1996-03

Progress Notes: March 1996

Parkinson's Disease Center at Boston University Medical Center

http://hdl.handle.net/2144/17894

Boston University
FROM THE COORDINATOR

Welcome to the first 1996 issue of Progress Notes. Please take time to review this newsletter and mark your calendars for upcoming events. In addition to local happenings, we have some regional activities planned. Planning of regional programs has been done with Donna Diaz and Gladys Tiedemann of the APDA Information and Referral Center at Saint Raphaels Hospital in New Haven, Connecticut and Katie Cullen of the I & R center at Roger Williams Medical Center in Providence, Rhode Island. Please feel free to call me with any questions and concerns at (617) 638-8466.

Sincerely yours,
Cathi Thomas, RN, MS

Parkinson WEB Site is established

The Parkinson's Web is an independent information resource on a part of the Internet known as the World Wide Web. The Parkinson's Web features the most extensive computerized compendium of Parkinson's information for patients and the general public. It serves the information requirements of the worldwide Parkinson's community by assembling and maintaining a centralized directory of current information about Parkinson's Disease and the resources available to help individuals and families cope with the disorder.

Anyone with a computer, Internet access, and web browser software can learn about new developments in Parkinson's research, look up medical terms in a glossary and get a listing of Parkinson's organizations and resources in the United States and countries around the world.

Although the cause of Parkinson's remains unclear, researchers have taken great strides in understanding Parkinson's and this has resulted in dramatic improvements in treating this disorder. These new developments also make treatment options more complex. Now, more than ever before, Parkinson's patients and families need to know as much as possible about the current scientific understanding of the disease, research in progress and new treatment strategies.

continued on page 2

MEDICAL UPDATE

Richard H. Myers, PhD
Professor of Neurology
Director, Neurogenetics Laboratory

Genetic Studies of Parkinson's Disease

Intense levels of investigation have failed to identify the cause of Parkinson's Disease (PD). At Boston University, we have embarked upon a study to determine if PD may be caused by a combination of two or more events rather than a single cause. Our study is based upon the past work of our own group of investigators as well as that of other scientists and doctors working in PD. Through the American Parkinson Disease Association Advanced Center for Parkinson Research here at Boston University, we are investigating the possibility that at least some cases of PD may be caused by a "genetic predisposition" which acts in combination with an exposure to substances potentially damaging or toxic to the brain. According to this model, most people will not suffer adverse effects from these exposures, but occasionally people have a genetic background which limits their body's ability to get rid of these potentially toxic materials. These people may have a high risk for developing PD. This model has been called the "Multifactorial Model" for Parkinson's Disease because it involves several factors. It is important to notice that people who do not have the genetic predisposition can have these exposures and will not develop PD, and even people who have the predisposition will not develop PD if they do not have the exposure. It is only those who have both the exposure and the genetic predisposition that develop PD, according to this hypothesis.

What is the current opinion about the genetics of PD?

Several studies have examined the patterns of familial clustering for PD. Nearly all have found an increased

continued on page 4
APDA Appoints New Medical Chairman

Dr. Roger Duvoisin, professor and chairman of the Department of Neurology at the University of Medicine and Dentistry of New Jersey, Robert Wood Johnson Medical School, has been appointed chairman of APDA's National Medical Advisory Board. Dr. Duvoisin is a world renowned authority on Parkinson's Disease and has written or co-written more than a hundred scientific articles. Dr. Duvoisin also authored Parkinson's Disease, A Guide for Patient and Family. This book has been read by thousands and is currently in its third edition. Dr. Duvoisin will be an invaluable asset to APDA, and we look forward to our affiliation with him to work together towards our common goal of finding a cure for Parkinson's Disease. *

Parkinson's Web cont. from page 1

In operation since March 1995, the Parkinson's Web was initiated by Ken Bernstein, who received the support of Dr. Anne Young, chief of neurology at the Massachusetts General Hospital. According to Bernstein, who serves as executive director, one objective of the Parkinson's Web is to use the Internet's capability to link people around the world who share a common concern and to use the internet to share information and build a worldwide Parkinson's community. Beyond sharing information on the Internet, project contributors hope that this web site can help speed the search for the cause of Parkinson's and the development of ever more effective treatment strategies.

Dr. Robert G. Feldman, chairman of the Department of Neurology at BUMC, writes: "What is universal in the treatment of Parkinson's Disease is the need for each person to know as much as possible about the condition and how certain insights, anticipations and adjustments lead to more effective living. A better understanding of Parkinson's Disease by everyone concerned will result in more effective coping, proper long-term management and a more successful therapeutic outcome managing their care...and have better long-term outcomes than patients who do not have such access."

The Parkinson's Web site is like a modern shopping mall, where an assortment of services are available under one roof. The Parkinson's Web site consists of information and publications from a wide range of resources, including major Parkinson's organizations, journals, books, research reports and extensive links to other neurological resources on the Internet. In some ways, the Parkinson's Web site is like a modern shopping mall, where an assortment of services are available under one roof. As such, it is also an invaluable resource for those editors, journalists, researchers and foundation staff who can influence the course of research and funding in medical care.

The Parkinson's Web is acknowledged as one of the "Top 5 percent of the Web" by Point Communications. Their review states that the Parkinson's Web, "offers information to people with Parkinson's Disease, their families and caregivers. If you're just learning about the disease, the online primer provides a thorough, easy to understand introduction."

Dr. William Langston, CEO of the Parkinson's Institute in California, and Dr. Anne Young formed an international board of prominent neurologists, neurosurgeons and neuroscientists who contribute reports and help maintain the quality of information on the Parkinson's Web.

Dr. Langston and Dr. Young were impressed by the enthusiasm expressed for this undertaking by leading scientists and physicians from Canada, England, Spain, Sweden, Israel, Japan and the United States. The members of the Medical Advisory Board understand that The Parkinson's Web could greatly facilitate communication, research and collaboration between scientists throughout the world. * (Press Release, January 1996, from PD Web, Ken Bernstein)

Parkinson's Web address:
http://harvard.edu/parkinsonsweb/Main/PDmain.html

Maine Chapter News

Carl Barker, newly appointed president of the Maine APDA Chapter, has announced that a full-day symposium for patients, family members and health care providers will be held on Thursday, September 5, 1996 at the Sheraton Tara in Portland, Maine. Registration information will be mailed during the summer.

Newly elected officers
Carl Barker
President
A. Christine Hillman
Vice President
Henry Brooker
2nd Vice President
Maple Christie
Secretary
William Irvine
Treasurer
Mass Chapter News

During the past six months, I have invested much time and energy speaking to individuals, family members and health care providers affected by Parkinson’s. It is such an exciting and encouraging time for us all with recent progress in the area of surgery and drug therapy. Although all of this brings great hope, I do feel that we need to increase awareness and funding. I was honored to attend the APDA National Board Meeting, and had the opportunity to share in the celebration of APDA’s 35th anniversary. I came away from this meeting realizing that a prestigious scientific advisory board is in place but in order for them to accomplish what needs to be done to find a cure, funding must be made available. It is for this reason that I am asking you to help with these upcoming fundraisers. Without financial support we cannot proceed towards our common goal — an end to PD. Review each activity and call me if you can help out. I have a job for everyone and each job is important no matter how big or small.

Sincerely,
Your President, Jim Maurer
1-800-343-3383

APDA Annual Walkathon

Saturday, May 11, 1996
9:30 a.m.-12 noon
Pond Meadow Park
Braintree, Massachusetts

Plans for the 1996 walkathon are underway. In addition to the above event, we anticipate other walks taking place in New England. Last year’s walks raised more than $23,000, which was used entirely for research funding. We hope to reach our goal and raise more this year but there is a great deal to be done and we need your help. Call Jim at 1-800-343-3383.

Putt for Parkinson’s Golf Event

Monday, September 16, 1996
Sterling Country Club
Sterling, Massachusetts

The first annual “Putt for Parkinson’s Disease Golf Tournament” will be held at the beautiful Sterling Country Club in Sterling, Massachusetts. Mark the date on your calendar and start working on your golf swing. We have a number of celebrities and sports figures signed up. Our goals, as stated by the event chairman, Kirby Howard are to increase Parkinson’s awareness, raise $50,000 for research and have fun.

Jordan Marsh/Macy’s Benefit Shopping Day

Wednesday, April 10, 1996

This fabulous fundraiser sponsored by Jordan Marsh/Macy’s at the Natick Mall will allow many non-profit organizations, including the Mass Chapter of the APDA, the opportunity to raise funds for programs and research. We are now selling VIP shopping passes for $5. In addition to store admission on the 10th, you will also receive three 20 percent discount coupons and two 10 percent discount coupons good for that day. Free food and entertainment will be featured on all levels of the store. Benefit Day shoppers will be entered in a drawing which includes a Caribbean cruise, a trip to New York City and much more. I ask each of you to please send in at least $5 for a ticket. For those of you unable to attend on April 10th, the Chapter is offering a chance to win Jordan Marsh Gift Certificates from $50 to $250 in value. In order to make this day successful, we need volunteers and support. If you are able to donate even one hour of time, call Jim at 1-800-343-3383 or the I & R Center at (617) 638-8466.

---

I wish to purchase (number of) ______ tickets at $5 each. __________ Total

Enclose check or money order and mail to APDA, 28 Indian Rd., Marshfield, MA 02050. Tickets will be sent by return mail.
frequency of PD among the parents, siblings and more distant relatives of PD patients but there is some disagreement about how much the risk may be increased. This kind of study is difficult to perform because it involves collecting information about the frequency of PD in the parents and siblings of people with PD and comparing this to the frequency expected by chance. The first difficulty is determining if a parent who died many years ago actually had PD. Second, brothers and sisters of the individual affected by PD may still be too young to develop the disease and so we cannot be confident that someone who is healthy today will remain so for his or her entire life. Finally, it is very difficult to find an accurate comparison group. Because husbands and wives may have exposures which are similar to the individual who is affected by PD, they do not make a good comparison group. Furthermore, it is inconvenient for people who are unfamiliar with the value of this research for PD to take the time and effort to complete lengthy evaluations of the occurrence of the disease in their families. Consequently, the studies in this area are not perfect and controversy remains.

Current estimates of the frequency of PD among the parents and siblings of people who are affected by PD is about 15 percent by age 90. Thus, if all parents and brothers and sisters were to survive to age 90, about one in every seven would be expected to develop PD by that age. In contrast, the frequency seen in the general population is below 5 percent by age 90. So the risk for PD appears to be about three times that expected by chance. Nevertheless, most parents or brothers and sisters do not develop PD. We expect that the risk to children would be similar to that estimated for the parents and siblings.

What sort of toxic exposures might be involved?

Several studies have reported an increased risk for PD associated with certain kinds of pollutants and specific chemical exposures. The exact compounds have not been established, therefore, more information is needed for a broad range of possible exposures. In addition, the source of the exposure is poorly understood. Some research suggests that drinking water may be an important source while other research has implicated exposures in the work place. Again, most scientists agree that we do not have an adequate understanding of how exposures may occur.

We have some thoughts about the kind of exposure that we believe to be involved, but we do not want to bias our studies by telling the exact exposure that we feel is most harmful. Instead, we are asking about both substances that we feel are unlikely to be causing PD as well as others that we believe to have a greater likelihood of causing PD to see if our hunch is correct.

What is hoped to be learned by this research?

According to our theory, we may be able to learn several things of importance to PD. First, we may learn that there are certain kinds of chemicals or materials that are important to avoid for people who have a relative with PD. This knowledge may help people who are susceptible to the toxic effects of these materials reduce their risk for PD. In addition, it may be possible to reduce the utilization of these materials in our environment on a broader scale. Both of these effects may be useful in reducing the risk for PD in the future.

In addition, if we can identify the materials that are damaging the brain in PD, this may assist us and others in investigating the means to detoxify these substances for persons whose bodies are incapable of doing so. We hope that this line of research may lead to new treatments to lessen the neurologic damage done in PD.

What research is already underway, and how might I help?

Several hundred persons seen through the PD clinic at Boston University have already participated in our research by being interviewed for this study. The interview takes about an hour and involves collecting information about PD among relatives and information about past medical history and various exposures. We have also collected this information from almost a hundred persons who are not affected by PD.

We very much appreciate the willingness of the many people who have participated in these studies and we want you to know how important your help has been to us. We particularly need interviews with “control” persons who are healthy (do not have PD and are someone other than a spouse, sibling or parent). In-laws and friends are good control participants. For those of you who know someone who may be willing to participate or who have questions, call Cathy Taylor, MSW, at 638-5105.

Are there laboratory studies?

We want you to know about the investigation of genes that we believe may be involved in the genetic predisposition to PD. We are investigating a series of nine possible genetic alterations in genes which supply proteins involved in the metabolism of substances that may be toxic in the brain. Many of these protein gene products came to the attention of clinical investigators over the past two decades because they affected patients’ ability to respond to or
Support Group News

New groups are formed
I am pleased to report that three new groups (listed below) have been established during the past six months. This brings the total to 37 groups in northern New England. Fabulous work for the Parkinson's community is being done by these groups! Hundreds of individuals affected by Parkinson's benefit from these meetings. We are fortunate to have many volunteers supporting this effort. For a complete listing of groups, call the I & R Center at (617) 638-8466.

New England Sinai Hospital Parkinson Support Group
contact: Pat Wilkinson, ACSW, LICSW
150 York Street
Stoughton, MA 02072
(617) 344-0600 X132

York County Parkinson Support Group
contact: Sandra V. Brooks
P.O. Box 1152
Wells, ME 04090
(207) 283-7767

Midcoast Parkinson Support Group
contact: Marla Davis/Barbara Gordon
Cook's Corner Mall
Brunswick, ME 04011
(207) 729-6134

Group Leaders Conference
The American Parkinson Disease Association Information and Referral Centers at BUMC, Hospital Of Saint Raphael and Roger Williams Medical Center are planning a conference for all support group leaders in New England. The conference will be held in Sturbridge, Massachusetts, on Wednesday, March 20, 1996. The conference will allow leaders to share ideas and learn what their neighbors are doing. Individuals interested in starting a group are invited. For information, call Kristine Annand at (617) 638-8587.

Parkinson's Disease Laboratory Dedicated at Boston University

School of Medicine Dean Aram Chobanian, right, presents John Nichols Jr. with a copy of the plaque that will hang on the wall of the Parkinson's Disease research laboratory named in Nichols' honor.

The generosity of an appreciative man will assist the School of Medicine in piloting a specific area of Parkinson's Disease research.

John Nichols Jr. wanted to do something to help gain an understanding of the disease. In memory of his wife Doris, Nichols donated funds for a laboratory focused on researching Parkinson's Disease at the molecular genetic level. “The research will focus on the complicated process that leads to the expression of Parkinson's Disease,” said Dr. Robert Feldman, professor and chairman of the Department of Neurology.

The John H. Nichols Jr. and Doris A. Nichols Laboratory for the Study of Molecular Genetics in Parkinson's Disease and Related Disorders was dedicated in September, in the School of Medicine's renovated Housman Building.

The Nichols Laboratory will become part of the center of excellence in research and treatment of Parkinson's Disease already established at Boston University Medical Center. The nationally recognized Parkinson's Disease Center at BUMC is an American Parkinson Disease Association Advanced Center for Parkinson Research and consists of several programs that offer comprehensive care to individuals and their families.

“Mr. Nichols has given us a great opportunity to do some very important research,” said Dr. Richard Myers, PhD, director of the Section of Neurogenetics in the Department of Neurology.
Medical Update cont. from page 4

tolerate a variety of drug therapies. Each of these proteins interacts with a wide range of drug therapies and natural and synthetic chemicals from the environment. Some information has come from correlations between the actions of these proteins in individuals as they affect metabolism of some common drugs and the incidence of several diseases, including PD. But these tests of protein effectiveness are difficult to administer and interpret, and we haven’t been able to draw firm conclusions about the involvement of these metabolic proteins and the development of PD. Now we can use molecular genetic techniques which allow us to determine, from one blood sample, exactly which kinds of proteins an individual will be able to produce from their specific gene profiles. We have collected about a hundred blood samples from persons who have PD and many others from persons who serve as healthy controls.

Some of the gene alterations that we are studying have been implicated in PD by other scientists and some are alterations that have not yet been studied in PD. Our present work will allow us to bring together more precise information about different genes in one study and, when used with our interview information, help us better understand the role of environmental exposure and genetic determinants of metabolic abilities in PD.

We have been very fortunate at Boston University to have benefited from the generosity of the Nichols family. Through a substantial financial gift, the Nichols Laboratory for Parkinson Research was recently established. This endowment has permitted the hiring on January 1, 1996, of a PhD scientist to undertake the laboratory studies of the genes potentially involved in PD. Dr. Oscar Joost has initiated the investigation to determine if individuals with PD have genetic alterations in the genes that lower their ability to rid the body of possible toxic materials.

We are hopeful that Dr. Joost’s efforts will lead to new understanding of the causes of PD. People who are interested in participating in these studies or who want more information may call Cathy Taylor, MSW, at (617) 638-5105.