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Progress Notes: BUMC Parkinson's Disease Center

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# Progress Notes: January 1994

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## FROM THE EDITOR

The Information and Referral Center had a very busy 1993 and is now planning activities for 1994. I invite all of you to offer suggestions on what you would like to have done during this year. An agenda of center activities including symposia, support group outreach and chapter events will be finalized at the February Mass. Chapter meeting (See Mass. Chapter News, page 4).

The Museum of Science evening, held November 7, 1993, was a great success. Over 400 individuals, including those with Parkinson's disease, their family members and health care providers, came together for a wonderful evening. Everyone had a chance to enjoy the "Decade of the Brain" exhibit, enjoy hors d'oeuvres and the sounds of a jazz trio. Dr. Robert G. Feldman, chairman of the Department of Neurology at Boston University Medical Center, gave an interesting talk on current developments in Parkinson's disease research entitled "Stimulating Discovery." The highlight of the evening was a presentation from the American Parkinson's Disease Association recognizing the Boston University Medical Center Department of Neurology as one of six American Parkinson's Disease Association Advanced Center for Parkinson's Research. The department will receive \$.5 million over a five-year period. This will be used to fund research taking place at Boston University Medical Center and the Veterans Hospital in Bedford and Jamaica Plain.

The APDA President, the Hon. Mario Esposito, and the Medical and Scientific Director, Dr. Paul Maestroni, presented the award to Dr. Feldman (see page 4 for more on this story.)

Many people volunteered their time and expertise to make the evening a success. Thank you to all. Special thanks to the events chairpersons, Jim Maurer, Ken Bernstein and Linda Weiss. I would also like to thank Athena Neurosciences, DuPont Pharmaceuticals, and Elan NutraPharma for their generous support.

Sincerely,

Cathi Thomas, RN, MS

## MEDICAL UPDATE:

### Constipation: Cause and Treatment

Marie Saint-Hilaire, MD

It is widely recognized that gastrointestinal (GI) symptoms are frequently reported in patients with Parkinson's disease. Patients with PD suffer more frequently from abnormal salivation, difficulty in swallowing (dysphagia), nausea, constipation and defecatory dysfunction. Constipation is a major complaint of patients; it is defined as less than three bowel movements a week, or hard stools. Several factors are implicated: medication, poor diet, decreased level of activity, and effect of the disease itself.

Anticholinergics are medications that commonly cause constipation: trihexyphenidyl, benzotropine, amantadine and oxybutynin, for example. These drugs are used to treat tremor and urinary frequency. Other medications include calcium, aluminum antacids, some antidepressants, anticonvulsants, analgesics and bismuth salts.

Elderly patients may have reduced thirst sensation and

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## Constipation

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may not drink enough water. Some have a decreased appetite and may not eat enough high-fiber foods such as fruits, vegetables, whole grain cereals and bread. In addition, many individuals have a decreased level of physical activity resulting in decreased tone of the muscles which aid in digestion.

The role of PD itself seems to be very important in developing constipation. A study has shown that 80 percent of Parkinsonian patients experience decreased colonic motility irrespective of dopaminergic drug therapy (levodopa, bromocriptine or pergolide). There is a high correlation between constipation and the duration and severity of PD. Patients with progressive worsening of their disease show increasing severity of constipation compared to patients with stable PD. This suggests that direct involvement of the GI tract from PD causes delayed colonic transit and is the primary factor in constipation. Lewy bodies (the pathological hallmark of PD in the brain) are found in the cells innervating the colon in a Parkinsonian patient.

In addition to constipation, many patients with PD suffer from defecatory dysfunction. This is felt as an increased need for straining and incompleteness of evacuation. This symptom, in contrast to constipation, is significantly more common

## Treatment:

Constipation should be treated first by simple measures:

- Consume a diet rich in fiber and containing plenty of fruits and vegetables. Fiber can be added to the diet by sprinkling three tablespoons of bran into apple sauce, onto cereals or mixed with yogurt. Add the fiber gradually to minimize bloating and gas;
- Drink ample amounts of fluid, particularly water (6 to 8 glasses a day);
- Get regular exercise to tone the muscles that aid in digestion;
- Make sure you attend to regular timing for bowel movements and prompt response to the urge to defecate;
- Limit intake of antacids.

Cisapride (Propulsid) is a new medication available to improve GI motility in a variety of disorders. It increases gastric motility, prevents gastroesophageal reflex as well as accelerates transit in the small and large bowels. The dosage is 10 to 40 mg. per day, and the main side effects consist of stomach cramping, diarrhea and flatulence.

If a laxative must be used for a brief period, milk of magnesia is suggested. Glycerine suppositories can ease the passage of hard stool. Docusate Sodium (Colace), a stool softener, is particularly useful for patients who have hard stools or painful anorectal conditions. The dose is 50 to 200 mg. daily. Several days of treatment are required before the effect becomes apparent. Frequent use of this agent does not result in dependence.

in patients being treated with dopaminergic medications. It is probably caused by abnormal control of the pelvic musculature along with paradoxical contraction of the anorectal muscles during straining, thus preventing the passage of stools.

It is recommended that patients undergo a screening for colon cancer as part of their yearly examination by their internist. This is especially important after the age of fifty if there is a significant change

in bowel habits or blood in the stools. Some internists recommend that patients over the age of 50 get a sigmoidoscopy every five years for a more complete evaluation.

Constipation is easier to prevent than to treat. Regardless of their medical condition, patients and their families should adopt a healthy lifestyle and diet to prevent constipation. ■



## Clinical Trial Update

Denyse Turpin, RN

Many thanks to all who inquired or participated in the clinical drug trials here at the Department of Neurology at Boston University Medical Center. Your time and cooperation is an essential component to a successful study.

We often receive calls regarding involvement in a clinical trial. Before a medication is approved by the FDA, clinical trials or drug studies are necessary to determine benefit and safety of the experimental drug.

Before the study begins, a pharmaceutical company develops a protocol which outlines the design of the study and offers information about the drug. This protocol is reviewed by the physician and study nurse(s) and then is sent to the

Institutional Review Board (IRB) at the Medical Center for approval to do the study. The IRB is bound by regulations established by the FDA to ensure that proper research procedures are carried out.

After approval is granted, the physician can begin to recruit patients into the study. An Informed Consent form is given to the potential candidate to read and discuss with the physician and staff. Questions are encouraged to ensure that the patient has full understanding of what the study is about and what is expected of him/her. Once an agreement has been made, signatures are necessary from the patient and physician, and then the study can begin.

Currently, there are two clinical drug trials going on at Boston University Medical Center's

Department of Neurology:

1) tolcapone, a COMT inhibitor for patients who experience motor fluctuation or "end of dose wearing off" and 2) ropinirole, a dopamine agonist for patients who have not taken any Parkinson medications.

A third study is to begin in January, 1994, also using the experimental drug tolcapone for patients who have a stable response (never had "end of dose wearing off") to Sinemet therapy. Patients will be treated for a minimum of six months and a maximum of eighteen months. There is no cost to the patients who participate.

*If you are interested in participating in this clinical trial, and you meet the eligibility requirements, please call the BUMC Health Connection at 617/638-6767. ■*

*Progress Notes is intended solely to provide you with information that you can discuss with your physician. You should not make any changes in your treatment without first discussing them with your physician.*

### Mass. Chapter Meeting

DATE: Wednesday, February 16  
 TIME: 7:00 p.m.  
 PLACE: #300 Crown Colony Drive, Crown Colony Park, Quincy, MA  
 RSVP: (617) 638-8466

FROM RTE. 3 NORTH OR SOUTH:

Take Quincy Center Exit (Quincy - Adams MBTA) onto Burgin Parkway; stay left coming off exit. At the first set of lights, turn left onto Centre Street. Take the first left and follow the road into complex.



## BUMC Physician Robert Feldman, MD, is honored with outstanding research award



Esposito, left, presented the 1993 Outstanding Research Award to BUMC Chief of Neurology Robert G. Feldman, MD. Esposito said the award was given in recognition of Feldman's many

important contributions to the understanding and treatment of Parkinson's disease. Also during the program, the APDA announced that BUMC will be

named one of a total of six Centers for Advanced Research in Parkinson's Disease in the nation. Feldman and his program will receive a grant of \$.5 million over five years to further the work of the BUMC group. Ongoing research in the center will deal with: long-term clinical management through pharmacologic and non-pharmacologic methods; epidemiology, biochemical and molecular genetics; mechanisms in the pathophysiology of Parkinson's disease and biomechanical and functional neurosurgery approaches. ■

During the Nov. 7, 1993 event at the Museum of Science in Cambridge, American Parkinson Disease Association (APDA) national President Mario

### MASS. Chapter News

Jeanne McCarthy

I would like to take this opportunity to wish you all a happy New Year, and to announce that I will be stepping down as president of the Mass. Chapter. By the time this newsletter reaches you, I should be home caring for newborn twins.

I have enjoyed my tenure as president. I have had the opportunity to meet many wonderful individuals who have worked very hard in our fight to find a cure for Parkinson's disease. Although I will not be serving as president, I will remain active in the chapter and look forward to introducing you to my children

at the spring walkathon.

Election of officers will take place at the next chapter meeting, which is scheduled for February 16, 1994, 7:00 p.m., at #300 Crown Colony Drive, Quincy. Please try and join us.

I am pleased to announce the nomination of Jim Maurer for president. As many of you know, Jim is very active in the Parkinson's community. He has participated in all of the chapter events during the past two years and was chairman of the very successful Museum of Science evening held in November. In his travels, Jim has met with many scientists and clinicians, across the country and abroad, who are doing work in

Parkinson's disease. Jim is also very active in the support group network; he is a member of Y.P.S.G and South Shore P.S.G., and has been a guest speaker at many other group meetings. He is a warm, compassionate man who has many friends and will be a terrific president.

Mr. Robert Sartini and Ms. Midge Stahowiak have agreed to continue as treasurer and first vice president.

There are two additional vacancies on the executive board: that of secretary and second vice president. The Board is accepting nominations up until the chapter meeting. For more information, please call (617) 638-8466. ■

## Support Group News

Cathi Thomas, RN, MS

Last October, the APDA Information and Referral Center sponsored a support group leaders' workshop at the Sheraton Tara in Braintree, MA. I was pleased to see more than forty support group leaders from northern New England attend the conference. Paul Smedberg, the APDA representative in Washington, D.C., gave a presentation on how to raise awareness of Parkinson's disease in Washington. Paul offered suggestions on phone campaigns, letter writing campaigns and personally meeting with your congressman and senator. Now is the time to get active... Remember your representatives are very influential in determining how research dollars are allocated and what research can be done.

**To contact Paul:**

Mr. Paul Smedberg  
APDA Regional Office  
807 South Alfred Street, #2  
Alexandria, VA 22314

A lovely luncheon was enjoyed by all. Special thanks to Sandoz Pharmaceuticals and Elan NutraPharma for their generous support.

**I would like to take this opportunity to welcome five new Parkinson Support Groups. They are:**

Fall River (Charlton Memorial Hospital)  
363 Highland Avenue  
Fall River, MA 02720  
Contact: Joan Janek  
(508) 679-3131 ext. 7056

Portland P.S.G.  
46 Hawthorne Court  
Cumberland, ME 04021  
Contact: William &  
Martha Irvine  
(207) 829-4070

Androscoggin Support Group  
Correspondence to:  
393 Center Street Apt. 38B  
Auburn, ME 04210  
Contact: Henry Booker  
(207) 782-8171

Lexington P.S.G.  
1475 Mass Avenue  
Lexington, MA 02173  
Contact: Karen Santucci  
(617) 861-0194

Springfield, VT P.S.G.  
Correspondence to:  
179 Commonwealth Ave.  
Springfield, VT 05156  
Contact: Ann Jennings  
(802) 885-2051

For a complete "updated" list of support groups in New England, call the APDA Center at (617) 638-8466.

## Information and Referral Center

The Information and Referral Center was established by the American Parkinson's Disease Association in 1980. Resources of the Information and Referral Center are available to all individuals regardless of their affiliation with Boston University Medical Center. The responsibilities of the Center are:

- To provide educational materials to patients, families and health care providers;
- To develop a regional resource referral network;
- To establish and maintain support groups;
- To plan and implement regional conferences; and
- To participate in community awareness and public relations activities.

*To contact the Information and Referral Center, please call (617) 638-8466.*



## Winter Do's

Linda Perry, RN

Here are some activities to consider during the winter months ahead.

- Telephone fellow support group members and let them know you are thinking about them, or leave a message on the answering machine—it's just like getting mail!

- Plan to meet with friends to mall walk or exercise at the YMCA.

- Send a typed letter to a friend or correspond by exchange of tape cassette recordings. This is much easier and more personal than writing. Relating to people is what being alive is all about!

- Play some music and practice singing.

- If you have a VCR, call your local video store and

request that its monthly catalogue be mailed to your home.

- Organize all those pictures into your photo albums.

- Re-pot your plants or start new seeds or bulbs with prepared bags of soil. Bulbs such as paper white narcissus, amaryllis and hyacinth grow well indoors and the blooms offer a touch of spring.

- Make time for yourself. Care for your skin with a bath of warm water and baby oil, follow with moisturizing lotion. If you cannot get to the hairdresser, call your local hospital or nursing home for the name of a hairdresser who will make home visits for shampoos, cuts, styling and beard trimming. Brush up on your dental habits. Dental floss holders and soft foam padding around your toothbrush handle make it easier.

- And, finally, curl up for a long winter's nap on your very own satin draw-sheet for extra

mobility and comfort. Here's how to make your own, inexpensively:

1. Measure the width of your bed and add 36 inches to that number. Measure the length of your body from neck to knees. Write down the measurements.

2. Purchase a piece of satin fabric from your local fabric store. The width you need is the measurement you obtained and the length may vary from four to five feet.

3. Sew the raw edges or use iron on witches tape to prevent fraying of the fabric. Witches tape can be purchased at Woolworth's.

4. Position the satin on your bed such that the draw sheet reaches from your neck to your knees.

5. Tuck in the sides (under the mattress) and secure the sheet in place with three or four safety pins along the sides of the mattress. ■

## Progress Notes

A Report from the Parkinson's Disease Center  
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