



THE

PADRECC

POST

SPRING 2007

THE PHILADELPHIA VA PARKINSON'S DISEASE RESEARCH, EDUCATION AND CLINICAL CENTER

Help Win the War on Parkinson's Disease John Duda, M.D.

HERO is not a word that should be used lightly when talking about the VA and veterans.

PADRECC takes great pride in serving our patients who deserve to be called *heroes*. Not only, for their heroic actions during their service to our country, but for their selfless acts to benefit their fellow man. I am talking about a different kind of hero. These are not veterans returning from service in the Middle East, these are veterans who are long past their days of military service. They too are fighting a war. They are fighting a war against Parkinson's Disease (PD). Everyone with PD is fighting a personal battle against the illness in their own lives. I believe the true heroes are those people with

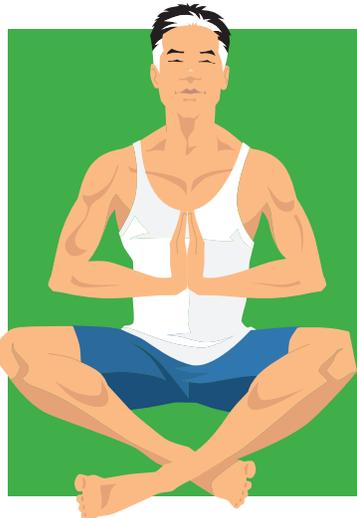
PD who contribute to the fight against PD, whether or not their actions will directly benefit themselves. They help the fight against PD in many ways.

One of the most important ways is participating as subjects in clinical research studies. At the PADRECC, many clinical research studies are designed to understand the disease better and do not include any form of treatment. These studies are risk-free and only require a commitment of time. The studies that include medications or treatments are either proven safe in other conditions, (for example the treatment of depression), but still need to be proven effective in the treatment of PD symptoms. PD patients may have different reactions to medications when compared to non-PD patients on

the same medication. PD patients also may have unexpected interactions with their PD medications. These are important studies that verify if these treatments work and if they are worth the risk of the side effects. Other studies compare two or more commonly used medications to determine which works the best. Studies on newly developed *continued on page 2...*

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Mind, Body & Spirit: Holistic Health and PD

Rebecca Martine, APRN, CS, BC

On April 28, 2006, the Philadelphia PADRECC family celebrated Parkinson's Awareness Month with an afternoon of relaxation, music, and dancing.

The Mind, Body & Spirit Fair was deemed our best education program to date by many attendees, which included PADRECC patients, relatives, and friends. The festivities started off with a yoga demonstration by Pana Flower, a yoga instructor of 36 years who *continued on back page...*

Philadelphia VA Travel Benefits



(An excerpt from the PVAMC Travel Benefits brochure.) Please note that this is *only* a reference and does not address *all* travel situations. Please contact the Travel Department at the numbers listed below for assistance with your travel needs.

Hours of Operation:
Monday-Friday
8:00am to 4:30pm

To schedule a transportation pick-up, please call by **2:45pm** the day before your scheduled appointment.

Travel Section Supervisor 215-823-4165
Travel Clerks 215-823-5810

Benefit Description

If you meet the below criteria, you may be eligible for VA Travel benefits to obtain VA health care services only. In most cases, travel benefits are subjected to a deductible. Exceptions to the deductible requirement are:

- Travel for compensation and pension examination.
- Travel by ambulance or a specially equipped van.
- *Travel by car service will cost \$3.00 per trip. In order to be picked up by transportation, you must already have an appointment in the VA's system.*

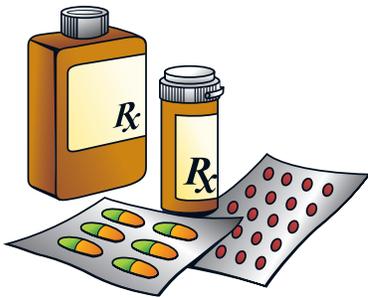
You Qualify If:

- You have a service-connected rating of 30% or more. *This travel will be for all scheduled VA appointments.*

- You are traveling for treatment of a service-connected condition. *This must be a service-connected condition already verified by the VA and if under 30% can only be used for that service-connected condition appointment.*
- You receive a VA pension.
- You are traveling for a scheduled compensation or pension examination.
- Your income does not exceed the maximum annual VA pension rate. *The veteran's income information must be updated yearly in the VA's system; the maximum amount for the means test is currently \$32,285 yr (call Travel Department for more information on **Income Verification**)*
- Your medical condition requires an ambulance or specially equipped van, you are unable to defray the cost, and the travel is pre-authorized (authorization is not required for emergencies if a delay would be hazardous to life or health). *This must be justified in writing by your physician on the VA's Request for Special Mode Transportation Form. Please contact your physician's clinic to have this form completed. Submitted requests 7-10 business days before scheduled visits.*

Please contact the Travel Department for a travel brochure or for further information on Deductible Provisions, Income Verification, Financial Assessment (Means Test), VA of Choice, and Claim Reimbursement

Help Win the War on Parkinson's Disease *(continued from front page)*



medications are a great way for patients to gain access to the latest therapies. Participation in these studies is essential to advance our understanding of the treatment for all patients suffering with PD.

A second way that patients help in the fight against PD is to volunteer for genetic studies. While PD is not considered an inherited disease, there are

certainly some genes that act as risk factors for developing PD. Current studies are finding those genes that may lead to novel therapeutic approaches for patients with PD. Patients with close relatives who have PD are valuable for these genetic studies.

Another powerful way patients help the fight is to devote time to PD advocacy. It gives them a sense of empowerment. Joining organizations like the **Parkinson's Action Network** who are committed to making sure patients, caregivers and researchers get the help they deserve from the federal government through publicity and lobbying efforts. With local advocacy teams in every state, they are always looking for enthusiastic new

recruits who are willing to tell their personal stories of how PD has affected their lives. Government officials listen to these recruits. Also, the teams inform representatives about ways the government can spend tax money to help fight the war against PD.

Finally, the most important way patients can help in the fight, is to sign up to make a brain donation at one of the research centers that collect and study the brains of patients with PD. Unfortunately, we still don't understand what goes wrong in the brain of a patient with PD, and studying their brains, when they are done using them, is one of the best ways to find out. *continued on the next page...*



Patient and Caregiver Support Group Schedule

The 2007 PADRECC Support Group Program will be held the **1st TUESDAY** of every month from **1:30pm-3:00pm** in the **4th Floor PADRECC Conference Room**.

Please Note Day and Time Change of Group:

1st Tuesday of each Month 1:30pm-3:00pm

April 3rd *Speaker:* Jayne Wilkinson, MD, PADRECC Fellow
Topic: Parkinson's Disease: The Symptoms You Don't Know About

May 1st *Discussion Group

June 5th *Speaker:* TBA *Topic:* TBA

July 3rd *Discussion Group

Aug 7th *Discussion Group

Sept. 4th *Speaker:* Dr. Weintraub, PADRECC Geriatric Psychiatrist

Topic: Compulsive Behaviors in PD

Oct. 2nd *Discussion Group

Nov. 6th *Speaker:* Lisette Bunting-Perry, RN, MSN, PADRECC Nurse

Topic: Parkinson's Disease and Pain

Dec 4th End of Year Party

* Discussion groups will be divided into patient and caregiver sessions. Topics will be informal and chosen by the attendees. **Please note:** Topics and locations may change without notice if speakers and/or rooms become unavailable.

Help Win the War on Parkinson's Disease *(continued from page 2)*

There are many misconceptions regarding brain donations. These keep many people from signing up for donation. Physician and nurses understand that it can be difficult—emotionally—to talk about. I encourage anyone who has considered brain donation to talk with their clinician to learn more about this special and valuable opportunity. The benefits include, but are not limited to: your family receiving an absolute diagnosis of the cause of PD symptoms (this will help your children or grandchildren, for their future); your loved ones receiving comfort, knowing that the last act of giving will help others with PD; and helping researchers find better treatments and a cure for many people who are living with this illness.



Donating is a personal decision with many factors involved, but every family I have know who has gone through this process was proud and comforted by the ultimate contribution made by their loved one.

I don't know if it is something ingrained in people who have served their country so proudly, but I am often told by veteran patients that they want to do anything they can to help. As a physician and researcher, I am truly inspired by their dedication.

I will always consider those patients who make these types of selfless contributions as heroes in the fight to find better treatments and even a cure for PD.

Patient and Caregiver Stories...

No More Dyskinesia

That is the wonderful gift I received from Deep Brain Stimulation Surgery. Why should I take a chance with DBS I asked? I don't have a tremor. On the video it showed how people improved their ability to live a "normal" life after they had DBS; it showed how their tremors completely stopped or subsided, and they almost looked normal again. It's not for me I said again, I don't have a tremor. But I had suffered the terrible side effects of too much medication...dyskinesia. I remember rolling around on the floor for hours, praying that it would stop. Now it has completely stopped, thanks to DBS.

A satisfied patient in the PADRECC Study Group who has been Dyskinesia free since surgery.

We are looking for YOUR stories...

If you have a story of hope, encouragement, struggle etc. living with PD or other movement disorder and you would like to share it, please follow the below guidelines and send them to us. Please keep in mind that our newsletter is published once a year and only one story will be published in each newsletter.

Submission guidelines:

*Your story should be **type written** and **no more than 150 words**. Your submission will remain anonymous.*

Please mail your story to:

Gretchen Glenn, PADRECC SW
3900 Woodland Ave #127
Philadelphia, PA 19104

Mind, Body & Spirit: Holistic Health and PD *(continued from front page)*

now offers specialized classes for people with PD. Lawrence Tran followed with a discussion of Zen Tissue Massage, a unique form of massage therapy that rejuvenates and heals stressed muscles and tissues. Nina Chychula, a VA Nurse Practitioner, and members of the American Tai Chi School reviewed the basic principles of Tai Chi and had attendees practice this form of “meditation in motion”. The presentations concluded with a dynamic session of singing and dancing lead by Misty Owens and William Wade, members of the Brooklyn based Mark Morris Dance Group. What a site...all 50+ participants holding hands while they swayed back and forth singing “New York, New York”!! Throughout the program, free massages were offered by students of the National Massage Therapy Institute. It is safe to say that everyone left the program feeling energized yet calm and light hearted.

New Additions

to the PADRECC Family

Eileen Hummel, RN, *Staff Nurse*

Esther Payton, *Patient Services Assistance*

Adrian Chan, MD, *Fellow*

Jayne Wilkinson, MD, *Fellow*

The PADRECC also has some new additions to our Extended Family:

Jackson Glenn

son of Gretchen Glenn, social worker

Johanna Duda

daughter of Dr. John Duda

Victoria Rose

daughter of Dawn McHale, Administrative Officer

Sophia Teri Rick Yudell

daughter of Dr. Jacqui Rick

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