

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.

Winter 2005

Carving for a Cause

Denny Neubauer of Des Moines has been carving miniature caricatures and Santas for 20 years. He has won many blue ribbons at the Iowa State Fair and other carving competitions. He also teaches woodcarving classes at his home studio in Des Moines. In 1983, Neubauer was diagnosed with Parkinson disease, and now he's carving for a cause – the Iowa Chapter of the American Parkinson Disease Association. He's currently vice president of the organization.

While his specialty is carving knives, Neubauer also carves golf balls. He first removes the hard, dimpled outer shell, and then carves intricate designs in the hard rubber core. For a \$15 contribution to the Iowa Chapter of APDA, you can have one of his fanciful and fun carvings. They make interesting holiday ornaments, as well as desk decorations. For more information about Neubauer, go to www.dennyknife.com. You can e-mail him at dennyknife@yahoo.com.

Pictured here are just three of many designs available, and each one is unique, as it is hand-carved. Top, is an acorn and leaf motif; in the center, a winter snowflake, star and tree design; and bottom, an angel. He's also carved logos for teams and businesses.



10 Tips for Family Caregivers

1. Choose to **take charge** of your life; don't let your loved one's illness/disability always take center stage.
2. Remember to **be good to yourself**. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
3. **Watch out** for signs of depression, and don't delay in getting professional help when you need it.
4. When people offer to help, **accept the offer** and suggest specific things that they can do.
5. **Educate yourself** about your loved one's condition. Information is empowering.
6. There's a difference between caring and doing. **Be open to technologies and ideas** that promote your loved one's independence.
7. **Trust your instincts**. Most of the time they'll lead you in the right direction.
8. Grieve for your losses, and then allow yourself to **dream new dreams**.
9. **Stand up for your rights** as a caregiver and a citizen.
10. **Seek support** from other caregivers. There is great strength in knowing you are not alone.

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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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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

Being Thankful ... as the year comes to an end it is important for us to thank everyone around us. Roger Summers, the Clarion support group facilitator, felt it was important for me to realize that without his wife's support he would be nowhere. Margaret Summers supports and assists with the coordinating of not only the support group but Roger's life. She has stood at his side as a partner, protector and, most importantly, a friend. They share a history of ups and downs, laughter and tears, and quiet moments. November was Caregiver's month. It's important to note that the care given by family members or friends does not end.

With that in mind take a moment to read the 10 Tips for Family caregivers in this newsletter and know we thank you.

From the Iowa APDA Chapter President – Barbara Moore

Happy Holiday Season ... As we go into the holiday season, some of us find that we become a little more emotional and need a little more support – from family and people who understand how Parkinson's affects our lives. Please remember that you are not alone. There are several support groups throughout Iowa, and they are there to help you and your family – that's their express purpose for existing. And the bonus is as they are helping you they are helping themselves as well.

As we plan for next year we are excited about working with Sam Erwin, coordinator of the APDA Referral & Information Center. She has some really great ideas to help us ease the burden of Parkinson's.

Happy Holidays!



Consider an end-of-year gift to the Iowa APDA Chapter. Your gift can help "ease the burden and find the cure," and it might help ease your 2005 tax burden, too, because your gift is likely tax-deductible. Send a check made out to
Iowa APDA Chapter to
APDA
PO Box 507
Waukee, Iowa 50263.



Iowa APDA Educational Supplement

Speech Therapy and Parkinson's Disease

Michelle McGregor, Speech-Language Pathologist
Iowa Health System-Des Moines

Since arriving at Iowa Methodist Medical Center five and half years ago I have been specializing in working with voice disorders. I work with area otolaryngologists and neurologists to assist patients with improving their vocal quality and overall communication. People with Parkinson's disease (PD) usually experience specific symptoms that affect communication. The main symptoms that are associated with Parkinson's disease that you may recognize are:

- Decreased volume
- Imprecise articulation
- Change in speech rate
- Monotone pitch
- Hoarse vocal quality
- Increased effort to talk

These problems can all be improved through speech therapy. There are specific exercises that a speech-language pathologist can teach you to increase volume, improve articulation, adjust speech rate and improve pitch and overall voice quality.

If you are not sure if you are experiencing any of these problems you may want to ask yourself:

- Am I asked to repeat what I say often?
- Am I asked to talk louder or "speak up"?
- Am I asked to slow down when talking?
- Do I feel like I'm running out of breath when talking?
- Are others asking me not to mumble when I talk?
- Do I feel like everyone I talk to has a hearing loss?
- Do I avoid talking

If you can relate to any of these questions it may be time for you to talk with your physician about participating in speech therapy. As a speech therapist I feel therapy can be beneficial even when experiencing subtle changes in one's voice. If you address these subtle changes and begin to work on your speech early in progression of the disease you will know how to work on maintaining your best voice and overall communication throughout the disease process.

Drugs Contraindicated for Parkinson's Disease Patients

Lynn K. Struck, M.D.

Often receive questions from patients about what medications they can safely take with their PD. In PD there are several medications that are not recommended. The term “contraindicated” means that the drug in question should not be given to a patient with PD. Many drugs alter the brain’s dopamine system and may not be recognized as having a potential detrimental effect on PD simply because the drugs are used for the treatment of other conditions. If you are taking one of these medications do not abruptly stop the medication, but discuss this with your treating physician. There are certain situations where these medications are required in PD patients.



Drug Category	Trade name	Generic Name
Antipsychotic	Haldol Trilafon Thorazine Stelazine Prolixin, Permitil Navane Mellaril Loxitane	Haloperidol Perphenazine Chlorpromazine Trifluoperazine Fluphenazine Thlothixene Thioridazine Loxapine HCl
Antidepressant	Triavil Ascendin Nardil Parnate	Combination of Perphenazine & Amitriptyline Amoxapine Phenelzine Tranylcypromine
Nausea/Vomiting	Compazine Reglan Torecan Phenergan	Porchlorperazine Metoclopramide Thiethylperazine Promethazine
Miscellaneous, Blood pressure, Post-op Medications	Serpasil Moderil Aldomet Lithium	Reserpine Rescinnamine Alpha-methyldopa None
Narcotic, Analgesic	*Demerol	Meperidine
*With Selegiline treatment		

A Run for my Dad

By Laura Coleman-Henderson
Cedar Rapids

The day of April 23, 2005, seemed to fly by faster than any other day of my life. It all started the summer before when I realized that whatever is your passion, it must be close to your heart.

My father was diagnosed with Parkinson's disease about 13 years ago. My role back then was to be supportive and learn about this mysterious disease. If you have watched the Oprah show, you know that I mean when I say. I finally had a "light bulb" moment. I am a runner and I love it! I look forward to putting on my running shoes and taking off. I sign up for all sorts of runs in the Cedar Rapids or Iowa City area. These races always benefit a foundation, disease or wonderful cause. The light went on for me, and I got in touch with Sam Erwin and Barbara Moore to tell them I would like to organize a Parkinson's awareness run and why it meant so much to me. Thankfully, they believed in my idea too.

Letters went out, volunteers were rounded up, and donations were collected. Barbara was told that all was going according to plan, registration brochures and press releases were developed, shirts were printed, the city trail was reserved, the course was determined. Entry forms began to arrive and last minute details were handled. April 23 arrived, and on that day, we raised money, awareness (and hope) in the Linn County area.

April 22, 2006, is the second annual Parkinson's 5K Run/1.5 Fun Walk. I look forward to the whole process of planning again, because it is a cause that is close to my heart and to the hearts of many others also.

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.

Ames
Virginia Dowling
515.239.2605

Clarion
Rodger Sumners
515.532.2507

Dubuque
Jane Osterhaus
563.582.7313

Mason City
Jennifer O'Gunderson
641.421.2577

Austin, MN
Ethel Mae
507.437.4079

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Don and Rita
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563.243.5585

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Carrie Jensen
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Newton
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641.791.4639

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563.332.5071

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Linda Smith/Kathy
Morain
515.386.2114

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641.628.3232

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Sara Fleecs
712.792.6974

**Des Moines
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515.643.2529
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Iowa City-Caregiver
www.wellspouse.org
Rev. Liz Koffron-
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319.351.5476
Stan Smith
319.354.2952

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M. Buckley

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Jackie Ryan
319.369.8139

Sioux City
Rosa Hobbs
712.458.2198

Clarinda
Marilyn Bousch
712.534.2545

**Young
Parkinson**
Des Moines
Sam Erwin
515.241.6379

Lehigh/Fort Dodge
Bob Martin
515.576.0777

Waterloo
Nancy Hart
319.235.3527 or (3590)

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Information on Parkinson's Disease

Single copies of the following publications may be obtained free by writing to the Iowa Information & Referral Center or by calling 877/872-6386 or via fax at 515/241-6393.

Educational Booklets

1. **Basic Information about Parkinson's Disease**
Parkinson's Disease Handbook
2. **PD 'n' Me – Coping with Parkinson's Disease**
3. **Be Active**
4. **Be Independent**
5. **Speaking Effectively**
6. **Good Nutrition in Parkinson's Disease**
7. **Young Parkinson's Handbook**
8. **How to start a Parkinson's Disease Support Group**
9. **Aquatic Exercise for Parkinson's Disease**
10. **My Mommy Has PD ... But It's Okay!**

Check out the APDA Web site at

www.apdaiowa.org for information about chapters, support groups, information & referral centers, clinical trials, publications, and numerous other resources.

Did you know?

- Parkinson's disease is a progressive disorder of the central nervous system affecting more than 1.5 million people in the United States.
 - In the 1960s, pathological and biochemical changes in the brains of patients were identified, opening the way to the first effective medication for the disease.
 - The frequency of the disease is considerably higher in the over-60 age group, even though there is an alarming increase of patients of younger age.
 - The American Parkinson Disease Association, Inc., founded in 1961, has sought to "Ease the Burden and Find the Cure" for this disease through research, patient and family support and education.
 - The APDA research program funds five types of grants:
1. **The Roger C. Duvoisin, MD Fellowship**, established in 2002, carries a stipend of \$80,000 for one year and is intended to support established researchers in Parkinson's disease studies.
 2. **The Cotzias Fellowship**, awarded to young neurologists for three consecutive years, with yearly stipends of \$70,000.
 3. **Research Grants** of up to \$50,000 a year are awarded to scientists working on Parkinson's disease.
 4. **Post-Doctoral Research Fellowships** of \$35,000 a year.
 5. **Medical Student Fellowships** in the amount of \$4,000 each per year.
- APDA also funds eight Centers for Advanced Research in institutions across the country at a level of \$100,000 a year for five consecutive years. More than \$2.3 million is allocated annually to support research projects

Thank You to Our Donors – *continued from page 6*

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

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 2004-2005 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.

Video Available



On July 13, the annual seminar was held at the Lutheran Church of Hope in West Des Moines led by Dr. Lynn K. Struck.

If you are interested in receiving a copy of the video and handouts of the July 13 seminar, please contact Barbara Moore at 515/993-5056 or 515/226-6803

Checkout our Web site

Check out our Web site www.apdaiowa.org. It is in need of information from your area, such as stories of individuals with Parkinson's disease, their challenges, poetry, artworks and hobbies.

Save The Date

The second annual APDA Fun Walk and Run will be held April 22 in Cedar Rapids . Watch for details in the spring 2006 issue of *The Informant*.

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.

Iowa American Parkinson Disease Association Information & Referral Center

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