</td>
<td>217-546-2125</td>
</tr>
<tr>
<td>Vandalia</td>
<td>Fayette</td>
<td>Fayette County Hospital 650 West Taylor, Conference Room</td>
<td>Last Tuesday</td>
<td>1:00 PM</td>
<td>Charlene “Pokie” Pryor</td>
<td>618-283-4633</td>
</tr>
</tbody>
</table>

Is a Support Group for Me?

Surprise groups offer a unique experience which provides several benefits for people with PD and family care partners. First, they aim to educate participants about the many aspects of this disease. Information about PD symptoms, treatments and medication side-effects, the significance of nutrition and exercise in PD, and resources for PD patients and care partners help participants gain useful knowledge about the disease and how to manage it.

Secondly, support groups enable participants to ask questions, discuss common concerns, and offer emotional support to one another. Support groups provide a place to share feelings in a caring, non-judgmental atmosphere and exchange helpful coping strategies like completing everyday tasks in more efficient and less stressful ways. The give-and-take nature of support groups encourages participants not only to receive information and support from others, but to give care and support to others as well.

Thirdly, support groups serve as social outlets where people with PD meet other people living with PD. Participants tend to form bonds of friendship in light of their common situation. Groups also offer comfort and hope from meeting others who are coping well under similar circumstances.

Support groups come in many different forms and may vary in size from just a few participants to much larger groups with twenty or more participants. Group membership typically consists of a combination of PD patients and family care partners. Specialized groups may be offered to address the needs of those who share a common interest, such as newly diagnosed patients, young-onset patients, DBS patients, or adult-children caregivers. Each support group will have its own character since its participants represent a range of symptoms, as well as a mix of personalities, age groups, religious
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.

<table>
<thead>
<tr>
<th>City</th>
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<th>Meeting Site</th>
<th>Day of Meeting</th>
<th>Time</th>
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<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clayton</td>
<td>St. Louis</td>
<td>Barnes Extended Care 401 Corporate Park Dr.</td>
<td>Wednesday &amp; Friday</td>
<td>1:30 PM</td>
<td>Sue Tucker, OT</td>
<td>314-289-4325</td>
</tr>
<tr>
<td>Chesterfield</td>
<td>St. Louis</td>
<td>St. John’s Mercy Rehabilitation Hospital 14561 N. Outer 40</td>
<td>Tuesday</td>
<td>1:00 PM</td>
<td>Deb Luetkemeyer, PT</td>
<td>314-881-4200</td>
</tr>
<tr>
<td>Chesterfield</td>
<td>St. Louis</td>
<td>St. Luke’s Hospital 232 S. Woods Mill Rd.</td>
<td>Tuesday</td>
<td>10:30 AM</td>
<td>Patty Seeling, PT</td>
<td>314-205-6934</td>
</tr>
<tr>
<td>Creve Coeur</td>
<td>St. Louis</td>
<td>Rainbow Village—Aquatic Exercise 1240 Dauteil Lane</td>
<td>Thursday</td>
<td>2:00 PM</td>
<td>Brenda Neumann</td>
<td>636-896-0999 ext. 312</td>
</tr>
<tr>
<td>South St. Louis County</td>
<td>St. Louis</td>
<td>Garden Villas South 13457 Tesson Ferry Rd.</td>
<td>Monday</td>
<td>11:30 AM</td>
<td>Sue Tucker, OT</td>
<td>314-289-4325</td>
</tr>
<tr>
<td>St. Peters</td>
<td>St. Charles</td>
<td>Barnes-Jewish St. Peters Hospital Ste. 117</td>
<td>Every Tuesday except 1st Tuesday</td>
<td>11:00 AM</td>
<td>Holly Evans, PT</td>
<td>636-916-9650</td>
</tr>
<tr>
<td>North St. Louis County</td>
<td>St. Louis</td>
<td>Garden Villas North 4505 Parker Rd.</td>
<td>Tuesday &amp; Thursday</td>
<td>10:00 AM</td>
<td>Bobby Lautenschlager, PTA</td>
<td>314-355-6100</td>
</tr>
<tr>
<td>Lake Ozark</td>
<td>Camden</td>
<td>Lake Ozark Christian Church 1560 Bagnell Dam Blvd.</td>
<td>Monday</td>
<td>4:00 PM</td>
<td>Alice Hammel, RN</td>
<td>573-964-6534</td>
</tr>
<tr>
<td>St. Louis City</td>
<td>St. Louis</td>
<td>The Rehab. Institute of St. Louis 4455 Duncan Ave.</td>
<td>Thursday</td>
<td>Noon</td>
<td>Janelle Davis, PT</td>
<td>314-658-3858</td>
</tr>
</tbody>
</table>

IS A SUPPORT GROUP FOR ME?

continued from previous page

prepare for the group experience. If possible, talk to the group facilitator in advance and explain your interests and concerns in joining the support group. Ask about the makeup of the group, the structure and ground rules of the group meetings (including respect for confidentiality), and what is expected with regard to group participation. If you do not receive the help you need after a meeting or two, try another group, or try the same group later when the time seems better.

Although support groups alone cannot give you all the education and emotional support needed to deal with PD, they can be a valuable source of help. Joining a support group should be just as important as regular visits to the doctor. To find out about the APDA network of support groups, contact the Information and Referral Center at 314-362-3299 or visit the St. Louis Chapter.

WANTED:

Patients for New Exercise Class

A new free exercise class for PwP is taking place at The Rehabilitation Institute of St. Louis (TRISL) every Thursday, 12:00–1:00 p.m., led by Janelle Davis, DPT. Call the APDA Information & Referral Center (314-362-3299) to register for this weekly class. Classes meet in the third floor gym at 4455 Duncan Ave., in the city of St. Louis and free parking is available across the street in a paved lot; accessible parking on the side of the building. Duncan Ave. is easily reached from Forest Park Parkway, east of Kingshighway and west of Grand. The APDA is indebted to TRISL for their willingness to provide an exercise class for city-dwellers with Parkinson’s disease and PwP living in Illinois communities close to downtown.
TRIBUTES & DONATIONS

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

HONORING
The Wedding of Chad & Bridget Allen & Arline Kolons
The Wedding of Kathy & Phil Charlotte Shelburne
The Birthday of Bill Bruchhauser Bruchhauser family
The Special Birthday of Debbie Dulin Phillip & Susan Schreiber
The 60th Anniversary of Dr. Maurice & Shirley Eichler Hilda Fendelman
The Special Birthday of Mark C. Kodner Ross Schumaker
The Mormino Family Anthony & Josephine Mormino
The Graduation of Laura Rosenberg Mital Lyons-Warren & Family
The Birthday of Elaine Varnadore Harry & Beverly Lee

REMEMBERING
Douglas Lee Allen Vera Ely
Tom Finneran David & Jenny Parcell Duane Preston
Lois Sterbenz William S. Thomas Rose Marie & Paul Turner
Reuben Balk Ralph & Helen Goldsticker
Francis Bizelli Clifton & Sharon Bizelli Dolores Bizelli
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Jim & Jackie Averbeck
Doug L. Bernier
Duane & Pamela Billhartz
Bill & Betty Brauer

continued on next page
CORPORATE MATCHING GIFTS

Did you know that you may be able to multiply your donation with a match from your company? Many employers sponsor matching gift programs and will match any charitable contributions made by their employees. To find out if your company has a matching gift policy, just ask! Matching gift programs have been established to support the interests and concerns of employees and to recognize and encourage active community involvement. The APDA is a non-profit tax-exempt 501(c)(3) organization which does not discriminate on the basis of race, color, religion, sex, national origin, age, disability, or any other characteristic. Therefore, we encourage you to ask your employer to match your wonderful charitable contributions made to the St. Louis APDA. Your voluntary support of our organization and your company’s support through a matching-gift program is most commendable and a reflection of what has been referred to as “responsible citizenship.” We consider it to be a wonderful benefit and are deeply appreciative when you request an employer match. Thanks for thinking of us, and thank your employer for making the policy to match these charitable contributions.

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4/17/10 PEEP MEETING

Richard W. Saffley
Eva Sketoe
R. Dennis Voisey
I’m torn between using a golf hole-in-one reference or a baseball analogy since we were very fortunate to have John Mozeliak, GM of the St. Louis Cardinals, as our Honorary Chairperson again this year. No matter how you slice it, our 12th Annual Nat Dubman Memorial Golf Classic was a “grand slam” and one of the best tournaments many of these golfers have ever played, in spite of the weather.

This was due in large part to our loyal sponsors: MASTERS level sponsor Benton Homebuilders Community Partnership; MAJOR level sponsor Carol House Furniture; TOURNAMENT level sponsors Aspenhome and Flexsteel Industries; BEVERAGE CART sponsors Catnapper and Montage Furniture; DRIVING RANGE sponsors The Gatesworth Communities and Howard Miller Clocks; PRACTICE GREEN sponsors Kincaid, Lane Furniture, Pulaski Furniture; and HOLE sponsors Berkline, Clayton Marcus Furniture, The Commerce Trust, Cooperative Home Care, Craftmaster Furniture, Larry & Sonya Davis, The Delmar Gardens Family, The Gatesworth Communities, Glideaway Sleep Harmony, Grey Eagle Distributors, Keith & Cindi Guller, La-Z-Boy-American Drew/Lea/Hammary, Lexington Home Brands, Nurses & Company, Riverside Furniture, Schnadig International, Serta, Universal Furniture, Shillington Box Company, Weintraub Advertising, and Zeigler Associates.

CHARITABLE CONTRIBUTIONS arrived in generous proportions from the following donors: Steve Bander, Best Chairs, Dabarco Sales Co., Bernie & Lois Frank, Patrick Hayes, Ron & Sharyn Kessler, Gail Kitis, David Link, Charles Manley, Joe Marchbein, Robert May, Jim Mednik, Frank Miskit, Steve Rachlin, Les Reiter, Rick Short, Dan Touchon, Daniel Tullmann, and Hal Wellford. There were exceptionally charitable donors raising their paddles during the FUND-A-NEED portion of our auction: Jack Strosnider, Christine & Dave Sadler, Alan Lemley, Tom Cordes, and Allison Wright Willis.

AUCTION ITEMS were donated from Amini’s Home, Rugs & Game rooms, Autohaus, Bentley Studio, BC’s Kitchen, BFC Enterprises, Bristol Seafood Grill, Carbite, Cathy Hartman Photography, Continuum, Bob Costas, Dierbergs Markets, Forest Hills Country Club (John Hayes), John Mozeliak, Panera Bread, The Pasta House Co., Christine & Dave Sadler, Sam’s Steakhouse, Seeger Toyota, St. Louis Blues, The St. Louis Brewery, St. Louis Cardinals, T.G.I. Friday’s, Addie Tompkins, Rusty Yost, Waterway Gas & Wash, Wellness by Design, Lynda & Bob Wiena, Wines for Humanity, and WineStyles.

And caps off to these special VENDORS who willingly came out of the rough and sank the putt through these in-kind donations: Alphagraphics (Bob Sanderson) for their wonderful invitations and program booklets; Paramount Apparel International (Alex Levinson) for their embroidered golf shirts; Natixis Global Associates for the sleeves of golf ball for our guests; Flemings Prime Steakhouse & Wine Bar of Frontenac for their delicious tenderloin skewers and seared tuna; Donatelli’s Bistro of Lake St. Louis for their tasty chicken spedini; Viviano’s Festa Italiano of Chesterfield for their deli sandwiches, cheese, and olives; The Ritz Carlton of St. Louis for their yummy gourmet cookies, which were all served on the course as the golfers toured from hole to hole; Lodging continued on next page
MINDS EYE INFORMATION SERVICE: BRINGING PRINTED WORDS TO LIFE

Janet Creath

Minds Eye is a free reading service for people who can no longer read due to visual or physical conditions that prevent them from seeing the printed word or holding print materials. Individuals who are diagnosed with Parkinson’s disease and who live within a 75-mile radius of St. Louis qualify to become a Minds Eye listener. Minds Eye listeners hear word-for-word readings from dozens of national and local newspapers, magazines and retail store ads in their own homes using closed-circuit radios that Minds Eye loans out at no charge. Listeners with internet access can use the service on their personal computer free of charge.


You can obtain a complete list of Minds Eye programs online at www.mindsyeyeradio.org.

In addition to recorded readings, Minds Eye broadcasts live, seven days a week, readings from the St. Louis Post Dispatch and Belleville News Democrat. Beginning with the front page, readers cover the entire paper. Each article is read, word for word, from start to finish. Names are read from the obituary listings and listeners may call Minds Eye for additional details. Listeners get an unedited, unbiased account of the news as it’s written, just as they would if they were reading each sentence themselves.

Over 11,000 men and women currently have access to a wealth of information through Minds Eye, and listeners appreciate hearing weekly grocery and pharmacy ads, as well as being able to listen to Minds Eye anytime during the day or night. Minds Eye helps listeners achieve greater self-reliance and a way to remain connected to their communities.

For more information or a listener application, call 314-241-3400, ext. 6444, or 618-394-6444.
On Saturday, June 26, the St. Louis Chapter of the APDA co-hosted a first-time event, Trash or Treasure, with the Kodner Gallery. Jon and David Kodner, trusted names in fine art appraisal, offered valuations on paintings, prints, and sculpture.

Additional professional appraisers offered valuations on rare books, sports collectibles, clocks, watches, music boxes, furniture, jewelry, coin and currency, historical documents, porcelain-ceramics-glass pieces, quilts, oriental rugs, stamps, toys and dolls. Over 140 appraisals were conducted over the course of the afternoon.

Thanks again to our fine appraisers who participated this year and to the Kodner Gallery for co-hosting and supporting this “antique road show” of sorts, benefiting the St. Louis APDA.