

MISSION

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

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

RESEARCH UPDATE

Joel Perlmutter, MD

I am delighted to provide this update for the activities at the APDA Center for Advanced Parkinson Research at Washington University. We have continued to make progress in care of patients as well as in research important for those with PD. Much of this work has been made possible by the support from the Greater St. Louis Chapter of the APDA, the National APDA, and you. I will review our personnel changes and then provide a research update. Separate articles will describe the exceptional work from Drs. Willis and Racette regarding environmental risk factor for parkinsonism, importance of clinicians in outcomes, and health care disparities in treatment. (February 2013 [LINK](#))



We are delighted to have another new fellow this year. Dr. Scott Norris started as a post-doctoral fellow on July 1, 2012. He completed his neurology residency at Washington University and had the honor of being named the Chief Resident of Neurology. He had worked with Dr. Tom Thach prior to medical school and then worked in my lab during his last year of residency on a project related to deep brain stimulation (DBS). He is focusing on learning neuroimaging methods including new MR-based methods to evaluate brain networks in people.

Dr. Samer Tabbal will be returning to Beirut, Lebanon, this next year. We will miss his outstanding clinical skills. As his first child is in his second year of life, the bond of family has drawn him home. We wish him all the best. In the interim, Dr. Mwiza Ushe will direct the DBS efforts. He has been involved with DBS for more than 10 years (including his time in my lab while a medical student).

Investigation of DBS continues to be a major area of our research activities. We continue our

studies on the effects of stimulation aimed at different parts of the subthalamic nucleus (STN). This small part of the brain is less than one-third of an inch in its greatest dimension, so this research is quite challenging. Nevertheless, we have determined which part of the STN should not be stimulated since this may cause a problem with specific mental tasks. On the other hand, we have found that stimulation in nearly any part of the STN will provide the same benefit in movement and walking. We have also found that the part of the brain’s response for this improvement in walking appears to

be at least two different networks, and that stimulation through either one may be sufficient to help. We continue to need more participants for these two-day studies. Many people have contributed effort to this work, including Drs. Kari-mi, Ushe, Norris, Tabbal, Hershey, Black, Earhart, Foster, Campbell, Videen, Dowling, and Rich; Kelly Hill (an undergraduate who is now a medical student at Washington University); and multiple staff including Johanna Hartlein, Dawn Lintzenich, Angie Wernle, Sandy Sagitto, Hugh Flores, Susan Donovan, and others. These studies, like the rest that I will describe, could not have been done without the Greater St. Louis Chapter support and our volunteer participants. These participants spend two days with us demonstrating their commitment to the cause. These studies are supported by an NIH grant to Dr. Hershey and one to me.

We also have made substantial progress on our studies of thinking problems that may occur in people with PD. In the past, we had thought that people with PD who developed thinking problems had at least a 50% chance of also hav-

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A MESSAGE FROM REBECCA DAMING, APDA ST. LOUIS BOARD PRESIDENT

Since May, I have had the pleasure of serving as president of the board of directors of the APDA St. Louis Chapter. Truly, this is an honor for me, though I feel more honored to be surrounded by such talented board members, volunteers, physicians, and staff. I am in awe of the dedication they have toward improving the quality of life for those suffering from PD.

I would like to thank Matt LaMartina for his service as past president to our chapter and all he has given and continues to give to us. The time that he devoted to the St. Louis APDA over the years has been invaluable and his guidance helped drive the organization's accomplishments. We are fortunate that he plans on continuing to support us in a leadership role in next year's golf tournament.

This year, the Board achieved several large objectives in service of our mission to ease the burden and to find a cure. In May, we created an educational DVD entitled "The Parkinson Journey." This DVD was made possible by the Fraternal Order of Eagles, who donated \$100,000 to educate their members living in rural communities about state-of-the-science PD diagnosis and treatment. Words cannot express how wonderfully it turned out. You have to see the DVD to understand how it can help patients and families relate to others and better understand PD. Please help us spread the word about this DVD with patients, caregivers, physician offices, and support groups. Please call 314-362-3299 if you are interested in obtaining a copy for yourself, your doctor, or a care provider in an assisted living facility.

In August, we opened the APDA Community Resource Center, located at 1415 Elbridge Payne, Suite 150, in

Chesterfield. The Board's goal was to provide a location accessible to the community we serve with accommodations that could comfortably support the expansion of our patient and family support groups and exercise classes as well as provide a top-notch resource library.

Much thought and time went into researching this location. The Community Resource Center Committee was led by John Basilio and Debbie Guyer and included Don Carlson, Bob Goldsticker, Tom Mackowiak, and Lynda Wiens. I thank each of you for your time and insight in selecting the

best location. The Center is open, so please visit!

We had two profitable fundraisers this year. The Nat Dubman Memorial Golf Classic was held in May at the Lake St. Louis golf course, and the 17th Annual Auction, Luncheon, and Fashion Show was held in October at the Sheraton Westport. Both events were well-attended and helped us raise much-needed funds for research. Thank you to Debbie Guyer, her staff, and the volunteers who made these events a success! In addition to offering these two fundraisers again next year, we're in the planning stages now for a Walk/Run event. If you're interested in serving on the Walk/Run Committee, please contact the APDA office at 314-362-3299. We hope you'll join us at one or all of these fun outings!

I continue to be impressed with the many achievements of the APDA St. Louis Chapter.

Together, we have accomplished much over the last year, but there is still much to do in addressing our mission. As we approach the end of the year, I ask you to please consider a donation to assist our efforts in making a difference to those experiencing PD. Thank you. ■



RESEARCH UPDATE

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ing Alzheimer's disease as the cause. Our new studies published in the last couple of months prove that everyone seen in the Movement Disorders Center with PD who had developed dementia had abnormal alpha-synuclein throughout many brain regions. Alpha-synuclein is the protein that is abnormally deposited in the motor control areas of the brain and is thought to cause the destruction of brain neurons. Dementia due to Alzheimer's disease requires two other proteins called amyloid and tau to be deposited in various brain areas. Based upon our examination of brains that have been donated to our research, we now know that some of the people with PD and dementia have abnormal amyloid but only rarely have abnormal tau—which means that Alzheimer's disease does not contribute to dementia in people with PD, at least those that come to a Movement Disorders Center.

We are continuing our studies using PET, thinking tests, MR scans, genetic markers, and spinal fluid examination to determine whether we can identify the specific causes in people while they are alive rather than waiting until after death to make the final diagnosis. We are continuing to make progress in this area. Our team for these studies includes Drs. Campbell, Foster, Cairns, Hershey, Kotzbauer, Ushe, and Norris as well as Johanna Hartlein, Joanne Markham, and Hugh Flores. This study was entirely funded by the Chapter for the first five years—the time needed to collect adequate preliminary data for an NIH grant application—and now we also have a five-year grant from NIH to continue this important work. Of course, like many of our projects, this would not be possible without our volunteers. We still need more people with PD, with or without thinking problems, and also need spouses or people without PD for comparisons. Please let us know if you would be interested in participating.

We also have made considerable progress using MRI methods to study the

activity of brain networks. These studies are done by collecting MR scans with a person just lying quietly in the scanner—with the entire process taking about one hour. We have been exploring how these so-called resting state networks change in people with PD. In fact, we have just had a paper accepted to a journal called *Brain* that describes our new findings. We found people without PD have strong connections between the striatum (that is the part of the brain that has a dopamine deficiency in PD) and several deep parts of the brain including the thalamus, brainstem, and an area called the cerebellum. These connections are substantially reduced in people with fairly advanced PD. This may help explain problems with walking, balance, and tremor. We are now in the process of determining what the status is of these and other connections before people with PD ever take any medication to make sure we sort out clearly the effects of medication on these networks. We also are using these methods in our study of cognitive problems in PD. These studies have been done by a variety of people including graduate student Carl Hacker as well as Drs. Avi Snyder, Meghan Campbell, and Susan Criswell. Drs. Kristen Pickett and Gammon Earhart also are using these techniques to investigate the brain mechanisms of how different rehabilitation strategies for helping walking in PD. In fact, Dr. Earhart just received a new five year NIH grant to continue this work. Once again, she was able to collect preliminary data with the support of the Greater St. Louis Chapter.

We have continued to make substantial progress in developing neuroimaging measures of PD severity. This is a critical area for development of treatments to slow disease progression since we must have an objective means to measure disease severity. We have published several papers about our results which have been rather surprising. First, we found that the degree of dopamine nerve cell loss needed to produce the motor manifestations of PD is much less than previously thought. We also found that the development of parkinsonism

relates closely to the degree of loss of the cell bodies rather than the end processes of these nerve cells. The practical importance of this seemingly small observation is that most people have been making measurement of PD severity in the wrong part of the brain—causing spurious results. And, now we know the cause of this problem. We also found that PET-based measures of these nerve cells are very good at detecting small changes, especially early in the condition, but again rather surprisingly, as the disease progresses, the PET measures no longer accurately reflect the degree of severity of PD. (As an aside, this is true whether the measurements are made with PET or the more commonly used SPECT scanner that is now ordered by some for evaluating people with PD. We do not use this method since we have not found it useful for clinical care of patients.) Fortunately, we now have found that aiming the PET at a different part of the brain can provide the needed measures of PD severity. We are in the process of submitting a manuscript describing this new finding. This work has primarily been done by Drs. Morvarid Karimi, LinLin Tian, Samer Tabbal, Steve Moerlein, Josh Shimony, and Avi Snyder as well as Chris Brown, who left us to start an MD/PhD program at the University of Kentucky. We also have been fortunate to have received another five year grant from NIH to support this ongoing research. The preliminary data for these studies were supported by the Greater St. Louis Chapter.

We have made progress on developing entirely new methods to measure progression of PD. Rather than focusing on the dopamine nerve cell, as noted in the above paragraph, we are working on trying to measure the amount of alpha-synuclein in the brain. Recall that this is protein that is abnormally deposited in the brain cells of people with PD. The idea is that measures of this protein may determine even early stages of PD and permit treatment to begin earlier and hopefully prevent development of

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symptoms. At least, that is the long-term goal. We have now identified a group of chemicals that may be suitable for making these types of measures using PET. This work has been driven primarily by Drs. Will Tu, Paul Kotzbauer, Bob Mach, and Jinbin Xu. We are also involved in a consortium with several other research groups across the country on this particular project that is supported by the Michael J. Fox Foundation.

Finally, everyone is anxiously waiting for this last part of my article. What has been the progress on our long-term study of a new drug that may slow the progression of PD? These studies have been done in collaboration with Dr. Laura Dugan at the University of California in San Diego. She had discovered this new drug called carboxyfullerene. This past year we completed the research studies and assembled the data and sent the data to Dr. Dugan for statistical

analysis. We have remained blinded to which subjects have been treated with the real drug and which with the placebo. This permits us to recheck data and remain scientific blinded—that way there can be no inadvertent bias in the data analysis. In any event, Dr. Dugan sent the data coded as Group A and Group B to a statistician. This statistician did not know whether Group A or Group B had received the real drug. The analysis was rather dramatic; one group was much better than the other. I still do not know which subjects were in which group, but I do know that the positive group was the real drug. At this point, we want to recheck one set of measurements—which we can do since we still are blinded to drug assignment for individual subjects. The main problem is that this reanalysis is very time consuming, taking several more months. This is far too important not to be certain of the results. So please try to remain patient. There are no short cuts in the business of research. This work was initially

supported by the Chapter and more recently has been supported by two separate NIH grants.

Once again, I have just hit some of the highlights from our research team. And, this is truly a team of investigators, staff, volunteers, and supporters. Drs. Racette, Willis, and Criswell together with some of the same team as well as others have made truly amazing progress as well. They will report some of their findings in separate articles. They focus primarily on environmental causes of PD and parkinsonism, the epidemiology of PD, and health-care disparities. This type of important work has potential impact on health-care policy in this country. Their work also has been generously supported by the Greater St. Louis Chapter.

Again, let me express my heartfelt thanks to the volunteers and caregivers that participate in our research. Without the volunteers, there would be no research. Of course, the continued financial support of the Greater St. Louis Chapter of the APDA and all of the donors make this work possible. If we have an idea on how to cure PD, we cannot go to NIH and ask for support until we collect preliminary data supporting our new ideas. That is where the Chapter has been particularly effective—providing seed money for new ideas. Many of these have now turned into major research studies funded by the National Institutes of Health. Together, we will continue this aggressive fight against PD.

Of course, no year-end summary of our research efforts can be complete without naming two key people. First, let me thank Debbie Guyer for all of her tireless efforts for the Chapter and our APDA Center for Advanced Parkinson Research. She makes a difference. And, I also want you to know that Susan Donovan, my administrative assistant for our research center, coordinates all of our research efforts including coordinating research participants across many studies—more than I can count. Without her help, we would be far less productive. She also deserves our appreciation. ■

TAKING YOUR PARKINSON MEDICATION—HOW TO BEST SCHEDULE DOSING

Morvarid Karimi, MD, Assistant Professor in Neurology, Washington University School of Medicine, Movement Disorders Section

You might notice that the pharmacy information accompanying your carbidopa/levodopa instructs you to take it on an empty stomach. They usually recommend taking it 30 minutes prior to or at least an hour after your meals. The idea is that the protein in your food reduces the absorption of levodopa. A three to four times a day medication intake during the day is already challenging. Following these strict recommendations can make compliance more difficult and cause additional worries about how to plan your meals and social activities around the medication intake. In addition, some patients are more prone to nausea or upset stomach if they take carbidopa/levodopa without food. Is it really worth the trouble?

Here is my approach: If you don't have dose failure (you take medication and nothing happens) or delay in onset of benefit (it takes longer than 30-45 minutes to be effective) just disregard what the pharmacy tells you! What matters most is (1) a consistent pattern in food and medication intake resulting in a predictable response to the Parkinson medication, and (2) that your physician can use to make further adjustments to control symptoms.

Finally, three times a day dosing does not mean you should take it every eight hours to cover 24 hours a day. You should divide the doses such that it covers your awake time. There is no need to wake yourself up from a sleep to take a dose of medication (unless so directed from your physician). So taking it around mealtimes is roughly a good start when beginning Parkinson medications. ■

SEEKING UNTREATED IDIOPATHIC PARKINSON DISEASE (IPD) PATIENTS FOR A NEW BRAIN IMAGING STUDY

Joel Perlmutter, MD, and Meghan Campbell, PhD

My colleagues and I at Washington University School of Medicine are undertaking a new study for people with IPD who have *never* been medically treated for their Parkinson Disease.

We are trying to determine if there are differences in the way the brain works in people with IPD who have never been treated for their IPD, people who have been chronically treated for their IPD, and normal control subjects with no IPD or other neurological problems. We want to study subjects before ever taking their very first dose of carbidopa/levodopa. Carbidopa/Levodopa (brand name Sinemet) is the primary medicine used to treat IPD and has been FDA approved for 40+ years for the treatment of IPD.

For this study, subjects come in for three separate visits. The first visit includes a free screening with neurological exam and history to confirm people

have IPD and that they are eligible for the study. That visit will last about one hour. The other two visits last about four hours each and are between one and two weeks apart. During each visit, subjects



undergo the following: memory and thinking games (about one hour per visit); a magnetic resonance imaging (MRI) scan (about one hour); two blood draws per visit (a small needle inserted into a

vein in your arm); and administration of carbidopa and administration of levodopa OR administration of a placebo (sugar pill). One day subjects will get levodopa, and one day subjects will get a sugar pill. An MRI machine is a large tube that makes loud noises while taking pictures of subject's brain structures and also looks at blood flow in the brain, which gives us important clues about brain function. Subjects will be reimbursed a total of \$200 if they complete the study and will be given lunch on both days. There is no cost to subjects or to

their insurance companies for any study procedures. Exclusions to the study would include having a "Parkinson Plus disorder" such as Corticobasal Ganglionic Degeneration (CBD or CBGD), Progressive Supranuclear Palsy (PSP), Multiple Systems Atrophy (MSA), or vascular parkinsonism (parkinsonism caused by small strokes); other neurological conditions such as a history of stroke, seizures, brain tumors or lesions, brain surgery, or traumatic brain injury); major psychiatric problems like suicidal depression, schizophrenia, or bipolar disorder; other major medical problems such as current cancer or end-stage organ failure; claustrophobia; or inability to have an MRI due to metal in the body (while most metal is okay, some metal excludes patients such as pacemakers or aneurysm clips).

If you have never taken medicine for your IPD and are interested in this study, please call my coordinator/nurse practitioner, Johanna Hartlein, at 314-362-0420 or email at johanna@wustl.edu. ■

DEAR PATIENTS, FAMILY MEMBERS, AND FRIENDS,

It is with a heavy heart that I'm writing this letter to let you know that the time has come for me to move back to Lebanon at the end of this year. The main reason for my decision is my family, aside from the fact that there are practically no movement disorder specialists for the 4 million people in Lebanon. I am leaving my current patients in the capable hands of several of our Movement Disorder physicians.

Although I had committed (since coming to the USA 19 years ago) to return one day to Lebanon, my decision to leave Washington University in St Louis was much more difficult than I had expected. This is because I am leaving a place where I bonded with colleagues and patients that have become family over the last nine years and because I know that I will never find a better team of doctors, researchers, fellows, nurses, and supporting staff anywhere in the world. This team is the secret of our center to providing excellent patient care, teaching, and research. Yes, I know that I am leaving the best job that I can imagine. My only consolation is that moving back to Lebanon may be the better choice for my immediate family, including my 18-month old son and my aging parents.

Peace,
Samer Tabbal, MD

CAREGIVERS SURVEYED

THE EMOTIONS WE EXPERIENCE

Patsy Ponder Dalton, Columbia/Lake Ozark Support Group Facilitator
Speech delivered at MU Parkinson Conference on August 18, 2012

Let's start things off by thanking these caregivers who are truly our partners in this Parkinson's journey. A couple of weeks ago I was shopping and I kept hearing this rendition of a 1968 Beatle's lyric, "Nothin's gonna change my world," and I thought, "Really, nothin's gonna change my world? Then you haven't met Parkinson's disease." I think I can safely say that the Parkinson's diagnosis has changed the lives of every one of us in this room. Those who have Parkinson's are the true heroes today because you deal with the constant changes in your bodies and minds, and how you appear to others. And for the caregiver, the partner in life, everything was altered with those simple words, "You have Parkinson's."

I asked caregivers in our support groups to discuss the range of emotions they deal with in their caregiver lives. I hope by talking about these, it will give all of us a better understanding of the caregiver who is there day in and day out, dealing with some of the same challenges as the person who has Parkinson's disease.

We all know that Parkinson's is a different disease for each person. It progresses at different rates for each person. No one treatment works for all, and there is still no "cure" for Parkinson's. We also remember that we are all at different stages of PD. Some are newly diagnosed and reeling with information overload, most of which you really don't want to hear. Some have been diagnosed for years but are still carrying on a pretty "normal" life. Some are feeling the physical, emotional, and cognitive impact now and things are changing more rapidly, but you're here at this conference. Then we have those we all know and love who are no longer able to get out much, and we miss them today. And, finally, there are those

we have lost over the years, and we still grieve their loss.

Eighteen years ago after hearing the Parkinson's diagnosis David and I got in the car, looked at each other and said, "Did you hear what I heard?" And from that time forward we added a third presence to our marriage. Just as the doctor predicted, the first five years after diagnosis, life wasn't too different. From five to 10 years it got serious and David took disability and retired at 51. In these past eight years, Parkinson's calls the shots in one way or another almost every day. And my emotions have intensified every year. I call myself the meanest woman in Missouri some days. I asked the caregivers in our support groups whether I was the only one who felt this way, and I found out I wasn't alone—still probably the meanest—but not alone.

The caregivers ranked FRUSTRATION as their No. 1 emotion experienced in their role as caregiver. Frustration consists of a number of emotions/feelings, but generally it is that feeling of having no control in your life anymore. Each day can be so different. The pills don't kick in the same way some days, the heat, unexpected company, too much activity that day—they all contribute. Then there are those dreaded discussions about life-changing decisions like giving up driving. Maybe it's time for the caregiver to take over the driving (certainly not a popular subject, but one that every family has to face). Impatience and patience came up in our discussions. We all try to be patient (after all, it is a virtue, right?), but no human being can be patient all the time, especially when things are in a constant state of transition: add an hour to get ready for church, take more time and be safe when you get in and out of the car, don't rush or turn too fast, do as much as you can when your pills are working

Spotlight on Caregivers

NOVEMBER IS NATIONAL CAREGIVERS MONTH!

Caregivers provide all those affected by PD selfless dedication, support, and hope as individuals face this chronic, progressive disease. Throughout the month of November, please take time to honor and express gratitude to the caregivers who are so critical to protecting and enhancing the quality of life of individuals who live every day with Parkinson Disease.

Join us in our celebration of caregivers during National Caregivers Month by sending a tribute honoring and thanking the caregivers you know and appreciate. This tribute will not only acknowledge and honor their personal contributions, but will also help the APDA Greater St. Louis Chapter continue to provide a wide array of resources for caregivers.

and rest when they aren't. How many of you can report hearing these comments at your house: "Did you take your pills? You're 30 minutes late and you know what that means." "Please, don't get up on that ladder, let me do it." "Are you almost ready?" "Are you almost ready?" "What, did you say something? I can't hear you." "Have you got your cane? I almost killed myself tripping over it this morning." "Please, drink more water. It will make you feel so much better in this heat." "Hurry up, we're going to be late. Take your time, don't rush." And, of course, the list goes on and on. You have to laugh sometimes. Humor gets us through all this, as David would say. That's the only way to keep things in the proper perspective.

But feeling like a nag or playing the parent role is a frustration. Caregivers worry that it will change their treasured

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relationships. Trying to protect our loved ones from a fall is a big concern because we all know that a bad fall can change everything, fast. Yet, we all want to be independent and do things for ourselves. (People with Parkinson's are encouraged to be independent for as long as possible.) Some caregivers reported feeling selfish in even mentioning this, but they now know that some of the plans they had for a life together will never happen. Disappointment in not being able to travel or buy that place in the country was mentioned by caregivers. Although they tried not to give in to it, sometimes there was that question, "Why did this happen to us?" This is when caregivers and the person with Parkinson's need to have open, honest, heartfelt discussions where all of these frustrations can be shared and dealt with. We just can't put off talking and communicating our feelings to one another.

The second most mentioned caregiver emotion was FEAR. Some of the comments were: What if I can't do this? Can I really take on these responsibilities? I've never had to count pills before or pay the bills or be the one to remember what the doctor said. Sometimes I can't even remember to take my own pills, how can I be sure she takes hers every four hours? What if he falls? I can't get him up, I'm not strong enough.

Can we handle staying home all the time and not going places? When should I quit my job and stay home? What if I get sick and can't do any of this? Who's going to help us? Will we need to move to assisted living soon? And the greatest fear, we all admit, is "What if I lose her? How can I live without him?" All of those questions place a huge load on a caregiver. We all decided that the old adage, "Live one day at a time," should be our mantra. That's supposed to guarantee good mental health. Many of our worries never really materialize, and if they do, they usually don't happen all at once. Remember that Parkinson's is a "progressive" disease, so most of the time

we can get used to one step before we move to the next one. Sometimes we just need to balance our fears with practicality. Maybe it's time to give up the boat at the lake and buy an occasional ticket on the big cruise boat with the money you save. A smaller house or apartment might be just the thing: easier to take care of and less to worry about. Let's try to balance activities and engagement with the rest of the world with some good rest for both the caregiver and the person with Parkinson's. We may need to cut back a little from the way we used to do things. Be social but schedule the quiet time too. Caregivers must take



care of themselves. On airplanes you are instructed to put the oxygen mask on yourself first and then help others. So strap on that oxygen mask. Get enough sleep, exercise, see friends and family, and maintain social contacts any way you can. Consider respite care so you get a break. **YOU NEED SOME TIME ALONE.** Start with an hour a day, move to a day a week and hope for a weekend every few months. Try to include your family and close friends in discussions about handling your fears. Consider joining a support group. Ask for help. Those who try to do it all alone will find their own health goes downhill. **ASK FOR HELP AND ACCEPT IT WHEN OFFERED.** That is so hard for most of us to do.

And here's an added responsibility... help educate those around you about Parkinson's. The more people know about the disease the more they can help. I know I make this sound easy, and believe me, I know it's not. It's

human nature to worry, and I'm an accomplished worrier myself. But it is a wasted emotion and will only bring us down. Often, many of us turn to a higher power for strength. At times you may need to seek professional help with emotional counseling or financial counseling. And, of course, you need to see your own doctor regularly.

Now, throw in a little ANGER, and we've got the toughest caregiver emotions covered. Most of us admit to being mad, most often at ourselves. Some reported colorful language wafting through the air at times. But we're dealing with something that is tough for the person with Parkinson's and for the caregiver. We don't want Parkinson's in our family. What if our children also get it? Changes are occurring every day. Some days, hours and minutes are good, some not so good. Sometimes a bad hour is followed by a good one. Maybe we see cognitive changes, or dementia, or hallucinations. This is when we need to work closely with our doctors with solid

details and a list. Physicians are depending more and more on caregivers to help them diagnose stages in Parkinson's and to deal with those stages. We need to report falls, recent changes and problems with pills. We're all only human. We can only handle so much. You may not get a break; you may be exhausted. Our loved one may not be the same person even though the change has been gradual. We are in a long grieving process as the Parkinson's progresses. And sometimes the anger just wells up.

ASK FOR HELP. Find someone to talk to. Look for something positive to do together or separately. Maybe we can't live our lives the way we used to, but we can find our form of therapy—gardening, games, phoning a good friend, planning, and moving into a more suitable home. Do something for yourself, something you like to do.

One last beautiful grouping of emo-

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CAREGIVERS SURVEYED

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tions to discuss: LOVE, THANKFULNESS, APPRECIATION, AND JOY. We love you. Caregivers are just that because of their strong love and admiration for the person you are. They feel helpless sometimes because they can't take the Parkinson's away. They admire you because you keep on going. You don't give up. And none of us are the people we once were. So what! We are still ourselves. It breaks our hearts that you can't live the life you may have planned. But we have such compassion for you and want to be there to help. It's our job, a job we take seriously—to care for you. And we know that you would do the same for us. Here's the way I look at it. David and I have had 18 years together since his diagnosis in 1994. Many of our friends have lost their loved ones suddenly. We have been able to share

the changes in our lives gradually and are now in the process of simplifying everything—as we should be. We are learning our limits. We are trying to blend positive thinking with practical thinking. That's a good idea for anyone. Caregivers reported feeling uncomfortable with accolades and words like angel, saint, heroic. What they want instead is someone who really listens and understands, pitches in from time to time, and treats their loved one with the admiration and respect they deserve. There are times we get downright protective of our “person with Parkinson's,” especially if they are not being treated respectfully.

I'm closing today with a sales pitch for support groups. I believe that support groups can make your life better. None of us are alone, and we shouldn't be. At these meetings we have guest speakers, as well as separate times for caregivers and people with Parkinson's to share

tips, experiences, and emotions. We allow time to vent frustrations. You might have to travel some to find a group, but you'll find it's worth it once a month.

Caregivers' stress is, unfortunately, a part of life when caring for someone with a chronic illness such as PD especially over an extended period of time. Have the courage to share your feelings as I have done with you today. Make a short list of specific tasks that would help you take better care of your loved one and get some much-needed respite.

Want to learn more? Check out the Caregiver Resources—Parkinson Caregiving 101 found on the National Parkinson Foundation website (at www.parkinson.org/Caregivers/Caring-for-the-caregiver). It will help you learn to navigate the various challenges of caring for someone with PD, what to expect at different stages, and how to recognize signs of caregiver stress. ■

SUPPORT GROUP FOR ADULT CHILDREN OF PARENTS WITH PD (ACOP)

MEETING ON WEDNESDAY, NOVEMBER 14, AT 6:00 PM

A *Bittersweet Season: Caring for Our Aging Parents...and Ourselves* is the title of a book by N.Y. Times blogger and author, Jane Gross, a national expert on issues related to caring for aging loved ones. She was recently in St. Louis as a guest speaker at a seminar sponsored by ElderLink. In her prologue, she writes, “I can tell you, from experience, that if you take charge too soon, you will patronize and humiliate your parents, but if you step in too late, their manageable problems will have turned unmanageable.” She gives advice for determining when the right time has arrived. “I can tell you that most bad decisions are made in the heat of a crisis, when alarm and ignorance collide. I can tell you that it is usually possible to slow things down—that you can refuse to be rushed by doctors, discharge planners, and others who have different agendas than yours—and that

you should demand time to consider alternatives calmly and deliberately.” She goes on to say, “I can tell you that it takes a while to learn that some decisions are far more important than others; some things are actually out of your hands and some not. What is vital, and well within your control, is being present in a consoling way and being respectful enough to bear witness to the inevitable.”

We tend to not want to think about our parents getting older. The elder care system is extremely complex, and while there are lots of good resources out there, most people don't have any idea where to begin. We think we have found a way by resurrecting a support group for adult children of parents with PD. We will meet on Wednesday, November 14, from 6:00 pm–7:00 pm at the new APDA Community Resource Center at 1415 Elbridge Payne, Suite

150, in Chesterfield, MO. The purpose of this group will be to make ourselves familiar with resources available on Parkinson disease and elder care. We hope you will join us for this important planning session. Participants will determine the best meeting date and time for our sessions in 2013, as well as generate a list of pertinent topics from emotional, familial, financial, and physical stress to navigating the assisted and skilled living maze. Together we will find coping mechanisms for caregiving and ways to enrich the remaining lives of our parents.

If you have an adult child who may be interested in attending, or are an adult child of a parent with Parkinson disease, this group is for you! It will give us an opportunity to benefit from the knowledge of a support group while preparing ourselves for caring for our aging parents...and ourselves. ■

FOR PAW PAW WITH LOVE

Erin Guyer Schreiber and Debbie Dalin Guyer

Because November is the month set aside to recognize special caregivers, and because as many of you may already know, I lost my father on July 13, I wanted to take the liberty as editor of this newsletter to remember my father, Dr. Harry Dalin, a devoted caregiver to my mom who we lost in February, 2011. I felt so proud to hear our daughter, Erin, give a eulogy at my father's memorial service that touched so many friends and family, and with Erin's permission, I wanted to share her words with you.

Paw Paw,

I think it is so hard to believe you are gone because of how full of life you have always been. This past week you were on your Kindle, using Skype and able to catch up with family on Facebook. Though you kept more current with technology than those half your age, your modern-ness belied someone very rooted in tradition. You were always a family man, married 66 years and separated only by death. You raised four children, traveling with them around the country and recording endless hours of video and photos that adorn your walls and bookshelves. You believed in hard work and perfecting your craft, always seeking out the latest information and technology, never settling for second best. Whether it was being a husband, a father, a dentist, a volunteer, or an athlete, you worked tirelessly to be the best. A life-long student, you studied bridge, took computer classes, and were always knowledgeable about politics, education, the market, sports, and technology. You could strike up a conversation with ease and never slowed down.

You were tireless as a husband, insisting on providing the best care for Maw Maw yourself, not content to leave a moment to chance. You put all four of your children through graduate school because it was so important to you, and paved the way for all ten of your grandchildren, too. You made sure we were

exposed to the arts and that we knew what was really in McDonalds French fries. You took each of us to Disney World at the age of four, just you and Maw Maw, and we made unforgettable memories together. It may be a "small world," Paw Paw, but you made it bigger. Your call was the first on our birth-



days, with you and Maw Maw singing "Happy Birthday" in unison. When we had trouble connecting, you left the message on my voicemail at work, and I never erased it.

You often spoke about how fortunate you felt to have met and known all ten of your grandchildren and your six great-grandchildren, noting that your own father didn't live to meet any of his grandchildren. But the gift wasn't just yours, Paw Paw...we were blessed to have you in our lives and to know you. To have you immersed in our lives and truly know us and impart your wisdom and your love is such an amazing gift. One of the books that had a profound impact on you was *Tuesdays with Morrie*. You read it many times and kept a flagged version on the shelf in your study. You quoted from it when talking about love and enduring relationships in the note you wrote me when I got married. But most striking to me is the

quote from the book you had taped in multiple places in your study, the one you had engraved on Maw Maw's headstone last year: "Death ends a life, not a relationship." And though you leave me with so many memories and so many life lessons, that's what stands out, Paw Paw. You built the kind of relationship

with all of us that withstands death, one that will endure as we age, as we contemplate our lives and as we make decisions about our futures. Though you left us unexpectedly, you didn't leave your thoughts unsaid or your values unclear. We knew exactly where you stood and what you hoped we might embrace, and you

did so with love. From wanting us to achieve a high level of education, to making financial decisions that would be wise long term, to recording and enjoying special moments with family... you left nothing unsaid. There is no questioning who you were or what you valued or what you loved, and family was at the top of that list. You traveled to many places in the world with Maw Maw, but your walls are covered in family photos, homemade artwork, and mementoes from each of your grandchildren. You were always interested in what we were doing in our professional lives, what our new interests were, and very often had an article to recommend or a news story you had seen recently that related to an interest of ours.

It is so clear that each of us carries a piece of your interests in what we ourselves love, be it current events, technol-

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FOR PAW PAW

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ogy, musicals, biographical books, investing, healthful food, and fitness...but perhaps most universally is our collective love of family. We share something that makes conversation and connection flow effortlessly, despite distance and time, and to have our grandparents at the center of that legacy is something we each bring to our lives, our families, and our futures. We will think of you when we look through the Dalin family calendar each year, and realize what you and Maw Maw began together is now 30 people strong and full of love. We will think of you when we celebrate anniversaries for the example you set of a long and dedicated and deeply loving relationship.

One phrase that you often used if you needed a moment was “wait awhile”...

if one of us was running ahead or you needed to get something... “Wait awhile!” you would call out. Paw Paw, we wish you had been able to “wait awhile” longer, but there’s not a thing you left undone or unsaid, and we are so appreciative of all the ways you will continue to be in our lives.

Yours,
Erin

Dad,

Following Mom’s diagnosis with Parkinson’s, you retired from your thriving dental practice to become a premier caregiver whose goal was to keep mom alive, which you did for so many years. You used to tell me that you knew the value of daily exercise long before our literature published those same findings along with the belief that it would slow down the pro-

gression of this disease. We marveled at the fact that when we were growing up, you couldn’t even find a fork in the kitchen, but when Mom had to finally relinquish cooking and cleaning duties in later years, you took cooking classes to learn how to prepare meals and introduced us to the latest and greatest cleaning products that we use today because of you. You “reinvented yourself” because no other caregiver could attain your high standards or love Mom as much as you did. Death ends a life, not a relationship, and we honor you for your skill in providing care for Mom for so many years. We miss you both and remember you every single day.

Always,
Debbie ■

BEAT THE FREEZE IN PARKINSON DISEASE

“When I “freeze,” I feel like my feet are glued to the ground! It’s frustrating and scary, especially if I am in a crowded place or crossing a parking lot or road. And sometimes my words and thoughts get frozen, too.”

Adrienne, 72, person with Parkinson’s.

About one third of people with Parkinson disease experience freezing episodes. Freezing episodes are sudden, short, transient blocks of movement that occur primarily with initiating walking, turning, navigating through narrow spaces or approaching obstacles. Freezing can last just a few seconds or up to several minutes. Freezing can limit household and community mobility, increase risk of falling and contributes to reduced socialization and quality of life.

Used with permission from:

Terry Ellis, PhD, PT, NCS, Director

Tami DeAngelis, PT, GCS, Coordinator

APDA National Rehab Resource Center at Boston University

and Diane Church, Editor of The Parkinson Companion ■

TEN TIPS TO PUT THE FREEZE ON FREEZING!

- 1 Try another movement:** raise an arm, touch your head, point to the ceiling; then re-start.
- 2 Change direction:** if you can’t move forward, try stepping sideways and then go forward.
- 3 Carry a laser pointer** in your pocket; when you freeze – shine the laser in front of your foot and step on the light – this cue can help you re-start.
- 4 Visualize** an object on the ground in front of you and try to step over it.
- 5 Wear a metronome** on your belt or carry a small one in your pocket; turn it on and the external beat can help you re-start.
- 6 Try humming a song** and time your re-start with the beat of the music.
- 7 Count “1-2-3-go”** and then step forward.
- 8 Shift weight** side to side to help initiate taking a step.
- 9 March in place** a few times and then step forward.
- 10 Don’t fight the freeze by trying harder to step forward** – shift your attention from moving the legs to moving the arms – then resume walking forward.



MISSOURI SUPPORT GROUP CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

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

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Ballwin	St. Louis	Meramec Bluffs Care Center 40 Meramec Trails Dr., Activities Rm.	4th Tuesday	1:30 PM	Gayle Truesdell	636-923-2364
Cape Girardeau	Cape Girardeau	Cape Girardeau Public Library 711 N Clark Street Oscar Hirsch Room	3rd Monday	6:00 PM	Desma Reno, RN, MSN	573-651-2939
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	1st Tuesday	10:30 AM	Mary Buck Lynda Wiens	636-532-6504 314-540-2662
Chesterfield	St. Louis	For Caregivers Only APDA Community Resource Center 1415 Elbridge Payne, Suite 150	2nd Monday	11:00 AM	Dee Jay Hubbard	314-362-3299
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	Young Onset Living and Working With PD Missouri Baptist Medical Center 3015 N. Ballas, Bldg. D, Conf. Rm. 6	3rd Tuesday	6:30 PM	Britt-Marie Schiller, PhD Rich Hofmann	314-754-3256 314-369-2624
Festus/Crystal City	Jefferson	Disability Resource Association 420 B S. Truman Blvd.	3rd Tuesday	1:00 PM	Penny Roth	636-931-7696 ext. 129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Melissa McGuire Nancy Robb	314-355-6100 314-869-5296
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Wednesday	3:00 PM	Jennifer Urich, PT	573-632-5440
Joplin	Jasper	The Alliance of Southwest Missouri 2914 East 32nd Street, Suite 102	Mondays	2:00 PM	Nancy Dunaway	417-623-5560
Kirkwood	St. Louis	Kirkwood United Methodist Church 201 W. Adams, Room 201	4th Tuesday	7:15 PM	Terri Hosto, MSW, LCSW	314-286-2418
Ladue	St. Louis	The Gatesworth 1 McKnight Place	2nd Wednesday	1:00 PM	Maureen Neusel, BSW	314-372-2369
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	3rd Thursday	Noon	Patsy Dalton	573-964-6534 573-434-4569
Rolla	Phelps	Rolla Apartments 1101 McCutchen	4th Thursday	2:30 PM	Hayley Wassilak Tyler Kiersz	573-201-7300
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider	314-846-5919
Springfield	Greene	Park Crest Baptist Church 816 W. Republic Road	Last Thursday	11:00 AM	Kay Meyer	417-350-1665
St. Peters	St. Charles	Spencer Road Library 427 Spencer Road, Room 259	1st Tuesday	1:00 PM	Sherrie Rieves Ann Ritter, RN	636-926-3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem.Hosp. Education Conference Room Hwy. 61 & 32 Intersection	2nd Wednesday	10:00 AM	Jean Griffard, RN	573-543-2162
Washington	Franklin	Washington Public Library 410 Lafayette Avenue	2nd Monday	6:30 PM	Carol Weber	314-713-4820
Webster Groves	St. Louis	Bethesda Institute 8175 Big Bend, Blvd., Suite 210	Last Friday	10:30 AM	Laurel Willis, BSW	314-373-7036



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

MAKE A DIFFERENCE

Whether you are an individual or a corporation/business, contributing to the Greater St. Louis Chapter of the APDA ensures that we can continue to provide programs and services for people with Parkinson disease in the Greater St. Louis area and fund critically important research being conducted to find causes and a cure for Parkinson Disease. It is a gift that truly benefits those in need.

Financially, there are a number of ways to contribute:

- **Donate** via regular mail, phone call, or online (www.stlapda.org), honoring a special occasion or memory of someone special or “just because.”
- **Contribute** via “recurring donations” or pledges made on a regular basis. You can have contributions automatically made using a credit card kept secure on file or through your banking institution.
- **Enroll** in our recently established “Optimism 500 Fund,” which offers you the opportunity to regularly donate throughout the year, targeting an amount of \$500 or more for each calendar year. You will be recognized in our newsletter and receive a tulip pin. Mention the Optimism 500 Fund on your donation form.
- **Ask your company** if it has a Matching Gift program, and complete your portion of the form to initiate a matching gift. It is always gratefully acknowledged and much appreciated.
- **Consider a gift of stock** and planned gifts. Name the Greater St. Louis Chapter of the APDA in your will. Consult with your attorney, accountant, or financial advisor.

Contact the Greater St. Louis APDA Center for further information: via phone: 314-362-3299; the website: www.stlapda.org, or by email: guyerd@neuro.wustl.edu. Please let us know if you are interested in learning more about ways to integrate your financial and philanthropic goals. All donations, big or small, make a difference. ■



EXERCISE CLASSES

Our Exercise Classes meet once a week or otherwise as noted.

Information that has changed since the last **LiNK** appears in **bold face**.

Attend one class per week at no charge, or, for \$20/month, attend as many classes as you want.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Clayton	St. Louis	The Center of Clayton 50 Gay Ave., Mind/Body Room	Wednesday & Friday	2:00 PM	Mike Scheller, PTA	314-289-4202
Chesterfield	St. Louis	St. Luke's Hospital 232 S. Woods Mill Rd.	Tuesday	11:00 AM	Patty Seeling, PT	314-205-6934
Chesterfield	St. Louis	Gardenview Chesterfield 1025 Chesterfield Pointe Parkway	Thursday	2:30 PM	Faye Bienstock, PT	636-537-3333 ext. 204
Chesterfield	St. Louis	Tai Chi APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Wednesday	10:00 AM	Craig Miller	314-362-3299
Chesterfield	St. Louis	APDA Community Resource Center 1415 Elbridge Payne, Suite 150	Monday	1:00 PM	Susan Mayer, MHSPT	314-362-3299
Creve Coeur	St. Louis	Aquatic Exercise Rainbow Village 1240 Dautel Lane	Summer session July 9-Sept. 14 Fall session Oct. 1-Dec. 7	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 Healthwise Center 6 Jungermann Circle	Every Tuesday except 1st Tuesday	11:00 AM	Holly Evans, COTA	636-916-9650
St. Peters	St. Charles	Aquatic Exercise St. Charles YMCA 3900 Shady Springs Ln.	Summer session July 9-Sept. 14 Fall session Oct. 1-Dec. 7	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

TANGO UPDATE: NEW OPPORTUNITIES IN 2013 AND BEYOND

Our weekly tango classes will draw to a close in December 2012. We are grateful for the loyal participants who have danced with us this year at the Center of Clayton. Thank you for your dedication and commitment to dancing your way to better health. We also owe a special thanks to our instructors, Robin Girard and Maya Matheis, for their outstanding teaching over the past year.

Our data continue to suggest that tango is an effective tool in the management of PD. Our most recent studies suggest that continued participation in tango may not only improve disease severity, balance, and walking but may also enhance participation in other life activities. As we move into 2013, we will launch a new study to determine how tango and other types of exercise may change brain function. As part of this study, we will offer tango classes, treadmill training classes, and stretching classes on a quarterly basis throughout 2013 and beyond.

If you are interested in learning more, please contact Ryan Duncan, PT, DPT at 314-286-1478 or Gammon Earhart, PhD, PT at (314)286-1425. ■

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.

HONORING

The 55th anniversary of M/M Laurence Alton
Penny Kodner

The special birthday of Bill Bruchhauser
The Bruchhauser Family

The special birthday of Rebecca Bruchhauser
The Bruchhauser Family

The 50th anniversary of Ralph and Sandy Buescher
Harold & Beverly Buescher

The birth of Grant Michael Daming
Debbie Guyer
Jack Strosnider
Robert & Lynda Wiens

Celeste Dillon
Jeanne Armistead
W. Earline Hayes
Michelle Ingerson
Deborah Wendler

The 90th birthday of Verne Erdman
Jan & Bill Erdman

Dr. James Goldring's research
Glenn & Anna Branson

The 60th birthday of Karl Guyer
Phillip & Susan Schreiber

The special birthday of Ralph Herzmark
Ralph Goldsticker

The special birthday of Hubert
Jerry & Beverly Silverman

Mark Kodner
Maxine & Roark Weil

The 75th birthday of Penny Kodner
Marilyn & Larry Alton
Maureen & Bob Greenberg
Virginia Haigler & Milton Fujita
Dr. Jules & Renee Hartstein
Lynn Pollak
Marlene & Bob Wolff

The marriage of Joe and Elissa Marchbein
Robert & Lynda Wiens

The special birthday of Kenneth W. Mihill
Doris Mihill

Dr. Joel Perlmutter's research
Glenn & Anna Branson

Nancy Potter
Paul & Carol Hatfield

Betty Rakestraw
Shelly & Sandra Sabath

The special birthday of Phyllis Ross
Anthony Berens
Robert & Doris Ebersole
Norm Ross

The special birthday of Kenneth Sandler
Gertrude Hulbert

The special anniversary of Sylvan & Ruth Sandler
Gertrude Hulbert

Terri Taylor
Nancy Mednik

David Vermillion
Mike & Jammie Anderson & family
Jennings Beardstown
Alison Behymer
Jeni Behymer
Chelsea Bigley
Kirk & Porsche Briggs
Erica & Brenton Dorsey
Griggsville/Pittsfield
Veterinary Clinic
Jessica & Joe Ham & family
Doug Hess
Ryan & Ashley Jackson
AJ & Kourtney Kassing & family
Aaron & Duskee Kassing & Sadee
Bob & Carolyn Kassing
Sean & Amanda Ketcham & family
Adam Llewellyn
Andrew Llewellyn
Bill & Lora Llewellyn
Cody Llewellyn
Jared Nuessen
Patty Parn
Dan Perry
Casey & Denim Perry
Rusty Perry
Jeremy & Leah Pruden
Mike Pruden
Alex Sheppard
Wil & Brenda Sheppard
Scott & Shannon Smith & family
Butch & Dee Sorrells
Jason & Jenny Sorrells & family
Josh & Larissa Sorrells & family
Tom & Monica Sorrells
Dana & Diane Stevens
Debbie Still
Fred & Betty Still
Janet Still

Kim Still
Roger & Julie Still & family
Steve & Tammy Still
Jade Umberger
Chris VanFleet
Carrie Vermillion & Tom
Danny Vermillion
Daryl & Sherry Vermillion
David & Diane Vermillion
Dick & Rita Vermillion
Drake & Gus Vermillion
Joe & Chase Vermillion
Levi & Jenna Vermillion & family
Scott & Jennifer Vermillion
Seth & Randi Vermillion & family
Thelma Vermillion
Perry Wilderson
Lindsey Wilkerson
Michelle Wilkerson
Alfred Williams, Tenna & Harley
Paula Windell & Austin
Rob & Lori Windell
Shawn Windell & Cindy

Dr. Robert Wiens
Dr. Murrell Cunningham

REMEMBERING

Brother of Irwin Albrecht
Linda Hyken

Opal Bailey
Mittie Ann Mosley

Robert M. Baker
Michelle Schmitt

Hortense Beitch
Mike & Bernice Resnick

Jake Berens
Bud & Phyllis Ross

Mae Berg
Mary Anne Delker

Mr. & Mrs. Max Blinder's Family
Penny Kodner

Fran Breslow
Harlan & Barbara Floom
Robert Hayman

Charlotte Kay Burris
Helen & Mook Allen
Bill & Lois Bain
Carol & Ronnie Boyd
Glenn & Sally Bruckert
David & Theresa Bryan
Joe & Lisa Burris
Ray & Cookie Chapman
William & Erin Devries
Ron & Maureen Elfrink
Bob & Nancy Goodson
Frank & Jenny Hamilton
Kenny & Deb Hanner

David & Donna Jarden
Steve Jarden
Krummelbein families
Gene & Marie Mullink
Thomas & Cindy Nasso
Wimpy & Dottie O'Connor
Carol & Gerald O'Keefe
Cheryl & Preetam Pagar
Nancy Perdun
Donald & Arlena Rull
Gary Rull
Kent, Charlene, & Sara Rutherford
Matt & Jen Rutherford
Ruth Ann Rutherford
Nicholas & Jessica Thyer
William & Phyllis Wood
Linda & David Wulf

Harry A. Dalin
Marilyn D. Baker
Jesse & Debbie Barash
Jack, Terri, & Sarah Becker
Marlene & Jess Becker
Jay & Joan Bender
Barry & Adrienne Bergen
Alan & Sandy Berk
Bea Borenstein
The Bruchhauser Family
Cliff & JoAnn Chelish
Paul & Linda Clark
Kim Cleary
Florence & Hanley Cohn
Ed & Linda Dahl
Marilyn & Saul Dien
Michael & Maureen DiSalvo
Elaine & Gary Dreher
Bobbie Dubuque
Allan & Susie Epstein
Byron Fiman
Cheryl & Al Finkelstein
Roselynn Gad
Larry & Gail Glenn
Eleanor Glick
Jane Goldberg
Michael, Marta, Daniel, & Kevin Goldberg
Stan & Andrea Goldenberg
Dr. Arnold & Marilyn Goldman
Ralph Goldsticker
Robert Goldsticker
Myron & Prisella Grodsky
Judy & Keith Grosz & family
Maurice & Rachel Guller
Blair Halpern
Jake Hoffman
Terri Hosto
Charles & Sunny Hunt
Dr. Arnold Jacobson
Lionel & Eleanor Kaiser
Ellen & Chuck Kessler
Danny, Lynn, Matt & Elliott Kleiman
Mark & Nancy Kodner

Sandford & Sandra
Krachmalnick
Seymour & Janet Krout
Ina Landsbaum
Buddy & Daas Leberman
Robert & Susan Levin
Barbara Liberman
The Lutz Family
Scott Malin
George & Nancy Marble
Joe Marchbein
Hiram & Cheryl Martin
Bill & Debbie Muzik
Allan & Ian Padratzik
Marcia Pankowski
Maryann & Leo Paradis
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American Parkinson's OPTIMISM EVENTS

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

**Tom Raftery & Kevin Sutter
 Golf Memorial Tournament
 \$2000.00**

Annual Vermillion's Bag Parkinson's Tournament \$1435.00

This event began because of David's enjoyment in playing the bag toss game after he was diagnosed with PD. Family and friends come together each year for a fish fry, bag toss tournament, and wine raffle. Proceeds from this event were donated to Dr. Samer Tabbal's DBS research in honor of David Vermillion.



7th Annual Hull of a Race 5K/10K \$10,000.00



The Mark Twain Area Parkinson Disease support group sponsors this race each year in August in Hull, Illinois

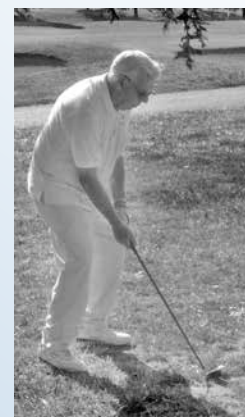
Barnes-Jewish St. Peters Hospital Parkinson Exercise Group Bake Sale \$700.00



The members of the exercise group sold their baked goodies and distributed APDA literature at Barnes-Jewish St. Peters Hospital to help raise money and awareness for the APDA.

Otto C. Hoelscher Family Golf Tournament \$100.00

The Hoelscher family had this tournament in memory of Otto. They collected donations in Otto's memory to help support Parkinson disease.



American Parkinson's OPTIMISM 500

We rolled out a campaign to recognize individuals who contribute \$500 or more during each calendar year. These two couples requested their contributions be designated for this campaign.

**Richard & Margaret Zimmerman
 Margo & John Maglione**

Over 400 people crowded the Versailles Ballroom at the Westport Sheraton Hotel on October 8, 2012, to support the APDA at the annual auction, luncheon, and fashion show. They happily took their seats after shopping for gorgeous baskets and irresistible items during the silent auction. Victoria Babu kept the commentary running and amusing as emcee. The guests were dazzled by the beautiful fashions they saw on the runway, but the real stars of the show were Debbie Guyer and Dr. Joel Perlmutter, who spoke enthusiastically of the progress being made for Parkinson patients and the promising research that is being conducted at Washington University School of Medicine.



Honorary Chair Steve Hurster and Dr. Joel Perlmutter

The event was a sweet success! We couldn't have done it without the help of our tireless volunteers. Honorary Chair, Steve Hurster, once again was instrumental in obtaining sponsorships for the event. Thank you, Steve, for the excellent job you do to inspire our community to take ownership in the fight to cure this disease. Each dollar Steve raised - he raised tens of thousands of dollars from friends, colleagues, neighbors, and anyone else whose path he crossed - will go directly toward research. We salute your dedication, Steve!



Lynda Wiens, with over 30 years of experience with other charities and a personal connection to ours, is the brains and beauty behind the baskets in the silent auction. Our committee bought wonderful items for the auction, and Lynda assembled them into beautiful, enticing displays. She sets the bar high and knows exactly what will sell and how

By
Christine
Karsh



Chairs Kathy Wunderlich, Christine Karsh and Lynda Wiens

to sell it in the most tasteful, thoughtful way. In addition, Lynda coordinated the wonderful partnership with Sweet Be's to provide the cutest candy bouquet centerpieces we've ever seen. We owe a great deal of gratitude to Lynda for all the hours and creative genius she has put into making the auction and the entire event our best ever!



Photographs by Margaret Rambo, Town & Style Magazine



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Continued on next page

A SWEET SUCCESS

continued from previous page

Co-chair Kathy Wunderlich gathered a lovely group of models and brought fresh ideas to the planning process for the show. In addition, Kathy arranged for and sponsored the St. Louis Sirens to sing some familiar songs, with a humorous twist, to the delight of our audience. We thank you, Kathy, for your time and input into infusing a dash of glamour onto the runway and leaving the audience wanting more.

Congratulations and our deep appreciation goes to our committee members who went from shop to shop, restaurant to restaurant, collecting items and gift cards for our auction, and many dipped into their own wallets to purchase items to complete an auction basket. And, congratulations and our sincere thanks to the five boutique owners (Cha, Distinctions, PURE by Jen, Marta's, Savvi Formalwear) who selected fashions from their racks and fit our models for the show. A round of applause goes to our 25 models. Heartfelt thanks to all the volunteers, bankers, and runners who made sure that the event progressed smoothly. It all came together for our most successful fundraiser to date, and you all had a role in our success.

Thank you to all who attended the event. We hope you had a great day. For a complete viewing of all of the photographs taken by and courtesy of Cathy Hartman Photography and video production by Larry Balsamo (Video Views), visit www.stlapda.org. ■

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