

Live it!

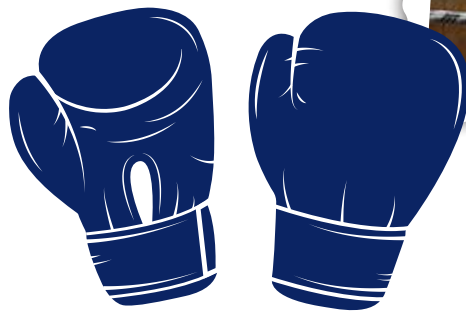
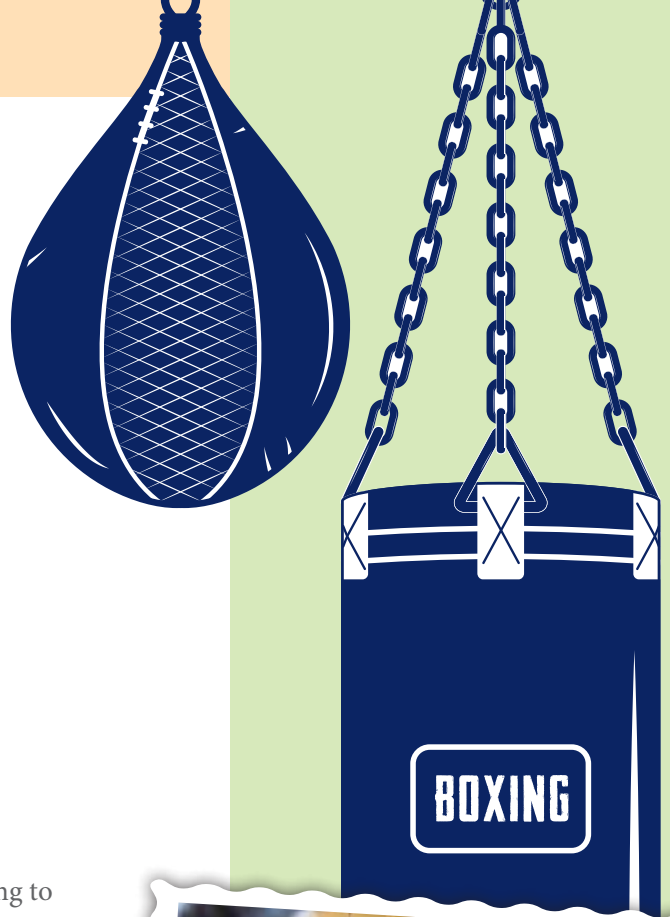
A Resource for Iowans
with Parkinson's Disease
and those who care for them.



***Iowans Embrace Boxing
to Combat Parkinson's Symptoms***

table of contents

- 3 • *From the Staff*
- 3 • **Contact Us**
- 4 • *From Our Medical Director*
- 5 • **The Right Tools for the Job**
- 6 • **Cover Story**
No More Excuses: Iowans Embrace Boxing to Combat Parkinson's Symptoms
- 9 • *Boxing is Just the Beginning
Boxing Classes in Iowa*
- 10 • **Past Events**
- 12 • *Donors, Donations*
- 14 • **Links, Resources, and Sign Language**
- 15 • *Support Groups*



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ONLINE

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Also, follow us on Facebook (www.facebook.com/lowalandR) and Twitter ([@lowaParkinson](https://twitter.com/lowaParkinson) twitter.com/lowaParkinson)



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. 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

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Medical Director: Lynn Struck, MD

Managing Editor: Crissanka Christadoss

Editors: Vicki Ingham, Linda Jordening,
and Sarah Purdy

Contributing Writers: Gary Johnson

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.

Dear *Live it!* Readers,

Thank you for your patience as we put out the Summer 2016 issue of *Live it!* magazine.

While we've been away, we've wrapped up Parkinson's Awareness Month and the 2016 Iowa Parkinson's Disease Conference. You can always view pictures and stay up to date with our events and other news by viewing our Facebook page at www.facebook.com/lowalandR (and we also cover some information on past events on pages 10 and 11).

At the Eastern Iowa Parkinson's Disease Symposium in April in Davenport, we had over 150 people attend, and over 500 people attended the Iowa Parkinson's Disease Conference in West Des Moines. This year was the first time we hosted a symposium in Davenport and it was a great experience! The focus of both was movement and perseverance, a common session in both educational events being boxing.

Yes, boxing! In this issue we are taking a jab at this newest exercise to hit the Parkinson's community and how it is motivating many Iowans and individuals nationwide to become active. Our co-president of the Iowa Chapter John Krumbholz talks about how he got started with the exercise, and Jon Jordan, WesleyLife wellness director/exercise instructor at Heritage House in Atlantic, talks about his passion for helping those with Parkinson's become fit and why he believes that boxing a great way to inspire others. Terry Hertges, support group leader in Waterloo, also talks about the benefits she has encountered after starting this sport.

Don't miss Dr. Lynn Struck's article on page 4 about how coffee consumption is related to Parkinson's disease and assistive technology guru (also known in the Iowa Parkinson's community as the "Gadgets and Gizmos Guy") Gary Johnson's article on container gardening on page 5.

We hope you enjoy the information and stories provided in this issue. We will see you in the Fall!

From,

Live it! Staff

contact us:



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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, 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.

Coffee Consumption in Parkinson's Disease

There have been several studies that have reviewed the relationship between coffee consumption and Parkinson's disease. Through these studies, it has been shown that there is a significantly decreased risk of Parkinson's disease in coffee drinkers. The caffeine in coffee can block the action of the adenosine A2A receptors in the brain that modulate the nigrostriatal dopamine system (this system controls locomotion and movement). Loss of dopamine in this system is one of the main features of Parkinson's. There are clinical research studies showing that blocking A2A receptors reduces the off time in Parkinson's patients with motor fluctuations.

Recently, there has been interest in reviewing whether coffee consumption decreases the risk of developing dyskinesias caused by extended use of levodopa, or L-DOPA, in Parkinson's patients. One clinical study reported reduced risk of developing dyskinesias among patients consuming more than 12 ounces of coffee per day compared to individuals consuming less than 4 ounces per day. Further study needs to be done to review whether this is truly the case in larger patient populations. There has also been research showing that small amounts of caffeine can reduce the fatigue in Parkinson's disease.

If you'd like to learn more about the potential for coffee/caffeine to relieve Parkinson's symptoms, please consult your physician. ■

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Making a Change to Container Gardening

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

For 30 years our garden was down a small hill and along a back fence line and. It served us well! But times and abilities change.

Physical challenges mean we have changed how we garden. Putting grass on the short but steep hill behind us, we now enjoy the world of container gardening. Almost all of our favorites grow well in our containers and by using container dollies (available from your local home improvement store) we can easily move our gardens to take advantage of sun, shade and rain/water source.

So, what do we grow in containers? The last few years we planted bush beans, bush cucumbers, strawberries, raspberries, kale, onions, tomatoes, and carrots. In smaller pots on top of a garden cart we planted chives, mint, parsley, and a pepper plant. For decorative purposes we also had geraniums and daylilies.



Things to think about:

The bulk of our garden containers are on a patio behind our house which also has a deck off a second floor which can be utilized for shade. A water faucet is available and a short 50-foot hose takes care of water when needed.

- If you are already a gardener you will know that plants have different light requirements. Although most of our containers are clustered on a patio, we take advantage of the sun and shade offered by other locations.
- We have had equal success with plastic, fiberglass, and ceramic plant containers. In an outdoor situation, they all have to have a drainage hole.
- Any large pot filled with soil is going to be heavy. We utilize the plant dollies, as shown in the photos, to easily move plants on the patio as needed for sun, shade or water.
- We store the garden containers in an unheated garage over the winter. Even though we let them dry out to keep from freezing and cracking the containers, the strawberries, raspberries, daylilies and even some of the geraniums make it to spring.

Late last fall while cleaning the containers and storing them in the garage, we came across a "volunteer" tomato plant. We planted it in a 12 inch pot and brought it in the house. Turned out it was an excellent cherry tomato plant that grew about three feet tall. Since just after Christmas it provided us with cherry tomatoes all winter long.

Let your porch, patio, or deck be your garden! ■



No More Excuses

Iowans Embrace Boxing to Combat Parkinson's Symptoms



Above and below: 2016 Iowa Parkinson Disease Conference attendees taking part in a Rock Steady Boxing session.



Tom Brown and Mike Van Horn, boxing class attendees in Cedar Rapids, help each other put on boxing gloves during a class. Photo courtesy of KCRG-TV9, Cedar Rapids.

Walk into any boxing gym in the U.S. and you'll find fighters. Not necessarily people looking for a brawl, but people fighting for their own personal goals and to become stronger, faster, and fitter. In a few of these gyms, you'll find a unique but equally motivated group—individuals with Parkinson's disease fighting back against the effects of the disease.

"When you're slugging a bag, you feel like you're fighting Parkinson's," said John Krumbholz, co-president of the Iowa Chapter of the American Parkinson Disease Association. John started a boxing group for people with Parkinson's in November 2015 at his local gym, TITLE Boxing Club in Cedar Rapids. Since then, a core group of five or six have boxed twice a week, and all say they've seen improvement in the quality of their movements.

There are several types of exercise and exercise programs that benefit those with Parkinson's. But boxing is not just a fad. The current popularity of boxing in the Parkinson's community has its roots in Rock Steady, a program founded in 2006 in Indianapolis by two friends, one diagnosed with Parkinson's and the other a former Golden Gloves boxer who wanted to help his friend combat the disease.

They opened a gym in 2011. The results were so impressive that the gym has been the focus of ongoing research by the University of Indianapolis. In a two-year study involving 88 participants with Parkinson's from across central Indiana, researchers compared boxers to those who did other forms of exercise. They found that people who did other activities maintained much of their function, but boxers maintained a higher level of function. This included better walking speed, better postural stability and ability to reach forward, and a more positive perception of their quality of life.

Researchers believe that these improvements are actually due to changes in the brain. High-intensity exercise like boxing can be neuroprotective, meaning they are capable of protecting brain structure and function. Researchers theorize that high-intensity exercise improves the growth of neurons



John Krumbholz, Mike Van Horn and Tom Brown with their instructor at TITLE Boxing Club in Cedar Rapids. Photo courtesy of KCRG-TV9, Cedar Rapids.

damaged by the disease and enhances uptake of dopamine in the brain. Many symptoms of Parkinson's are due to the loss of neurons that produce dopamine.

"When your body lacks dopamine, you lose the ability to move freely," said John. "Movement that crosses the mid-line of the body, like a punch, helps develop new neural pathways and improves muscle memory."

Over the several months John has been boxing, he has experienced a general freeing of movement. Some of it feels almost miraculous—for the first time in many years, he can jump rope again and even runs laps in between exercises.

Boxing caught John's interest three years ago at the World Parkinson Congress. It was there he met representatives of Rock Steady, and he was impressed with what they had to say about the benefits of boxing for those with Parkinson's. As the Iowa Chapter of the APDA's co-president, he was aware of the many classes already available in the Cedar Rapids area—the Delay the Disease exercise program, Parkinsingers (for voice strengthening), and PD Dance Moves. But John believes in providing a wide range of exercise to suit all levels of activity—"I want to eliminate excuses"—so he decided to start a boxing class as well. Rock Steady offers certification for trainers, but John wasn't ready for that yet. He wanted to test out the benefits of boxing on a smaller scale first.

It wasn't quite that easy. Boxing is expensive to do without a pre-existing gym. Fortunately, Cedar Rapids had TITLE Boxing, who John approached to ask if they'd be willing to help them start a class. Generously, the gym offered its location, equipment, and trainers to the Parkinson's group at a nominal cost.

The class is now held twice a week, led by a trainer from the gym using the gym's routine and exercises - slightly modified for the group. "A young person who doesn't have Parkinson's might take up boxing with the goal of becoming physically fit. But I'm a 65-year-old person diagnosed with Parkinson's, and my goal is to be active. I want to be able to move more efficiently. The secret is just to try, and everyone does what they are capable of doing," said John.

The boxing class is non-contact, as is the Rock Steady program, meaning the participants don't hit each other, though punching bags are still fair game. The exercises target symptoms - stretching alleviates stiffness. Punching helps to steady tremors and improve their ability to reach forward. Core strengthening and abdominal exercises help overall strength. Footwork helps with balance and regaining a sense of inner rhythm. The combination of hand and foot movement with the help of an instructor is especially beneficial to regaining an ease of movement in everyday life.

Another benefit of the boxing group, which can also be found in other exercise classes, is social interaction. Instead of sitting isolated at home, people are building camaraderie. "When someone misses a class, people notice, and ask where you were the next time you come in," said John. "You know you can't give up, and other people support you in that belief. It's not just other Parkinson's patients, but others at the gym, who have all been very welcoming."

John encourages people around the state to approach local boxing gyms to see if they'd be willing to help in the same way TITLE has, but he also recognizes that many

may not be near a boxing gym or be capable of boxing. In that case, he insists people seek out other forms of exercise as it is one of the most important ways to manage Parkinson's disease.

Always on the lookout for new opportunities to engage the Parkinson's community in exercise, John hopes to start a bicycling group in the near future.

While John's group continues to test the benefits of boxing before potentially pursuing Rock Steady training, others in Iowa are already taking that leap. At WesleyLife, a health and wellness network that operates seven Communities for Healthy Living throughout Iowa as well as offering home-based care and services, team members are planning to incorporate the Rock Steady program at some of their communities.

WesleyLife Wellness Directors Jon Jordan of Heritage House in Atlantic and Natasha Nikkel from Hearthstone in Pella attended a four-day Rock Steady training session in May to become certified instructors.

Jon, whose father lived with Parkinson's for 30 years, has led a Delay the Disease class for patients with Parkinson's. Seeing the benefits of boxing, he and other WesleyLife wellness directors feel Rock Steady may be even more beneficial for certain individuals with the disease.

"I'm passionate about helping Parkinson's patients through exercise because of my experiences with the great things exercise can do," Jon said. "One of my Delay the Disease class participants has been thrilled with the way his walking has improved. The spouse of another participant told me that before her husband started class, she had to help him with everything, but now he's more self-sufficient."

Jon said, while nothing can stop the progression of Parkinson's, he and his fellow wellness directors hope to help people living with the disease become better able to perform daily tasks. John Krumbholz shares that sentiment; boxing is not a cure – "but until there is a cure, we're going to fight." ■



Exercise Instructor and Iowa Chapter APDA Board Member Kris Cameron teaches a boxing class in Cedar Rapids for individuals with Parkinson's. Photo courtesy of The Gazette, Cedar Rapids.



2016 Iowa Parkinson Disease Conference attendees taking part in a Rock Steady Boxing session.

Terry Hertges and her friend Kevin Cruz at the Cedar Valley Boxing Club in Waterloo, IA.



Boxing is Just the Beginning

Terry Hertges of Elk Run Heights, Iowa, started boxing in March 2015. She was curious about the sport after she had heard about Rock Steady boxing in a Parkinson's chat room online.

She contacted her local boxing club, the Cedar Valley Boxing Club, and started receiving one-on-one boxing instruction from Steve Rice, an ex-Golden Gloves champion. Steve hadn't heard about Parkinson's disease and called Rock Steady boxing in Indianapolis to see how he could adapt boxing routines and exercises to help Terry.

"I didn't think I would last a month - Steve admits that he didn't think I would last a day!" said Terry.

After two years of boxing, Terry not only continues but has encouraged seven more people from the Parkinson's support group she leads in Waterloo to come to the boxing class with her.

Terry credits her physical activity for feeling the best she has felt since her Parkinson's diagnosis in 2008. She can even hula hoop, something she wasn't able to do before.

Terry is also a singer -- she sings with the Waverly Warblers, a singing group comprised of individuals with Parkinson's. And she is looking forward to more opportunities.

"Next, I am working on bringing dance classes for the Parkinson's community to Waterloo," she said. ■



Boxing Classes In Iowa

Locations listed as "Rock Steady Boxing Affiliate" have a certified instructor in the Rock Steady Boxing Program – for more information on Rock Steady Boxing please visit www.rocksteadyboxing.org. If a class is not listed as an affiliate, these programs still have a certified exercise instructor knowledgeable in boxing and working with individuals with Parkinson's. These and other exercise classes for individuals with Parkinson's will be updated regularly and listed on our website at www.apdaiowa.org.



Atlantic (Rock Steady Boxing Affiliate)

Classes scheduled to start on Monday, October 3, 2016
Heritage House Wellness Studio, Heritage House
1200 Brookridge Cir, Atlantic, IA 50022
Contact class instructor Jon Jordan at (712) 243-1850 or
JJordan@wesleylife.org for more information.

Cedar Rapids

Boxing Class for Parkinson's

Title Boxing
5313 N Park Pl NE, Cedar Rapids, IA 52402
Contact John Krumbholz at (319) 350-7482 or
krummy1968@gmail.com for more information.

Fight for PD, Thursdays at 1 p.m.

Title Boxing
5313 N Park Pl NE, Cedar Rapids, IA 52402
Contact class instructor Kris Cameron at (319) 361-7673
or Kris@renuyourlife.com for more information.

Central Iowa/Des Moines

(Rock Steady Boxing Affiliate)

Classes scheduled to start in September 2016
FYZICAL Therapy & Balance Centers
3735 86th Street, Urbandale, IA, 50322
Contact FYZICAL at (515) 985-7530 for more information.

Pella (Rock Steady Boxing Affiliate)

Mondays & Thursdays, 1:00-2:00 p.m.
Pella Recreation Center
308 SE 9th Street, Pella, IA 50219
Contact class instructor Natasha Nikkel at (641) 628-1244
or NNikkel@wesleylife.org for more information.

Waterloo

Boxing Class for Parkinson's

Wednesdays and Fridays at 9 a.m.
Cedar Valley Boxing Club
616 E 4th St, Waterloo, IA 50703
Contact Terry Hertges at (319) 239-6865 or
beno08@aol.com for more information.

Iowa Parkinson's Disease Conference Friday, June 17

The 2016 Iowa Parkinson's Disease Conference was a wonderful day spent with those impacted by Parkinson's from all across Iowa. There were over 500 attendees this year. Various topics were presented such as boxing, research, laughter yoga, self-compassion, pain, medical treatment, living well, women and Parkinson's, fall prevention, deep brain stimulation, and sleep.

Our keynote speaker, Tim Hague, Sr., was very well received on his talk about perseverance and living your best.

Thank you to our sponsors: UnityPoint Health – Des Moines, Abbvie, Medtronic, Teva, US World Meds, Acadia, Impax, and Lundbeck.

You can view videos and conference notes on our website, www.apdaiowa.org.



Parkinson's Research Forum Thursday, April 7

Iowa State University Assistant Professor and Researcher Dr. Elizabeth Stegemoller and the Department of Kinesiology hosts the annual Parkinson's Research Forum. This year, Dr. Daniel Corcos from Northwestern University and Dr. Ergun Uc from the University of Iowa spoke on the topics of exercise and Parkinson's. The lectures were followed by a poster reception with ISU undergraduate and graduate students sharing their research topics.



Eastern Iowa Parkinson's Symposium Friday, April 15

This year was the first year the Iowa Chapter APDA held the Eastern Iowa Parkinson's Disease Symposium in Davenport. Over 160 attendees came to hear topics related to living well. Thank you to our wonderful speakers: John Krumbholz, Iowa APDA co-president; Tallis Straub, dance instructor; Sarah Kent, dietician-health coach from Froedtert & Medical College of Wisconsin; Kris Cameron, Iowa Chapter APDA board member and exercise instructor; and Lyle Gibson, athlete, author, and Parkinson's advocate.

Bingo Bash – Saturday, April 30

The Iowa Chapter APDA's Annual Bingo Bash, Silent & Live Auction took place at Edgewater in West Des Moines. Thank you to Edgewater, generous donors, and attendees for a wonderful event. Over \$7,000 was raised for the Iowa Chapter APDA.

PD Awareness 5K Fun Run & Walk Saturday, April 30

Even rain didn't keep away runners/walkers! Kick off events were held at the Bandshell in City Park in Clear Lake. After the run, events were held indoors. The silent auction, food, information booths, and music were enjoyed by many, and approximately \$23,000 was raised to fund research for Parkinson's Disease. This event was led by Geri Berding of Clear Lake, Iowa.



Please visit
www.apdaiowa.org
to see
upcoming
events!

donors

October 2015 – April 2016
(May – August will be in the fall issue of *Live it!*)

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

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

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Paul and Delsie Hoffey
Karen Hopp
Colee J. Hospers
Carolyn and Marvin Hotz
Carlton and Sharon Johnson
Kenneth K. Kinsey Family Foundation
Pat Krukoski
Frank and Vivian Moughin
Audrey L. Murphy
George and Kathy Murphy
Dianne Oliver
Linda and Ron Perry
Richard Pieper
Steven and Pamela Quigley
Norma Rarick
Patricia E. Sanders
Fred and Cleanne Schieber
Semler Insurance
Tim and Linda Sondgeroth
Jerry Stilwell
Matt and Christine Stilwell
Joyce L. Stumme
James and Elaine Warth
Jeffrey A. Weaver
Mr. and Mrs. Raymond Welsh
Julia A. Wiedner
Stephanie and John Wilkinson
Jane Young
David and Margaret Winegarden
Lowell and Margaret Weaver
Doris Wilson
Jean and Steve Wilson





links

and other resources



Web Links

Here are a few helpful websites.

Parkinson's Disease - 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
Senior Health Information Program	www.therightcalliowa.gov
Telecommunications Access Iowa/Relay Iowa.....	www.relayiowa.com/tai
UERS (Used Equipment Referral Service).....	www.eastersealsia.at4all.com

Parkinson's Disease - General

American Parkinson Disease Association	www.apdaparkinson.org
American Parkinson Disease Association, Iowa Chapter	www.apdaiowa.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
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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Paper

The sign for “paper” uses a repeated backward movement of the dominant hand. If you are right-handed, strike the left palm with the right palm twice. The right hand moves. The left hand doesn't.



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
Jen Carr
jeni@algonaymca.org
(515) 295-7701

Ames/Story County
Becky Erickson
ericksonr@mgmc.com
(515) 239-2323

Anamosa/Jones County
Allison J. Niedermann
Allison.Niedermann@unitypoint.org
(319) 481-6195

Atlantic/Cass County
Jon Jordan, JJordan@wesleylife.org
(712) 243-1850

Burlington/Des Moines County
Elaine Baxter
elainbax@msn.com
(319) 754-4372

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

Cascade/Dubuque County
Brenda Williams
circleb@netins.net
(563) 590-4364

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

Cedar Rapids/Linn County
John Krumbholz
krummy68@gmail.com
(319) 350-7482

Centerville/Appanose County
Katy Dykes
kdykes@mercydesmoines.org
(641) 437-3432

Charles City/Floyd County
Carol Quade
carol@fiai.net
(641) 228-5053

Clinton/Clinton County
Don and Rita Schneider
RSchneider@wpf-cpa.com
(563) 243-5585; (563) 357-0562

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
Eugene Kenyon
ekenyon@aol.com
(563) 549-7890

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) 209-1159

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

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

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

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
Sally Reinert
sreinert@evertek.net

Storm Lake/Buena Vista County
Bonnie Hunter
bjhunter6@mediacombb.net
(712) 732-3383

Vinton/Benton County
Stacey Hodges
shodges@vghinc.com
(319) 472-6372

Waterloo/Black Hawk County
Terry Hertges
Beno08@aol.com
(319) 239-6865

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

West Des Moines/Polk County
Mary Adkins
bjamla@aol.com
(515) 480-4090

Trenton, MO
Gloria Koon,
(660) 485-6558

Donate to the Iowa Chapter APDA!

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

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- Professional
- Family Member

Check here if this is a change of address

If you are making an additional donation at this time, please check one of the following:

- In Honor of: _____ In Memory of: _____
- General Operating Support Research

American Parkinson Disease Association
Iowa Parkinson Disease Information and Referral Center
UnityPoint Health – Des Moines
1200 Pleasant Street, E524
Des Moines, IA 50309

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and for your support
of the Parkinson's disease community.**