Progress Notes: July 1989

Parkinson's Disease Center at Boston University Medical Center

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Boston University
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 ['wear-ing-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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tement, 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.

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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 disease 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.

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.

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 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.

## 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.
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 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

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

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.

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

- **Shaughnnessy 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 Leeth
  508-470-3800
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A Report from the Parkinson's Disease Center at Boston University Medical Center
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