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Boston University



Progress Notes

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

July 1991

FROM THE EDITOR

Special thanks to all who have helped out this Spring at the center. April (Parkinson's Awareness Month) was certainly a busy time. In this issue we will report on the activities of April and also tell you about some exciting events in July.

The APDA National Office has just completed an excellent manual for the establishment and maintenance of support groups. In addition, a new resource library is available at the center and also can be made available to each support group upon request. If you are interested in joining an already existing support group, or would like to start a new group, please call the center at (617) 638-8456.

Enjoy your summer!

Sincerely,

Cathi Thomas, R.N., M.S.

MEDICAL UPDATE:

Sinemet CR: A Controlled Release Formulation

by Marie Saint-Hilaire, M.D.

The combination of levodopa and carbidopa (Sinemet) has been the most effective medication to relieve the symptoms of Parkinson's disease (PD). However the long term use of Sinemet may cause complications in many patients. These complications include fluctuations in mobility (wearing-off and on-off phenomena) and abnormal involuntary movements (dyskinesias). These complications usually occur about five years after beginning Sinemet. The patient notices that the duration of each dose of Sinemet shortens and that the PD symptoms slowly return before it is time for the next dose (wearing off). As time goes on, the effect of the doses gradually get shorter, and some doses may not be effective at all. This is associated with the occurrence of abnormal involuntary movements. Eventually, the duration of each dose is very short, the benefit appears very quickly, stops abruptly (on-off phenomenon) and is

often unpredictable.

The mechanism of these fluctuations may be due, at least in part, to the decreased ability to store dopamine in the brain as the PD progresses, and as the cells producing the dopamine no longer work. When Sinemet is given continuously through an intravenous infusion (a tube inserted into the vein) the fluctuations are relieved. This is because Levodopa is supplied continuously to the brain, and can be turned into dopamine at a regular rate, without needing to be stored.

Unfortunately, having a tube in a vein is not practical on a long-term basis. This is why a new formulation of Sinemet was developed. This new formulation, Sinemet CR (for controlled release), stays longer in the blood stream, and therefore acts longer than regular Sinemet. Blood levels are sus-

continued on page 2

Parkinson's Disease Patient Defines the Art of Living Well

by Susan H. Plumb

(This story originally appeared in the June 1991 issue of *Connections*, The University Hospital's employee newspaper, and is reprinted with permission.)



Glenna Atwood

"Life was beautiful in 1978," writes UH Parkinson's disease patient Glenna Atwood in the opening pages of her new book, *Living Well With Parkinson's*.

With a solid marriage, grown children, and a rewarding career, Atwood felt that her life was in place. Then, in 1981, she was diagnosed with Parkinson's disease, a progressive neurological disease that affects 1.5 million Americans. Atwood, who recently visited UH for a book-signing reception in her honor, shares openly with her readers about her life's experiences.

continued on page 3



Exercise Tips for Summer Fun

by Louise Joyce, R.P.T., and Linda Perry, R.N., M.Ed.

As we get older, exercise becomes more important to our physical and emotional well-being. Along with increasing strength, flexibility and cardiovascular efficiency, exercise also helps to decrease fatigue and improve one's outlook on life.

Medications are given to decrease muscle stiffness from Parkinson's disease. However, a well-known fact is that exercise is as important as medication in preventing complications from this rigidity. Please remember that it is always best to consult your doctor before starting any exercise program.

One of the most enjoyable and effective methods of exercise is walking. If you choose to make walking a part of your daily routine, the following guidelines should be observed:

- Wear supportive, comfortable shoes.
- Walk in the morning or evening, as it is cooler.
- Wear sunblock and a hat if you are out during the day.
- Use sidewalks or level grass areas.
- Slowly increase endurance; increase by one house or block per day. Don't over do it.
- Pay attention to posture—pull stomach in, tuck your behind under and lift your head up.
- Walk with feet 12 inches apart, practice U-turns, and swing your arms.
- Leave pocketbooks at home. Try a belted waist pack for keys and money.
- Exercise when you are "on."
- Walk with others.

For other types of exercise consider the following:

- Ride a stationary bicycle while watching television.
- Try swimming or water aerobics (supervised, of course).
- Join a low-impact aerobic class or use video instruction.
- Ask members of your support group who live near one another about starting a walking club or weekly exercise group.
- Check your local YMCA or Senior Center for exercise programs in your area.
- Listen to music when you exercise. Head phones can be used safely when walking on sidewalks or exercising at home.

The idea is to have fun and challenge yourself. Rest as often as you need to. Stay well-hydrated by drinking a large glass of water one hour before exercise and another after exercise. Be alert to such signs of over-exertion as shortness of breath, palpitations, muscle cramping, profuse sweating, excessive fatigue or light-headedness.

A list of available exercise videos and booklets as well as a copy of The University Hospital home exercise program is available by calling the center at (617) 638-8466. The Newton-Wellesley Parkinson Support Group also has a weekly exercise program. For information on that program, call (617) 894-5598.

Linda Perry is coordinator of the Parkinson Day Program and Louise Joyce is physical therapy supervisor of the Neurology and Rehabilitation units at The University Hospital.

Sinemet

continued from page 1

tained longer and vary less. Each Sinemet CR pill contains 50mg of Carbidopa and 200mg of Levodopa (50/200). Sinemet CR may be beneficial in the following situations:

- In patients who have wearing-off, because the doses of Sinemet CR will overlap and prevent the early appearance of PD symptoms;
- In newly diagnosed patients with mild symptoms who will need less frequent dosing of Sinemet;
- In patients who have difficulty moving at night.

It is also suggested by some that when new patients start with Sinemet CR rather than regular Sinemet, they may develop less complications although this has not been proven. Sinemet CR can also be taken with other anti-Parkinson medications, including Eldepryl, bromocriptine (Parlodel), and Pergolide (Permax), to enhance its effectiveness and smooth out fluctuations. Sinemet CR does have some drawbacks:

- Morning doses may take a longer time to kick in because blood levels rise more slowly, and therefore some patients may need an extra dose of regular Sinemet to get going faster;
- When patients are switched from regular Sinemet to Sinemet CR, they have to go through a careful titration since it can be more difficult to adjust the dose of Sinemet CR;
- Some patients may get no benefit or have more side-effects with Sinemet CR. This is seen particularly in patients who have severe on-off phenomenon or severe dyskinesias and find the effect of Sinemet CR to be less predictable than regular Sinemet.

Based on our research using Sinemet CR with both early and advanced patients, the advantages of Sinemet CR over regular Sinemet far outweigh the inconveniences. It is a major advance in the treatment of Parkinson's disease, and will be available in four weeks.

Atwood

continued from page 1

When Atwood was diagnosed with Parkinson's disease, she and her husband, Blaine, had mixed emotions. "We were relieved that it wasn't a brain tumor and determined that we could handle it," she writes. Her next step was to find the right physician.

"I was really searching for a good doctor. I had been to three different ones, but I still was not happy," she remembers. Atwood was hopeful when a friend recommended Robert G. Feldman, M.D., Chief of the Department of Neurology at The University Hospital.

"After meeting Dr. Feldman, I said, 'This is it,'" she notes. "Now after a decade together, we have a relationship based on mutual trust and respect."

Atwood, who had worked as a teacher for 26 years, was urged by Feldman to educate others. "You've been telling me things that I should be telling my patients," he told me. "You really should write a book, because you have a great deal to share."

Atwood took Feldman's advice: "When I would have a bad day or get upset, I would write. If I was really happy, I wrote that down too. I then would tuck the papers away. It was very therapeutic," she says.

Atwood did most of her writing while traveling with her husband in their 33-foot Winnebago. "We love to travel," she says, "and on the road there are no distractions.

"After I had finished the book, I said to myself 'Now the hard work is over, and I can sit back and relax.' In my heart, though, I knew that God was not through with me. So, I have started to do a lot of speaking at conferences and other events," she says.

Atwood says she will continue to speak and to help others for as long as she can. "If there's one thing that I have learned, it's that we all tend to underestimate ourselves."

"Living Well With Parkinson's" is published by John Wiley and Sons, Inc., and is available in most book stores.

SUPPORT GROUPS

New Additions

- **Winchester Parkinson Support Group** at Jenks Senior Center, 109 Skillings Rd., Winchester, MA 01890. The group meets the first Thursday of each month at 10 a.m. Contact Barbara Ciampa at (617) 721-7136.
- **Fitchburg Parkinson Support Group** at the Emmanuel Lutheran Church, John Fitch Highway, Fitchburg, MA 01420. The group meets every second Thursday of each month at 7 p.m. Contact Jane Cotner at (508) 342-2846.

Notes

Plans have been made to start a Young Parkinson Support Group. To kick off this group, a mini-symposium will take place on Saturday, July 20, 1991, from 9:30 a.m. to 2 p.m. The group is being formed to assist individuals and their families with issues commonly shared by those affected by Parkinson's disease. The symposium will be held at Boston University's College of Liberal Arts, Third Floor, Auditorium 313, 725 Comm. Ave., Boston, MA. Parking will be available at the rear of the building. To register please call (617) 638-8466.

Agenda

- 9:30 Registration & Coffee
 - 10:00 Dr. Marie Saint-Hilaire will review recent developments in pharmacology, epidemiology, transplantation, and prevention.
 - 11:00 Psychologists Gloria and Henry Burkin will facilitate concurrent sessions on Coping with Parkinson's disease. One session will be for patients, the other for spouses and significant others.
 - 12:00 Lunch. A good time to meet others while you have lunch at one of the local sandwich shops.
 - 1:00 Business Session. Cathi Thomas and Dick Dionne will moderate a discussion of questions such as: Should we meet again? If so, how often, and how do we want to organize ourselves?
 - 2:00 Adjourn
- Congratulations Newton-Wellesley Support Group for 10 very successful years.
 - Dick Goldstein of the South Shore Support Group is working on a large project with the APDA Information and Referral Center. He is putting together information packets for each library in the state. If anyone is interested in assisting him with this project please call (617) 638-8456.
 - Plans are under way for a support group leader conference in the Fall. Details will be sent out soon.

Respite Program Update

by Linda Perry, R.N., M.Ed.

I'd like to inform our readers of a new respite care facility in the Boston area. Norwood Hospital recently has started a short-term respite program providing private, comfortable rooms with 24-hour supervised care for families seeking respite for a day, a weekend, or any time up to 14 days. Meals, TV, telephone, socialization and assistance with personal care are included for \$145 a day. Advance reservations are required, and a preliminary interview is necessary to obtain basic medical information before the anticipated respite date.

Other respite facilities include Blair House in Milford and Sudbury

Pines Nursing Home in Sudbury. These facilities provide respite at \$130 a day for semi-private rooms.

In addition, we have names of a few individuals who are available to carry out respite care in the client's home.

For more information call the Parkinson's Center at (617) 638-8466 or Norwood Hospital at (617) 769-2950, ext. 2139, during normal business hours (except Thursdays). The next issue of *Progress Notes* will provide a list of all facilities offering respite in Massachusetts.

As a reminder, free instruction on caring for an individual with Parkinson's disease is available through the Parkinson Day program.

Mass. Chapter News

by Jeanne McCarthy

I would like to take this opportunity to thank everyone who helped support the Michel Monnot-Sandoz walkathons. As you know walkathons were held all over the country to raise money for research. I am very happy to report that four walks were held in Massachusetts.

The first walk, which was held on April 12, was put on by the Hebrew Rehabilitation Center for the Aged. Ms. Riye Aoki and Ms. Diane Kolodzy helped organize this event for staff and residents. The walk was held at the Arnold Arboretum.

The next day, the fifth annual walk in Boston took place. For the first time in five years, walkers arrived at Cleveland Circle and were not greeted with rain. One hundred and ten walkers came to pledge their support. At least \$4,000 was collected on site and sent to New York for research.

The Parkinson Educational Program of Cape Cod held a Michel Monnot Walk-a-thon on April 27. Twenty-five walkers joined Mrs. Helen Perreault along the scenic Cape Cod Rail Trail.

With the encouragement of PEP, the patients, staff and volunteers of the Mayflower Nursing Center in West Yarmouth held a "mini walk-a-thon." Mrs. Ann Hallett, activities director, coordinated the event. William Brunagim was chairman of fundraising. Twenty percent of the patients in the nursing home have Parkinson's disease, and this was the first time a nursing center on Cape Cod had participated in this event.

The two Cape Cod groups raised \$5,100 for APDA to use solely for research into the cause and cure of Parkinson's disease.

Finally, thanks to all of you who came into Boston to walk the

Freedom Trail with Michel Monnot and Ava Crowder. Michel and Ava were kicking off their "Road to Dignity Walk." This walk began in May in Miami. Michel and Eva plan to walk several miles along the East Coast and to finish in Portland, Maine, on August 1. We will be welcoming them once again on Tuesday, July 30, in Boston.

Special thanks to our Walkathon Supporters

The University Hospital
Coolidge Corner Clubhouse
Charles Playhouse
John Hancock Financial Services
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(Mr. John Murphy)
Patti Jacobs
(publicity)
Ed McCarthy
Mrs. Barbara Yacos
Theresa Kane
Dr. and Mrs. Robert Feldman
John Berardi
The Bishop Family
Nicks Comedy
Marty Thomas

If you know of anyone who would like to be on our mailing list, or if you have an address correction, please contact Cathi Thomas, editor.

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