

PARKINSON'S PERSPECTIVE

Published by the Wisconsin Chapter APDA in collaboration with the APDA Information & Referral Center at St. Mary's Hospital, Madison

UPCOMING EVENTS

Wine Tasting

Saturday, February 12
Blackhawk Country Club
Madison
6:30 p.m.

Walk-a-Thon

Sunday, May 1
East Towne Mall, Madison
12:00 p.m.
More information on page 3

Madison Marathon

Sunday, May 29
Madison
Nate Nasett is running the marathon in honor of his dad. Donations can be made at the chapter website or sent to the chapter P.O. box earmarked "Nasett Marathon."

Annual Membership Picnic

July 13
Watch for information

Mary's Wish Golf Outing

Sunday, September 25
Door Creek Golf Course
Cottage Grove
9 a.m. Shotgun Start
Lunch at 2 p.m.
www.maryswishgolf.com
608/220-6737

"I Learned Something New"

by Patrick Pelkey

To learn how to carve, I must go out of town
My first year in Branson, I learned from Steve Brown
I now caught the bug, and again I must go
This time I learned, from the great Harold Enlow
They both make it look, like this is so simple
Like a wrinkle here and there, and even a dimple
I think they're fortunate and lucky, to do what they do
Some day I hope, that I can teach others too
My only regret, is that I live so far away
I drove over 700 miles, all in one day
I'd be sitting at home, full of doubt and self pity
If it wasn't for the host, that's "Silver Dollar City"
I was diagnosed with Parkinson's, that's when
I started to whittle
I never knew I had the talent, not even a little
I want to wish you all, a great big "Thank You"
Don't let life be a handicap, find something to do

"Parkinson's Came Early"

by Patrick Pelkey

Parkinson's came early, of this I've been told
I'm not really young, but I'm not very old
My mind starts to wander, and my thoughts all go blank
I start driving to the store, but end up at the bank
I take meds everyday, to slow down my shake
But tremors alone, does not Parkinson's make
It affects balance and memory, and slowness of gait
What you used to do quickly, sometimes now has to wait
There's hope in Love, Trust, and Faith, that's a sure bet
Because there is no known cure, that is as of yet
Do whatever it takes, but don't let it get you down
The more you stay active, the longer you'll be around

From the President

Michelle Ciucci



This newsletter is about inspiration. What inspires us? I have been asking myself that question and asking other people about what inspires them. Most of the people I have asked have recently been through something difficult, and from these conversations, I have

learned several things. First, inspiration can come from many different sources: a place that is beautiful, a song that is moving, or a person you admire. Inspiration is defined by many as an entity that transcends our perceptions of our own limitations and helps us to believe in ourselves. It is intricately linked with motivation, probably feeding that motivation. This catalyst to motivation helps us to be excellent parents, climb a mountain, win the Nobel Prize, create something original, or sometimes even get out of bed.

However, inspiration doesn't always come barreling down upon us. In searching for my definition of inspiration, I also came across a

lot of statements regarding courage. This particular quote got my attention:

"Courage doesn't always roar. Sometimes courage is the quiet voice at the end of the day saying, 'I will try again tomorrow.'"

— Mary Anne Radmacher

And, let's not underestimate the power of laughter:

". . . as far as being on the verge of being a sick man I don't take any stock in that. I have been on the verge of being an angel all of my life, but it's never happened yet."

— Mark Twain, *a Biography*

The days are getting longer, spring is around the corner, and each day we have the opportunity to get up and try again. Be gentle with yourself, but keep up the spirit of inspiration that infuses us from many sources. You may not know it, but you may be an inspiration to someone! Let's all try to be a little bit more inspired and a lot more inspirational. Happy New Year!

Prestigious Award

The chapter extends congratulations to president Michelle Ciucci, who received the "Award for Early Career Contributions in Research" in November. The award was presented in Philadelphia during the American Speech Language and Hearing Association National Convention.

The award is designed to acknowledge significant scientific accomplishments by individuals beyond the dissertation and

within five years of receiving their doctoral or other terminal degree.

Michelle is an Assistant Professor in the Department of Surgery, Division of Otolaryngology and the Department of Communicative Disorders at the University of Wisconsin-Madison. Her research interests include translational models for movement neuroscience, sensorimotor control for voice and swallowing, dysphagia (swallowing disorders), and Parkinson's disease.



From the Information & Referral Center

Jessica Olejniczak



Time sure does fly by. It seems like just yesterday I wrote my article for the last newsletter and informed everyone that I will be going on maternity leave in February. Since then, we have been working out arrangements for coverage while I am out of the office.

During my time off, please contact APDA National at 800-223-2732 for any educational materials you may need. If you are looking for information specific to Wisconsin, the chapter website (www.wichapterapda.org) has been updated with the latest information. For information about events, don't hesitate to contact the chapter at 608-258-6413 or chapter@wichapterapda.org.

I hope this newsletter inspires you. There are many people with Parkinson's disease who don't sit by and let the disease take over their lives; they are fighting. That is my hope

for all people with Parkinson's disease: to be a fighter.

Fighting can mean different things to different people. Fighting can mean changing your attitude, so you don't think that having Parkinson's disease means you can't do something. If you find you can't do something any more, find a different way of doing it, or if it takes you longer to accomplish, at least you did it. If there is a hobby you enjoy but find it hard to do now, find another hobby. You may find that you enjoy the new hobby more or realize you're talented in another area.

Some people, like Patrick Pelkey, find writing poetry helps them fight the disease. To some, fighting may mean exercising (be sure to get your doctor's okay before starting any exercise regimen), and to others it could mean volunteering.

As you can tell from this newsletter, people fight this disease in many ways. How are you going to fight your Parkinson's?

"You know, everyone gets their bag of hammers; this is just my bag of hammers, and I can handle it."

— Michael J. Fox

Sixth Annual Parkinson's Disease Walk-A-Thon

May 1, 2011

East Towne Mall, Madison

12:00-1:30 p.m.

Check-in starts at 11:00 a.m.

Cost is \$10 per person

To register online: http://apdaparkinson.donordrive.com/event/2011_WI_Walk

To register by mail: Contact Allison Schaser at 262-751-3649 or schaser@surgery.wisc.edu

For the first time, this event is being organized by the Wisconsin Chapter APDA in collaboration with the University of Wisconsin-Madison Chapter of the National Student Speech, Language, and Hearing Association.

Exercise Program

by Michelle Ciucci

The Wisconsin Chapter APDA has successfully launched our new exercise program at Harbor Athletic Center in Middleton!

In July 2010, we brought in two experts, Becky Farley, PhD, PT, and Stephanie Christenson, CSCS, RYT-200, AEA, who developed the "Parkinson's Wellness Recovery," or "PWR," project that provides Parkinson's disease-specific exercise programs. Their home base is in Tucson, Arizona, but they will take their program on the road to increase availability to facilities in need of state-of-the-art training.

Through the generous support of Harbor Athletic Center and our annual wine tasting

fundraising efforts, we were able to train 20 local exercise therapy specialists and now offer five free classes at Harbor:

Monday, 10:35-11:20 a.m.

Wednesday, 1:00-2:15 p.m.

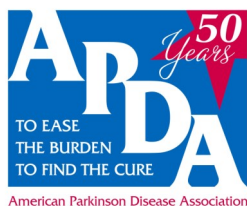
Thursday, 5:00-6:00 p.m.

Friday, 1:15-2:00 p.m. (Zumba)

Saturday, 10:15-11:00 a.m.

Please continue to support our efforts by donating to this program. Exercise is one of the most important activities that promotes wellness, especially for those with PD. We look forward to seeing you out there and moving!

For more information, please contact Harbor Athletic Club at 608/821-6501.



HAPPY 50TH ANNIVERSARY AMERICAN PARKINSON DISEASE ASSOCIATION

How I Stay Positive

by Dave Wilson

I was diagnosed with Parkinson's two and a half years ago. I went to see a sleep doctor about my REM behavior sleep disorder. She treated me with ropinirole and clonazepam and referred me to a movement disorders doctor to check for Parkinson's. Dr. Perez said I did have Parkinson's. He increased my nighttime ropinirole to 1 mg and put me on 1 mg of Azilect each morning. I'm now also taking 1.5 mg of clonazepam at night.

Dr. Perez emphasized the importance of exercise in dealing with Parkinson's. He especially recommended T'ai-Chi, so I've been taking two classes a week at the T'ai-Chi Center of Madison ever since then. I also went to see Julie, a PT at Dean, to work out a set of exercises to do at home. And,

most recently, I added the Parkinson's exercise class offered by the local APDA chapter. I continued the exercises I was already doing, walking and climbing to the ninth floor at the start of each work day.

My wife and I also joined the Edgewood Community Choir to help keep my voice in shape. It had been a quarter of a century since we had sung with the Madison Symphony Chorus.

My symptoms are still hardly noticeable to most people. I have an occasional tremor in my left hand, and on a treadmill my arm swing is not good. My memory is not as good as it once was, but I don't know if that's due to the Parkinson's or to being 67 years old. I still move around and vocalize in my sleep but not as much as I did before treatment.

I like my job as a computer programmer for the University. I'm still working full-time.

For those with Parkinson's disease — A Program of Regular Exercise Can Help! Close to Home! Affordable! Enthusiastic Training!

by Connie Fausett

Are you looking for an exercise program designed by physical therapists and personal trainers for people with Parkinson's disease? I discovered a class in Hartford that fits the needs of many people with the disease. For six months now, I have been working on flexibility, strength, improved posture, balance, trunk mobility, and gait training. The class has helped make exercise fun, and I've made new friends, too.

The group in Hartford is small, but this is a good thing as many people are there for other health concerns. People in the P.E.G. (Parkinson's Exercise Group) are treated with respect and admiration for what they can do, not emphasizing what they cannot do.

Each person has different Parkinson's symptoms. In class, we work on being LOUDER as many people with Parkinson's have a hard time being heard. We work on moving well and BIGGER as many people with PD take little steps. We work on having a good ATTITUDE by surrounding ourselves with people who care about even small victories that we make.

LAUGHTER IS CONTAGEOUS. I find I laugh and smile a lot more after six months of

class. We yawn out loud, make faces in the mirror, and generally try to help each other.

The class is offered in two locations, the West Bend YMCA and the Aurora Medical Rehab Center in Hartford, twice a week. It's a reasonable distance from Horicon, Mayville, Lomira, Iron Ridge, or other cities, and it's affordable, too. Your family doctor must recommend medical clearance through an evaluation by a physical therapist. The one-hour class is divided between stretching and balance exercises with a half hour dedicated to walking on the treadmill.

"The best thing is the caring instructors," says participant Bill Holmes. "It's very individualized, and I try to stand taller and to walk with more balance and control." He continues to farm and drives a tractor at his home with his wife close to Hartford. Being active and living fully is what we all wish for as we grow older, and people who have Parkinson's are no different. Bill gardens and enjoys photography as some of his hobbies.

People in all stages of Parkinson's are welcome. The theory behind the exercise is that improved trunk mobility combined with an aerobic conditioning program will lead to improvement in and maintenance of functional activities for everyday life.

Join us by calling Anne or Beth in West Bend at 262-306-6100, or Kris, Sharon, or Jenna in Hartford at 262-670-4300. It can and has made my life fuller and better.

"Words of Wisdom"

by Patrick Pelkey

- We don't stop playing because we grow old; we grow old because we stop playing.
- Every day above ground is a good day.
- The best things in life aren't things.
- Why survive when you can live?

APDA Support Groups

The following support groups are sponsored by the Wisconsin Chapter of the American Parkinson Disease Association. For information on other support groups in the state, please contact Jessica at 608/229-7628 or visit www.wichapterapda.org.

Endeavor

Short Circuiting Support Group
Contact: Renee Bloss, 608/566-3379

Fitchburg

Fitchburg Senior Center
5510 Lacy Road
2nd Friday at 9:30 a.m.
Contact: Mary Hoffman, 608/249-9109

Madison

Parkinson's Disease Caregiver Support Group
(caregivers only)
East Madison/Monona Coalition
4142 Monona Drive
1st Tuesday at 4:00 p.m.
Contact: Jessica, 608/229-7628

Young Onset PD Support Group
St. Mary's Hospital
700 South Park Street
Conference Center
1st Thursday at 6:00 p.m.
Contact: Jessica, 608/229-7628

Asbury United Methodist Church
6101 University Avenue
3rd Thursday at 6:00 p.m.
No meeting in December
Contact: Jessica, 608/229-7628

Mount Horeb

Mount Horeb Senior Center
107 North Grove Street
3rd Tuesday at 10:00 a.m.
Contact: Rita Stanton, 608/437-6959

Portage

Bethlehem Lutheran Church
W8267 Highway 33
3rd Thursday at 2:00 p.m.
Contact: Elayne Hanson, 608/742-2410

Sun Prairie

Colonial Club Senior Center
301 Blankenheim Lane
Therapy Room
4th Monday at 1:00 p.m.
Contact: Jessica Olejniczak, 608/229-7628

Waunakee

Village Center of Waunakee
Senior Center Stage
333 South Madison Street
4th Tuesday at 2:00 p.m.
Contact: Dee Henning, 608/849-8834

Resource Book

Copies of the *Wisconsin Parkinson's Disease Resource Book* are available from Jessica at 608/229-7628 or parkinson_assn@ssmhc.com. The resource book also is available at the Wisconsin Chapter APDA website, www.wichapterapda.org.

*HAPPY
VALENTINE'S
DAY*

"This disease is like falling in love: First thing you think about when you wake up and last thing you think about when you go to bed."
— Mary Hoffman

My Diagnosis of Parkinson's Disease

by Barb Dobie

A diagnosis of Parkinson's disease never entered my mind. After all, it was just a toe with a tremor that wouldn't stop that moved to my arm that affected my balance, sleep, and everything else in one way or another. I didn't know anyone with PD much less what it could do to me. After another appointment with my neurologist, I went to my car in the clinic parking lot, called my husband who was working in another state, and cried until my lunch hour was over. I went back to work, because I didn't know what else to do.

Yes, it's hard to be cheerful on those bad days. Once in awhile, I have a "pity party," and I'm the only guest who shows up. I struggled with how to tell my adult sons without being negative or morose and how much to tell my employer. I wanted to keep my career with no special allowances but had no clue what challenges PD might mean, much less when and how it would change my abilities. I refused to be defeated and vowed to push through the challenges of daily life.

Usually, that means adjusting my goals at any moment in time.

Laughter is essential. If I can laugh at myself and have other people laugh with me, we all benefit. I can now claim I'm an expert at shaken, not stirred martinis and ring a bell automatically for the Salvation Army. I'm a grandma with a bouncing lap, and my grandson sees nothing unusual with that.

Support is crucial in my life. I have many new friends I never would have met if PD hadn't surprised me. My friends and relatives still love me even if the word "normal" has a different meaning now. Without the encouragement of other PD'ers and caregivers in support groups, it would be much more difficult to face the future. My new employer allows me to adjust my hours and start later in the morning to help avoid fatigue.

No one knows what their future holds, and we are no exception. I continue to hope that research and medical advances will mean a cure some day. Until then, life goes on, and hopefully our days have more good in them than bad. When I see you, smile, tell a joke, and let's laugh together. It makes going forward easier, and it's a lot more fun than tears!

Caregiver Respite Program

by Pamela Crapp

The Wisconsin Chapter APDA exists to serve people with Parkinson's disease, and we take that responsibility very seriously. We also realize the importance of taking care of caregivers.

The board of directors is excited to announce a partnership between the chapter and Independent Living, Inc., to provide respite services to caregivers of people with Parkinson's disease in Dane County. Eligibility criteria include a Parkinson's diagnosis, membership in the Wisconsin Chapter APDA, and Dane County residency.

We encourage caregivers to take advantage of this opportunity. Remember, you must take care of yourself first.

To apply for services or for more information, please contact Christina Snider, In-Home Services Program Manager, Independent Living, at 608/274-7900.

A not-for-profit organization, Independent Living, Inc. (www.indepenliving.com), has been providing comprehensive in-home and other services to older adults and those with disabilities in Dane County for over 35 years. Our agencies look forward to a successful collaboration in and growth of this endeavor.

The Joy of Zumba Gold — New Class Targets Parkinson's Disease with Latin Dance

by Jane A. Busch

The rhythmic beat of the Latin salsa music would be enough reason for anyone to want to move, but for this weekly Zumba Gold dance fitness class, the participants not only want to move, they need to move.

This diverse group of men and women, who range in age from 40 to 75 and who include a lawyer who ran for state governor, a woman whose career is volunteering, and a bicyclist who recently rode the Florida Keys to benefit AIDS research, all have one thing in common—they have Parkinson's disease.

Parkinson's disease is a movement disorder characterized by slow, stiff movement and difficulty with balance. What better way to combat a movement disorder than to move? "Dancing is great, because it not only is exercise for the body, it is exercise for the brain," says participant Bob Nasett. "It is a big challenge to move my legs in one direction and my arms in another."

Research is beginning to support this belief. The first controlled study to examine the benefits of dance therapy for Parkinson's, published in the December 2007 *Journal of Neurologic Physical Therapy*, focused on another style of Latin dance, the Argentine tango. Researchers at Washington University School of Medicine in St. Louis say dance targets problems specific to PD patients, such as balance, moving backward, initiation of movement, and moving at a variety of speeds. The results showed that patients who danced the tango demonstrated significant improvement in balance and mobility when compared with patients who did conventional exercise. In addition, what was found

interesting is that of those who participated in the tango classes, over half continued the dance classes after completion of the study, while all of those who took part in conventional exercise dropped out. The reason they continued: it was fun. The key to making exercise beneficial over a lifetime is to make it fun, make it engaging.

Zumba Gold does just that. Zumba Gold is a new version of the ever-popular Zumba, a Latin-inspired workout. Zumba Gold is targeted to the baby-boomer population. Like Zumba, it incorporates dance fitness routines choreographed to Latin and international music. Like Zumba, its philosophy is simple: feel the music, move the body. But Zumba Gold differs in that it is a low-impact version, performed at a more moderate pace. It is being offered in fitness centers, retirement communities, and even cardiac rehabilitation centers. We believe, though, that our class is the first Zumba Gold class in the nation specifically modified for and offered only to people with Parkinson's.

The class is supported by the Wisconsin Chapter of the American Parkinson Disease Association (APDA) and is offered weekly, free of charge to attendees.

Instructor fees have been waived, and Harbor Athletic Club, which further supports PD programs with its PWR Moves class, has donated the space and assisted in marketing. In lieu of charging a class fee, donations may be made to the Wisconsin Chapter APDA where they will be earmarked into a special fund for future dance and exercise programs.

I know that Zumba Gold works for people with Parkinson's. I know it works, because I have taken Zumba classes for over two years. I have completed both Zumba and Zumba Gold instructor certification courses, and I am the Zumba Gold instructor for this group. But, most significant is this: I have Parkinson's disease.

Continued on Page 9



Zumba

Continued from page 8

Most people would say PD has changed their life. For me, Zumba has changed my life. Even with PD, I am now more fit than ever. Though I may wake up stiff and slow, one hour of Latin dancing allows me to be virtually symptom free the rest of the day. Dance has been my Parkinson's therapy, and now I have the opportunity to share it with others, and these participants give me as much support and motivation as I give them. Most arrive at class early to talk as we all have Parkinson's in common. We have become a support group that dances and a dance group that supports.

The movements may be less than perfect, but the pride of accomplishment is second to none. One gentleman asked me, "Please tell

my wife I can cha cha. She doesn't believe me. She sees me as stiff and slow to move." We invited his wife to visit, and his credibility was restored as she watched him cha cha, salsa, and mambo across the room.

Our class may be an eclectic mix of personalities, but what binds us together is our journey with PD and our joy of dance. We believe in the healing power of music and dance. When we hear the steady rhythms of the Latin music, our bodies move fluidly, our brains create new pathways, and our hearts feel joy.

If you are interested in joining a Zumba Gold exercise class for people with Parkinson's disease and live in the Madison area, please contact Harbor Athletic Club at 608/821-6501. The class takes place on Friday afternoons at 1:15.

My PD Perspective

by Carla Marlot

I was diagnosed in October 2004 at the age of 41. Like most everyone else who gets handed the news, especially those of us who fall into the young onset category, I was unprepared, overwhelmed, and devastated. I've always led a fairly active lifestyle—vacation and leisure time pursuits typically rotated between backpacking, bicycle touring, or cross-country skiing—which made my diagnosis seem all the more unfair.

I've been living with the disease for almost seven years, and for the most part, it's been pretty easy to ignore. It's progressed at a blessedly slow pace and, thus far, has not kept me from doing anything that I've wanted to do. I still ride a bike, my hands are still able to knit and bead, I'm learning to play the ukulele, and I still work full time. But I know the losses are coming. Not knowing how quickly they will come or to what extent they will impact my lifestyle is one of the hardest aspects of living with the disease for me. As it

progresses and pushes its way into my life and daily routine, I feel that I must come to terms with the disease. To learn how to live with it—peaceably, gracefully—that is my resolution for this new year.

But just as PD steals away something immeasurable—precious, free-flowing, fluid movement—so also does it give something that's equally difficult to assess in terms of value upon a person's life. Being diagnosed with PD at a young age has provided me with the opportunity to evaluate my life from a new perspective and prompted me to make changes in my life that I might not have otherwise made. And my life is better for it. Having the disease has helped me appreciate what a strong, loving, and supportive family I belong to. Having the disease allowed me to hear the most sincere, loving, and selfless statement that I think I've ever heard. Having the disease encourages me to wring as much joy as possible out of each day, and there's something to be said for a built-in reminder to live life to the fullest.

TRIBUTES

The Wisconsin Chapter received the following donations from September through December 2010. These gifts are gratefully accepted to support the chapter's programs and activities.

In Memory

Cheryl Bower

Karen Shawkey

Charles Ciucci

Stephen Ciucci

Helen Finneran

Southwest Education Association Staff

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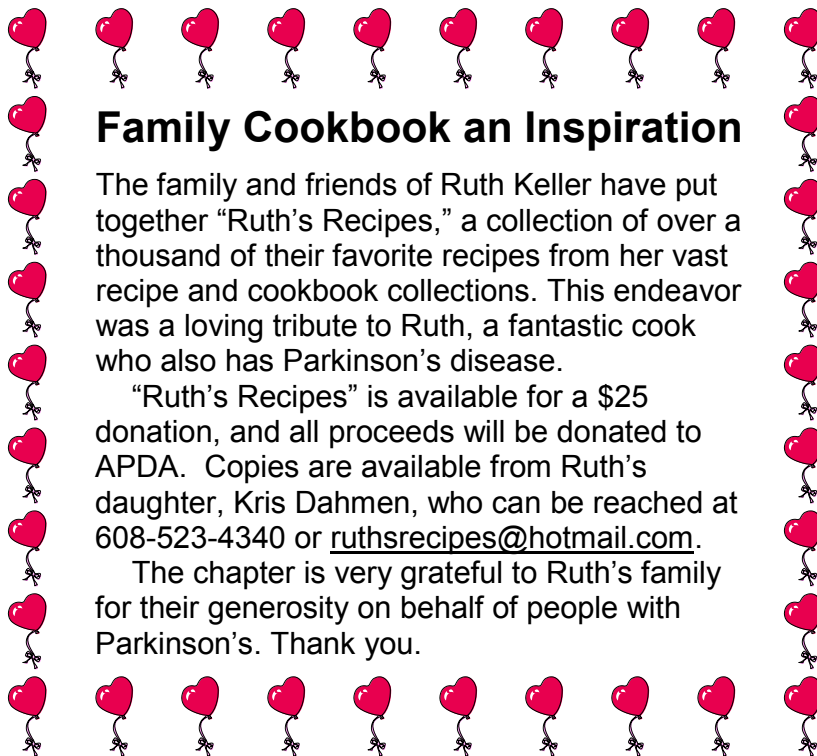
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Family Cookbook an Inspiration

The family and friends of Ruth Keller have put together "Ruth's Recipes," a collection of over a thousand of their favorite recipes from her vast recipe and cookbook collections. This endeavor was a loving tribute to Ruth, a fantastic cook who also has Parkinson's disease.

"Ruth's Recipes" is available for a \$25 donation, and all proceeds will be donated to APDA. Copies are available from Ruth's daughter, Kris Dahmen, who can be reached at 608-523-4340 or ruthsrecipes@hotmail.com.

The chapter is very grateful to Ruth's family for their generosity on behalf of people with Parkinson's. Thank you.

Helpful Hint

Sew Velcro where buttons are, so you don't have to mess with buttoning and unbuttoning when your hands aren't working.

This hint comes from a caregiver of someone with Lewy body dementia.

If you have a helpful hint to share, contact Jessica at 608/229-7628 or parkinson_assn@ssmhc.com.

If you received this newsletter via mail and would like it electronically, please contact Jessica at 608/229-7628 or parkinson_assn@ssmhc.com.

It was a pleasure working on this newsletter. The words of the contributors are truly inspirational, and I am grateful they shared their stories and poetry.

— Pam Crapp

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The board of directors meets the second Wednesday of the month at 5:30 p.m. in Bistro B at St. Mary's Hospital.

APDA Information & Referral Center

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PARKINSON'S PERSPECTIVE

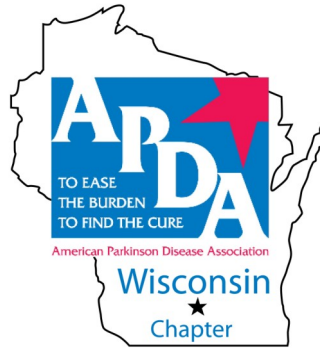
This newsletter is published three times a year for Parkinson's patients, their families, and caregivers by the APDA Information & Referral Center and the Wisconsin Chapter of the APDA.

If you no longer wish to receive the newsletter, please contact Jessica at 608/229-7628 or parkinson_assn@ssmhc.com.

The newsletter is intended for educational purposes only and should not be interpreted as providing medical recommendations. Patients are advised not to change their treatment without the advice and consent of their treating physician. Newsletter content is the sole responsibility of the editors.

INSIDE

- How to stay positive with PD
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- Caregiver respite
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