



American Parkinson Disease Association
Information & Referral Center

The Informant

Newsletter for individuals and families impacted by Parkinson' Disease
Spring 2007

Information & Referral Center

Iowa Health-Des Moines
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Des Moines, IA 50309

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Lynn K. Struck, MD
Medical Director

Sam Erwin
Coordinator



The Red Tulip—Worldwide Symbol of Parkinson's disease

The tulip has been adopted as a symbol by many Parkinson's disease organizations around the world.

By wearing the Red Tulip, you are raising awareness and showing your support for people living with Parkinson's disease and their families around the globe.

Thank you

April is Parkinson Disease Awareness Month

Parkinson's disease is a movement disorder. The four key symptoms are shaking (tremor), slowness, stiffness, and problems with balance and posture. These symptoms result from the loss of dopamine-producing cells in the brain, but the cause of cell loss is not know. Medications and surgical treatments can relieve symptoms but do not cure the disease. Nutrition, exercise, social support and other non-medical interventions are also important for maintaining quality of life.

Statewide events

- **April 10-** Cedar Rapids Young Onset Support Group, Sam Erwin, I & R Coordinator will be speaking.
- **April 19-** Sioux Center Support Group, Sam Erwin, I & R Coordinator will be speaking.
- **April 21-** Annual walk/run Cedar Rapids. Cedar Lake Trail at 8a.m. cost is \$20 which includes a t-shirt. Awards and door prizes will be given.
- **April 21-** Patient & Family Education Seminar Cedar Rapids, St. Luke's Hospital. Two neurologists, Dr. Lynn K. Struck and Dr. Robert Rodnitzky and a Parkinson Action Network (PAN) representative will be speaking.
- **April 28-**Community Day Des Moines, Merle Hay Mall 10:00 am – 4:00 pm

Resources. Information and Referral Center located in Iowa Methodist Medical Campus in Des Moines has resources available to anyone looking for additional information on Parkinson's disease.

Website. www.apdaiowa.org take a moment and look at our website. If you would like to see additional resources available there contact us.

Support. Also take this month to locate a support group in your area. Share your story with a friend or a neighbor.

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Update on Parkinson's Medications 2007

Lynn K. Struck, M.D.
Medical Director

In 2006, there were several new medications that were released. I have received multiple questions from patients and their families regarding these medications and if they are appropriate candidates for these medications. I am going to spend most of my time in the articles in 2007 going over the new medications that were released in 2006 and medications that will likely be released in 2007. I hope this will answer many questions.

Levodopa is the most commonly prescribed medication in Parkinson's disease. Over time, patients will often develop a "wearing off" or "on/off fluctuations" in their Parkinson's disease. Approximately 40% of patients develop these motor fluctuations after 4 to 6 years of treatment with levodopa. Adjunctive therapy is necessary to improve the clinical response to levodopa. Selegiline is a selective and irreversible monoamine oxidase type B inhibitor that is approved for this purpose. The monoamine oxidase type B enzyme is utilized in the breakdown of a dopamine in the brain. Therefore a monoamine oxidase type B inhibitor allows a longer response of levodopa.



Conventional Selegiline has some disadvantages including its low bioavailability, extensive liver metabolism and it produces amphetamine metabolites. Zelapar® (Zydis Selegiline) has several advantages over conventional Selegiline. Zelapar® dissolves in the mouth on contact with saliva and undergoes absorption directly in the mouth. No water is required. It, therefore, provides higher concentration of Selegiline. Zelapar® has been shown to decrease daily "off" time. It also increases dyskinesias-free daily "on" time. The main side effects associated with Zelapar® are nausea and dizziness. There are some medications that should not be administered with Zelapar® and you should discuss this with your physician before starting medication.

In summary, Zelapar® safely provides improved motor control as evidenced by reduced "off" time when used as an adjunctive therapy with levodopa in Parkinson's disease patients.

Information and Referral Center

The Iowa chapter of APDA funds the printing and distribution of this newsletter through your financial support. Because of your strong support my hours here at the Information and Referral Center has been expanded to full-time. This means additional time to expand support throughout the state in the manner of seminars, public speaking and with a wider communication to support groups. We have added Sioux Center, Wesley Acres, West Des Moines and a young onset group in Cedar Rapids to our listing.



A special thanks goes out to Jodi Parrot, Jeff Glass, Mary Polson and the American Legion, due to their support the I & R Center has increased in resources and storage. I ask you to join them in stepping forward to help spread information and resources to the many individuals impacted by Parkinson's disease (PD) by sharing this newsletter with them or giving out our contact information located on the front page.

On the back page of this newsletter are the dates of the annual walk/run in Cedar Rapids for research, Patient and Family PD Education Seminar, annual golf tournament and conference in West Des Moines. Invite your family and join us for these events.

We could use individuals with skills in accounting, nursing, communications, and graphic art to assist us in our planning of future events. If you are interested please contact me at 515.241.6379 or erwinjs@ihs.org.

Chapter News

APDA Chapter of Iowa
PO Box 507
Waukee, IA 50263

President
Barbara Moore

1st Vice President
Fundraising
Joel Jacobsen

3rd Vice President
Publicity
Polly Flug

Treasurer
Jim Brannen

Recording Secretary
Dee Marshall

PAN Representative
Deb Wityk

Directors:
Laura Coleman-Henderson
Kristin Meyer

Matching Gifts

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 the cure". Gifts can be in memory of a loved one or friend or to celebrate a special occasion. A card is sent to the designated person telling them of your generosity and thoughtfulness.



Presidents Report

Barb Moore, Board President

Well we finally made it through the Holidays in one piece or at least we think we did. I hope that you were all well and happy.

How many of you made New Year resolutions? I hope that at least one of the resolutions was to exercise at least 30 minutes every day. It could

save your life, slow down the progression of Parkinson's and maybe even repair some of the damage that has been done. Wishful thinking? Maybe not.

It is never too late to start exercising and exciting to see the positive results that occur. Side affects of exercising are: feeling good generally, improved breathing habits, weight stabilization, lowers high blood pressure, helps with memory loss, good for your bones and that is important with menopause sneaking up on some of us. There are no negative side affects of exercising.

How You Can Help

- **Donations:** to help us develop services and additional statewide programs
- **Join us:** we have 1300 individuals receiving this newsletter. The more individuals we have on our list the louder our voice is in the campaign for a better quality of life for people with and those impacted by Parkinson's disease.
- **Volunteer: local and nationally** by joining a committee, share your talents with us to improve the services available.
- **Fundraising:** contact the Iowa Chapter of APDA for information.
- **A gift in your will:** leave a legacy in your name. A gift in your will to American Parkinson Disease Association (APDA) will help us continue to improve treatments, care and support.

Thank You

- **Donations:** We would like to thank the following donors
Jim Brannen, Sharon Bruene, Danita Cook, Denise Ditto,
Rebecca Howe, Joel Jacobsen, Jennifer Marks, Dee Marshall,
William Oddy, Angela Plagman, Rita Rosenberg, Melissa West
- **Memorials** Max Polson

This is what I have to write . . .

Apathy, depression, grief, sadness...I don't really care what the word is; all I know is that I have lost something since my diagnosis of Parkinson's disease. Many have told me that I seem to sit in a trance many times, and they need to call me by name several times for me to acknowledge their presence.

I feel very lonely many days as I fail to do the simple things my parents taught me, like getting out of bed, brushing my teeth and getting up from the commode. I am frightened that someday everyone will forget me or would not want me.

But with all of that I do have to sigh with relief because my partner has me by the hand and with a gentle smile guides me to a large seat, large enough for the two of us. My goodness that reminds me of when we were younger and starting to date, my hands still shake from being in the presence of the one I love (Parkinson's may be helping me a little with that shaking.)

I know that I am loved and although I am not normal anymore to many, I am still that same person to the many that still yearn for my smile. I just have to remember to tell myself to smile BIG, and show my teeth.

. . . *someone with PD*



The things kids say about their parents with PD.

Used with permission from <http://www.youngparkinsons.org/pages/index/siteindex.htm>

The best thing that you can do to help your parent is to simply be there for them. Pay attention and always offer to help with even the most simple tasks, because quite often they will not ask for it. A lot of times we see our dad having a really hard time with something, and will ask him if we can do something for him, and he'll say that he is fine and can do it. Then, a few minutes later, he'll say that yes, he does need help, but he's not happy about needing the help and will be frustrated.

...Sean



I agree with Sean. The main thing you can do for someone with Parkinson's is to just be there. Don't go around feeling sorry for them. Just treat them like anyone else, and do what you can to help them. Sometimes that means adding an extra chore or to your usual stuff and picking up the slack when someone is having a bad day.

...Michael



American Legion, \$1000 donation to the Information and Referral Center for resources on exercise to support our support groups.

Jodi Parrott, for the time you gave to arrange the delivery and setup of furniture donated by FBL Financial Group, Inc.

Jeff Glass, processing the grant of \$500 for our lending library through Schwarz Pharma

Mary Polson, donating a U-step walker for our loaning closet.

PD and Employment

Workforce Centers in Iowa are part of a federally-sponsored employment and training system developed to bring together services into one place to make it easier for job seekers. This system is designed and required to meet the needs of all job seekers, who want to use the system. Information and services about available jobs, job search, career planning, training opportunities, and support services are provided.

Disability Program Navigators:

The disability program navigator role is funded by the Department of Labor and Social Security Administration to facilitate access to employment and services for Iowa job seekers with disabilities. The navigator may:

- Assist people with disabilities in accessing resources and services of Workforce Centers
- Provide access to SSA Benefits planning and assistance
- Troubleshoot problem areas
- Conduct outreach
- Provide information and support to employers in employing Iowans with disabilities

Individuals interested in learning more about opportunities in their community are encouraged to contact their local navigator:

Local Workforce Center [<http://www.iowaworkforce.org/centers/regionalsites.htm>]

Local navigator [<http://www.iowaworkforce.org/access/navigatorcontact.html>]



The following **PD and Employment Brief** highlights the ADA, employer/employee rights and responsibilities, job accommodations related to PD, vocational rehabilitation services, information and referral services, employment supports, plus benefits and financial planning.

Employment and the Americans with Disabilities Act (ADA)—Balance of Rights and Responsibilities

You have both rights and responsibilities in the area of employment. An employer cannot discriminate against you because of your disability, if you are qualified for the job. To be qualified you have to be able to do the essential functions of the job, with or without reasonable accommodation. An employer must provide you a reasonable accommodation to help you carry out the essential functions of the job. You also have responsibilities. You must be qualified (with or without reasonable accommodation) and you must meet the employment expectations of your employer. You must, in most circumstances, request the accommodation you need.

Questions to Consider:

1. What limitations is the employee with Parkinson's disease experiencing?
2. How do these limitations affect the employee and the employee's job performance?
3. What specific job tasks are problematic as a result of these limitations?

4. What accommodations are available to reduce or eliminate these problems? Are all possible resources being used to determine possible accommodations?
5. Has the employee with Parkinson's disease been consulted regarding possible accommodations?
6. Once accommodations are in place, would it be useful to meet with the employee with Parkinson's disease to evaluate the effectiveness of the accommodations and to determine whether additional accommodations are needed?
7. Do supervisory personnel and employees need training regarding Parkinson's disease?

Financial Planning

Learn more about available disability benefits including short-, long-term and Social Security disability before they are needed. Contact your employer, private insurance, and the Social Security Administration (800-772-1213) to determine estimated benefits, eligibility requirements, and application process.

Family Medical Leave Act Fact Sheet

<http://www.dol.gov/esa/regs/compliance/whd/whdfs28.htm>

Resources

The Americans with Disabilities Act Employer/Employee Rights & Responsibilities A Guide for Iowans

Reasonable Accommodations--Pages 23-25

<http://www.state.ia.us/government/dhr/pd/publications/AmericDisabilActTitleI.pdf>

Published by The Client Assistance Program

Job Accommodation Network

(800)526-7234 (V)

(877)781-9403 (TTY)

<http://www.jan.wvu.edu/>

Iowa Vocational Rehabilitation Services (IVRS)

Work for and with individuals with disabilities to achieve their employment, independence, and economic goals.

<http://www.ivrs.iowa.gov/index.html>

1-800-735-2942

Iowa COMPASS

Iowa's free, statewide information and referral service for people with disabilities, their families, service providers, and other members of the community.

<http://www.iowacompass.org/>

A free service of the Office of Disability Employment Policy (ODEP) of the U. S. Department of Labor facilitates the employment and retention of workers with disabilities by providing employers, employment providers, people with disabilities, their family members and other interested parties with information on job accommodations.

Publication: *Employees with Parkinson's Disease* [Accommodation and Compliance Series]

<http://www.jan.wvu.edu/media/PD.pdf>

Provides information about PD, ADA information, accommodation ideas, and resources. Accommodations should be made on a case by case basis, considering each employee's individual limitations and accommodation needs.

1-800-779-2001

Social Security Employment Supports

<http://www.ssa.gov/work/>

1-800-772-1213

Iowa Work Incentive Planning and Assistance (Iowa WIPA) for beneficiaries of Social Security

www.iowawipa.org

1-877-424-9472

Linda Kelly—Disability Program Navigator—Iowa Workforce Development--Des Moines

linda.kelly@iwd.iowa.gov

Iowa Parkinson Disease Support Groups

A Parkinson's disease support group offers patients, families and others interested in Parkinson's disease an opportunity to broaden their knowledge of the illness. Besides the physical changes in the patient with Parkinson's disease, there are also social and emotional changes resulting in social adaptations and readjustments that the patient, family and friends have to face.

<p>Ames Virginia Dowling 515/239-2605</p>	<p>Clarion Roger Sumners 515/532-2507</p>	<p>Dubuque Jane Osterhaus 563/582-7313</p>	<p>Sioux Center Alysia Miller 712/7122.8325</p>
<p>Boone Kay Heimes 515/432-2196 Jerry Kemperman 515/432-8379</p>	<p>Clinton Don & Rita Schneider 563/332-5071</p>	<p>Fort Dodge Bob Martin 515/573-6707</p>	<p>Washington 319/653-5473</p>
<p>Burlington Sherry Engberg 319/752-3359</p>	<p>Decorah 563/568-5040</p>	<p>Iowa City Judi Gust 319/351-5248</p>	<p>Waterloo Nancy Hart 319/235-3590</p>
<p>Carroll Melissa Schultes 712/794-1539</p>	<p>Davenport Nancy 563/332-4098 Joe 309/762-9231</p>	<p>Jefferson Kathy Morain/Linda Smith 515/386-2114</p>	<p>Waukon 563/568-5040</p>
<p>Cedar Rapids Jackie Ryan 319/369-8139</p>	<p>Des Moines Patrice Webber 515/241-2442 Valerie Stickel 515/643-2529</p>	<p>Mason City Ginger Hood 641/424-6216</p>	<p>West Des Moines Sam Erwin 515/241-6379</p>
<p>Cedar Rapids Young Onset Betty Holmes 319/363-8500</p>	<p>Des Moines Wesley Acres Elizabeth Heath 515/271-6505</p>	<p>Newton John McConeghey 641/791-4639</p>	<p>Trenton, MO Gloria Koon 660/485-6558</p>
<p>Charles City 641/228-5053</p>	<p>Des Moines Young Onset Denny Neubauer 515/265-4889</p>	<p>Pella Esther Deprenger 641/628-3138</p>	
<p>Clarinda Marilyn Bousch 712/534-2545</p>	<p>Dike Bill Hinkle 319/989-2110</p>	<p>Sioux City Marilee Lynn 712/389-2954</p>	

If you are interested in forming a support group or we are not listing your support group please contact the American Parkinson Disease Association Information and Referral Center, 1.877.872.6386 for information.

\$1000 received from American Legion to support Parkinson's Disease...

Through applying for a grant the Information and Referral Center received \$1000 to be used for support of exercise for people diagnosed with Parkinson's disease. These resources include:

- Parkinson's disease & the Art of Moving-John Argue
- Music Imagery and Parkinson's-Janalea Hoffman
- The Sitting Mountain Series; chair Yoga-Lakshmi Voelker
- Water exercises for Parkinson's-Ann A. Rosenstein
- Motivating Moves for People with Parkinson's-Janet Hamburg
- Sit and be Fit; Parkinson's Workout II-Mary Ann Wilson
- Gentle Fitness-Catherine MacRae
- The Book of Exercise and Yoga for those with Parkinson's disease
- Axial Mobility Exercise Program; a home exercise program to improve functional ability
- How to tame Parkinson's by keeping fit, Anderson, D.H.

These resources are available for support group use and information sharing.





Note from Deb

It seems I am becoming a regular in this newsletter. This time I would like to share my DBS (deep brain stimulation) activation story. It has been quite a roller coaster ride to try to

figure out the new me.

As I accept my new normal after activation and subsequent tweaking, I would admit this procedure has made my life more manageable, and better in quality. I would do it again in a heartbeat but--- there are payoffs I think I may need to learn to accept.

Activation has been very Sci-Fi. That first activation was a very emotional day, but also physically it was exhausting. It takes time and patience to go thru each of the different possibilities. I started out so excited for the potential of the whole idea, but by the time we were done I was just glad it was over for the day. I learned they can shock me, turn my toes up or under. It was scary when I went into what I call "the Black Hole." It tucked me in and I almost passed out. But I can also walk un-medicated, and not a 'shuffle walk.' It was like a miracle.

It is so freeing not to battle the dyskinesias that I had every time I was at a good med place. I still have some tremor, but I don't have the rigidity in my arm and leg. I have some Dystonia in my foot, and when I get tired my foot still may drag a little.

This may all be able to be worked out. One of the benefits I had not counted on was better sleep, maybe because I can move in my sleep.

We are still trying to work out the right combination of meds and power. I am starting to get a sense of amplitude, rate and pulse (new language).

My tweaking just before Christmas was unnerving. It gave me a sense of power that exists in my



brain. After 24 hours it turned my hand and arm inward, and it was pulsating as it pulled. My speech was slurring and I wasn't thinking

clearly. A co-worker took me to the office where they turned me down. I had a duh moment when I remembered I could have turned myself off.

I can say with humor Sci-Fi; but with tremendous seriousness scary and life changing. As we (Jen, Karen and Dr. Struck and me) get this new cocktail designed I know in my heart this is going to allow me to do the things I love.

Side note I have started crocheting again. I am doing "therapy" as I learn to knit also.

Feel free to contact me about my experience with DBS may contact me at Deb Wityk P.O. Box 968, Waukee, IA 50263 or 515/577-2990.

Walk to *Ease the Burden & Find the Cure* April 21-Cedar Rapids

Whether you walk or run, you can make a difference by participating in the APDA 5k Run or 1/2 mile Fun Walk, at 8 a.m. Saturday, April 21, Cedar Lake Trail in Cedar Rapids.

With awards given for the three top male and female runners and walkers, there will also be door prizes. Money raised at this event will go to fund research.

Family and friends can join you for this event. To register go to www.apdaiowa.org or send a check payable to American Parkinson Disease Association, Inc., to Laura Coleman-Henderson, 1640 C Ave., Cedar Rapids, IA 52402. Registration is \$20 and includes a t-shirt.



APDA is the country's largest grass roots organization serving the Parkinson's community. It is a 501(c)(3) not-for-profit organization and receives no governmental or public funding. Each year APDA contributes more than \$3 million for research and more than \$3 million for direct patient and caregiver support through the generous support of individual and corporate donations. You can be a partner in easing the burden and find a cure with a tax-deductible gift to the American Parkinson Disease Association, Inc.



Patient & Family Education Seminar

St. Luke's Hospital
Cedar Rapids, Iowa
April 21, 2007
1:00-3:00 pm

Dr. Robert L. Rodnitzky and Dr. Lynn K. Struck, two Iowa neurologists, will speak on Parkinson's disease and treatment with conversation on advocacy from Parkinson Action Network (PAN). If you would like to attend this free presentation, please call toll-free 1-800-424-3258, to make your reservation. Space is limited.



Methodist • Lutheran • Blank

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Des Moines, IA 50309

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