Thank you!

for reading Live it! Magazine,
and for your support
of the Parkinson’s disease community.
Greetings Live it! Readers,

As summer turns into autumn, we become excited about the thought of cooler days—a welcome change from the humidity and heat of an Iowa summer. You may also notice many progressive changes taking place at the Iowa Chapter of the American Parkinson Disease Association (APDA). We have a new logo and color scheme, a new website, and a focused vision: Every day, the American Parkinson Disease Association provides the support, education, and research that will help everyone impacted by Parkinson’s disease live life to the fullest.

There has also been transition within the Iowa Chapter Board of Directors and the Information and Referral Center (I & R Center). Bob Miller, a retired superintendent, has stepped into the role of board president, and we have welcomed a handful of other new board members. New I & R Center Director Kylie Thompson is settling into her position. “I cannot tell you how excited and grateful I am to be in a position where I can help people with Parkinson’s and their loved ones every single day,” said Kylie, who was lucky to meet many of you at our 2017 Iowa Parkinson’s Disease Conference. The conference was a hit, and we had approximately 540 attendees! If you haven’t viewed pictures from the event, you can see them on our Facebook page at www.facebook.com/IowaIandR.

On behalf of the Live it! staff, thank you for your patience as we put out this Fall 2017 issue of Live it! magazine. We can assure you it was worth the wait! This issue is all about movement—from the good to the bad. In her letter on page 4, Dr. Lynn Struck, MD, gives us a rundown on dystonia and how it can be managed. On page 9, Ethel Sylvester of Lynnville, Iowa, shares another poem about her journey with Parkinson’s, but this time it’s about boxing! For our cover story on page 6, Ruth Roghair of Orange City shares her Parkinson’s story and reminds us that you can fight back against your PD at any age. Finally, on page 8 Diana Whited shares information about Volkssporting with Parkinson’s and an invitation to attend monthly group walking events and educational programs. We hope this issue of Live it! fills you with hope and optimism.

Best,
Live it! Staff

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Iowa Parkinson Disease Information and Referral Center
UnityPoint Health – Des Moines
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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.

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Scan the QR code at left to go directly to www.apdaparkinson.org/iowa
Live it! is also available online! Visit www.apdaparkinson.org/iowa for an electronic copy.

Also, follow us on Facebook (www.facebook.com/IowaIandR) and Twitter (@IowaParkinson (twitter.com/IowaParkinson)
Dystonia and Parkinson’s Disease

Dystonia is a condition that can occur in Parkinson’s disease and several other illnesses. Patients experiencing dystonia exhibit an abnormality of motor control, causing sustained or intermittent muscle contraction. This can result in repetitive postures or movements, such as frequently twisting or turning. Dystonia can be precipitated or worsened by voluntary actions such as walking or running.

Dystonia can affect different parts of the body, including the eyes and neck—which are respectively referred to as blepharospasm and torticollis. It can also affect the entire trunk of the body, as well as the extremities, which is called limb dystonia.

This posturing can interfere with normal function. In Parkinson’s disease, dystonia frequently occurs when a patient is having an “off” period. This is because dopamine levels are low. A physician will likely increase the levodopa dosage and/or frequency. Other options include adding longer-lasting medications in addition to the levodopa. Muscle relaxers or anticholinergics may be useful in certain situations.

The most common time for dystonia is in the early-morning hours before the first dosage of levodopa has been taken, often impacting one or both of an individual’s legs. Typically, as the daytime medications kick in, this will resolve or at least improve. There are other times during the day that dystonia can occur, and it is important that patients keep a diary to record when it occurs and how long it lasts so they can discuss it with their physicians.

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Managing Constipation

a Common Non-Motor Symptom of Parkinson’s Disease

By Kylie Thompson, MS, RD

Parkinson’s disease has a way of slowing down certain things in daily life, like buttoning a shirt or making a sandwich. Parkinson’s disease is also known to slow down the gastrointestinal system and cause constipation, a common non-motor symptom. A recent study reported that 46.8% of people with Parkinson’s experience constipation, as compared to 6.8% in the general population. It is important to note that constipation is not the lack of a daily bowel movement. In fact, it is normal to have a bowel movement every three to four days. The key is to know what is normal for you.

Just as constipation takes time to develop, it will also take time and patience to resolve. Making small dietary changes is the first step in resolving constipation. We will focus on two key changes: increasing fiber intake and increasing water intake.

1. Increasing Fiber Intake: The average American adult only consumes 15 grams of fiber per day. It is recommended that men over the age of 50 consume 30 grams of fiber per day, and that women over the age of 50 consume 21 grams of fiber per day. Sources of fiber include fruits, vegetables, beans, peas, lentils, nuts and nut butters, and whole grain products (brown rice, 100% whole wheat bread products, quinoa, bran cereal, oatmeal, etc.).

2. Increasing Water Intake: This piece is critical, since eating a large amount of fiber without drinking the recommended amount of water can actually make constipation worse. It is recommended to drink six to eight glasses of water (eight oz. each) per day. This does not include caffeine or alcohol, which can make constipation worse.

You may be wondering how you can track your fiber and water intake. Here are a few strategies:

- MyFitnessPal is a website and mobile app that allows you to track the food you eat and monitor your daily fiber and fluid intake. There are also many other food-tracking tools available on the internet.
- Use the chart below to estimate your fiber intake.
- Use a water bottle that has defined measurements. You may be wondering how you can track your fiber and water intake. Here are a few strategies:

   - Take a couple of months to notice a reduction in symptoms. If your constipation does not improve, then discuss the next step with your physician or Registered Dietitian.

Again, be mindful that these changes will not occur overnight. It can take a couple of months to notice a reduction in symptoms. If your constipation does not improve, then discuss the next step with your physician or Registered Dietitian.

<table>
<thead>
<tr>
<th>FOOD GROUP</th>
<th>(serving size)</th>
<th># of servings</th>
<th>X</th>
<th>Approximate Fiber Content Per Serving (grams)</th>
<th>= Fiber Intake (grams)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whole Fruit</td>
<td>1 medium</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Vegetables</td>
<td>1 cup</td>
<td>1</td>
<td>4</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Whole Grains</td>
<td>1 slice or 1/2 cup cooked rice, pasta, oatmeal</td>
<td>1</td>
<td>6</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Beans, Peas and Lentils</td>
<td>1/2 cup cooked</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Nuts &amp; Nut Butters</td>
<td>1/4 cup or 2 Tbsp</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Whole Grain Breakfast Cereals</td>
<td>See Nutrition Facts label on package</td>
<td>1</td>
<td>5</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

My Parkinson’s Journey

By Ruth Roghair

Parkinson’s disease is a journey that challenges you to keep active and refrain from sitting in your chair feeling sorry for yourself!

My symptoms started with restless legs. Later in the year, the pharmacist informed me the drug I was taking for that was for Parkinson’s. I started having tremors in my right hand, and a few weeks later in my right foot. I asked the doctor if this was Parkinson’s. No answer, but he said he would refer me to a neurologist.

I had also been having some back issues for which I required several weeks of physical therapy. Then the numbness and tingling started in my legs and feet. Our daughter, who is an RN, said, “It’s time for a second opinion to verify what’s going on.”

During the consult appointment, I had to reveal all my medical issues. In addition to the tremors and numbness, I also had a lipoma mass under my right arm that I was planning to have taken care of when the autumn farm work was near completion. The doctor was so concerned he said, “You will have an MRI of your back and the mass yet this afternoon.”

The MRI of my back showed spinal stenosis. Back surgery was more urgent than the mass, but nothing would be done until I had had an extensive neurological consult and all the tests for confirmation of a Parkinson’s diagnosis. I was put on a Sinemet schedule of four doses a day: before each meal and at bedtime. Sometimes it took care of the tremors, and sometimes it didn’t. To top it off, the neurologist who diagnosed me left the state for another practice six weeks later!

I had the back surgery with bone graft and fusion instead of rods. It would take longer to heal, but the surgeon said it would be a better option even though I’d be in a back brace for almost a year. I followed his orders of walking a lot and reclining when sitting in a chair. Nine weeks later, I had the lipoma mass surgery. It was benign! The surgeon put me in a second immobilizer, saying it would heal faster if I couldn’t move my right arm. Are we having fun yet?

I’m a retired certified nursing assistant/patient care technician. I used to work on a medical-surgical floor, and I learned the patient role quickly after years of being the caregiver. Thankfully, my husband accepted the caregiver role throughout the healing process.

I was fortunate to get a new neurologist who was also a movement specialist for Parkinson’s disease and multiple sclerosis. The first visit took longer because she wanted to see my movements instead of just reading what the other neurologist had written in his dictation. She completely changed my med schedule to one Sinemet between 4:30 and 5:00 p.m., followed by a second dose at 9:00 p.m. At 9:00 p.m., I would also take a two-milligram ropinirole extended release. No more drugs until those times the next day. It’s amazing that that schedule worked, and I’ve been on it ever since—almost four years!

I’m counting my blessings that my back and mass area have both healed. I have a 45-pound weight-lifting restriction for my back, and I take no pain meds. When I sit in the chair, I sing to keep my voice strong and embroider or write letters to keep my hands busy.

In early 2014, my husband and I decided it was probably time to leave the family farm after we both had some health issues. It was a hard decision because my husband had lived there for 75 years, and I had shared this experience with him for 53 years. We bought a handicap-accessible house in Orange City, which was eight miles from the farm. This town has all the needed services, and the golf course and walking/biking path are just across the road from our house.

Moving, having sales, and sorting a lifetime accumulation were traumatic and exhausting. We had no family to take over the acreage where we had restored a 1916 barn with the Iowa Barn Foundation. We also had flower gardens, which had been open to the public for viewing since 1991. I wanted to take some of my favorite flowers to town, which was an undertaking before the acreage was sold! Wouldn’t you agree that I had plenty of exercise to keep the tremors away?

In the spring of 2015, Parkinson’s again showed its ugly head. This time it was “shake-the-bed” tremors, which lasted for an hour before an extra Sinemet kicked in. I was walking the 3.2-mile golf course path, gardening, working in the yard, and doing everything else a household demands. I was having these tremors two to three times per week. It was depressing, so I called the neurologist and asked if I could try group exercise classes at the fitness center. Within six weeks, I was down to two times per month. Kickboxing and BodyPump are my two favorite classes, but I also do PiYo, and Zumba. At my next neurologist appointment, she was totally amazed at what the strenuous, vigorous exercise had done for me!

In 2016, the time elapsed since my last two shake-the-bed tremors was 10 months and 1 week. I call that a major improvement!

I am 74 years old, the grandma in every class.

I attend classes five or six days per week.

I have a four-foot bar, weights, stretchy straps, and a yoga mat at home to use between classes and when the weather is inclement. “I can’t” isn’t in my vocabulary. I’ll try to do what I can. I’m embracing what I have, not chasing what I had yesterday. My attitude is “move it or lose it!”

My husband and I both attend a PD support group. We count our blessings for the positive outcome of our PD journey thus far and for all the encouragement we receive from others.
Today I was told I have Parkinson’s
I thought; another issue to complicate my life
Wonder what it is? And what will it do to me?
I was anxious to learn more
My computer would tell me what I wanted to know
So much information, my mind was overloaded
How would I know what was new and also true?
Ah, the local library should have up-to-date material
They told me the definition of Parkinson’s and a few other things
I wanted material that was newer—at least 2010.
I decided to go to a large bookstore
They surely would have lots of information
That was up-to-date and easy reading.
I found it: Parkinson’s for Dummies actually exists!
When I went to a local Parkinson’s support group
Guess what! Hurrah books with new information
Reading and studying the material in the books
Helped me a great deal to understand Parkinson’s
Also found that the State of Iowa Parkinson’s Association
Had many books and leaflets about Parkinson’s
All free and easy to obtain—too bad it took me so long to find
Three things I found very important for people with Parkinson’s:
• Find a Neurologist who specializes in Parkinson’s or
  a Movement Disorder Specialist, one who listens and adjusts
  your medicines to your needs
• Exercise, Exercise, Exercise—even a short walk will help
• Keep a positive attitude—not easy, but keep trying.
– a poem submission by Ethel Sylvester

Prior to retirement from my position as a school administrator three years ago, I began my search for a group that would combine my desire for social contact and regular exercise, as well as my love of the outdoors. By luck, I ran across an article in the paper announcing an upcoming walk at Big Creek State Park sponsored by the Greater Des Moines Volkssport Association. Intrigued by the name and the familiar setting, I decided to attend. I was welcomed by a group of lively, friendly people who were passionate about their sport. One walk and I was hooked! This group met all my needs and so much more.

When I was diagnosed with Parkinson’s a year ago, one of my first thoughts was how this would affect my ability to join my friends on walks. My neurologist encouraged me to continue my regular activities and shared research about the benefits of regular exercise for Parkinson’s patients. I now walk with a new sense of purpose and count each walk as one more day I have beaten Parkinson’s.

So, just what is volkssporting? Volkssporting is an international sports phenomenon that promotes personal physical fitness and good health by providing fun-filled, safe exercise in a stress-free environment through self-paced walks, bike rides, and swims. Walking is the most popular of all U.S. volkssporting activities and has been identified by the U.S. Surgeon General as the most beneficial form of exercise.
Iowa Parkinson’s Disease Conference
Yet again, the Iowa Parkinson’s Disease Conference was a hit—thank you to all for coming out! We had over 20 speakers who covered topics like non-motor symptoms, walking, reclaiming intimacy, art therapy, and so much more. We hope you walked away with skills you are continuing to use as you fight back against Parkinson’s.

Eastern Iowa Parkinson’s Disease Symposium
About 90 people with Parkinson’s and their caregivers attended the Eastern Iowa Symposium on April 22. The event, organized by John Krumholtz and the Cedar Rapids area support group, helped make people hopeful for the future. This year, Brian Grant was the keynote speaker. He spoke of his diagnosis from the beginning; how it has shaped his life; problems he has run into, such as depression; and the work of the Brian Grant Foundation. Several other speakers presented on topics ranging from exercise to applying for medical disability.

Iowa State Parkinson’s Disease Research Forum
Two academic researchers, Dr. Kanthasamy from Iowa State University and Dr. Gammon Earhart from Washington University, discussed their current Parkinson’s research. Dr. Kanthasamy spoke on findings in animal models of PD and their implications for future treatments. Dr. Earhart spoke on her research on exercise and dance and their impact on both motor symptoms and quality of life. Matt Jefferson, a Ph.D., spoke about inflammation in PD. Graduate and undergraduate students also presented their Parkinson’s research during a poster session. Thank you in part to Medtronic for its support.

Shake, Rattle, and Stroll 5K
The air was cold, but the skies were clear the morning of April 29 for the 2nd Annual Shake, Rattle, and Stroll 5K along the shores of historic Clear Lake. More than 120 walkers, joggers, and runners participated in the event, generating $7,250 for the Iowa Chapter of the APDA. ACADIA Pharmaceuticals, Inc., was the signature sponsor for the day, with Hy-Vee providing refreshments. Next year’s event is scheduled to occur on April 29, with plans for an even bigger turnout and more sponsors and activities for people with Parkinson’s and their caregivers, family, and friends.

The 9th Annual Shake, Rattle and Roll Motorcycle Ride and Fundraiser
Saturday, August 26, 2017
Thank you to the Lost Cause Motorcycle Group for raising over $20,000 for the Iowa Chapter of the American Parkinson Disease Association. Each year, the group organizes a ride through different cities in north-central Iowa and ends the ride with a raffle and silent auction. As always, a special thank you to event organizers Chad “Beads” and Kristen “Teen” Pierson for their support.
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 Hurdling at (712) 792-3581 or Melissa Schultes at (712) 794-8515. 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 Jon@atlantewealth.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 Jon@atlantewealth.org for more information.

Clay County/Sperner - 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) 262-3792.

Davis County/County
Delay the Disease: Heritage House, 1200 Brookridge Cir, Atlantic, IA 50022. Classes are held every Thursday and Saturday from 12:30-1:30 p.m. Contact class instructor Kristi Kelley at the Great River Medical Center High Performance Center at (319) 768-4112 for more information. Cost: $5 a class.

Polk County/Clive & Des Moines
• Delay the Disease: Mercy Health & Fitness Center, 12493 University Ave, Clive, IA 50325. Classes are held Monday & Wednesday 6-7 p.m. and Fridays from 1-2:30 p.m. Contact the Mercy Health & Fitness Center at (515) 226-9622 for more information.
• Delay the Disease: Wesley Acres, 3520 Grand Ave, Des Moines, IA 50112. Classes are held every Wednesday from 1-2:30 p.m. and Fridays from 1-2:30 p.m. Contact: Lindsey Payne at (515) 962-4741 or lpayne@wesleylife.org for more information.

Linn County/Cedar Rapids (continued)
• PO Dance Moves: Cannon Studios, 2603rd Ave, Cedar Rapids, IA 52404. Classes are held Wednesdays from 10:30 – 11:30 a.m. Contact Tallis Straub at (319) 329-5151 or tallis.dance@gmail.com
• Fighting PD: Bruce TKD, 139 Marion Blvd, Marion, IA. Classes are held Mondays from 1:30-3:00 p.m. Contact instructor Kris Cameron at (319) 361-7673 or Kris@renuyourlife.com for more information.
• Fighting PD: Down to Fight MMA, 1500 20th St SW, Cedar Rapids, IA 52404. Classes are held Thursdays from 1:30-3:20 p.m. Contact instructor Kris Cameron at (319) 361-7673 or Kris@renuyourlife.com for more information.

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Muscatine County/Muscadine - 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 Kumbholz at (319) 981-3321 or AnthonyKumbholz@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 6-7 p.m. and Fridays from 1-2:30 p.m. Contact the Mercy Health & Fitness Center at (515) 226-9622 for more information.
• Delay the Disease: Wesley Acres, 3520 Grand Ave, Des Moines, IA 50112. Classes are held every Wednesday from 1-2:30 p.m. and Fridays from 1-2:30 p.m. Contact: Lindsey Payne at (515) 962-4741 or lpayne@wesleylife.org for more information.
• Rock Steady Boxing: 9225 Cascade Ave, West Des Moines, IA 50266. Classes are held every Tuesday and Thursday 11-12 p.m. Pre-registration is required. Call Abby Harlacher, (515) 978-2404 for more information and to register.

Wesley Acres, 3520 Grand Ave, Des Moines, IA 50112. Classes are held every Wednesday from 1-2:30 p.m. and Fridays from 1-2:30 p.m. Pre-registration is required. Call Abby Harlacher, (515) 978-2404 for more information and to register.

Rock Steady Boxing: Tanglefoot Lane, Muscatine, IA 52761. Classes are held every Tuesday and Thursday 11-12:30 p.m. Pre-registration is required. Call Abby Harlacher, (515) 978-2404 for more information and to register.

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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 Parkinson Disease Information and Referral
1200 Pleasant Street, E-524, Des Moines, IA 50309
apdaparkinson.org/iowa

In Honor
Angi Lawson, Roger Hefel & Marlene Errthum
Parkinsons Awareness of Clayton County

Dennis Neubauer
Dennis & Rebecca Neubauer
In Honor of Ervin Fogma - Team Rock for Ervin
Klye's Tire Service Inc.

Grandpa Oehlerich
Stefanie Melcher

In Honor of
Dennis Neubauer
Dennis & Rebecca Neubauer

In Honor of
Ervin Fopma - Team Rock for Ervin
Klye's Tire Service Inc.

In Honor of
Grandpa Oehlerich
Stefanie Melcher

In Honor of
Jerry Carlson
Davis Sanders

In Honor of
Keith Fritz

In Honor of
Roger Sievers
Dave & Kristi Pyburn

In Honor of
Sheri Terrell
Charles A De Vore JR

In Honor of
The IA Chapter of APDA and all their volunteer time to help those diagnosed with PD
LaDona Molander

Jim & Judy Anderson
Craig Van Hook

In Support
2017 Eastern Iowa Parkinson’s Disease Symposium

2017 Iowa Parkinson’s Disease Conference

2017 Northwest Iowa Parkinson’s Disease Symposium

Introducing
APDA Launches Online Support Site
In collaboration with Smart Patients, APDA has launched an online support forum, through which people with Parkinson’s, their care partners and families can interact and learn from each other in a safe, supportive environment.

smartpatients.com/partners/apda
In Memory of

In Memory of Al Noble
Kimberly Groves

In Memory of Aunt Mary
Joseph J. and Aunt Mary

In Memory of Bonnie Staadt and Marcus Quade
Parkinson’s Support Group

In Memory of

Catherine A. Kloever
Rhonda Byers

In Memory of Craig Tjaden
Marc & Carol Caudo

In Memory of

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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!

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