OCT, NOV, DEC 2011

INDY PD UPDATE

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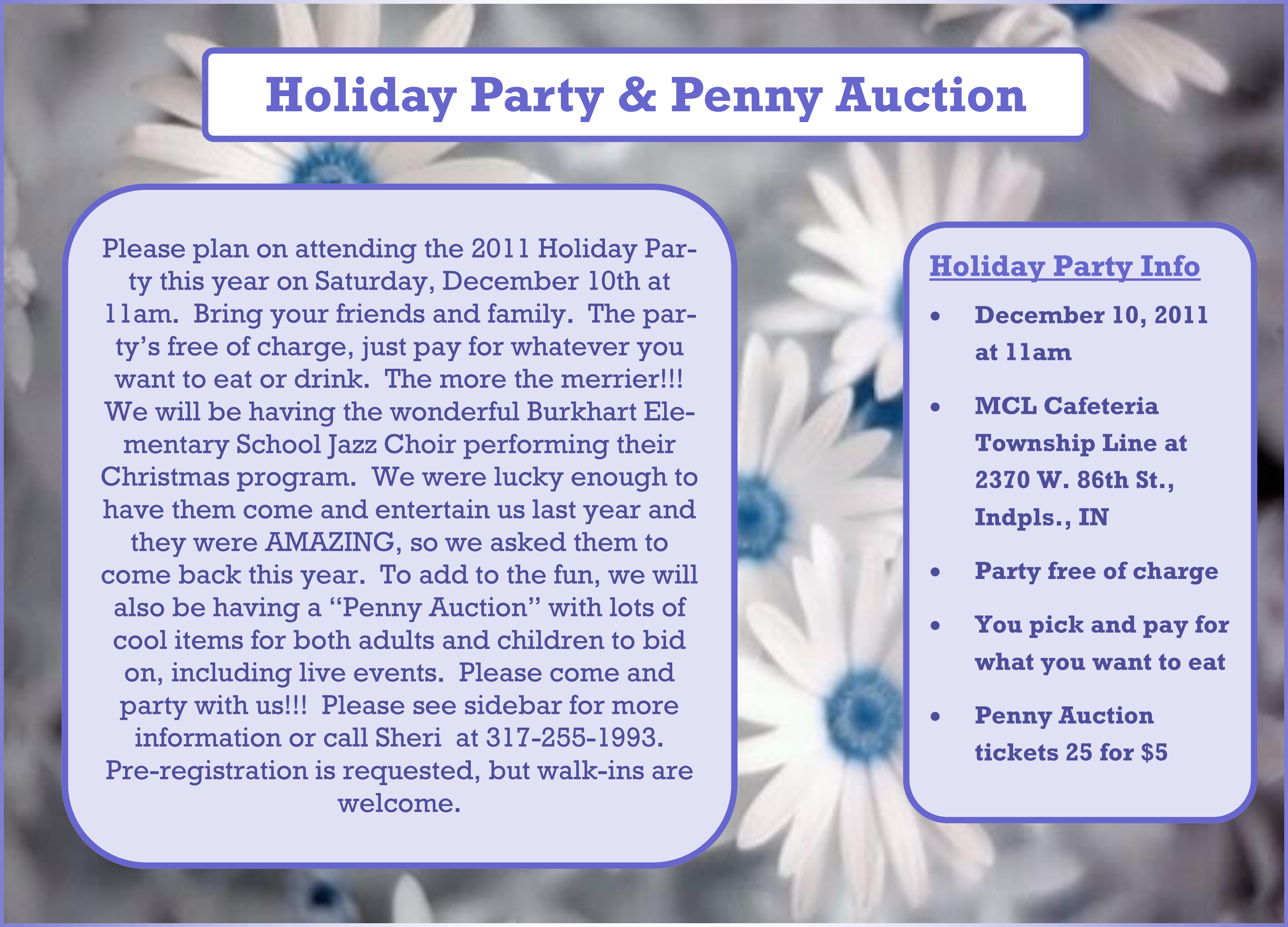

Holiday Party & Penny Auction

Please plan on attending the 2011 Holiday Party this year on Saturday, December 10th at 11am. Bring your friends and family. The party's free of charge, just pay for whatever you want to eat or drink. The more the merrier!!! We will be having the wonderful Burkhart Elementary School Jazz Choir performing their Christmas program. We were lucky enough to have them come and entertain us last year and they were AMAZING, so we asked them to come back this year. To add to the fun, we will also be having a "Penny Auction" with lots of cool items for both adults and children to bid on, including live events. Please come and party with us!!! Please see sidebar for more information or call Sheri at 317-255-1993. Pre-registration is requested, but walk-ins are welcome.

Holiday Party Info

- **December 10, 2011 at 11am**
- **MCL Cafeteria Township Line at 2370 W. 86th St., Indpls., IN**
- **Party free of charge**
- **You pick and pay for what you want to eat**
- **Penny Auction tickets 25 for $5**

This Newsletter courtesy of Teva Neuroscience.

Symposium was great!

Look for articles and pictures from the Symposium in the next newsletter. Special thanks to our event sponsors: ***Teva Neuroscience and UCB.***

Inside this issue:

Putting the Brakes on Driving

By: Nancy Pressner, R.N., Caregiver

One of the biggest life changes associated with the progression of Parkinson's disease is the point at which driving a car is no longer a possibility. This is a very difficult freedom to lose as we have had this privilege, which enables us to be independent, all our adult lives. Some Parkinson patients recognize the need to no longer drive, but others will cling to this ability and fight for it to the very last moment. This puts the responsibility on the caregiver or those closest to them to protect their safety and that of others.

Several symptoms of Parkinson's disease can interfere with the ability to drive, which is a complex task even without difficulties. Tremors in various limbs or the head, stiffness of the trunk and limbs, the bradykinesia (slowness of movement), and impaired balance can make the physical act of driving a real challenge. Add to that, the cognitive deficits which can develop, with language, thinking, and problem-solving impairments. These symptoms all develop and progress over varying lengths of time for each individual.

> It is important to stress that the safety of your loved one is your primary concern.

Another factor to consider is that of medication side effects. Many Parkinson meds can cause drowsiness, while others can lower blood pressure which may cause dizziness. Either way, it may be necessary to coordinate the timing of taking meds with the time you plan to drive. It is important to discuss the issue of continued driving with your physician. They can refer you to an occupational therapist or a specialist in your area who can give you an off-road driving test to assess that your driving skills are still quick and safe enough to allow you to be on the road. The Association for Driver Rehabilitation Services at 1-800-290-2344 or their website www.driver-ed.org will also help you find a person near you who does these evaluations.

> It may be necessary to coordinate the timing of taking meds with the the time you plan to drive.

As a caregiver, it is important for you to observe your loved one for everyday signs that continued driving may not be advisable. Some of these are poor coordination, confusion or memory loss, difficulty judging depth and distance, and a decreased ability to multi-task, make decisions or process new information. Even if a specialized evaluation shows that the person with Parkinson's can still drive safely, they will still require close and frequent monitoring. You should also watch for driving too slowly, stopping in traffic, straying out of the lane, not heeding traffic signs, getting lost or disoriented on familiar routes, becoming drowsy while driving, and not noticing pedestrians, other vehicles and road hazards.

So how do you actually approach the subject of driving cessation with the patient? Most of the time a serious, honest discussion with the person with Parkinson's along with your family members or a physician will be enough to encourage your loved one to taper back or cease driving. Limiting driving routes and their length and time of day is a start. It is important to stress that the safety of your loved one is your primary concern. They must also think beyond themselves to ensure the safety of others who could be injured by just the tiniest miscalculation in their driving (ie. another car full of passengers or a child on the sidewalk). It is wise to begin the transition from driver to non or limited driver ahead of time by arranging alternate forms of transportation. Arrange with family and friends to provide rides. Also, most communities have taxis, public transportation, shuttles or vans, many offered at a discounted rate.

In the event that the person with Parkinson's refuses to voluntarily stop driving, a more aggressive plan of action may need to be followed, which includes hiding the keys, disabling the car or removing the car from their accessibility. It may also be necessary to involve your local police department to insure they remain off the street, if they are a definite threat to public safety.

This is clearly one of the most difficult and devastating sacrifices that Parkinson's disease forces upon most people. As a caregiver you must remain strong in encouraging the right decision at the right time, with support if needed. The last thing your or your family need is an additional impairment or tragedy for someone already dealing with this difficult challenge.

Depression Series 3rd Edition
By: Joseph Pressner, Ph.D.

This is the third in a series of articles providing suggestions for those suffering from Parkinson's Disease and their caretakers on managing the stresses of the disease. The first article provided the basis for this approach and suggested record keeping for the purposes of an experiment. The second article focused on interpreting the record keeping, and discussed the impact of thoughts on our emotional well-being. This, the third article in the series, focuses on methods that we can use to deal with these thoughts and thus to lessen anxiety, depression, and the stresses that we experience.

Before this though, I would like you to imagine something. As vividly as you can, imagine someone coming up to you and feigning a punch to your mid-section. Try to see the person, and to see the punch. Now scan your body and you will probably notice how your abdominal muscles involuntarily tightened. That's probably only the tip of the iceberg in terms of how your body has been charged. It's highly likely that MOST of your muscles have tensed up – even the frontalis muscle in the middle of your forehead, and we're imaging a feigned punch to your mid-section.

Now thoughts are like that too except that they are more insidious. Each negative thought is like a pesky little jab that is extraordinarily effective in striking us at our weakest points because of how well targeted they have become over the course of the years. Each pesky little 'thought-jabs' causes us to tense up, to be stressed, to become depressed, to become anxious – in both mind and body. Hopefully because you have done your homework from the first two articles, you now have first hand knowledge of how this works.

The question then is what we do when those pesky thoughts dance in front of our minds? That is what this article is all about. It's going to describe what you might begin to practice when you notice yourself angry, anxious, depressed, or physically tensed up.

One of the things that has struck me (as it has struck others who are far more knowledgeable than I) is the similarity between the approaches taught by wonderful teachers from widely diverse backgrounds. The ways that Christian teachers, Buddhist teachers, and more recently medical and mental health professionals all advocate are surprisingly similar even though they come from very different points of reference. We will look briefly at all three approaches so that you can see what I mean.

First, let us consider one Christian approach. Rev. Thomas Keating is a Trappist monk who has written over twenty books on meditation, contemplation, and radical self-acceptance. He is now 88-years-old, and remains an active teacher and spiritual guide. (By the way if you Google his name you can find some video clips of him teaching on You Tube). He and others following his lead have an approach called "The Welcoming Prayer" that describes what we might do with those thoughts of past or future that we find so troubling.

If you have practiced the homework, you should have some ability at this time to recognize the thoughts that you might be having at any particular point in time. Suppose that you are having one of those thoughts right now – a worry about bill paying tomorrow, regrets over something you said yesterday, etc. What might you do?

The first step in the Welcoming Prayer is to notice not only the thought, but the body sensation, and emotion that you might be experiencing at that point in time. They advise "sinking into the feeling," not fighting it at all. Instead they advise letting yourself experience the moment.

The second step is counter-intuitive. Most of us will do anything that we can to run away from such discomfort. Our natural tendency is to try to ignore the discomfort, to pretend that it isn't there, or to decide that we are going to just "tough it out." Instead they advise *welcoming the experience* – to acknowledge that the feeling, the thought, the emotion is simply where we genuinely are at that point in time. It's okay to be experiencing this. Anyone in your shoes would be experiencing this.

The third step is letting go of the thought, the feeling, the emotion. This means simply letting the emotional energy that charges the event to pass. We realize that all thoughts, or emotions are only temporary and will blow away like the clouds. It may help to recite some simple phrases each with a relaxing breath to facilitate this process:

"I let go of the desire for security" – while slowly exhaling.
"I let go of the desire for affection" – while slowly exhaling.
"I let go of the desire for control" – while slowly exhaling.
"I let go of the desire to change this feeling" -- while slowly exhaling.

These statements are quoted from the e-course on Welcoming Prayer by Spirituality and Practice.

What will happen when you do this? I cannot predict, but I do know that whatever it is that you might experience will be human and genuine. You may find some immediate relief – perhaps increasing peace. However, you may not notice a difference at all.

Yet if you get into the habit of doing this many times throughout the day, (and you might notice that this will not at all disrupt your day. No one will even notice what you are doing!) your perspective on your life will begin to change moving you towards greater peace, and greater resilience in the face of the stresses that life provides.

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It's an extraordinarily simple process. You are probably tired of hearing this from me over and over again, but I think that I should repeat that this is not a magic pill or some fast food fix. It is a process which over time, and with repeated practice will bring positive results.

Now, let us look at a very similar set of suggestions from a Buddhist point of view. Pema Chodron in her book **Taking the Leap** wrote "Someone once sent me a bone-shaped dog tag that you could wear on a cord around your neck. Instead of a dog's name, it said, 'Sit. Stay. Heal.' We can heal ourselves and the world by training in this way." Every time I read this it makes me smile and makes me want to get one of those tags.

Chodron described the specifics of the approach later in her book. She wrote, "One of the most helpful methods I've found is the practice of compassionate abiding. This is a way of bringing warmth to unwanted feelings. It is a direct method for embracing our experience rather than rejecting it. So the next time you realize that you're hooked, you could experiment with this approach. Contacting the experience of being hooked, you breath it, allowing the feeling completely and opening to it. The in-breath can be deep and relaxed – anything that helps you to let the feeling be there, anything that helps you not push it away. Then, still abiding with the urge and edginess of feelings such as craving or aggression, as you breathe out you relax and give the feeling space." Although she does not describe a "one, two, three approach" or specific phrases, her approach of "compassionate abiding" seems very much like the approach by Father Keating and his associates.
Given these similarities it probably shouldn't surprise us too much to find that similar techniques are being practiced and heavily researched by the western scientific community as well.

Perhaps the most influential scientific voice in terms of mindfulness and meditation is Jon Kabat-Zinn who received his Ph.D. in molecular biology n 1971 from MIT. In mid-life he became very interested in eastern thought. Since then he has researched and promoted the usefulness of meditation and mindfulness practices for many severe, chronic illnesses. His most famous book, **Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness** is on the recommended list for both patients and caregivers by the Washington Chapter of the American Parkinson Disease Association.

Perhaps of greatest importance for members of Parkinson's Associations is the fact that last year a study was published documenting the helpfulness of Kabat-Zinn's program for *Parkinson's patients*. ("A qualitative analysis of mindfulness-based cognitive therapy (MBCT) in Parkinson's disease" by Fitzpatrick, Simpson and Smith **Psychology and Psychotherapy: Theory Research and Practice** June, 2010).

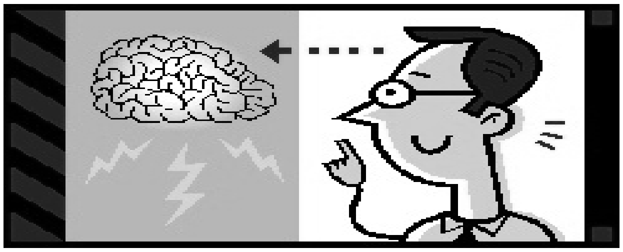
Kabat-Zinn has developed a very rigorous, detailed program that can be practiced on an individual or group basis. For anyone interested I would highly recommend **Full Catastrophe Living**, and would also recommend his book **Wherever You Go There You Are.** Kabat-Zinn's program goes far beyond what we are writing today, but aspects of his program are similar to those of Keating and Chodron described above. One brief quote from **Wherever You Go There You Are** illustrates this.

He wrote, "Experiment with being soft when your impulse is to be hard, generous when your impulse is to be withholding, open when you impulse is to close up or shut down emotionally. When there is grief or sadness, try letting it be here. Allow yourself to feel whatever you are feeling. Notice any labels you attach to crying or feeling vulnerable. Let go of the labels. Just feel what you are feeling, all the while cultivating moment-to-moment awareness, riding the waves of 'up' and 'down,' ''good' and 'bad,' 'weak' and 'strong,' until you see that they are all inadequate to fully describe your experience. Be with the experience itself. Trust in your deepest strength of all: to be present, to be wakeful."

I think that there are some significant commonalities in all of these approaches. It may be helpful to us to stop avoiding, running away, or denying our pain both physical and mental or doing the opposite by catastrophizing it. We can face that which is making us anxious, depressed, or angry, without analyzing it or judging it Rather, by using one of the techniques described above, we can learn to let it go.

Chodron wrote, "Gradually we can begin to cherish the preciousness of our whole life just as it is with its ups and downs, its failures and successes, its roughness and smoothness," and with that can come greater peace, serenity and capacity to face all of life's difficult challenges." I can attest to that.

Brain Donation: The Ultimate Gift



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. 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. Sometimes brain donation can be done at no charge to the family, if you participate in a particular dementia study that results in brain donation; otherwise brain donation can cost up to $2,000. If you are interested in donating your brain after passing please speak clearly with your physician regarding your wishes to donate your brain and your desire to find a study that may allow you to do this at no charge to your family. For instance, the study currently being done at the Indiana Alzheimer's Disease Center, which includes autopsy and brain donation is called the CORE study. If you're interested in this particular study please call 317-274-4939 or for general information about brain donation please call Leo at 317-274-4398. Special thanks to Johanna Hartlein, Nurse Practioner and Research Coordinator, Washington University School of Medicine and The Link, St. Louis APDA for sharing this article with us.

Hospice Care: High Quality Care At The End of Life

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 care 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

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Hospice ….Continued from page 5

and may cover supplies such as incontinence products.

The hospice provider must also cover the cost of certain medications. The medication 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 a 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. 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.

This article courtesy of Stacey K. Barton, MSW, LCSW, Clinical Social Worker, Dept. of Neurology, Washington School of Medicine and The Link, St. Louis APDA.

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

Help with Medications

Medicare currently offers a low-income subsidy for prescription drug costs. If you are

-currently enrolled in Medicare Part D drug benefit program

-receiving the Medicare Low-Income Subside for prescription drugs

-over the age of 65 and receiving Medicaid

You may be eligible for brand name prescription co-pays of $6.30 or less. To apply call Social Security toll-free at 1-800-SSA-1213 or visit www.socialsecurity.gov/extrahelp.

If you aren't eligible for low-income subsidy you might be able to get help with your prescription drugs through the drug company that makes your drug. Even if you are not generally eligible for help you might be eligible during the "donut hole" of medicaid, but you must include the information that you are in the "donut hole".

PAACI Now Accepts Credit Cards!

Please consider making your end-of-year tax-deductible donation to PAACI this year, or if you'd prefer you can set up a small monthly donation with your credit card.

Name:____

Phone:____

Donation Info: Circle One

Amount:_______________ one-time or monthly

Card: (circle one) Mastercard Visa Discover

Card #:____

Expiration Date:_______________ CVV2 Code:______________

(CVV2 Code is the 3 digit code on the back of the card)

In Honor/Memory of:_________________________________

Please Notify:_______________________________________

Address:____

City, State, Zip:_____________________________________

Comments:____

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Upcoming Webinars from the Parkinson's Disease Foundation

These webinars are free, but you must register. You can participate via a toll free number or via the web. Registration is available approximately 4 weeks prior to the event. Visit http://www.pdf.org/ or call 800-457-6676 for more information or to register. This year's PD Expert Briefing series has been made possible by an educational grant from Teva Neuroscience.

Caring for a Person with Late Stage Parkinson's

Tuesday, November 22, 2011, 1:00PM ET- 2:00PM ET

Driving & Parkinson's: Balancing Independence & Safety

Tuesday, January 31, 2012, 1:00PM ET– 2:00PM ET

A Closer Look at Anxiety and Depression in Parkinson's

Tuesday, March 6, 2012, 1:00PM ET– 2:00PM ET

Parkinson's Medications: Today and Tomorrow

Tuesday, April 17, 2012, 1:00PM ET– 2:00PM ET

Understanding the Progression of Parkinson's

Tuesday, June 26, 2012, 1:00PM ET– 2:00PM ET

Research Opportunities

Exercise & PD at
University of Indianapolis

Requirements: diagnosis of PD, live at home, symptoms of PD and able to walk, no neurological conditions other than PD, have not had brain surgery, can follow 3-step instructions, able to travel to research sessions.

If interested call Stephanie Combs at 317-788-3523 or scombs@uindy.edu

Speech Treatment Study at
Purdue University

Requirements: diagnosis of idiopathic PD, problems with speech, native speaker of American English, no neurologic conditions other than PD, no asthma or respiratory problems, no heart problems including hypertension, no history of laryngeal, throat or oral cancer, no head, neck or chest surgery (except mastectomy or implant/ablation surgery for PD), non smoking for the last 5 years.

Compensation $180

If interested call Meghan Darling at 765-494-6488 .

FDA Drug Safety Communication

The U.S. Food and Drug Administration has reported that there are currently ongoing safety reviews of Stalevo with regards to possible increased cardiovascular risk and possible development of prostate cancer. At this time, FDA's review of Stalevo is ongoing and no new conclusions or recommendations about the use of this drug have been made. You doctor should regularly evaluate your cardiovascular status, especially if you have a history of cardiovascular disease. FDA has not concluded that Stalevo increases the risk of developing prostate cancer. The agency is still reviewing the available information regarding safety concerns. Patients should **not** stop taking Stalevo unless told to do so by their doctor. The FDA is exploring additional ways to assess Stalevo and will update the public when this review is complete. For more information please go to www.fda.gov.

Essential Info about PD
(Part 1)

For the next few newsletters we will be including information and/or check lists that you may want to keep on hand or have available for doctor and/or ER visits. Please use what is appropriate for you and your family.

I personally exhibit the marked characteristics of Parkinson's Disease

◊ Tremor
◊ Rigidity/stiffness of muscles
◊ Bradykinesia (slowness of movement)
◊ Stooped movement
◊ Low blood pressure
◊ Difficulty walking/imbalance/falls
◊ Difficulty swallowing
◊ Dementia/hallucinations/confusion
◊ Speech problems (reduced volume/slurred)
◊ Constipation & urinary symptoms
◊ Drooling
◊ Sleep disturbances (daytime somnolence, night time insomnia, acting out dreams)
◊ "Masked face" (flattened effect)

Factors That Worsen PD Symptoms

- Not getting medications on time
- Taking Carbidopa/Levodopa, Sinemet®, Parcopa® with protein or iron
- Stress, anxiety, lack of exercise and/or the need for rest
- Being prescribed incompatible medications
- Infection

If you have a deep brain stimulation implant you should keep your DBS nurses phone number on hand. DBS questions can also be directed to Medtronics at 1-800-328-0810. Please keep in mind that diathermy (therapy which uses high-frequency current) is completely contraindicated; MRIs can only be done following strict guidelines

Information included on this page is courtesy of the National Parkinson Foundation, Center for Care and the Parkinson's Resources of Oregon and OHSU's Parkinson Center of Oregon.

PD Medication Information

You should **ALWAYS** keep a list of your medications, doses and allergies with you, just in case.

Medications ***Contraindicated*** for use in PD Patients:

- Haloperidol (Haldol)
- Chlorpromazine (Thorazine)
- Thioridazine (Mellaril)
- Molindone (Moban)
- Perphenazine (Trilafon)
- Perpenazine & amitriptyline (Triavil)
- Benzodiazapines
- Thiothixene (Navane)
- Flufenazine (Prolixin)
- Risperdal
- Zyprexa
- Geodon
- Abilify
- Promethazine/Phenergan
- Prochlorperazine
- Metoclopramide (Reglan)
- *Dextromethorphan
- *Benadryl

*These can worsen confusion, particularly in elderly PD patients.

Potential Serious PD medication side effects:

- MAO-B Inhibitors (selegeline, rasagiline, Selapar): ***Demerol must never be given with MAO-B inhibitors!*** If possible, MAO-B inhibitors should be stopped for two weeks prior to surgery. It is imperative that the attending physicians verify and stipulate this interval. These medications may be given with SSRI's safely.

- COM-T Inhibitors (Stalevo, Comtan, Tasmar): These medications can cause severe diarrhea which will resolve one the medication is changed.

- Dopamine Agonists (Requip, Mirapex, Parlodel): Watch for obsessive-compulsive behavior, hallucinations, swelling, and psychosis.

- Atypical Anti-psychotics (Seroquel, Clozapine): These drugs are utilized to help control hallucinations and delusions. May cause hypotension, clozapine must be monitored with weekly CBC's/diff for neutropenia.

Exercise Groups

Rock Steady Boxing—317-205-9198
Peak Performance Fitness Center
5030 E.62nd St., Indpls., IN
Classes free to people with PD including Advanced boxing, intermediate, beginners, and advanced stages of PD. There is a monthly $25 gym fee. Please call for dates and times or visit www.rocksteadyboxing.org

The Climb is a faith based exercise program run by a certified physical therapist based on the book "Delay the Disease" by David Zid. Please call for class dates and times.

The Climb North - 317-774-7252
White River Christian Church
1685 N. 10th St., Noblesville, IN
$10 per week—Financial assistance available
Spouses and caregivers are free.
http://indianaparkinson.org

The Climb South— 317-946-5340
New Hope Church in Greenwood
5307 West Fairview Rd., Greenwood, IN
$5 per session or $45 for 10-week pass, first class free
Caregivers and spouses encouraged to attend

Physical Therapy Class—317-823-6841
Westminster Village North, 11050 Presbyterian Dr.
Wednesday—12pm, Free of charge

Aqua Classes & Personal Training for Parkinson's
Pam Runyan—317-547-8349
Hilltop Pool at North Central High School
Call for dates, times and cost

Chair Exercise Class—317-872-4567
Morningside of College Park, 8810 Colby Boulevard
Monday-Tuesday-Friday at 1pm, Free of charge

Ft. Wayne Exercise Classes—260-486-4893
Turnstone Center, 3320 N. Clinton St., Ft. Wayne, IN
Monday & Wednesday 10:30-11:30am

If I missed your exercise or support group please accept my apology and call me or send me an e-mail at sheripaaci@sbcglobal.net so I can get you added into the next newsletter.

Support Groups

Northside Indy

2nd Presbyterian Church
Call Bunny Alexander—317-726-5413

Wabash Valley PD Support at
Westminster Village North, 11050 Presbyterian Dr.
4th Friday each month at 10am and
3rd Thursday each month at 5pm
Call Donna—765-463-2620

Young Parkinsons of Indiana
Call the PAACI Office for info at 317-255-1993

Westside Indy

Westside Support Group
Westside Garden Plaza at 8616 W. 10th St.
2nd Sunday each month at 2pm
Call Julia— 317-244-4463

Outside of Indy

Kokomo PD Support Group
Howard Regional West Campus
Call Sherry Otto—765-454-4544

South Bend Parkinson's Support Group
1st Monday each month
Call Bill Siri for info—574-674-6542

Muncie Support Group
Call Dora at 765-284-5848 or
Margaret at 765-282-3758 for date, times and topics

Ft. Wayne Parkinson's Support Group
Turnstone Center, 3320 N. Clinton St.
3rd Tuesday each month at 7pm (except Dec.)
Call Dan Spangler—260-486-4893

Cut out and keep in your wallet.

PARKINSON'S AWARENESS ASSOCIATION OF CENTRAL INDIANA
317-255-1993

Medical Alert: I have **Parkinson's Disease** which could make me move slowly and have difficulty standing or speaking. I am not INTOXICATED. Please call my family or physician for help.

Caregiver Support Groups

Parkinson's Care Partner Support Group
3rd Tuesday of each month, call for more information
Call Glenda—317-867-2075 or Nancy—317-462-1663

Northside Indy—Caregiver Support Group
Fairview Presbyterian Church, 4609 N. Capitol Ave.
Call 317-261-3378 for dates, times & topics

Southside Indy—Caregiver Support Group
St. Mark Catholic School, 535 E. Edgewood Ave, Rm. 8
Call 317-261-3378 for dates, times & topics

Ft Wayne—Caregiver Class
Turnstone Center, 3320 N. Clinton St., Ft. Wayne, IN
Wednesdays—10:30-11:30am
Call Dan Spangler at 260-486-4893 for more info

Questions???

Perhaps you have some questions regarding depression or Parkinson's Disease that you would like Dr. Pressner or Dr. Beristain to address. If so please forward them to the editor. The doctors will attempt to address them. Also if you have any general questions about the mental health aspects of Parkinson's Disease, Dr. Pressner would be happy to address them in future articles. Unfortunately, we are unable to give individual advice because we simply would not have enough information about any individual's life and situation. We would, instead, encourage you to consult with your current physician or mental health professional.

If you do have questions please either e-mail Sheri at sheripaaci@sbcglobal.net or send via snail mail to PAACI, 4755 Kingsway Dr., #333, Indpls., IN 46205

Please cut out card and carry with you ⇩

Name____

Address____

Person to call_________________________________

Phone____

Address____

Physician____

Phone____

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Congratulations to…

David & Glenda Ockerman who are celebrating their 50th Anniversary...Wow!!!
Rose Green just turned 92...Amazing!!!
Fred Schmidt who lives his life beautifully despite Parkinson's Disease...Phenomenal!!!
David Waterman & Susie Wolf both got engaged, but not to each other...Great News!!!
Christine Mackey & Ryan Giltner tied the knot...Yah!!!

Helpful Phone Numbers

*****PAACI Office**—317-255-1993***

Young Parkinsons of Indiana
317-255-1993

Indiana Parkinson's Foundation
317-630-0315

Westside Support Group
317-244-4463

Parkinson's Care Partner Support Group—317-867-2075 or 902-7373

Caregiver's Support Group
317-261-3378

Dr. Xabier Beristain—317-863-2095

Dr. Joanne Wojcieszek &
Dr. Liz Zauber—317-944-4000

Indiana Reading & Information Services—317-715-2004

CICOA—317-2545465

RX for Indiana—1-877-793-0765

Don't' Forget…
Open enrollment for Medicare ends December 7th, 2011.

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PARKINSON'S AWARENESS ASSOCIATION OF CENTRAL INDIANA, INC. (PAACI)

PAACI
4755 Kingsway Dr., #333
Indpls., IN 46205

Phone: 317-255-1993
or
E-mail: sheripaaci@sbcglobal.net

WE'RE ON THE WEB...

Visit us at paaci.org or on Facebook at Indianapolis Parkinson

Name, Address, Etc.

Show your support for PAACI
Shirts, travel mugs & bags available

If you'd like to support PAACI and show your support for your friends and family with Parkinson's Disease, purchase one of our Parkinson's Awareness t-shirts, mugs or bags.

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(pink, yellow or blue)

Bags—$10
(black w/pink, green or red)

Travel Mug—$5
(purple & black)