



PADRECC

NEWS

The Newsletter of the Veterans Health Administration's
Richmond/ Southeast Parkinson's Disease Research Education and Clinical Center

A Year in Review

By Miriam L. Hirsch, M.S., R.N., Associate Director of Education

2003 was a busy year for the Richmond/Southeast PADRECC. Currently, over 300 veterans with Parkinson's disease have been evaluated in our interdisciplinary clinic that involves neurology, physiatry, neuropsychology and nursing assessments.

The PADRECC neurosurgery clinic has been growing steadily. A full-page article on the success of the program recently appeared in the *Richmond Times Dispatch*, a newspaper that is distributed throughout the state of Virginia with a daily circulation estimated at 200,000 copies. Dr. Kathryn Holloway, the PADRECC neurosurgeon currently serves as the Veterans Health Administration's (VHA) National Chair for the Prosthetics and Clinical Management Committee for the Use of Deep Brain Stimulation.

A telemedicine clinic was developed in an effort to expand specialty care services offered by the PADRECC throughout the southeastern United States. This clinic is one of the most successful telemedicine clinics at McGuire VAMC and involves a live, interactive telecommunication link between the remote site (the closest VA hospital or outpatient clinic) and our VAMC. The primary goal of the program is to deliver PADRECC specialty care to remote sites as well as to reduce the long distance travel time of patients. Veterans from as far away as Miami and Alabama have been seen in our clinic. It was estimated that over 3,000 miles and nearly 52 hours of travel time was saved for just 14 telemedicine visits. The clinic has expanded by 50% over the past year.

The PADRECC sponsored its first conference for patients and families in the spring of 2003. It was quite a success with over 215 attendees. We teamed up with the American Parkinson Disease Association (APDA) Information and Referral Center of Virginia as well as the University of Virginia Health System and Virginia Commonwealth University Medical Center. The all-day program featured presentations on current research, speech therapy, surgical intervention, memory and behavioral changes and caring for the caregiver. The second annual PADRECC conference is scheduled for June 2004. Please refer to page four for details.

Numerous research projects were conducted at the Richmond/Southeast PADRECC in 2003. They include, but are not limited to the following:

- Promising new medicines including a monoamine oxidase inhibitor and transdermal dopamine agonist patch. The patch has recently been approved by the FDA.
- Stem cell research investigating the potential of using adult stem cells for cell replacement strategies.

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Moving on with Parkinson's Disease

An All-Day Conference
for People with Parkinson's
Disease and their Caregivers

See page 4 for details



Southeast PADRECC

In 2001, the Veterans Health Administration (VHA) created six Parkinson's Disease Research, Education and Clinical Centers (PADRECC) in an effort to improve care for veterans suffering from Parkinson's disease and to pursue treatments and a cure for this condition. The centers are located in Philadelphia, Richmond, Houston, Portland/Seattle, San Francisco and West Los Angeles.

The Hunter Holmes McGuire VA Medical Center in Richmond, VA is home to the PADRECC for the southeastern region of the United States. PADRECC services include but are not limited to interdisciplinary assessment and treatment, clinical trials, physician consultation, medical management, surgical interventions, neuropsychological services, physical and occupational therapy, speech therapy, nursing services, caregiver resources, educational materials, community education programs and support services.

To learn more about the Richmond/Southeast PADRECC please contact:

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Richmond PADRECC website:
www.va.gov/netsix-padrecc/

National PADRECC website:
www.va.gov/padrecc

A Year in Review Continued...

- Ambulation training with auditory and visual cueing and its impact on gait mechanics.
- Effect of Parkinson's disease on eye and head movements during reading.
- Pain perception in people with Parkinson's disease.
- Basal ganglia research examining the electrophysiological activity in areas of the brain that are involved in Parkinson's disease.

An interdisciplinary database was completed in 2003 and serves as a clinical, research, and program evaluation tool. Information is collected that will help track disease symptomatology and progression, treatments and response to intervention. This local database will be part of a national VA database of PD, the largest PD database in the world.

2003 was a busy and productive year for the Richmond/Southeast PADRECC. We look forward to accomplishing our goals for 2004 and are thankful for the opportunity to offer our veterans expert clinical care, support services, research and educational opportunities



PADRECC Support Group

The Richmond/Southeast PADRECC sponsors a monthly support group for veterans with Parkinson's disease and their families. Our group meets every 4th Thursday of each month from 1:00-2:30 and involves a 40-minute educational session by a guest speaker followed by separate groups for patients and caregivers. The 2004 meeting agenda is as follows:

February 26	Educational Resources for Veterans
March 25	Caregiving in Parkinson's Disease
April 22	Getting the Care You Need
May 27	Rehabilitation Issues in Parkinson's
June 24	Fall Prevention Strategies
July 22	Medical Management of Parkinson's
August 26	Nutritional Needs and Concerns
September 23	Stress Management Techniques
October 28	Speech and Swallowing Issues
November 18	New Developments in Deep Brain Stimulation
December 16	Holiday Gathering

Caregiving 101: What Caregivers Need to Know

By Phillip Pegg, PhD, PADRECC Psychology Fellow

Parkinson's disease is a common chronic motor system disorder that is associated with the loss of dopamine producing brain cells. The loss of dopamine causes certain nerve cells to fire out of control. This causes difficulty in one's ability to direct or control movement in a normal manner. The four primary symptoms of PD include tremor or trembling in hands, arms, legs, jaw, and face; rigidity or stiffness of the limbs and trunk; *bradykinesia*, or slowness of movement; and postural instability or impaired balance and coordination. Individuals with PD may also have difficulty walking, talking, and/or completing simple tasks.

Because of the progressive nature of PD, patients may find themselves needing assistance from others at some point.

Caregiving assistance is generally categorized in two ways. First, there is paid or *formal caregiving* provided by trained professionals. The second form of caregiving is *informal caregiving* that refers to the caring support offered by friends and families. The majority of care is provided by these informal caregivers. It goes without saying that caregivers are vital in the management of people with PD and they deserve to be nurtured and supported in this valuable role.

While most of the attention of the healthcare community naturally falls on treating the person with PD, the difficulties that caregivers can experience need to be addressed also. Different aspects of the stress or burden that caregivers may experience have been

identified. *Kasuya* describes caregiver burden as the strain or load borne by a person who cares for an elderly, chronically ill or disabled family member or other person.¹ At its most extreme, such caregiver burden becomes so great that neither the caregiver nor the patient receiving care can continue without some type of outside support options (such as assisted living).

Many factors contribute to caregiver burden and the response to that burden. Factors including the physical, psychological, social, financial, and emotional health or well being of the caregiver can influence one's perception of his or her burden. In addition, if the caregiver develops a physical illness or becomes emotionally exhausted, he or she

may no longer be able to effectively provide care and assistance. Some of the problems faced by caregivers include feelings of discouragement, the need for more information, the need for better sleep and a break from the obligations of caregiving from time to time. Research has shown that caregivers who ignore their own physical and mental health are more prone to serious illness themselves.

Informal caregivers provide a valuable service that is often under-appreciated. It is important that caregivers take care of themselves. The following tips may be helpful in learning how to do this:

Caregivers who ignore their own physical and mental health are more prone to serious illness themselves.

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Caregiving 101 Continued...

► **Don't be afraid to ask others for help.** Don't try to "go it alone." People may want to help but are waiting to be asked.

► **Make time for yourself.** Take small breaks - shop, get your hair done, or take a walk. While they may be more difficult to arrange, occasional weekend getaways may be refreshing.

► **Ask questions.** Learning about PD can help caregivers feel more in control. Doctors, nurses and social workers can be a wonderful source of information. Read the literature that is available and if accessible, visit the PD websites.

► **Make sure prescribed medications are taken correctly.** This may help reduce unnecessary trips to the doctor.

► **Be realistic about finances.** Seek financial advice to get your finances more in order.

► **Watch the quality and pattern of sleep.** Broken or fragmented sleep is a major contributor to caregiver burden. Why are you not sleeping well? Are you awakened by your loved one during the night? Are you sleeping "with one eye open?" If so, talk to your doctor about these concerns.

► **Don't neglect your physical health.**

► **Make time for friends.** Socializing can help ease the burden.

► **Laugh as much as you can.**

► **Appreciate what PD has not affected.** While not able to do some things, you and your loved one can still find some pleasurable pursuits that can be enjoyed together.

► **Discuss depressed, anxious or worried feelings with someone such as a mental health professional.**

► **Strengthen your spiritual faith if you are so inclined.**

Reference:

Kasuya, RT, Polgar-Bailey, P., and Takeuch, R. Caregiver Burden and Burnout. Postgraduate Medicine. Volume 108, Number 7, December 2000.



Moving on with Parkinson's Disease

2nd Annual Patient and Family Symposium

The 2nd annual PADRECC sponsored patient and family symposium will be held on June 12, 2004 in Richmond, VA. The all-day program features the following:

9:00 a.m.	Arrival & Check In
9:30 a.m.	Welcome & Introductions
9:45 a.m.	Parkinson's Disease & the Art of Moving – Part I
11:00 a.m.	Break
11:15 a.m.	Parkinson's Disease & the Art of Moving – Part II
12:15 p.m.	Lunch
1:30 p.m.	<i>Concurrent Programs</i> New Discoveries in Parkinson's Disease Management and Care Training Workshop for Fitness and Rehabilitation Professionals
3:30 p.m.	Closing Remarks
3:45 p.m.	Adjournment

The morning session will feature Mr. John Argue, actor, director and theatre arts teacher who has developed a unique and powerful exercise program for people with Parkinson's disease. Mr. Argue will demonstrate and teach an *artful way* of moving and speaking. He will offer an afternoon workshop for exercise and rehabilitation professionals.

A distinguished panel of physicians who specialize in the treatment and management of Parkinson's disease and who are involved in cutting-edge research will share the latest developments in the quest to find better treatments and ultimately a cure for Parkinson's disease.

For more information about the conference or to request a brochure, please call Miriam Hirsch, PADRECC Associate Director of Education at (804) 675-6952.



The Benefits of Rehabilitation Medicine in the Management of Parkinson's Disease

By Abu Qutubuddin, M.D., PADRECC Clinical Instructor and Fellow

The term "rehabilitation" can be defined as the development of a person to his or her fullest physical, psychological, social, vocational, avocational, and educational potential, consistent with his or her physiological or anatomic impairment and environmental limitation. In 1199 AD, *Maimonides*, a philosopher from Spain, said that "anyone who lives a sedentary life and does not exercise, even if he eats good foods and takes care of himself according to proper medical principles – all his days will be painful ones and his strength shall wane."

As a rehabilitation physician (also known as a physiatrist), I always encourage my patients to be as actively healthy as possible but the question is how?

While taking the proper medications is essential in managing Parkinson's disease, there are other factors that need to be considered as well. Good eating habits, rest during the day, proper sleep-wake cycle that involves adequate sleep at the proper time of day and regular, consistent exercise all play important roles in Parkinson's disease rehabilitation.

A skilled physiatrist will be able to suggest appropriate exercises based on one's current level of functioning and medical difficulties. Referrals are made to physical therapists who evaluate gait, balance and exercise tolerance. Access to community resources such as the YMCA, transportation services and formal therapy clinics is important to assess. Physiatrists can

help to determine what adaptive equipment is needed such as a cane, walker, wheelchair, scooter and bathroom accessories like grab bars and shower benches.

Rehabilitation in Parkinson's disease focuses on muscle strength, coordination of movement, one's ability to perform day-to-day activities, walking and balance. A physiatrist helps to identify the areas of disability experienced by the patient and prioritizes them according to his/her need. The treatment plan addresses the management of the disabilities through:

- ❖ Determining and ordering the most appropriate assistive devices such as a cane or wheelchair.
- ❖ Instruction in adaptations to everyday tasks performed at home as well as to home exercise programs.
- ❖ Development of home exercise programs.
- ❖ Education of patient and family about the disease process and the purpose of specific therapies and exercises.
- ❖ Provision of counseling and access to support groups and community services.
- ❖ Regular follow-up evaluations of one's medical and rehabilitation status to ensure that the treatment programs are appropriate with disease progression.

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Rehabilitation Medicine Continued...

A variety of therapy approaches focus on the different symptoms of Parkinson's disease. Gait, balance and postural difficulties can be treated with various physical therapy techniques including *kinesiotherapy* (exercise principles that enhance strength, endurance and mobility), Tai chi and yoga as well as through the use of adaptive equipment. Some of the therapies include the following:

- ❖ Occupational therapy, adaptive equipments for tremor, bradykinesia and rigidity.
- ❖ Speech and language therapy for speech and swallowing.
- ❖ Medications for autonomic dysfunction.
- ❖ Physical therapy and kinesiotherapy, occupational therapy and adaptive equipments to compensate for reduced cardiopulmonary functioning.
- ❖ Psychology, counseling, occupational therapy for changes in cognition and for depression.
- ❖ Occupational therapy and kinesiotherapy to help with activities of daily living.

Despite the progressive nature of Parkinson's disease, it is important to remember that there is usually something that can be done to improve quality of life. Consistent and on-going exercise programs performed at home or in a neighborhood health club are an important complement to the medical management of Parkinson's disease.



Information About Parkinson's Disease

A variety of free educational materials including booklets, fact sheets, videotapes, and magazines are available through the Richmond/Southeast PADRECC lending library. In addition, our staff is available to answer questions about Parkinson's disease and its treatment. Please call (804) 675-6952 if you need assistance.



American Veterans (AMVETS) 2003 Veterans Day Speech

The following excerpts from the 2003 AMVETS Veterans Day Speech have been reprinted with permission

As a nation, we have prospered because we've always had citizens willing to stand up and answer the call in times of danger. Whether at peace or at war, the important role of the veteran cannot be denied.

Peace itself demands continuing effort and renewed sacrifice by those who serve. And when peace fails, and freedom is threatened, Americans have always responded. For no matter where or when our veterans have served, they've always served with distinction.

Veterans represent men and women from all walks of life – some ordinary, some famous. They represent a great cross-section of America, but they share one thing in common - a love of country. It is a bridge that every generation has lengthened. The spans have built courage, dedication and patriotism.

We must extend a helping hand to those veterans who may need support- and our understanding. We can ensure that they receive adequate medical care, opportunities for employment- and a good education. In doing so, we celebrate their heroism, their dedication and selfless commitment to our country.

To these military veterans, whose service spans every decade, every year, every day of our country's existence, we owe a great deal. We owe them our freedom. We owe them our heritage. We owe them our gratitude.

Thank you – and God Bless America.

To view the speech in its entirety, please visit the AMVETS website at www.amvets.org

Nationwide Teleconference on Parkinson's Disease A Success!

A three-hour educational program for healthcare professionals has been developed by the Parkinson's Disease Research Education and Clinical Center (PADRECC) network within the Veterans Health Administration, the Employee Education System (EES), and the Virginia, Western Reserve, Mountain State and Pennsylvania Consortia of Geriatric Education Centers.

The program was originally presented in November 2003 as a nationwide teleconference at which over 1,000 healthcare professionals throughout VHA and the private sector viewed the training materials. The program offers specialized training for clinicians including physicians, nurses and allied staff in the treatment and management of people with Parkinson's disease. It consists of six, 30-minute educational modules which include an overview of Parkinson's disease, medical management, rehabilitation strategies, cognitive and behavioral changes, surgical intervention and research.

The training materials can now be purchased for \$30.00 and include two videocassette tapes and a packet of handouts. Please call the Richmond/Southeast PADRECC at (804) 675-6952 for more information or visit the national PADRECC website at www.va.gov/padrecc for more information and an order form.

Meet the Staff

In an effort to help improve the quality of care to veterans with Parkinson's disease and their families and to increase public awareness and understanding of this condition, the Richmond/Southeast PADRECC is staffed with many caring and knowledgeable people. The PADRECC team includes:

Vincent Calabrese, M.D.
Director and Neurologist

Mark Baron, M.D.
Associate Director of Research and Neurologist

Rashelle Brown, B.S.
Clinical Research Fellow

William Carne, Ph.D.
Psychologist

David Cifu, M.D.
*Associate Director of
Patient Care Services and Psychiatrist*

Helen Fillmore, Ph.D.
Adult Stem Cell Lab Director

Miriam Hirsch, M.S., R.N.
Associate Director of Education and Editor

Kathryn Holloway, M.D.
Neurosurgical Director and Neurosurgeon

Kelli Massey-Makhoul, R.N.
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Phillip Pegg, Ph.D.
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Abu Qutubuddin, M.D.
Clinical Instructor and Psychiatry Fellow