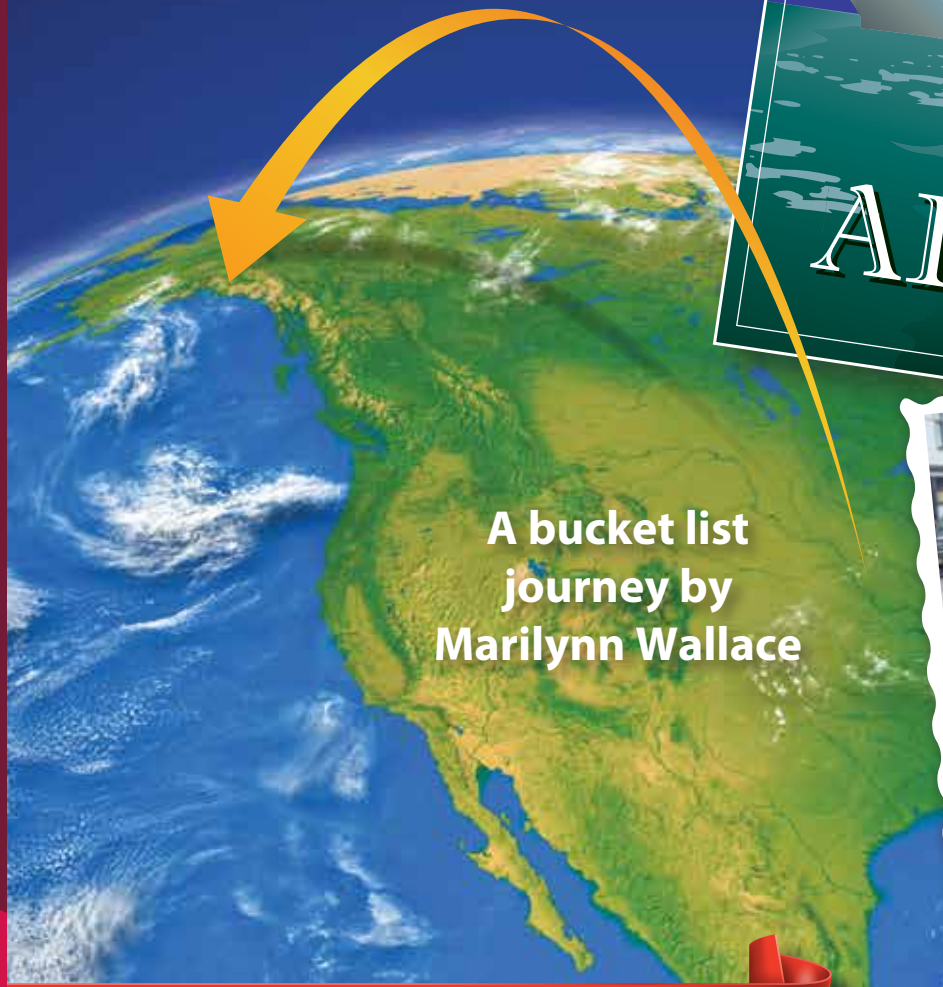


# Live it!

A Resource for Iowans with Parkinson's Disease and those who care for them.

## Traveling with Parkinson's "Yes, I can!"



A bucket list journey by  
Marilynn Wallace



SEASON'S GREETINGS AND

**HAPPY NEW YEAR**



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ONLINE**

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### Reader Submissions

*Live it!* magazine is intended to be a voice for the Parkinson's disease community, and we are pleased to consider article, art, and photo submissions for future issues from our readers. Please send your submission requests to Iowa Parkinson Disease Information and Referral at UnityPoint Health – Des Moines, 1200 Pleasant St. E-524, Des Moines, Iowa 50309, with *Live it!* on the attention line, or email them to [apdaiowa@apdaparkinson.org](mailto:apdaiowa@apdaparkinson.org). Please note: The decision to include reader submissions is at the discretion of the editorial staff. The editorial staff reserves the right to edit or otherwise alter any material submitted. If you would like submission material returned to you, please include a stamped, self-addressed envelope.

# letter from the editor

## Season's Greetings and Happy New Year!

We have several things to share with you in this issue of *Live it!* as we wrap up 2016. We had our NW Iowa Parkinson's Disease Symposium back in October in Sioux City and we also thank the organizers and volunteers for the wonderful fundraisers that have taken place – we are lucky to have such a great group of friends and supporters who've conducted these fundraisers the past many years.

*Live it!* isn't *Live it!* without stories and experiences from the Parkinson's community. We hope these stories inspire you to live your best and work toward any goals you may have in 2017. For our cover story Marilyn Wallace of Cedar Rapids shares a particular goal – a trip to Alaska! She initially doubted she could ever do this trip, but with some help and preparation she crossed an item off of her bucket list.

It's safe to say that winter in Iowa means staying indoors a good amount of the time. Our board member Kris Cameron, an exercise specialist, shares some tips for being active during these few months right in your own home. Staying indoors also means less exposure to the sun, a source of Vitamin D. Our medical director Dr. Struck covers what the medical community understands about Vitamin D and its connection to Parkinson's disease.

This past fall several Iowa Chapter APDA board members attended the World Parkinson Congress in Portland, Oregon. This event takes place every three years and is attended by over 4,600 people from all over the world. Bob and Victoria Miller share their experiences at the Congress this year.

A couple of special items in this issue: Ethel Sylvester of Lynnvile, Iowa, shares a poem about her journey with Parkinson's and Amy Haas of Clive, Iowa, invites those with Young Onset Parkinson's and their families to join a newly formed Young Onset Support Group that also meets virtually!

We are grateful for your continued support of our organization and the Parkinson's community – do consider making a tax-deductible donation to help us continue serving the state with this magazine, educational events throughout the year and funding the Information & Referral Center.

*Till we meet again in the spring!*

Crissanka Christadoss  
Managing Editor, *Live it!* magazine  
Director, Iowa Parkinson Disease Information & Referral Center

### **Live it! Staff**

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Vicki Ingham

Linda Jordening

Patrick Vaassen

### **Request for Submissions:**

The staff would like to invite words and photographs from you. Share with us photographs of you, your artwork, your words – anything that shows how you *Live it!* Please see submission guidelines on the bottom of page 2.

### **Disclaimer:**

All material related to Parkinson's disease contained in this magazine is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's physician. Specific articles reflect the opinion of the writer and are not necessarily the opinion of the editorial staff, the Information and Referral Center, the medical director of the Center, The Iowa Chapter of APDA, or the APDA.

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from our  
**medical  
director**



**Lynn K. Struck, MD**  
Neurologist  
Physician Specialty Clinic  
UnityPoint Health – Des Moines

*The Iowa Parkinson Disease Information and Referral Center and Live it! magazine are privileged to have board-certified clinical neurologist Lynn Struck, MD, as our advisory medical director.*

*Dr. Struck is on staff with UnityPoint Health Physicians, Des Moines, and is a leading expert in movement disorders in Iowa. She has focused her career on advances in treatment of her many patients with Parkinson's disease and ongoing research to find better treatments and, ultimately, a cure.*

### **Vitamin D Levels and the Risk of Parkinson's**

Vitamin D receptors and 1-alpha hydroxylase, the enzyme that activates vitamin D, are widespread in the brain. There are some animal models that suggest the possibility that vitamin D may provide neuroprotection. There are numerous studies reporting that vitamin D levels are lower in persons with Parkinson's compared to those without Parkinson's. Individuals with Parkinson's disease (PD) may have low vitamin D because of their reduced access to sunlight, which is related to decreased mobility, and lower intake of foods enriched with vitamin D due to appetite loss. These reports imply that factors associated with living with PD may be responsible for the low levels of vitamin D. It is uncertain whether low vitamin D levels are caused by or correlate with PD.

The Mini-Finland Health Survey reviewed this issue. It was a prospective study that showed an association between low vitamin D levels and PD. Another recent major study, though, showed that there was no association between vitamin D and the incidence of Parkinson's.

Either way, Parkinson's patients are at risk for falls. For normal bone health, it is important to have adequate levels of vitamin D. For this reason alone, I feel it is important to monitor at-risk individuals.

Please discuss this topic with your neurologist for more information about vitamin D and Parkinson's disease. ■

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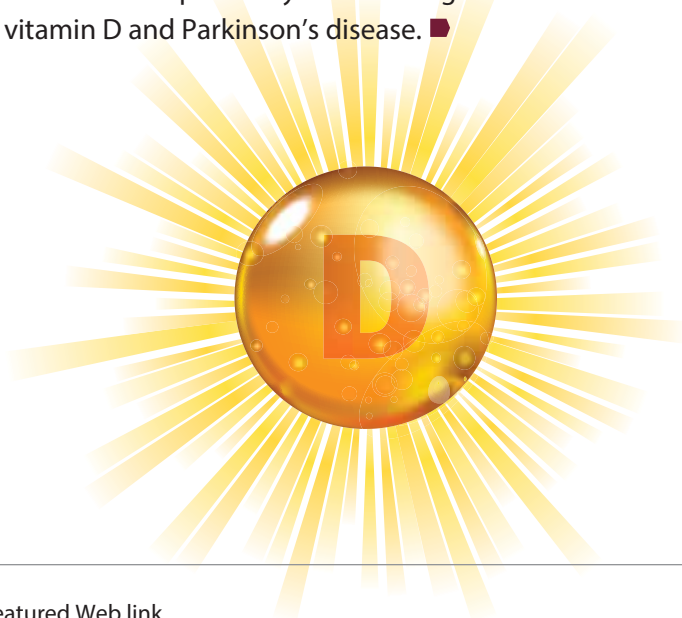
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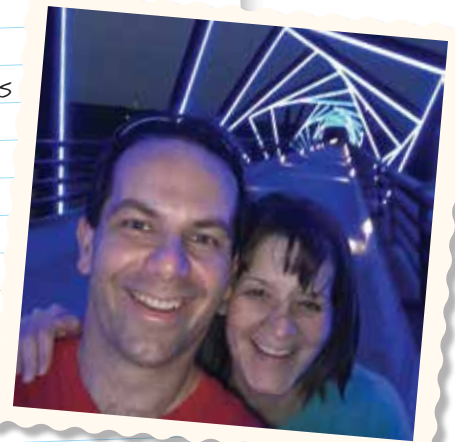
# Greater Des Moines (and Virtual Greater Iowa) Young-Onset Support Group

My husband, Craig, was diagnosed in October 2015 at the age of 45. Our daughters were 8 and 11 years old. To say that our lives were turned upside-down would be an understatement. We didn't really have anywhere to turn until Craig became a board member of the IA APDA and they took us right under their wing.

Connecting with other relatively young people who are dealing with PD is a challenge. At the June 2016 Des Moines Conference, we met another young-onset couple. We chatted and exchanged information. Later that day, I saw them again and found out they had met another young-onset couple. We promised to get together and parted ways.

A few weeks later, Craig and I invited everyone over to our home. Three hours flew by! We decided we had formed the Greater Des Moines Young-Onset Support Group!

The Young-Onset Support Group has helped to give meaning and purpose to our challenge and helped us forge new friendships. It has peeled layers off my eyes and ears. To hear a woman who has been diagnosed share that she wants to continue putting on makeup every day while she can helps me better understand what my husband is going through. Those are words that speak to my heart. Words that my husband would never say, but that made sense to me and touched me so deeply.



Amy and Craig Haas

We all know that we need to work a little harder at everything now-day-to-day activities, insurance, transportation, help with children, work (do you even tell them?), telling family and friends (again, whom do you tell? when?).

Dreams. The future. You don't have to do it alone. That is what we have found in our support group. And it is growing! With Iowa being rural and technology being what it is, we are adding the virtual option to our meetings as well. Join us from anywhere in the state!

Check us out! The more the merrier!

Amy Haas

For more information about the Greater Des Moines Young-Onset Support Group, contact me at [anymchaas@gmail.com](mailto:anymchaas@gmail.com)



Members of the Greater Des Moines Young-Onset Support Group

For more support group listings, see page 19

# Traveling with Parkinsons

*Written by Marilyn Wallace, Cedar Rapids, IA*

On Halloween 2013, I was told by a neurologist that I had Parkinson's disease.



A few months later, a friend told me about Delay the Disease, an exercise class for people with Parkinson's. I began going to classes twice a week. At that time, I was using a walker. I have to admit that I am not well-disciplined and did not attend regularly for a while. It turns out I just needed something to motivate me!

I am eternally grateful to all those who devote so much time and effort to make these classes available. Right before our trip to Alaska, there was a day that I walked unassisted.

There were several things we looked into before we left for the trip. First, duties were assigned to my trusty travel companions. My daughter-in-law Joan who travels a lot for work, made all the airline reservations and would keep all the boarding passes available on her cell phone. My daughter Michelle made the cruise line reservations, wheelchair arrangements, and excursion bookings. My daughter Lynn had the duty of looking after me and making sure I had everything I needed before and during the trip.



For many years, I had dreamed of going on a cruise to Alaska. I had all but let this dream fade away until Mother's Day 2015. I was having dinner with my family and my daughter Michelle asked me if I had anything left on my bucket list. I told her about the cruise to Alaska—with my health, I didn't believe it would be possible. Michelle said she would come with me on the trip, which was a huge surprise because she has motion sickness. It didn't take much convincing—soon my daughter-in-law Joan and my daughter Lynn said they would also come along.

I was thrilled to have travel companions, but I wondered: can I travel with Parkinson's disease?

The answer is yes! I will tell you how I did it.

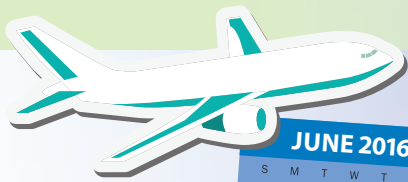
I do not have the strength or the stamina that I used to have. In addition to Parkinson's, asthma and arthritis also keep me from moving as fast as I would like to go. I decided to take better advantage of the Parkinson's exercise classes to help me increase my stamina and mobility. With a goal in mind and my motivation (Alaska), I began to exercise with a lot more discipline. Before I left for my trip, I graduated from the walker to a cane..

Joan ordered a wheelchair at each airport and for the ship. The cruise line does not have wheelchairs or scooters available (except for emergencies). They did have the name of a company that would deliver a wheelchair to the ship's cabin and pick it up at our last stop for a very reasonable cost.

I had been watching the weather forecasts for several weeks and thought I knew how to pack. Fortunately, a friend of Lynn's gave us some tips, which required some repacking. We included a few warmer pieces of clothing and a rainproof jacket because rain was in the forecast. Thankfully, it only rained a couple of days.

I also made sure I went to the bank to get money for tips. While tips were included with the cost of the cruise, airports and hotels are a different matter. Keep your tips handy and accessible because you will not have time to get them out of a pocket or bag.





## Alaska or Bust

**Friday, June 17, 2016**

We were finally on our way!

We left from the airport in Cedar Rapids. There were lines everywhere we went. Most moved very fast, but a wheelchair helped tremendously, as I would not have been able to keep up on my own or stand for long periods of time.

Throughout the trip, the wheelchair often expedited the way to shorter lines and opened doors to elevators for us. It also got me the front seat in the tour bus a couple of times! Note: it takes a lot of energy to sightsee, even from a wheelchair. **Plan time to rest each day.**

We left Cedar Rapids mid-afternoon on a Friday with the help of a kind gate attendant who took me to the door of the plane in the wheelchair. This was just the first of many staff members and strangers we met along the way who were willing to help. We arrived at our destination hotel late at night. Again, a wheelchair was already waiting at the front desk before we checked in (Thank you, Michelle!). We were to board the ship on Saturday afternoon.

**Saturday, June 18, 2016**

The first thing we saw when we opened the hotel room drapes the next morning was our ship just outside our hotel window.

Not long after we boarded the ship, there was a safety drill. Anyone who didn't show up would be escorted off the ship. We were a little disoriented but found a helpful staff member who pointed out the way we should go. Yes, it was raining and cold. Thank goodness we were gathered on a deck below the life boats so we were partially protected from the rain. And thank goodness for long sleeves and a waterproof jacket! Cabin numbers and names were called out for our assigned lifeboats, and after everyone was accounted for we were dismissed.

Dinner was at 5:30 p.m. We had the same table and the same staff each night in our main dining room. The first



night they learned all our names . . . except mine. It was too difficult, and I soon became "Mom" and was greeted that way throughout the trip. I can't say enough kind things about the cruise ship staff!

**Sunday, June 19, 2016**

We were at sea all day and night. We met our room stewards as we were leaving for a different part of the ship that morning. They also tried to learn our names, but again mine was too difficult, so I became "Mom" to them as well.

**Monday, June 20, 2016**

We arrived in Juneau at about noon — Michelle booked us all a whale-watching excursion! Anyone leaving the ship for an excursion was to go to a room at the front of the ship for instructions; the wheelchair and elevator came in handy because we had to move quickly. We boarded a ship's tender (after the staff confirmed that I could walk short distances, I had to get out of the wheelchair and take a few steps to get into and off of the boat). The tender boat took us to land, where we got onto a bus, had a quick tour through part of Juneau (steps to get on and off of the bus), and got to the whale-watching boat (where I stayed in the wheelchair until we got onto the boat and could sit on one of the bench seats). We were finally off on our whale-watching adventure.



Marilynn whale watching in Alaska

We were told that if we didn't see whales, we would receive a partial refund. I have to admit I was skeptical that I was going to see a whale. But guess what? We saw many whales that day, including a mother and calf just outside the window where I was sitting! There was also a whale breach close by. We were late getting back to the ship for dinner and therefore had to go to another dining room on the ship—but it was ok! Watching the whales was so worth it!

**Tuesday, June 21, 2016**

We sailed through the night and arrived at Skagway, Alaska, early the next morning.

We were able to spend several hours there. This was my favorite stop. It was a small town with wooden walkways. All the buildings were very old, brightly colored, and full of history from the Gold Rush days. Michelle took me from one end of the town to the other. I loved every minute of it. Thank you, Michelle, for being my "chauffeur," aka "Pushy-girl."



Michelle and I posing in Skagway, Alaska!

**Wednesday, June 22, 2016**

We spent the day on the ship sailing through Glacier Bay National Park. Park rangers came onboard and spent the day talking about all the wonders of Glacier Bay, answering questions, and pointing out wildlife (their eyes were much better than mine, as I did not see the mountain goats they mentioned). I could not see this because so many people (there were about 2,000 guests) did not make way for anyone with a disability. I was amazed that there were so few ice floes in the water of the bay (they looked more like ice cubes in a punch bowl rather than the huge icebergs that I have seen on television).

After the viewing area started to become quite crowded, we went back to our cabin to take advantage of our private viewing space.



I am taking a look at Glacier Bay National Park - brrrrrrrr!!!



Michelle took a photo of me all bundled up and enjoying the spectacular scenery from a chair while Lynn is leaning against the railing in only shirtsleeves.





## Thursday, June 23, 2016

Ketchikan was our next stop. We were able to do a little shopping, took a few pictures, and ate lunch.

It was very cold with the wind coming off the water, so we went back to the ship after a short time.



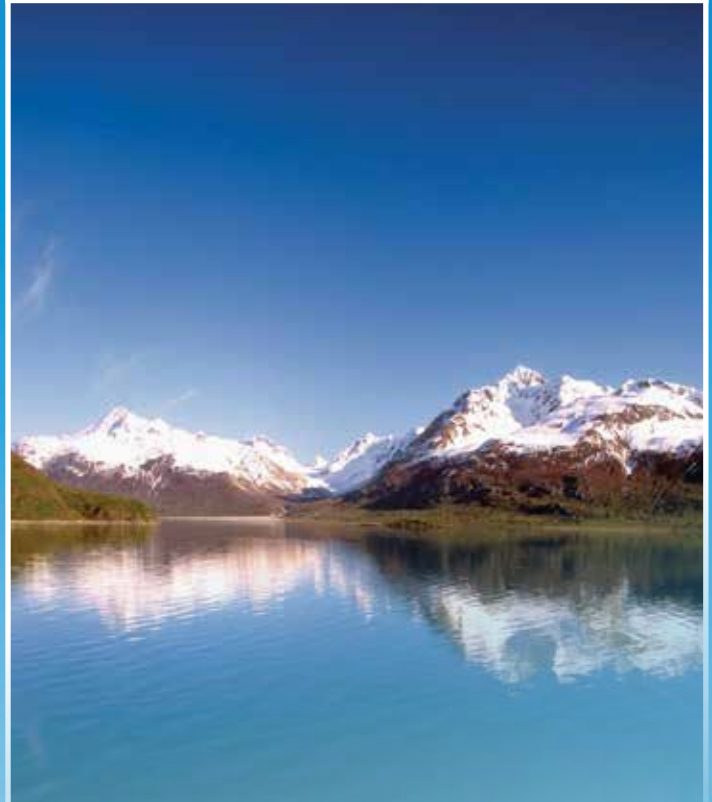
## Friday, June 24, 2016

We had a full day at sea to rest up, spending time in some of our favorite shipboard locations, packing (oh, the fun of getting everything packed!), and saying goodbye to our helpful and wonderful crew members.

During the trip, I found myself sitting on the edge of the bed doing some of the exercises that I had learned at the Parkinson's exercise classes. I also take advantage of this knowledge here at home when I have a night when I need extra help getting to sleep.

*So, can I travel with  
Parkinson's disease?*

*Yes, I can!*





## Attending the 2016 World Parkinson Congress

*Written by Bob and Victoria Miller,  
board members of the Iowa Chapter of the APDA*

We attended the 2016 World Parkinson Congress with our fellow board members, Jeff and LaDonna Molander and John Krumbholz and his wife, Sam. It was held at the Oregon Convention Center in downtown Portland.

The WPC is held every three years and aims to share a number of things, but mostly Parkinson's research, optimism, and insight. The Congress is attended by 4,500 people with Parkinson's disease, caregivers, medical professionals, research scientists, and other health professionals from over 67 countries around the world. Scientists share information with one another, bringing us closer to a cure, and most certainly closer to help with everyday living. Because of the research sharing, scientists from around the world are spurred to contemplate more "what ifs," thus moving forward with help and hope.

We attended the opening ceremonies, which were so inspirational! This year was the first year they had a World Parkinson's Choir—they sang a song written especially for this conference, and Victoria had the privilege of singing with this unique choir.

The rest of the opening ceremonies was highlighted by keynote addresses from Maryum Ali (daughter of the late Muhammed Ali) and Brian Grant, a former NBA player who heads the Brian Grant Foundation after being diagnosed with Parkinson's at the age of 36. Both of the addresses focused on the power of a good attitude and having a positive outlook. The Oregon drumline marched us all out of the room to the reception hosted by the WPC. It was a wonderful way to kick off the Congress.

Each day of the Congress began with technical scientific research lectures called "Hot Topics." From there, a lecture and slide presentation would be given in the largest Exhibit Hall. The topics ranged from deep brain stimulation to genetics and stem cell research. These

talks were broken into four 30-minute segments from experts across the globe. While the talks were very technical, they did give insight into how the world of research works, what provides research momentum, and the progress being made.

Breakout sessions were held in locations throughout the convention center, even during lunch. One particular session featured Tim Hague, the first winner of The Amazing Race Canada, who was also the keynote speaker at last summer's Iowa PD State Conference. Brian Grant also spoke again, this time on how he and other Parkinson's patients climbed Mount St. Helens, a feat that took six hours but nonetheless was quite an accomplishment. The third presenter was Linda Olson, a physician who at an early age lost both legs and her right arm in a car-train accident. Later, she was diagnosed with Parkinson's disease, after which she talked about her "happy gene" (a positive attitude) taking over. Linda had such a great attitude about life, leaving few dry eyes in the house as she finished inspiring us to live life to the fullest, no matter what has happened.

The afternoons were broken into more learning sessions, ranging from technical to rather general and covering basic science, clinical science, and comprehensive care. The afternoons finished with roundtable discussions in which people could sign up for small group discussions on various topics. There were seven sessions and seven roundtables to choose from in the early afternoon, followed by another seven sessions and seven roundtables in the later afternoon session. So much information!

One of the most interesting aspects of the World Parkinson Congress was visiting with and meeting new people from around the globe and our own country. We were amazed at the number of young people attending the conference who had been diagnosed with young-onset Parkinson's. The first day, we met one young man,

24, who had recently had deep brain stimulation (DBS). We were also delighted to run into fellow lowans like Shirley Burke from West Des Moines. Shirley wants to get more involved with the young-onset Parkinson's community in the state of Iowa, which we believe is needed in our state. So many people of all ages are hungry for knowledge concerning Parkinson's.

The convention center was a great venue for the many people who attended who had specific medical issues and needs.

There was also artwork created by those impacted by Parkinson's and a renewal room where massages and Reiki massages were available. There were also different rooms for dance, exercise, and even meditation. Another entire room was dedicated to rows and rows of research posters and researchers from different universities and other organizations. Over 650 posters were presented during the course of the Congress. It just goes to show that there is an abundance of research on Parkinson's which will spur new questions and therefore new research.

We all agreed that we are fortunate to have several outstanding educational events in our state that give lowans the opportunity to gather information. Knowledge is power. As we look back on the week in Portland at the World Parkinson's Congress, we are indeed inspired by the amount of work being done around the world to help those with Parkinson's disease. The last two verses of the song sung by the WPC choir accurately describes my feelings about the week:

*"Yes! We can imagine a world without Parkinson's,  
A world without tremors or shakes.  
We care enough, so we will make it happen.  
Yes, we'll make the effort it takes.*

*"So soon we'll reflect on the week that's gone by.  
Enlightened, empowered, our spirits are high.  
Even more optimistic that soon we shall see  
A world that is Parkinson-free,  
A world that is Parkinson-free." ■*

The Parkinson's Quilt Project on display.



Victoria taking part in Congress activities.



Attendees taking part in exercise and movement.



John and Sam Krumbholz posing with Parky the Raccoon, the WPC's mascot.



Victoria singing in the opening ceremony with the World Parkinson's Choir.



Maryum Ali, daughter of Muhammed Ali, and Brian Grant, former professional basketball player and Parkinson's advocate, addressing attendees during the opening ceremony.

# Keeping Active During Winter

By Kris Cameron, BS

Iowa APDA Board Member

ReNu Your Life Fitness & Parkinson's Wellness

American Council on Exercise Certified Personal Trainer



Staying active during the winter can be a challenge in a cold-weather climate like Iowa. Spring through autumn, it is much easier to get outside to walk, garden, or engage in any number of activities that you enjoy doing. Shorter days, cold temperatures, and ice or snow can make getting outside a challenge. This often leads to isolating oneself indoors, which isn't healthy for someone with PD or their caregiver!

Safety is always the primary concern during the winter. If sidewalks and streets are icy, it is definitely better to stay indoors and not risk falling or being involved in an auto accident. If the weather isn't cooperating, have an indoor exercise plan in your home. Visit the following websites for ideas on exercises you can do at home in front of your computer:

- Delay the Disease - [www.delaythedisease.com/](http://www.delaythedisease.com/)
- Patrick LoSasso - [www.smartxpd.com/](http://www.smartxpd.com/)
- Power for Parkinson's - [www.powerforparkinsons.org/](http://www.powerforparkinsons.org/) (visit their YouTube page)
- My site, ReNu Your Life Fitness & Parkinson's Wellness - [www.renuyourlife.com](http://www.renuyourlife.com)
- Search YouTube for "Parkinson's disease exercise" for more suggestions.

If you have an exercise bike or other exercise equipment at home, dust it off! Be sure to use supervision with a treadmill if you have balance issues. If you don't have internet access or exercise equipment, chart out a path in your home to walk. Set a timer for the length of time you want to walk, put on your favorite music, and start walking! You can add in sit-to-stands from a sturdy chair to really help strengthen the legs and wall push-ups for the upper body.

If the sidewalks are clear but the temps are a bit chilly, bundle up to avoid hypothermia and walk outside with your caregiver or a friend. If you don't have a Parkinson's-specific exercise program in your area, look for a chair exercise program or a program such as SilverSneakers to join. Of course, if you are able to be more active than that, join any class and have fun!

Isolation during the winter months can take a toll on our mental health. Depression can increase during the winter. It is important to stay active and connected to others, not just for people with Parkinson's, but for all of us, especially caregivers.

Don't forget to stay hydrated during the winter. We tend to think more about drinking water during the warm months. However, dehydration can occur at any time in any type of weather. It is especially important for people with Parkinson's disease to stay hydrated. Hydration helps with brain function, blood pressure, and energy. If you are concerned about frequent urination, reduce your water consumption in the evening before bedtime.

You can stay active during the winter months. It just takes planning and sometimes a little creativity. Check out the Iowa APDA website for Parkinson's-specific exercise programs near you. ■

To receive an APDA *Be Active & Beyond* booklet, call the Iowa APDA at (877) 872-6386 or email us at [apdaiowa@apdaiowa.org](mailto:apdaiowa@apdaiowa.org)

Visit [www.apdaiowa.org](http://www.apdaiowa.org) to see neurowellness/exercise classes available to the Parkinson's community in Iowa.





Poem Submission By Ethel Sylvester



# Parkinson's - My Experience

Two fingers side by side-begin shaking, and shaking  
 I could not tell them to stop or to start; they just did it  
 They stuck together as though they were best friends  
 A movement disorder specialist could tell me why this is happening.  
 Do I really want to know!

So off I go to see why the shaking; from someone I do not know  
 Questions, questions, questions! A walk down the hall  
 And just like that the neurologist said, "You have Parkinson"  
 Not maybe or I think you do, but without any hesitation-PARKINSON  
 Now what do I do and what is Parkinson anyway, and why me,

Home at last in front of my trusty computer  
 To discover everything I need to know or want to know about Parkinson  
 Just wish it would go away and I could forget about it  
 But Parkinson will still be there in the morning, and day after day;  
 My friend and my constant companion

Medicine, exercise, positive attitude helps me a great deal  
 Am I ready to go to a Parkinson's support group-No not yet!  
 I do not want to see my future in other people's faces  
 Or hear them tell about their experiences with Parkinson  
 Found the nearest Parkinson support group, but hesitated  
 Do I really want to go!

I went to Iowa Parkinson Conference in Des Moines  
 I met a person; she asked me to attend her support group  
 I attended with her and later by myself and I discovered how  
 helpful it was  
 Surprise how my attitude changed over the months  
 Do I really want to go? YES

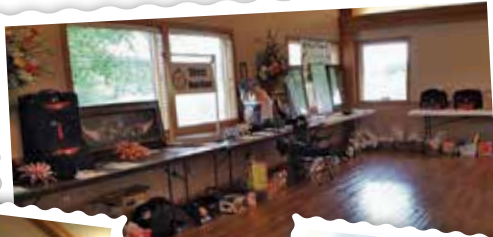
Today I accept that Parkinson will always be with me.  
 I have more knowledge about the disease and how it may affect me  
 in the future.  
 I also know how important it is to exercise, keep a positive attitude,  
 And will always remember: I have Parkinson but I will not let it  
 rule my life  
 Do I really still want to learn more? YES

Sept. 10, 2016

## **The 10th Annual Eastern Iowa Parkinson's Golf Classic**

**Saturday, August 27, 2016**

This year's Golf Classic took place at the Pleasant Valley Golf Course in Iowa City. The event is organized by the Iowa Chapter of the APDA's Co-President, John Krumbholz. Over \$20,000 dollars was raised to support the Iowa Chapter of the American Parkinson Disease Association.



## **The 6th Annual Grey-Out Night hosted by the East Sac High Volleyball Team**

**Tuesday, September 27, 2016**

Thank you to the East Sac High School Girls' Varsity Volleyball Team in Sac City, Iowa, for hosting their annual Grey-Out Night! They raised over \$3,500 for the Iowa Chapter of the APDA. This is the sixth year the team has held the fundraiser in honor of their coach, Dave Waggle, who has Parkinson's and is a teacher at East Sac High.



## **The 8th Annual Shake, Rattle and Roll Motorcycle Ride and Fundraiser**

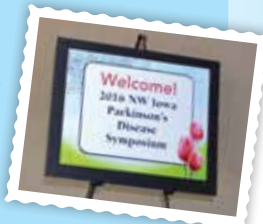
**Saturday, August 27, 2016**

Thank you to the Lost Cause Motorcycle Group for raising over \$26,000 for the Iowa Chapter of the American Parkinson Disease Association. Each year, the group organizes a ride through different cities in north-central Iowa and ends the ride with a raffle and silent auction. As always, a special thank you to event organizers Chad "Beads" and Kristen "Teen" Pierson for their support.

## The NW Iowa Parkinson's Disease Symposium

Friday, October 14, 2016

Over 100 attendees came to this year's symposium at the Hilton Garden Inn in Sioux City. Topics presented included Tai chi, tips for caregiving, yoga therapy, risk factors of Parkinson's disease, exercise and deep brain stimulation. Thank you to event sponsors Medtronic and Abbvie.



## Dancing and Movement Class

Saturday, September 17

Tuesday, November 8, Des Moines

The Iowa Chapter of the APDA, in partnership with Des Moines University, offered a free dance and movement class to individuals with Parkinson's and their caregivers. Iowa Chapter of the APDA board members Kristin Lowry, Victoria Miller, and Becky Robel led the effort to bring this class to the Des Moines community. Class instructor Becky Robel led the classes each week in dances like the fox trot and the waltz. DMU students served as spotters and partners for class attendees. There is evidence that movement improves function in Parkinson's, especially when paired with music.



Photos provided by Des Moines University

## The 1st Annual C4 Workout (aka Craig's Workout)

Saturday, October 22, 2016

The Iowa Chapter of the APDA's treasurer, Craig Haas, held this fundraiser in honor of his one-year diagnosis of Parkinson's disease and raised over \$5,000. He was joined by special guest Allison Toepperwein, American Ninja Warrior contestant and Parkinson's advocate. Over 25 people joined Craig for a four-hour workout (with breaks) that included a dance jam, weightlifting, kickboxing and yoga.



## The 9th annual PD Walkers at the Des Moines Marathon

Saturday and Sunday, October 15 and 16, 2016

This year, the PD Walkers raised over \$9,000. Thank you to the PD Walkers for their continued support and efforts. (In a previous issue of *Live it!*, we had stated that 2015 would be the last year that PD Walkers would participate in the marathon. Fortunately for the Iowa Chapter of the APDA, Brian Town, who has participated in the PD Walkers for many years, offered to lead the efforts this year. Thank you to Brian!)




# donors May – October 2016

Many companies and corporations will match your tax-deductible gift and double or triple the amount contributed to continue the APDA mission, "To ease the burden and find a cure." Gifts can be in the memory of a loved one or friend, or to celebrate a special occasion. A letter is sent to the designated person telling them of your generosity and thoughtfulness.

**Please send your donations to:**

- Iowa Chapter of the American Parkinson Disease Association, Inc.  
PO Box 507, Waukee, IA 50263

[apdaiowa.org](http://apdaiowa.org) 

**Iowa Chapter of the APDA**

**Co-Presidents:** John Krumbholz and Jeff Molander

**Treasurer:** Craig Haas

**Directors:** Connie Bever, Shirley Burke, Jan Friedel, Keith Fritz, Sean Jenkins, Kristin Lowry, Dave McNeil, Bob Miller, Victoria Miller, Rich Mills, LaDona Molander, Becky Robel, Marisa Tank and Jennifer Voorhees

- American Parkinson Disease Association, Inc. - National Office  
135 Parkinson Avenue, Staten Island, NY 10305  
(800) 223-2732, [apdaparkinson.org](http://apdaparkinson.org) 

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# acknowledgements



The Iowa Parkinson Disease Information and Referral Center is grant funded by American Parkinson Disease Association.

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**In Support of C4 Workout Event**

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**PD Walkers**

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**Shake, Rattle & Roll Event**

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## **Future Events/Save the Date**

**Friday, June 16, 2017**

**Iowa Parkinson's Disease  
Conference at the Lutheran Church  
of Hope in West Des Moines**



## links

## and other resources



**Web Links:** Here are a few helpful websites.

### Iowa Statewide Resources

Easter Seals Iowa Assistive Technology Center.....	www.eastersealsia.org
Easter Seals Rural Solutions Program.....	www.easterseals.com/ia/our-programs/rural-solutions
Iowa Family Caregiver.....	www.i4a.org
Iowa Legal Aid.....	www.iowaLegalAid.org
LifeLong Links.....	www.lifelonglinks.org
Relay Iowa.....	www.relayiowa.com
Senior Health Information Program.....	www.therightcalliowa.gov
Telecommunications Access Iowa.....	www.relayiowa.com/tai
UERS (Used Equipment Referral Service).....	www.eastersealsia.at4all.com

### Parkinson's Disease - General

23andme.....	www.23andme.com/pd
American Parkinson Disease Association.....	www.apdaparkinson.org
American Parkinson Disease Association, Iowa Chapter.....	www.apdaiowa.org
American Academy of Neurology.....	www.aan.com
Davis Phinney Foundation for Parkinson's.....	www.davisphinneyfoundation.org
The Movement Disorder Society.....	www.movementdisorders.org
Living Well with Parkinson's Disease.....	www.pdplan4life.com
Michael J. Fox Foundation.....	www.michaeljfox.com
National Institutes of Health: Parkinson's Disease.....	nihseniorhealth.gov
National Parkinson Foundation.....	www.parkinson.org & www.awareincare.org
Parkinson Disease Foundation.....	www.pdf.org
World Parkinson Congress.....	www.worldpdcoalition.org

### Caregivers

National Family Caregiving Association.....	www.nfcares.org
Iowa State University Extension Family Caregiving.....	www.extension.org/family+caregiving
Lotsa Helping Hands.....	www.lotsahelpinghands.com
Caregiver Action Network.....	www.caregiveraction.org
AARP Caregiving Resources.....	www.aarp.org/caregiving

## sign language

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### Vacation

The sign for "vacation" can also mean "time off from work," break time, holiday, leisure time, and related concepts. To sign "vacation" (lightly) jab your thumbs into your chest an inch or two from your armpits. If you use a single motion it means "time off" or "off work." If you use a double motion it means an actual "vacation" or "period of not working."

**Memory aid:** Think of a farmer taking a break or a vacation and sticking his thumbs in his overall's suspenders.





*A special Thank You to all support group facilitators and members for all they do in spreading awareness across Iowa. Thank you for all you do!*

# support groups

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**Anamosa/Jones County**  
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Allison.Niedermann@unitypoint.org  
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**Atlantic/Cass County**  
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**Burlington/Des Moines County**  
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**Carroll/Carroll County**  
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**Clive/Polk County**  
**Young Onset Support Group**  
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**Trenton, Missouri**  
Gloria Koon  
(660) 339-8006

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