

# Parkinson's Perspective

A newsletter from the UW Health Movement Disorders Program

## *From the Editor's Pen . . .*

A new medication may be approved this year for the treatment of Parkinson's disease. This new medication, called rasagiline, is an inhibitor of a brain enzyme called monoamine oxidase type B similar to selegiline (trade name Eldepryl). Rasagiline can improve the symptoms of Parkinson's disease, but the exciting possibility is that it may help to slow the progression of Parkinson's disease. In other words, rasagiline may be neuroprotective by slowing the loss of dopamine neurons from the brain.

To some readers, this may sound like déjà vu. Many years ago, many in the medical community hoped selegiline would slow the progression of Parkinson's disease and indeed, initial studies strongly suggested that it did. However, there was a controversy: whether the apparent neuroprotective effects were really due to improvement in the symptoms of Parkinson's disease or due to actual slowing of the loss of dopamine neurons. In the "fine print" of the original article, those patients whose symptoms did not improve on selegiline still had a slower rate of symptom progression compared to placebo (a

"sugar pill"). This suggests that the slower rate of progression was not simply due to improvement in symptoms.

For many neurologists, selegiline fell out of favor and was not prescribed. Some physicians, like

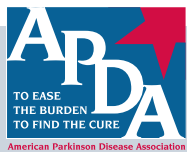
myself, continued to prescribe it because it was very well tolerated and relatively inexpensive. Thus, there seemed to be relatively little downside to taking the selegiline, and there was at least the possibility that selegiline would slow the progression of the disease.

In one clinical study, one group of patients was started immediately on rasagiline and another group started on placebo. During the first six months, the symptoms for those on the placebo got worse faster than those on rasagiline. When the group that was initially started on placebo was subsequently started on rasagiline, their symptoms improved but not to the same degree as those on rasagiline from the beginning. This suggests — but does not prove — that rasagiline may have some neuroprotective effect. If the improvement on rasagiline was only because the symptoms got better, than the group that was started on rasagiline six months later should have improved to the same degree as those on rasagiline from the beginning. This was not the case.

The question now is what to do about selegiline, both now and when rasagiline is approved by the FDA for general use. The suggestion that rasagiline may be neuroprotective suggests that monoamine oxidase type B inhibitors, in general, may have neuroprotective effects. At the least, this suggests that physicians should consider the use of selegiline in those newly diagnosed or mildly affected by Parkinson's disease.

Whether rasagiline is more effective than selegiline is an open question, and whether those patients on selegiline should be converted to rasagiline is unclear.

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### *Parkinson's Perspective*

is published three times a year for Parkinson's patients, their families and caregivers. It is produced by the UW Health Movement Disorders Program with the financial support of the American Parkinson Disease Information and Referral Center. If you no longer wish to receive this newsletter, please call 608/263-7991.

# Support Groups: *A Matter of Support and Understanding*

By Jessica Hahn

Whether you are newly diagnosed or have years of diagnosis under your belt, you might find value in a support group as a way to learn about the latest on Parkinson's Disease and to talk to others who are experiencing what you are.

A person with Parkinson's Disease will gain some information about treatment from their neurologist, but unless that neurologist has Parkinson's, he or she cannot really know the extremes that one may have with this debilitating disease.

This is when a support group comes in handy. Many people have mentioned that sometimes they can't get all their questions answered from the neurologist because there is not enough time. A support group can help a person with this, because remaining questions can be asked at the meeting to see if and how others found a workable answer. This way, people have a better understanding about what they are going through so they don't have unmanageable fear about the disease.

Support groups help people develop a better attitude about Parkinson's Disease, because they know where to turn for information. Having a great attitude about the disease helps people do better with the disease process.

Support groups help people with Parkinson's no matter what stage they are in with this disease. People have mentioned to me that, when they are first diagnosed with Parkinson's, it is hard for them to go to a group because they don't want to see what can happen to them. But this is when a group can be the most beneficial because it will help them gain information about what they have and not be so confused about it.

As stated in the booklet, "How

to Start a Parkinson's Disease Support Group" by the American Parkinson's Disease Association, "the basic goals of support group members are to offer friendship, support and encouragement to one another, and to gain as much information as possible." I find this to be true. Of the support groups I lead, I find friendships being born and people being there for one another through difficult times in their lives. I know people from the various groups will even call each other if they need to just sit and talk to someone.

These groups aren't just for the patients but for caregivers, family and friends as well. Everyone involved with this disease can benefit from a support group. It allows people to let out frustrations so that they don't end up blowing up and ruining relationships. People are able to communicate better to one another. Caregivers, family members and friends will also gain a better understanding about the disease and what the patient is going through. We encourage everyone to keep in mind that it may take a person time to open up at a support group. But when a patient does give it time, the group can become so helpful with getting him or her through some of the unknowns with this disease.

Not all support groups are the same. Some are strictly educational; where speakers come in and discuss a particular topic related to Parkinson's Disease to help a person become more educated. Some are strictly support groups; where they offer support between the members to gain information. Others provide a mix of support and education

Some people have a preference as to the type of group they would like to belong to. If you go to one group and it doesn't suit you, try a

different one until you find the group that suits you. A group should work for you since you are the one needing support and help. If you are going to a group that doesn't suit you and there are no others around, I would be happy to help you set up a new group.

If something isn't helping you in the group you attend, don't hesitate to go up to the facilitator to offer suggestions or mention your concerns. Maybe others are having those same concerns, and the group can work through them to help you out. I want people to come up to me to offer suggestions on what you want with the groups I facilitate; I am not the one going through what you are, and I want to help you as much as I can.

I cannot stress enough the importance of a support group to help get through this debilitating disease. There is always something new that emerges as people learn to cope with Parkinson's. Remember: a support group will help a person have a positive attitude with the disease. Please consider attending one so you have a better understanding about the disease and have a better quality of life with it.

*For support group information in your area, please contact Jessica Hahn at 608.263.2991 or [hahn@neurology.wisc.edu](mailto:hahn@neurology.wisc.edu).*

## *Editor's Pen . . .*

*continued from page 1*

Clinical trials clearly demonstrate that even if not neuroprotective, rasagiline improves the symptoms of Parkinson's disease. Clinical experience suggests that selegiline improves symptoms only modestly. Unfortunately, there is no study that directly compares selegiline to rasagiline and it's unlikely that there ever will be. Consequently, patients and caregivers are left to their own judgment in consultation with their physician as whether selegiline or rasagiline is preferable. Always looming in the background is how much of this decision will be determined by insurance companies.

Sincerely,



Erwin B. Montgomery Jr. MD

***After this letter was written, rasagiline (AZILECT) was approved by the Food and Drug Administration. After this letter was written, rasagiline (AZILECT) was approved by the Food and Drug Administration.***

## Meet the Staff

I would like to introduce you to the director of the movement disorders program at UW Hospital and Clinics:

### **Erwin B. Montgomery, Jr., M.D.**

He received his B.S. in biochemistry in 1972 and four years later received his medical degree from State University of New York. After receiving his medical degree, Dr. Montgomery did a fellowship in the Laboratory of Neurophysiology at State University of New York. He then followed up with another fellowship at Washington University in motor neurophysiology and movement disorders.

When Dr. Montgomery first started his career, he was a research instructor, assistant neurologist and medical director of the American Parkinson Disease Association (APDA) Information and Referral Center at Washington University in St. Louis. From there he went to Tucson, AZ and became the medical director of the APDA Information and Referral center, faculty member, associate professor



***Erwin B. Montgomery, Jr., M.D.***

and consultant to the National Center for neurogenic communications disorders. 1997 brought another move for Dr. Montgomery when he went to the Cleveland Clinic and became a staff neurologist and clinical professor of medicine (neurology), medical director of the APDA Information and Referral Center and director of the movement disorders program. In that year, he also became a member of the Scientific Advisory Board for the APDA and continues to serve on that board. After five years at the Cleveland Clinic, Dr. Montgomery decided to move to Wisconsin when his wife was offered a job here. He is now working as the director of the movement disorders program and medical director of the APDA Information and Referral Office.

Besides these roles, Dr. Montgomery is involved with research for Parkinson's Disease at the National Primate Research Center at UW-Madison. The research he does with monkeys is to try to find a cure for Parkinson's Disease. He uses monkeys because they are the closest animal model to the human race.

Dr. Montgomery is a busy man with seeing patients, research and traveling to give talks to groups about the latest on Parkinson's Disease. It's a wonder that he has time for himself. We are glad to have Dr. Montgomery as a part of this great team!

# Parkinson's Walk-A-Thon a Big Success

The first local Parkinson's Walk-A-Thon held on April 2<sup>nd</sup> at East Towne Mall was very successful. Sponsored by local firms and individuals, the event was organized by the newly formed Wisconsin Chapter of the American Parkinson Disease Association (APDA) and the APDA Information and Referral Office located in Madison. More than \$15,000 was raised, all of which goes directly towards research to help find a cure for this disease.

**Walk Coordinators** – Tim Martinson and Jessica Hahn

**Volunteers** — Angel Hodsdon, Gwenn Davies, Linda Martinson, Lindsey Schultz, Christa Gustafson, Pam Crapp, Lynn Freimuth, Guy Ferris, Jan Ferris, Bill Freimuth, Floyd Carlstrom, Gary Crapp, Sandy Dorshak, Linda Jackson, Julia,

Michelle McNeil, Dave Davies, Julie Cabbage, Timara Budack

**Corporate Sponsors** — High Energy Mobile DJs, East Towne Mall, Novartis, Medtronic, Allergan, Teva Neuroscience, Research Products, Dale's Service & Refrigeration, Rubicon Systems, Inc, American TV, Carlstrom Parts, Riley Tavern, State Bank of Cross Plains, Rural Insurance, Mortinson, Matzelle & Meldrum, Capitol Underground, Smith Service Center, Advance Dry Carpet, Door Creek Dental

**Special Donations** — E-Pill.com, Bagels Forever, Panera Bread, Village Hearth, Auntie Anne's, Coke, Rejuvenation Salon, Zimbrick, John Lancaster Toyota, Condon Jewelers, G. Heideman Gallery, Exclusive Company, Parkinsonian Publications, Lenscrafters, Into The Woods, Group

Health Cooperative, Steak Escape, Culvers, Outback Steakhouse, Red Lobster, Prairie Athletic Club, Studio FX, Quizno's, Prairie Lanes, Steve & Barry's University Sportswear, Milios, Fanny Garver Gallery, Wal-Mart, Meeting Life's Challenges, Family Video, Hobby Lobby, Princess of India, Wild Birds Unlimited, Little Luxuries, Soulman, Java Bay, Tropic Jewel, Double Take Salon, Shakti, Community Pharmacy, Peacock, Sunshine Daydream, Studio K, Pick N Save, Star Cinema, Ryan Hair Designs, Rogers and Hollands, Kirlin's Hallmark, Michael's Frozen Custard, PDQ, Kathleen Kocs

**Thank you** to all who participated to make this such a successful walk. Plans are already underway for next years event scheduled to be held April 15, 2007 at East Towne Mall.

## The Reason We Walked

*"To Ease the Burden To Find The Cure"*

*If we left a loved one out or you want to add someone,  
please let us know.*

### ***Walked for in Memory of***

Amos Nelson  
Andy Mijokovic  
Canon Rev Karl Hansen  
Charlie Doll  
Clifford J. Pfeifer  
Clifford Nyhus  
Don Schermetzler  
Donald Misbauer  
Eugene Kocs  
Gerth & Florence Hendrickson  
Gr. Gr. Ma Nina Schwartz  
Harold C. Berghammer  
John Snyder  
Kathleen Lynch  
Keven Jones Lynaugh  
Lea Hendrickson  
Margaret Stolen  
Melvin Breunig  
Nina Schwartz  
Norman Goldberg  
Russell H.  
Sophia Evreniadis  
Thomas J. McCann  
Tom C. Brown  
William Fagerstrom  
Russell H. Stehr  
Angie Vanden Heuvel

### ***Walked for in Honor of***

Brandi Cooper  
Canon Rev. Karl Hansen  
Cathi Kocs  
Charlie Getka  
Cheryl Rykken  
Dale Carlstrom  
Darlene Liptow  
Deborah Kassulke  
Don Behnke  
E. Stony Steinbach  
Ed Wittlin  
Frank Brady  
Gary Crapp  
Gordon Schultz  
Grandpa Edmund Anderson  
Katherine Kocs  
Kathi Kocs  
Lea Hendrickson  
Linda Martinson  
Mark Getka  
Marty Hansen  
Mike Herman  
Nancy Ninmann  
Paul Pfeffer  
Robert Auchter  
Sandy Dorshak  
Tony Hamann

# A Great Success!!

By Jessica Hahn, APDA Coordinator

I can't thank everyone enough for the hard work and dedication put into the first annual Parkinson's disease Walk-A-Thon. This includes volunteers and of course all the people who turned out to join us for this great event. Because of all of you, we have raised more than \$15,000 for research to help find a cure for this debilitating disease.

People of all ages showed up to help us in our efforts. Helping us start the event, Senator Mark Miller said a few words and then told everyone to start their engines and start walking. After a couple of laps around the mall, UW's lively Bucky Badger and the UW Cheerleaders showed up to keep people revved up and walking. They did cheers and flips and Bucky even stood on his head. After the flips and cheers were done, members of the American Family Insurance Choir sang for the crowd. Their performance was great and well received by everyone.

In the mist of all the entertainment and walking, we also had a DJ from High Energy Mobile DJs come and entertain the walkers while they were walking. All this entertainment helped make for a great event. But let's not forget why we were there: to walk and raise awareness about Parkinson's disease.

Everyone was at the event for a reason. If it weren't because the walker has Parkinson's disease, it was because a family member or a friend has it. "I was walking in memory and honor of my grandpa Lea Hendrickson who had Parkinson's disease. He passed



away in 1997," stated Erik Hendrickson who walked 26 laps for 2006.

I would especially like to thank Tim Martinson and the Wisconsin Chapter for all the hard work put into this event. A big "THANK YOU" goes out to all the sponsors, especially East Towne Mall, who helped us put this event on. Without all this help/support, this event would not have been possible.

Mark your calendars for next year's walk, which will be Sunday, April 15, 2007.



# Save the Dates

Check out [www.apdawi.org](http://www.apdawi.org) for more information or contact Jessica Hahn at 608.263.7991

1 <sup>st</sup> Thursdays of the month	Young Parkinson's Support Group	UW Hospital G5/152	6–8 pm
2 <sup>nd</sup> Wednesdays of the month	Support Group	Fitchburg Senior Center	1–3 pm
3 <sup>rd</sup> Mondays of the month	Support Group	Baraboo	2–4 pm
3 <sup>rd</sup> Thursdays of the month	Support Group	Madison	7–9 pm
4 <sup>th</sup> Mondays of the month	Support Group	Sun Prairie	1–3 pm
4 <sup>th</sup> Wednesdays of the month	Support Group	Stoughton	1–3 pm
September 23, 2006	Parkinson's Disease Public Lecture	Holiday Inn, Stevens Point	1–4 pm
October 1, 2006	Parkinson's Disease Public Lecture	Health Sciences Learning Ctr. (Connected to UW Hospital)	1–4 pm
April 15, 2007	Parkinson's Disease Walk-A-Thon	East Towne Mall, Madison	

## Additional Help

Looking for a place to feel like you're making a difference? Know of someone who is a go-getter? Then look no further to the Wisconsin Chapter of the APDA. You may be thinking that only people with Parkinson's disease or caregivers can join, but that is not the case. Anyone can join this great cause of promoting awareness and helping ease the burden of Wisconsin's Parkinson's population. More than just the patient and caregiver are affected by Parkinson's disease. You have to take into account their family and friends and we want to help educate everyone so they know more about Parkinson's disease. If you would like more information about this great chapter, please email [apdawi@gmail.com](mailto:apdawi@gmail.com) or contact Jessica Hahn at 608.263.7991. I hope you consider joining this great effort of "Easing the Burden to Find a Cure."

## Annual Public Lecture in Madison

**Where:** Fitchburg Senior Center

**When:** October 1, 2006  
1–4 pm

**Where:** Health Sciences Learning Center, UW  
750 Highland Ave,  
Madison

This event is for everyone to learn more about Parkinson's Disease

## Have You Had Parkinson's Disease for at Least Five Years?

If you or a loved one answers yes, you may be interested in learning about a new clinical research study in Parkinson's disease called STEPS.

Rush-Presbyterian—St. Luke's Medical Center in Chicago is conducting the STEPS clinical research study to evaluate a new treatment being developed for Parkinson's disease. To participate in the study, you must be between the ages of 30 and 70, have had Parkinson's disease for at least five years and currently experience insufficient control of your Parkinson's disease symptoms even with optimal oral medical treatment.

If you are interested in potentially participating in STEPS and would like more information, take the first STEP and call 1-866-STEPS-03 (1-866-783-7703)

## Support Group Now in Fitchburg

**Who:** Parkinson's patients, caregivers and their family

**What:** Support group to come and talk to each other about their disease and what's going on

**Where:** Fitchburg Senior Center  
5510 Lacy Road  
Library  
Fitchburg, WI

**When:** 2<sup>nd</sup> Wednesday of every month at 1pm

**Contact:** Jessica Hahn at (608) 263-7991 or [hahn@neurology.wisc.edu](mailto:hahn@neurology.wisc.edu) for further information.

## Interested in becoming a Support Group leader?

We do have areas of the state that do not have any nearby support groups. If you or someone you know is interested in helping to organize a support group, call Jessica at the I & R Office at 608-263-7991 and she will get you on your way to facilitating a successful group! If you are looking for information on a support group close to you, please call the office as well.

## Subjects with ALS or Parkinson's Disease Needed for Speech Research

### ***If you are...***

- between ages 40–70
- native speaker of English
- diagnosed with ALS or Parkinson's disease and having trouble with speech

You are invited to participate in a research study of speech movements.

Please contact the X-Ray Microbeam Speech Production Research Study

(608) 265–5282 – Shevawn Leahy  
(608) 263–5048 – Carl Johnson  
Waisman Center  
University of Wisconsin  
1500 Highland Avenue  
Madison, WI 53705–2280

A fee and travel expenses will be paid. Research procedures have been reviewed and approved by the University of Wisconsin–Madison Health Sciences Human Subject Committee.

## Please help us update our mailing list!!

If you have permanent address change or know of someone who would like to be added to our list, please complete the information below and return to the address shown below.

New Address

Add to your list

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip Code: \_\_\_\_\_

Phone Number: \_\_\_\_\_

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Mail to:  
Jessica Hahn, Coordinator  
600 Highland Avenue  
H6/569 CSC  
Madison, WI 53792-5132

# Questions & Answers

This section is devoted to answering your questions. If you have any questions about Parkinson's care, please send them to Jessica Hahn know at [hahn@neurology.wisc.edu](mailto:hahn@neurology.wisc.edu), or mail them to 600 Highland Avenue, H6/569 CSC, Madison, WI 53792-5132.

**Q: Please explain the symptoms of Atypical Parkinson's disease.**

**A:** Atypical means that it is not typical or not usual. In the context of PD, it means a form of PD other than the common idiopathic PD. You may have the inability to look up and down; your blood pressure can plunge just by standing up; the conditions are symmetrical instead of just happening one side at a time; and there is a tendency for hallucinations and seizures.

# Here to Serve You!

The American Parkinson Disease Association Information and Referral Office is here to serve you. It provides information in a variety of ways: books that the APDA gives out at no charge to anyone looking for more information; information on support groups around Wisconsin; lists of neurologists who help PD patients; and information on respite care in the Madison area. Our mission is to “find a cure, ease the burden”—and that is what we want to do: ease as much of the burden as we can. Please contact Jessica Hahn at (608) 263-7991 or [hahn@neurology.wisc.edu](mailto:hahn@neurology.wisc.edu) for further information.

This newsletter is intended for educational purposes only and should not be interpreted as providing medical recommendations. Patients are advised not to change their treatment without the advice and consent of their treating physician. The editor of the newsletter is solely responsible for its content.

**UWHealth**

A Parkinson's Publication  
Movement Disorders Program  
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