

Live it!

INSIDE THIS ISSUE:
Details about the Annual
Conference/Victory Summit
held on June 5!

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



Singing and the Brain

Dr. Elizabeth Stegemoller

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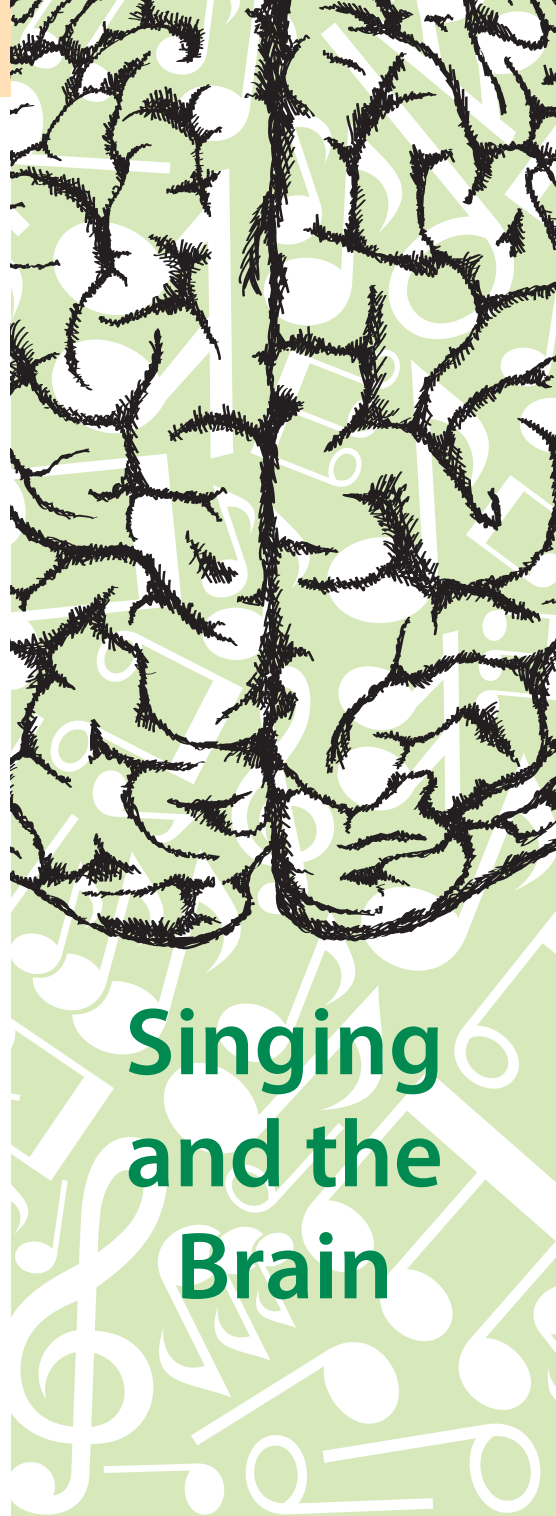


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Live it!
ONLINE

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Also, follow us on Facebook (www.facebook.com/lowalandR) and Twitter (twitter.com/lowaParkinson)



Singing and the Brain

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 informreferral@apdaiowa.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 *Live it!* staff

Live it! Staff

Medical Director: Lynn Struck, M.D.

Managing Editor: Crissanka Christadoss

Editors: Linda Jordening and Vicki Ingham

Contributing Writers: Gary Johnson and
Trina Radske-Suchan

Art Director: Patrick Vaassen

Live it! Editorial Board

Lynn Struck, M.D., Medical Director

Crissanka Christadoss, Coordinator,

Iowa Parkinson Disease Information and Referral

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.

Greetings *Live it!* Readers,

This year has gone by so fast, as it always does, but we've been busy and there are some great things happening on the horizon.

We've just wrapped up Parkinson's Awareness Month! Governor Branstad declared Parkinson's Awareness Month through a video message (available through our website), we held the Eastern Iowa Parkinson's Symposium for the second year in a row and we had a very successful silent/live auction to benefit the Iowa Chapter of the APDA. Visit our past events page to see what else we were up to!

An update on our Annual Iowa Parkinson's Conference: You may have heard we are doing something a little different this year. We have partnered with the Davis Phinney Foundation for Parkinson's to bring you the Des Moines Victory Summit on Friday, June 5. The Victory Summit is the Davis Phinney Foundation's premier event that they bring to different regions across the country. This year they have chosen Des Moines as one of their locations. Please see page 5 for more information and details. We will resume our regular Iowa Parkinson's Conference in June 2016. This is a free event with complimentary lunch included, you won't want to miss it!

It's also been a big year for treatment options for Parkinson's. The FDA approved two new Parkinson's drugs that are currently on the market. The national headquarters of the American Parkinson Disease Association released an article about it earlier this year: see page 6 for details.

We generally bring you a person or family impacted by Parkinson's disease as our cover story for each issue. This issue we tried something else – we are sharing the research of one Iowa State University professor, Dr. Elizabeth Stegemoller, that is sure to bring a smile to your face. Dr. Stegemoller is a neuroscientist and music therapist, and she uses music to help those with Parkinson's. Learn more about Dr. Stegemoller's research on page 8.

Another story we bring you is Connie Hoogeveen's. Connie, of Van Meter, Iowa, uses social media to share her journey with Parkinson's disease and to teach her friends and family about deep brain stimulation surgery! ("I Facebook'd My DBS Surgery!" is on page 12).

Look to upcoming events on page 19 to see what we have scheduled for the rest of the year. If you want to keep better tabs on us, sign up for our monthly e-newsletter through our website on www.apdaiowa.org or follow us on Facebook and Twitter!

Till next time,

The Iowa Chapter of the American Parkinson Disease Association

contact us:



Iowa Parkinson Disease
INFORMATION AND REFERRAL

American Parkinson Disease Association
Iowa Parkinson Disease Information and Referral Center
UnityPoint Health – Des Moines
1200 Pleasant Street E-524, Des Moines, Iowa 50309
(877) 872-6386 | www.apdaiowa.org

from our
**medical
director**



Lynn K. Struck, M.D.
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.

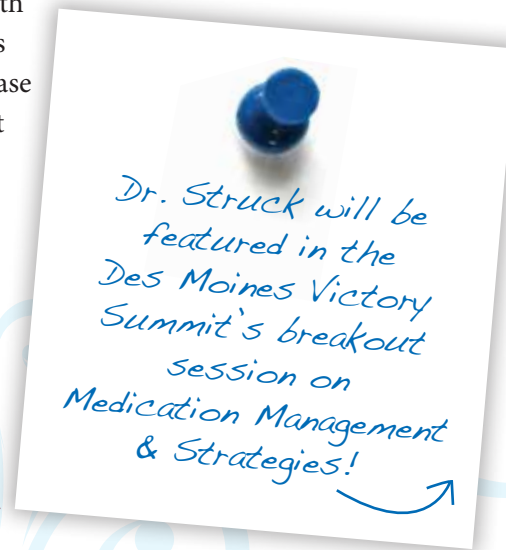
Dr. Struck is on staff with UnityPoint Health Physicians, Des Moines, and is a leading expert in movement disorders in Iowa. She has focused her career on advances in treatment of her many patients with Parkinson's disease and ongoing research to find better treatments and, ultimately, a cure.

Amantadine in the Treatment of Parkinson's Disease

In unique situations, medications taken for one purpose may reveal an unexpected benefit. This is the case with amantadine. In the 1960s, amantadine was found to have inhibitory effects against several strands of the influenza virus. In October of 1966, the Food and Drug Administration approved it as a prophylactic agent specifically against the Asian flu. Due to the influenza virus's frequent mutations and the advent of new drugs, it is no longer a favored treatment.

In April of 1968, a 58-year-old woman with Parkinson's reported to a neurologist that she had improvement in rigidity, tremor and akinesia when she took amantadine for the flu. When she stopped the medication, her Parkinson's symptoms worsened. One of the initial studies showed that 7 out of 10 patients reported improvement in Parkinson's symptoms without significant side effects. The first clinical trial of amantadine for Parkinson's disease was in June of 1968. There were 163 patients in the trial. In the article, amantadine showed improvement in symptoms in 66% of patients with Parkinson's disease. Further research continued to show there were benefits in patients with Parkinson's. In April of 1973, the Food and Drug Administration approved the use of amantadine for alleviating symptoms of Parkinson's disease. Currently, amantadine is used in the early stage of Parkinson's disease, especially in individuals with tremor. The mechanism of action is believed to enhance dopamine release from presynaptic terminals. Also, it has been found to be beneficial in treating dyskinesias in some Parkinson's disease patients.

The discovery of amantadine as a Parkinson's drug started with a single patient and doctor interaction. It is now a drug that we can continue to use for the treatment of Parkinson's disease. ■



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The Victory Summit

The Iowa Chapter of the American Parkinson Disease Association is delighted to partner with the Davis Phinney Foundation in presenting the Des Moines Victory Summit. **The Victory Summit will replace our regular summer conference this year.**

We will resume the Iowa Parkinson's Disease Conference in June 2016. Please join us on Friday, June 5, for the Des Moines Victory Summit!

SAVE THE DATE


DAVIS PHINNEY
Foundation For Parkinson's
every victory counts®



THE VICTORY SUMMIT®:
A Davis Phinney Foundation Event for People Living with Parkinson's
Friday, June 5, 2015
Holiday Inn Des Moines
Airport, 6111 Fleur Drive, Des Moines, IA 50321
10:00am-3:45 pm, complimentary lunch included

This is a full-day conference that includes keynote sessions presented by national speakers and two breakout sessions featuring local and regional speakers. Topics covered in the keynote sessions include Parkinson's basics, non-motor symptoms, living well, exercise and a talk by Davis Phinney.

Breakout session topics include deep brain stimulation, medication management and strategies, caregiving/carepartner strategies, depression and mood, medicare and disability insurance, sleep disturbances and fall prevention, among others.

Local event partners for the Des Moines Victory Summit include the Iowa Chapter of the American Parkinson Disease Association, UnityPoint Health – Des Moines and Mercy Neurosurgery (a member of Mercy Medical Center – Des Moines).

For more information on the Davis Phinney Foundation, visit www.davisphinneyfoundation.org.

Online registration is open at:
<http://TheVictorySummit.Kintera.org/DesMoines>

Or call (888) 364-6168 to register.

Recent Treatments in Parkinson's

News from the American Parkinson Disease Association Headquarters in Staten Island, New York

The American Parkinson Disease Association is pleased to share with the Parkinson's community the arrival of two new medications in the treatment arsenal to address Parkinson's symptoms. Both of these therapies offer a better way to deliver carbidopa/levodopa medication.

RYTARY™ (pronounced rye-TAR-ee), approved by the Food and Drug Administration on January 8, is an extended-release formulation of carbidopa/levodopa and is manufactured by Impax Pharmaceuticals. RYTARY™ is designed to address one of the most significant unmet needs for patients living with Parkinson's disease, which is to reduce the amount of time during the day when their symptoms are not adequately controlled. This is a significant treatment option for the one million patients living with Parkinson's.

Patients who take carbidopa/levodopa may find over time that the drug becomes less effective and may experience a worsening of symptoms as the drug ceases to work successfully. As RYTARY™ is developed to release more slowly over time it will maintain the levodopa levels and will provide greater treatment stability. This treatment will help those in the middle stages of Parkinson's disease who have problems with wearing off of their medication.

RYTARY™ contains immediate-release and extended-release beads, with a specific amount of carbidopa and levodopa in a 1:4 ratio, and provides both initial and extended levodopa plasma concentrations after a single dose. RYTARY™ may be swallowed whole or, for patients who have trouble swallowing, the capsule may be opened and the beads sprinkled on applesauce and consumed immediately. It will be available for commercial distribution in February 2015.

Approved January 12 by the U.S. Food and Drug Administration is DUOPA™ (carbidopa and levodopa), developed by AbbVie, an enteral suspension for the treatment of motor fluctuations for people with advanced Parkinson's disease. DUOPA™ is administered using a small, portable infusion pump that delivers carbidopa and levodopa directly into the small intestine for 16 continuous hours via a procedurally-placed tube.

DUOPA™ is the first and only treatment providing 16 continuous hours of carbidopa and levodopa for motor fluctuations in advanced Parkinson's disease. In a clinical trial, patients treated with DUOPA™ experienced significantly greater improvement in symptom control than patients treated with oral carbidopa-levodopa immediate-release tablets.

DUOPA™ is for those patients with advanced Parkinson's disease who experience wearing off or dyskinesia and who cannot manage symptoms with regular tablets and other oral medications. In Parkinson's disease patients, the spontaneous emptying of the stomach becomes delayed and unpredictable, which can affect the timing of when orally administered medicines leave the stomach and are absorbed in the small intestine. DUOPA™ provides patients with the same active ingredients as orally administered carbidopa and levodopa immediate release, but is delivered in a suspension that goes directly into the small intestine via a tube placed by a percutaneous endoscopic gastrostomy procedure with jejunal extension (PEG-J). This type of administration is intended to bypass the stomach.

Dr. David G. Standaert, chairman of Scientific & Advisory Board of the American Parkinson Disease Association, said, "These are two very exciting new treatments which offer new opportunities to patients at different stages of their disease and help to better control their symptoms."

American Parkinson Disease Association recommends discussing these therapies with your neurologist before making any changes to your treatment plan.



Who Is Your Home Built For?

Seven Tips for Building Your Home For You

By Gary Johnson, ATP - Iowa Program for Assistive Technology, University of Iowa

Most homes are tailored for a certain type of person: a healthy, fit, young person of average height. Using the concept of Universal Design, which means making a home accessible for anyone, several features can make any home more comfortable for a wide range of people and families:

- Families with young children
- People who want to stay in their homes as they grow older and acquire physical limitations
- People who want to simplify their housekeeping
- People who are taller or shorter than average
- People who use wheelchairs or walkers

Here are seven things that you may find make a lot of sense in your home:

- 1.** Lever-style door handles instead of round doorknobs. Whether it is the front door, bathroom, bedroom or hall closet, this type of door handle is useful if you have decreased ability to use your hands or if your hands are full—you can simply press the lever and push the door open. An inexpensive home improvement, these are readily available from home improvement stores.
- 2.** Install a shelf outside the entry door. This solution is helpful to set down items while you open the door. Install the shelf on a porch railing or attached to the wall. You might need to get to your house keys or simply need a hand to open the door handle; it's always great to have a place to put your purse or packages. Another option is to have a lidded trashcan, bench or chair next to the door.
- 3.** Rocker-style switches. Whether you have a physical limitation or have something in your hand, it is easy to rock the switch on or off.



- 4.** Lighted switches that are visible in the dark. Although applicable anywhere in the home, lighted switches are most helpful in bathrooms. They are also highly applicable for bedrooms. Why fumble around in the dark?



- 5.** Adjustable height, hand-held shower heads with controls that are conveniently placed and easy to operate. Adjustable height means that the shower head is mounted on a vertical bar, allowing for the showerhead to be raised for standing and lowered if someone is shorter or sitting on a bench or shower chair. The hand-held shower head can be removed from the wall mount for more convenient washing and rinsing. Ask anyone who has had surgery how important this can be!



- 6.** Install sturdy hand rails on both sides of all stairways. You can do this both inside and outside the home. For round rails, the usual size is 1¼ to 1½ inches in diameter. Not only will they allow stability and balance but they also provide that all-important grip that can prevent a fall.

- 7.** Utilize visible and audible smoke and carbon monoxide detectors. Not everyone has perfect sight and hearing. You want your alarms to be as effective as possible.



All of these suggestions are lower cost and readily available from a local home improvement center. For further information on these suggestions as well as other tips that may be applicable to you, visit the Iowa Program of Assistive Technology website at www.iowaat.org/udbooklet.

The Iowa Program for Assistive Technology (IPAT) supports Iowa Compass, a free service for all Iowans, to provide information on types of available assistive technology devices and possible funding sources. Contact them by phone at (800) 779-2001 or log on to www.iowacompass.org.

Research You Can Sing About



Elizabeth Stegemoller, Ph.D., MT-BC

Questions and Answers

On a cold winter afternoon in January, a group of people at the First Baptist Church of Ames sing “Show me the way to go, Show me the way to go, Show me the way to go home!” accompanied by the piano playing of Elizabeth Stegemoller, Ph.D., MT-BC, Iowa State University assistant professor in the Department of Kinesiology. The singing isn’t just for fun – it is also helping the singers with their Parkinson’s symptoms.

“I didn’t choose to work with people with Parkinson’s. This field chose me. It was rewarding for me to work with people with Parkinson’s as a student,” said Dr. Stegemoller. “When I did music therapy with patients, I saw people making bigger movements with a larger range of motion, walking much better and overcoming freezing altogether.”

As an undergraduate student at the University of Missouri – Kansas City, Dr. Stegemoller double majored in music therapy and biology. During periods of clinical work, in which she would provide music therapy to clients, she noticed patients with Parkinson’s would respond well to singing, in terms of symptoms and quality of life. She asked her mentor in the music therapy department why that was – she was told to go ask her mentor in neuroscience. Her neuroscience mentor also wasn’t sure what the specific correlation was between singing and improvement in Parkinson’s symptoms.

To get answers to her questions, Dr. Stegemoller pursued a Ph.D. in Neuroscience at Northwestern University in Evanston, Illinois, to study the effects of music on Parkinson’s disease. She currently conducts research and teaches at Iowa State University.

In the summer of 2014, Dr. Stegemoller set up four study sites at Parkinson’s support groups around Iowa: West Des Moines, Des Moines, Ames and Waverly. This was an eight-week study in which participants underwent structured singing training.



Before the study started, all participants were assessed for their voice, swallowing and quality of life. After the study, participants were assessed on the same attributes again.

The results showed that participants developed a louder voice and the ability to breathe in and out better. They also had positive changes in the muscles involved with swallowing and overall positive changes in quality of life.

“We think that music helps strengthen the current brain connections in those with Parkinson’s, which in turn improves Parkinson’s symptoms. Further research will tell us what exactly is happening in the brain with music and symptom improvement,” said Dr. Stegemoller.

For those who went through the eight-week study, Dr. Stegemoller holds an optional singing group once a week in Ames. Kara Rewerts, MT-BC, certified neurologic music therapist at Waverly Health Center, runs the singing group in Waverly.

The research she conducts is novel; very few researchers are looking at music therapy as a means of improving movement and speech in Parkinson’s and trying to understand the science behind it, said Dr. Colum MacKinnon, Ph.D., assistant professor in neurology at the University of Minnesota.

“Data shows us that listening to music increases dopamine – a cheap way to get dopamine, but you want to do that in a way that makes sense and that is backed by empirical data. If you can get the body to create dopamine through music, instead of getting it through medications, you have a higher chance to wire the brain in a beneficial way,” said Dr. MacKinnon.

The application of Dr. Stegemoller’s research could be a significant method in terms of managing the disease.

“There is mounting evidence to support the idea that singing can benefit Parkinson’s disease patients. Dr. Stegemoller’s study shows that benefits extend beyond just the voice, which is interesting and may have practical implications for the field. More research will be needed, but in the meantime, singing seems to be a safe and promising therapy,” said Michael S. Okun, M.D., University of Florida Health, professor of neurology and national medical director for the National Parkinson Foundation.

Dr. Stegemoller plans on doing a follow-up study that will show the differences in those who kept up with singing and those who didn’t, to see if the positive changes were maintained. Eventually, she will tackle a multisite singing study in locations across the United States.

Can’t Sing? No Problem

Dr. Stegemoller didn’t find it difficult to get participants for her research study. She saw many people eager to be involved in research, though there were many who questioned their singing skills.

“Many of the participants never sang before in their lives or it had been a while since they sang, but I am not too concerned about that. I just want people to know that the purpose of singing and my studying it is to help them improve their speech, swallowing, quality of life and emotional support.”

Over the course of the eight-week study, the participants grew closer through singing, and the study became its own support group. “There were lots of smiles, laughter and getting over the fear of not being able to sing,” said Dr. Stegemoller.

Betty Wright of Ames, 82, was diagnosed with Parkinson’s three years ago. She sang in her church choir as a soprano a long time ago, she said.

“I joined the study because I wanted to get to know other people with Parkinson’s. A lot of people don’t care to hear about what I am going through, but being involved with the study and meeting and talking with others is very helpful,” said Betty.

Beverly Van Fossen of Ames, 82, sang in her high school choir. She sings, but only while she is running the vacuum or doing other chores. This was the first time she participated in research. She joined because a friend of hers was also doing the study.

“Elizabeth (Dr. Stegemoller) is tremendous and makes it fun. The people I sing with are good people. We have a great time and this work is also helping us,” said Beverly.

Both Beverly and Betty felt that their voices have improved after the study, and they enjoy going to the singing group each week. They both enjoy the song “Show Me the Way to Go Home” by Irving King (the English songwriting team of James Campbell and Reginald Connelly).

Dr. Stegemoller chose songs for the eight-week study that focused on functions such as vocal range and breath support and songs the participants would be familiar with. The once-a-week singing group is directed by what the participants want to hear and sing.

Betty agrees with her singing group partner Beverly – the group wouldn’t be the same without their new friend, Dr. Stegemoller.

“One of my favorite parts of the group is Dr. Stegemoller. She is very enthusiastic and wants us to do well. I want to give her all the credit for making this group what it is,” she said.

Sing Everywhere and with Everyone

Dr. Stegemoller suggests the best way to incorporate music into your life is to listen to music, but just not any music – listen to your favorite preferred songs.

“Sing in the car, sing in the shower. It doesn’t matter. Take time out of your day to sing to whatever you want. It will help with your mood and will work the muscles that affect swallowing and speech,” she said. “Try singing with your grandchildren, children or spouse. These interactions help build some wonderful memories.”

Just as one may have a physical therapist or an occupational therapist, Dr. Stegemoller suggests going to a music therapist for more one-on-one interaction.



And it doesn't have to end with singing. Singing is just the beginning.

"If you are singing, might as well dance a little, too!"

Support Research at Iowa State University

If you are interested in signing up for research studies at the Department of Kinesiology at Iowa State University or financially supporting the research, contact Dr. Elizabeth Stegemoller at (515) 294-5966 or esteg@iastate.edu. For a \$25 donation, donors will receive two tickets to the Reiman Gardens at Iowa State University in Ames.

Learn more about Dr. Stegemoller's research at her lab's web page, www.neuromotorlab.com.

Learn more about music therapy or find a music therapist:

- www.musictherapy.org
- www.cbmt.org



After the eight-week Parkinson's Singing Study, study participants performed for their family and friends in September 2014.



I Facebook'd My DBS Surgery!



Facebook, Twitter, Snapchat, Instagram – you either use them or you’ve heard of them. Facebook is one of the most popular social media outlets on the Internet. It is a method of sharing news and connecting with friends and family online. In this issue we are featuring Connie Hoogeveen, who shared a significant part of her Parkinson’s journey on Facebook as a way to share with friends and family and teach others about deep brain stimulation.

Connie Hoogeveen believes in the power of sharing. Sharing is a part of her nature, but it is also a part of her having Parkinson’s disease.

“Before I was diagnosed, I was very busy being ‘Super Woman,’ doing lots of volunteer work. Once I was diagnosed, I had to cut back on most activities, but I discovered a talent for taking pictures and making videos. I learned the power of connecting through social media when I set up a Facebook page for my 40th high school class reunion,” said Connie. “It’s a great way to stay in touch with people. Facebook is efficient and I love efficiency.”

Connie was diagnosed with Parkinson’s disease in May 2005 at the age of 50. Six months after first hearing the word “Parkinson’s” from her doctor, she was happy to finally know

what she had. “It was a huge relief for me. It is awful not knowing,” she said. “At the time I had not really heard about Parkinson’s disease. All I knew was that Michael J. Fox had it.”

After several years of managing her Parkinson’s with drug therapy alone, Connie asked her neurologist about deep brain stimulation surgery. She was at a point in her diagnosis where the side effects of medications were negatively affecting her quality of life and she wanted to investigate other options for treatment and management of her symptoms.

Deep brain stimulation is a surgery that reduces Parkinson’s symptoms by triggering electrical currents in the brain. The surgery includes inserting electrodes in the brain and a battery pack in the chest, which are both linked through wires underneath the skin. After the surgery, programming of the DBS takes place and is adjusted as needed to make DBS work optimally in the patient.

Connie was put through a series of tests to see if she was a candidate for the surgery, and she passed them all. She was a perfect candidate for deep brain stimulation. “I had no doubt at all that was what I wanted to do,” said Connie.

She had her surgery in August 2013 at the University of Iowa, performed by Dr. Jeremy Greenlee, and was programmed the following October at the office of her neurologist, Dr. Lynn Struck at UnityPoint Health in Des Moines.

Connie capitalized on this opportunity to share her DBS experience and surgery with friends and family on Facebook.

“It seemed like a no-brainer, considering that I would be awake for the surgery. You rarely see costs of a surgery as it is happening. I had lots of people praying for me and lots of people



delighted to experience this along with me,” said Connie. “I got a lot of mileage out of posting on Facebook.”

Logistics were involved in posting to Facebook. Connie did ask permission to take photos and videos with her phone before she embarked on this venture. “I, or the doctor or nurse, would take the shot and then I would post it. Our daughter was on hand that day to add commentary and updates from the staff,” said Connie.

Her Facebook posts included her initial announcement that she would have DBS, countdowns to surgery day, the actual day of surgery and day of DBS programming and updates about her overall well-being. Near the end of the surgery, she had the nurse take a video of her singing while the doctor was stitching her up. “It’s a beautiful day in the neighborhood!” her personal theme song, received hearty applause from the doctors and nurses.

A few days after she was programmed, she posted a picture of the Energizer bunny that said, “How I felt today.” “One thing DBS doesn’t fix is stamina. But I make sure I get good rest so that I am more energetic throughout the day. You learn how to manage your life,” she said.

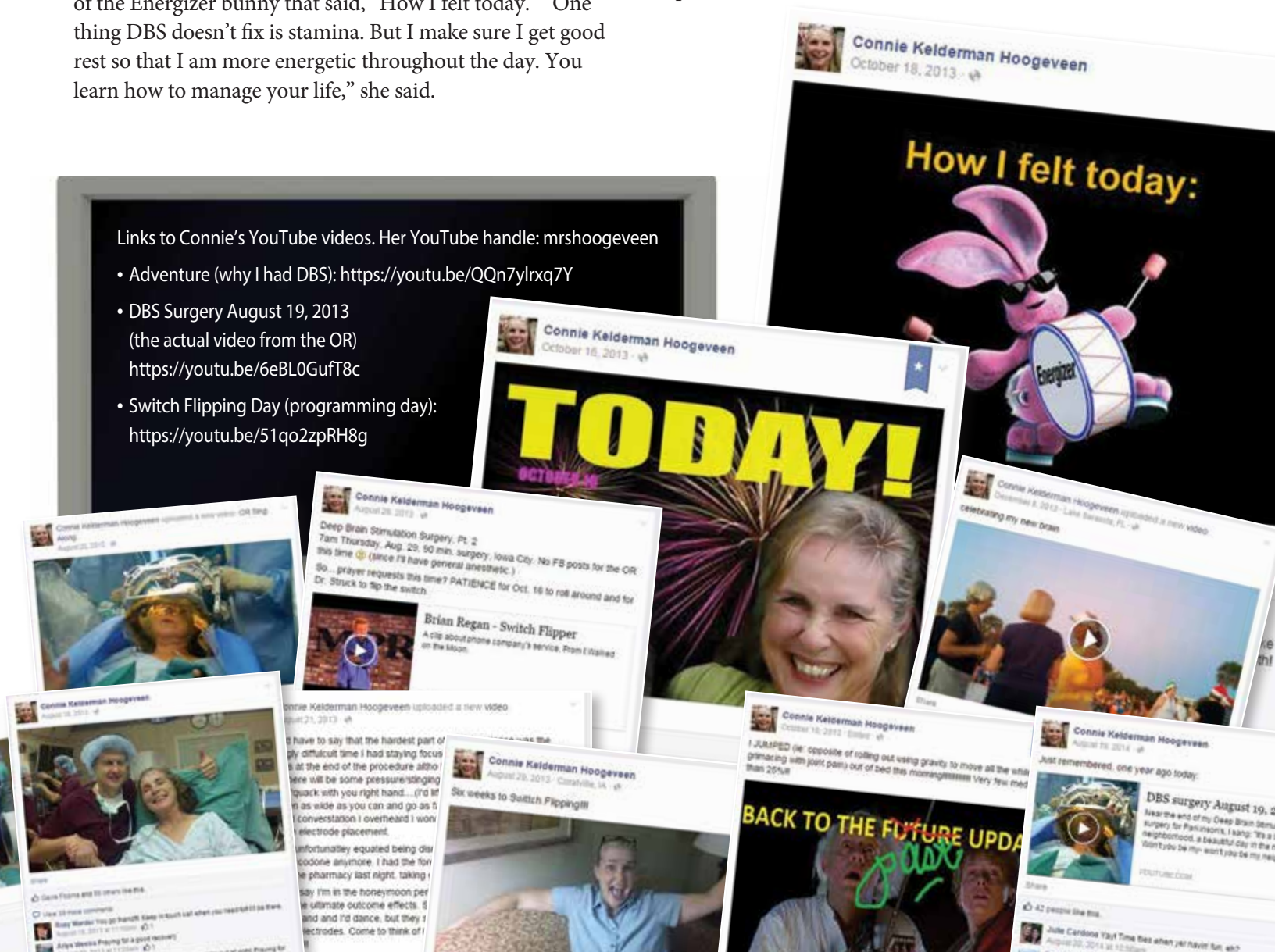
Almost a year and a half after her surgery, Connie is still feeling good and she is able to enjoy time with her husband and family. “My husband is fantastic; I could not have done it without him. He gives me a 45-minute foot rub each night – I am spoiled rotten and loving it!” she said. She also gets to be a full-time grandmother to 14 grandchildren, who range from 3 months to 17 years old. “They are my passion. For the kids that live close by, we get to have adventures all the time,” she said.

Connie doesn’t hesitate to talk about her experiences with Parkinson’s with anyone who asks. Even though the thought of someone drilling into your head can be off-putting, she encourages persons with Parkinson’s to consider DBS surgery and to talk to their neurologist about this surgical option.

“I now have an inkling of what Lazarus must’ve felt walking out of his tomb. It’s the closest thing to a miracle I’ve experienced!”

Links to Connie’s YouTube videos. Her YouTube handle: mrshoogveen

- Adventure (why I had DBS): <https://youtu.be/QQn7yIrxq7Y>
- DBS Surgery August 19, 2013 (the actual video from the OR) <https://youtu.be/6eBL0GufT8c>
- Switch Flipping Day (programming day): <https://youtu.be/51qo2zpRH8g>



Exercise:

As Important as Medicine

By Trina Radske-Suchan

Medical Program Executive, YMCA Healthy Living Center, Clive, Iowa

Participation in an exercise program should be an integral part of the management of Parkinson's disease to optimize quality of life and day-to-day function.

There is mounting research demonstrating the positive effects of exercise on the symptoms of Parkinson's disease. In a recent study conducted by Beth Fisher et al., researchers at the University of Southern California found that exercise has a positive effect on the brain. On a day-to-day basis people with Parkinson's who exercised moved more normally than those who did not. Based on these findings, they believe that exercise may be helping the brain to maintain old connections, form new ones and restore lost ones. They suggest that, in certain situations, the neuroplasticity created from exercise in patients with Parkinson's may actually outweigh the effects of neurodegeneration.

Important components of an exercise program include the practice of strategies to improve daily activities such as moving in bed and rising from a chair, walking, strength and balance training, exercises to increase flexibility and joint motion, and cardiovascular training. Before you begin any exercise regimen, check with your doctor to ensure your safety.

You don't need fancy equipment or facilities to start moving. Do what you can every day and know that some days might not be optimal. Choose things you enjoy doing and schedule exercise time when you are likely to stay committed to it.

Walking is an integral part of daily living. Terry Ellis, director of the American Parkinson Disease Association's National Rehabilitation Resource Center, and other researchers found that walking can be improved in those with Parkinson's with the help of external cues:

- Find music with a beat that guides you to walk continuously and at a brisk but comfortable speed.
- Choose music that motivates you.
- Use a metronome.
- Do gait training on a treadmill, which improves stride length and gait speed.
- Could use a visual flash of light via LED attached to glasses or laser beams.
- Could use natural environment cues such as lines in the sidewalk or tape on the floor if you have a tendency to freeze in a specific area.

Exercise is always more fun with a buddy or group of friends. More and more group exercise programs are developed with chronic disease or conditions in mind. Some programs are evidence-based for Parkinson's disease like Delay the Disease or LSVT BIG, and others are geared more for general health restoration or prevention. Check with your local YMCA, community center or parks and recreation department to see what group exercise programs they have to offer.



The YMCA Healthy Living Center (Y-HLC) in Clive, Iowa, is a medical-based fitness facility specifically designed to provide ample opportunities for exercise and wellness programs for individuals at all levels of health. Specifically, the Y-HLC provides physicians the chance to refer their patients suffering from a chronic disease or condition into medically guided individualized exercise and wellness plans and group exercise programming. The Y-HLC has a strong population of people with Parkinson's disease and other similar conditions participating in Delay the Disease, Cycling for Neuro Wellness, Aquatic Neuro Wellness, and Tai Chi for Fall Prevention.

Delay the Disease is an evidence-based exercise program working on all elements of fitness for people with Parkinson's disease and similar conditions. The exercise component focuses on improving functional movement like getting on and off the floor, walking and balance training. This is a group exercise class format that provides a lot of fun along with the hard work. Two instructors present the class and usually have physical therapy students available to help those that need extra assistance. The class is offered Tuesday and Friday at 1:15 p.m.

Neuro Wellness Cycling is modeled after an evidence-based exercise program where participants ride stationary bikes fitted to their specifications. This class is a little more vigorous in intensity and would be great for those who have an active lifestyle or early to mid-diagnosis of their disease-condition. The class is offered on Mondays at 1:15 p.m. and Thursdays at 5:45 p.m.

Aquatic Neuro Wellness is a group water exercise program that can help lessen your symptoms of disease or injury. The program is designed to improve your balance, flexibility, strength and walking ability through the water's buoyant environment. Water allows you the freedom to move with more ease and less pain. The class is offered on Thursdays at 1:00 p.m.

Tai Chi for Fall Prevention has been proven to reduce the risk of falls for those over 65 and for individuals with a chronic disease or condition. The goals of Tai Chi are to improve balance and coordination, promote deep breathing and relaxation, increase flexibility, reduce stress and decrease pain. Classes are offered on Wednesdays at 9:00 a.m. and at 1:15 p.m. for those who may need extra assistance.

Whether you partake in group exercise or do it from the comforts of home, remember that it is important to move throughout the day. Make exercise part of your lifestyle and allow it to nurture your body.

For more information about the programs within the YMCA of Greater Des Moines, you can call Morgan Hoover, medical program director at the Y-HLC, at (515) 645-3348, or Trina Radske-Suchan, medical program executive, at (515) 645-3342. Referrals from physicians can be faxed to (515) 224-2907 to get patients participating in the above programs along with individualized exercise and wellness plans.

For more information on offerings at the YMCA Healthy Living Center, visit www.ymcahealthylivingcenter.org.

To see if there is a Delay the Disease exercise class in your area, visit www.apdaiowa.org.

For other resources and questions about exercise, contact the Iowa Parkinson Disease Information and Referral Center at (877) 872-6386 or email informreferral@apdaiowa.org.

Delay the Disease/Neuro Wellness Classes

Delay the Disease is a fitness program designed to empower people with Parkinson's disease by optimizing their physical function. For more information on Delay the Disease, visit delaythedisease.com or apdaiowa.org/exercise-groups-in-iowa.

Black Hawk County/Waterloo

Covenant Wellness Center, 3421 W 9th St, Waterloo, IA 50702. **Cost:** Classes are \$20 for an eight-week session. Contact class instructor Timi Brown, Med-Fit Facilitator at Wheaton Franciscan Healthcare- Iowa, at (319) 272-1755 for more information.

Carroll County/Carroll

St. Anthony's Hospital, 311 S Clark St, Carroll, IA 51401. Classes are held every Thursday at 11 a.m. **Cost:** Free. Contact class instructor Melanie Hundling at (712) 792-3581 or Melissa Schultes at (712) 794-5815.

Cass County/Atlantic

Heritage House, 1200 Brookridge Cir, Atlantic, IA 50022. Classes are held every Monday from 1–2 p.m. **Cost:** Free. Contact class instructor Jon Jordan at (712) 243-1850 or JJordan@wesleylife.org for more information.

Clay County/Spencer

Spencer YMCA, 1001 11th Avenue West, Spencer, IA 51301. Classes are held Mondays and Wednesdays, 10:15–11:15 a.m. **Cost:** Free if a Spencer YMCA member; payment required for non-members. Class instructor is Josh Kelly. Contact the Spencer YMCA for more information at (712) 262-3782.

Des Moines County/West Burlington

Great River Medical Center, Hawkeye Room, 1221 S Gear Ave, West Burlington, IA 52655. Classes held every Thursday from 12:30–1:30 p.m. Class instructor is Matt Kelley. Contact the Great River Medical Center High Performance Center at (319) 768-4112 for more information.

Burlington Area YMCA, 2410 Mt. Pleasant St, Burlington, IA, 52601. Classes held every Monday and Wednesday from 1–2 p.m. **Cost:** Free for YMCA members; \$5 a class for non-members. Contact the Burlington Area YMCA at (319) 753-6734 or cara@burlingtony.org for more information.

Iowa County/Williamsburg

Highland Ridge, 100 Village View Cir, Williamsburg, IA 52361. Classes held every Wednesday from 9–10 a.m. **Cost:** Free. Contact instructor Kris Cameron at (319) 361-7673 or email renuyourlifep@gmail.com for more information.

Johnson County/Iowa City

Iowa City Senior Center, 28 South Linn Street, Iowa City, IA 52240. Classes are held Wednesdays and Sundays from 12:45–1:45 p.m. **Cost:** \$5 per class, punch card available. Contact instructor Kris Cameron at (319) 361-7673 or email renuyourlifep@gmail.com for more information.

Kossuth County/Algona

Algona Family YMCA, 2101 E. McGregor, Algona, IA 50511. Classes held every Tuesday from 1–2 p.m. at the Algona Family YMCA. Every third Tuesday of the month the class meets at Van

Buren Terrace, 520 S Blackford St., Algona. **Cost:** \$12.00 for a six-week session or \$3.00 for a one-day pass. Contact the Algona Family YMCA at (515) 295-7701 or email jeni@algonaymca.org for more information.

Linn County/Cedar Rapids

Stonebridge Church, 1829 Stoney Point Rd, Cedar Rapids, IA 52404. Classes are held Mondays and Fridays from 10:30–11:30 p.m. **Cost:** Free. Contact instructor Kris Cameron at (319) 361-7673 or email renuyourlifep@gmail.com for more information.

Starting Tuesday, May 5: The Church on Northland, 5200 Northland Ave NE, Cedar Rapids, IA 52404. Classes are held Tuesdays and Thursdays from 11:00 a.m. – Noon. **Cost:** Free. Contact instructor Kris Cameron at (319) 361-7673 or email renuyourlifep@gmail.com for more information.

Muscatine County/Muscatine

Hillcrest Baptist Church, 1613 Bidwell Road, Muscatine, IA 52761. Classes are held twice a week: Rotating schedule of Tuesdays and Thursdays for four weeks followed by Mondays and Wednesdays for four weeks. **Cost:** \$5 per class. Contact instructor Anthony Krumbholz at 319-981-3321 or AnthonyKrumbholz@yahoo.com.

Polk County/Clive

YMCA Healthy Living Center, 12493 University Ave, Clive, IA 50325. Classes are held Tuesdays 1–2 p.m. and Fridays from 1:15–2:15 p.m. **Cost:** Free if a YMCA member; payment required for non-members. Instructors are LaDona Molander and Jennifer Voorhees. Contact the YMCA Healthy Living Center at (515) 226-9622 for more information.

Polk County/Des Moines

Wesley Acres, 3520 Grand Ave., Des Moines, IA 50312. Classes are held every Wednesday from 1–2 p.m. **Cost:** Free. Pre-registration is required. Call (515) 271-6500 for more information and to register.

Union County/Creston

Southern Prairie YMCA, 1201 W Townline, Creston, IA 50801. Classes are held Mondays and Wednesday from 9–10 a.m. **Cost:** Free for Southern Prairie YMCA members; \$25/month for non-members. Class instructor is Mandy Henderson. Contact the Southern Prairie YMCA at (641) 782-9622 for more information.

Woodbury County/South Sioux City, Nebraska

Norm Waitt Sr. YMCA, 601 Riverview Dr, South Sioux City, NE 68776. Classes are held Mondays and Wednesdays 11 a.m.–Noon. **Cost:** \$5 per class ; \$50 for a 10-class punch card. Contact instructor Jacque Perez, wellness programs coordinator, at jperez@nwsymca.org or call (402) 404-8439.

Cycle for Neuro Wellness

YMCA Healthy Living Center, 12493 University Ave, Clive, IA 50325. Classes are held Monday & Thursdays from 5:45–6:30 p.m. Contact YMCA Physical and Aquatic Therapy clinic at (515) 645-3350 for more information.

Questions about Parkinson's?

Connect with the Information & Referral
Center / Iowa Chapter APDA

We have a library of resources and
lots of free information available.
Contact us today!

- Call: (877) 872-6386
- Email: informreferral@apdaiowa.org



Connect with the Iowa Chapter of the
American Parkinson Disease Association

- www.apdaiowa.org
- Facebook.com/IowaLandR
- www.twitter.com/IowaParkinson



Parkinson's Disease Quick Facts

Over 1.5 million individuals
are diagnosed with
Parkinson's disease in
this country.

An estimated over 60,000
additional individuals will be
diagnosed this year.

Motor Symptoms

(Not all people with PD develop all
symptoms.)

- Freezing
- Postural instability
- Difficulty turning in bed
- **Nonmotor Symptoms**
- Diminished sense of smell
- Low voice volume
- Painful foot cramps
- Sleep disturbance
- Depression
- Constipation
- Drooling
- Increased sweating
- Urinary frequency/urgency

Parkinson's disease is a
movement disorder. It means the
brain's ability to gradually
control muscles will gradually
decline over time. In people
with Parkinson's disease, a
part of the brain, the
substantia nigra, slowly decreases.
This causes the muscles to
shrink and become stiff. The
muscles become weaker and
less coordinated. A loss of
control over the muscles leads to
Parkinson's disease.

on support
publications,

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Past Events

April was
Parkinson's Awareness
Month - here's what
we were up to!

Parkinson's Disease Research Forum at Iowa State University – Thursday, April 9

Iowa State University Assistant Professor and Researcher Dr. Elizabeth Stegemoller and the Department of Kinesiology hosts this annual Parkinson's Research Forum. This year Dr. Jay Alberts from the Cleveland Clinic shared his research topic "Can Exercise Be Used to Alter the Course of Parkinson's Disease?" and Dr. Rachel Seidler shared her research topic "Predicting Individual Differences in Medication Responsiveness in Parkinson's Disease." The lectures were followed by a poster reception with research displayed by ISU undergraduate and graduate students.



Parkinson's Action Network Forum – Washington, D.C.

The PAN Forum is a three-day conference held in Washington, D.C., bringing together Parkinson's disease advocates from across the nation. This year it was held March 23-25. Attendees gather to learn the latest in Parkinson's public policy and research and meet with the members of Congress. Working together, forum attendees increase awareness of Parkinson's and learn to advocate for better treatments and a cure. Assistant state directors for Iowa are Crissanka Christadoss, director of the Iowa Parkinson Disease Information and Referral Center, and Dr. Elizabeth Stegemoller, Iowa State University assistant professor and researcher (both pictured above in front of the U.S. Capitol).



2015 Eastern Iowa Parkinson's Disease Symposium, Parkinson's Dirty Little Secrets – Friday, April 17

Over 130 people attended this symposium in Waterloo this year. Topics on non-motor symptoms, hospice and palliative care, music therapy to aid speech and swallowing and LSVT LOUD® therapy were covered by some wonderful speakers: Michael Rezak, MD, movement disorders specialist at the Central DuPage Hospital in Winfield, Illinois; Michele Friedman, ANRP, nurse practitioner at UnityPoint at Home in Waterloo; Elizabeth Stegemoller, PhD, MT-BC, assistant professor at Iowa State University in Ames; and Mary Ochoa, MS, CCC-SLP, speech-language pathologist at the Waverly Health Center.



Bingo Bash Against Parkinson's! – Saturday, April 25

Iowa Chapter APDA's Annual Silent Auction and Fundraiser took place at Woodlands Creek Active Retirement in Clive, Iowa. Much fun was had and we raised over \$6,000 for the Iowa Chapter APDA.



what's coming up?

MAY

Parkinson's Update 2015 – Friday, May 29

901 Montgomery St., Decorah, Iowa

This program is conducted by the Park Nicollet – Struthers Parkinson's Center.

In their continued efforts to raise public awareness and improve services for those with Parkinson's disease, the Decorah Area Parkinson's Support Group will sponsor a free seminar for area health professionals with speakers from the nationally recognized Struthers Parkinson's Center, a National Parkinson Foundation Center of Excellence.

Health professional program is 9 a.m.–Noon and the patient program is from 1 – 4 p.m.

For more information on the programs, visit www.apdaiowa.org. This event is FREE but space is limited. Call (563) 387-3146 to register.

JUNE

The Davis Phinney Foundation for Parkinson's Victory Summit in Des Moines – Friday, June 5

Holiday Inn Conference Center, 6111 Fleur Dr., Des Moines.

This educational conference will replace our regular Iowa Parkinson's Disease Conference this year. We will resume our conference in June 2016. See more details on page 5.

Register one of the following ways:

- Online - <http://TheVictorySummit.Kintera.org/DesMoines>
- Call 1-888-364-6168.

AUGUST

9th Annual Eastern Iowa Parkinson's Fall Classic for Parkinson's Support – Saturday, August 22

Registration starts at 8 a.m., Shotgun Start at 9 a.m. Amana Colonies Golf Course

Entry Fee: \$350 per team–includes 18 holes of golf, cart rental and lunch (four-person scramble with pin, flight and door prizes).

To register visit www.apdaiowa.org to download registration forms. For more information contact John Krumbholz, Iowa Chapter APDA co-president, at krummy1968@gmail.com or call (319) 350-7482.

6th Annual Shake, Rattle and Roll Motorcycle Fundraiser for Parkinson's – Saturday, August 29

The ride will start in Maxwell and go through St. Anthony, Radcliffe and end at the Moose Lodge in Iowa Falls.

Raffle tickets will be available for \$10 at a chance to win \$1000 and there will be a silent auction. T-shirts, koozies, patches and other goodies will be available for purchase. If you are interested in sponsoring the event, donating items for the silent auction or more information, please call event organizer Kristen Pierson at (641) 751-7293.

OCTOBER

NW Iowa Parkinson's Disease Symposium, Sioux City – Saturday, October 31

1132 Larsen Park Rd, Sioux City, IA 51103

Registration details available in September 2015. Stay tuned!

May						
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August						
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October						
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11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31


donors

December 2014 – April 2015

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 card 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

www.apdaiowa.org 


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acknowledgements



Iowa Parkinson Disease
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links

and other resources



Web Links

Here are a few helpful websites.

Parkinson's Disease - Iowa Statewide Resources

Assistive Technology and Possible Funding Sources.....	www.iowacompass.org
Caregiving Information	www.iowafamilycaregiver.org
Easter Seals Iowa Assistive Technology Center	www.eastersealsia.org
Iowa Prescription Drug Corporation (Prescription Aid).....	www.iowapdc.org
LifeLong Links.....	www.lifelonglinks.org
Senior Health Insurance Information Program	www.therightcalliowa.gov
The Iowa Area Agencies on Aging	www.iowaaging.gov/iowas-area-agencies-aging

Parkinson's Disease - General

American Parkinson Disease Association	www.apdaparkinson.org
American Parkinson Disease Association, Iowa Chapter	www.apdaiowa.org
American Parkinson Disease Young Onset Center	www.youngparkinsons.org
Parkinson's Action Network	www.parkinsonsaction.org
American Academy of Neurology	www.aan.com
The Movement Disorder Society	www.movementdisorders.org
Living Well with Parkinson's Disease	www.pdplan4life.com
National Institutes of Health: Parkinson's Disease	nihseniorhealth.gov

Caregivers

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

sign language

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Medicine

The sign for medicine: Touch your right hand middle finger to your left hand palm. Then pivot the right hand side to side a couple times.



support groups

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!

Algona/Kossuth County
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(515) 341-3440

Ames/Story County
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(515) 239-2323

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John L. Wagner
John.Wagner@unitypoint.org
(319) 481-6195

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Melissa Schultes
mschultes@stanthonyhospital.org
(712) 794-5815

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St. Luke's Hospital Resource Center
Jen Jenatscheck
Jennifer.Jenatscheck@unitypoint.org
(319)369-7331

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John Krumbholz
krummy68@gmail.com
(319) 350-7482

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Katy Paxton
kpaxton@mercydesmoines.org
(641) 437-3432

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(641) 228-5053

Council Bluffs/Pottawattamie County
Molly George
mcampbell@foxrunassisted.com
(712) 256-2741

Creston/Union County
Myra & Chuck Spindler
chuck.spindlerii@gmail.com
(641) 344-6629

Davenport/Scott County
Eileen Benson
jbenson979@aol.com
(563) 332-6497

Decorah/Winneshiek County
David Dobson
davidpauldobson@hotmail.com
(563) 382-6477

Des Moines/Polk County
Valerie Stickel-Diehl
vstickel-diehl@mercydesmoines.org
(515) 358-0002

Dubuque/Dubuque County
Gerry Osterhaus
gerryosty@mchsi.com
(563) 582-7313

Dyersville/Dubuque County
Catherine Tegeler
spikesina123@yahoo.com
(563) 875-7029

Estherville/Emmet County
Eric Erickson
eerickson@seasonscenter.org
(712) 580-4363

Fort Dodge/Webster County
Andrew Duarte
aduarte@jmcsmfg.net
(515) 570-0360

Independence/Buchanan County
Betty Orr
jorrb@indytel.com
(319) 938-2825

Indianola/Warren County
Jan Pack
jpack@good-sam.com
(515) 962-2540

Iowa City/Johnson County
Ed Pierson
e.pierson2325@gmail.com
(319) 430-8512

Lenox/Adam & Taylor County
Melissa Kennan
Life@vintageparkapts.com
(641) 333-2233

Marshalltown/Marshall County
Dennis Eige
(641) 753-8463

Mason City/Cerro Gordo County
Janelle Nevermann
leallenn@mchsi.com
(641) 424-4277

Muscatine/Muscatine County
Wayne & Pat Corriell
pat.corriell@gmail.com (563) 649-2285
John & Karen Schaub
jschaub@machlink.com (563) 263-1866

Newton/Jasper County
Eloise Prater
jeprater@iowatelecom.net
(641) 791-1018

Parkersburg/Butler County
Jennifer Wolff
jdwot01@hotmail.com
(319) 290-9402

Pella/Marion County
Natasha Nikkel
nnikkel@wesleylife.org
(641) 621-0316

Sioux Center/Sioux County
Glenda Vanlaren
Glenda.VanLaren@schospital.org
(712) 722-8256

Sioux City/Woodbury County
Jack Sherrman, jespas@juno.com
(712) 277-9337

Spencer/Clay County
Betty Groen
kbgroen@smunet.net
(712) 262-3653

Storm Lake/Buena Vista County
Bonnie Hunter
bjhunter6@mediacombb.net
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Stacey Hodges
shodges@vghinc.com
(319) 472-6372

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Terry Hertges
Beno08@aol.com
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Waverly/Bremer County
Jennifer Wolff
jdwot01@hotmail.com
(319) 290-9402

West Burlington/Des Moines Co.
Tim Zimmerman
T.S.Zimmerman1022@gmail.com
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Mary Adkins, bjamla@aol.com
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Donations help us with our mission: Ease the burden and find a cure for those impacted by Parkinson's disease in communities across Iowa.

Complete this form, detach and mail with a check to:

Iowa Chapter of the APDA
PO Box 507
Waukee, IA 50263

Mr. Mrs. Ms. (Please print)

Last Name: _____

First Name: _____

Spouse's Name: _____

Address: _____

City: _____ County: _____ State: _____ Zip: _____

Phone: (____) _____ Email: _____ Amount Enclosed: \$ _____

Please check one of the following:

- Diagnosed
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Check here if this is a change of address

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