

INDY PD UPDATE

PRODUCED AND DISTRIBUTED BY: PAACI
PARKINSON'S AWARENESS ASSOCIATION OF CENTRAL INDIANA, INC.

Parkinson's Unity Picnic

April 28, 2012 at 2pm

Garfield Park—in the Pagoda

*With Fonda and the
County Road Band.*

*Please plan to join us for our first ever Parkinson's Unity Picnic. We are inviting all the local Parkinson's groups to come and join us in making this an incredible event to celebrate **Parkinson's Awareness Month**. Come make new friends, enjoy good food and enjoy the beautiful music of Fonda and the County Road Band. Fonda and her band are part of the Michael J. Fox Foundation and are donating their time and talents to make our picnic amazing. We hope that you come with your family and friends and enjoy a relaxing afternoon in the park. For those of you that would like to bring your children or grandchildren they are more than welcome and there is a play place right next to the pagoda, where they can play while you enjoy the music.*

Adults- \$10 each

Children ages 5-10—\$5 each

Children under 5 are free

**Please call Sheri at 317-255-1993 to purchase tickets
or visit our website at www.paaci.org.**

Visit Fonda's website at myfonda.com

Save the Date

Symposium 2012
will be held on
October 6, 2012.
Please save the date
and plan to attend.

This Newsletter
courtesy of Teva
Neuroscience.

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Caregiver's Corner

By: Nancy Pressner, RN, BSN

Dear Friends-

I found the following article and wanted to share it with you since it so wonderfully points out one of a variety of emotions which we experience as caregivers. When you envision caregiving it tends to evoke more gentle emotions such as nurturing, compassion, loving and maybe sadness for the loved one with the illness. When anger begins to appear it is somewhat unexpected and knowing how to cope with it and how it fits into the overall picture is often confusing, yet very normal. From personal experience and sharing with others in a support group situation, I know you can experience anger in many forms: anger at the illness, at the loss of your former life/career, loss of the freedom to live a "normal" family life; one that isn't limited by or focused on dealing with a long term incurable illness. The last item deals with hundreds of things that we do daily that are taken for granted until Parkinsons' disease takes them away from us, the patient and the caregiver. I think the following article explains all of this very well. I encourage you to get the support you need in dealing with this aspect of caregiving, whether from family, friends, medical professionals or support groups. There are other people in your same situation who can share your feelings and thoughts, even the ones you thought no one else had but you.

Sincerely,

Nancy

Coping with Caregiver Anger



How to deal with the Three F's of Flipping Out . . . Fatigue . . . Fear . . . & Frustration

As a caregiver, the number of situations and people with which you can become upset are practically limitless. You may be angry at the disease or the injury. You may be mad at your care receiver, the medical community, the military, insurance companies, Medicare, Medicaid, siblings, children, friends, and coworkers. The list goes on and on.

It helps to know that anger is actually a predictable and normal response to circumstances over which we have little or no control. So as a caregiver, the question is not whether or not you will experience anger – because you will. The reality is, unless you have just recently ascended, you are going to get mad. You are going to lose it! You are going to explode! So don't beat yourself up for experiencing the emotion. The important thing is to figure out how you can manage that anger without causing harm to yourself or to your care receiver.

In addition to trying to manage an already difficult situation, most caregivers also struggle with The Three F's of Caregiving . . . Fatigue . . . Fear . . . and Frustration.

Fatigue:

Caregivers can reach a point of physical, mental, and emotional tiredness that most people can't even begin to perceive. If you are experiencing exhaustion on any or all of these levels, it is important to find a way to get some rest and relief from your day-to-day responsibilities.

Strategies for dealing with fatigue:

Set aside some time for yourself each day to do something you enjoy. Let your care receiver know that this is your time and you do not want to be disturbed.

- ◆ Get involved in a caregiver support group. Sharing your stories with other caregivers can provide a safe environment to express negative emotions.
- ◆ Seek respite care. If you do not have family or friends who can relieve you, there are people who will come into your home and stay with your loved one. There are also places where he/she can go for a few hours, or even for several days. Some of these programs are free; some are based on income and your ability to pay.

Fear:

Fear is like the boogie man in the closet or the monster under the bed. As a caregiver, you know the disease or the injury is there. What you don't know is how bad it's going to get, how long it's going to last, or how much it's going to cost. And you aren't at all sure that either one of you is strong enough to handle it.

Strategies for handling fear:

On a piece of paper list the things that frighten you the most.

- ◆ After you've completed the list, ask yourself: "What is the worst thing that could possibly happen?"
- ◆ Examine which fears are based on events that are inevitable and which feelings are based on situations that may never occur, and then make a decision.
- ◆ If you know that the worst thing that could happen will happen, and if there is nothing you can do to control the events or the outcome, take charge by deciding what you can do to get prepared.
- ◆ If you decide that the worst thing that could happen may not happen, you may want to lessen your emotional stress by choosing to release your fear and live in the moment.

Frustration:

Knowing that you have very little or no control over the recovery of an injury or the progression of an illness is extremely frustrating. It is likely that every new day will bring with it a series of challenges and complications that will frustrate and upset you.

Strategies for coping with frustration:

- ◆ Take a break and get some physical exercise. Go for a walk, run, or bike ride. A quick trip to a gym or an exercise class can help blow off steam.
- ◆ If you can't get away for more than a few minutes, go outside and breathe in deeply. Feel the fresh air fill your lungs and your abdomen. Breathe in for 8 seconds. Hold your breath for a count of 8 seconds. Release it to the count of 8 seconds. Repeat.
- ◆ Deep breathing elevates the oxygen in your blood, releases stress, and can help lower your blood pressure.

- ◆ Call someone. Expressing your frustration can help relieve pressure. If you cannot discuss your frustration with your care receiver, call a friend or a relative who will allow you to rant. Bottling up your emotions can lead to explosions and/or depression. (Again, caregiver support groups are a tremendous place to express emotions and seek support.)

The important thing is to understand that taking a break from the physical, mental, and emotional challenges of caregiving is not a selfish act. Getting the rest you need and participating in activities you enjoy will benefit both you and your care receiver. Because when you are refreshed, you will feel more loving and patient, and you will be better equipped to deal with the ongoing challenges and frustrations of caring for someone who can no longer care for him/herself.

Elaine K. Sanchez is a Caregiver Survivalist, author, and speaker whose passion is helping people cope with the emotional stress of caregiving. To read more articles, watch videos, sign up for her free newsletter, or contact her about speaking for your group, visit her website at: www.ElaineKSanchez.com.

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Newsletter

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Nutrition for Digestion & Absorption with Parkinson's

By Jae Allen

Overview

Parkinson's disease affects many of the body's systems, including gastrointestinal function. Patients with Parkinson's disease commonly suffer a general slowing of the digestive process, and conflicts between nutrients, dietary supplements and nutrition strategies can reduce some of the problems associated with poor digestion and absorption.



Coenzyme Q10

Coenzyme Q10 is a micronutrient sold in the United States as a dietary supplement. Although further research is needed to support the use of coenzyme Q10 as a nutritional supplement for patients with Parkinson's disease, it is believed that its supplementation can improve the function of the metabolism, aiding digestion and absorption of nutrients. Generally, an adult dose of coenzyme Q10 falls in the range of 100 to 300 mg, but doses up to 3,000 mg per day have been used—under medical supervision—in the treatment of early stage Parkinson's disease.

Proteins

Patients with Parkinson's disease commonly experience a general slowing of the digestive system, which can affect the efficiency of nutrient absorption. In addition to ensuring sufficient nutrient consumption, it may be important to consider the timing of food and medication. Levodopa is one of the medications commonly used to treat Parkinson's disease. However, levodopa must be absorbed through the small intestine, and here it is in competition with proteins consumed in food. Therefore, you may need to take your medications at a different time than your meals in order to ensure better absorption of dietary protein and your medications.

Meal Schedule

It is particularly important for patients with Parkinson's disease to avoid skipping meals. Nausea and a loss of appetite may be symptoms of the disease itself, or a side effect of Parkinson's related gastrointestinal issues. However, maintaining a regular meal schedule is vital for increasing the efficiency of digestion and absorption. Levodopa absorption is negatively affected by oral intake of leucine, isoleucine or phenylalanine, so you should space your medication schedule separately to your meal schedule.

Considerations

The Parkinson's Disease Foundation indicates that patients with Parkinson's disease often suffer from constipation. Although patients can reduce their risk of chronic constipation through lifestyle changes such as eating a high-fiber diet, constipation typically arises as part of the disease itself. Therefore, many patients with Parkinson's disease take laxatives to combat constipation. Long-term laxative use may reduce your absorption rate of nutrients and dietary supplements, perhaps leading to the need to consume higher doses of certain nutrients in order to absorb the amount you need. Talk to your doctor or a dietitian for advice regarding laxative use and nutrient absorption.

References

- * Linus Pauling Institute: Coenzyme Q10
- * Parkinson's Disease Foundation: Nutrition and Parkinson's Disease: What matters Most?
- * National Parkinson Foundation: What are Common Nutritional Concerns for People with PD?
- * PubMed.gov: The "On-Off" Phenomenon in Parkinson's Disease

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Dancing & Parkinson's

Dance for Parkinson's is a dance class based on the fundamental premise that dancers are movement experts whose knowledge is useful to persons with PD. Dancers know all about stretching and strengthening muscles, and about balance and rhythm. Dancers know about the power of dance to concentrate mind, body and emotion on movement because they use their thoughts, imagination, eyes, ears and touch to control their bodies every day. For this reason, persons with Parkinson's and dancers both have to bring mindful consciousness to every movement, and have to pay attention to the intention, quality and sequence of their movements.

Exercise of all kinds is encouraged by many neurologists and may be helpful in easing symptoms and delaying the disease. The aesthetic and social components of dance help connect mind and body, and help people break the cycle of isolation and depression that often comes along with the disease.

Dance classes incorporate six elements that are unique to dance in comparison to other forms of movement:

- Classical and contemporary technique training to build strength, flexibility and coordination skills
- Improvisation and aesthetic interpretation to stimulate creativity and the imagination
- Choreographic repertory and new movement sequences to develop cognitive strategies
- Circle dances, line dances and scene work to foster social interaction and create a sense of community
- A strong emphasis on rhythm and the relationship between movement and music



Dance for Parkinson's program comes to Indy **Based on acclaimed Dance for PD program**

The Indianapolis Senior Center and Dance for Parkinson's-Indy announce the launch of a six-week pilot dance program in Indianapolis geared to help those living with Parkinson's disease. Based on the Mark Morris Dance Group's acclaimed Brooklyn-based collaboration with the Brooklyn Parkinson Group called "Dance for PD®", four Indianapolis residents are collaborating to bring a similar program here in March.

"Although participants from all over the world tell us they find elements of the class therapeutic, the primary goal of our program is for people to enjoy dance for dancing's sake in a group setting—and to explore the range of physical and creative possibilities that are still very much open to them," said David Leventhal, program manager for the Mark Morris Dance Group's Dance for PD program and one of its founding teachers. Trish Martin will be the lead teacher for the Indianapolis pilot program that started in Mid-March, with alternate assistants Roberta Wong and Janet Thornton.

"I want to be mindful of varying abilities and stages of the disease", said Martin. "My aim is to create a joyful experience while improving balance, flexibility, coordination and overall confidence." The planning team's objective is to cultivate enough participation to bring the program here permanently. The Indianapolis Senior Center has offered the space and encourages members, non-members, and care-takers to join in the fun. More information is available at www.danceforpd.org.

Location: Indianapolis Senior Center - 708 E Michigan (downtown)

Dates: Started March 16th and available thru April 27th

Times: Fridays from 10:30am-12:00pm

Cost: FREE to all participants

Call (317)263-6272 to reserve your space!

Exercise – Newest Drug for Parkinson’s Disease

Help for Parkinson’s and the Caregiver



By Jackie Russell, RN, BSN, CNOR

Daily exercise is showing great potential for symptomatic improvement in Parkinson’s Disease (PD). Researchers are boasting that a daily Parkinson’s-specific fitness agenda may indeed be the newest “drug” for PD. (Zigmond MJ) It is soothing tremor, smoothing steps, relaxing stiffness, rekindling smiles and giving people with Parkinson’s (PWP) control over their lives. PD no longer needs to define you – it is a manageable condition with the use of the right tools in your toolbox. Exercise is a very important tool.

How does exercise work for PWP? Laboratory research highlights the disease-modifying effects of exercise in the animal population. Parkinsonian rats that participated in forced exercise seemed to exhibit a slower progression of the disease. (Zigmond, Cameron, Leak) Conclusions from these studies speculate that exercise increases a protective brain chemical - “Miracle-Grow for the Brain” that may slow the degeneration of healthy cells. This concept is called “neuroplasticity” – the brain can really change and adapt to trauma or disease, no matter what age. Translation to the human subject is just around the corner. This idea of “neuroprotection”, or slowing the degenerative process in the brain with exercise is exciting.

Delay the Disease is a Parkinson’s-specific fitness program designed to inspire and empower PWP by optimizing their physical function and helping to delay the progression of symptoms. This program, based on the current evidence gleaned from leading researchers in the field, is the foundation of community-based exercise classes that started in Columbus, Ohio, USA.

“I have a sense of hope now, and less dread of the future because I know that I am taking care of myself now, for the future”, states one participant. Another brags, “In fact, it has given me my life back. People that see me on the street have no idea I have Parkinson’s, and I want to keep it that way. My husband boasts “Exercise has given me my wife back.”

Neuroprotection,
slowing the
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Some of our participants that started exercise class in their wheelchairs are now proudly walking in with walkers, canes, even unassisted. Some boast that they are back to driving themselves to class. The energy created with the camaraderie in these classes is contagious – it not just about exercise, but an important social interaction for PWP and caregivers alike.

When PWP are affected in a positive manner with the results of exercise, the ripple effect is huge. The caregiver feels it – they don’t need to provide as much help with daily activities. The independence that returns is reflected in the increase in free time for the caregiver. Sons and daughters feel a sense of ease as they watch their parent gain back their sense of self worth. Friends notice the attitude change, husbands and wives start to go out to dinner again, and return to a life they thought was gone forever. Confidence is restored, falls decrease, and the spirit is fueled with optimism. That’s a lot of benefits from simply adding some exercise daily. Why wouldn’t you try it?

So how can the caregiver grow the enthusiasm for adding exercise to their loved one’s day? Start with gentle encouragement to try 5 minutes a day. Even if the first few days are difficult, stay positive. Soon, there will be an improvement in posture or arm swing or the ability to get out of a chair and they will be hooked. Encourage movements to be exagger-

ated; movements must be bigger than they think is possible. Reach higher, step larger, talk louder than normal. The PWP perceive they are talking loudly or moving big, but in reality they are not. So as the cheerleader for exercise, the caregiver should encourage proper form, technique and repetition. Repeated good movement over and over again, usually makes it very easy to reproduce.

However, to be an effective exercise cheerleader, the caregiver must make a point to take care of themselves. To take on all the caregiver skills of being on call 24/7, staying well-informed, organized, watchful, patient, accepting of change –all that takes inner strength and determination to balance these new demands. So as a caregiver, one must keep an open mind; stay flexible.

Take your own personal space and private time – everyone needs that. Be ruthless in your analysis of “can do” and “can’t do”. Evaluate your ability for heavy lifting, helping with bathing, 24/7 care, financial burden. Be willing to accept help, and plan your “B” team. Those are the folks that are willing and capable to help you get some free time. Be specific with your requests to your “B” team – don’t ask for some help, ask for 3 hours of help on each Monday afternoon. If you have to pay for help in the home, now is the time to do it. Don’t save for a rainy day when it is pouring outside! Fatigue is dangerous, especially for the caregiver. Make certain that you are getting adequate and good quality rest.(Imke)

Functional fitness is key; in other words, applicable exercises to help with daily functional tasks such as getting out of bed, getting off the floor after a fall, getting out of the car, getting out of a chair, and getting dressed. A newly released DVD “Delay the Disease – Functional Fitness for Parkinson’s” demonstrates methods and tips for all of these activities and more. There is also a list of exercises to practice for each activity to help maintain independence.

To answer the needs of the caregiver, Delay the Disease has initiated a “Train the Caregiver Workshop” that instructs caregivers on techniques and exercise tips to help their loved one exercise at home every day. It is an interactive conference for caregivers and other non-healthcare individuals who would like to understand and assist PWP in an exercise program. Research is showing that daily exercise yields the most robust improvement in symptoms, even ten or fifteen minutes a day proves beneficial. The caregiver can possess tools to provide exercise and hope to PWP, help maintain and improve their independence, thereby allowing them to have more free time of their own. This is definitely a win/win proposition – maintains quality of life for the caregiver as well as PWP.

David Zid, BA, ACE, APG certified functional fitness trainer and Jackie Russell, RN, BSN, CNOR are partners in Delay the Disease (www.delaythedisease.com) and are passionate about the positive impact that daily exercise appears to have on this disease process. Their community-based Delay the Disease exercise programs seem to be catching fire all over the country. Zid and Russell have become popular inspirational speakers at Parkinson’s conferences nationally and in Canada providing hope, optimism, and courage to a group of people that have been dealt a devastating diagnosis. They invite PWP to take control of the disease by demonstrating the benefits of participating in a daily program of Parkinson’s-specific exercise. With increasing scientific support for daily exercise for PWP this topic cannot be ignored. If there is a chance that PWP can maintain independence and manage a progressive neurological disease with simple daily exercise, why not try it! It changes attitudes, physical function and redefines quality of life. Exercise may just be the trump card in your hand that proves, “you may have Parkinson’s disease but it does not have you”!

***BIO -Jackie Russell, RN, BSN, CNOR – An Ohio State University graduate with a 30 year career as a registered nurse in Columbus, Ohio, Jackie is credentialed with professional achievement in perioperative nursing (CNOR) and has practiced specialized nursing in neurosurgery, cardiology, oculoplastic surgery, and orthopedics. Touched by PD when her mother-in-law battled the disease, Jackie became professionally involved in the PD community in 2006 while working for Dr. Thomas Mallory, an orthopedic surgeon diagnosed with PD. She has joined forces with David Zid, Parkinson’s Fitness Specialist and together they spread the message of hope and optimism that daily exercise can empower people to face this disease with a proactive approach. Visit their website at www.delaythedisease.com.

Depression Series, 4th Edition

By: Joseph Pressner, Ph.D.



This is the concluding column exploring the topics of anxiety, depression and stress management. The first three columns have focused on self-assessment, and learning how to live in a mindful way. The primary message has been that much of our suffering is related to thoughts about the past or worries about the future, and that life is much more manageable, meaningful, and fulfilling when we focus on the present.

There is nothing that can be done to change the past, and the future seldom turns out precisely the way that we predict that it will. The recent winter weather has reminded me that if I constantly worry about the storm that may arrive over the weekend, I may not enjoy the glorious weather that we have today. It seems like we spend a lot of time worrying about those storms predicted for the future, and less time just experiencing the current moment with all that it has to offer.

In many ways the topic of this final column could well have been the topic of the very first column in the series because it is about discovering the “true self” that is an island of tranquility despite the hurricane winds buffeting us at times.

Most of us tend to confuse the “true self” with that part of the brain that is experiencing an emotion or thinking about something. This “true self” is actually hidden by the emotion or thinking. It is sort of the self behind the curtain observing everything else that is going on in the brain.

I know that this may seem a little “out there” to some people who may be reading this, but a few little exercises may help to understand what I’m writing about.



If you would, I would like you to merely move your index finger a bit, and watch the movement. I think that it is safe to say that you wouldn’t tell me that you ARE your index finger. You would probably tell me that “you” are watching the finger move.

Now for a more mental exercise. I suggest that you try to observe what is going on in your mind the way that you watched your finger move. Ready? Remember the goal here is to observe what’s going on between your ears.

Here goes . . .

I would like you to NOT picture a giraffe with a bow tie!

What did you observe about your mind? Was your mind a blank or did you have such an image? Did you smile a bit to yourself when this picture came into your mind? Did you observe your mind doing something that you were requested NOT to do? What thoughts came into your mind? Did you have some thought about the psychologist who suggested this? What did you observe about your mind when you did this exercise?

The point here is subtle, but did you, in fact, watch yourself thinking and imaging just as you had watched your finger move? Can you do that even now as you are reading this sentence?

If you did, I hope that you can see that there is a deeper part of you that is an observer, a part to you that is able to see yourself when you think, when you image, or when you feel an emotion. That observer part is getting closer to what I mean by the “true self.”

The sad fact is that most of us are unaware of this “true self.” We are so involved in the whirlwind of thoughts, emotions, images, and actions, that we do not even realize that we have a tranquil “true self” that is unaffected by these things, and is simply observing.

In fact, the more we begin to identify and live the “true self,” the more that we can manage the hurly-burly around us because we can see it for what it is. This is the shared wisdom of the ages, but something to which most of us have never even been exposed.

So, how does one begin to identify and live the “true self?” The answer to this question is both deceptively easy and deceptively difficult.

It is deceptively difficult because the true self cannot be engaged in thoughts. It is beyond thought. However, as this series of articles has pointed out, we have come to value thinking as THE activity in which to engage.

The “true self” is also not something that can be approached in actions because it is timeless and beyond action. In fact, most of us are very accomplished thinkers and doers, and this fact in-and-of-itself contributes to our anxiety and depression, and our alienation from our true selves.

Thus we have not learned how to be without thoughts and actions. Yet the “true self” can be experienced best in silence and inaction. When I mean silence, I mean much more than just an absence of sensory inputs. I mean not only this, but a silent mind as well.

Shared wisdom suggests that a silent mind can be approached through the practice of meditation. This term seems to mean many things to many people, but the way that I use the term is for a particular form of healing practice.

Here are the steps

- 1) Sit comfortably with your feet on the floor. The position should be comfortable enough not to distract you for twenty minutes, but not so comfortable as to promote sleep. Eyes may be open or shut, but most people seem to prefer eyes shut.
- 2) Begin to watch yourself breathe, noticing how it feels to inhale, to exhale, how the air feels going in and going out, the gentle pause between breaths.
- 3) Then either continue to focus on your breathing or focus on a simple word or phrase of your choice. This could be a word such as “peace,” “tranquility,” or a short phrase such as “I am calm,” “Loved by God.,” etc. It is likely that you will find some word or phrase that becomes especially consonant with your own being. Then you gently and silently repeat this word or phrase once with each breath.
- 4) Continue this practice for approximately twenty minutes, and practice twice a day.

You will no doubt find that your mind wants to be as busy as ever and will begin to intrude with the typical concerns and worries of the day. That is okay – even if it happens a hundred times during your practice. When you realize that you are having such a thought, gently let it go and return to your word, phrase, or focus again on your breathing. Note that it is not recommended that you begin to think about what peace, or tranquility, or your relationship with God is about. This is a time for quiescence. The focus on breath or a word or a phrase is a way of experiencing the self in a different manner rather than providing avenues for thoughts or worries.

It is helpful to be gentle and forgiving of yourself and your practice. It is inevitable that there will be multiple interruptions – even every few seconds – since we have so trained our minds over decades to spend every moment thinking, it has become quite alien to us to live in another fashion.

It is also important to realize that you will not notice any immediate changes. As I have emphasized repeatedly in these articles – there’s no such things as a quick fix that actually works. However over the course of weeks and months, you will gradually begin to notice that you worry less, are less depressed, and people will begin to notice your patience and kindness to them. You will begin to become truly centered. You will begin to know, and to engage in far less self-deception. Your “real self” is *so beautiful* despite all the scars that life has inflicted on you.

One common objection especially for care givers is this: “I don’t have any time the way it is. How am I going to find twenty minutes twice a day?” I promise you this – you will not miss the time. At least two things happen. 1) With daily practice you will have so much more energy and be so much more focused that you will be able to accomplish even more in the other hours of the day. 2) As you become more centered some activities will become far less useful to you and you will want to discard them. I know, for instance, that I watch far less television than at one point in my life. I no longer need the diversion from myself.

Depression article continued from page 9...

There are many books written about meditation. I have cited several of them in previous articles. Reading such books is a very good way to refine your practice. It is also helpful to join a centering prayer group or a meditation group. This provides help and guidance from others who may already have years of practice. They have probably encountered many of the road-blocks that you have encountered and can provide helpful reassurance to you in your practice.

Finally one word of caution. Before embarking upon meditation it would be helpful to discuss this practice with your health care professional. The effects of meditation are real and powerful. Meditation may, in fact, interact with the medications that you are taking or other treatments in which you are involved. This is particularly important for the individual with Parkinson's Disease who may be taking multiple prescribed medications.

Perhaps you have some questions about this or the previous three articles. If so please forward them to the editor. I will attempt to address them. Also if you have any general questions about the mental health aspects of Parkinson's Disease, I can address them in future articles. Unfortunately, I cannot give individual advice because I simply would not have enough information about any individual's life and situation.

WOMEN'S RETREAT

In November of 2011 the Second Annual Women with Parkinson's Disease Retreat was held in Brown County, Indiana. Twenty-one women gathered together for three days of bonding, sharing, learning and of course eating and shopping. John Baumann, an inspirational speaker and also a proud person with Parkinson's, came and spoke about positive thinking, repeating his mantra; "I ain't dead yet". Mr. Baumann was an unexpected surprise that we all thoroughly enjoyed. A wide variety of Parkinson's related topics were covered during the retreat, which included clinical studies, caregivers, how to handle being hospitalized and being a couple when you both have PD. For information

on the Third Annual Women with PD Retreat to be held in late summer or early fall contact Linda at hinkle.l@sbcglobal.net or Mary at mdyeaman@juno.com or call the PAACI Office at 317-255-1993.

Important Medication/Dietary Information

Not all these items listed may pertain to your, however those that do are important and should be shared with medical staff upon hospitalization.

Medication dosing, timing, and administration: The timing of my medication is very important to help minimize my symptoms and "off" times. I must be given my medication(s) promptly at the times specified. If this is not possible, consult my admitting physician for authorization to administer my own medication, or alternatively, to have it administered by my caregiver.

IN PARTICULAR, my carbidopa/levodopa (or Sinemet) must be taken 30-60 minutes before or two hours after my meals, because protein prevents the maximum amount of dopamine from reaching the brain. The relationship of protein consumption and medication timing greatly affects my condition.

If I am not able to swallow, my medications may need to be crushed and administered by a stomach tube (exception: Sinemet CR must not be crushed) or the dissolvable form Parcopa®—should be ordered. If I am on Sinemet and Intravenous Protein (TPA) is proposed, my neurologist must first be contacted because the dosage may need to be adjusted.

PD and Surgery

1. If possible, stop MAO-B Inhibitors (Eldepryl/selegiline, Azilect, Zelapar) two weeks prior to surgery.
2. Pre-operative dosing instructions: There should be no reason to skip PD medications prior to surgery even if directions are NPO (nothing by mouth) for 6-10 hours prior to surgery. Discuss with surgeon or anesthesiologist.
3. Restart PD medications post-surgery (except MAO-B Inhibitors) as soon as possible even if NPO; discuss with surgeon.
4. Be aware that PD patients have a lower threshold response to analgesics (sedation/pain medications) and could experience hallucinations; however, this is not a contraindication (reason to avoid) their administration.



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PAACI Office—317-255-1993
 Parkinson’s Care Partner Support Group
 317-867-2075 or 902-7373
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Helpful Phone Numbers

Aqua classes—317-547-8349
 Caregivers Spt Grp w/Catholic Charities—317-261-3378
 CICOA—317-254-5465
 Dr. Ruth Ann Baird—317-217-3000
 Dr. Joanne Wojcieszek & Dr. Liz Zauber—317-944-4000
 Chair exercise classes—317-872-4567
 Ft. Wayne exercise classes—260-486-4893
 Indiana Parkinson’s Foundation—317-630-0315
 Indiana Reading & Information Services—317-715-2004
 Physical therapy—317-823-6841
 Rock Steady Boxing—317-205-9198
 Rx for Indiana—1-877-793-0765
 Shelby Cty PD Exercise & Support—317-398-7614
 (Currently limited to Shelby County residents and Major Health Partners patients)
 The Climb North—317-774-7252
 The Climb South—317-946-5340
 Westside Support Group—317-244-4463
 Young Parkinsons of Indiana—317-203-3049

**Memorials, Contributions,
 Dues & Purchases**

Circle one:

\$25 dues Honorarium Memorials
 Tshirt (\$20) Bag (\$10) Mug (\$5)

Tshirt/Bag color preference: _____

Tshirt size: _____ Mens or Womens

Special Donations Amount: _____

In celebration of wedding, birthday, anniversary, etc.

Please specify: _____

PAACI accepts cash, checks, Visa and Mastercard.

Circle one: Visa or Mastercard

Credit Card #: _____

Exp. Date: _____

3-digit Security Code: _____
 (on the back of your card)

Where can we send an acknowledgement letter/card?

In Honor or Memory of: _____

Name of Donor: _____

Address, City, State & Zip: _____

Name of Recipient or Family: _____

Address, City, State & Zip: _____

Please mail your tax deductible donation to:

PAACI, 4755 Kingsway Dr., #333

Indpls., IN 46205

Exercise Groups



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

Dance for Parkinson's—263-6272

Indianapolis Senior Center, 708 E. Michigan St.

March 16 thru April 27, Fridays—10:30am-12pm

Free of charge

Delay the Disease—

Noblesville Athletic Club, Rte. 38 & South Harbour Rd.

April 20th @ 1PM, minimal fee to be determined.

Ft. Wayne Exercise Classes—260-486-4893

Turnstone Center, 3320 N. Clinton St., Ft. Wayne, IN

Monday & Wednesday 10:30-11:30am

Physical Therapy Class—317-823-6841

Westminster Village North, 11050 Presbyterian Dr.

Wednesday—12pm, Free of charge

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

Support Groups

Downtown Indy

Indianapolis Senior Center Support Group

Initial Meeting April 13, 2012 @ 1:30pm—263-6272

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

Northeast Side of Indy

Positive Directions, 10:30am-12:30am

May 21st & July 16th at Riverview Rehab Center

Call Linda—317-374-4201

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

Danville Parkinson's Support Group

Hendricks County Senior Center

Call Beth Ann Leach—317-745-4303

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

Kokomo PD Support Group

Howard Regional West Campus

Call Sherry Otto—765-454-4544

Muncie Support Group

Call Dora at 765-284-5848 or

Margaret at 765-282-3758 for date, times and topics

South Bend Parkinson's Support Group

1st Monday each month

Call Bill Siri for info—574-674-6542

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

(This group is run by Catholic Charities of Indianapolis and is for all caregivers, not just those with PD.)
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

Patient Education Afternoon—317-944-4000

To be determined, July 14, 1pm-6pm

Parkinson's Unity Picnic (PUP) Invite to all PD Related Groups

If your Parkinson's support, exercise or any other Parkinson's related group weren't contacted regarding the PUP Picnic and you'd like to come, please contact Sheri at 317-255-1993 or sheripaaci@sbcglobal.net.

Rock Steady Food Truck Festival With Silent Auction

June 24th, 2012

Time and further info to follow

Information Needed

If you currently run or know of a Parkinson's support group or exercise group that is not mentioned in this newsletter please let us know. You can send an email to sheripaaci@sbcglobal.net. We would like to be able to share as much information as possible to our members. We have found that the best way to do that is to ask our members to keep us informed of anything going on in their neighborhood. This allows us to inform others in your neighborhood of resources that they may not otherwise be able to find. Thanks for all your help!

Casual Get-Together's

It has come to our attention that it might be nice to meet on a regular basis just to visit and catch up, so PAACI will be holding regular Get-Togethers all over town. We hope that many of you will take advantage of them and come eat brunch or dinner, visit and see what everyone else has going on. Everyone is welcome so bring with you whomever you like. Below is a list of some of the first Get-Together dates and locations. If you have any questions or need information please call Sheri at 317-255-1993 or email sheripaaci@sbcglobal.net. PAACI will choose one lucky winner to pay for their meal at each Get-Together.

We look forward to seeing you there.

Southside Get-Togethers

May 1, 2012 @ 11am - Steak & Shake
4020 S. East St., Indpls, IN

June 7, 2012 @ 11am—Lincoln Square Pancake House
8041 Madison Ave., Greenwood, IN

Northside Get-Togethers

May 8, 2012 @ 11am -Marcos Restaurant & Lounge
2380 E. 54th St., Indpls., IN
(We will be in the restaurant section in the back)

June 14, 2012 @ 12pm—Jim Dandy Family Restaurant,
2301 E. Conner St., Noblesville, IN

Westside Get-Togethers

May 17, 2012 @ 11am—Charlie Brown's Pancake/Steakhouse,
1038 Main St., Indpls, IN

June 19, 2012 @ 11am—Applebees
1436 W. 86th St., Indpls, IN

Eastside Get-Togethers

May 22, 2012 @ 11am—Steak & Shake
5360 N. Keystone Ave., Indpls, IN

June 28, 2012 @ 11am—Lincoln Square Pancake House
7308 E. 21st St., Indpls, IN

****Date, times and locations can be flexible, so if you have suggestions for the future please call Sheri at 317-255-1993 or email at sheripaaci@sbcglobal.net.

Rest in Peace Dear Friends...

Ted Aichele	Barbara Freeman	Charles Norvell
Bob Arkins	Jim Gabbard	Ruth Ann Phelps Thompson
John Bradley	George Hill	Mary Connie Robbins
Minnie Brown	Norman Kinder	Richard Smitley
Darlene Conway	Mimi Kosene	Sterling Sutton
Sydney P. Cook	Donald Kottlowski	James "Don" Thompson
Paul Csillag	Terez Kovacs	Ruth Ann Thompson
Glenn Douglas	Marianna Landis	Kenneth E. Thompson
John Duguid	Geraldine Lawson	Clifford Turk
Nancy Fields	Father of Linda Hinkle	Robert S. Wells
Frank Flynn	Viola Deanie Martin	Marilyn Zartman
Wesley Ford	Thomas Means	Charles Zebell
Shirley Foucet Miller	Charlotte Moore	

Honorariums... Some of our PD friends wanted to Honor their friends and/or loved ones with a donations. Those honored in this Newsletter are **Betty Fields, Elaine Gust, Glenda Ockerman, Peter Rhetts, Helen Schafer and Alva M. Ward.**

Happy Birthday!
Carolyn Spence (61)
Jack Spence (81)
Ross Rega (60)



Multiple Memorial Donations

Special thanks to our members families who thought of PAACI at a very difficult time in their lives. These are our members whose families remembered us in their loved ones obituaries or at their memorial services. Thanks to the families of Bob Arkins, Ted Aichele, Carol Boyce, Minnie Brown, Herbert Coffey, Darlene Conway, Frank Flynn, Wesley Ford, Barbara Freeman, Terez Kovacs, Deanie Martin, Charles Norvell, Marsha Riley, Mary C. Robbins, Don & Ruth Ann Thompson and Phillip Williams.

Dues / Donations

Robert & Linda Arnold
Emmy Bachmann
Donald & Betty Fields
Frank & Audrey Gentzke
Thomas Irwin
Norma & Roger Jacobson
Karl & Barbara Kovacs
Roy Levin
Mary Neffner
Jimmy & Lucy Reed
Mary Sutton
Geneva St. Claire
Rosemary Ward
Patsy Wilson
Mary Yeaman

Donations made in loving remembrance

of... Fred Bachmann, Floyd Chandler, Edwin & Marjorie Schultz and James Skinner.

Donations of \$1,000

Carl J. VanRooy

Donations of \$100 & Over

Andrejasich Blessing Fund
Emmy Bachmann
Charles & Diane Bell Gifts Fund
Birthday Club
Marie Bridge & Family
Dick & Dorothy Crane
Dave & Yvonne Davis & Family
David & Dee Garrett

Thomas & Patricia Grabill
Helen Kottlowski
Jeffrey Madden
Charles Matsumoto
Murray & Sylvia Mills
Mitchell Hurst Dick
McNelis, LLC
MSFG Risk Management Dept.
Mary Neffner
Pamela J. O'Rourke
David Pickhardt
Mary Skinner
Phillip & Bette Tevis
Martin & Carol Zagarinsky

Donations of Under \$100

George & Debra Abel

Eric Altherr

Peggy & Chad Barnes

Regina Bridgman

Elsie & Larry Burgess

Russ & Nancy Burk

Debbie Carney

Robert Conway

Bob & Sara Cox

Claudia Davis

John Deck

Donald & Betty Fields

Susan Fleeger

Robert Ford

Clara Gadd

Eric Hofmeyer

Michael Hurst

Pam Jackson

Michelle Kowal

Charles & Pat Lacy

Faith B. Laird

James & Kathy Lauck

Bernard & Draga Lindblom

John & Grace Long

Patrick & Lori Mahoney

William & Diana Mann

Bob & Lois Mannfeld

Jan Nelson

Carolyn Nichols

Joe Poliquin

Mickie Poliquin

Jimmy & Lucy Reed

Raymond & Alberta Reed

Elaine Rhetts

William & Virg Schreckengast

Susie & Tom Siegel

Mabel & Greg Smith

Jerry & Cindy Teter

Nancy Thompson

Roland Thompson & Family

Rosemary Ward

Hendry D. Weaver

Dave & Addie Yoder

Donations Under \$50

Andrioles RJNJA

Gene & Jane Beyt

Ernie & Nancy Blake

Emma Chandler

Dean & Clara Claycamp

Jerry K. Day

Linda Deig

Karen Derderian

Clarita Donaldson

Virginia Sue Eldridge

Dick & Marilyn Ellis

Dan & Becky Esbaum

James Fairfield

Farm Bureau, Home Office &
Field Personnel

Morris & Maxine Fix

Uncle & Aunt of Mary & Paul
Fleener

Bob & Noel Franke

Katerina Fulton

Joe & Debbie Harker

Betty Hart

Michael & Cindy Hogan

Patricia Hoon

Elaine Johnson

J.P. & M.V. Kansky

Karen Kerderian

Alice Kilgore

Carolyn Kinney

Peter Kirch & Family

Jean Kobe

Willy & Darlene Kommans

Karl & Birgit Kreck

Joe & Dee LaRosa

Karl & Birgit Kreck

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Laura Mulligan

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Nancy Ostrander

Lee & Sharon Perkins

Judith Rail

Joe & Dawn Sahn

Dennis & Linda Schafer

Beverly Snodgrass

Mary Teipen

William Work

Donald & Joyce Yost

Bill & Debbie Zimmerman

2 Annonymous Donations

**Parkinson's Awareness Association of
Central Indiana, Inc. (PAACI)**
4755 Kingsway Dr., #333, Indpls, IN 46205
317-255-1993 www.paaci.org
Facebook: Indianapolis Parkinsons
Email: sheripaaci@sbcglobal.net

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Parkinson's Awareness Month Special Calendar & Donation Form

It's spring and April is Parkinson's Awareness Month. We hope that all of you will be able to come to one, if not all of this month's Parkinson's events.

April 19th @ 5:30pm

RSB Pacers Game

317-205-9198

April 20th @ 5pm

IPF Banquet

317-690-0315

April 21st @8:15am

Northwest Indiana Support Group

Symposium

219-945-0888

April 28th @ 2pm

PAACI's Parkinson's Unity Picnic

Concert by Fonda & the CRB

317-255-1993

Please consider celebrating Parkinson's Awareness Month by honoring someone you love with a donation to the Parkinson's Awareness Association of Central Indiana, Inc. We love what we do and we're happy to be here to help you. The best way to keep us working for you and those that follow you is by making a tax-deductible donation. We're thankful for every donation we get, no matter how big or small, we appreciate your thoughtfulness.

In Honor/Memory of: _____

By: _____

Cash Check Visa Mastercard Discover

Credit Card #: _____

Exp. Date: _____ Security Code _____

Donation Amount: _____

Please send card to: _____
