



### **NEWS**

Volume 8 Number I Summer 2010

The Newsletter of the Veterans Health Administration's **SOUTHEAST PADRECC** (Parkinson's Disease Research Education & Clinical Center) at McGuire VAMC

# Parkinson's Disease is Added to List of Presumptive Illnesses for Vietnam Veterans Exposed to Agent Orange VA Publishes Final Regulation on August 31, 2010

News Release from Department of Veterans Affairs, Office of Public Affairs, August 30, 2010:

VA Publishes Final Regulation to Aid Veterans Exposed to Agent Orange VA Health Care and Benefits Provided for Many Vietnam Veterans



WASHINGTON – Veterans exposed to herbicides while serving in Vietnam and other areas will have an easier path to access quality health care and qualify for disability compensation under a final regulation that will be published on August 31, 2010 in the Federal Register by the Department of Veterans Affairs (VA). The new rule expands the list of health problems VA will presume to be related to Agent Orange and other herbicide exposures to add two new conditions and expand one existing category of conditions.

"Last October, based on the requirements of the Agent Orange Act of 1991 and the Institute of Medicine's 2008 Update on Agent Orange, I determined that the evidence provided was sufficient to award presumptions of service connection for these three additional diseases," said Secretary of Veterans Affairs Eric K. Shinseki. "It was the right decision, and the President and I are proud to finally provide this group of Veterans the care and benefits they have long deserved."

Continued on page 5

## VA Research: Deep Brain Stimulation Corner Equally Effective in Two Sites



On June 3, 2010, the New England Journal of Medicine (NEJM) published the results from the largest ever, randomized, controlled study of deep brain stimulation (DBS) for advanced Parkinson's disease. Kathryn Holloway, MD, Neurosurgeon at Southeast PADRECC and Virginia Commonwealth University (VCU) Medical Center in Richmond, Virginia is one of the study authors. PADRECC and VCU were two of the thirteen sites for the study.

The study found that DBS at two different targets, the subthalamic nucleus (STN) and the globus pallidus interna (GPi), produces similar motor and quality of life improvements for Parkinson's patients.

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Highlights



### **Southeast PADRECC Staff**

Mark Baron MD
Director, Southeast
PADRECC Neurologist
Movement Disorder Specialist



Kathryn Holloway MD Director, PADRECC Neurosurgical Services Neurosurgeon





**Multidisciplinary Team** 

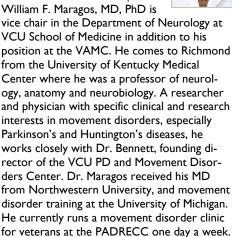
Vanessa Banks, Program
Support Assistant
William Carne, PhD
Psychologist
George Gitchel, MS
Research Assistant
Miriam Hirsch, MS, RN
Neurosurgical Nurse Coordinator
Lynn Klanchar, RN, MS
Associate Director of Education
Cathy McGrady,
Administrative Officer
Peggy Roberge, RN, Clinic

Our doctors have dual appointments and academic affiliations at Virginia Commonwealth University (VCU).

Nurse Coordinator

Please Welcome
Will Maragos, MD
Chief, Neurology McGuire
VAMC

Neurologist Movement Disorder Specialist



### In the PADRECC Clinic

Services offered for Veterans with Movement disorders such as Parkinson's Disease (PD) & Essential Tremor (ET)

- New and follow up visits
- Telemedicine visits—for Veterans who live farther distances from Richmond
- Multidisciplinary Approach—assessment/treatment/education by:
  - -Movement Disorder Specialist
  - -Registered Nurse
  - -Rehabilitation Doctor/Physiatrist
  - -Neuropsychologist
  - -Neurosurgeon and Neurosurgical nurse
- Medications and medical management
- Deep Brain Stimulation (DBS) surgery and programming
- Rehabilitation evaluation and referrals to PT, OT, Speech and Social Work
- Neuropsychological assessment of cognitive and emotional status
- Educational materials, support groups, exercise group, and educational events
- Caregiver resources
- Palliative care and hospice care referrals
- Clinical trials/research studies

Hunter Holmes McGuire VAMC Richmond, Virginia

Home to Southeast PADRECC
PADRECC Clinic is located on 2C, next to
Neurology Department (2B) on 2nd floor.
Follow signs from the South Elevators

to PADRECC (2C). Check-in: Room 2C-110 Phone (804) 675-5931

#### How do I get an appointment?

- To receive treatment at the PADRECC Clinic, you must be a Veteran & enrolled in VA Health Care. Call Veterans Health Benefits Service Center 1-877-222-VETS (8387) to learn about enrollment.
- Once enrolled, your primary care doctor will refer you to the PADRECC Clinic. The main clinic number is (804) 675-5931.
- VA doctors must order an electronic referral entitled "Movement Disorders/Parkinsons/PADRECC". Outside the Richmond VAMC catchment area, a CPRS (electronic record) inter-facility consult (IFC) is required.

#### **Research Opportunities**

Occasionally, there are research projects and clinical trials that recruit from the community in addition to PADRECC patients. Non-Veterans and non-enrolled Veterans may meet the criteria for participation. Inquire at the PADRECC.

**PADRECC Support Group** meets monthly and is open to the Parkinson community. You do not have to be a Veteran or enrolled in VA Health Care to attend the support group held at McGuire VAMC. Call (804) 675-6952 for information.



### **Parkinson's Education Programs**

### Oct 16, 2010 - 8am-3:30pm Richmond, VA **Annual Parkinson's Disease Community Education Day**

This is a joint effort of:

- APDA Richmond Metro Chapter
- APDA I & R Center of Virginia
- PADRECC Southeast
- VCU Parkinson's Disease Center

#### **Held at Koger Conference Center** Holiday Inn Select, Richmond, VA

Contact a planning committee member for questions or a registration form. Cost is \$20 per person. Scholarships available.

Kathy Morton (APDA Richmond Metro Chapter) (804) 730-1336 Susan Dietrich (APDA I & R Center) (434) 982-4482

Lynn Klanchar or Miriam Hirsch (PADRECC) (804) 675-6952/6284)

Andrea Perseghin (VCU Parkinson's Disease Center) (804) 828-0819







### Russell, RN, BSN Delay the Disease: Exercise & PD ✓ James P. Bennett, Jr., MD, PhD

✓ David Zid, BA, ACE, APG Jackie

- William Maragos, MD, PhD Tiffany Voss, MD Physician Panel
- √ G. Frederick Wooten, MD APDA I&R Center Director, UVa
- ✓ Miriam Hirsch, MS, RN PD 101

Speaker Lineup:

Challenges

 Judy Cameron, PhD **Neuroprotective Effects of** 

**Exercise: From Lab to Clinic** • Susan Imke, RN, MS: Family

Care giving: Choices and



### October 15-17, 2010 Atlanta, GA

### Southeastern Parkinson Disease Conference

Sponsored by the Northwest Georgia Parkinson Disease Association www.gaparkinsons.org

### Parkinson's Disease Across the Lifespan: A Roadmap for Nurses

A free online course designed by Parkinson's nurse specialists to help other nurses better understand how to deliver comprehensive care to people and families living with Parkinson's disease (PD). Earn up to 7.5 hours

Parkinson's Disease Across the Lifespan: A Roadmap for Nurses

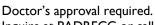
of nursing continuing education by taking this course before May 2011. Go to: http://support.pdf.org/nursing

### LSVT® BIG & LOUD Training Certification Workshop for Therapists

These two-day program are designed to train physical and occupational therapists in an intensive whole body amplitudebased training protocol, and speech therapists in Parkinson-specific speech therapy for individuals with PD. To find a LSVT certified professional, or find out when the next training is offered, call I-888-438-5788 or go to: www.LSVTGlobal.com.

### Parkinson's Exercise Classes

PADRECC - Fridays at I lam - I 2 noon Located at Sitter & Barfoot **Veterans Care Center** 



Inquire at PADRECC or call (804) 675-6952

**Exercise Class for** 

John Rolfe Family YMCA Richmond call (804) 360-8767

Tuesdays & Thursdays I I am - I2 noon







### National Organizations, Regional Groups, and **Centers for Parkinson's Disease**

#### NATIONAL

**PDF** Parkinson's Disease Foundation and **PINS Parkinson's Information Service** (800) 457-6676 www.pdf.org

**PAN Parkinson Action** Network (800) 457-6676 www.parkinsonsaction.org

**APDA** American Parkinson **Disease Association** (800) 223-2732 www.apdaparkinson.org

**NPF National Parkinson** Foundation (800) 327-4545 www.parkinson.org

MJFF Michael J Fox Foundation for Parkinson's Research (800) 708-7644 www.michaeljfox.org

WeMove Worldwide Education and Awareness for **Movement Disorders** 

www.wemove.org

The Parkinson Alliance (800) 579-8440

www.parkinsonalliance.org

**PDTrials** a collaborative initiative of Parkinson's organizations dedicated to research. (800) 457-6676 www.PDtrials.org

**Every Victory Counts Davis Phinney Foundation for** Parkinson's (877) 279-5277 www.davisphinneyfoundation. org



Lynn Klanchar with Davis Phinney at Victory Summit June 5, 2010 in Charlotte, NC

#### REGIONAL (Southeast)

**APDA Richmond Metro** Chapter Richmond, VA (804) 730-1336

www.parkinsonrichmond.com

**APDA** Hampton Roads Chapter Virginia Beach, VA (757) 495-3062 www.hrparkinsons.com

**PFNCA Parkinson** Foundation of the National Capital Area (serving the Washington, DC Metropolitan area) (703) 891-0821 www.parkinsonfoundation.org

Parkinson Association of the Carolinas, Charlotte, NC (serving North and South Carolina) (866) 903-7275 or

www.parkinsonassociation.org

(704) 248-3722

**NWGA** Northwest Georgia Parkinson Disease Association, Rome, GA (706) 413-3264 www.gaparkinsons.org

**PSCKY Parkinson Support** Center of Kentuckiana,

Louisville, KY (502) 426-0888 www.pscky.org

**PRF Parkinson Research** Foundation Sarasota, FL (941) 870-4438

www.parkinsonresearchfounda tion.org

PRF's mission is to cure PD and improve the lives of all people affected by PD. PRF funds research, publishes scientific findings, and provides services to people with PD. PRF established a Center of Excellence at USF in Tampa, that is affiliated with VAMC Tampa involved in research and care of veterans with PD.

### APDA I&R Centers (Southeast)



Atlanta GA (404) 728-6552

**Baltimore MD** (410) 328-0916

Birmingham AL (205) 934-9100

Charlottesville VA (434) 982-4482

Deerfield Beach FL (800) 825-2732

Jacksonville FL (904) 953-7030

Lexington, KY (859) 257-2732

**Memphis TN** (901) 516-0677

Nashville TN (615) 342-4635

St. Petersburg FL (727) 328-6246

**APDA Armed Forces Veterans Center VAMC** Reno, NV (775) 328-1715

**APDA National Young Onset Center** Winfield IL (877) 223-3801

www.youngparkinson.org

### NPF **Centers of Excellence** (Southeast)



Augusta, GA Medical College of Georgia (703) 721-4895

Baltimore, MD Johns Hopkins (410) 955-8795

Chapel Hill, NC University of North Carolina at Chapel Hill (919) 843-1657

Durham, NC **Duke University** (919) 668-1538

Gainesville, FL University of Florida (352) 273-5550

Louisville, KY University of Louisville (502) 852-3655

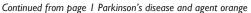
Miami, FL University of Miami (305) 243-6732

Nashville, TN Vanderbilt University (615) 936-5517

Tampa, FL University of South Florida (813) 844-4547

Washington, DC Georgetown University Hospital (202) 444-1762

#### SE PADRECC News



The final regulation follows Shinseki's determination to expand the list of conditions for which service connection for Vietnam Veterans is presumed. VA is adding **Parkinson's disease** and ischemic heart disease and expanding chronic lymphocytic leukemia to include all chronic B cell leukemias, such as hairy cell leukemia.

In practical terms, Veterans who served in Vietnam during the war and who have a "presumed" illness don't have to prove an association between their medical problems and their military service. By helping Veterans overcome evidentiary requirements that might otherwise present significant challenges, this "presumption" simplifies and speeds up the application process and ensure that Veterans receive the benefits they deserve.

The Secretary's decision to add these presumptives is based on the latest evidence provided in a 2008 independent study by the Institute of Medicine concerning health problems caused by herbicides like Agent Orange.

Veterans who served in Vietnam anytime during the period beginning January 9, 1962, and ending on May 7, 1975, are presumed to have been exposed to herbicides.

More than 150,000 Veterans are expected to submit Agent Orange claims in the next 12 to 18 months, many of whom are potentially eligible for retroactive disability payments based on past claims. Additionally, VA will review approximately 90,000 previously denied claims by Vietnam Veterans for service connection for these conditions. All those awarded service-connection who are not currently eligible for enrollment into the VA healthcare system will become eligible.

This historic regulation is subject to provisions of the Congressional Review Act that require a 60-day Congressional review period before implementation. After the review period, VA can begin paying benefits for new claims and may award benefits retroactively for earlier periods. For new claims, VA may pay benefits retroactive to the effective date of the regulation or to one year before the date VA receives the application, whichever is later. For pending claims and claims that were previously denied, VA may pay benefits retroactive to the date it received the claim.

VA encourages Vietnam Veterans with these three diseases to submit their applications for access to VA health care and compensation now so the agency can begin development of their claims.

Individuals can go to a website at <a href="http://www.vba.va.gov/bln/21/AO/claimherbicide.htm">http://www.vba.va.gov/bln/21/AO/claimherbicide.htm</a> to get an understanding of how to file a claim for presumptive conditions related to herbicide exposure, as well as what evidence is needed by VA to make a decision about disability compensation or survivors benefits.

Additional information about Agent Orange and VA's services for Veterans exposed to the chemical is available at <a href="https://www.publichealth.va.gov/exposures/agentorange">www.publichealth.va.gov/exposures/agentorange</a>.

The regulation is available on the Office of the Federal Register website at <a href="http://www.ofr.gov/">http://www.ofr.gov/</a>.

The Department of Veterans Affairs (VA) has announced that **Parkinson's Disease** has been included as a disease associated with Agent Orange.

Additional information about Agent Orange and VA's services for Veterans exposed to the chemical are available at www.publichealth.va.gov/exposures/agentorange

Oľ

call I-800-749-8387, press 3 to obtain more information.

Call I-800-827-1000 to receive the "VA's Guide to Agent Orange Claims"

### Other Sources about PD, Agent Orange, and Disability Benefits

US Military Veterans with Parkinson's (USMVP) - Online information at Yahoo! Groups. www.yahoo.com Search vets\_parkinsons\_agentorange Contact: Alan B. Oates, Director, Legislative Issues, Research Review & Special Projects. email: oldvet@aol.com Phone: (540) 325-1232

Parkinson's Action Network
www.parkinsonsaction.org
\* see article on page 9 of this
newsletter

Military Update a weekly news column by Tom Philpott, syndicated columnist and freelance writer who has covered the US military for over 30 years.

www.militaryupdate.com

Vietnam Veterans of America (800) VVA-1316 www.vva.org publishes the "VVA Self-Help Guide to Service-Connected Disability Compensation for Exposure to Agent Orange"

Veterans Service
Organizations (VSO) offer free assistance to veterans who wish to file a claim.

Agent Orange Clerk at McGuire VAMC: (804) 675-5000 ext 4665.



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Continued from page 1

Estimates are that the VA cares for about 40,000 Veterans with Parkinson's Disease (PD). PD is a degenerative disorder that affects the central nervous system. Key symptoms include loss of movement, muscle stiffness and tremor, which progress to the point of causing significant physical disability. The cause or causes are unknown and currently there is no cure.

For PD patients who suffer from the long-term complications of levodopa, DBS has become increasingly accepted as a surgical alternative for symptom management. Stimulation of two brain regions, the STN or the GPi, have shown to be effective in relieving motor fluctuations and uncontrolled movements of limb(s) associated with PD.



Neurosurgeon Kathryn Holloway, MD (center), with her neurosurgical DBS nurses: Miriam Hirsch, MS, RN (PADRECC) on left and Holley Stone, RN (VCU) on right..

This VA Cooperative Studies Program (CSP) #468 or "A Comparison of Best Medical Therapy and Deep Brain Stimulation of Subthalamic Nucleus (STN) and Globus Pallidus (GPi) for the Treatment of Parkinson's Disease" had two phases: Phase I compared best medical therapy (medications and non-drug therapy) to deep brain stimulation (surgical intervention) for improving motor symptoms at six months; and Phase II, the subject of the recent paper in the NEJM, compared long-term (2 year) outcomes of surgical target for DBS (STN vs. GPi) in improving motor function and reducing symptoms of PD.

Phase II enrolled 299 patients from seven VAMCs and six affiliated university hospitals across the US up until 2006. The primary outcome for Phase II was the change in motor function based on the Unified Parkinson's Disease Rating Scale (UPDRS) at 24 months. The average age for patients was 62 with a range from 37-83 years old. 96% were white, 83% were male, 80% living with family, 25% had a family history of PD, and I4% were employed.



### Study Results and Implications:

- Both the GPi and STN groups improved significantly on UPDRS motor function scores following DBS. There was no difference in motor function between 6 months and 24 months, suggesting a stable response to DBS over the study period. We cannot conclude that one target is superior to the other.
- Medications were reduced in both groups following DBS, but the reduction was greater in the STN group.
- Quality of life improved in both groups after surgery. Visuomotor (motor activity involving sight) processing speed declined more after STN DBS than after GPi DBS. GPi patients had improvement on a depression rating inventory, whereas STN patients had a worsening.
- There was no significant difference in the number of serious adverse events between the groups at 24 months.
- Choice of DBS target need not focus solely on motor improvement.
   Selection of target should take into consideration motor and non-motor symptoms that define quality of life in PD as well as goals of therapy and physician preference based on experience or technical considerations.
- In current practice, STN has been the preferred target for DBS in PD, in part because of the ability to reduce medication needs following surgery. However, a large controlled trial has not been undertaken to compare the relative benefits of the two targets.

In addition to CSP, support for this trial was provided by the National Institute of Neurological Disorders and Stroke (NINDS) and Medtronic Neurological, Inc. VA study sites included the six VA supported Parkinson's Disease Research, Education and Clinical Centers (PADRECCs).

If you are considering DBS or want more information, contact: Miriam Hirsch, MS, RN at Southeast PADRECC (804) 675-6284 or Holley Stone, RN at VCU (804) 828-5235

### The editor of this newsletter posed a question to Dr. Kathryn Holloway

LK: "What is the take home message about this research for people who might want to pursue DBS?"

KH: "This study was very valuable because it corrected a misconception that the STN nucleus was superior to the GPi. The very small differences seen between the 2 targets were mostly in favor of GPi. We still use both targets, but we tend to use the STN for patients with more severe tremor and GPi for patients with a history of depression or mild cognitive issues. There will be further studies looking at the finer details of many aspects of this treasure trove of valuable data. We hope to provide more information and guidance for Parkinsonian patients many years into the future."



### **Southeast PADRECC Research**



### **Eye Study Update**

By George Gitchel, MS, Research Assistant

We are continuing to investigate the eye movements of patients with various movement disorders in the clinic. This research has proven to be sensitive in differentiating different types of movement disorder from one another. For example, patients with essential tremor may outwardly have symptoms very similar to that of Parkinson's disease, but their eye movements are drastically different. In addition, some data suggest that this research may be able to detect Parkinson's disease before any outward symptoms are shown, and perhaps even before a person notices any symptoms.

We hope to continue this research, and investigate the eye movements of all types of movement disorders, so that in the future we can use this test to definitively diagnose a patient early on. The first paper concerning this research will be published soon, with many more to follow.



## Rotigotine Patch Study and Osteoporosis Research

By Abu Qutubuddin, MD and William Carne PhD

PADRECC Southeast continues to conduct a number of ongoing research studies. Presently we are involved with the **Rotigotine Transdermal Patch study** which also includes our former Medical Director, Dr. Vincent Calabrese. We have already enrolled six patients in this phase 3, multicenter, double-blind, placebocontrolled, parallel-group, 5 -arm, fixed dose trial of rotigotine in subjects with advanced stage Parkinson's disease. It is anticipated that approximately 700 subjects will be enrolled in the study from 80 sites, including India.

A second active PADRECC study is examining the relationship between Parkinson's patients and fracture risk and potential mechanisms for osteoporosis in males. The study is being conducted in conjunction with the Richmond VAMC Endocrinology department.

We are also planning two new studies. The first is a pilot study examining the impact of forced exercise on Parkinson's disease. The second study is in the early stages of planning and intends to examine the relationship of Parkinson's disease and pain perception. These two studies will need to be submitted to the Institutional Review Board for final approval before patients can be enrolled.

Please contact Peggy Roberge, RN, clinical nurse coordinator for more information regarding these and other studies at PADRECC clinic (804) 675-5931.



### In and Around the Movement Disorder Community

### **PD Community Education Day 2009**



Dave with conference planning committee (left to right): Kathy Morton, Susan Dietrich, Dave Iverson, Lynn Klanchar, and Miriam Hirsch

David Iverson, Television Producer of the PBS special documentary about Parkinson's Disease "My Father, My Brother and Me" was the keynote speaker on Nov 7, 2009 at last year's Parkinson's Disease Community Education Day. Other speakers included: Dr. Becky Farley, researcher and developer of LSVT BIG; Jim Dyess, caregiver and author; and Dr. James Bennett, founding director of the VCU Parkinson's Center.

Over 200 people attended this event at the Koger Center in Richmond, sponsored by American Parkinson Disease Association (APDA) Richmond Metro Chapter, APDA Information and Referral (I & R) Center of Virginia, and the Parkinson's Disease Research, Education and Clinical Center.

The PD Community Education Day is an annual event. Next conference is October 16, 2010 in Richmond, VA (see page 3 for details).

### Reasons to Hope: Essential Tremor Symposium at McGuire VAMC



Peter Muller (I) greets a symposium participant

And you thought it was just benign tremor...

isolation

rejection
frustration

humiliation

Hopelessness

Hape through research, awareness and support

Essential Tremor (ET) is the nations number one neurological condition, affecting approximately 10 million Americans. March has been designated as "National Essential Tremor Awareness Month".

PADRECC partnered with the International Essential Tremor Foundation's (IETF) Community Ambassador Peter Muller to sponsor the first ever ET symposium at McGuire VAMC on Saturday March 20, 2010. The program was called "Reasons to Hope" and 100 persons attended the half day seminar. Mark Baron, MD, Movement Disorder Specialist from PADRECC presented "ET: What really is it? Do I definitely have it? And what can I do about it? ". Scott Wylie, PhD, Neuropsychologist from University of Virginia discussed "Beyond the Tremor: Cognitive and Emotional Aspects of ET", and Dietrich Haubenberger, MD, Neurologist and researcher from the National Institute of Neurological Disorders and Stroke, spoke on "Genetics in ET", plus gave a thorough update about the latest in ET research.

Many more resources for ET can be found on IETF's website <u>www.essentialtremor.org</u>. An ET group meets the 3rd Tuesday, 6:30 pm in Richmond, VA. Contact Diana Campbell at (804) 556-2345, or email to ET.RichmondVA@yahoo.com.



Peter Muller (standing left) introduces Dr. Dietrich Haubenberger (standing right) to the audience





Dr. Mark Baron



Richmond ET support group leaders and volunteers help at the check in table

#### SE PADRECC News





### Parkinson's Action Network



**AUGUST 31, 2010** 

#### VA Publishes Final Regulation to Aid Vietnam Veterans Exposed to Agent Orange

The Department of Veterans Affairs (VA) today, August 31, published its final regulation establishing Parkinson's disease, ischemic heart condition, and B-cell leukemias as service-connected disabilities for Vietnam veterans exposed to Agent Orange. The final regulation grants a 100% disability rating for Parkinson's disease, as well as retroactive veteran and survivor payments for qualifying veterans.

#### What Does this Mean For Vietnam Vets with PD?

Accessing health care and disability compensation will be easier for qualifying veterans. If a veteran served in Vietnam from January 9, 1962 to May 7, 1975 and now has been diagnosed with Parkinson's disease, they are presumed to have been exposed to herbicides. The veteran does not have to prove an association between their disease and their military service. The presumption simplifies and speeds up the application process for disability compensation, and all those awarded service-connection will become eligible to join the VA healthcare system.

The VA will now review approximately 90,000 previously denied claims by Vietnam veterans for service-connection for these three conditions. Some additional veterans will be eligible for retroactive benefits. For new claims, VA may pay benefits retroactive to the effective date of the regulation or to one year before the date VA receives the application, whichever is later. For pending claims and claims that were previously denied, VA may pay benefits retroactive to the date it received the claim.

#### So When Will This Go Into Effect?

Even though the final regulation is published, the regulation is subject to a 60-day review period by Congress before the VA can begin paying benefits for new claims.

The Senate Veterans Affairs Committee is scheduled to hold a hearing on September 23 to review the rule and to discuss how the VA Secretary makes his decision to establish a disease as a service-connected disability. There certainly is no intention for Congress to actually block the implementation of the final rule, but the VA will have to wait 60 days before they can start compensating veterans.

#### What the Final Rule Didn't Do

The Parkinson's community sent nearly 400 comments to the VA in support of the proposed regulation. Many of the comments urged the VA to clarify its definition of Parkinson's to include diseases of Parkinsonism (primary, atypical, and secondary Parkinsonian syndromes). Unfortunately, the final rule did not expand the definition of Parkinson's disease to include Parkinsonism. VA argues that the current medical evidence does not support the expansion of the definition at this time but will reconsider if the Institute of Medicine (IOM) provides additional guidance in future reports.

PAN will continue to work with the VA to ensure that all veterans living with Parkinson's and Parkinsonism receive access to the healthcare and benefits they wholeheartedly deserve.

#### Apply for Benefits

If you are a Vietnam veteran with Parkinson's and have not applied for benefits, we encourage you to submit your application for compensation now—even before the VA can start paying claims. For more information about applying for VA benefits and Agent Orange, visit **VA Website** (<a href="http://www.vba.va.gov/bln/21/AO/claimherbicide.htm">http://www.vba.va.gov/bln/21/AO/claimherbicide.htm</a>)



### Eligibility/Enrollment for VA Healthcare

#### Who is eligible for Veterans Affairs (VA) Health Care and care at the PADRECC?

#### All Veterans are potentially eligible.

Eligibility for most veterans' health care benefits is based on active military service in the U.S. Army, Navy, Air Force, Marines, or Coast Guard (or Merchant Marines during WWII), and other than dishonorable discharge conditions.

#### All veterans are encouraged to apply and have their enrollment eligibility determined.

- Complete VA Form 10-10EZ, Application for Health Benefits
- This form can be obtained by:
  - -Calling toll free (877)-222-VETS (8387)
  - -Go in person to the Eligibility/Health Benefits Office at a VAMC
  - -Online at www.va.gov. Look for Veterans Services, Health Care Information, and submit the application on-line.
- After your application is processed, you will be assigned a priority group which range from 1 through 8.
- In January 2003, VA made the difficult decision to stop enrolling new priority group 8 (high income) Veterans. This was to ensure the availability of quality and timely health care to veterans with service connected conditions, special authority based on military service, low income, and those with special health care needs.

#### **Changes to Priority Group 8 Enrollment Restriction:**

New regulations went into effect on June 15, 2009 and enable VA to relax income restrictions on enrollment for health benefits. While this new provision does not remove consideration of income, it does increase income thresholds.

- <u>If you applied for enrollment between January 1, 2009 and June 15, 2009</u> and were denied enrollment because your income exceeded the VA income thresholds, you were reconsidered for enrollment. You would have been contacted by mail from VA if you qualify.
- If you applied for enrollment before January 1, 2009 and were denied enrollment because your income was too high, VA encourages you to take advantage of a financial calculator (on the website) to assist you in determining if you are now eligible for enrollment under this new regulation based on your 2008 income.

Catastrophic Disability: Veterans may request a "Catastrophic Disability Evaluation" by contacting the enrollment coordinator at their local VA health care facility. To be considered, Veterans must have a severely disabling injury, disorder or disease that permanently compromises their ability to carry out the activities of daily living. If it is determined by VA that the Veteran is catastrophically disabled, their priority will be upgraded to priority group 4.

Eligibility/Health Benefits Enrollment Office at McGuire VAMC is located on the first floor, Room 1B-232. Call (804) 675-5611 or McGuire VAMC main number (804) 675-5000 and Press 4 (for Centralized Registration, Eligibility/Health Benefits).



### **MyHealtheVet**

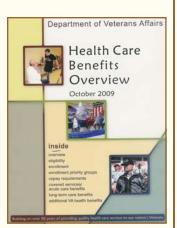
VA's Award-Wining Personal Health Record

Anywhere
Any Time
Internet Access
to VA Health Care

Help with MyHealtheVet available at McGuire VAMC Room 1B-217 near the Red & Green Clinics

### Health Care Overview Brochure

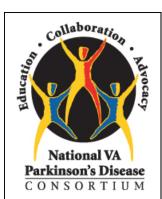
This 24 page guide was designed to provide information needed to understand VA's health care system: eligibility requirements, enrollment process, priority groups, co-pays that may be charged, and the health benefits and services available. Included is information about **MyHealtheVet**, Credible Coverage for Medicare Part D, Income Verification and medically related travel benefits.



To download a copy of this brochure, go to: www.va.gov/health eligibility/library/pubs/healthcareoverview.



### National VA Parkinson's Disease Consortium Center Network



The National VA Parkinson's Disease Consortium Network is designed to broaden the impact of the six Parkinson's Disease Research Education and Clinical Centers (PADRECCs). The goal is to provide up-to-date, quality health care for all veterans with movement disorders.

In 2006, a network of Consortium Centers with Directors (often Movement Disorder Specialists) was established and continues to grow. Currently there are 50 Centers established across the country, representing every VISN.

This hub and spoke model of care together with the PADRECCs, helps provide effective and convenient services to all veterans regardless of where they live. Veterans unable to access services at a PADRECC, can receive specialized care at the nearest Consortium Center.

For more info, go to www.parkinsons.va.gov

### **PADRECCs**

Philadelphia John Duda, MD, Director (215) 823-5934

Southeast (Richmond) Mark Baron, MD, Director (804) 675-5931

#### Houston

Eugene C. Lai, MD, PhD Director **(713) 794-7841** 

Northwest (Portland/Seattle) Joseph Quinn, MD Director (503) 721-1091

San Francisco William J. Marks, Jr., MD Director (415) 379-5530

Southwest (West Los Angeles) Jeff Bronstein, MD, PhD Director (310) 478-3711 x48001

### Southeast Network



### Consortium Centers & Directors

Atlanta (Decatur), GA (VISN 7) Marion Evatt, MD (404) 321-6111 x7121

Augusta, GA (VISN 7) John Morgan, MD, PhD (706) 733-0188 x2421

Birmingham, AL (VISN 7) Anthony Nicholas, MD (205) 933-8101 x4734

**Durham, NC** (VISN 6) Burton Scott, MD (919) 286-0411 x5611

Gainesville, FL (VISN 8) Frank Skidmore, MD (352) 374-6058

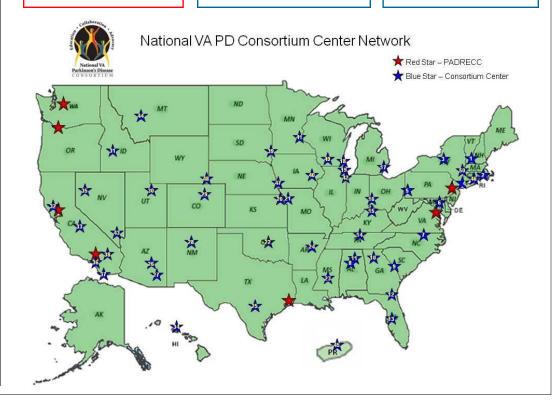
Lexington, KY (VISN 9) John Slevin, MD (859) 281-4920

**Nashville, TN** (VISN 9) John Fang, MD (615) 327-4751 x67510

Tampa, FI (VISN 8) Theresa Zesiewicz, MD (813) 972-7633

Tuscaloosa, AL (VISN 7) Fernando Franco, MD (205) 554-2000 x4136

San Juan, Puerto Rico (VISN 8) Ana Vidal-Cardona, MD (787) 641-7582 x31684



### Virginia Support Group Highlights (please note this is not a complete list of all the meetings available )

#### **PARKINSON'S DISEASE**

Call the APDA I&R office at (434) 243-5422 for most updated and complete list. Please call the contacts listed, especially if it is your first meeting.

**Bedford: 2nd Thurs at 2:30pm,** Carillon Bedford Memorial Hospital. Contact: Dave or Meg Ballard (540) 586-1406.

Charlottesville: 2nd Mon at 2pm, Westminster Canterbury of the Blue Ridge (on Pantops). Contact: Susan Dietrich (434) 243-5422.

Fishersville: Ist Sat at 2pm, Blue Ridge Church of Christ. Contact: Keith Shank (540) 255-1847

Fredericksburg: last Wed at 1030am, The Disability Resource Center. Contact: Earline Haney (540) 371-7334.

Front Royal: Ist Wed at Ipm, The Sutherlands. Contact: Lee Mangene (540) 635-8122. Hampton: Ist Tues at 3pm, 4000 Coliseum Drive, Sentara Careplex. Contact: Susie Garrison (757) 827-2170.

Harrisonburg: 3rd Sat at 1pm, Cancer Center, Rockingham Memorial Hospital. Contact: Eva Showalter (540) 879-9743.

Newport News: 3rd Wed at Ipm, Mary Immaculate Conference Center. Contact: Cynthia Dowd (757) 886-6381.

Newport News: 4th Wed at 7pm, Riverside Regional Medical Center. Contact: Sandy Snapp (757) 534-5408.

Norfolk: 3rd Wed at 5:30pm (dinner), 6:30pm (meeting), First Baptist Church. Contact: Ann Perkins (757) 486-5677.

Northern Neck/Middle Peninsula: 3rd Wed at Ipm, and Care partners group, 1st Mon at 10:30 am Rappahannock Westminster Canterbury. Contact: Rita DePew (804) 435-9553.

Richmond PADRECC: 4th Thurs at Ipm, (speaker & discussion), McGuire VAMC Room 2K113/115, Contact: Lynn Klanchar (804) 675-6952.

Richmond: 3rd Sun at 2pm, (educational), Health South, 5700 Fitzhugh Avenue. Contact: Kathy Morton (804) 730-1336.

Richmond: 1st Tues at 7pm (discussion) Circle Center, 4900 W. Marshall Street (behind Krispy Kreme on Broad Street near Staples Mill Road. Contact: Ann Spinks (804) 355-5717.

Suffolk, Chesapeake, Portsmouth: 1st Sat at 1pm, Church of St. Therese. Contact:
Barb Voelkel (757) 538-0655.

Virginia Beach: Ist Wed at 10am, St. Andrew's United Methodist Church. Contact: Zelia Graham (757) 638-8899.

Williamsburg: 2nd Mon at 1:30 pm, 5700 Williamsburg Landing. Contact: Bob or Joan Byrne (757) 898-6674.

#### YOUNG PARKINSON'S

Tidewater area Contact: Ann Perkins (757) 486-5677 Charlottesville Contact: Debra Pressman (434) 996-1718 or debra.presssman@gmail.com

#### **ESSENTIAL TREMOR**

International Essential Tremor Foundation (IETF) www.essentialtremor.org

Community Ambassadors: Peter Muller (703) 543-8131 Preston Boggess (540) 651-6777

Charlottesville: 2nd Thurs,
Contact: John Watterson
(434) 973-2510
Richmond: 3rd Tues at
6:30pm, Our Lady of Hope,
13700 Gayton Rd. Contact:
Diana Campbell (804) 556-2345
or ET.RichmondVA@yahoo.com
Richmond: daytime group
Contact: Peter Muller
(804) 754-4455.
Lexington: Contact:

Mary Barker (540) 463-7269. Lynchburg: Contact: Terry Houck (434) 525-6085. Roanoke: Contact: Mike Hopkins (540) 721-2087.



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Fax: 804-675-5939

Web: www.parkinsons.va.gov



Please report address changes or contact us if you would like to be added or deleted from the mailing list.

Please contact the editor: Lynn Klanchar, Associate Director of Education,

Southeast PADRECC. Phone (804) 675-6952

or email: lynn.klanchar@va.gov