

# 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.

Spring 2006

## Walk to Ease the Burden and Find the Cure

Whether you walk or run, you can make a difference by participating in the American Parkinson Disease Association 5K & 1/2 mile Fun Walk, at 8 a.m. Saturday, April 22, Cedar Lake Trail in Cedar Rapids.

This is the second annual Fun Walk to be held in Iowa, and medals will be awarded for the three top male and female runners, as well as the top male and female walkers. There will be plenty of other fun awards and many door prizes, too.



To register, go to [www.apdaparkinson.org](http://www.apdaparkinson.org), or send a check payable to American Parkinson Disease Association, Inc., to Laura Coleman-Henderson, 1640 C Ave., Cedar Rapids, IA 52402. Registration fee is \$20, and includes a T-shirt. A form is available on page 7 of this newsletter.

Money raised at the Fun Walk will go to the American Parkinson Disease Association for research. Real progress is being made in the fight against Parkinson's disease, including identification of causal genes, development of safer, more effective surgical therapies and the development of more effective drugs. However, the ultimate goals of discovering the cause and cure remain elusive.

Family and friends can join you for this fun, but very important, walk. And participants may want to raise money for APDA

by sponsorship donations. For details, log on to [www.apdaparkinson.org](http://www.apdaparkinson.org).

Some important facts:

- About 3 million people in the United States have Parkinson-like disorders; 1.5 million of whom have been diagnosed with Parkinson's disease.

- Parkinson's is a progressive brain disorder resulting in the loss of Dopamine production. Dopamine is a substance that is essential to normal nerve activity in the brain.
- Parkinson's affects all ages – and even some children. Most people with Parkinson's are over 60, but an estimated 20 percent are young adults under 50.



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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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APDA Information & Research Center  
Iowa Health - Des Moines  
1200 Pleasant St., E-524  
Des Moines, IA 50309  
Toll free: 877/872-6386  
Fax: 515/ 241-6393  
E-mail: erwinjs@ihs.org

## Information & Referral Center Coordinator

Sam Erwin

## Medical Director

Lynn K. Struck, M.D.

## APDA-Iowa Chapter

Barbara Moore  
President

Joel Jacobsen  
1st Vice President - Fund Raising

Dennis Neubauer  
2nd Vice President - Programs

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Jim Brannen  
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Recording Secretary

Deb Wityk  
Membership Secretary

## Directors:

Kristin Meyer  
Laura Coleman-Henderson  
Jana Mentzer

Iowa Chapter APDA  
PO Box 507  
Waukee, IA 50263

## www.apdaiowa.org

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

– Sam Erwin



Exercise. Yes, exercise is a topic in this newsletter – and for the entire year of 2006. It does not matter if you are sitting watching television, move those arms, kick out those legs, move your fingers and yes, exercise your voice. When you are in bed, stretch your arms and legs, reach out with your limbs and embrace the world. Walk around your dining room table or to your mailbox, go visit your neighbor or go window shopping. So take a moment and walk 10 steps today – or 10 minutes – with plans to do more tomorrow.

One way to get some exercise is to join us for the APDA Fun Walk and Run in Cedar Rapids on April 22. See details on page 1. Invite your family and friends to join you. It will be good for all participants, and it's good for APDA because it raises needed funds for research.

We come to love not by finding a perfect person, but by learning to see an imperfect person perfectly.

- Sam Keen

## From the Iowa APDA Chapter President – Barbara Moore

With spring comes renewed energy and hopefully good weather so you can take advantage of having more energy. Sam, our information and referral coordinator, has planned some activities, such as organizing a walking club utilizing a pedometer to count steps, a hiking retreat in New Mexico and a retreat for Young Onset at Prairiewoods in Hiawatha Iowa. She is also helping to organize exercise classes for people with Parkinson's. These classes will target people with movement disorders. Our planned fundraisers for 2006 such as the National Walk-a-thon and the Golf-a-thon will also get us outdoors and moving.



Exercising sustains our ability to keep moving – if we don't use our muscles there is the risk that we will lose mobility. Walking also helps with gait, balance, depression and a host of Parkinson's secondary symptoms.

We are also busy setting up a reference manual by collecting current events and articles that will be available to answer the many questions that arise.

If you have any questions regarding any of the above mentioned activities or want some information that the support groups in your area need, please call us at 515-241-6379 or e-mail at [erwinjs@ihs.org](mailto:erwinjs@ihs.org).

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If you'd like to get involved in the Iowa APDA Chapter, contact Barbara Moore, via e-mail at [Barbara.moore@fblfinancial.com](mailto:Barbara.moore@fblfinancial.com), or write to Iowa APDA, PO Box 507, Waukee, Iowa 50263.

# Exercise and Parkinson's Disease

By Cheryl Suvic, Physical Therapist  
Iowa Health System-Des Moines

In my work as a therapist, I am more and more convinced of how important exercise is – not only to those suffering from Parkinson's disease (PD), but to all of us, including caregivers. I can almost see some of you grimacing and thinking, "Oh no, not this lecture again." But if your doctor offered you a pill that could give you more energy, make your muscles stronger and more flexible, help you control your blood pressure, lift your mood and fight depression, reduce your risk of heart attack and improve your balance without harmful side effects, would you take it? I'll bet you would and gladly pay top dollar for it, too!

Those are all benefits of a regular exercise program for PD individuals and caregivers alike. You should check with your physician before beginning any exercise program and a physical therapist can be helpful in designing your own personal program to address your specific needs. Some of the impairments associated with PD that an exercise program can address are rigidity-tightness and resistance to movement in muscles and joints, bradykinesia or slowness of movement, and impaired postural reactions causing increased loss of balance and falls.

A good exercise program has three basic components: stretching, strengthening and aerobic conditioning. Each component is important, and all are necessary to allow you to remain as active as possible. Stretching helps you fight against the rigidity and keeps your muscles and joints more flexible. Stretching also helps with posture, relaxation, circulation and helps protect against muscle sprains or strains. It should be done at least twice a day and always before other exercises.

Tips for stretching:

- stretch until you feel a gentle pull, not pain
- hold each stretch for 20-30 seconds and complete 3 repetitions
- DON'T BOUNCE
- combine stretches with breathing in and out
- support the area being stretched
- avoid pain

Strengthening is another important part of an exercise program. You can do strength training by lifting weights, using elastic resistance bands (i.e. TheraBand), or household items, such as soup cans or plastic bottles filled with water or sand. Some exercises don't need added weight – just your own body weight can be used as resistance for squats or prone on elbows.

You should avoid pain, perform the movement slowly, breathing in while performing the movement and

breathing out while relaxing the movement. Begin with weight that will allow you to perform 10 repetitions and gradually increase to three sets of 10 repetitions. Then increase the weight gradually. Strengthening exercises should not be done two days in a row, so skip a day or perform arm strengthening one day and work your legs the next. The benefits you receive from strengthening include stronger muscles to help you stand up straighter and get out of a chair more easily, decreased joint pain, and strengthening of bones, so if you do fall you will be less likely to break a bone.

The last component of a good exercise program is aerobic conditioning. This does not only mean running or fast-paced aerobics. It can mean anything you enjoy doing in which you are performing sustained movement with arms, legs, or both, for at least 15-20 minutes at least three times per week. Examples are walking, biking, water aerobics, dancing, swimming or household chores, such as vacuuming, gardening or yard work. Again start slowly and gradually work up to at least 20 minutes.

The benefits of conditioning are impressive. It will help strengthen your heart and lungs, improve your stamina, reduce stress, elevate your mood and aid in controlling your blood pressure and cholesterol.

How do you get started? Come up with a plan and try it for at least three months regularly. Results take time but see if you don't feel better. Exercise at a time when you are well rested and your medication level is at its peak. Wear loose comfortable clothing and good supportive footwear.

Remember the improvements will not happen overnight. Your muscles may be tired and slightly painful. If your fatigue lasts more than one hour afterward or muscle soreness lasts through the next day, your intensity needs to be decreased. However, don't stop, maybe miss a session, but get back to it. Expect good days and bad days, but stick it out. The benefits are well worth it!

Iowa American Parkinson Disease Association  
& Iowa Health-Des Moines

## Information at a glance

**Trip:** 6 days/5 nights  
**Dates:** Sept. 11-16, 2006  
**Trip Rating:** Moderately easy with moderate options  
**Cost:** \$1,995  
**Single Supplement:** \$550  
**Gateway City:** Albuquerque, New Mexico  
**Meeting Place:** Santa Fe, New Mexico  
**Activities:** Hike (5½ days)

A deposit of \$500 is due March 31, and the remaining amount of \$1,495 is due by June 1. The price of \$1,995 includes all meals from the noon lunch of the first day through the noon lunch of the sixth day.

Check out The World Outdoors Web site for other trip ideas; <http://www.theworldoutdoors.com/>. For additional information or questions call American Parkinson Disease Association Information and Referral Center; 515.241.6379



### From the APDA Web Master

Hello! I'm Steve Sanda, and I am the Web master of the new APDAIowa.org Web site. Sam and I have been working diligently over the past few months to collect useful information in a single and convenient location. The site is designed for ease in navigation to find resources, events and support groups. As Web master, it's my job to ensure the functionality of the site for all who visit. If there are any components of the Web site you feel can work better, or components that should be added, please let me know. You can email me at [web@apdaiowa.org](mailto:web@apdaiowa.org). I hope that as the Web site evolves we find more features to better serve our visitors – you!

### Resource Library

In the Information and Referral Center we are beginning a resource library of books, videos and other items for checkout. If you have a particular Parkinson's disease resource you would like to donate to the library please send it to:

APDA I & R Center  
Iowa Health-Des Moines  
1200 Pleasant Street, E-524  
Des Moines, IA 50309

A listing of these materials is available by request or on our Web site, [www.apdaiowa.org](http://www.apdaiowa.org).

### Reader's Corner

#### A Parkinsonian Prayer

*By Sister Mary Simone Wilmes, CHM  
Johnston, Iowa*

Pardon me, Lord  
Are you listening?  
Right now when I'm fearing the future  
Kindly ease the stress.  
I trust in your care for me.  
No one can know but me  
Such anguish I endure.  
O, be my strength,  
Never let PD keep us apart.

Doctors are working hard  
It is their endeavors which give us courage;  
Such talent they share with us.  
Every attempt is being made  
All research is giving us hope.  
So I ask for me and for them  
Every blessing only you can bestow on us  
Parkinsonians.

# The Role of Exercise in Parkinson's Disease

Lynn K. Struck, M.D.

## I. Introduction

- Exercise is important in maintaining your health.
- Always check with your physician before commencing any new exercise activity.
- Exercise can be completed sitting or standing.

## II. The Safe and Correct way to Exercise

- Always exercise at a time when you are well-rested and your symptoms are under control.
- Stretch, work at your own pace, and drink lots of water.
- **Stop** if you feel tired.

## III. Warm-up Exercises

- Get your body loose and relaxed.
- Move your body only to the point of resistance and take deep breaths.

## IV. Deep Exercise Moves

- Try deeper exercises to create strength and balance.

## V. Cool Down

- At the end of exercise, take a few deep breaths and relax.

## VI. Conclusion

- Good exercise can help you cope with Parkinson's disease by maintaining your mobility, vitality and stamina.



Parkinson's disease affects everyone differently. There are many treatment options and changes in lifestyle that can help better manage the disease, regardless of these differences. One option that is especially beneficial is regular exercise. It can help maintain flexibility, promote good posture, keep muscles strong and joints supple. Exercise also improves circulation to the heart and lungs and helps to deal with stress. Various exercises that can be beneficial include walking, riding an exercise bike or swimming. Yoga or Tai Chi focus on balance, flexibility and movement.

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## 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).

### Ames

Virginia Dowling  
515.239.2605

### Austin, MN

Ethel Mae  
507.437.4079

### Burlington, West

Sherry Engberg  
319.752.3359

### Carroll

Have location, need facilitator

### Cedar Falls

Young Onset  
Mark Ewing  
319.277.3939

### Cedar Rapids

Jackie Ryan  
319.369.8139

### Clarinda

Marilyn Bousch  
712.534.2545

### Clarion

Rodger Sumners  
515.532.2507

### Clinton

Don & Rita Schneider  
563.243.5585

### Davenport

Dot Christiansen  
563.332.5071

### Des Moines Area

Valerie Stickel  
515.643.2529  
Patrice Webber  
515.241.2445

### Des Moines

#### Young Onset

Sam Erwin  
515.241.6379

#### Dubuque

Jane Osterhaus  
563.582.7313

#### Exira

Carrie Jensen  
712.268.2653

#### Greene County/Jefferson

Linda Smith/Kathy Morain  
515.386.2114

#### Iowa City-Caregiver

[www.wellspouse.org](http://www.wellspouse.org)  
Rev. Liz Koffron-Eisen  
319.351.5476  
Stan Smith  
319.354.2952

### Fort Dodge

Bob Martin  
515.573.6707

### Mason City

Jennifer O'Gunderson  
641.421.2577

### Newton

John McConeghey  
641.791.4639

### Pella

Henry Schimmel  
641.628.3232

### Red Oak

M. Buckley

### Sioux City

Rosa Hobbs  
712.458.2198

### Waterloo

Nancy Hart - 319.235.3527

## Walking for Life

by Bob Moore

If you are not exercising regularly, start today! Exercise can help make living with Parkinson's disease easier by first helping you feel more in control of your movements. Regular exercise reduces gait problems and muscle and joint injuries, improves flexibility, increases muscle strength and balance, as well as increasing energy, stamina and cardiovascular health. An excellent form of exercise is walking while using a pedometer to track every step you take.

### Getting Started

**Clothing** – If you are walking on a treadmill, wear loose-fitting clothes. If you prefer to be outside, be sure to dress accordingly. If the weather is cooler, dress in layers so you can peel them off as you warm up. Don't forget sunscreen and a hat!

**Shoes** – A good quality athletic shoe that is cushioned in the heel and forefoot and is flexible is a must. Make sure it's not too tight because your feet will swell as you walk. Be sure to wear socks that wick away moisture and help prevent blisters.

**Water Bottle** – Drink before you start and always during your walk, more if you are sweating.

**Pedometer** – It is much easier to measure the number of steps you take than it is to measure how many miles you have walked. And it can be more encouraging, too.

**Chart** – Keep a daily chart to log your steps and show your progress.

### Workout

- If you haven't been very active, start slowly.
- Use your pedometer to track your steps each day.
- Record your total each day.
- Try to increase slightly your daily total. Set your goal at 10,000 steps and work to achieve your goal. Don't try to reach your goal all at once; increase your steps by 10 percent each week until you reach your goal.
- Once you reach your goal of 10,000 steps, you can raise the number of steps or stay at 10,000 and work to do it in less time.

## World Parkinson Congress Report

by Deb Wityk, Membership Secretary

**O**n Feb. 22, 2006, Sam Erwin and I started a five-day, nine-hour a day marathon of Parkinson information. We attended the World Parkinson Congress in Washington DC. Never before had the world community of people with Parkinson, their care partners, physicians, researchers, physical therapist, occupational therapists, nurses and other interested people come together in one place.

People came from all walks of life, at all stages of the disease, as presenters, and/or participants. There were physicians, lawyers, musicians, artists, teachers, researchers, actors, retirees, computer programmers, secretaries, mothers, fathers, sons, daughters, husbands and wives. This disease knows no limits. Michael J. Fox, perhaps the most famous person to have Parkinson's, spoke at the opening ceremony, and he made it clear that he will only be happy when there is a cure.

The difficulty I encountered was picking only one session at each time slot. Every imaginable topic was available ... from scientific information on genetics or environment, to motor or non-motor symptoms, advocacy, music and art therapy, complimentary medicine, deep brain stimulator, drumming, even sessions especially for the children of chronically ill parents.

I learned so much it has been hard to process all the information. I met so many new people with ideas well worth implementing. One of the most exciting ideas was the implementation of a national registry of people with Parkinson. That being said, it will probably be far in the future. Nebraska has started a registry, and California is also setting one up. I hope to see Iowa set up a registry, and I plan to work toward that goal. The facts gathered will help answer some of the questions about how many people have this disease, where we live, and most of all, hopefully, help to find a cure.

Educating ourselves and supporting each other in this cause can happen on many levels. The congress was at a level I can only hope everyone could experience, but we do have an opportunity to come together and learn at the Annual Seminar on June 30, 2006, at the Lutheran Church of Hope. SEE YOU THERE!



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. In 2004-2005, the APDA budget for research was more than \$2.5 million, plus APDA funded 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.

## SAVE THE DATE

Parkinson's Disease Patient Education Seminar, 12:30-4 p.m. Friday, June 30, Lutheran Church of Hope, 925 Jordan Creek Pkwy., West Des Moines, Iowa. Registration required. For more information, log on to [www.apdaiowa.org](http://www.apdaiowa.org)

I'm Dennis Neubauer, second vice president – programs for the Iowa Chapter of APDA. We have been given a room at the Seminar on June 30 to show arts, crafts and hobbies. With our work, we will show that we are still capable of doing many of the things that we did before we were diagnosed with PD. We've maybe made a few adjustments along the way, and we might be a little slower than before, but we still can make some beautiful things.

We're looking for other people who have Parkinson's who would like to share their art, craft or hobby and possibly inspire others to carry on. I carve – golf balls and wood – and I know there are others who could show their work, too. Let me know if you'd like to be a part of this inspiring show. Contact me at 515.265.4889 or [dennyknife@yahoo.com](mailto:dennyknife@yahoo.com).

You can make contributions to the Iowa Chapter by sending a check made out to Iowa Chapter APDA to APDA, PO Box 507, Waukee, Iowa 50263.

Your donations are used for the purchase of books and other resources, support for PD support groups, operating expenses for the Iowa chapter and research funded by the national APDA office.

**April is Parkinson's Disease Awareness Month**

### **Iowa American Parkinson Disease Association Information & Referral Center**

Iowa Health - Des Moines  
1200 Pleasant Street, E524  
Des Moines, IA 50309-1493

