

Parkinson's Perspective

A newsletter from the UW Health Movement Disorders Program

From the Editor's Pen . . .

We are very fortunate that Jessica Hahn has joined our staff as coordinator of the American Parkinson Disease Association at the University of Wisconsin–Madison. We are now fully staffed and ready to work hard for the Parkinson community of Wisconsin and northern Illinois. We have a lot planned.

- We again will hold our annual public symposium this fall — the date is being finalized.
- The newsletter will appear regularly.
- We are developing a reference for support services in our area.
- And we are continuing the monthly support group meetings at the Asbury United Methodist Church on the third Thursday evening of each month (except December, January, July and August). As usual, we have a telephone line (263–7991) for answers to questions and referrals for service.

Our new major goal is to establish a chapter of the American Parkinson Disease Association in Madison. This chapter will serve several important functions. It will have its own executive board and will run the

monthly Madison support group. Jessica will continue to provide administrative and logistical support. The chapter will have a medical advisor, and I am very pleased to play that role. Most importantly, the local chapter, through its execu-

tive board, will help identify and meet the needs of Parkinson's disease patients, their family members, caregivers and friends. The executive board will act as a liaison between the Parkinson community and the staff of the movement disorders program at the University of Wisconsin–Madison.

The local chapter will play a vital role in patient advocacy and in fund raising to meet local needs and to contribute to the national effort against Parkinson's disease, in partnership with the national office of the American Parkinson Disease Association. This will be a great way for all those hurt by this disease to fight back.

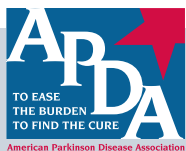
As Tennyson wrote in his poem *Ulysses*, "It is better to dull with use than to rust in disuse." Don't let us rust in disuse. Tell us how we can be of more help to you — write or call. Also, spread the word! Share this newsletter with others. Tell them to call and place their name on our mailing list. Come to the support group meetings.

I have greatly benefited, both professionally and personally, from the innumerable kindnesses given me by the Parkinson community. I am sure my colleagues can say the same. Give us a chance to pay some of it back.

Sincerely,



Erwin B. Montgomery Jr. MD



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 608/265-6470.

Meet the Staff



Jessica Hahn

Let us introduce you to **Jessica Hahn**, the American Parkinson Disease Information and Referral Office Coordinator at University of

Wisconsin-Madison. With a bachelor of science degree in business from the University of Wisconsin-Stevens Point, she has a love of helping and supporting people.

Since graduating a year and a half ago, Jessica had been working as an assistant manager at Family Video before joining our team the end of February. While in school, she worked in the alumni office at UWSP. Jessica has always shared a passion for helping people in need, and that only grew stronger when she volunteered a couple of times at the nursing home where her father worked.

I&R Coordinators work with Parkinson's patients, their families and the community, educating them on the disease. Jessica does this by relaying any information that comes her way from the APDA national office or getting answers for Parkinson's questions that patients, families and caregivers may have.

Please feel free to email or call her with any questions, concerns,

or comments you may have. Her number is (608) 263-7991. Jessica's e-mail address is hahn@neurology.wisc.edu.

Support Group

As usual, the Madison-area support group meeting will be held the 3rd Thursday of every month at Asbury United Methodist Church on University Ave. There will be no meetings in July and August. The church is wheelchair-accessible and parking is, of course, free. We hope to see you there!

FDA Reassessing Use of Certain Medications

The Food and Drug Administration is re-evaluating the use of "atypical anti-psychotics," such as Seroquel and Clozaril, because of studies indicating a higher risk of death in patients receiving these medications. In a study of 5106 persons, the risk of death was 4.5% or roughly 4 1/2 out of 100 in patients taking these medications, compared to 2.6 or roughly 2 1/2 out of 100 for patients not taking the medications. This means that the chances of death are two out of 100 higher if a person takes these medications.

There are risks with any treatment or medication, and each individual patient (or caregivers) must decide whether or not the potential benefits outweigh the risks. For many Parkinson's patients, the use

Parkinson-Related Dysphonia Study (H-2003-0429): Do you qualify?

Participation in this study will require two sessions. The first session will include voice assessment and voice questionnaire immediately before your Cymetra injection; the second will be for voice assessment and the questionnaire repeated. The testing will take about 30 minutes for each of the 22 testing sessions, and again, is part of your clinical care.

We would like to collect information about you and your voice on a subject log. The log will contain a research subject number that will be consecutive from 1-10: name, age, gender, and medical record number. On a separate data collection form, the research subject number will be used to collect past history of medical or surgical treatment, behavioral (voice) therapy, past history of medications, and surgeries as related to IPD, head and neck disease, and/or voice disorders; current medications and medication cycle; disease duration. No other medical record review will take place.

If you require additional information or have any questions, please contact Gregory K. Sewall, MD at (608) 265-0494.

of these anti-psychotic medications is the only way they can tolerate their anti-Parkinson's medication. The anti-psychotics control hallucinations and delusions that can be caused by their anti-parkinson medications. Unfortunately, hallucinations and delusions are a major reason why some Parkinson's patients ultimately enter a long-term care facility.

When considering the risks of a treatment or medication, one also has to consider the risks of not taking that medication. These include the risks associated with untreated Parkinson's disease. Each individual patient is different and thus, the decision about using these medications should be made after discussions with the patient's physician.

Why a Tulip?

Tulips have gained wide acceptance as a symbol of our hope for a cure for Parkinson Disease. In 1980 a Dutch horticulturalist (who had PD) gave the name "Dr. James Parkinson" to the prize-winning red and white tulip he had developed. He chose the name to honor Dr. James Parkinson, the English doctor who described the condition in his 1817 "Essay On The Shaking Palsy".

The tulip received the 1980 Award of Merit from the Royal Horticultural Society in London, England and in 1981 received the Trial Garden Award from the Royal General Bulb Growers of Holland. The registered description of the tulip is: "exterior, glowing cardinal red, small feathered white edge, outer base whitish; inside, currant-red to turkey-red, broad feathered white edge, anthers pale yellow."

What is a Swallowing Problem?

By Jackie Hind, MC/CCC-SLP

Enjoying food and drink is essential to our quality of life and plays an important role in our social interactions and celebrations.

Unfortunately, difficulty swallowing is common among those with Parkinson's disease (PD). As many as 50 percent of individuals with PD experience difficulty chewing and swallowing (*dysphagia*).

Swallowing is a highly complex balancing act using approximately 30 mouth and throat muscles and multiple nerves performing precise and synchronized actions. When the swallowing mechanism is impaired, food or liquid may "go down the wrong pipe," toward the airway (termed *aspiration*). If untreated, dysphagia can cause pneumonia, malnutrition, and/or dehydration.

Signs and Symptoms of a Swallowing Problem

- Coughing when eating or drinking is common with dysphagia, but is not always observed when food/liquid goes "down the wrong pipe." Some people do not cough because they have decreased sensation in their throat (termed *silent aspiration*).
- Weight loss
- Frequent respiratory infections or pneumonia
- Taking longer to eat meals

Who Do I see for a Swallowing Problem?

Your physician will likely refer you to see a speech pathologist (SP). The SP will complete a thorough diagnostic battery and recommend

a treatment plan for the management of your dysphagia.

How is a Swallowing Problem Diagnosed?

The most common diagnostic method used to evaluate a swallowing problem is the videofluoroscopic examination (VFG). The VFG is a moving x-ray that allows the SP and radiologist to view the throat and airway while individuals eat and drink items containing barium a chalky liquid that shows up on x-ray. The SP observes if any food or liquid goes toward the airway and identifies the most effective treatment for preventing aspiration and making swallowing safer.

How are Swallowing Problems Treated?

The most common treatment strategies for swallowing problems include postural changes such as a chin tuck or head turn and dietary modifications such as softened foods to make food easier to swallow. Additionally, active rehabilitation of the muscles used in swallowing can be effective for some individuals. Treatment strategies are specifically prescribed by an SP and could be more harmful than beneficial if attempted in the absence of a thorough evaluation.

Occasionally, the swallowing problem may be severe and require alternatives to taking food and liquids by mouth. In these situations, a tube can be placed directly into the stomach and nourishment given through the tube.

Is There Clinical Research Being Done for Swallowing Problems and PD?

At UW–Madison, two clinical research trials, headed by JoAnne Robbins, PhD, are underway for swallowing and PD. In fact, the largest randomized clinical trial ever to be funded by the National Institutes of Health (NIH) for swallowing is based at UW. If you are interested in more information about ongoing clinical research projects, please call Jackie Hind at (608) 256–1901, ext. 11337.

Clinical Trial for PD Patients: Are You Eligible?

You may qualify to take part in a study of an experimental medicine to help control symptoms. The study has physical exams, ECGs, and blood sampling. You will be asked to fill out a diary to monitor your symptoms. In this study, 75% of all participants receive the study drug. Your participation in the study may last up to 5 months.

- **If you would like more information, call Dave at (608) 263–9418.**

Is it for you?

Of the 1.5–2 million people with Parkinson Disease, roughly 10 to 20% are under the age of 50. These “young onset” patients have different issues they face than when older people are diagnosed with it. These issues include questions like when to tell an employer about one’s diagnosis, how to tell one’s young children, and so on.

A new support group is being set up for these Young Onset patients. This support group meeting is for patients, family and friends. The three criteria to be considered a Young Onset patient are still being gainfully employed, having minor children or being under the age of 50.

The support group will get started in the fall. If you would like to help out with this, please contact Jessica Hahn at (608) 263–7991 or hahn@neurology.wisc.edu.

We need you!

We need volunteers to serve on the steering committee to create the Madison chapter of the American Parkinson Disease Association. This committee will establish the bylaws, organize the chapter, and complete the application process. Once the chapter is formed, we are hoping the steering committee will morph into the executive board of the chapter. If you or someone you know is able and interested in volunteering, please call Jessica Hahn at (608) 263-7991, or email hahn@neurology.wisc.edu.

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.



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