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# Parkinson's Perspective

A newsletter from the UW Health Movement <sup>L</sup>Disorders Program

# From the Editor's Pen . . .

Readers of this newsletter probably know better than most about the limitations of our current treatments for Parkinson's disease. While most patients achieve marked improvement with current treatments, for some the improvement is temporary, and still there is no cure or prevention. The answer for stopping Parkinson's disease will only come from research. And it is a matter of historical fact that research in monkeys has been critical to the advances since 1980 and is still critical for any future advances.

Unfortunately, there is a minority that wants to take away the hopes of Parkinson's disease patients, family members, and all those who care about the patient. The reader may know these people as "animal rights activists". But those who seek to ban all animal research-particularly those who act illegally to do so-are actually anti-patients' rights. Clearly, animals used in research need to be protected and strong laws are in place to protect animals from unreasonable use. But the animal liberators are not satisfied and seek to stop, by threats and intimidation, what they could not halt by reasonable laws and regulations. They seek to embarrass scientists and technicians directly. They recently have threatened anyone who might be indirectly associated with animal research, including companies that do the laundry.



**Parkinson's Perspective** is published quarterly 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. The animal activists say that animal research, particularly studies involving monkeys, is unnecessary. They say such research does not translate into better treatment for humans. This is not true for research in Parkinson's disease.

Prior to 1980 we had treatments only to improve the symptoms of Parkinson's disease. Before 1960, the only medications were relatives of the belladonna plant extracts. The dramatic breakthrough was the discovery that patients with Parkinson's lost neurons that make dopamine and that levodopa (the active ingredient in Sinemet) could improve similar symptoms in rodents. Since 1980, scientists and physicians have made dramatic advances. For the first time we have medications like selegiline and rasagiline that may slow the progress of Parkinson's disease. We have deep brain stimulation (DBS), particularly of the subthalamic nucleus, which provides help when medications fail. We now understand a great deal more about what may cause the complications sometimes associated with medications.

What happened in 1980 that resulted in such dramatic breakthroughs? The answer is clearly the discovery of the neurotoxin called MPTP. Scientists are able to create animal models of Parkinson's disease, allowing them to better understand its cause and how to stop it. Interestingly, MPTP was first discovered to produce a form of Parkinson's disease in humans. Intravenous-drug abusers in the San Francisco area were injecting themselves with what they thought was a synthetic form of Demerol, a narcotic pain reliever. However, the manufacturers produced MPTP and the drug users developed a severe and irreversible form of Parkinson's disease.

Scientists subsequently injected rodents and other laboratory animals with MPTP in an attempt to produce the animal model, but they all failed. Researchers were about to give up when scientists, as a last resort, injected the MPTP into monkeys and only these animals developed Parkinsonism. We now know that other animals can be made parkinsonian, but had it not been for the research in monkeys, all the benefits from MPTP research would have been lost.

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# Genetics and Parkinson's Disease

#### Cathy Gallagher MD Erwin B. Montgomery Jr. MD

We still don't know what causes Parkinson's disease for the majority of those who get the illness. Leading theories include a genetic predisposition or exposure to something in the environment. More likely, it will be a combination of both.

However, for a few families, a genetic cause has been discovered. Genes are the blueprints for building human beings and everyone gets two sets, one from each parent. Abnormalities in the genes or blueprints can result in abnormal function, leading to disease.

At least nine genetic defects have been identified, but their direct relevance to the majority of Parkinson's disease patients is unknown. The first genetic abnormality discovered was the gene that is the instruction for a protein called alpha-synuclein. The precise role that alpha-synuclein plays in the brain cell is unknown, and therefore how abnormal alpha-synuclein affects brain cell function also is unknown.

Other genes found to be abnormal in certain families with Parkinson's disease include a group

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Jennifer

called the Parkin mutations, which appear to affect a system called the ubiquitin system. This system is important for the health of the brain cell. The ubiquitin system is like the "garbage disposal" of the brain cell it gets rid of old proteins, which are the building blocks of brain cells. One of the ways that the Parkin gene mutations may cause Parkinson's disease is by reducing the ability of this system to get rid of the old proteins, which then can accumulate in the brain cell and cause damage. In fact, the Lewy body, which is the telltale finding in brain cells from persons with Parkinson's disease, contains old proteins combined with ubiquitin. Interestingly, alpha-synuclein (described above) is a component of the Lewy body. If these theories prove true, then it may be possible some day to prevent the accumulation of these old proteins in brain cells and maybe prevent Parkinson's disease.

The Parkinson's disease caused by these known genetic abnormalities is a bit different from the common type of Parkinson's disease. For example, nearly 90% of those patients with the genetic form have symptoms before age 30, whereas

### Meet the Staff



Jennifer Winchell

and Clinics. With a master's degree in science from UW–Madison and five years of nursing experience, she loves the patient contact portion of her job. "There are a wide variety of patients and two people are never the same," she notes. She enjoys educating patients about their disease and the treatment options available for them.

Jennifer is new to the nurse practitioner field, but by no means to neuroscience. Before joining our program, she worked as a staff nurse on the neuroscience unit. From there, she worked on the general care floor and in the ICU before joining this elite group. After working in the ICU, Jennifer learned that a position in the neurosurgery department became available and she decided to snatch it up. She is happy she decided to take the position in neurosurgery because she enjoys working with the patient population.

fewer than 10% of patients with the common form are diagnosed before age 40. Most patients with the genetic form of Parkinson's have several family members who are also affected. For these reasons, we generally do not recommend genetic testing for patients with Parkinson's disease or their family members.

It is understandable that the possibility of a parent passing on the risk to their children can be upsetting. However, it is important to keep this in perspective. Certainly, someone with a first-degree relative (brother, sister, parent or child) with Parkinson's disease is at higher risk for Parkinson's disease themselves, but this risk is less than %. For those with a family history, the best advice is routine periodic examinations by their physician. It is important to let the physician know that one has a family member with Parkinson's disease. If there is any question that someone may have any symptoms of Parkinson's disease, they should consult with a movement disorders specialist. There may be medications that can be used to slow the progression of Parkinson's disease if it is detected early enough.

#### Join our Mailing List

To join the APDA Information and Referral Office's mailing list, contact Jessica Hahn: (608) 263–7991, or hahn@neurology.wisc.edu.

This newsletter is intended for educational puposes 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.

#### *Editor's Pen* . . . continued from page 1

How has the use of MPTP in research benefited patients with Parkinson's disease? There are countless examples but a few will serve to prove the point. It was discovered that for MPTP to produce Parkinsonism in laboratory monkeys, MPTP had to be converted to MPP+ by an enzyme called monoamine oxidase. Blocking that enzyme prevented MPTP from producing Parkinsonism. It turns out that selegiline and rasagiline both block monoamine oxidase. These important observations lead to the clinical testing of these medications to prevent or slow the progression of Parkinson's disease.

Research using MPTP-treated monkeys also was important for the

development of DBS of the subthalamic nucleus, which is the most widely used and effective type of DBS. Studies in these animals demonstrated that neurons in the subthalamic nucleus were abnormal and that perhaps DBS would quiet those neurons. And the rest, as they say, is history.

Clearly, these advances would not have been possible without animal research and particularly research involving monkeys. Will animal activists everadmit this? Will they tell your government representatives that this research should be continued? That is highly unlikely. So the question is, what should the reader do? First, it is important that your voice is heard and not just those of the animal activists. Write to your local, state, and federal representatives and tell them you rec-

ognize the need for animal research. Second, tell your friends, and ask them to help. Third, insist that animal activists who violate the law when they threaten, intimidate, and vandalize are prosecuted to the maximum under the law. Fourth, do not contribute, and ask friends and relatives not to contribute, to organizations that directly or indirectly support animal rights activists. Do contribute to organizations that educate lawmakers and your fellow citizens about the need for animal research. These include the National Association for Biomedical Research and its state chapters, the Foundation for Biomedical Research, Americans for Medical Progress, States United for Biomedical Research, and Incurably Ill for Animal Research.

## Swallowing Study

Swallowing problems — when food or liquids "go down the wrong pipe" toward the lungs instead of the stomach — are common in people with Parkinson's disease (PD) and have been linked as a cause of pneumonia. In fact, bronchopneumonia is the leading cause of death in people with PD.

To help prevent pneumonia, the UW/VA Swallowing Clinical and Research Program continues to lead the largest ever, multi-site clinical trial for swallowing problems. Funded by the National Institutes of Health, this study is entitled Protocol 201: Randomized Study of Two Interventions for Liquid Aspiration: Short- and Long-term Effects and is headed by JoAnne Robbins, Ph.D. The purpose of the study is to determine which of two common treatments is better at preventing pneumonia in elders diagnosed with dementia and/or Parkinson's disease.

As study chair and director, Dr. Robbins heads the Clinical Research Swallowing Program that is the central laboratory for this study and plays a critical role in subject recruitment, nationwide data analysis and clinician training. The study is now in its sixth year and is progressing well, having accrued more than 700 subjects with swallowing problems. There are more than 100 hospitals and more than 200 skilled nursing homes participating nationwide. Anyone interested in more information about this study should call the UW/VA Swallowing Program at (608) 256–1901 ext. 11125.

## Looking for information on Parkinson's Disease?

A Parkinson's Disease Public Lecture was held in Madison last year, at the School of Pharmacy. This year, we are planning another lecture in Madison, plus two more: one in Appleton and one in La Crosse.

*La Crosse Public Lecture:* September 18, 2005 Radisson Center, 1–4 p.m. *Madison Public Lecture:* October 2, 2005, School of Pharmacy, 777 Highland Avenue, Room 2006 1–4 p.m. Appleton Public Lecture: November 20, 2005, Radisson Paper Valley Hotel 1–4 p.m.

Hope to see you there!

## **Questions & Answers**

Welcome to our new section of the newsletter! This section is for your questions to be answered. If you have any questions about Parkinson's care, please let Jessica Hahn know at hahn@neurology.wisc.edu, or mail them to 600 Highland Avenue, H6/569 CSC, Madison, WI 53792–5132.

#### Q: What is a Multidisciplinary Team?

**A:** A **multidisciplinary team** consists of health care providers who can help you through the health care system and who specialize in different fields. These include nurses, doctors, physical therapists, occupational therapists, speech/ language specialists, swallow specialists, social workers, etc. When patients have complex needs, it requires a team approach to provide the best quality care. One example is the speech/language specialists, here at UW Hospital and Clinics, who are certified in the Lee Silverman Voice Therapy. This is a special therapy designed for treating the unique voice and speaking needs of patients with Parkinson's Disease.

Here to Serve You! The American Parkinson Disease Association Information and Referral Office is here to serve you. There is a lot of information it can give you: books that the APDA gives out at no charge to any-one 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 from you. Please contact Jessica Hahn at (608) 263–7991 or hahn@neurology.wisc.edu for further information.

#### **UWHealth**

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