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PARKINSON FOUNDATION of the National Capital Area

Parkinson Update

A Newsletter for the National Capital Area Parkinson Community

March/April 2002

Support Group Happenings

Community Support Group News

Author Morton Kondracke to Speak at PFNCA Meeting

The Parkinson Foundation of the National Capital Area is extremely pleased to announce that Morton Kondracke, author of the book *Saving Milly*: *Love, Politics, and Parkinson's Disease* will be our guest at the March meeting of the **Parkinson's Community Support Group**. Mr. Kondracke, also the editor-in-chief of *Roll Call* magazine, will discuss his book, his experiences dealing with Parkinson's disease, as well as his role in Parkinson's activism. Please join us for this exciting evening on Wednesday, March 13, 2002 at 6:30 pm. The PFNCA Community Support Group is held at the Epiphany Byzantine Church located at 3410 Woodburn Road, Annandale, VA. Please call Carolyn McCornac, PFNCA Patient Services & Outreach Coordinator, at 703-356-2151 for more information.

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Parkinson Foundation Hosts Second Annual Gala to Benefit Parkinson's Research

By Michelle Zerihun, Executive Director

On Friday, April 19, 2002, the Parkinson Foundation will be hosting its second annual Gala for Hope ~ Celebrating the Buddy Awards to benefit Parkinson's disease research at the Ritz~Carlton, Tysons Corner. We are committed to a cure and this annual gala has become a vehicle for turning that hope into reality. The planning for the event is being directed by the dedicated volunteer members of the Gala Executive Committee, with the help and support of a host of volunteers.

Just as with our inaugural event, the centerpiece of the evening is the Buddy Awards, which honor persons who, despite suffering from Parkinson's disease, make extraordinary contributions to the betterment of humankind in their work, family life or charitable endeavors. Video vignettes highlighting each awardee's unique story and special contributions will be shown during the evening's program.

This year we are honoring four outstanding individuals who will be present at the event to accept their awards. They are: Nina King, editor and book reviewer for the Washington Post; Wilbur McBay, a local businessman and philanthropist; J. Robert Porter, Parkinson's advocate and writer; and former Attorney General Janet Reno.

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INSIDE THIS ISSUE

Parkinson Foundation
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Open Call for Submissions

PFNCA invites & encourages its readers to submit articles, announcements and other items to the *Parkinson Update*. Submissions can be faxed to (703) 356-8963, mailed to the above address or emailed to info@parkinsonfoundation.org.

PFNCA reserves the right to refuse to print submitted items or to edit them as necessary.

President's Message:

WELCOME ABOARD AND THANK YOU

By Lawrence Hoffheimer

I would like to take this opportunity to express my heartfelt appreciation to Susan Hamburger for her tireless service to our Parkinson community during her tenure as Vice President and Chairperson of our Patient Services Committee. Susan recently resigned from her position on the Parkinson Foundation of the National Capital Area Board of Directors for personal reasons. Her voice will be missed there. Susan was a steadfast champion of the needs of persons suffering from Parkinson's disease.

The Board of Directors has elected Randy Levenson, who has been a member of our Board, to serve as Vice President of the Parkinson Foundation of the National Capital Area. As a member of the Board, Randy has demonstrated his dedication and commitment to finding a cure for Parkinson's disease. Randy serves as chair of our research committee, which utilizes the expertise of distinguished medical researchers to help us identify the most promising research to fund with the proceeds of our annual Gala for Hope. Randy's responsibilities as Vice President will include a variety of activities designed to help us achieve our overall mission and goals.

Randy's father, Buddy, after whom we have named the Buddy Awards, suffered from Parkinson's disease until his passing two years ago. The entire Levenson family has remained active in supporting our foundation, for which we are very grateful.

(Gala - Continued from page 1)

This year's Master of Ceremonies will be Wendy Rieger, NBC4's weekend news anchor and weekday general assignment reporter. The event, which kicks off at 7:00 pm, will also feature Silent and Live Auctions and music by Glenn Pearson and Floating Opera. Tickets to the event are $250 per person. Tables of ten are $2,500. Sponsorship opportunities are still available.

Parkinson Update subscribers will receive invitations to the event during the second week of March. Participate in the fight against PD and the search for a cure. Even if you cannot attend, please consider supporting the event's mission with your tax deductible contribution. For more information, please contact the Parkinson Foundation at 703-356-2151, extension 419 or visit our website at www.parkinsonfoundation.org and click on 'Gala for Hope'.

Help us make our second annual Gala for Hope a tremendous success on the road to a cure. We hope to see you on April 19, 2002!

Volunteer Visions and Victories

By Michelle Zerihun, Executive Director

Volunteer involvement is essential to the Parkinson Foundation's success and can be a fulfilling and rewarding experience for the volunteer. From planning fundraising events like our Gala, to providing support in the office, to contributing articles to this newsletter, to helping with projects like our medical equipment loan closet, Parkinson library and other programs that serve the Parkinson community, there is something for everyone! Thank you to everyone who has joined the effort. Your contribution makes a difference.

We need you! Following are some of the Parkinson Foundation's current volunteer opportunities:

1. **Gala Event Volunteers Needed for April 19, 2002**: Volunteers are needed to assist with general set-up, decorations, auction set-up, registration, silent auction and much more for the day of the second annual Gala for Hope ~ Celebrating the Buddy Awards at the Ritz~Carlton, Tysons Corner. Last year's event was a blast and went off without a hitch, due in large part to the day-of-event volunteers who helped execute the careful planning and preparation. Volunteers are needed during the day between 10:00 am – 6:00 pm to assist with set-up. Volunteers for the event itself are needed from 5:00 pm to midnight. 25+ volunteers are needed, so please call now if you are interested in helping with this exciting event.

2. **Office Volunteers to Assist with Gala Reservations Process**: 3-6 volunteers are needed to assist with the Gala Reservations process by working at the Parkinson Foundation office 1-2 times per week from March 18-April 18. Time slots are tentatively set for Mondays and Wednesdays from 1:00 pm – 3:00 pm. Basic duties will include processing of incoming reservations, filling seating requests, etc. Training will be provided.

3. **Spotters for Providence Exercise Class Still Needed**: Additional volunteers are needed weekly on Tuesdays from 10:45 am – 12:15 pm to spot exercise participants and to assist the instructor, Judy Cooper, with the Parkinson Exercise Class at Providence Recreation Center in Falls Church, Virginia. Training will be provided.

If you are interested in any of the above volunteer assignments or would like to learn more about volunteering for the Parkinson Foundation in general, please contact me at 703-356-2151, extension 11 or by email at michelle@parkinsonfoundation.org for more information. Thank you!

Reflections on Support Group Training

My Experience with the Providence Parkinson Group

By Kelly Cregan

"Do you have any ideas about where I can find a group? I'd like to have group as my second modality." This was my question to my supervisor, Leon Paparella, in January 2001 - an inquiry that led to my nine-month journey as a participant-observer in a weekly psychosocial support group for adults living with Parkinson's disease.

I am in my second year of the Clinical Program on Psychotherapy Practice at the Washington School of Psychiatry (WSP). In January 2001 I attended a conference at WSP that focused on existential and interpersonal themes in group psychotherapy. The meaning of life and death, loss, illness, and how to negotiate endings were frequent themes throughout the conference. The impact on me professionally and personally was, I believe, profoundly connected to the experiential and dynamic group process throughout the conference. It is why I chose group as my second modality. Little did I know that in a few months I would be intimately involved with a group of people who live these existential realities in a pronounced way because they live with Parkinson's disease.

I knew next to nothing about Parkinson's disease (other than that Michael J. Fox and Janet Reno have it) and only some textbook theory on group dynamics when I started with the group last May. I felt a mixture of excitement for this opportunity and anxiety about how I would fit into the group. I was the newcomer. The group had met for about 70 sessions. I was also the only person in the group who did not have Parkinson's disease. The group leader also has Parkinson's.

Prior to beginning with the group, I educated myself by doing some reading about Parkinson's. I learned a whole new vocabulary: Sinemet, tremors, dyskinesia, bradykinesia, deep brain stimulation, L-dopa. Words used everyday by Parkinsonians, but new to me. I read *Saving Milly* by Morton Kondracke, a deeply moving story of the personal transformation one man experienced as he cared for his wife stricken with Parkinson's. And I read several articles on group therapy with medically ill patients. While my knowledge about Parkinson's increased, many questions remained: How would I fit in? Would I be accepted in the group? How could I be helpful and empathetic without seeming presumptuous?

(*Continued on page 13*)

Caregiver's Corner

Can we find any humor in what we do?

By Susan Hamburger

The correct answer is – we had better! Good humor is the health of the soul and it certainly can make our lives more enjoyable. It's sometimes hard to find things to laugh about in caregiving, isn't it? – especially if our loved one has advanced disease. However humor is probably the most effective way we have of getting through the harder times and darkest moments. Humor is a coping mechanism that is important not simply as a diversion. Rather, it is an essential requirement for preserving our mental and physical health. Humor in almost any form can spontaneously relieve fear, anxiety, anger and depression. It enhances our everyday quality of life and makes the whole caregiving experience better – guaranteed! Medical experts say that laughter is as good for those who are sick as it is for those who care for them and want to stay well. Remember caregivers who laugh, last!

Early in Stan's disease we laughed a lot and we made fun of ourselves. Laughter did not change the situation or the progress of the disease but it sure made it easier to deal with and helped ease tension. If I was young enough to have any memory left, I would give you some examples, but alas! Just suffice it to say that we both loved to laugh and did - in spite of how our lives were changing. Stan has a fabulous, dry sense of humor that has always made me laugh. When he does not show it, I know I have more trouble coping and finding the humor in situations by myself. I know that when his sense of humor appears and cracks me up, this difficult job is much more doable. When I am able to laugh at something, he is much more likely to perk up and become more cheerful, especially if it is something uncomfortable for him. We feel closer to each other, less tense and are able to see things in a more refreshing way. As the disease has progressed and we have more difficulty, it is harder to find things to laugh about, but we are still trying.

I do remember one incident recently – I was attempting to clean up a mess and was trying to get Stan to stand up straight for a minute. I raised his arms over his head and I asked him to pretend someone above was pulling him up by a string. His comeback, while he was barely able to stand was, 'Well, tell them to pull harder'. How can you not feel better when you both laugh?

Dr. Seuss said, "From there to here, from here to there, funny things are everywhere." Everybody has a sense of humor even if it's not used very often. Sometimes it just seems to disappear, doesn't it? But we can bring it back to life by really looking at the flip side of all aspects of caregiving – there is a funny side to everything if you look for it. Try to find something to laugh at every day! Remember Henny Youngman? Take my husband…please!

Spring Cleaning?

Get rid of clutter by making a tax deductible donation to the Medical Equipment Loan Closet!

We are proud to offer our Medical Equipment Loan Closet, a program that lends out medical assistance devices to members of the Parkinson's community free of charge. This program has been made possible through contributions made by people like you. Items such as canes, walkers, bedpans, and transfer chairs have been donated to the loan closet by families and caregivers after they are no longer needed, and then loaned out to individuals on an as-needed basis. Dr. Mitch Mills, a dedicated member and volunteer, has been running the loan closet since its inception over a year ago.This program has been quite successful. We are currently running out of much of our stock. If you would,please check your basements, attics, and closets for any of the following, and please consider making a tax deductible donation to the Foundation:

- Wheelchairs
- 4-Wheeled walkers (with brakes, basket, and seat)
- Toilet seat frames
- Toilet seat extenders
- Portable trapeze bars
- Bed rails
- Voice amplifiers
- Shower chairs or stools
- Tub transfer chairs
- Transfer chairs (lightweight wheelchairs)

For more information on donating or borrowing an item from the Loan Closet, please contact Carolyn McCornac, Patient Services and Outreach Coordinator, at the Foundation office at 703-356-2151.

Member Profile
Dana Gunnison
By Hilary Blue

If you were in New York one Sunday in September 2000, in Central Park, you might have seen some unusual activity. That would have been the Parkinson's Unity Walk. And if you had looked a little closer, you might have seen a banner announcing the presence of a group of Washington, DC area PwP's. And waving the banner you would have seen Dana Gunnison and his daughter, Alex. Dana has young onset Parkinson's disease, and is a member of the Chevy Chase support group.

Dana was born on September 11, 1945 in Girard, Pennsylvania. His family moved to Bethesda in 1948. He has two younger brothers and a younger sister. He graduated from Bethesda-Chevy Chase High School in 1964. In 1963 he had enlisted in the Navy Reserve, and was called up for active duty in 1965. In 1968, he was discharged as a third class petty officer.

He attended Union College in Barbourville, Kentucky, graduating in 1971 with a B.S. in Social Work. After working for several years in southeast Kentucky, he moved to Louisville, Kentucky and eventually attended the University of Louisville where he received his Masters degree in Social Work in 1981. He has been working in social services, both public and private for 30 years. He also has a certificate in training from Georgetown University.

Dana's contribution to social work was recognized when he was named employee of the year for Montgomery County Department of Social Services in 1992. He currently works as an outreach social worker with the Department's Aging and Disabilities Services in Rockville, Maryland where he provides case management services for disabled adults and seniors.

But it is not all work for Dana. He is active in a number of different areas. He belongs to the Parkinson Action Network and our own Parkinson Foundation of the National Capital Area; he participates in the Young Onset Support Group in Chevy Chase. Much of his time and attention goes to raising his daughter, who is a freshman at Blair High School in Silver Spring, Maryland. Not surprisingly, he enjoys sailing, and owns two sailboats. He enjoys playing strategy games on his computer, creating projects using print shop and surfing the Internet. He also serves as a committee chairperson with his church, Cedar Lane Unitarian Universalist in Bethesda.

Dana was diagnosed with Parkinson's in 1998, but he feels he has probably had symptoms since 1980. He says the major effect has been more psychological than physical up to this point. He has suffered from situational and clinical depression for about two years. Decision-making has become more difficult and his thought processes have slowed down. His employers have been cooperative and supportive, allowing him a smaller caseload.

One of Dana's favorite fundraisers is the annual Parkinson Unity Walk. The Walk helps raise money and brings together in a cooperative effort six different Parkinson's organizations that are raising funds for research into a cure for Parkinson's disease. It's great fun and inspiring as well. The 2001 Walk was rescheduled, because of the 9/11 tragedy, and will take place on Sunday, April 14, 2002 to coincide with Parkinson's Awareness Month. (See pages 8-9 for information about other Parkinson's Awareness Month activities.)

Dana would like to lead a walk team from the national capital area to the Unity Walk. Details can be found at the Walk web site: www.unitywalk.org or by contacting Dana Gunnison at danagunn@juno.com. You can also call direct to the Unity Walk headquarters in New York at 1-866-789-9200.

NIH Parkinson's Disease Research Agenda: Recent Meeting Cites Progress, Future Directions, and Common Themes

Scientists, patient advocates, and representatives of nine National Institutes of Health (NIH) components gathered January 9-10 to review progress made in implementing the agency's Parkinson's Disease Research Agenda. In her welcoming remarks, NIH Director Dr. Ruth Kirschstein spoke of the "unprecedented push, unseen ever before," that the NIH has made in Parkinson's disease research since the document was written. Originally released in March 2000, the Agenda describes areas of significant scientific opportunity in Parkinson's research to be explored over the following five years. The January 2002 meeting reviewed progress made towards accomplishing the goals set forth in the Agenda, identified newly emerging areas of interest, and prioritized future research goals.

The general consensus of the attendees is that the NIH is doing a good job implementing the Agenda's initiatives. However, participants identified additional areas of interest too new to have been stressed in the original document, and at least one area, rehabilitation, where current knowledge of the field indicates that additional efforts would be worthwhile.

Two breakout groups - one on the basic mechanisms of Parkinson's disease, the other on its treatment - discussed goals believed to be obtainable over the next 3 years. At the closing plenary session, participants identified several common themes that reinforce these goals:

- Emphasize translational research. Commonly described as "bench to bedside and back," such research incorporates both basic and clinical components into one interactive program to the benefit of both. While such programs are traditionally run by one center or group, the possibility of a virtual center was also discussed, as was the possibility of expanding NIH Intramural efforts in this area. The NIH is already planning a program that may address many of these needs.

- Better understand the abnormal brain circuitry seen in Parkinson's disease. Although many factors that may contribute to the breakdown of dopamine neurons have been identified, the cellular targets and processes are not fully understood. Such knowledge would enable scientists to devise therapies to treat patients after these neurons have been depleted.

- Increase studies on non-motor aspects of Parkinson's disease. These symptoms, which include dementia, depression, sleep abnormalities, and speech and swallowing problems, often bother individuals with Parkinson's more than tremor and rigidity.

- Locate risk and susceptibility factors and identify physiologic, genetic and environmental biomarkers to aid in preclinical diagnosis, evaluate progression of the disease, assess therapies, and speed clinical trials while reducing their costs. Large population studies would help achieve these goals.

- Pursue research related to gene therapy. Studies to determine the best vectors for delivering gene therapy and encouraging sharing of vectors should be emphasized. ***(See box for information about foundation-funded research in this area***.)

- Develop better animal models, particular for dyskinesias and non-motor symptoms.

Other significant issues targeted by the participants include:

- The need for clinical trials of neuroprotective agents and ways to reduce or eliminate dyskinesias.

- The development of surrogate measures, such as imaging and behavioral markers, to better assess non-motor symptoms, disease progression, and screen at-risk populations.

- Studies on the long-term effects of deep brain stimulation on both motor and non-motor symptoms, its mechanism of action, and its unintended consequences.

- Role of behavioral interventions such as voice therapy and exercise.

- Scientifically proven assessments of current treatments.

- Studies on how aberrations in the processing of the alpha-synuclein protein leads to the death of dopaminergic nerve cells.

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- Development of assays to screen drugs.
- The need to draw young investigators and scientists from other fields into Parkinson's research.
- The development of resource banks to facilitate access to animal models and critical research tools.

"The feedback from all the participants was extremely gratifying," said Dr. Audrey S. Penn, Acting Director of the National Institute of Neurological Disorders and Stroke, which hosted the meeting, "but I was particularly encouraged by the positive feedback from the patient advocates."

A detailed account of the meeting proceedings is being prepared for submission to the Congress and will be available on the Parkinson's Disease Research Web site (http://www.ninds.nih.gov/parkinsonsweb/index.htm) after it is cleared for release.

Did you know...?

The JCA Senior HelpLine, a service of the Jewish Council on Aging, offers information on housing options, in-home care, financial aid, and other programs offered for free or low cost in the national capital region. This service is free to anyone in the Washington, DC metropolitan area. The HelpLine is open weekdays (excluding holidays) 9:00 am – 5:00 pm. You can reach the HelpLine for your area by calling:

DC and Suburban MD: 301-255-4200
Northern VA: 703-425-0999
TDD: 301-881-5263

Looking for Nutrition Information?

Eat Well, Stay Well with Parkinson's Disease, a nutrition handbook, is available for sale through the PFNCA office. This wonderful, easy-to-read book comes with dining tips, as well as recipes, and contains valuable information on vitamins, constipation, weight loss, and chewing and swallowing. And for a limited time this book is on sale for 50% off its original price – now **just $10!** Call the Foundation office now at 703-356-2151 for your copy of this fantastic book! Hurry! Supplies are limited.

Foundation-Funded Research Continues

As reported in our September/October 2001 newsletter*, through proceeds from our 2001 Gala for Hope ~ Celebrating The Buddy Awards, the Parkinson Foundation's Research Program is currently funding two gene therapy experiments being conducted by Jeffrey Kordower, PhD. Dr. Kordower is the Director of the Research Center for Brain Repair, Neuroscience Section Head and Professor of Neurological Sciences at Rush Presbyterian Medical Center in Chicago, Illinois. Below Dr. Kordower provides an update on the progress made over the last quarter.

Gene Therapy for Parkinson's Disease: Progress Report

Jeffrey H. Kordower, PhD

We have been studying the effect of gene delivery of a trophic factor called glial cell derived neurotrophic factor (GDNF) in primate models of Parkinson's disease. We originally discovered that this gene delivery prevented the loss of dopamine neurons, the very dopamine neurons that die in PD. Not only did we prevent the loss of the cells, but behavioral changes in Parkinsonian monkeys were reversed.

We now have discovered a new phenomenon following gene delivery of GDNF. In both aged monkeys and Parkinsonian monkeys, we have found that gene delivery of GDNF induces a seven to eight-fold increase in the number of dopamine cells located directly in the striatum. These new cells have the neurochemical machinery to be functional dopamine neurons. It is possible that this new population of dopamine cells may, in part, be responsible for the functional recovery seen in monkeys following gene delivery of GDNF. A manuscript describing this data is currently under review.

*For a copy of the feature-length article in our September/October 2001 newsletter, *Foundation-Funded Research Underway: Gene Therapy for Parkinson's Disease*, on Dr. Kordower's research projects funded by the Parkinson Foundation, please call the Foundation at 703-356-2151 or visit our website, www.parkinsonfoundation.org and click on "Newsletters" to download a copy.

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The Parkinson Foundation of the National Capital Area gratefully acknowledges the following gifts received between 12/08/01-02/01/02. These contributions will help support research designed to find more effective treatments and a cure for Parkinson's disease, and will provide services to improve the lives of Parkinson's patients and their families.

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In Memoriam

With the help of these and many other donors, the fight to end PD continues as a tribute to the following people:

In memory of Conway Austin
Employees of Stein Mart

In memory of Jane Bornstead
Eugene and Margaret Johnson

In memory of Theodore Cray
Suzanne Richardson

In memory of Hazel DaDamio
Donald and Patricia Ayers
Robert and Sue Barnard
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Mark and Julie Simms
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Debra Timpe
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In memory of Ralph William Evely, Jr.
Edith and Shelly Laffoon

In memory of Rudy Goddard
Theodore & Roberta Roumel

In memory of Nancy Ann Graham
Suzanne Kaytis and Family

In memory of Jack Leschen
Helen Pixton

In memory of Herbert Long
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In memory of Jose Ossorio
Theodore & Roberta Roumel

In memory of Leroy Smith
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William and Reschia Wagner

In memory of Ray Smith
Lilian Lafont

In memory of Mabel Staveley
Mr. and Mrs. Edward T. Rosmarin

In memory of Milton Surkin
Theodore & Roberta Roumel

In memory of Minnie L. Swiscz
Mrs. H. Hagemann

In memory of James Taylor, Jr.
Col. and Mrs. Richard Bayus

In memory of Audrey Hope Wouters
Alice and Don Gross

Please note that all names have been carefully reviewed. Nevertheless, errors or omissions may occur. If your name has been misprinted or omitted, please accept our apologies. Questions or corrections should be directed to Kathy Kelley, Project Coordinator, at the Parkinson Foundation at (703) 356-2151.

Parkinson's Resource Library: NEWS & VIEWS

Beginning with this issue, each newsletter will feature a book review from our Parkinson's Resource Library. All of the books featured will be available for loan from the library.

This month's book is *Parkinson's Disease: A Complete Guide for Patients & Families*, written by William J. Weiner, MD, Lisa Shulman, MD, and Anthony Lang, MD (Johns Hopkins University Press, Baltimore, MD, 2001). The following review was written by Alice Gross and Rusty Glazer, PhD (PFNCA members and volunteers).

Three neurologists who specialize in the treatment of Parkinson's disease have written an informative and easily understood guide for patients and families. This extremely helpful book is clearly written and carefully describes the disease, signs and symptoms, methods of diagnosis, surgical and medicinal therapies, value of appropriate diet, exercise, and alternative therapies. Other issues include the relationship of PD to other diseases and problems of hospitalization of PD patients. Finally, the authors offer discussion of current research as well as a 'Question and Answer' section that provides thoughtful responses to inquiries about all facets of PD.

This book and many others are available for loan through our Parkinson's Resource Library. The library contains over 140 titles of books and videos available for loan to the PFNCA community. With new books arriving often, you're sure to find something of interest to you. For more information on what's available or to borrow a book or video from our library, please call the PFNCA office at 703-356-2151.

Parkinsonian Perspectives

PD and Me, a sketch of how I get along with PD

By Jack Simmonds

"I am going to diagnose you with Parkinson's disease." Thus ended almost six months of uneasy suspicion. Nevertheless, the moment when I shared this information with my wife produced tears and a feeling of depression that was to endure for several weeks. I may have succeeded in masking my inner feelings with a smile, but the truth was that my mind was in turmoil. My neurologist had given me a pamphlet describing the disease and his own words were something like, "Oh, you can expect to go on more or less normally for 5, 10 or perhaps even 15 years." One of my regular companions had a friend who had been living with PD for many years (a case of early onset). He apparently was leading a very active life. With the passage of time, I too learned to live with PD almost as though it was that "little shadow that goes in and out with me". I read what my encyclopedia had to say about PD. I purchased a book on the disease that was written for recently diagnosed patients. I am not certain how I learned of the existence of the Parkinson Foundation. In any event, it was months before I finally visited the office, met Michelle and sought her advice on supports groups that I might attend. It was another couple of months before I actually turned up at the Tuesday morning exercise group. In fact, what really got me moving was a chance meeting with Jim Victor at a Monday afternoon bridge group which I had begun attending after several years of hiatus. After the bridge party, Jim diplomatically asked whether I was a Parkinsonian. I had already entertained the very same suspicion about him. From that moment, we were bonded as though we had known each other for years.

The upshot of this acquaintance propelled me into the exercise group where I met many other people who were coping successfully with PD. Among them was Alice Gross who invited me to take part in the organization of the foundation's collection of books and videos. It was the process of reviewing these books and videos that gave me a quantum leap in my understanding of PD. **(See page 11 for more information on the Foundation's Resource Library.)** It was also the friendship of so many others sharing my experience that set me on what I consider a positive and productive life with PD.

If someone were to ask me, "How do you cope with PD?" I would answer: I am very careful to take my medicine regularly as prescribed, I attend the exercise group assiduously and I seek opportunities to make myself useful both in the local foundation and by maintaining those activities which I enjoyed before PD came on the scene. I volunteer at the Newseum once a week and I teach sailing at a local sailing school. If my morale is good it is because my wife, who works full time, makes me feel needed as housekeeper and right hand person on the domestic scene. She pushes me past my inertia and onto the street for walks around the neighborhood. She is also quick to sense when I do not feel like preparing the evening meal and we are off to a local restaurant, which is sustenance for soul and body.

Joke of the Month: *Poor Translations from Around the World*

Submitted By Michel Margosis

Cocktail lounge, Norway: Ladies are requested not to have children in the bar.

At a Budapest zoo: Please do not feed the animals. If you have any suitable food, give it to the guard on duty.

In a Nairobi restaurant: Customers who find our waitresses rude ought to see the manager.

On a menu at a Swiss restaurant: Our wines leave you nothing to hope for.

(Reflections -- Continued from page 3)

I learned that Parkinson's disease is a degenerative neurological illness caused by insufficient amounts of the neurotransmitter dopamine. Parkinson's disease progressively affects the control of movement and can alter posture, voice, and gait. The disease can have a significant impact on self-esteem as well as one's sense of efficacy in the world. Among other things, the weekly psychosocial support group provides a community for Parkinsonians who might otherwise be isolated by the devastating effects of the illness.

But the most powerful learning occurred within my experience in the group and from the Parkinsonians. Witnessing the supportive relationships that developed among group members, the members' commitment to attend the group despite numerous obstacles to physically getting there, and their willingness to be with each other in the pain and hope of this disease was, for this therapist-in-training, incredibly rich professionally, and deeply moving personally.

I remember in the first session I attended a member asked me, "How do you feel about disabled people?" Perhaps I should have anticipated such a question. At the time, I did not think about people with Parkinson's as being "disabled", but rather as having a chronic illness. I can't remember how I responded, but I do recall feeling a sort of "survivor's guilt." I often went running just before the group met. I wanted to hide my health. Ironically, group members frequently talked about wanting to hide their symptoms. Despite my fear of being presumptuous and my feelings of guilt, the group members consistently welcomed and accepted me into their world.

I knew the group was alive in me when, in early September, I had a dream about the group. In the dream I was late in arriving for the start of the group. I felt extremely anxious and irresponsible. When I arrived in the room where the group meets, I couldn't find the group. There were 12 doors in the room and I opened each door desperately searching for the group. Interestingly, there are 12 members in the group. What could this mean? I think it speaks to the growing importance of the group for me and my desire to be "a part of it." In subsequent groups, members shared their own desire to be recognized and accepted as more than their Parkinson's diagnosis.

A frequent topic in many group sessions was loss. We all experience loss on many levels, and the ability to adapt to our losses and seek deeper meaning in them is a shared human struggle. I learned that for people living with Parkinson's, losses are experienced in multiple ways: from the obvious loss of control over one's body movements to the loss of one's own (and others') perception of competence in the interpersonal and occupational world. What immediately struck me about the group was the care and support members extended to one another despite their own physical and emotional pain and despite their fear of perhaps having to personally endure a particular loss (of ability to work, walk, drive, etc…) that another member was currently coping with.

During my time in the group, one member's father died. Another member experienced great disappointment over having not been completely cured by an innovative form of treatment, deep-brain stimulation. The group is currently coming to terms with the unexpected death of one of its members. On September 11, group members shared their feelings of horror about the terrorist attacks on innocent civilians, as well as the trauma and invasion of Parkinson's in their own bodies.

For myself, I am now feeling the loss of the group in my life. It feels strange, after nine months, not to drive to Fairfax on Tuesday mornings. I miss knowing how the group members are doing. I miss the discussions about the group with my supervisor.

As time went on, my fears about fitting in and connecting with the group members diminished, in part, because I was open to the experience and in part because the group was open to me. As with any group of people, real differences will always separate one member from another. My experience in this group was that issues related to acceptance, competency, and loss became points of connection despite the differences in what each individual was experiencing at the time. For me, the interpersonal connection, sparked by our common struggle with existential realities, is where the healing occurs.

I want to thank the members of the Providence Recreation Center group for sharing their group and their lives with me. I would especially like to thank my supervisor, Leon Paparella, for his confidence in my abilities and his gentle guidance.

SUPPORT GROUP HAPPENINGS

Community Support Group News, continued

Dr. Linda Sigmund Offers the A-B-C's of Parkinson's Disease

The April meeting of the **Parkinson's Community Support Group** will feature PFNCA's Medical Director, Dr. Linda Sigmund. Dr. Sigmund will discuss the basics of the disease, as well as current therapies and practices. This meeting should prove valuable for everyone in the Parkinson's community. We look forward to seeing you on Wednesday, April 10, 2002 at 6:30 pm at the Epiphany Byzantine Church in Annandale, VA for this educational presentation. Please call Carolyn McCornac, PFNCA Patient Services & Outreach Coordinator, at 703-356-2151 for more information.

Anne-Marie Barry, PT, Presents the Importance of Exercise

The January 2002 meeting of the Parkinson Foundation's Community Support Group featured a presentation by physical therapist Anne-Marie Barry of Health-South Sports Medicine in Fairfax, VA. Ms. Barry discussed various exercise and stretching techniques designed to increase strength and flexibility. She spent a good deal of time demonstrating different exercises and generously gave out Thera-Bands (elastic exercise bands) to everyone who participated. Finally, Ms. Barry offered several very helpful tips for everyday activities, such as dressing and getting in and out of the car. Everyone in attendance benefited from this fun and educational meeting.

Panel Forum Discusses the Carepartner Relationship

Our February **Community Support Group** meeting featured a very insightful and thought-provoking panel discussion on the carepartner relationship. Moderated by PFNCA's Support Group Specialist Leon Paparella, the panel represented several perspectives on caregiving. Panelists included full-time, long-term caregivers, individuals with PD who are the recipients of such care, and individuals with PD living alone. The Foundation wishes to thank everyone who participated in this candid and stimulating presentation.

Other Support Group News

Young Parkinson Network to Discuss NIH Clinical Trials on Cognition and Neuroprotection in PD

Bernard Ravina, MD will address the Chevy Chase Young Parkinson Network on Thursday, March 21, 2002. Dr. Ravina recently joined the NIH staff at the NINDS. His time is split between intramural and extramural programs at NIH. For the intramural he conducts research on cognition in PD and he currently has a study testing the effects of Aricept (an Alzheimer's medication) on PD. In the extramural program Dr. Ravina is working on the large scale neuroprotection clinical trials that are being planned by NIH. This will be a very interesting meeting. The Young Parkinson Network meets on the third Thursday monthly at 7:30 pm at the Carlton Condominium, 4550 North Park Avenue, Chevy Chase, MD. For more information, contact Perry Cohen at 202-686-9430.

IONA Group In Search of Members

The IONA Senior Services Parkinson's Group is a small group of men and women of various ages with diverse symptoms and characteristics of PD. This group provides the members with the opportunity to go beyond describing symptoms and medications. An effort is made to explore the experience of living with Parkinson's disease and the psychosocial aspects of our relationship world. The IONA group meets at 11:00 am Friday mornings at IONA Senior Services at 4125 Albemarle Street, NW in Washington, DC. If interested in this group, please call one of the group leaders: Leon Paparella (PFNCA Support Group Specialist) at 202-966-4450, or Deb Rubenstein (IONA Social Worker) at 202-895-0249.

Financial Assistance

The PFNCA Patient Assistance Fund provides financial assistance to help cover essential medical care needs of Parkinson's patients in the National Capital Area who demonstrate adequate need. To request an application that outlines the grant criteria, please contact the Foundation office at 703-356-2151.

Support Groups in the National Capital Area

MARYLAND

BETHESDA

Parkinson Exercise Class
Mondays & Wednesdays at 11:00 am
$30/8-week session
CALL FOR SESSION DATES.
Bethesda Senior Source
4805 Edgemoor Lane
Contact: Bethesda Senior Source
Telephone: (301) 951-1990
Judy Cooper, Instructor

Parkinson Beginning Exercise
Fridays at 11:00 am
$20/8-week session
CALL FOR SESSION DATES.
Bethesda Senior Source
4805 Edgemoor Lane
Contact: Bethesda Senior Source
Telephone: (301) 951-1990
Judy Cooper, Instructor

Bethesda Carepartners Group
Every Monday at 11:00 am
Bethesda Senior Source
4805 Edgemoor Lane
Contact: Leon Paparella
Telephone: (703) 356-2151

CHEVY CHASE

Young Parkinson Network
3rd Thursday monthly at 7:30 pm
The Carlton Condominium
4550 North Park Avenue
Contact: Perry Cohen
Telephone: (202) 686-9430

VIRGINIA

ANNANDALE

PFNCA Community Support Group
2nd Wednesday monthly at 6:30 pm
Epiphany Byzantine Church
3410 Woodburn Road
Contact: Leon Paparella
Telephone: (703) 356-2151

ARLINGTON

Arlington Group
2nd Tuesday monthly at 2:00 pm
Calvary United Methodist Church
23rd & South Grant Streets
Contact: Leon Paparella
Telephone: (703) 356-2151

CENTREVILLE/CHANTILLY

Sully Group
4th Saturday monthly at 10:00 am
Sully Senior Center
5690 Sully Road (Route 28)
Contact: Darryl Edwards
Telephone: (703) 378-9213

FAIRFAX

Little River Glen Group
3rd Thursday monthly at 2:00 pm
Little River Glen Senior Center
4001 Barker Court
Contact: Leon Paparella
Telephone: (202) 966-4450

FALLS CHURCH

Providence Parkinson Group
Every Tuesday at 10:15 am
Speak to Leon if interested in joining.
Providence Recreation Center
7525 Marc Drive
Contact: Leon Paparella
Telephone: (703) 356-2151

Parkinson Exercise Class & Providence Carepartners Group
Every Tuesday at 11:00 am
RUN SIMULTANEOUSLY.
$5 fee for exercise class
Providence Recreation Center
7525 Marc Drive
Contact: Leon Paparella
Telephone: (703) 356-2151
Judy Cooper, Instructor

MANASSAS

Manassas Group
2nd Monday monthly at 7:00 pm
Westover Baptist Church
10301 Sudley Manor Drive
Contact: Betty Gray
Telephone: (540) 439-0996

MCLEAN

Young Onset Group
1st Thursday monthly at 7:00 pm
Dolly Madison Library Meeting Room
Ingleside Road
Contact: Hilary Blue
Telephone: (703) 821-1393

WOODBRIDGE

Woodbridge Group
2nd Saturday monthly at 10:30 am
River Run Apartments, Building One
13901 Hedgewood Drive
Contact: Bonnie Clegg
Telephone: (703) 590-1938

WASHINGTON, DC

Georgetown Group
3rd Monday monthly at 2:00 pm
Georgetown University Medical Center
Lombardi Cancer Center
Martin Marietta Room
3800 Reservoir Road, NW
Contact: Leon Paparella
Telephone: (703) 356-2151

IONA Parkinson Group
Every Friday at 11:00 am
Speak to Leon if interested in joining.
IONA Senior Services
4125 Albemarle Street, NW
Contact: Leon Paparella (PFNCA)
Telephone: (202) 966-4450
Contact: Deb Rubenstein (IONA)
Telephone: (202) 895-0249

Sibley Group
2nd Thursday monthly at 4:00 pm
Sibley Memorial Hospital
Renaissance Building
1st Floor Meeting Room
5255 Loughboro Road, NW
Contact: George Marsh
Telephone: (202) 537-4491

For more information about any of these Area Parkinson Support Groups, Exercise Classes or Carepartner Support Groups, please contact Carolyn McCornac, Patient Services and Outreach Coordinator, at the Parkinson Foundation of the National Capital Area office at: (703) 356-2151.

Support the Parkinson Foundation of the National Capital Area!

03/02

The Parkinson Foundation of the National Capital Area's (PFNCA) mission is to provide patient services and support for people with Parkinson's disease, to support promising Parkinson's disease research, and to raise awareness about the disease and our search for a cure. We support our programs and activities entirely through private funding from donors like you.

By making a contribution to the Parkinson Foundation, you show your support of our mission. As a PFNCA Member/Supporter, you'll receive this newsletter, the *Parkinson Update*, which features articles on new treatments and research in the Parkinson's disease arena, on what's new in the National Capital Area Parkinson's community, and on upcoming PFNCA activities. You'll be eligible to attend any of our Parkinson or Caregiver Support Groups and Parkinson Exercise Classes throughout the DC/VA/MD Metropolitan area. You'll also receive special mailings on upcoming PFNCA events and symposia. The basic annual membership dues is $30. Larger contributions are greatly appreciated. We will graciously accept whatever you can afford. PFNCA is a 501(c)(3) nonprofit organization. All contributions are tax deductible to the extent permitted by law.

We hope you will consider making a contribution to PFNCA today!

Return this completed form with your contribution.

Please make checks payable to the ***Parkinson Foundation of the National Capital Area*** & mail to:

Parkinson Foundation • 7531 Leesburg Pike • Suite 402 • Falls Church, VA 22043

I would like to: ☐ Become a PFNCA Member ☐ Renew my Membership ☐ Make a Contribution (please ✓ one)

Here is my contribution for: ☐ $30 ☐ $50 ☐ $100 ☐ $500 ☐ $ ______ Other (please ✓ one)

Name: ______________________________

Address: ______________________________ City: ______________

State: ______ Zip Code: ______________ Phone: ______________ E-mail: ______________

Support Group/s Attended (if any): ______________________________

*My Visa/Mastercard credit card number is: ______________________ Expiration Date: __________

Signature: ______________________ *Name and address listed above should match credit card billing information.

Parkinson Foundation
of the National Capital Area
7531 Leesburg Pike, Suite 402
Falls Church, VA 22043-2120

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