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Boston University



Progress Notes

A Report from the Parkinson's Disease Center at Boston University Medical Center

July 1989

It is with great pleasure that I introduce the first newsletter from the American Parkinson Disease Information and Referral Center at Boston University Medical Center. The Information and Referral Center has been an important part of the Parkinson Program of the Department of Neurology for the past ten years. Dr. Robert G. Feldman has served as Medical Director during this time.

As Coordinator of the Center for the past four years, I have recognized the need to establish a newsletter to share information within the Parkinson community. This initial newsletter will familiarize you with the function of the APDA Center, provide medical information, describe recent events, and provide information on upcoming activities. In addition, a column will be designated for Chapter and Support Groups to exchange information.

The Roles of the Information and Referral Center:

- Provide educational material on Parkinson's disease to patients, family members, health care professionals and other interested individuals. We maintain a library of APDA handbooks, books, and video tapes.
- Refer individuals to health care professionals, support groups and community agencies according to special needs.
- Assist in establishing patient support groups and provide professional input as requested.
- Increase public awareness of Parkinson's disease.
- Present lectures, conferences and symposia on Parkinson's disease to patients, families, health care providers and social agencies.
- Assist the Massachusetts Chapter with fundraising activities.

It is my hope that this newsletter will be a strong addition to our Center. We welcome your contributions and suggestions at any time. For further information call 617-638-8466.

*Sincerely,
Cathi Thomas, R.N., M.S.
Coordinator of the APDA Information and Referral Center*

MEDICAL UPDATE:

The Use of Deprenyl in Parkinson's Disease

by Marie Saint-Hilaire, M.D., FRCPC

Deprenyl is a drug being studied for the treatment of Parkinson's disease. It was discovered in Hungary in 1964, and first used to treat Parkinson's disease in Europe in 1975. In the United States, where Deprenyl is not yet approved by the Food and Drug Administration (FDA), studies are evaluating two potential uses of this medication. One use of Deprenyl is as an adjuvant to levodopa (Sinemet), and the second is to examine the potential effect of Deprenyl on the progression of Parkinson's disease.

Deprenyl as an adjunct to Sinemet

Levodopa/carbidopa (Sinemet) is the most widely used and accepted treatment of Parkinson's disease. Levodopa enters the brain where it is converted into dopamine, the missing transmitter in Parkinson's disease. Dopamine is then inactivated by an enzyme called monoamine oxidase-b (MAO-B). The blocking of this enzyme, which normally inactivates dopamine, would maintain desirable levels of dopamine produced in the brain by patients taking levodopa, and thus increase the effectiveness of levodopa.

Many clinical trials of Deprenyl have been carried out, chiefly in Europe, where it has gained acceptance as a useful addition to levodopa therapy. It has been used mainly in patients who have fluctuations in mobility when taking Sinemet ("wearing-off" and "on-off" phenomenon), and has been found to smooth out mild oscillations in about 50 percent of cases. In some patients it also increased mental energy and improved attention. It

is a safe drug in general, but can exacerbate a previous stomach ulcer. The main reported adverse reactions are related to an increase in the effects of Sinemet leading to nausea, abnormal involuntary movements, and confusion. This is why the dose of Sinemet often has to be decreased after the Deprenyl is started. Finally, it is

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The New Parkinson's Day Program at The University Hospital

Responding to a need identified by the Parkinson's team in the Department of Neurology at Boston University Medical Center, the Parkinson's Day Program was developed and has been thriving since last July. This day-long program designed for individuals with Parkinson's disease and their families is another innovative way in which the University Hospital at Boston University Medical Center provides outpatient care services.

The program was designed specifically to provide closer physician/nurse monitoring of the patient's medication response (especially where changes have been prescribed) and emphasize the Parkinson team's philosophy that increasing learning and understanding about your condition, including the latest research, leads to healthy adjust-

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Parkinson's Day

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ment, proper management, and therapeutic success. With more information we feel that a patient becomes an active participant in his/her care, rather than being a victim of Parkinson's disease.

Admission to the day program is made after consultation by physicians in the Neurological Referral Center. In addition to physician and nursing observation, activities center around aspects of living and coping with Parkinson's disease and include teaching, discussion, exercise demonstrations, counseling, and emotional support services as well as exercises in enhancing the patient's self-concept and continuing social enrichment.

The Parkinson's Day Program is directed by Dr. Marie Saint-Hilaire, who specializes in the treatment of movement disorders. Linda Perry, R.N., who coordinates the program, also has extensive experience working with Parkinson patients as a former staff nurse at the Harold and Ellen Wald inpatient neurology unit at the University Hospital.

For more information on this program please call (617) 266-1565 or (617) 638-8466.



For several years, the Harold and Ellen Wald Parkinson's Disease Fund has supported research and clinical programs at the University Hospital and the Hospital's Department of Neurology. Mrs. Wald is shown here with her son, Stephen Wald (left) and Dr. Robert Feldman (right) during the dedication of the Harold and Ellen Wald Inpatient Neurology Unit at the University Hospital.

Deprenyl

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important to emphasize that Deprenyl taken without Sinemet has no effect on the symptoms of Parkinson's disease.

A 1983 discovery

In 1983, it was discovered that a chemical by the shorthand name of MPTP, which is a contaminant of a certain "synthetic heroin", rapidly and selectively destroys the same group of brain cells that slowly degenerate in Parkinson's disease. The explosion of research on MPTP-induced Parkinsonism gave birth to the idea that natural Parkinson's dis-

ease may be caused by prolonged exposure to low levels of an environmental toxin. It also turned out that in experimental animals, the toxic effect of MPTP was blocked by Deprenyl. If natural Parkinson's disease is caused by an environmental chemical like MPTP, Deprenyl might prevent the production of the toxic agent and protect the susceptible brain cells.

In addition, some researchers believe that the brain cell degeneration in Parkinson's disease may be inflicted by other chemicals generated by the degradation of Dopamine by the MAO. The administration of Deprenyl might be protective in this way too, since it blocks the MAO, as we discussed previously.

So far there is insufficient information to determine if Deprenyl can in fact slow down the progression of Parkinson's disease. A multi-center trial studying this hypothesis is now taking place in the United States and Canada, but results will not be available for at least two years.

In conclusion, Deprenyl is a valuable adjunct to long-term levodopa therapy. It is unclear if it will slow the progression of Parkinson's disease. It is not available by prescription in the United States but we hope it will be approved in the near future.

For further information please contact the Information and Referral Center at (617) 638-8466.

Parkinson Center Happenings 1989

January

Cathi Thomas, R.N., M.S., and Linda Perry, R.N., visited the Concord support group and presented an update on Parkinson's disease.

Dr. David Staskin of the UH Urology Department visited the South Shore Hospital Parkinson Support Group and presented a lecture on urological problems with PD.

February

Dr. Peter Mosbach spoke to members of the Newton Wellesley support group about coping with Parkinson's disease. Linda Perry, R.N., presented a lecture on medications used for Parkinson patients to the nursing staff at the University Hospital.

Dr. Peter Mosbach gave a presentation on "Hallucinations in Parkinson's Disease" at Neurology Grand Rounds at the Boston VA Medical Center.

March

Dr. Robert Feldman presented a talk on lifestyles and Parkinson's disease at the South Shore Hospital support group.

Dr. Marie Saint-Hilaire was interviewed by Boston radio station WROR and presented an update on Parkinson's disease.

Dr. Marie Saint-Hilaire and Linda Perry, R.N., were interviewed on radio station WODS on the role of the new day program.

April "Parkinson's Awareness Month"

Cathi Thomas, R.N., M.S., Edith Devegvar, LICSW, and Dr. Peter Mosbach presented a conference entitled "Sharing and Caring" at Norwood Hospital. In attendance were representatives from most of the support groups in New England.

Ms. Jean Dietz, a columnist for the *Boston Globe*, visited the Parkinson's Day Program at the University Hospital.

Cathi Thomas, R.N., M.S., attended a meeting at the South Shore Hospital and presented an update on Parkinson's disease.

Linda Perry, R.N., presented a lecture to Welch Home Care services on management of the Parkinson patient.

Dr. Robert Feldman attended an International Symposium in London, organized by Merck, Sharpe and Doehme, where he presented the results of a study comparing controlled-release and standard Sinemet in patients with stage II and early stage III Parkinson's disease.

May

Dr. Robert G. Feldman presented medical grand rounds at Beverly Hospital on Parkinson's disease.

Linda Perry, R.N., spoke to Curry College nursing students on Parkinson's disease.

Mr. John Hogan of Sandoz Pharmaceuticals presented an in-service on a new patient education series called PATH. For further information call the Center.

Cathi Thomas, R.N., M.S., visited the Norwood support group and observed their unique exercise and dance program.

Dr. Marie Saint-Hilaire presented an update on Parkinson's disease at the Emerson Hospital support group in Concord, MA.

RESEARCH UPDATE

On April 27, Dr. Robert Feldman presented a paper concerning research done by the Parkinson team at Boston University Medical Center on Sinemet CR at the International Symposium on Therapeutic Approaches in the Treatment of Parkinson's Disease. The symposium, which took place in London, was sponsored by Merck, Sharp and Doehme Pharmaceutical Co. The research examined a group of individuals with stage two and stage three Parkinson's disease and their response to Sinemet CR (controlled-release form) as compared with standard Sinemet. Results of this study will soon be published in the journal *Neurology*.

Pergolide, a new dopamine agonist, has been approved by the Food and Drug Administration and will be available by prescription July 1st. Clinical trials of this medication have been ongoing at Boston University Medical Center under the direction of Dr. Feldman since 1982.

The American Parkinson Disease Association has awarded a \$20,000 grant to the Department of Neurology at Boston University Medical Center to initiate a pilot study looking at the incidence and prevalence of Parkinson's disease and identifying possible environmental risk factors associated with the etiology. The Framingham Heart Study population as well as the population at BUMC will be studied.

Mass. Chapter News

by Jeanne Murphy

I would like to take this opportunity to welcome you to the Chapter column. As many of you know, the Massachusetts Chapter of the American Parkinson Disease Association was established in May of 1987. We are one of several chapters located throughout the United States. A primary role of the chapter is to raise funds for research, to increase public awareness of Parkinson's disease, and to assist the Information and Referral Center with their programs. At present the Chapter forwards 60 percent of funds raised to the APDA headquarters in New York while the remaining 40 percent is kept in the state for local programs. APDA uses these funds to further national programs in patient care and research.

The Chapter is strictly made up of volunteers, and, as with any other non-profit organization, we can always use

Young Parkinsonian's Counseling Group

by Peter Mosbach, Ph.D.

Young Parkinsonians often have concerns that differ from those of older individuals with Parkinson's disease. For example, younger individuals may be dealing with issues related to work and raising a family. In order to meet the needs of younger patients, I have started a counseling group which will meet on a monthly basis. The group provides an opportunity for patients and family members to share their experiences and express their concerns. The group is designed to offer a supportive environment where individuals feel comfortable helping others by discussing their experiences in coping with Parkinson's disease.

One group has recently started in the South Shore area and meets bi-monthly in Weymouth. If there is sufficient interest, a second group will be started which would be convenient to individuals living north of Boston. If you would like additional information about the group please contact me at (617) 266-1565.

more volunteers. In the past two years we have coordinated three walkathons and held a large symposium. Recently, with much help from the Norwood Support Group, we invited all support group leaders from New England to a workshop for group leaders to share ideas. Our various activities have included a murder mystery ball held April 1st, and as we went to press, we have been concentrating on our largest fundraiser, a "Night at the Pops," on June 18, 1989.

As President of the Chapter, I encourage all of you to become members of the chapter and hope that many of you can take an active role. It is with your involvement that we can "Ease the Burden and Find the Cure".

With Best Wishes,
Jeanne Murphy, President



Walkers receive T-shirts and register for the Third Annual Michel Monnot-Sandoz Pharmaceuticals APDA Walkathon.

Chapter News

Officers

Jeanne Murphy, President
Suzanne Morin and Midge Stahoviak, Vice Presidents
Robert Sartini, Treasurer
Cathi Thomas, Secretary
Sophia Camann, Chairperson of Fundraising

1989 Michel Monnot-Sandoz Pharmaceuticals Walkathon

On April 15, 125 participants gathered under the red and white tent to participate in the third annual walkathon to raise funds for Parkinson's disease. The participants donned tee-shirts provided to help publicize the event. Over \$5,000 was raised solely by individuals who came to walk the five-mile route. We would like to take this opportunity to thank all of the walkers and their sponsors in making this a successful event. We would like to thank the following companies and/or individuals for their time and donations:

John Hancock Financial Services
Matt Garrett's Restaurants
Ultima Cosmetics
Nick's Comedy Stop
Robert G. Feldman
Trophies and Awards by John Murphy
Sandoz Pharmaceuticals
Mr. John Hogan
Norma McDonough



The Information and Referral Center Staff. From left to right: Robert G. Feldman, M.D.; Jeanne Murphy; Marie Saint Hilaire, M.D.; Linda Perry, R.N.; Peter Mosbach, Ph.D.; and Cathi Thomas, R.N., M.S.

Support Groups

Massachusetts, like other New England states, is fortunate to have a strong network of support groups. Many individuals are often hesitant to attend support group meetings, but once they do attend, they often find these meetings to be beneficial. In general, support groups offer a great opportunity for Parkinsonians and family members to share common experiences and helpful hints on living with Parkinson's disease. There is also a strong educational component to these groups. It is well known that individuals who understand their condition adjust better to activities of daily living. The most important aspect of support groups is the opportunity to socialize. Many individuals with Parkinson's disease and their spouses become isolated due to a decrease in socialization.

In this first issue, we list the support group names and contact persons. We would like to share any information from support groups in future issues and therefore will devote a column just for this purpose.

- Emerson Hospital Support Group
9 Old Acre Corner
Concord, MA 01742
Contact: Linda Moran
617-369-1400, ext. 416
- Newton-Wellesley
Parkinson's Support Group
Angelside Road #47-4
Waltham, MA 01742
Contact: Dorothy Halpern
617-894-5598
- Norwood Hospital Parkinson's
Support Group Inc.
725 Neponset Street
Norwood, MA 02062
Contact: Dorrie Hefferman
617-762-2754
- Shaughnessy Hospital
Dove Avenue
Salem, MA 01970
Contact: Kathy Sloss
617-745-9000, ext. 122
- Parkinson's Support Group of
Cape Cod
16 Katy Hatch Road
Falmouth, MA 02540
Contact: Dr. Christopher Mamonas
508-896-5587
- Parkinson's Support Group of
Greater Springfield
VNA 600 Berkshire Avenue
Springfield, MA 01109
Contact: Edith Dorang
413-781-5070
- North Shore
Parkinson's Support Group
137 Winter Street
Saugus, MA 01906
Contact: Mary Unger
617-233-4868
- Hebrew Rehabilitation Center
for the Aged
1200 Centre Street
Roslindale, MA 02131
Contact: Olga T. Hurley
617-325-8000, ext. 380
- PEP of Plymouth Area
Plymouth Council of Aging
130 Court Street
Plymouth, MA 02360
Contact: Lee Anderson
508-746-4030
- South Shore
Parkinson's Support Group
Sparks
80 Mediterranean Drive
Weymouth, MA 02188
Contact: Dick Goldstein
617-331-2690
- Southwood Community Hospital
Parkinson's Support Group
111 Dedham Street
Norfolk, MA 02056
Contact: Joan Engstrom
508-543-8859
- Parkinson's Society of
Greater Worcester
47 Harvard Street
Worcester, MA 01608
Contact: Andrew McCarthy
508-757-0424
- Charlton Memorial Hospital
Parkinson's Support Group
Highland Avenue
Fall River, MA 02720
Contact: Kathryn Cullen
401-722-6000
- Andover Parkinson's Disease
Support Group
Andover Council on Aging
36 Bartlett Street
Andover, MA 01810
Contact: Elizabeth Leed
508-470-3800

Progress Notes

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