LiNK St.Louis APDA

APDA
www.stlapda.org

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

MISSION

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

IN THIS ISSUE

NEWSLETTER DISCLAIMER

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

A SPECIAL PERSON REMEMBERED— A BEAUTIFUL LIFE HONORED

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

As many of you know, my mom passed away in the early hours of February 12, one week after the birth of our first grandchildren—twin girls. We were all at her bedside, and she looked at each of our faces, one by one. I know she was intent on staying with us until the girls arrived, making sure that everyone was safe and sound.

While this has had a very profound effect on me, I am sharing some thoughts that I shared with friends and family at my mom's memorial service. I am proud to tell you that my family requested memorial contributions to the APDA in order to enable us to achieve our mission. There have been many others who have lost their loved ones and done the same thing, as you will see on the tribute pages in this and every newsletter. I have asked Stacey Barton, our social worker, to share her expertise and knowledge of hospice, having been the director of a hospice agency before coming to Washington University School of Medicine. Because of Stacey's recommendations for using hospice services, my family was able to take advantage of this wonderful service. In addition, there is an article on brain donation, by Johanna Hartlein, included in this newsletter so that you will better understand this ultimate gift a patient and their family can make. Thank you for your support, prayers, thoughts, and contributions made during this challenging time. It has been an emotional roller coaster, and as many have pointed out, represents the circle of life.

Mom, you made us believe you could almost live forever—or did you linger to allow us time to get things in order and accept your final passage? Having your family around was always the most important thing in the world, so it was only fitting that we gathered during your final weeks, surrounding you at your bedside, reminiscing about so many memories from years gone by. How fortunate we were to have the experience of a hospice team along the way as our companion and guide, providing services and answering questions day or night for 18 days. The journey was a challenging one, but being present with you in your own home when you took your last breath was such a powerful experience and one I will never forget.

You were sweetness and kindness, warmth and thoughtfulness…always seeing the good in everyone. I never once heard you complain, not one day, before or after receiving the diagnosis of Parkinson's disease over 21 years ago. In fact, you always told me there were others suffering far worse. You not only put a smile on my face, you put a smile on my heart.

For every tear that we've shed, there are a thousand reasons to smile. Even when the Parkinson's mask was present, visitors coming through the door always brought a smile to your face. And when the words wouldn't come or were spoken too softly, you still managed to convey what needed to be said. We understood each other, didn't we, Mom?

Each of us carries a part of you with us and will remember you every day of our lives. And now, we have just welcomed the first of many great grandchildren to come who will carry their beloved Maw Maw's name. You set the standard that we strive to achieve as wives, mothers, and now grandmothers.

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Call to make appointment

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EDITOR
Deborah D. Guyer

APDA 50 Years
TO EASE THE BURDEN TO FIND THE CURE
American Parkinson Disease Association

Ask the Doctor

Lee W. Tempel, MD

As a relatively newly diagnosed patient, how do I know when it's time to be put on medication? I have heard that Sinemet is only effective for so long, so isn't it better to put off starting it for as long as possible?

The time to start treatment is when symptoms become significantly bothersome—this may vary from person to person.

One patient may be retired and tolerate a certain degree of symptoms while another may still be working and not tolerate the same degree of symptoms because of job demands. Someone may have a position in the public eye and not be able to “afford” even minor symptoms (such as a mild rest tremor) because of the public's (incorrect) assumption that such symptoms make him/her “unfit.” In any case, it is important to begin treatment before significant gait or balance symptoms that might put the person at risk for a fall.

It is important to realize that it is NOT true that Sinemet is only effective for so long. It always remains effective. As time goes on, the dose needs to be increased but it will always give benefit. However, with time there is a complex interaction of disease progression and need for increase in dose that can lead to accompanying side effects such as dyskinesias (involuntary movements) that may certainly complicate therapy.

One well done trial suggests that up to 50% of patients may develop dyskinesias after five years of being on Sinemet. Of course, dyskinesia initially is quite mild and may not be a significant problem until later. Once dyskinesia is significantly severe and/or there are uncontrolled times of being “off” despite “fine tuning” of medication, it is worthwhile to consider a Deep Brain Stimulator (DBS). Also, we now have several available medications that can be used in the “best” combination for each individual and potentially minimize or delay unwanted side effects. So we may not start out with Sinemet in all patients and are unlikely to just use Sinemet alone in most patients. Instead we try to strategically use a combination of medications. There is no one “correct way” to do this. The choice among the medications must be individualized based on the patient's age, general health, other medications, whether there is any accompanying cognitive impairment present, how severe the PD symptoms are, what the goals of therapy are (what degree of symptom control is desired), tolerance of medication side effects, etc.

There is a suggestion in some of the current literature that it may even be better to start therapy earlier rather than later in terms of long-term performance and outcome but that is not actually known yet. It is being looked at in more detail in some current trials.

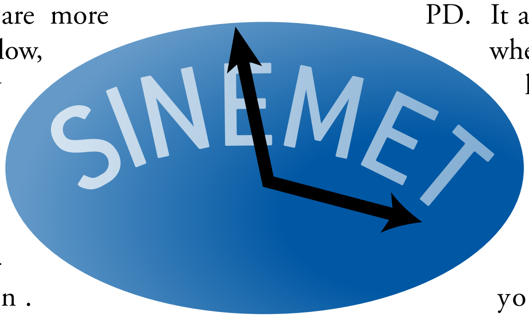
Finally, there is very little we yet have to offer in terms of medications that are “disease modifying” (ability to slow down the progression of the disease). The best evidence exists for rasagiline (Azilect) as a medication used alone in early PD (before other medications are needed for symptomatic control) that seems to slow progression modestly compared to a group that does not use it. Further medications are under development. Once we have a medication with proven efficacy to dramatically slow progression, it will be very important to begin it as soon as possible once the diagnosis of PD is made. ■

ON/OFF—WEARING OFF OF MEDICATIONS

Johanna Hartlein, Nurse Practitioner & Research Coordinator, Washington University School of Medicine

If you have PD or have a loved one with PD, you have probably heard about the phenomenon of medication effectiveness “wearing off.” When people with PD take Parkinson medications, especially if they take carbidopa/levodopa (Sinemet), it usually relieves or improves their PD motor symptoms of tremor, rigidity, slowness, and small movements. PD medicines may also make it easier to walk and get in and out of chairs.

When people first start taking Sinemet or similar PD medications, they usually have a very smooth benefit from one dose to the next throughout the day, meaning that their symptoms are pretty stable throughout the course of the day. However, as their PD becomes more advanced, people may notice “wearing off.” Wearing off means that sometime before or right after they take a dose of PD meds, their motor symptoms return and they are more stiff, tremulous, slow, etc. Then they have to wait for their next dose to “kick in” before their symptoms improve again. Sometimes when people feel their medicine “kick in,” they also get dyskinesia, which can look like writhing movements (Michael J. Fox has these movements). Doctors may sometimes ask patients to keep track of when their medications kick in and wear off. We recently have become aware of a free resource to track wearing off using your computer. This service was designed by the sister of someone with young onset PD. It allows you to track when your medicine kicks in, when it wears off, how you are feeling, and dyskinesia (if applicable). Since it charts your on/off time, this could be helpful for your doctor to better understand which medications may need to be adjusted.



If you are interested, please use the log at **www.datadrivenhealth.org**. You can track your symptoms and then print out your charts and take them to your doctor visits for review. ■

A SPECIAL PERSON REMEMBERED

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We couldn’t have reached this milestone of celebrating your 86 years were it not for Dad who knew that healthy eating and exercise translated into delaying the progression of the disease, even before research proved it. Even when you could barely walk, you willingly got on the treadmill every morning and playfully caught and threw a ball, both exercises Dad wanted you to do each day to maintain your functioning. His care was tireless, and he remained 110% committed to the cause of keeping his bride with him. The loving care you received from your family and dedicated care providers and from the hospice staff made your generous heart and joyful presence known even in these last months, weeks, and days.

There is a prayer that says, “When we have joy we crave to share, we will remember…When we have decisions that are difficult to make, we will remember.” Mom, we will remember your strength that amazed us, your courage that impressed us, your grace that inspired us, and your eternal love which will guide each of us always. We’re so blessed to have had you in our lives. A friend offered this beautiful observation when comforting me. She said, “Deb, it took two to take the place of your mom.” Cradling Abby and Lily in my arms so represents the circle of life. But nothing, and no one can take your place, ever.

So many people have sent so many generous tributes to the APDA to honor your memory, Mom. Their donations will enable us to continue to do critical research and to support needed patient services. I smile when they say how proud you must have been of my accomplishments. I couldn’t be prouder of how you lived, in spite of struggling with this terrible disease for over 20 years. It is through these memorial contributions and tributes honoring those we love that we continue our commitment at the APDA to “ease the burden and help find the causes and cure” of this dreadful disease. Thank you to all the families who have requested donations in honor and in loving memory of their loved ones, and for those who have given the ultimate gift of a brain donation.

Mom, I will never forget your face, the sound of your voice, the gentleness of your touch, the stories you told, the traditions you handed down, the lessons you taught, the things you stood for, as these are the true gifts and your legacy. I promise to honor you every day in how I live and who I am. ■

CAREGIVER SUPPORT GROUP FACILITATORS

Seeking interested care providers (present and past) who wish to be trained to act as facilitators for our new For Caregivers Only monthly support groups. Please contact the center for more information on the training program and criteria for becoming a facilitator of such a group.

BRAIN DONATION: THE ULTIMATE GIFT

Johanna Hartlein, Nurse Practitioner & Research Coordinator, Washington University School of Medicine

Donation of your brain is one of the most important gifts that you can give in helping doctors and scientists to better understand the way that parkinsonism and thinking problems affect the brain.

Although it may seem morbid or even scary to think of your own passing, arranging for brain donation for you or your family member sooner rather than later can often provide family members with closure in knowing the wishes of their loved one in advance of death or mental incapacity. It also is invaluable in helping us to get closer to finding better treatments and cures. Brain donation allows us to try to better understand which brain structures are most affected by different forms of parkinsonism, to study important protein inclusions that contribute to these diseases, and try to correlate specific parkinsonian symptoms with different brain pathology. If you are a patient at the Movement Disorders Center (MDC) at Washington University School of Medicine (WUSM), we would be grateful for the gift of your brain. It is important that you are a clinical patient at the MDC for brain donation to be helpful to us because it is critical to be able to correlate the findings of brain autopsy with clinical symptoms and history which have been obtained via multiple visits over years and even decades. Brain donation is generally acceptable to patients of all religions and backgrounds, and it does not in any way affect your ability to have an open casket if those are your wishes. Your clinical doctor at the MDC would call your family with the brain autopsy results about six months after your brain is received. If you are interested in brain donation or would like more information on brain donation, please contact Johanna Hartlein, Nurse Practitioner and Research Coordinator for Joel Perlmutter at WUSM at 314-362-0420 or at johanna@npg.wustl.edu. ■

HOSPICE CARE: HIGH QUALITY CARE AT THE END OF LIFE

By Stacey K. Barton, MSW, LCSW
Clinical Social Worker, Department of Neurology, Washington University School of Medicine

As Parkinson's Disease (PD) naturally progresses, there may come a time when even the best medical interventions no longer provide relief of symptoms. People with PD may find themselves having difficulty swallowing or maintaining their weight, getting infections, needing hospitalization, falling, or otherwise requiring more assistance. Caregivers can become overwhelmed, struggling with the challenges of balancing the usual demands of life with the increasing demands physically, emotionally, and financially of caring for someone with advanced Parkinson's. Families are often frustrated by a lack of resources to provide quality care. When the time comes that a person's needs have grown, treatment is not providing enough relief, and the desire for more aggressive attempts at care is waning, it may be time to consider hospice care.

What Is Hospice?

Hospice care is a program of expert care in managing symptoms at the end stages of disease, maximizing patient choice and providing physical, emotional, and spiritual support to not only the person with PD but also those who provide care. The focus is "high touch, not high tech" although they incorporate the latest practices in providing palliative, or comfort-focused, medical care. Ideally, people utilizing hospice services will be under hospice care for about the last six months of life. While hospices are capable of caring for people in the last days of life, the best hospice outcomes come from relationships with patients and families that started months ago.

What Hospice Isn't

Hospice is not a place; rather, hospice is delivered to a person where they live, whether that is in their own home, assisted living, or nursing home. Hospice does not provide 24-hour, hands-on care except in very rare, time-limited circumstances. Hospice care is not costly. It typically costs the patient and family nothing, and it also tends to cost insurance companies and Medicare less than traditional care. It is not a type of care only for those in their last weeks of life, or only for people who do not want to be resuscitated. Hospice understands that people will have a range of wishes at the end of their life, and they work to respect those wishes and make them a reality.

What Services Are Provided Under Hospice?

Hospice provides a team of qualified staff who fill a variety of roles: nurse, nurse aide, social worker, chaplain, volunteers, and sometimes therapists work in conjunction with the hospice doctor and the patient's doctor. A nurse is on call 24 hours a day. In addition, under the Medicare hospice benefit (and also many private insurers), the hospice provides the necessary medical equipment such as wheelchairs, commodes, and hospital beds and may cover supplies

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HOSPICE CARE

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such as incontinence products.

The hospice provider must also cover the cost of certain medications. The medications covered are those required for symptom control or comfort for the diagnosis for which the person is receiving hospice. For example, if a person with PD enters hospice, they should expect that the hospice will cover the cost of many PD drugs, as they relieve uncomfortable PD symptoms. However, if the person also has high blood pressure, the hospice will not cover those medications. This does not mean that the person can no longer take their blood pressure pills; it just means that it falls outside of the responsibility of hospice.

While most care is provided at home, there may also be times when the family either needs a break or cannot be there for a period of a few days. In these cases, hospice can provide respite care. In hospice, this typically means that the care of a person will be temporarily transferred to a nursing facility and hospice bears the cost. After respite is over, the person returns home. There may also be rare occasions when a person's medical condition cannot be handled at home. In these instances, the hospice would cover the cost of in-patient care. Inpatient care can be received either in a hospital or a skilled nursing facility.

An important focus of hospice is the support the family receives in addition to the care provided to the patient. Because of this, in addition to the services already mentioned, hospice provides at least a year of bereavement care following the hospice patient's death.

Cost and Coverage

Most people with PD who would enter hospice will be covered by Medicare or Medicaid, but private insurance also typically covers this care. While private insurance may operate differently, in most cases hospices are reimbursed a flat daily rate for all care provided. In the majority of cases, patients pay nothing for this care.

When Is the Right Time for Hospice?

Hospice is a robust program that provides high quality of care that is well received by families. Unfortunately, for many people, hospice comes in far too late. While the standard for hospice is that people must be (in the best estimate of the physicians) within the last six months of their life, most people are only in hospice for a few weeks. According to the National Hospice and Palliative Care Organization, in 2009 almost 50% of all hospice patients died within two weeks of beginning care. This is not because hospice hastens death; rather, it is because people are referred to this type of care too late. It is a myth that patients cannot be in hospice longer than six months. Patients can remain in hospice for as long as necessary, as long as they continue to meet enrollment criteria. The best hospice care is provided when the patient, family, and hospice team have the time necessary to establish a relationship, trust, and a solid plan of care. Please see the sidebar for more information about discerning when a person with PD might meet criteria for admission into hospice care.

Finding a Hospice Program

There are many hospice programs available throughout the region. Some are affiliated with hospitals, nursing homes, or home-care agencies while some are stand-alone agencies. Some are for-profit agencies, others are not-for-profit. Hospices may vary slightly in their philosophies, the services they provide, and what they cover. If you are considering hospice, it is useful to meet with a couple of agencies to talk about these differences and get a feel for the care you would receive. For people who reside in nursing homes, the facility typically has contracts with a few agencies from which you can choose. For people living at home, you can ask your physician for a referral, and you can also search the National Hospice and Palliative Care Organization website at **www.nhpco.org**.

Discussing Hospice with Loved Ones and Doctors

It can be difficult to broach the subject of hospice with family. There is help available for these discussions, and it is acceptable to ask your doctor or other healthcare providers about this option for you or your loved one. Oftentimes, people are all thinking about the care to be delivered, but are hesitant to bring up these sensitive issues. Hospice is not giving up—it is about providing the best care possible in the absence of a cure. ■

GUIDELINES FOR KNOWING WHEN TO BEGIN HOSPICE

Medicare has specific criteria for hospice admission. Here are some problems a person with PD might be experiencing that would be clues that hospice may be appropriate.

- Inability to dress, bathe, or feed oneself
- Incontinence
- Inability to communicate well
- Multiple hospitalizations or ER visits
- Development of other problems such as pneumonia, urinary tract infections, sepsis, bed sores, or recurrent fever
- Weight loss (10% in the last six months is significant)
- Swallowing problems, needing to change food consistency
- Inability to walk without assistance
- Other co-occurring severe medical conditions
- Dementia
- Rigidity
- Increase in sleeping or severe fatigue

BROKEN ANGEL

We were so touched by this poem—it is a moving reflection on the experience of caring for a parent with Parkinson's Disease. We hope it will bring encouragement to adult caregivers in our readership. The author's courage in honestly approaching this subject and her feelings demands that we respect her privacy by withholding her identity.

She sits in the doctor's waiting room
Angry
So angry she can't speak for awhile
"He won't let me go home"
"I want to talk to the doctor again"
Our appointment was over five minutes ago
The doctor was kind and firm,
And he has other patients

Dad says
Let's go get a frosty
I don't want a damn frosty
She snarls…
I want to go home

Mom doesn't recall her actions
Denies the fact that
She can't dress herself without help
She doesn't recall
using the plastic drink cooler
To soak her feet

We're making up stories about her…
Exaggerations, she calls them..
With a pained expression
And a flip of her hand

She tells the doctor
She knows that she sees people sometimes
Who really aren't there

We tell him politely
how she packs up belongings
in tote bags and pillowcases
To catch a train that's not coming
She's certain everyone is moving out and
"I'll be the last one left"
"The others don't notice it
But I do"…

Today
she answers the doctor's questions right
She knows it's Monday
And what she had for lunch
(But first she said she didn't have lunch yet)
It's 3:00 p.m.

But what does it matter, she thinks
No matter what I say
The doctor says I can't go home
Damn doctor, what does he know?

Her arms are bony and thin in her print
t-shirt
Her pants are two sizes too big and stained
(Didn't anyone notice this before she left?)
She steps on the scale and the doctor says
Good! You are holding your own!
One hundred nineteen pounds
You gained a pound!

Dad is there, biting his tongue
She warned him in advance
"I want to talk to the doctor first"
"I'll let you talk when I am done"

She resents him for not being with her
Because he gets to stay in their old home
while she had to go to
"that place"
She still can't say the words "nursing home"

"That place"…
With the silly bingo, and the sing-a-longs
And people who talk to themselves
Or don't talk at all.
And they don't even cook right
I can cook better than that.
Yes, she could…past tense

Why can't I come home?
But…I can manage with a little help…
The doctor answers patiently
You are doing well now
This is the best place for you
Remember?
Your husband took you home against
doctor's orders once
And it didn't go well at home…
Remember?

She looks bewildered…

I kiss her goodbye
And cry in the car on the way back to work
Damn!

On the front seat of my car lays
the ceramic angel
from Mom's room at "that place"
Broken at the waist
It was a gift
The angel has no face but carries a
pineapple
A symbol of hospitality

Mom gave hospitality in her day
She loved out-of-town company
from either side of the family
At our house on our familiar street
Relatives brought their kids
For the summertime weekend

They ate well
For she could really cook…
They laughed and drank beer and played
cards
Cousins ran wild in the huge yard
Ate watermelon, drank kool-aid
Played baseball with fervor
Were escorted on scary trips
to the cemetery nearby

And exhausted, slept soundly
with mismatched blankets and pillows
on the living room floor
And a good time was had by all

Kisses and hugs goodbye…

There she sits now
The Broken Angel
On my car seat awaiting the glue
That will put her back together
for Mom

The angel-holding-pineapple
will return to "that place"
with the electric twin bed and TV,
A room cluttered
with greeting cards "borrowed" from the
main room
Newspapers and magazines,
Pens and lipsticks-without-lids,
A worn prayer book and rosary
and clothes strewn about the floor

The Holy Spirit made Mom
an angel of love and hospitality
If only I had some magic "glue"
that would fix…Mom

Our Broken Angel

—*Anonymous*

PARKINSON'S DISEASE WORK-RELATED DISABILITY ASSESSMENT

Through their work in the Parkinson's community, the Parkinson's Action Network has learned that people with Parkinson's may have trouble receiving Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits due to inadequate documentation of symptoms in their medical record.

A form has been developed to ensure that information that may be relevant to how Parkinson's disease affects your ability to work is included in your medical record, particularly if you think you may apply for SSDI or SSI. This form may also aid in conversation of symptoms not as commonly discussed with a physician related to a patient's ability to work. This form is not intended to offer or replace individual legal or other professional advice and should be used at your own discretion. This form is not a Social Security Administration (SSA) form and does not replace or change the Social Security application. For more information about applying for SSDI or SSI, please visit **www.socialsecurity.gov**. The SSA Parkinson's disability evaluation definition is available on the Web at **www.ssa.gov/disability/professionals/bluebook/11.00-Neurological-Adult.htm**.

This form may be completed by you (patient) or by your doctor and kept by your doctor in your medical record. This form is available at **www.parkinsonsaction.org/PDform** or by contacting the Parkinson's Action Network at 800-850-4726 or **info@parkinsonsaction.org**. ■

CUT THIS OUT AND RETURN TO APDA CENTER

APDA—GREATER ST. LOUIS CHAPTER

PATIENT NEEDS/SERVICES SURVEY

We need your input to provide the best service to the Parkinson's community. The APDA Board wants patient services which have the biggest impact on improving the quality of life for Parkinson's patients and their families to be our focus.

To accomplish this goal, we are surveying our membership to determine what needs you have (or anticipate having) and programs that you would like the board to consider as they discuss how best to utilize funding for patient services.

Examples of new programs:

1. Transportation (to doctor appointments, support group meetings, exercise classes, educational programs)
2. In-home care—homemaker/companion for those who live alone (to provide assistance with household chores, cleaning, laundry, grocery shopping, picking up medications)
3. Incontinence supplies—reusable vs. disposable
4. Out-state services—respite care, exercise classes, transportation in hard-to-reach Missouri and southern/central Illinois communities served by the Greater St. Louis Chapter

Please List Your Top 5 Needs Below:

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________

Do you participate in APDA patient service programs? ______(yes) ______(no)

Circle Which APDA Services You Presently Use:

Support Group   Exercise Class   Dance Class   Aquatic Class

Respite Care:_____in-home ______adult day program

Emergency Response System:____Lifeline____Extended Independence

PEP Meetings (educational programs)   Quarterly Newsletters

Comments:

____

____

____

____

Are you a:

___________Patient
___________Family member
___________Caregiver

Is a non-family member caregiver used in the home? ______(yes) ______(no)

MISSOURI SUPPORT GROUP CALENDAR

Sponsored by the St. Louis American Parkinson Disease Association

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

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Cape Girardeau	Cape Girardeau	The Chateau Girardeau 3120 Independence St. St. Francis Med. Ctr. 211 St. Francis Dr., SFMC Cafeteria	Feb. 1, Aug. 2 May 3, Nov. 1	3:30 PM 6:00 PM	Desma Reno, RN, MSN	573-651-2939
Chesterfield	St. Louis	APDA Satellite Resource Center 1415 Elbridge Payne, Suite 168	1st Tuesday	10:30 AM	**Vicky Young** **Debbie Guyer**	**636-343-8280** **314-362-3299**
Columbia	Boone	Lenoir Community Center 1 Hourigan Drive	1st Thursday	4:00 PM	Doris Heuer Mary Green	573-815-3718
Creve Coeur	St. Louis	For Caregivers Only Shaare Emeth, Library Conf. Room 11645 Ladue Rd.	2nd Monday	11:00 AM	Dee Jay Hubbard, PhD	314-362-3299
Creve Coeur	St. Louis	Young Onset Living and Working With PD Missouri Baptist Medical Center 3015 N. Ballas, Bldg. D, Conf. Rm. 6	3rd Tuesday	6:30 PM	Linda Pevnick, MSW, LCSW, BCD Rich Hofmann	314-362-3299 314-369-2624
Festus/Crystal City	Jefferson	Disability Resource Association 420 B S. Truman Blvd.	3rd Tuesday	1:00 PM	Penny Roth	636-931-7696 ext. 129
Florissant	St. Louis	Garden Villas North 4505 Parker Rd.	4th Thursday	11:00 AM	Julie Berthold Paula Simmons **Nancy Robb**	314-355-6100 **314-869-5296**
Jefferson City	Cole	Capital Regional Medical Center SW Campus, Cafeteria	3rd Monday	3:00 PM	Jennifer Urich, PT	573-632-5440
Joplin	Jasper	St. Johns Regional Medical Ctr. 2931 McClelland	Mondays	1:30 PM	Nancy Dunaway	417-659-6694
Kirkwood	St. Louis	Kirkwood United Methodist 201 W. Adams	1st Monday	7:00 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
Oakland/ Webster Groves	St. Louis	Bethesda Institute 8175 Big Bend, Blvd., Suite 210	Last Friday	10:30 AM	Laurel Willis, BSW	314-373-7036
Rolla	Phelps	Rolla Apartments 1101 McCutchen	4th Thursday	2:30 PM	Hayley Wassilak Tyler Kiersz	573-201-7300
Sedalia	Pettis	1st Christian Church (Disciples of Christ) 200 South Limit	3rd Monday	4:00 PM	Barbara Schulz	660-826-6039
South St. Louis	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	2nd Wednesday	10:00 AM	Jack Strosnider	314-846-5919
St. Peters	St. Charles	1st Baptist Church of Harvester 4075 Hwy. 94 S.	1st Tuesday	1:00 PM	**Sherrie Rieves** Ann Ritter, RN	636-926-3722
Ste. Genevieve	Ste. Genevieve	Ste. Genevieve County Mem.Hosp. Education Conference Room Hwy. 61 & 32 Intersection	2nd Wednesday	10:00 AM	Jean Griffard	573-543-2162
St. Louis	St. Louis	Pre/Post-DBS Sunrise on Clayton Senior Living 7920 Clayton Rd.	3rd Thursday	1:00 PM	Steve Balven Stan Wilensky	314-249-8812 314-997-5114

DELAY THE DISEASE—FUNCTIONAL FITNESS

David Zid

The ability to twist or rotate diminishes as you age, and Parkinson's disease magnifies this problem. If someone taps you on the back to talk to you, do you find yourself taking many small steps to turn to look and listen to them? Wouldn't you rather be able to simply turn and look at them in one movement? These exercises will help you regain your ability to turn around when standing or seated. Good luck and stay flexible. ■

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

Standing Rotation

STANDING WOOD CHOPS

While standing erect, hold a weighted ball, dumb bell, or other weight in your hands. If this is too difficult to perform with a weight, do the exercise without a weight. Hold the weight over your head off to one side, arms slightly bent. Now bring the weight across your body to your knees on the opposite side of your body, as if you were chopping wood. Perform 5–10 repetitions on both sides of the body.

SIDE-TO-SIDE WOOD CHOPS

Take a large stride with one leg and hold in a lunge position. Take your weighted ball and twist side to side as far as you can tolerate. Repeat 5–10 times; repeat with opposite leg in front.

HIGH KNEES WITH A TWIST

While standing tall, lift one knee high and try to touch it with the opposite elbow, keeping elbow flexed at 90 degrees. Don't worry if you cannot touch it; just move your elbow towards your knee. Alternate sides. Perform 5–10 repetitions on each side.

WALL TAPS

Stand with your back to the wall, 2 to 4 inches away. Rotate to the right and try to touch the wall with your right hand. Try to look over your left shoulder while twisting. Repeat on the opposite side. Perform 5–10 repetitions on each side.

ROTATIONAL STEP

Stand with feet parallel, knees slightly bent. Take a wide step slightly backwards, turning your foot out. As you step, keep your head and shoulders facing forward. Return to starting position. Repeat this motion on the opposite side. Continue to alternate sides for 5–10 repetitions.

GRAB YOUR SUIT AND MAKE A SPLASH IN THE WATER!

Are you ready to enjoy exercise now that it is getting warm and easier to get outside?

Come join our Parkinson's Aquatic Exercise Class and have fun in the water! We currently have two classes which meet for a 10-week Spring Session (April 7–June 9) on Thursdays from 2:00–3:00 pm, and if there is enough interest, we would like to start a class in the Chesterfield area, near Highway 64/40 and Olive/Clarkson.

Our class in St. Charles County meets at the St. Charles County YMCA at 3900 Shady Springs Rd., (near Highway 70 and Cave Springs Road), and our St. Louis County class is currently meeting at Rainbow Village at 1240 Dautel Lane, north from Olive Street, between Lindbergh and Schuetz (in Creve Coeur). If you are interested in attending a class held in the Chesterfield area, or would like more information about joining our other classes, please call the office of Show Me Aquatics and talk to Brenda at 636-896-0999 or call the APDA Information & Referral Center at 314-362-3299. ■

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.

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	Mary Frierdich Jodi Gardner	618-234-4410 x7031 or 7033
Carbondale	Jackson	Southern IL Healthcare Headquarters University Mall	1st Wednesday	1:00 PM	Tom Hippensteel	618-684-4282
Carmi	White	Phoenix Rehab. & Nursing 615 West Webb St.	4th Tuesday	1:00 PM	Carolyn Chastain	618-382-4932
Decatur	Macon	St. Paul's Lutheran Church 352 W. Wood St.	3rd Thursday	1:30 PM	Cathy Watts	217-428-7716
Greenville	Bond	Greenville Regional Hospital 200 Healthcare Dr. Edu. Dept., Edu. Classroom	2nd Monday	1:00 PM	Alice Wright	618-664-0808 ext. 3703
Matoon	Coles	First General Baptist Church 708 S. 9th St.	Last Tuesday	1:30 PM	Marcia Smith	217-254-4869
Mt. Vernon	Jefferson	Greentree of Mt. Vernon, 2nd Floor	4th Thursday	6:30 PM	Donna & Bill Peacock	618-242-4492
Quincy	Adams	Fellowship Hall of Salem Evangelical Church of Christ 9th & State	3rd Thursday	12:00 PM	Barb Robertson	217-228-9318
Springfield	Sangamon	Christ the King Parish Ctr. 1930 Brentwood Dr.	3rd Sunday in Jan., Mar., May, July, Sept., & Nov.	2:00 PM	Dan Vonberg	217-546-2125

MANY THANKS

to the volunteers who assisted us with our first 2011

PEP Meeting held at The Ritz Carlton, St. Louis. A large crowd assembled on April 30 to hear Dr. Jennifer Goldman explain the cognitive and other neuropsychiatric features in Lewy Body Disorders in PD; Dr. Gary Behrman spoke to caregivers about partnering in care vs. giving care; Amanda Landsbaum demonstrated adaptive equipment and suggested simple and useful modifications for home to help make living with PD much easier; and Kathy Bednarek engaged the patient audience in LOUD Talk. Dr. Lee Tempel and Dr. Sylvia Awadalla were on hand for Ask the Doctor, a new feature of our PEP programs. Special thanks to Teva Neuroscience for their support of this wonderful and well-attended educational program to raise awareness about PD.

HONOR THY MOTHER AND FATHER

Trying to find the perfect gift for someone special this Mother's Day (May 8) or Father's Day (June 19)? Making a tribute gift to the Greater St. Louis Chapter of the APDA might be just the answer! Generous gifts such as these assist our chapter in providing patient services such as respite care, exercise classes, aquatic therapy and LOUD Crowd, or funding critical research leading to new discoveries such as Dr. Willis's recent published work on incidence and prevalence, Dr. Perlmutter's team's work in the area of dementia, and Dr. Kotzbauer's study of the intestinal gel leading to finding the causes and cure of Parkinson's disease.

Mother's Day and Father's Day are fast approaching; so make your gift today. You may use our website **www.stlapda.org** OR the blue tribute envelope inside this newsletter OR call the center at 314-362-3299. We'll send a special note to let your recipient know about this very special gift. Not only will you be supporting our mission "to ease the burden and find the causes and cure for Parkinson's disease," but you will be honoring someone who is so very special in your life. ■

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**.

City	County	Meeting Site	Day of Meeting	Time	Leader(s)	Phone
Clayton	St. Louis	Barnes Extended Care 401 Corporate Park Dr.	Wednesday & Friday	1:30 PM	**Mike Scheller, OT**	**314-289-4202**
Chesterfield	St. Louis	St. John's Mercy Rehabilitation Hospital 14561 N. Outer 40	Tuesday	1:00 PM	Deb Luetkemeyer, PT	314-881-4200
Chesterfield	St. Louis	St. Luke's Hospital 232 S. Woods Mill Rd.	Tuesday	10:30 AM	Patty Seeling, PT	314-205-6934
Chesterfield	St. Louis	**Gardenview Chesterfield** **1025 Chesterfield Pointe Parkway**	Thursday	2:30 PM	Faye Bienstock, PT	314-754-2180
Creve Coeur	St. Louis	Aquatic Exercise —Rainbow Village 1240 Dautel Lane	**Thursday** **Apr. 7 – June 9**	2:00 PM	Brenda Neumann	636-896-0999 ext. 21
South St. Louis County	St. Louis	Garden Villas South 13457 Tesson Ferry Rd.	Monday	11:30 AM	**Mike Scheller, OT**	**314-289-4202**
St. Peters	St. Charles	Barnes-Jewish St. Peters Hospital Ste. 117	Every Tuesday except 1st Tuesday	11:00 AM	Holly Evans, PT	636-916-9650
St. Peters	St. Charles	Aquatic Exercise—St. Charles YMCA 3900 Shady Springs Ln.	**Thursday** **Apr. 7 – June 9**	2:00 PM	Brenda Neumann	636-896-0999 ext. 21
North St. Louis County	St. Louis	Garden Villas North 4505 Parker Rd.	Tuesday & Thursday	10:00 AM	Bobby Lautenschleger, PTA	314-355-6100
Lake Ozark	Camden	Lake Ozark Christian Church 1560 Bagnell Dam Blvd.	Monday	4:00 PM	Alice Hammel, RN	573-964-6534
St. Louis City	St. Louis	The Rehab. Institute of St. Louis 4455 Duncan Ave.	Thursday	Noon	**Janelle Burge, PT, DPT**	314-658-3858

PARKINSON'S DISEASE AND PSYCHOSIS STUDY

Dr. Kevin Black at Washington University School of Medicine is participating in a research study investigating a medication for Parkinson's Disease related Psychosis (PDP) sponsored by ACADIA Pharmaceuticals, Inc. The most common symptoms of PDP are hallucinations (seeing, hearing, and/or feeling something that is not actually present) and delusions (believing in something that is not true, often including paranoid thoughts). The study will research the safety and effectiveness of an investigational medication compared to placebo (an inactive look alike substance) in individuals who are experiencing hallucinations and/or delusions.

To take part in the study, individuals must be at least 40 years old with a diagnosis of PD for at least one year and have been experiencing PDP symptoms for at least the past month. It is important that caregivers are able to accompany the subject to all study visits. Participation will last approximately twelve weeks and includes up to five office visits and two phone contacts. For more information, please contact Mary at 314-362-7651 or **maryc@npg.wustl.edu**. ■

HELP WANTED! VOLUNTEER OPPORTUNITES

We are seeking a volunteer or two to help at the satellite resource center in Chesterfield. Responsibilities would include answering the telephones, assisting visitors with DVD viewing, or locating information in books in our resource library. Volunteers would welcome support group members as they convene at the satellite center for their monthly meeting. Occasional assistance with special projects from the Information & Referral Center and/or with collection of baskets for our auctions may also be needed.

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).

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JOIN US *for an* EVENT WHERE **GIVING WON'T JUST FEEL GOOD,** IT'LL TASTE GOOD.

American Parkinson's Disease Association

APDA 50 *Years*
TO EASE
THE BURDEN
TO FIND THE CURE

We're having a fundraiser at California Pizza Kitchen.
Just bring in this flyer on May 23, 2011,
present it to your server when ordering, and 20% of your check
will be donated to the St. Louis Chapter of the APDA.

The Original BBQ Chicken Pizza

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May 23, 2011

California Pizza Kitchen
All 4 locations!
Creve Coeur, St. Louis Galleria,
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Available all day for dine in or takeout!

YOU MUST BRING THIS FLYER

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Don't forget eScrip

Another easy way to contribute to the APDA during these tough economic times is to request an eScrip card.

Every time you shop at Schnucks, they will automatically contribute up to 3% of every dollar you spend to the St. Louis APDA by using this card. If you do not have an eScrip card, call St. Louis APDA at 314-362-3299 and request a Schnucks eScrip community card. We will enroll you and mail the card out the same day.

THE FRATERNAL ORDER OF EAGLES IS *TAKIN' IT TO THE STREETS*

The Fraternal Order of Eagles of Missouri State Presidents, Joe Lambing and Roxanne DeLapp, chose the APDA for their state charity this year. They are eager to raise funds to make the DVD *Takin' It to the Streets* a reality. Outside of the major metropolitan areas there can be limited information available on Parkinson's disease for medical professionals, medical support staff, and Parkinson's patients and their families. Because of the complexity of PD and the fact that the symptoms can be similar to those of other diseases, education is a critical component in the treatment of the disease as well as for ensuring the best quality of life for the patient. Early intervention enables individuals to learn characteristics and treatment options, to better manage symptoms and to learn about lifestyle modifications which can delay the progression of the disease and reduce overall long-term care costs. The Greater St. Louis APDA Board, as part of its strategic planning process, felt it was important to support the entire service area and not just metropolitan St. Louis. While there are 40,000 Parkinson patients in Missouri, we are only reaching 5,500 or less than 14% of those diagnosed with PD across the state.

This DVD presentation provides easy access of information to medical professionals, patients, families, and care providers in order to improve the quality of life for anyone directly or indirectly impacted by Parkinson's disease (physicians and nurses, senior living facilities, home healthcare providers, nursing homes, public libraries, churches, senior centers, and support groups). The initial focus will be upon underserved areas such as rural communities where needs are growing and unmet. There are over 130,000 newly diagnosed individuals with Parkinson's disease on an annual basis in this country. By raising the awareness, this project will encourage early and accurate diagnosis. With education, patients and their physicians can better manage symptoms with proactive treatments and life-style modifications.

Jack, & Billie Tyler, Rhonda Lawrence, Bob Goldsticker, Roxanne DeLapp, Joe Lambing

On March 19 the Fraternal Order of Eagles charity team Chairman and Co-Chairmen, Rhonda Lawrence and Billie and Jack Tyler, presented their first check for $10,000 to Bob Goldsticker, Greater St. Louis APDA Board Vice-President. Joe and Roxanne expressed pride that the charity is moving along so well and that "reaching our goal is looking very promising." The final check for this DVD program will be presented to Debbie Guyer in June, and they are looking forward to seeing what the state Aerie and Auxiliaries have raised to "ease the burden" of those individuals and families who struggle with this devastating disease. The State Presidents feel privileged to help with the education of residents of Missouri and the benefit to all Parkinson patients across the U.S. who will benefit from *Takin' It to the Streets*. ■

USEFUL RESOURCES

New books in our Resource Library

Swallow Safely—How Swallowing Problems Threaten the Elderly and Others: A Caregiver's Guide to Recognition, Treatment, and Prevention by Roya Sayadi, Ph.D., CCC-SLP, & Joel Herskowitz, M.D.

Take Charge of Parkinson's Disease – Dynamic Lifestyle Changes Put YOU in the Driver's Seat by Anne Cutter Mikkelsen with Carolyn Stinson

What's Shakin'—An Insider's Look at the Humorous Side of Parkinson's Disease by John Brissette

Websites worth visiting

www.laweasy.com

This site is run by Martin Shenkman, JD, MBA, CPA. Martin's wife has MS and his brother-in-law has Parkinson's disease. Martin and his wife started a not-for-profit called Law Easy. Their mission is to educate professional advisers on planning for clients living with chronic illness, to educate consumers, to build awareness, and to help charities serving those living with chronic illness raise money. Law Easy's goal is to get meaningful legal information available to the masses since generally only those with wealth can afford good legal services. The goal of **www.rv4thecause.org** is to create a planning resource for those living with chronic illness and their advisors.

http://www.teachparentstech.org

Peggy Neufeld, PhD, OTR/L, FAOTA, wanted us to share this with seniors who might benefit from easy instructions on how to carry out Internet/computer functions. Browse through the left sidebar to see all the video how-to instructions. ■

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

NON-PROFIT
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PAID
ST. LOUIS, MO
PERMIT NO. 1032

SAVE THESE DATES!

Please call the satellite resource center at 636-537-5455 to make certain we have a volunteer available to meet you at the time when you'd like to stop in to visit our center (1415 Elbridge Payne, Suite 168, off the Chesterfield Parkway near Clarkson Rd., behind PF Changs parking lot)

Mon., May 16 **Nat Dubman Memorial Golf Tournament**

Lake Forest Country Club in Lake St. Louis

For those of you wishing to register for our annual golf tournament, there are still spots available for individuals and foursomes. Call the center to request your invitation or visit our website **www.stlapda.org** for further details. Please support the restaurants/vendors who have already committed to returning this year to provide golfers with a complimentary lunch on the course: Donatelli's, Flemings Prime Steak House & Wine Bar, Viviano's of Chesterfield, Sheraton Westport, and The Ritz-Carlton.

Mon., May 23 **California Pizza Kitchen Fundraiser**

Be sure to visit or call in an order for pick up from the California Pizza Kitchen nearest to your home or work place on Monday, May 23, to support the Greater St. Louis Chapter. **Clip out the flyer on page 14 of this newsletter, present it to your server, and 20% of the value of your order will be donated to the St. Louis APDA.** Supporting your favorite charity never tasted so good!

Mon., October 10 **Focus on Fashion "Guys & Dolls"**

Sheraton Westport Chalet in Creve Coeur

RSVP required; invitation to follow.

Volunteers wanting to serve on the fashion show or auction committee are encouraged to contact the center.