

Live it!

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

The Patient-Physician Relationship

by Michael A. Cassaday, D.O.

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and Save Green!**

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via email.

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Live it!
ONLINE

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



Live it! Staff

Medical Director: Lynn Struck, MD
Managing Editor: Kylie Thompson
Editors: Vicki Ingham, Linda Jordening, and Sarah Purdy
Art Director: Patrick Vaassen

Live it! Editorial Board

Lynn Struck, M.D., Medical Director
Kylie Thompson, Coordinator, Iowa Parkinson Disease Information and Referral
Vicki Ingham
Linda Jordening
Patrick Vaassen

Reader Submissions

Live it! magazine is intended to be a voice for the Parkinson's disease community. We encourage and are pleased to consider your words, an article, art, and photo submissions for future issues from our readers – anything that shows how you Live it! 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.

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.

letter from the editor

contact us:

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.apdaparkinson.org/iowa



Greetings *Live it!* Readers,

By now, the novelty of the New Year has passed, but we at the Iowa Chapter of the American Parkinson Disease Association are still reflecting on the generosity and engagement shown by the Iowa Parkinson's disease community in 2017. We owe a thank you to all our generous donors throughout the year, who helped to provide support, education, and research that will help Iowans impacted by Parkinson's disease live life to the fullest each and every day.

The Iowa Chapter will continue to commit our efforts and resources to providing outstanding education and support services, such as *Live it!* magazine. We are also excited to announce a new, important, and family-friendly fundraising event that will help us continue to serve our community! The first annual Optimism Walk will be held on September 29 at On With Life in Ankeny. See page 9 for more details about the walk and how to get involved!

The focus of this issue of *Live it!* is helping you untangle the confusion that can accompany a Parkinson's disease diagnosis. A Parkinson's disease diagnosis requires you as the patient or caregiver to become an expert on the disease, adapt to a new way of living, and develop new relationships with health care professionals. The articles and stories in this issue aim to improve your navigation through the health care system and help you become more confident when making health care decisions.

Last, but not least, we can't wait to see you at this year's Iowa Parkinson's Disease Conference, which will be held on Friday, June 15, 2018, at Lutheran Church of Hope in West Des Moines. Our keynote speaker will be Jimmy Choi, a person with Young Onset Parkinson's disease and 2017 contestant on TV's American Ninja Warrior.

As always, we hope this issue of *Live it!* fills you with hope and optimism.

Best,

Live it! Staff

apda

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.

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Medical Hype in the News

Media consumption has largely shifted to the online environment. Recent survey data reports 91% of physicians have patients who are making inquiries about information they found online.

Medical information is readily available online and on social media platforms. This presents unique opportunities, but it also creates important challenges.

Inaccurate information found online can lead to early use of unproven therapies and possibly negative health outcomes. Writers for traditional media often compete with social media writers, who are not bound by the same code of professional ethics. As a result, there has been an explosion in the number of low-quality or fraudulent news stories. Headlines are also increasingly designed to elicit an emotional response. This can lead to complicated scientific discoveries becoming simple sound bites, overly simplified reports, and exaggerated claims.

Patients and families who seek health information online will need to better understand the importance of recognizing quality health information. Tools to assist the public include Sense About Science and the Understanding Health Research resource. More importantly, patients should discuss these issues with their health care providers.

The goal should be to bring together scientific, media, and patient communities to better understand how to most effectively utilize online information to improve patient care. ■

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Parkinson's Research Update

By Matthew A. Jefferson, Iowa State University

The past 20 years have been monumental for advancing PD research and treatment. While the daily struggles of living with PD can understandably overshadow such progress, make no mistake that we are closer to the development of disease-modifying therapies than ever before. Scientists have moved beyond the traditional confines of their respective disciplines and begun to fluidly integrate knowledge from other fields, creating opportunities for discovery like never before. In addition, large, traditional pharmaceutical companies have transitioned away from in-house R&D and begun to acquire smaller, academic-based startups that introduce cutting-edge drug and treatment options.

We have seen a series of FDA approvals in recent years that are expected to address unmet medical needs and greatly improve PD management. Adamas' Gocovri—an extended-release form of amantadine—is the only FDA-approved therapy for levodopa-induced dyskinesia that will reduce the need for repeated daily dosing and limit OFF periods. Newron's Zadago (safinamide) is another add-on therapy for those currently on levodopa/carpidopa that will work to reduce OFF time.

Soon-to-be approved therapies can be expected from Sunovion and Acorda. Their rapid-release forms of apomorphine (Sunovion's APL-130277) and levodopa (Acorda's Inbrija) will quickly allow patients to kick ON. Acadia's Nuplazid is another notable FDA approval—it is the first medication to treat auditory and visual delusions. This is important for the recognition of common non-motor symptoms in PD that have a major impact on quality of life. It will ideally spur the development of additional non-motor therapies. While these products may not alter the progression of the disease, they provide important solutions for the day-to-day frustrations of living with PD.

Therapies with the potential to alter the progression of PD are currently in Phase 2 clinical trials to determine their safety and efficacy. Roche and Prothena have pioneered mono-clonal antibodies that can target Lewy bodies

(α -synuclein)—the mis-folded proteins that are the classic hallmark of PD in the brain. These antibodies work to neutralize α -synuclein and stop them from killing brain cells, slowing disease progression. Readouts from this phase will be vital to determining if this approach can make a substantial impact on PD.

As for basic research, it used to be that academics would independently study the various cellular deficits that contribute to PD development. These are all still very active areas of research, but more than ever scientists are integrating their knowledge from one field to another. As a result, we're gaining a more cohesive understanding of PD. Much of this new insight has highlighted the influence the immune system can have on the brain. Particularly, there is a strong link between PD and our gut microbial population. Recent studies on microglia, our brain's inflammatory cells, have provided groundbreaking insight into how neurodegeneration in the brain may be driven forward by these overactivated cells.

From benchtop research to breakthrough therapies, science is positioning us closer than ever to getting out in front of PD. Stay well and know there is a wealth of people diligently working to make a difference in your life. ■



Matthew A. Jefferson, M.S., is a Ph.D. Candidate in the Neuroscience Graduate Program at Iowa State University.

The Patient-Physician Relationship

By Michael A. Cassaday, DO

Parkinson's disease, by its very nature, provides special challenges and relationships, especially involving the patient and the physician. Being a chronic, progressive, and multi-symptom disorder, it also necessitates careful decision making regarding overall medical management. As a physician practicing gastroenterology for over 41 years and now a patient with Parkinson's disease for the last 5 years, I would like to provide some insight into the special patient-physician relationship.

Initially, the diagnosis may seem rather straightforward. Patients often present a one-sided tremor, stiff or slow and flat-footed gait, expressionless face, voice changes, fatigue, and constipation complaints. However, the review of symptoms may seem all positive with complaints or findings. A good neurology exam is helpful in ruling out some other issues, but most lab work or imaging tests tend to be normal.

The good news is that this condition does not lead to unusually early deaths, but it is a lifelong issue. Some patients are devastated by the diagnosis, while many others are relieved it is not something worse, like cancer or ALS. Fortunately, Parkinson's disease does not tend to affect the heart, liver, pancreas, or kidneys. Patients can still experience all the other medical problems or complications of aging (heart disease, diabetes, cancer, bone disorders, cirrhosis, and kidney failure).

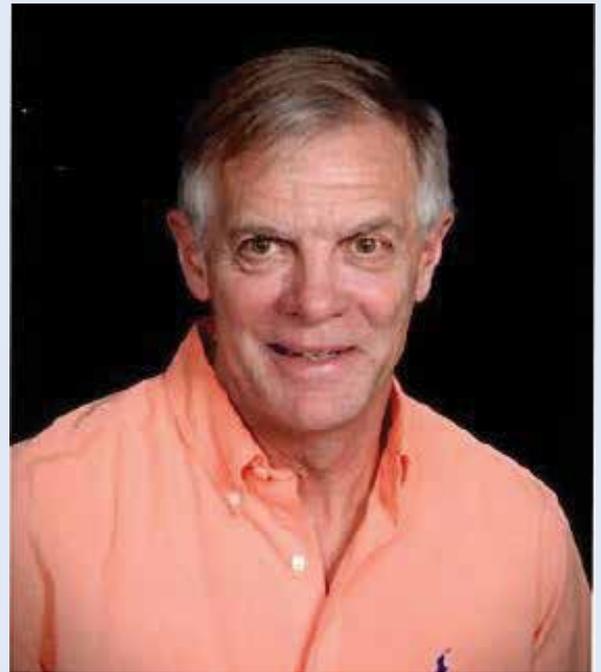
If the diagnosis remains obscure, then a referral to certain specialties should be considered, or a second opinion by a neurologist. Most physicians are not offended by second opinions; in fact, many may be relieved by your request because it amounts to "informed consent" regarding possible diagnosis and treatment options. Informed consent allows you, as the patient, to make decisions.

Most patients will likely have both a primary doctor and a neurologist at some point in their disease progression, and that is probably the best situation. This all requires coordination between clinics and the usual documentation exchange. It is best to have an idea of the date of your next appointment, whether it is once or twice a year. Going longer than a year between appointments is probably not the best situation with PD, unless you are very early or very stable. Be aware of neurological alarm signs, such as one-sided weakness, inability to speak, sudden severe headache, unexplained falling, or thought changes.

Despite the burden of a family member, friend, or spouse accompanying you to your appointments, they can be very valuable. We all "audition" in front of medical providers to avoid additional lab work, imaging or other tests. Providing a balanced history can prompt a better decision about changes in management or routine follow ups by the provider and patient. But, don't be bullied by either the spouse or the physician. You are making the informed-consent decision. Remember though, medical providers are basing their recommendations on the best records available and truthful responses presented.

I have found most PD patients to be cooperative and even spirited. They do require more time per appointment due to different issues, so both parties need to be patient. Short suspense follow-up appointments may be needed. Any acutely changing medical issues obviously may require more lab work, imaging, or ER evaluations, or even direct admission to the hospital to monitor, observe, and expedite studies. Be sure to always bring an updated list of your medications or the actual medication bottles.

In my case, one office visit and neurological exam with walking suggested I had PD, and I was offered a trial of carbidopa/levodopa, with a slow increase of the medication over one month and follow-up to monitor the effect of the meds. I felt better and looked better. The diagnosis of Parkinsonism was made without any new lab work or imaging done. For others, diagnosis may be more problematic. Careful follow-up and monitoring over time will verify the diagnosis. I hope this helps with your initial or follow-up medical visits. ■



Michael A. Cassaday, DO, Colonel US Army (Retired), Gastroenterologist (Retired), Parkinson's Advocate

A native of the Clinton, Iowa, area, Mike is retired from clinical practice and wishes to share his insights regarding medical care of Parkinson's patients by sharing his personal diagnosis. Mike was diagnosed in 2013 and has a special interest in the "non-movement" features of the disease. He also provides insights into "gut"-related issues with Parkinsonism. A lifelong distance runner, Mike qualified for the 1980 and 1984 Olympic Marathon Trials. Married to Diane for nearly 40 years, they lived in Europe for 8 years with the U.S. military and have two sons, Ian and Derek. Mike and Diane were German wine importers for 15 years, and Mike likes to do mass plantings of zinnias and cosmos flowers in the summer. He hopes to provide guidance and inspiration to the patient and their families.

Disclosure: Dr. Cassaday is not affiliated with any product, device, or medication other than limited stock in Gilead Sciences and Novartis.

Disclaimer: Dr. Cassaday is an Iowa- and Illinois-licensed physician who retired from clinical practice as of July 2017. Any diagnoses or treatment issues should be discussed with the individual's medical provider.

Parkinson's Awareness Month

Saturday, April 28, 2018: Shake, Rattle, and Stroll 5K, Clear Lake

The Third Annual Shake, Rattle, and Stroll 5K and Parkinson's Disease Awareness Day will be held on Saturday, April 28, at City Park. Proceeds from the 5K will benefit the Iowa Chapter of the American Parkinson Disease Association. This race is a family-friendly event and welcomes walkers and runners. Registration is \$25 per person and includes a t-shirt.

Register online at: www.apdaparkinson.org/community/iowa/events-ia/



save the date

Friday, June 15, 2018:

Iowa Parkinson's Disease Conference, Lutheran Church of Hope, West Des Moines

Join us on June 15 for our biggest event of the year: the 2018 Iowa Parkinson's Disease Conference! Expect a full day of education about Parkinson's disease, connecting with others impacted by PD, and learning ways to live well with Parkinson's. Our keynote speaker is Jimmy Choi, a person with young onset Parkinson's and contestant on TV's American Ninja Warrior. This day is intended for anyone impacted by Parkinson's disease—from people with Parkinson's to caregivers, spouses, partners, family members, friends, and health professionals. CEUs will be available. Look for more information in your mail, or register online at:

www.apdaparkinson.org/community/iowa/events-ia/



Saturday, September 29, 2018: First Annual Iowa Optimism Walk, On With Life, Ankeny

Friends and family, lace up your sneakers! The First Annual Optimism Walk will be held on Saturday, September 29, at On With Life's brand new Therapy Grounds. We are excited to announce that the event's emcee will be KCCI's Todd Magel. This is a family-friendly event that will include interactive activities, vendor booths, and entertainment. Hy-Vee will provide a grill-out for all walkers. Walking distances will range from 0.25 to 1 mile.

We hope you will invite all your friends, colleagues, and family members to our Optimism Walk! Participants who raise \$100 or more will receive an Optimism Walk t-shirt, and participants who raise \$500 or more will receive an Optimism Walk hat. For more information on the walk and to register online, visit our website: www.apdaparkinson.org/iowa. If you would like registration information to be mailed to you, please contact us at apdaiowa@apdaparkinson.org or call (515) 241-6379.



AMERICAN PARKINSON DISEASE ASSOCIATION

Strength in optimism. Hope in progress.



JOIN US!

Iowa Optimism Walk
Saturday, September 29, 2018

On With Life
 Therapy Grounds
 715 SW Ankeny Road
 Ankeny, IA

Arrive: 9:00 am • Walk: 10:30 am

Register online today!
apdaparkinson.org/iowa



Strength in optimism. Hope in progress.

ph 515.241.6379

What is an Optimism Walk?

- A fun-filled fundraising event!
- A short non-competitive walk with family-friendly activities!

Raise \$100 or more and get a free Optimism Walk T-shirt!

Why Walk?

- Every 9 minutes someone is diagnosed with Parkinson's disease.
- Funds raised provide local support, education and research.
- **The more funds we raise, the more people we can help.**

Walk with us and help put an end to Parkinson's disease!

NATIONAL SPONSORS



The Tenth Annual PD Walkers at the Des Moines Marathon

This year marked the tenth and final year of the PD Walkers team as the Iowa Chapter transitions our fundraising efforts to the APDA Iowa Optimism Walk, which will take place September 29, 2018. Thank you to the PD Walkers for raising over \$20,000 this year. It is fundraisers such as this that allow us to share the importance of exercise for Iowans with Parkinson's.



Delay the Disease Certification

The Iowa Chapter of APDA was proud to present the OhioHealth™ Delay the Disease Certification Training on November 17–18, 2018. Co-founders of the program, David Zid and Jackie Russell, travelled from Columbus, Ohio, to Des Moines to certify 20 new Delay the Disease trainers from across the state of Iowa. It is a priority of the Iowa Chapter to make Parkinson's exercise programs available to all Iowans with Parkinson's disease. Thanks are due to LaDonna Molander, founder of PD Walkers and Iowa APDA Chapter board member, and Community Health Partners, who funded, organized and marketed the event.

Parkinson's Disease 101 with Dr. Struck

It was a cold January evening, but that didn't stop the Parkinson's community from coming to Iowa Methodist Medical Center to listen to Dr. Lynn Struck, M.D., present Parkinson's Disease 101. Dr. Struck ended the evening by discussing some of the newer advancements in Parkinson's disease research and development, leaving people with a sense of hope and optimism for the future.

C4 Workout to Beat Parkinson's Disease

Research proves that many forms of exercise are good for people with Parkinson's. Craig Haas was diagnosed with PD at the age of 45 in 2015. He has been using exercise in his battle ever since and has turned his passion into a fundraiser for the Iowa Chapter.

Each fall, near the anniversary of his diagnosis, Craig hosts C4 Workout to Beat Parkinson's. This year, the four-part workout took place on October 21 and included ballroom dancing, cycling, kickboxing, and yoga. Look for more information coming soon about the workout happening this fall!



The Seventh Annual Grey-Out

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 \$1,000 for the Iowa Chapter of the APDA. This is the seventh 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.

Music and Movement Dance Class

For the second year, the Iowa Chapter of the APDA, in partnership with Des Moines University (DMU), offered a free dance and movement class to individuals with Parkinson's and their caregivers. Instructor Becky Robel led the classes each week in dances like the foxtrot and waltz. DMU students served as spotters and partners for class attendees. New this year was the addition of a music therapist, whose role was to better adapt the rhythm to the movement of the class. There is evidence that movement improves function in people with PD, especially when paired with music.



2017 Northwest Iowa Parkinson's Disease Symposium

More than 75 people with Parkinson's and their caregivers enjoyed a fall day in Sioux City for the Northwest Iowa Parkinson's Disease Symposium on October 20. This year, speakers travelled from Omaha, Des Moines, and Minneapolis to share expertise on living well with Parkinson's. Topics included cognition in PD, art therapy, the immune system in PD, and assistive technology for PD. The day also included interactive demonstrations of Delay the Disease, tai chi, and chair yoga.





Exercise Classes

Black Hawk County/Waterloo - *Delay the Disease*

Covenant Wellness Center, 3421 W 9th St, Waterloo, IA 50702. Classes are held Wednesday and Friday from 1:30-2:15 p.m. Contact class instructor Timi Brown, Med-Fit Facilitator at Wheaton Franciscan Healthcare, at (319) 272-1755 for more information. **Cost:** \$20 for an 8 week session.

Carroll County/Carroll - *Delay the Disease*

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

Cass County/Atlantic

- *Delay the Disease:* Heritage House, 1200 Brookridge Cir, Atlantic, IA 50022. Classes are held every Monday from 1-2 p.m. Contact class instructor Jon Jordan at (712) 243-9458 or JJordan@wesleylife.org for more information. **Cost:** Free
- *Rock Steady Boxing:* Heritage House Wellness Studio, Heritage House, 1200 Brookridge Cir, Atlantic, IA 50022. Contact: Jon Jordan, class instructor, at (712) 243-1850 or JJordan@wesleylife.org for more information.

Clay County/Spencer - *Delay the Disease*

Spencer YMCA, 1001 11th Avenue West, Spencer, IA 51301. Classes are held Monday and Wednesday from 10:15 – 11:15 a.m. Class instructor is Josh Kelly. Contact the Spencer YMCA for more information at (712) 262-3782.

Des Moines County/West Burlington

- *Delay the Disease:* Great River Medical Center, Hawkeye Room, 1221 S Gear Ave, West Burlington, IA 52655. Classes held every Tuesday and Thursday from 12:30 – 1:30 p.m. Contact class instructor Matt Kelley at the Great River Medical Center High Performance Center at (319) 768-4112 for more information. **Cost:** \$5 a class.
- *Gentle Yoga Class at the Great River Medical Center High Performance Center:* Classes held every Monday at 12:45 p.m. in the Chief Room. Contact class instructor Julie Kirk at (319) 768-4112 for more information.
- *Delay the Disease:* Burlington Area YMCA, 2410 Mt. Pleasant St, Burlington, IA, 52601. Classes held every Monday and Wednesday from 1 – 2 p.m. Contact the Burlington Area YMCA at (319) 753-6734 or cara@burlingtony.org for more information. **Cost:** Free for YMCA members; \$5 a class for non-members.

Iowa County/Williamsburg - *Moving with Parkinson's:*

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

Cost: Free

Johnson County/Iowa City

- *Moving with Parkinson's:* 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. Contact instructor Kris Cameron at (319) 361-7673 or Kris@renuyourlife.com for more information. **Cost:** \$5 per class or \$50 punch card available.
- *Movement with PD:* Nolte Dance Academy, 1619 2nd St, Coralville, IA 52241. Classes are held Thursdays from 1:00 – 1:45 p.m. Contact Leslie Nolte at (319) 688-9289 or frontdesk@nolteacademy.com. **Cost:** \$3 per class
- *Rock Steady Boxing:* ICOR Boxing, 1127 Shirken Dr., Iowa City. Classes are held Thursdays from 3:30-5:00 p.m. and Saturdays from 12:00 – 1:30 p.m. Contact Emily or Cliff at (319) 244-8282 or iowacity@rsbaffiliate.com

Jones County/Anamosa - *Delay the Disease*

UnityPoint Health – Jones Regional Medical Center, 1795 HWY 64 East, Anamosa, IA 52205. Classes are held Monday and Wednesday from 3:15-4:15 p.m. at the therapy department. Contact class instructor John Wagner, PT, DPT at (319) 481-6195 or John.Wagner@unitypoint.org. **Cost:** FREE

Kossuth County/Algona - *Delay the Disease*

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. Contact the Algona Family YMCA at 515-295-7701 or jeni@algonaymca.org for more information. **Cost:** \$12 for a 6 week session or \$3 for a one day pass.

Linn County/Cedar Rapids

ALL CLASSES ARE HELD AT THE EASTERN IOWA PARKINSON'S WELLNESS & RESOURCE CENTER, 260 33rd Ave SW, Suite G (2nd floor Cannon Studios) Cedar Rapids. Call (319) 361-7673 or email crmparkinsons@gmail.com for more information.

- *Moving with Parkinson's:* Mondays, Tuesdays, Thursdays, and Fridays 10:30-11:30 a.m.
- *Moving with Parkinson's Level 1 (beginner or those who require additional assistance):* Mondays, Thursdays 12:00-12:45 p.m.
- *Fighting PD Boxing:* Mondays & Thursdays 1:30pm-2:30 p.m.
- *PD Dance Moves:* Wednesdays 11:00-12:00 p.m.
- *Parkinsingers (singing & vocal class):* Wednesdays 1:00-2:00 p.m.

Muscatine County/Muscatine - *Delay the Disease*

Hillcrest Baptist Church, 1613 Bidwell Road, Muscatine, IA 52761. Classes are held twice a week: A rotating schedule of Tuesdays and Thursdays for 4 weeks followed by Mondays and Wednesdays for 4 weeks. Contact instructor Anthony Krumbholz at (319) 981-3321 or AnthonyKrumbholz@yahoo.com for more information. **Cost:** \$5 per class.

Polk County/Clive & Des Moines

- *Delay the Disease:* Mercy Health & Fitness Center, 12493 University Ave, Clive, IA 50325. Classes are held Monday & Wednesday 1 – 2 p.m. and Fridays from 1:15 – 2:15 p.m. Contact the Mercy Health & Fitness Center at (515) 226-9622 for more information.
- *Delay the Disease:* Walnut Creek family YMCA, 948 73rd St, Windsor Hts, IA 50324. Classes are held Tuesday & Thursdays from 2:15-3:15 p.m. Contact Walnut Creek YMCA at (515) 224-1888 for more information and to register.
- *Delay the Disease:* Wesley Acres, 3520 Grand Ave, Des Moines, IA 50312. Classes are held every Wednesday from 1-2pm. Pre-registration is required. Call (515) 271-6500 for more information and to register.
- *Rock Steady Boxing:* Edgewater, WesleyLife, 9225 Cascade Avenue, West Des Moines, IA 50266. Classes are held every Tuesday and Thursday 11-12pm. Pre-registration is required. Call Abby Harlacher, (515) 978-2404 for more information and to register.
- *Rock Steady Boxing:* Title Boxing 9500 University Ave, Suite 1105, West Des Moines, IA 50266. Classes are held Monday, Wednesday and Friday 10:30-12 p.m. Call (515) 493-4486.
- *Stroke and Parkinson's Program (Urbandale and Ankeny):* The goal of this 1 hour program is to provide meaningful exercise with the addition of fun, laughter, socialization and the overall sensation of accomplishment! **(Urbandale)** Courage League Sports, 4405 121st St, Urbandale, IA 50323. Mondays/Fridays from 9:30 – 10:30 a.m. or 1:00 to 2:00 p.m. **(Ankeny)** Courage League Sports, 110 N Ankeny Blvd, Ankeny, IA 50023. Mondays through Fridays from 9:30 – 10:30 a.m. **Cost:** Monthly Membership: \$55/family | 10-Visit Punch Card: \$65 (financial assistance may be available). Call (515) 421-4021 for more information and to register.

Poweshiek County/Grinnell - *Rock Steady Boxing*

Contact Georgia Plumb at (641) 236-9570.

Scott County/ Bettendorf & Davenport

- *Delay the Disease:* Genesis West Medical Center, 1401 Central Park Ave, **Davenport**, IA 52804. Classes are held Monday and Thursday from 12:15 – 1 p.m. Contact class instructor Katie Kostichek at (563) 421-4540 for more information. **Cost:** \$35 for an 8-class card.
- *Delay the Disease:* Scott County YMCA, 3800 Tanglefoot Ln, **Bettendorf**, IA 52722. Classes are held Tuesday and Thursday from 11:15 a.m – 12 p.m. Contact The Scott County YMCA at (563) 359-9622 or class instructor Marli Apt at (563) 345-4287. **Cost:** FREE for YMCA members; \$30 for 16 weeks for **non-members**.
- *Rock Steady Boxing:* 3565 Utica Ridge Road, Suite B, **Bettendorf**, IA 52722. Mondays, Wednesdays, and Fridays from 11 a.m. – 12 p.m. Contact: Barb Park at (563) 650-1417 or back2actionpt@yahoo.com
- *Pedaling for Parkinson's:* Bettendorf Family YMCA, 3800 Tanglefoot Lane, **Bettendorf**, IA 52722. Mondays, Wednesdays, and Fridays from 9 – 9:45 a.m. Contact the YMCA at (309) 755-0092

Union County/Creston - *Neurowellness Exercise Class for*

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

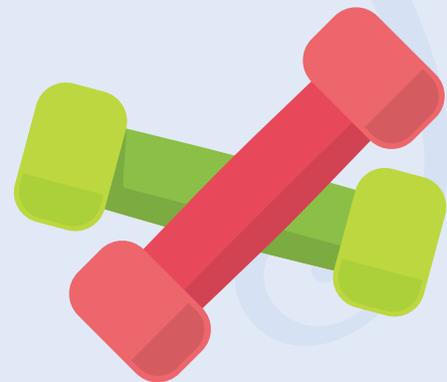
Warren County/ Indianola - *Rock Steady Boxing*

Location: Anytime Fitness, 402 N Jefferson Way, Indianola, IA 50125. Dates/Times: Classes are held Monday and Thursday from 1 – 2:30 p.m. Contact: Lindsey Payne at (515) 962-4741 or lpayne@wesleylife.org for more information.

Woodbury County/South Sioux City, Nebraska -

Delay the Disease

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



Health Literacy

The Key to Informed Medical Decision Making

By Jo Kline, J.D.

In 1976, 21-year-old Karen Ann Quinlan put a face on the right to informed consent in medical decision making. The attention of the court, lawmakers, and media at the time was solely on the use of life-prolonging measures at the end of life, and that's where their focus has remained.

However, for the 117 million Americans now living with chronic illness—such as Parkinson's disease—and their caregivers, the reality of decision making is very different. A lot has changed since 1976. The complexity of available treatment options and caregiving alternatives make decision making an ongoing and long-term challenge. What hasn't changed is that to preserve the right to informed consent, one must be informed—and that requires health literacy.

Health literacy means having the tools and information-gathering processes needed to be an empowered decision maker, for yourself or as a caregiver. In studies evaluating health literacy over the past 30 years, Americans have consistently scored poorly. It's not surprising to learn that people with lower health literacy also tend to be underserved patients who die sooner.

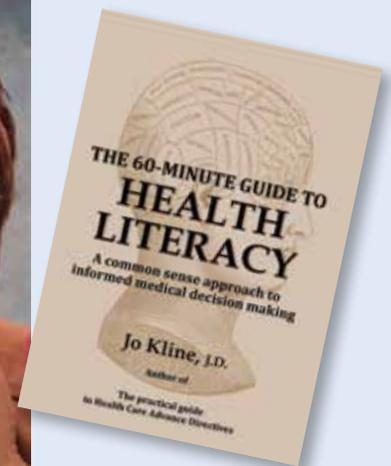
We can do better, and we must because a lack of health literacy is not the only challenge we face. The number of those aged 65 and older in America will increase 60 percent by 2030; there will be 172,000 more senior lowans than there are today. At the same time, the Boomers' mass retirement will continue to cause health care labor shortages. This approaching perfect storm threatens everyone's access to effectual health care, with health literacy being the only element truly in our control.

Many have suggested that the remedy for low health literacy is to dumb down patient-provider communication. I don't agree. I think you're plenty smart; you just haven't been given the tools you need to get the information you need—until now. There are three building blocks of health literacy:

1. Access to health care resources. Find reliable and up-to-date information and ask providers as many questions as it takes. Mastering decision-making lingo is key to practicing effective patient-provider communication.

2. Shared decision making. This step-by-step process applies whether you're considering a new prescription or facing a life-limiting diagnosis. It incorporates the patient's perspective, all relevant information, and thoughtful consideration of suitable options before informed consent is granted.
3. Documentation of action steps. Make a record of all medications and have an annual evaluation, called a "Brown Bag Checkup." Second, keep a written profile of medical conditions, allergies, devices, and important documents. Finally, execute advance directives. Without them, Iowa law specifies certain family members to act as "proxy-by-statute," but not until the patient is terminally ill or irreversibly unconscious. And unrelated persons—such as a domestic partner, an in-law, or a best friend—are not recognized to act as substitute decision makers.

Achieving health literacy is essential to being an empowered patient, a decisive health care proxy, or even a more engaged provider. Managing health care for yourself or a loved one is a challenging journey. But here's the good news: Achieving health literacy is your roadmap. ■



Attorney Jo Kline has been writing and speaking about medical decision making for over a decade. Her most recent book is *THE 60-MINUTE GUIDE TO HEALTH LITERACY – A common sense approach to medical decision making*. Her column, "Health Literacy 101," currently appears in The Des Moines Register. Visit www.JoKline.net for more info.

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acknowledgements



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Laughter is the Best Medicine

A collection of jokes co-authored by Brady Kinesia, Iva Tremor and John McConeghey (founder of the Newton Support Group).

GREAT NEWS!

They are going to open an amusement park just for PwPs! It will be called Dyskinesia Land.



How do PwPs close a business deal?

They shake on it!

MORE GOOD NEWS!

Next year, the first annual Parkinson's Special Olympics will be held in Shaker Heights. The first year there will be four events:

- Free Falling
- Vest Buttoning
- Door Way Obstacle Course
- 100 Yard Shuffle (a second prize will be awarded in this event to the contestant who can stop first).



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

Algona/Kossuth County (EG)
Jen Carr, jeni@algonaymca.org
(515) 295-7701

Ames/Story County
Elizabeth Stegemoller
esteg@iastate.edu
(515) 294-5966

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

Ankeny/Polk County
Kalais Slaubaugh
Kalais.kuhlmann@rockvalleypt.com
Colleen Shannon
collen.shannon@rockvalleypt.com
(515) 964-2559

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

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

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

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

Cedar Rapids/Linn County
John Krumbholz
Krummy1968@gmail.com
(319) 350-7482

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

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

Clinton/Clinton County
Don and Rita Schneider
RSchneider@wpcf-cpa.com
(563) 357-0562

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

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

Davenport/Scott County (C)
Barb Warren
Barb/warwar@gmail.com
(563) 579-7378

Decorah/Winneshiek County
David Dobson
davidpauldobson@hotmail.com
(563) 735-5836

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

Des Moines/Polk County Women and Parkinson's Support Group
Sam Erwin
spiritartmove@gmail.com
(515) 419-3307

Des Moines/Polk County
Lindsay Waechter
lwaechter@wesleylife.org
(515) 271-6596

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

Grinnell/Poweshiek County
Georgia Plumb
plumbge@gmail.com
(641) 236-9570

Guttenberg/Clayton County
Billee Jo Hefel
bhefel@abcmcorp.com
(563) 252-2288 ext. 128

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

Iowa City/Johnson County
Dottie Armens
d_armens@hotmail.com
(319) 400-0506

Marshalltown/Marshall County
Dennis Eige, ldeige@hotmail.com
(641) 753-8463

Mason City/Cerro Gordo County
Martha Boyes,
marthaboyes@gmail.com
(641) 357-3609 (home)
(641) 231-0007 (cell)

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
jeprater1607@gmail.com
(641) 791-1018

Pella/Marion County
Natasha Nikkel
nnikkel@wesleylife.org
(641) 620-4219

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

Sioux City/Woodbury County
Sally Reinert
sreinert@evertek.net
(712) 253-2104

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

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

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

Waukee/Dallas County
Renee' LePera
RLePera@seniorhelpers.com
(515) 402-6263

Waverly/Bremer County
Mary Ochoa
mochoa@waverlyhealthcenter.org
(319) 352-4961

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

West Des Moines/Polk County Edgewater & WesleyLife Community
Betty Bush
bettyjbush@gmail.com
(515) 978-2937

West Des Moines/Polk County Young Onset Support Group
Sean Jenkins
sjenk@gmail.com
Shirley Burke
xsli77@yahoo.com
Has ability for people to join through online video.

Winterset/Madison County
Tamara Bridgeman
tbridgeman@madisonhealth.com
(515) 202-6151

Moline, Illinois
Marilyn Woelke
mewoelke@gmail.com
(309) 781-6462

Trenton, Missouri
Gloria Koon,
(660) 339-8006

(EG) = Exercise group
also available

(C) = Caregiver group
also available



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
- On With Life www.onwithlife.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.apdaparkinson.org/iowa
- 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

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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.

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