

# The Informant



Newsletter for members and friends of American Parkinson Disease Association Information and Referral Center and the Iowa Chapter of the American Parkinson Disease Association.

Fall 2005

## Information and Referral Center Opens in Des Moines

Iowa Health DM is pleased to have the APDA Information and Referral Center open on the campus of Iowa Methodist Medical Center. The Center will provide a great service to all Parkinson Disease patients and families. New educational, support and outreach programs, including public symposia and workshops, will be coordinated through this office. Referral services and maintenance of a comprehensive resource library will be additionally offered by the Center. We are also blessed and excited to have Sam Erwin accept the position as the Center's coordinator. Ms. Erwin comes to us with a wealth of experience in program development, planning and coordination. Her energy, enthusiasm, and creativity will ensure the success and growth of the Center.

*Mark W. Purtle, M.D.  
Vice President Medical Affairs  
Iowa Health Des Moines*

## The First APDA Fun Walk and Run

The first APDA Fun Walk and Run was held April 23 at the Cedar Lake Trail in Cedar Rapids. There were nearly 100 participants who braved the cold to walk or run in the event. More than \$13,000 was raised for the national APDA organization for research and education.



Prizes were donated by many organizations and distributed to participants by a drawing.

Special thanks go to Laura Coleman-Henderson for her contributions and hard work in preparation for this first Iowa event.

Plans are in the works for an April 2006 APDA Fun Walk and Run in Cedar Rapids. This event is a great opportunity to increase awareness of APDA, as well as raise needed funds for research and education. Watch upcoming newsletters for more information.



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The material in this newsletter is presented solely for the information of the reader. It is not intended for treatment purposes, but rather for discussion with the patient's physician.

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You can make contributions to the Iowa Chapter by making a check out to Iowa Chapter APDA, and sending it to:

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All material related to Parkinson 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 & Referral Center, the medical director of the Center or the APDA.

## From the Coordinator of the APDA Referral & Information Center

**As coordinator of the Referral and Information Center**, I've had the opportunity to meet with facilitators of some of the 20-plus Iowa



groups, and when invited, I meet with members, too. I thank Sherry from Burlington, Carrie from Exira, and Patrice and Valerie in Des Moines for their warm welcome. I'm looking forward meeting soon with Virginia in Ames and Roger in Clarion. And I hope to meet with more of you as I travel to additional support groups this fall.

It seems that when you are faced with a chronic illness, such as Parkinson Disease, you need specialists and other support people to come along side you. Dr. Lynn K. Struck, our medical director, is a neurologist and movement disorder specialist who has treated more than 800 Parkinson Disease patients. In this issue, she provides information to help you have a more positive doctor-patient relationship. In upcoming issues, we will feature other experts, such as Michelle McGregor, a speech-language pathologist, who will discuss speech therapy.

Enjoy our constantly changing weather as we say good-bye to summer and hello to fall.

Sam Erwin,  
Coordinator, Information & Research Center

## From the Iowa APDA Chapter President

**Welcome to the first issue of the Informant**, a newsletter developed for members and friends of the new Iowa Chapter of American Parkinson Disease Association and in collaboration with Iowa Health – Des Moines.

We hope that this quarterly publication will provide you with information you will find helpful as you seek solutions and ideas to improve your quality of life.

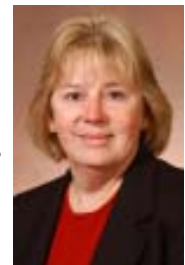
If you haven't joined the American Parkinson Disease Association, please take a moment to do so. The organization motto is "To Ease the burden to find the cure." They do that through research, fundraising, education, patient and caregiver support and by increasing awareness of the disease. Your membership helps with all those things.

For more information, you can log on to [www.apdaparkinson.org](http://www.apdaparkinson.org), or call 718/981-8001. You can also make contributions to the Iowa Chapter by making a check out to Iowa Chapter APDA, and sending it to APDA, PO Box 507, Waukee, Iowa 50263.

As the Iowa Chapter develops, and with your support, we will be helping support groups throughout the state by providing resources. You'll also be hearing about fundraisers we are planning.

Thank you for your interest and support. We look forward to serving you.

Barbara Moore,  
President, Iowa Chapter American Parkinson Disease Association



## Make the Most of a Visit to Your Doctor

Going to your physician, particularly when the appointment is with a specialist, can seem a bit intimidating. But being prepared can help you to get your questions answered and the information you need to be an active part of your own healthcare. Lynn K. Struck, M.D., who is a neurologist movement disorder specialist, provides these tips to help you prepare for a visit with your doctor.



### Communication:

- Be an active participant in your partnership with your physician and nursing staff by asking questions
  - Talk openly and honestly and divulge all information to the medical personnel
- Relay information pertinent to the medical issue to make your visit more effective and have the major issues addressed

### Planning (Plan for your visit ahead of time):

- Keep a medical diary of pertinent symptoms between your clinic visits, include any
  - Change in level of activity
  - New symptoms
  - Physical or mental change you feel may be attributed to medication you are taking.
- Have a written list of questions and concerns you want to discuss; limit this to no more than 5 issues, so each can be dealt with effectively
- Be familiar with your medications
  - Correct spelling
  - Dosages
  - When the medication was started and for what reason
  - Exact time of day that you take the medication
  - List all over-the-counter medications you are taking, including vitamins, as well as the dosages and number of doses per day
  - List other medications you have tried and why they were discontinued

### For an Initial Visit:

- Briefly state the history of your illness and why you sought medical attention
- List the tests previously performed, and, prior to your appointment, make sure all the results of previous tests are forwarded to your consultant's office for review prior to the appointment
- List all prior treatments
- List all medications you are currently taking and, if you have been on other medications, why those medications were discontinued

### A message from Dr. Struck:

I want to say a special thank you to the APDA for funding the Information and Referral Center, and Sam Erwin, coordinator, for her hard work. What you and all the volunteers are doing is truly making a difference.

### World Parkinson Congress

Feb. 22-26, 2006, Washington, D.C.

The World Parkinson Congress, Inc. is a nonprofit organization dedicated to providing an international forum for the best scientific discoveries, medical practices and caregiver initiatives related to Parkinson's disease. By bringing physicians, scientists, allied health professionals, caregivers and people with Parkinson's disease together, we hope to create a worldwide dialogue that will help expedite the discovery of a cure and best treatment practices for this devastating disease.

Did you know?

Iowa Governor Tom Vilsack declared April 2005 Parkinson Disease Awareness Month.

The American Parkinson Disease Association, Inc., was founded in 1961 to "ease the burden and find a cure" for Parkinson disease. Headquartered in New York, the organization focuses its energies on research, patient services, education and raising public awareness of the disease. The APDA national office also coordinates the efforts of chapters and information and referral centers across the nation. The APDA research budget for 2004-2004 is more than two and half million dollars, plus the funding of eight advanced centers for PD research. Annually, the APDA scientific Advisory Board reviews grant applications and recommend funding for researchers whose work shows promise for new breakthroughs or improved treatments.

## Parkinson Disease Support Groups

Contact the facilitator for time and location of support group meetings. For additional information, please contact the Information and Referral Center at 515/241-6379, or toll-free at 877/872-6386, or via e-mail at [erwinjs@ihs.org](mailto:erwinjs@ihs.org).

### **Burlington**

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319/752-3359

### **Clarion**

Roger Sumners  
515/532-2545

### **Des Moines Area**

Valerie Stickel  
515/643-2529  
Patrice Webber  
515/241-2445

### **Young Parkinson Support Group**

Sam Erwin  
515/241-6379

### **Iowa City**

Caregivers Support Group  
Liz Koffron-Eisen  
319/351-5476  
Stan Smith  
319/354-2952

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