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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."

LEVODOPA-CARBIDOPA INTESTINAL GEL— A NEW DELIVERY SYSTEM FOR AN OLD DRUG

Paul T. Kotzbauer, M.D., Ph.D., Assistant Professor, Department of Neurology, Movement Disorders Section, Washington University School of Medicine

Ongoing clinical studies are currently evaluating a promising new delivery system for levodopa-carbidopa, one of the most commonly used drugs for managing the symptoms of Parkinson's disease (PD). This new approach uses a pump to deliver the medication to the small intestine, and aims to overcome issues such as variable absorption and short half-life that can limit the drug's effectiveness when taken in tablet form.

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

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

When people with Parkinson's develop difficulty with either "wearing off" or dyskinesias, symptoms can sometimes remain well-controlled by adjusting medication doses to keep levodopa levels in the optimal range, or by adding other medications that work in combination with levodopa. However as time goes on, "off" periods and dyskinesias may become more challenging despite attempts to optimize medication.

Deep brain stimulation surgery is a current treatment option that can improve fluctuations, but an additional option to directly address the fluctuations in levodopa levels is currently being evaluated. Carbidopa-levodopa has been formulated into a gel that can be delivered directly to the small intestine by a pump. A tube is inserted through the skin of the abdomen into the small intestine. The intestinal gel infusion system then continuously delivers the medication to the small intestine, the place where it is normally absorbed. This bypasses the unpredictable time required for tablets taken by mouth to move from the stomach to the small intestine. The pump can be programmed to deliver the gel at a rate that is optimized for each individual, a potential improvement over the irregular delivery that occurs with tablets. The risks of the surgical procedure required to insert the tube and the need to carry the pump are potential drawbacks, but the pump can be carried in a number of ways including a belt bag worn around the waist.

Studies of the levodopa-carbidopa intestinal gel delivery system have been previously

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EDITOR
Deborah D. Guyer

GRIEVING LOSSES WITH PARKINSON'S DISEASE

Jeff Shaw, Psy.D., Booth Gardner Parkinson's Care Center

The saying, "Adversity is the workshop for growth" comes to mind when I think about a person being diagnosed with Parkinson's disease. The process of receiving the Parkinson's diagnosis is usually both a relief and an overwhelming experience. It is comforting to finally have an explanation for the symptoms that gradually crept up over the years. However, the prospect of being diagnosed with a condition that is expected to get worse over time and has no present cure can feel demoralizing. We often assume the worst will happen and we worry about being severely disabled and completely dependent on others. Diagnosis can also be a workshop for worry and insecurity.

People have been found to have a fairly predictable way of dealing with bad news. Grief is a natural and expected response to loss. The duration of grieving varies quite a bit from one person to another and each person will go through the process a little differently. The five common stages of Grieving have been labeled Denial, Anger, Bargaining, Depression, and Acceptance (as identified by the author Elizabeth Kubler-Ross). At the time of diagnosis, many individuals will doubt that the condition really is Parkinson's. At this time, people are often vulnerable to false promises of alternative treatments that profess to cure or stop the progression of Parkinson's.

Ignorance Is Bliss

The Denial phase is time where hope remains strong, and there is quite a bit of energy expended on getting additional opinions and potential treatment options. Family members may be distressed and the diagnosed individual may show poor motivation to follow up with treatment. Alternatively, family members may deny the diagnosis is correct, or overly invest in the belief that there is an available cure. Denial is not necessarily bad, as it allows for individuals to deal with the situation a little bit at a time and can help foster hope. Denial is problematic when it prevents people from making necessary changes or adjusting plans.

Who Is to Blame?

The second phase of grieving, Anger, is often directed inward, believing that we caused the Parkinson's. Alternatively, we may blame others (including our relatives) for genetic or environmental risk factors, or our employers for putting us in the way of harm. We may question our belief system for allowing such a condition to happen to us. Often we become angry at the diagnosing doctor or at Science and Medicine for failing us. Anger is often helpful as it can be energizing, but it can have the negative effect of stirring up more conflict and alienating those who try to help us. Anger is often directed toward those that provide care, and cheats them of the rewards associated with being a caregiver. Caregivers may therefore physically and/or emotionally disengage from us, making us even angrier at the world.

Let's Make a Deal

The Bargaining often involves magical thinking. We may believe that if we act a certain way, the reality of the diagnosis will disappear or there will be no progression of symptoms. Bargaining can be helpful in that sometimes people adhere more to an exercise or treatment regimen. It can be unhelpful if the belief or action takes away from proven treatments and activities.

Getting Closer

Depression signals that we are wrestling with the negative aspects of the diagnosis (both real and imagined). Often depression sets in because the imagined

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GRIEVING

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future is more negative than it actually will be. Depression is strongest when it focuses on a negative view of one's self, a negative future, and a view of the world as being a cold, flawed place. Depression often resolves with the stage of Acceptance, which incorporates the losses with a balancing sense of realistic hope and faith in one's ability to cope with adversity. Concerns regarding physical changes can be balanced by reassurance that there are ways of adapting activities despite some limitations.

Do I Need to Use All Stages?

Why not cut out all those useless stages and simply start with Acceptance? As it turns out, the process of exploring options and feeling overwhelmed is often necessary to integrate all possibilities and to remind an individual of his or her personal fortitude and coping abilities. Thanks to the stages of Denial and Bargaining, many people do stumble onto very helpful resources. A relatively brief period of depression allows us to experience the losses, and then work through them. Parkinson's can be particularly tricky because it often involves a series of multiple losses. As we learn to settle for reduced agility, there may be additional difficulties with speech volume, multitasking, and increased risk while driving. There can be financial pressures, loss in confidence, and humility associated with receiving more help from others. Many of these losses are common as people age, but Parkinson's disease seems to accelerate the difficulties. Many people struggle with losing credibility in relationships and feel as if they are treated like children.

Zero to Coping in Six Seconds

People who reach the acceptance stage the easiest tend to be those who have already struggled with adversity and found answers to the questions, such as "Why Me?" Acceptance involves seeking advice from others to help balance initial reactions of denial and anger. Openness to input from others is very important. We often need reminders of how we have coped with adversity before, and a vote of assurance that we can do it again (even if it takes some help). We can attend support groups to receive guidance from others who have been stuck in the same places (and we may help to un-stick others). We need to take perspective from a spiritual point of view. We will need to be flexible in adjusting to situations that are seemingly unfair. We make statements like "This is my life, and I will make the best of it" and "That was then, this is now." We start off thoughts with "I am lucky because…" We will be gracious care-receivers and allow others to see our appreciation for their caregiving. We will care for others in need. We will maintain and develop friendships, and find purpose in our lives. Acceptance includes appreciation of the fact that life is filled with struggles and there are some aspects of our future that remain beyond our control. We remember that our partners and care providers are likely experiencing similar losses. Acceptance involves taking the good with the bad, and focusing our energies in a helpful direction. Acceptance is a process. ■

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Article appeared in the September-October 2010 Pathfinder *newsletter.*

DELAY THE DISEASE—FUNCTIONAL FITNESS

David Zid

SQUAT AND WIDEN

Place a short exercise band around your knees so you have some resistance while in a squat stance. Perform 10 – 20 squats with knees far enough apart to maintain resistance on the band.

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.

Incontinence

Every time I mention incontinence, it draws the attention of everyone in the room. The active use of the pelvic floor muscles is directly related to your ability to have adequate bowel and bladder control. These exercises will help alleviate this problem, as well as prevent future loss of bowel and bladder control. If you don't have a problem with incontinence, do you want one? So get moving! ■

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

SQUAT AND SQUEEZE

Stand erect and hold a pillow or playground ball between your knees. Perform a squat while squeezing the ball between your knees. Continue squeezing the ball throughout the entire squatting motion. Repeat 10 – 20 times.

Love & Other Drugs Sheds Light on Issues Faced by Individuals with Young Onset PD

Rich Hofmann, Co-Facilitator of the Living & Working with PD Support Group

When Russ Kirkland, Jeff Wilsey and I formed the "Living and Working with PD" Support Group in 2008, we sought to focus on the issues of interest to PD patients who were still working and/or supporting their families, including those not employed outside the home. We categorized these issues into three areas: financial, physical and personal. As time went on, we later realized that we also had three types of members: singles, married individuals with children at home, and empty nesters, perhaps the fastest growing group of people with Parkinson's.

The recent movie *Love & Other Drugs* is an excellent love story that sheds light on issues facing young onset PD patients, especially the relationship issues of a young single woman. It has a happy, reaffirming Hollywood ending, to the extent that any story about PD can be considered to have a happy ending. I offer the following as a review of the movie and a commentary on other issues faced by young onset Parkinson patients.

Financial Issues

In our first year, our support group focused on the severe financial issues faced by early onset patients. It is understandable that a romantic film would gloss over these issues. Although the Anne Hathaway character seems to be an independent artist, she always has lots of cash for doctors and medications. Most of our members do not. They worry about how much longer they will be able to work and how they will be able to support themselves and their families as their condition deteriorates. Although many of our members have very supportive employers who accommodate them as best they can on the job, others have had to leave jobs in which they can no longer perform. Once diagnosed, people with Parkinson's have difficulty obtaining disability or medical insurance other than through their employer. Then, if they are not old enough or disabled enough to be eligible for Social Security or Medicare benefits, they become solely dependent on their partner (if they have one) for both financial and physical support.

Physical Issues

In our second year, our group focused on medication, exercise, safety, dietary and other "daily life" issues for addressing more advanced PD symptoms. For our members, these issues are generally no different than for "late onset" Parkinson patients with the exception of occupational therapy. Occupational therapists tend to focus on helping patients alter their home environment so they may lead a normal life, as much as possible. Our members are more interested in altering their work environment or job description so they can remain employed as long as possible.

Because the movie is intended to be an upbeat holiday romance, the Hathaway character exhibits only a minor tremor. She has yet to experience the ever increasing symptoms that we deal with everyday. The film does expose the audience to these symptoms when the Hathaway character is invited to attend her first young onset PD support group meeting while attending a pharmaceutical convention in Chicago with her lover. The camaraderie and interaction do wonders for her outlook and self-esteem.

Caution #1: In order to lighten up the presentation of these issues, the film's directors chose to structure the support group's meeting more like open-mic night at a risqué comedy club; i.e., some members use profanity to express their feelings about the disease. Just cover your ears. You already know what they're angry about.

Personal Issues

For some time now, our group has been trying to find someone to speak to us about the psychological and family dynamic issues for PD patients and their partners. In some cases, these "personal" issues may be the most important for young onset patients. This hit home for me while watching the film. While I was focused on the "technical" PD-related aspects of the film, I was slow to notice the impact the movie was having on my wife, Sue. One scene brought her to tears when Hathaway's lover, while entering the support group meeting room, encounters the spouse of a late stage PD patient bolting out of the room and admonishing him to leave his partner and run away as fast as he can (before living through the advanced stages of development of the disease).

The reactions of partners to the diagnosis of young onset PD range from total denial of the disease to total rejection and abandonment of the partner. Rather than accept an inevitable reality, Hathaway's young defiant lover sets out to "fix her," only to be frustrated that there are no drugs to cure her or to prevent advancement of the disease. This is a common reaction for young onset PD patients and their partners. Eventually he concedes defeat and in the end commits to staying with her for the long term, and there is nary a dry eye in the theater.

The key question is, will he still be around for the sequel? Many partners split when their relationship does not evolve the way they had anticipated. Other partners seek therapy to cope with the stresses and frustrations of assuming the role of both breadwinner and care provider, especially when they have to stand by and watch their loved one slowly fade away.

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LOVE & OTHER DRUGS

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Caution #2: Early on, the film does contain nudity and sex in scenes which may be offensive. Close your eyes and stay with it. I believe these scenes were included to highlight the despair and reckless abandon of a single young onset patient who fears that she will never be able to find a partner willing to marry someone who is "damaged goods."

PD issues aside, the film is informative about:

- drug company marketing strategies to generate demand for their products by running commercials and courting doctors and/or their staff to pass out samples and prescribe their products
- the plight of "late onset" patients in trying to find affordable medications
- the frustrations of doctors (especially internists), in dealing with insurance companies while trying to survive financially in the current managed care medical environment.

In conclusion, I hoped that there would be enough romance, sex and social commentary in the film to make it successful at the box office, and in doing so, educate the general public about some of the issues faced by people in our "Living and Working with PD" Support Group. Unfortunately, that didn't seem to happen, and the film disappeared quickly from the theaters. Some of you may want to recommend renting the film (noting the cautions above) to friends or loved ones who are interested in learning more about the disease and issues faced by PD patients and their families. But for Parkinson patients themselves who may consider renting or buying it, I warn that this look in the mirror may be a difficult one, especially for our partners. Instead, we should use the film ourselves as a personal reminder to always be very appreciative of our partners, family members and friends who support us. ■

PD RISK IN URBAN AREAS

Allison W. Willis, M.D., Assistant Professor, Department of Neurology, Movement Disorders Section, Washington University School of Medicine

Many risk factors have been proposed for Parkinson Disease (PD), e.g., pesticides, magnetic fields, well water, and metals. However, most of this data was obtained using small study groups in isolated parts of the country. Our recent data suggested that when the incidence (number of new cases of PD/ total population) is calculated for the entire country, PD clusters in the Midwest and Northeast. Many studies of PD have focused on risk factors in rural areas, and have suggested that high dose exposure to herbicides and pesticides increase risk in those areas. My research interest is in the environmental risk factors which exist for those who live in urban areas, not on a farm or near sprayed crops. To investigate this further, we performed a study to look into the incidence of Parkinson Disease in urban areas according to local amounts/ variations of pollution. The pollutants we chose were metals: copper, manganese, and lead, as these are all pollutants that may cause nervous system injury, and have been associated with PD in other studies.

From our Medicare beneficiary data, which identifies 500,000 PD cases per year, we located 35,000 people with PD who lived in an urban area, had not moved for at least 10 years before their diagnosis, and whose diagnosis had been made or confirmed by a neurologist. We estimated copper, manganese, and lead amounts using the Environmental Protection Agencies Toxic Release Inventory data, which is a publically available industry release and disposal report database. We compared the incidence of Parkinson Disease in areas with the highest amounts of copper, manganese and lead.

Our study had several exciting results. First, we found that copper, manganese, and lead come from many different industrial sources – from the food and beverage industry, to clothing and metal working industries. Second, the areas where these pollutants were released did not vary differently from a socioeconomic standpoint. That is, these metals are released into high and low income areas alike. Finally, the incidence of Parkinson Disease in areas with the highest manganese release was 78% higher than in those with no copper, lead, or manganese release. High levels of copper in the environment increased Parkinson's risk by 11%.

These are preliminary results which will require confirmation. However, this study is a great first step in answering the often asked question, "I do not live on a farm or use pesticides, why did I get PD?" We will follow-up this investigation by collecting information about residential and occupational histories, health habits, and clinical symptoms which will be included in a nationwide urban Parkinson Disease risk and outcomes study. If you are (randomly) selected to participate, please fill in the questionnaire and send it back! ■

Willis AW, Evanoff BA, Lian M, Galarza A, Wegrzyn A, Schootman M, Racette BA. "Metal emissions and urban incident Parkinson disease: a community health study of medicare beneficiaries using geographic information systems." American Journal of Epidemiology, *online Oct. 19, 2010.*

Funding from the National Institute for Environmental Health Sciences, the National Institute of Neurological Disorders and Stroke, the National Institutes of Health, the St. Louis Chapter of the American Parkinson Disease Association, the American Parkinson Disease Association, Walter and Connie Donius, and the Robert Renschen Fund supported this research.

Parkinson's Disease—A Family Illness

Debbie Guyer, Coordinator, APDA Information & Referral Center

I was really excited when I received an email shortly before Thanksgiving announcing the release on November 24th of a holiday movie that included a leading character with young onset Parkinson's disease. I thought the film might be a great opportunity to raise the awareness of PD in the general population, although since taking the position of Coordinator in 2007, I rarely meet a person who doesn't know someone with Parkinson's disease.

Coordinators across the country began emailing one another and making plans to sponsor various events surrounding the showing of the movie, *Love & Other Drugs*, a Twentieth Century Fox release about a young pharmaceutical salesman (Jake Gyllenhaal) who falls in love with a young woman (Anne Hathaway) who has just been diagnosed with Parkinson's disease. While the film's producers have said that their work is meant to be a love story with insight into the pharmaceutical sales industry, rather than a "disease" film, we hoped it would be an excellent opportunity to raise awareness of PD and especially the experience of young onset patients.

My husband and I went to the theater the day the movie was released. I recall leaning over to him during the movie and questioning if it had much to do with PD at all. Later that week, I received an email from Rich Hofmann, a PD patient and a co-facilitator of our "Living and Working with PD" Support Group, sharing his thoughts and concerns about the movie. "My wife and I went to see the movie on Sunday, and you may wish to think twice before hosting an event to 'screen' the film. I would also caution any members of our early onset support group before going to see it, especially with your spouse/partner."

Of course, receiving this email prompted a phone conversation with Rich, and he suggested that I also speak to his wife, Sue, about her impressions of the movie. Sue is an RN by occupation and a wife by choice. I found it interesting that she emphasized that throughout Rich's illness, she has not been interested in PD (from a medical standpoint) but rather interested in her husband and in being supportive during his journey. Her observations are that perhaps people who have been diagnosed with PD (or any other neurological disease) are so focused on trying simply to navigate through life that they may lose sight of the impact that PD has on their whole family who come along for the ride.

For Rich, the film was an epiphany on the stresses and strains that early diagnosis of the disease can have on existing and/or potential future relationships. He reflects that "PD patients fortunate enough to have care partners, whether spouses, family and/or friends, need to remember that their partners may have altered their career plans and aspirations to support them while on their journey." Sue shared her memories of when Rich was first diagnosed and several people asked her if she was "going to leave him." Sue went on to say how ridiculous a question that seemed then and now because even though you may know the outcome in a chronic illness, you are still partners and in this together. In the movie we learn, as you know all too well, that Parkinson's disease is about good days and bad days. In an interview with Anne Hathaway, she revealed that Director Ed Zwick and she wanted to be sure her character, Maggie, showed the bad days honestly on-screen. "But what so much of it is, is anxiety–anxiety of the future and learning what is happening to your body. And, so, I realized that it was so important to imbue Maggie with the psychological trauma of her diagnosis. Maggie is caught up in a world where all she can see is her disease and throughout the course of the film she learns to accept it with that wonderful line in the movie, 'Parkinson's isn't my life. I have Parkinson's. Why does it have to be my life?'"

Rich is extremely grateful for Sue's commitment, but cautions that unfortunately, not all partners are as dedicated to staying the long downhill course that is PD. So he reminds PD patients to be vigilant in expressing appreciation to their partners and not be so self-absorbed as to ignore the affect that their disease and behavior have on their partners' lives. "While our motor skills deteriorate and our cognitive skills may wane," he says, "our eyes, ears and hearts still work, so we should be aware of the feelings, and compassionate to the needs, of our care partners and families."

I quite agree with Sue and Rich and am mindful that both the person with PD and the family members actually experience this disease together. This illness does not exclusively belong to the person with the diagnosis. Developing and sustaining a support system is so important that we have recently formed a dedicated caregiver support group (check our listing) led by Dr. Dee Jay Hubbard and enlisted the services of Linda Pevnick, LCSW, as the new facilitator for the Living & Working with PD Support Group starting in February. Linda specializes in relationship counseling for individuals and couples and has significant experience working with couples coping with chronic diseases. We implemented these changes to help PD patients and their partners realize that while they can't control what happens to them, support is available to relieve stress on their relationships and facilitate living a productive, happy life. ■

IRA & CHARITIES—WORKING WELL TOGETHER

David Dankmyer, J.D., LL.M, Financial Management Partners
Jarad K. Mitchell Stiles, J.D., LL.M.

If you are planning to make a charitable gift from your estate, consider leaving your taxable IRA assets to the St. Louis American Parkinson Disease Association. If you leave an IRA to your heirs, they may face double taxation (income taxes and possibly federal estate taxes). Instead of having the federal government tax more than half of your IRA assets, you can apply 100% of those assets to a charitable purpose that is important to you. In essence, the value of your charitable contributions grow as the tax liabilities shrink…a WIN-WIN!

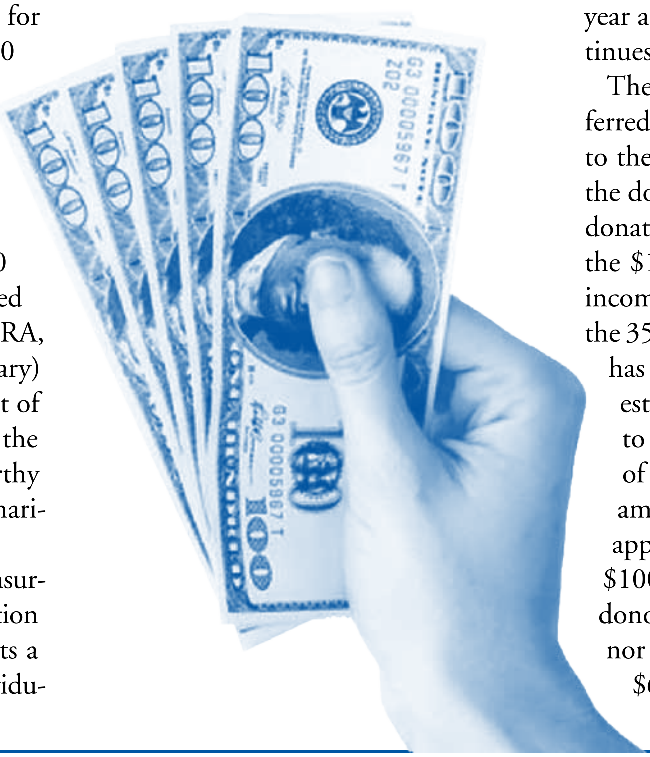
An IRA (except Roth IRAs) may be subject to two levels of taxation upon a donor's death as it is subject to estate tax and income tax levels (the lump sum is considered ordinary income). Essentially, if the donor's unified credit has been expended, the IRA is taxed at a staggering effective rate of 57.75%. This is using the rates of 2011, as currently enacted; the effective rate in 2013 is an even higher 72.1%.

To illustrate: if a donor dies in 2011 and their IRA has a value of $1 million, the donor's unified credit is expended and the taxable rate is 35%. $350,000 ($550,000 in 2013) would be due for estate taxes. The remaining $650,000 ($450,000 in 2013) is taxed as ordinary income to the beneficiary (at 35%), resulting in another tax liability of $227,500 ($171,000 in 2013). The beneficiary receives $422,500 ($279,000 in 2013). Had this IRA been gifted to a charity as a tax-free rollover IRA, the charity (listed as the beneficiary) would receive the entire face amount of $1 million. This more than doubles the charitable dollars donated to a worthy cause and is a way to spend your charitable dollars wisely.

The Tax Relief, Unemployment Insurance Reauthorization, and Job Creation Act of 2010 (Tax Relief Bill), presents a rare opportunity for qualifying individuals to make current charitable donations by rolling over their IRA to a charity. Normally, the deduction would be subject to income tax and only eligible for a below-the-line deduction, which could be subject to limitations and phase outs which could erase or minimize the tax benefits of the contribution. For 2010 and 2011, such limitations are not possible for donations of up to $100,000 from an IRA. Specifically, the Tax Relief Bill amends the Internal Revenue Code and extends tax-free rollover IRA distributions from individual retirement plans until Dec. 31, 2011.

Here is how the tax free IRA rollover works. The charity is directly transferred funds from your IRA. Any amount transferred from the IRA does not pass onto the donor and thereby the donor does not realize any income. The donor avoids paying income tax. To qualify to make a charitable tax-free IRA rollover, the donor must be qualified and the donation must be made to a charity.

To be a qualified donor, the donor must be at least 70½ years of age at the time of the distribution. The reason 70½ is the age is because at age 70½ someone holding an IRA has a required minimum distribution. If someone who is 70½ fails to take the required minimum distribution, penalties of up to 50% may apply to 401Ks and IRAs. If a donor makes distributions to a charity this will count. If the donor forgot to take a minimum distribution for 2010, they can rectify this at any time before Feb. 1, 2011 without incurring penalties.



This tax-free distribution from the IRA must be made to a qualified charity and not a donor advised fund or supporting organization. After attaining qualified donor status the amount donated from the IRA is limited to $100,000. In lieu of an income tax deduction for naming a beneficiary, it is treated as an above the line deduction, essentially never happening for income tax purposes. This is in fact better than a deduction as an above the line deduction is taken off of your gross income, and as such, is available to everyone without any phase out or limitation. The timing of the distribution is important, distributing it as late in the taxable year as possible, so that the income continues to grow.

The actual cost of the $100,000 transferred to the charity is substantially less to the donor, so there is more value for the donor's dollar. The actual $100,000 donation costs the donor less because the $100,000 donated is pre-taxed (no income tax has been paid). Assuming the 35% rate of income tax (the taxpayer has already been placed into the highest tax bracket from other income), to make this an effective donation of $100,000 in post tax dollars, the amount of money earned would be approximately $153,846.15. If the $100,000 was instead received by the donor (beneficiary of the IRA), the donor would receive after-tax income of $65,000. ■

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	Lisa Ackerman Lynda Wiens	314-725-1888 636-537-5455
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	314-355-6100
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	First 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	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 Grifford	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

APDA WELLNESS COURSE

FOR PEOPLE WITH PARKINSON'S DISEASE AND THEIR CAREGIVERS

What is a Wellness Course?

The Wellness Course is an education and support group of 10-12 people with PD and their family members who meet once a week for 6 weeks (two-hour sessions). The course is designed to develop skills and confidence for managing the everyday activities and relationships that may be challenging when living with PD.

Occupational therapists with training in Parkinson's disease facilitate the weekly small-group discussions that enable members to share ideas for resources and adaptations, express feelings and problem solve challenges. The APDA offers the course at no charge.

What will you gain from participating in the Wellness Course?

In a supportive group you can:

- Examine your lifestyle to identify obstacles and available support for feeling well
- Develop self-help skills to manage the consequences of living with PD
- Identify community resources and build supportive networks.

Course topics selected by the group members include past topics such as:

- Coping with emotional and physical changes
- Adaptations for daily living skills at home and work
- Maintaining fitness routines and healthy eating habits
- Tips for managing medications and everyday activities
- Long-range planning for life with Parkinson's disease
- Caregiver and care-receiver relationships
- Cognitive and communication concerns.

We anticipate offering two courses in 2011—one this spring and another in the summer. You must register for the course to attend. Please sign up using the form below as class size is limited and courses fill up quickly. ■

Name ______________________________

Address ______________________________

City, State, Zip ______________ Phone Number (________)______________

Best time(s) of day to attend course:

___ Morning ___ Afternoon ___ Evening

Preferred location(s):

___West County ___ South County___ North County ___St. Louis city ___ St. Charles

Other (specify) ______________________

Cut out and return to:

St. Louis APDA, Campus Box 8111, 660 S. Euclid Ave., St. Louis, MO 63110
OR fax to 314-747-1601, email to guyerd@neuro.wustl.edu or call 314-362-3299

LEVODOPA-CARBIDOPA

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conducted in Europe, where it is approved and marketed under the brand name Duodopa. Those studies indicated that levodopa levels in the bloodstream are maintained at a more constant level compared to tablets, allowing people to remain more consistently in the "on" state without troublesome dyskinesias.

Further studies in the United States are currently in progress to determine whether the levodopa-carbidopa intestinal gel (LCIG) system is safe and effective, which would enable the system to be approved by the FDA for use in this country. The Movement Disorders Center at Washington University School of Medicine is one of many sites participating in these ongoing clinical studies to evaluate this levodopa delivery system as a new option to improve the control of PD symptoms. ■

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	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

THE LOUD CROWD

The Problem: More than 1.5 million people in the United States have Parkinson's disease, a neurodegenerative disorder with familiar symptoms of tremor, slowness of movement and impaired balance. Less recognized is that nearly 89% of people with PD have difficulty simply speaking, creating an inability to be heard and understood even by family members and friends. Onset of the communication problem may be so gradual that many patients do not realize they need help until their speech has severely deteriorated, making treatment even more challenging. Early intervention is essential in maintaining the ability to communicate effectively.

The Symptoms:

- vocal fatigue
- decreased volume (soft voice)
- decreased ability to project one's voice
- hoarse, scratchy or breathy vocal quality
- imprecise articulation or slurring of words

LSVT LOUD: The LSVT method helps 90% of people with PD improve their functional communication and has been found to minimize mild swallowing difficulties. In 16 treatment sessions administered over 4 consecutive weeks, patients learn to use increased effort when communicating, improving overall strength, endurance and coordination of speech.

The LOUD Crowd: The practice doesn't stop after a month. As the disease progresses, speech can become more difficult and patients fall back into old habits. Since Parkinson's disease is progressive and continually challenging to those who have it, the LOUD Crowd group was developed through the efforts of Samantha Elandary, an LSVT certified clinician in Dallas and Director of the Texas Voice Project for Parkinson's Disease. This maintenance group was conceived to provide ongoing accountability and encouragement. Upon completion of the LSVT, patients participate in monthly group speech therapy sessions designed to maintain the communication skills they have regained through the intensive 4 week LSVT LOUD program.

Role-playing exercises and exchanges in various communication environments provide the setting for practicing the newly acquired LOUD voice (which is really a voice produced in the normal range). The group members hold conversations, read stories and

continued on next page

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	Sue Tucker, OT Mike Scheller, OT	314-289-4325
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	The Cedars at JCA	Thursday	2:30 PM	Faye Bienstock, PT	314-754-2180
Creve Coeur	St. Louis	Aquatic Exercise —Rainbow Village 1240 Dautel Lane	Thursday Oct. 7 – Dec. 16	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	Sue Tucker, OT Mike Scheller, OT	314-289-4325
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 Oct. 7 – Dec. 16	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 Davis, PT	314-658-3858

THE LOUD CROWD

continued from previous page

emit prolonged "aahhs" as the certified LSVT clinician records the decibel levels and compares the scores to the last session. Parkinson's disease skews sensory perception, leading some to speak in softer tones to the point that their vocal cords are so weak they become mute. The muscles needed for speaking and swallowing weaken from lack of use, primarily because they've received miscues from the brain for months or years. The problem starts as a sensory problem. The patient thinks they are speaking normally, but it's actually very soft. Then they lose muscle strength and the physical endurance to speak at appropriate loudness levels. Only a small percentage of Parkinson's patients (4%) ever receive speech therapy throughout the course of the disease. This LOUD Crowd group will once again be offered, in partnership with Missouri Baptist Medical Center and the St. Louis APDA incorporating practice and play, preserving skills that people with PD have worked so hard to regain.

The LOUD Crowd group will begin in May at Missouri Baptist Medical Center on Ballas Road. If you are interested in joining the next session of the LOUD Crowd, please contact Debbie at the APDA Information & Referral Center at 314-362-3299. ■

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.

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

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Parkinson Education Program—April 30, 2011

Lewy Body Dementia

April is Parkinson Awareness Month and in celebration, we are excited to announce the first Parkinson Education Program (PEP) of 2011. This educational program will be held at The Ritz-Carlton St. Louis and will feature several speakers and topics. Invitations will be mailed out in March, and reservations are required. Jennifer G. Goldman, M.D., M.S., Assistant Professor in the Department of Neurological Sciences, Section of Parkinson's Disease and Movement Disorders at Rush University Medical Center in Chicago, IL, will be our keynote speaker on Saturday, April 30, addressing the topic of "Cognitive and Other Neuropsychiatric Features in Lewy Body Disorders."

Dr. Goldman graduated from Princeton University with degrees in Psychology and Music Performance and received her M.D. from Northwestern University Medical School. She completed her neurology residency training at Washington University in St. Louis, followed by a movement disorder fellowship and a Master of Science degree in Clinical Research at Rush University in Chicago. As a movement disorder specialist, Dr. Goldman treats patients with Parkinson's disease, dementia with Lewy bodies, atypical parkinsonism, and occupational dystonia, as well as other movement-related conditions. Her research focuses on cognitive and neuropsychiatric features of Parkinson's disease and dementia with Lewy bodies.

Dr. Goldman will be joined on the program by Dr. Gary Behrman, Ph.D., LCSW, M.Div. Dr. Behrman will be speaking about "Giving Care vs. Partnering in Care." He obtained his doctoral degree in Social Welfare from the University of Albany in New York, his Master of Social Work from Saint Louis University and his Master of Divinity from St. Meinrad School of Theology. He is a Gero-Ed Center Expert Trainer on Aging with the Council Social Work Education. His research and publica-

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HELP FOR CAREGIVERS—ADULT DAY CENTERS

Maggie Menefee, M.S.W., Program Director, Adult Day Center at the Jewish Community Center

According to the Department of Health and Senior Services, the demand for informal caregivers such as family members, friends or neighbors is expected to increase by more than 20% in the next 15 years. It is estimated that in the next 40 years as baby boomers age, this will increase to 85%. Nearly 62 million Americans already care for another adult at least part time.

The toll this is placing on families has an impact on them financially, emotionally and physically. Evidence of this toll was indicated recently in a 2010 study completed by the National Alliance for Caregiving and the MetLife Mature Market Institute. The study compared noncaregivers with caregivers indicating that 11% of caretakers say they "almost always" feel stressed at home compared to 7% of noncaregivers. "The impacts can have a cascading effect" on a caregiver, says Marc Agronin, a geriatric psychiatrist and author of "How We Age." He also stated that the stress and physical demands can bring about higher medical expenses for anyone tending to another person.

Research also supports that caregivers of all ages have a heightened risk for chronic health problems. Among working women 50 and older, 20% of caregivers report just fair or poor health, more than double the number of non-caregivers, the MetLife/NAC study found. Nearly 26% of adult men under the age of 39 say the same, more than three times the rate of non-caregivers in that group. Among the most common chronic health conditions reported at higher rates were diabetes, hypertension and high cholesterol.

How to combat this and what is available?

Adult day services (ADS) centers are key providers of long-term care services in the United States. They provide a program of activities, health monitoring, socialization, and assistance with daily activities which allows individuals to continue to live in their homes and receive needed care in a supportive, professionally staffed, community-based setting.

Adult day services also benefit family caregivers by enabling them to remain in the workforce or receive needed respite and by providing them with direct services (e.g., educational programs, support groups). They provide cost-effective care, while supporting individual autonomy, allowing individuals to "age in place," and enhancing the quality of life for both participants and family caregivers.

With the projected growth in the older population and resulting increase in the number of individuals who will require long-term care, the need for community-based providers such as adult day services centers will continue to grow. Families of loved ones diagnosed with early stage dementia, Alzheimer's, the developmentally delayed, brain trauma, and other brain disorders, such as Parkinson's disease can all benefit from the services of adult day programs. The passage of the Patient Protection and Affordable Care Act (the health-care reform bill) and an increasing focus on managing chronic illness within the Medicare program speak to the importance of developing care models that will be able to meet these growing needs. Adult day services play an important role in meeting the care needs of today's population and may hold the answer to the pressing question, "How can we meet our future care needs in a fiscally efficient and ethically responsible manner?"

What to look for in choosing an Adult Day Center

As caregivers you want to consider a program that you feel totally confident with in taking care of your loved one during the day. Trust is an important factor. Some questions to consider include: What types of services will be offered? Will transportation be a part of this? Will there be an assessment to determine the appropriateness of placement? Is there adequate staff coverage for the number of participants throughout the day? Does it include medical assessments? What additional services are available for the caregiver? How do I even begin?

Whom do I contact first?

The Missouri Adult Day Services Association can provide you with a list of licensed Adult Day Centers in your community. To contact them directly simply call Ann at **573-634-3566** or go to **www.moadsa.org**. ■

PARKINSON EDUCATION PROGRAM

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tions focus on how and why people flourish following a crisis and the functions of religion and spirituality in this process. He is a frequent speaker at national and local conferences and currently teaches at Lindenwood University where he is the Department Chair and BSW Program Director. Dr. Behrman has a father with PD and can share insights on caregiving from an up close and personal perspective in addition to the professional insights he will share with the audience of caregivers only.

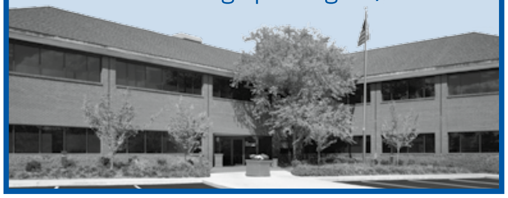
As the caregivers learn about caring for the caregiver, patients will participate in an enriching session with Amanda Landsbaum, MS, OTL/R on Adaptive Equipment -Making Life Easier and Kathy Bednarek, MA, CCC-SLP who will be demonstrating a LOUD Crowd session.

If you do not receive an invitation to this special event by April 1, please contact the Center at 314-362-3299 to request one. ■

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

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)



Sat., April 30	**Spring PEP Meeting: Inform, Enlighten & Enrich** Dr. Jennifer Goldman "Cognitive & Other Neuropsychiatric Features in Lewy Body Disorders" Dr. Gary Behrman "Giving Care vs. Partnering in Care" Amanda Landsbaum "Adaptive Equipment Available to Make Life Easier" Kathy Bednarek "Let's Talk LOUD!" 10:30 am–2:30 pm (lunch provided) The Ritz-Carlton in Clayton RSVP required; invitation to follow
Mon., May 16	**Nat Dubman Memorial Golf Tournament** Lake Forest Country Club in Lake St. Louis RSVP required; invitation to follow
Mon., May 23	**FUNdraiser** For those who dine at CPK on this date AND present the flyer, CPK will donate 20% of their check (food & drink) back to the APDA, excluding tax and tip. Look for the special flyer to be distributed in the May newsletter and at other events. California Pizza Kitchen (CPK), all 4 St. Louis locations: Creve Coeur, Chesterfield Mall, St. Louis Galleria, West County Shopping Mall
Mon., October 10	**Fashion Show & Luncheon** Sheraton Westport Chalet in Creve Coeur RSVP required; invitation to follow