



FOR INDIVIDUALS IMPACTED BY PARKINSON'S DISEASE

THE INFORMANT

SPRING 2008

I & R Center

Iowa Health-Des Moines
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Des Moines, Iowa 50309

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All material related to Parkinson's disease contained in this newsletter 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 editor, the Information and Referral Center, the medical director of the Center or the APDA.

GADGETS & GIZMOS-APRIL PROGRAM

In 1817 James Parkinson noticed individuals displaying a list of symptoms that brought his interest into writing the widely known publication, "An Essay on Shaking Palsy."

Today individuals are still taking notes of symptoms and research has moved to symptom relief and empowerment. From sharing words of wisdom and advise in support groups the individuals impacted by the diagnosis of Parkinson's disease continue to move forward together.

This year of 2008 the American Parkinson Disease Association (APDA) of Iowa have joined with Iowa Program of Assistive Technology (IPACT) to bring a program, "Gadgets & Gizmos."

When looking around the world today there are gadgets for everything, the remote for your television, light switches, pots and pans with handles, and pens and pencils with different finger grips. For others it is the computer or special guides to preserve your finger when working with electric saws. From the moment that you wake up in the morning until going to bed, there are gadgets or devices to make the tasks you do easier or possible.

Gary Johnson is from Illinois Program for Assistive Technology, a program of the Center for Disabilities and Development at the University of Iowa Hospitals and Clinics. He will discuss various

gadgets of devices that would assist in the home and/or work environment.



Illinois Program Assistive Technology's primary focus on education, employment, community living, information technology and telecommunications.

Their mission is to enable people with disabilities so they can fully participate in all aspects of life.

Dates, location and contact information for the Gadgets & Gizmos

April 1
Mason City
641.424.6216

April 7
Holstein
712.368.2285

April 17
Burlington
217.458.2481

April 24
Sioux Center
712.722.8325

April 2
Des Moines
515.241.3445

April 8
Carroll
712.794.1539

April 19
Davenport
563.332.4098

April 3
Charles City
641.228.5063

April 14
Creston;
641.344.9065

April 21
Newton
641.791.1018

April 4
Cedar Rapids
319.369.8139

April 16
Jefferson
515.386.2114

April 23
Waterloo
319.235.3590

For additional information on the Gadget & Gizmos Program contact the Information and Referral Center, 877.872.6386

HOSPITALIZATION & PARKINSON'S DISEASE



Lynn K. Struck, MD
Medical Director



I receive a number of questions from patients and their families about what to do if an individual with Parkinson's disease is hospitalized. The first and most important thing is for the individual to write down what medications they take and what time. Often in the hospital, medications will be given on a schedule, and these may not be the appropriate times necessary for the patient. Do not assume medical personnel will understand the disease and the importance of taking medication at a specific time interval.

Also, if a patient has a procedure and has to be

NPO, medications should be resumed as soon as possible afterwards.

If you are participating in a research trial, please provide information regarding the experimental drug and let the study coordinator of your trial know you are in the hospital. All of this information will need to be collected.

There are several medications that can intensify the symptoms of Parkinson's disease. Specifically, some drugs used for nausea or psychiatric drugs are the medications that frequently can intensify Parkinson's symptoms. There are 2 nausea medications

that are usually well tolerated. These are trimethobenzamide (Tigan®) and ondansetron (Zofran®). If there is a concern about a particular medication, you should contact your neurologist's office.

If you have a deep brain stimulator implant, you should notify the staff of this. You should bring your access review or magnet device to turn the stimulator on and off for procedures there can be trouble obtaining an ECG or using heart monitors in patients with deep brain stimulation. That is why it is necessary to turn the device off to avoid electrical interference.

ADVOCATING-PARKINSON'S ACTION NETWORK



Sam Erwin
coordinator

It was my pleasure to accept an invitation to travel to Washington, DC scheduled February 2-4, 2008 to attend the Parkinson's Action Network Forum. In brief, presentations and discussion boards focused on three items that were to be discussed when we met with our state representatives on Monday February 4th.

The 2008 Parkinson's Action Network Legislative requests were for **NETRP**: Neurotoxin Exposure Treatment

Research Parkinson's (NETRP), **FDA**: Food and Drug Administration specifically Critical Path drug development research funding, **NIH**: National Institutes of Health.

It was an amazing learning experience for intern, Heidi Sisler and myself as we followed Iowa PAN coordinator, Karla Hansen throughout the scheduled meetings.

If you are interested in additional information on the

forum I invite you to go to their website or contact Karla Hansen.

www.parkinsonsaction.org
Karla Hansen
712.368.5080

If you are interested in advocating locally, consider joining the YIPS support group on April 10th as they are displaying their artwork at our state capitol on April 10th. Contact Lois Cole, 515.288.1250. for additional information.

IOWA CHAPTER—PRESIDENT’S REPORT

Iowa Chapter of APDA
 PO Box 507
 Waukee, IA 50263

President
 Joel Jacobsen

1st Vice President
 Shirley Winters
 Fundraising

Treasurer
 Tim Bigley

Recording Secretary
 Dee Marshall

PAN Representative
 Karla Hansen

Directors:
 Cynthia Bowen
 Lori Geadelmann, Legal
 Laura Coleman-Henderson,
 Walk-A-Thon
 Kyle Lawler,
 Kristin Meyer, Pharmacy
 Denny Nuebauer
 Deb Wityk
 Deb Yount-Woods

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.



Greetings!

I trust this finds you looking forward to warmer weather and spring. Trust me, it will arrive soon! I would like to invite you to explore two upcoming opportunities for some outdoor fun. The Walk-a-thon on May 3 in Cedar Rapids is the first. This event supports the National Chapter of APDA and 100% of the funds raised during this event go to the National Chapter. Laura Coleman-Henderson does a great job coordinating this event and you can contact her at 319.896.4622 for more information. Our third annual golf event is scheduled for June 11 at Beaver Creek golf club near Grimes. This event has been renamed the Barbara Moore Golf Tournament for Parkinsons in honor of our first chapter president. You can contact Amy Harper at 515 .225.5684 for more information.

-Respectfully submitted, Joel Jacobsen President, Iowa Chapter of APDA

FUNDRAISING EVENTS

Walk-a-thon
 May 3, 2008
 Cedar Rapids
 Laura Coleman-Henderson
 319.896.4622
Golf

Tournament
 June 11, 2008
 Grimes
 Amy Harper
 515.225.5684

“Ease the Burden...” Walk
 September 13, 2008
 West Des Moines
 Sam Erwin
 515.241.6379



Fundraising for Research

Pictured are (front row): Stacey Erickson (my sister, half marathon); Rick Town (my dad); Me; Wyatt Erickson (nephew, Kids Run 5th Place!); (back row): Kurt Erickson (brother-in-law, half marathon); Brent Town (brother, marathon); Cory Hughes (family friend, marathon) Team Town for the Des Moines Marathon and Parkinson's research. Together we have raised \$5,380.00 smashing our team goal of \$2,500.00!

EASTER SEALS ASSISTIVE TECHNOLOGY DEMONSTRATION CENTER

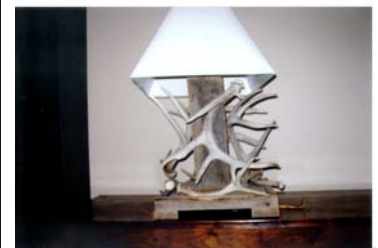
The Easter Seals Assistive Technology Demonstration Center is located at Easter Seals Camp Sunnyside. It is a place where individuals can come to learn more about assistive technology items that they may want to purchase to get a clearer picture of how these items could assist them. Many of these items are available in the center to see and try out. Although the center does not sell assistive technology items, many of the items available for display can also

be checked out for assessment in the environment they would actually be used.

Assistive technology can range from modifications to everyday items such as eating utensils to environmental modifications such as ramps or roll in showers. There are many ways that assistive technology can assist people with Parkinson's disease and make their lives easier. Many items can reduce tremors or compensate for changes in balance, muscle rigidity, or loss of skills. Assistive tech-

nology can increase a person's independence in many ways, including dressing, bathing, eating, cooking, and mobility, to name just a few.

The Assistive Technology Demonstration Center is adding new items all the time and we encourage you to come see what we have. If you would like more information or would like to visit, contact info@easterseals.ia.org or call 515.309.2395.



ART @ THE CAPITOL

**April 10, 2008
Iowa State Capitol
First Floor Rotunda
9:00 am—3:00 pm**

**Contact Lois Cole,
515.288.1250**

The tools used by the artists vary from wood saws, carving knives, pencils, pastels, camera, sewing machines, paint brushes, glue and a little bit of nature.

The scene will be artists with the diagnosis of Parkinson's disease to display art that they discovered or re-discovered. Many state that it is a great stress reliever and it soothes the soul when they spend time working on their choice of art.

Some artists are unable to travel because of their symptoms and a table is reserved for them and the

artists attends will proudly stand by these folks in recognizing their art. For others they have asked a family member to go instead but either way it is with pride these artists attend this day prepared to show their art ability and to discuss how Parkinson's disease has impacted their lives.

This event is open to the public.



10 LESSONS

The group will discuss strategies for people with disabilities to promote health and well-being, and to understand the way people adapt to disabilities, the meaning it holds in their lives.

Leaders:
Kathy Reardon & Sam Erwin

Plymouth Congregation Church

\$110, includes book

May 7—June 23 weekly, 6:00—7:30 pm

(scholarships are available)

Uses the book, *"Living with Illness or Disability"*

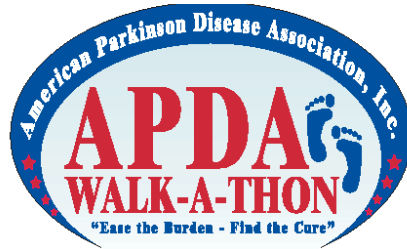
For additional information

515.241.6379 or erwinjs@ihs.org

Artwork shown are the work of

- Pat Healy, Cedar Rapids
- Jerry Booth, Urbandale
- Denny Neubauer, Des Moines
- Lois Cole, Des Moines

WALK-A-THON & PARKINSON DISEASE SEMINAR



Walk-a-thon & Parkinson Disease Seminar
 Saturday, May 3, 2008
 8:00 am
 Cedar Lake Trail
 Cedar Rapids, Iowa

For additional information contact Laura Coleman-Henderson,
 319.896.4622

Parkinson Disease Seminar
 St. Luke's Hospital

Noon-Box lunch
 1:00-1:45 pm *Parkinson Disease*
 Ergun Uc, MD
 2:00-2:45 pm *Music therapy & Parkinson Disease*
 Kara Mills Kroen, MA, MT-BC
 3:00-3:45 pm *The Walking Gait of Parkinson's Disease*
 Erich Streib, MD & Renee Crumley, PT NCS



If you would like to attend this free presentation,
 please call toll-free 1-800-424-3258, to make your reservation.
 Space is limited.



INSPIRE ME WITH...WORDS...COLOR...MOVEMENT...LAUGHTER...TASTE...TOUCH



May 31, 2008
 10:00 am—2:30 pm
 Mary Greeley Hospital
 111 Duff Avenue
 Ames, Iowa

Free
Registration is Necessary

Words

Kathy Reardon, RN, MS, is a holistic nurse, a spiritual director, and a certified healing touch practitioner in practice at the Des Moines Pastoral Counseling Center. Kathy will lead discussion on change and how it impacts our life.

Color

It is amazing to imagine what someone will do with color, texture and glue. Everyone will be given the same items but the image will differ for everyone when the project is completed.

Taste

For lunch it will be filled with finger food, food that will be filled with color, taste and imagination. Use your fork only if you really want to.

Movement

Janet Shoeman well respected in the disability and TaiChi population will bring simple thought and movement to sitting, standing and walking.

Touch

Kayde Heite a licensed massage therapist will bring us back to the simple thing, touch.

SUPPORT GROUPS

Ames
Sue Wolfe
Sue Trevillyan
515.239.2600

Atlantic
Wendy Ogel
712.243.1850

Burlington
Ruth Newton
217.453.2481
Sherry Engberg
319.752.3359

Carroll
Melissa Schultes
712.794.1539

Cedar Rapids
Jackie Ryan
319.369.8139

Charles City
Carol Quade
641.228.5053

Clarinda
Marilyn Bousch
712.534.2545

Creston
Myra Schindler
641.344.9065

Clinton
Don & Rita Schneider
563.332.5071

Decorah
563.568.5040

Davenport
Nancy VanHook
563.332.4098
Joe McCarthy
309.762.9231

Des Moines
Patrice Webber
515.241.3445
Valerie Stickel
515.358-0002

Des Moines
Wesley Acres
Sam Erwin
515.241.6379

Dike
Bill Hinkle
319.989.2110

Dubuque
Jane Osterhaus
563.582.7313

Fontanelle
Lavon Lutz
641.745.5044

Holstein
Karla Hansen
712.368.2285

Indianola
Heather Bahr
515.962.4741

Iowa City
Judi Gust
319.351.5248

Jefferson
Annette Ganoe
515.386.2114

Leon
Jim LeFleur
641.4446.7456

Marshalltown
Joyce Hughes
641.752.0349

Mason City
Ginger Hood
641.424.6216
Joann Hammerstedt
641.423.3634

Newton
Eloise Pater
641.791.1018

Pella
Esther Deprenger
641.628.3138

Sioux Center
Mandi Roskam
712.722.8325

Sioux City
Marilee Lynn
712.389.2954
712.258.4944

Washington
319.653.5473

Waterloo
Nancy Hart
319.235.3590

Waukon
563.568.5040

Trenton, MO
Gloria Koon
660.485.6558

DBS
Deb Wityk
515.833.2575

Young Onset Groups
Cedar Rapids
Betty Holmes
319.363.8500
Dave Jones
319.396.7852

West Des Moines
Denny Neubauer
515.265.488



Just a line to say I'm living, that I'm not among the dead;
Though I'm getting more forgetful and mixed up in my head.
Sometimes I cannot remember when I stand at the foot of the stair.
If I must go up for something, or I've just come down from there.
And often before the refrigerator, my mind is filled with doubt;
Have I just put the food away, or have I come to take it out?
And there are times when it is dark out, with a nightcap on my head
I don't know if I'm retiring, or just getting out of bed.
So, if it's my turn to write you, there's no need for getting sore.
I may think that I have written and I don't want to be a bore.
So remember, I do love you, and I wish that you were here,
But now it's nearly mail time and I *must* say goodbye, my dear.
There I stood beside the mail box with a face so very red.
Instead of mailing you my letter, I opened it instead.

-Anonymous

From Elmer Kruse at the support group in Carroll

PD CONFERENCE 2008—MOVING FORWARD TOGETHER

Friday, June 13, 2008
Lutheran Church of Hope
925 Jordan Creek Parkway
West Des Moines

Morning Session

- 8:00 Registration
- 8:30 Tai Chi on the Floor – Margaret Gass
- 9:15 Parkinson's Disease and Exercise, the research side – Jay Alberts, Ph.D.
- 9:45 Break
- 10:15 Chair Yoga – Margaret Gass
- 10:30 Parkinson's Disease and Nutrition – Kathrynne Holden,
- 11:30 Lunch (sack lunch available)

Optional sessions during the lunch hour will be

- (1) Spirituality and Chronic Illness (2) Experience Hypnotherapy
- (3) Young Onset Parkinson's Disease Information & Referral Center (4) Parkinson Action Network



Afternoon Session

- 1:00 Parkinson's Pyramid – David Heydrick, M.D.
- 1:45 Break
- 2:15 Living, Coping and Advocating with Parkinson's Disease – Jackie Hunt Christensen
- 3:00 Updates – Lynn K. Struck, M.D.

MOVING FORWARD TOGETHER TEAM

These folks came together to be photographed for the public service announcement that will be distributed statewide for Parkinson's Disease Awareness Month. To give the public another image of Parkinson's disease.

Coming from various locations in Iowa they strive to make changes in public awareness of an individual diagnosed with Parkinson's disease.

- Bill Hinkle from Dike rode RAGBRAI 2007 with Pedaling for Parkinson team with plans to ride 2008.
- Ladona Molander from Urbandale has just completed a walk marathon for the cure of cancer. She has plans to form a team for Parkinson's disease.
- Mike Ketcham lives in Creston and is seen with his guitar. He joined his fellow band members in support of fundraising to support folks diagnosed with Parkinson's disease.
- Marc Quade volunteers building houses in the Gulf Coast area and resides in Charles City. His advise is to get a dog and walk the dog daily.
- Deb Wityk is from Redfield and she strives to support individuals who choose deep-brain stimulation (DBS) by sharing her personal story with the public.
- Gwen Peterson brought support to Wesley Acres





Methodist • Lutheran • Blank

Parkinson Disease Information & Referral Center

1200 Pleasant Street, E-524

Des Moines, Iowa 50309

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WHAT IS APDA?

The American Parkinson Disease Association, Inc. was founded in 1961 to “ease the burden and find a cure” for Parkinson’s disease. Headquartered in New York, the organization focuses its energies on research, patient services, education and raising public awareness about the disease. The 2007-2008 APDA budget for research is more than \$3.5 million plus the funding of 8 Centers for Advanced Research. \$2.6 million is provided for patient services, including 60 regional Information & Referral Centers and the APDA National Young-Onset Center. Each year the APDA Scientific Advisory Board reviews grant applications and submits recommendations for funding researchers whose work shows promise for making scientific breakthroughs or finding improved treatments for Parkinson’s disease. The APDA national office also coordinates the efforts of 56 chapters and 250 affiliated support groups across the nation.

I & R CALENDAR OF EVENTS-AT A GLANCE

March

- 4—Des Moines; Wesley Acres
- 10—Creston; Support Group meeting
- 14—Iowa City; Support Group meeting

April

- 1—Mason City; Gadgets & Gizmos
- 2—Des Moines; Gadgets & Gizmos
- 3—Charles City; Gadgets & Gizmos
- 4—Cedar Rapids; Gadgets & Gizmos
- 7—Holstein; Gadgets & Gizmos
- 8—Carroll; Gadgets & Gizmos
- 10—Des Moines; Art @ the Capitol
- 14—Creston; Gadgets & Gizmos
- 16—Jefferson; Gadgets & Gizmos
- 17—Burlington; Gadgets & Gizmos
- 19—Davenport; Gadgets & Gizmos
- 21—Newton; Gadgets & Gizmos
- 23—Waterloo; Gadgets & Gizmos
- 24—Sioux Center; Gadgets & Gizmos

May

- 3—Cedar Rapids; Walk-a-thon & Education Seminar
- 28—Waterloo; Support Group meeting
- 31—Ames; Inspire Me With...

June

- 11—Grimes; Golf Tournament
- 13—West Des Moines; Parkinson Disease Conference 2008