



NEWS

Volume 6 Number 1
Summer 2008

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

Virginia's Governor Kaine Proclaims April as Parkinson's Disease Awareness Month

WHEREAS, the health and well-being of the citizens of our great Commonwealth are of the utmost importance to the prosperity and livelihood of Virginia's families and communities; and

WHEREAS, the Commonwealth of Virginia is committed to supporting efforts of scientists and doctors to find a cure for Parkinson's disease, one of the most common late life diseases found in the United States; and

WHEREAS, Parkinson's disease is a chronic, progressive, neuro-degenerative disease that disrupts controlled body movements and causes muscle actions ranging from uncontrollable tremors to muscular rigidity; and

WHEREAS, people with Parkinson's disease are amazing and talented individuals, and Parkinson's Disease Awareness Month offers a great opportunity for all Virginians to recognize their many contributions to the prosperity of our Commonwealth and nation;

NOW, THEREFORE, I, Timothy M. Kaine, do hereby recognize **April 2008** as **PARKINSON'S DISEASE AWARENESS MONTH** in the **COMMONWEALTH OF VIRGINIA**, and I call this observance to the attention of all our citizens.

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World PD Day Luncheon at Kabob Grille



Southeast PADRECC tried something a little different this year to commemorate April 11, World Parkinson's Disease Awareness Day and the birthday of Dr. James Parkinson, for whom the disease is named. Forty-six people from the PADRECC support group packed the Kabob Grille restaurant in Midlothian,

Virginia on a sunny spring Friday to socialize and enjoy a buffet of Indian and Pakistani food. Dr. Abu Qutubuddin, PADRECC's Psychiatrist, gave a short presentation on the history of PD and medications. Many thanks to all the staff at Kabob Grille for accommodating our group.





Southeast PADRECC Staff

Our team of caring and qualified professionals consists of full-time, part-time, government, contract, and fee-basis employees. We have some volunteers that work without compensation too. Many staff have academic affiliations at Virginia Commonwealth University (VCU) Medical Center.

Movement Disorder Specialists Neurologists

Mark Baron, MD
Director, PADRECC Southeast
Anna Hristova, MD
Assoc. Director, Patient Care

Physiatrist

Abu Qutubuddin, MD
Assoc. Director, Rehabilitation

Neurosurgeon:

Kathryn Holloway, MD
Director, PADRECC
Neurosurgical Services

Multidisciplinary Team

Lynn Klanchar, RN, MS

Assoc. Director of Education

Peggy Roberge, RN

Clinic Nurse Coordinator

Miriam Hirsch, MS, RN

Neurosurg Nurse Coordinator

William Carne, PhD

Psychologist

Gopi Kasturi, MD, Fellow

Cathy McGrady

Administrative Officer

Odetta Semple

Program Support Assistant

Research Assistants

George Gitchel

Craig Kelman

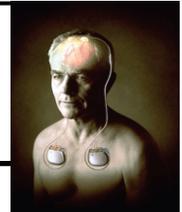
Ezekiel Sachs

SO LONG, FAREWELL

Thank you and best wishes to **Barry Skoblar, PsyD** who served as SE PADRECC Associate Director of Research from July 2007-May 2008. We wish him well in his new position in Wilmington NC.

DBS Corner

by Miriam Hirsch, MS, RN, Neurosurgical Nurse
and Kathryn Holloway, MD, Neurosurgeon, Southeast PADRECC



RICHMOND PADRECC STUDY AIMED AT IMPROVING THE ACCURACY OF DEEP BRAIN STIMULATION SURGERY

Deep brain stimulation (DBS) is a surgical intervention used to treat movement disorders such as essential tremor, Parkinson's disease and dystonia. DBS involves placing a "wire" or lead into specific area(s) of the brain so that a well-controlled electrical current can be administered. This electrical current functions as an "off switch" by disrupting abnormal brain signals responsible for the disability caused by these disorders. The effectiveness of the DBS procedure depends on accurate placement of the lead(s) and a variety of tests are performed during surgery to help guide its placement. However, the exact location is normally not known for sure until after the operation is over, when the patient has been transported out of the operating room and has had a post-operative computerized tomography (CT) scan.

Dr. Kathryn Holloway, the Southeast PADRECC neurosurgeon, performs DBS surgery using a frameless method. In this technique, five small bone screws are used to guide the placement of the brain lead(s) rather than the traditional metal halo or "frame". With the frameless method, patients can move their heads during surgery and/or adjust their body position if needed. The framed approach on the other hand creates complete immobilization of the head and neck and obscures the patient's line of vision.

Dr. Holloway recently completed a study aimed at improving the frameless approach to DBS surgery through the use of an intra-operative (during surgery) "O-arm" scanner. This small, portable scanner has the ability to take 2-D pictures like an x-ray as well as 3-D pictures like a regular CT but uses only 1/2 of the radiation of a regular CT scanner.

The study data is currently being examined to determine whether or not images from this "O-arm" technology can be used to improve the accuracy and efficiency of DBS lead placement and whether or not it may one day replace the need for the bone screws that are currently a standard part of the DBS procedure.

For more information, talk to RNs: Miriam Hirsch at McGuire VAMC (804) 675-6284 or Tammy Searles at VCU Medical Center (804) 828-5235.



2008: Upcoming PD Education Programs

JULY 18 in Lansing, MI

Attend in person or via live Webcast from home computer
Mind, Mood & Body: Understanding Non-Motor Symptoms of PD
Contact: Parkinson's Disease Foundation (PDF) with the Michigan Parkinson Foundation at (800) 457-6676 or www.pdf.org/webcast

AUGUST 7-9 in Atlanta, GA

6th Annual Young-Onset Parkinson Network Conference
Omni Hotel at CNN Center
Contact: National Parkinson Foundation (NPF) at (800) 457-6676 or khoughton@parkinson.org

AUGUST 8-10 in Ligonier, PA

Living Well with Parkinson's Disease Retreat
Contact: David Von Hofen at the Parkinson Foundation of Western Pennsylvania (412) 365-2086

OCTOBER 11 in Richmond, VA

Annual PD Community Education Day for PWP & Caregivers
Holiday Inn Select, Koger South Conference Center
Contact: APDA Richmond Metro Chapter at www.parkinsonrichmond.com or APDA I&R Center (434) 982-4482 or PADRECC (804) 675-6952

OCTOBER 11 in Spokane, WA

Attend in person or via live Webcast from home computer
Surgical Advances: DBS and Parkinson's Disease
Contact: Parkinson's Disease Foundation (PDF) with the Northwest Parkinson's Foundation at (800) 457-6676 or www.pdf.org/webcast

NOVEMBER 7-8 in Chesapeake, VA

Meet & Greet on the 7th/Annual Conference on the 8th - at Greenbrier Marriott Springhill Suites
Contact: Barb Voelkel, APDA Hampton Roads Chapter (757) 538-0655 or bvoelkel@charter.net

NOVEMBER 7-9 in Georgia

2008 Southeastern Parkinson Conference
Contact: Northwest Georgia Parkinson Disease Association at www.gaparkinsons.org

APRIL 4, 2009 in Houston, TX

Attend in person or via live Webcast from home computer
Quality of Life and Parkinson's Disease
Contact: Parkinson's Disease Foundation (PDF) with the Houston Area Parkinson Foundation at (800) 457-6676 or www.pdf.org/webcast



Ongoing Education Programs

An Introduction to Parkinson's Disease

2 hour class
at Southeast PADRECC
McGuire VAMC

Inquire when you visit the clinic or call Lynn at (804) 675-6952



Develop a plan to live life to the fullest while managing Parkinson's Disease

Exercise Class



Moving to agility, balance and joy"

Fridays at 11am - 12noon

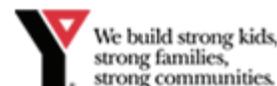
at Southeast PADRECC
McGuire VAMC

Doctor's approval required.
Inquire when you visit the clinic or call Lynn at (804) 675-6952

Exercise Class for People Living with Parkinson's Disease

Tuesdays and Thursdays 11am - 12 noon

at John Rolfe Family YMCA, 2244 John Rolfe Parkway, Richmond
call Keith Overstreet at (804) 360-8767
\$30 per 6 week session (YMCA member)
\$60 per 6 week session (community member)





Southeast Region Resources
**National Organizations, APDA Information & Referral Centers,
NPF Centers of Excellence, and Regional Chapters/Groups**

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

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

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

PAN (Parkinson Action Network)
((800) 457-6676 or (202) 842-4101
www.parkinsonsaction.org

APDA I & R Centers

Atlanta GA:
(404) 728-6552

Birmingham AL: (205) 833-4940 or (205) 934-9100

Charlottesville VA:
(434) 982-4482

Durham NC: (919) 681-2033 or (919) 668-2938

Hot Springs AR: (501) 321-2811 or (501) 922-4976

Jacksonville FL:
(904) 953-7030

Memphis TN:
(901) 516-0677

Nashville TN: (615) 342-4635 or (800) 493-2842

APDA I & R Centers
Pompano Beach FL:
(800) 825-2732

St. Petersburg FL:
(727) 898-2732

Reno, NV: (888) 838-6256 ext 1715 or (775) 328-1715
A center dedicated to serving armed forces veterans

Glenbrook IL: (847) 657-5787 or (800) 223-9776
A center dedicated to young onset PD

NPF Centers
Washington, DC
Georgetown University Hospital

Gainesville, FL
University of Florida PD & Movement Disorders Center

Miami, FL
University of Miami, Miller School of Medicine

Tampa, FL
University of South Florida, PD & Movement Disorders Center

Augusta, GA
Medical College of Georgia, Movement Disorders Program

Louisville, KY
University of Louisville Division of Movement Disorders

Chapel Hill, NC
University of NC at Chapel Hill, School of Medicine

Nashville, TN
Vanderbilt University Medical Center

NPF Chapters
McLean, VA
Parkinson Foundation of the National Capital Area
(703) 891-0821

Nashville, TN
Middle Tennessee Chapter
(615) 662-4379

Rome, GA
Northwest Georgia PD Association
(706) 235-3164

Savannah, GA
Parkinson's in the Park
(912) 655-5293

Grovetown, GA
Central Savannah River Area Parkinson Support Group, Augusta Chapter
(706) 721-1238

Boca Raton, FL
South Palm Beach County Chapter
(561) 482-2867

Coral Gables, FL
The Park Optimists NPF
(305) 476-8782

Naples, FL
Parkinson Association of Southwest Florida NPF
(239) 254-7791

Orlando, FL
Southeast PD Association
(407) 489-4124

Ormond Beach, FL
The Parkinson Association of Greater Daytona Beach
(386) 252-8959

St. Augustine, FL
St. Augustine PD Support Group
(904) 824-7776

Tallahassee, FL
North Florida Parkinson Awareness Group
(850)-385-8186

Vero Beach, FL
Alzheimer/Parkinson Association of Indian River County
(772) 563-0505

Carolina, PR
Asociacion Puertorriquena de Parkinson
(787) 768-5565

San Juan, PR
Fundacion Puertorriquena de Parkinson
(787) 764-4898

Regional Groups
Richmond Virginia Metro Chapter APDA
(804) 730-1336
www.parkinsonrichmond.com

Hampton Roads Virginia Chapter APDA
(757) 495-3062
www.hrparkinsons.com

Parkinson Association of the Carolinas (serving North and South Carolina)
(704) 248-3722
www.parkinsonassociation.org



Not Just Parkinson's Disease. Please Help Spread the Word... PADRECC Treats All Types of Movement Disorders!

Although the nickname for our clinic (PADRECC) is built from the words Parkinson's Disease (PD), a more accurate description of our clinic would be "**Movement Disorder Research, Education, and Clinical Center**". PADRECC makes appointments for veterans with many other types of movement disorders, not just PD.

Parkinsonism Isn't Parkinson's Disease

The same symptoms that indicate PD can also indicate other conditions. Therefore, *parkinsonism* is the generic term used to refer to slowness and mobility problems that look like PD. Parkinsonism is a feature in several conditions that have different and possibly known causes. These conditions don't progress like PD. As a result, years may go by before the differences between PD and the other disorder are apparent. The PD diagnosis may then be reversed.

Taking anti-parkinsonian medicine (such as levodopa) may be the first indicator that parkinsonism isn't actually PD. By definition, PD promptly responds to this medication, which improves symptoms in a consistent way. But in parkinsonism, improvement is often erratic or nonexistent from the beginning. In fact, your neurologist will always closely monitor your response to treatment in order to rule out the possibility that your condition is a disorder other than PD.

Essential Tremor: Another Source of Confusion

In addition to primary and secondary parkinsonism, essential tremor (ET) is another source of possible confusion. As the most common movement disorder (as many as 1 in 20 people older than 40, and 1 in 5 people over 65 may have ET). There may be as many as 10 million people with ET in the United States and many more worldwide.

ET's only symptom is a tremor that usually affects the hands, but it may also affect the head and neck (causing shaking), face, jaw, tongue, and voice (causing a shaking or quivering sound), the trunk, and rarely the legs and feet.

Essential tremor is much more common than most neurologic disease, with the exception of stroke, and is more common than Parkinson's Disease.

Many things cause tremor, and not all tremors are ET. There are more than 20 kinds of tremors. Excessive caffeine, alcohol withdrawal, problems with thyroid or copper metabolism, or the use of certain medications may cause tremor. A major difference between ET and other tremor types is that in ET tremor is the only symptom. Muscle tone, strength, and balance are not usually affected.

While no cure has been found for ET, pharmaceutical and surgical treatments can help control tremor in many patients. Read more about ET and the International Essential Tremor Foundation on the next page.



Parkinsonian disorders (parkinsonism) can be classified into two major groups, primary and secondary.

Primary parkinsonism

◆ Parkinson's Disease

◆ **Atypical Parkinsonian Disorders** previously known as **Parkinson's Plus Syndromes**. This group of neurological, degenerative disorders has parkinsonian features, such as *bradykinesia* (slowness), *rigidity* (stiffness), *tremor* (shaking), and *gait disturbances* (balance). However, they are also associated with other complex neurological symptoms that reflect problems in brain areas other than the *dopaminergic system* (the network of neurons able to make and release the neurotransmitter dopamine). These disorders progress much more rapidly than PD and don't respond as well (or at all) to anti-parkinsonian medications. Balance problems and falling may occur early in the disease course.

The most common of the atypical disorders are:

- **Progressive Supranuclear Palsy (PSP)**
- **Corticobasal Degeneration (CBD)**
- **Multiple System Atrophy (MSA)**
- **Dementia with Lewy Body (DLB)**

Secondary parkinsonism

The symptoms of these disorders relate to well-defined lesions in the brain from strokes, tumors, infections, traumas, or certain drugs or toxins. Like atypical disorders, these problems are usually less responsive to levodopa. However, if the primary cause of the parkinsonism is controlled, these symptoms tend to be less progressive.

Some examples:

- **Medications (e.g. neuroleptics)**
- **Metabolic, infectious, or vascular diseases**
- **Normal pressure hydrocephalus (NPH)**
- **Repetitive trauma (e.g. boxer)**
- **Heavy metals (e.g. manganese)**
- **Toxins (e.g. MPTP)**



ET—There is NO CURE, But for Some it CAN be CONTROLLED

What is it?

Essential tremor is a very common but complex neurologic movement disorder. It is called “essential” because in the past, it had no known cause. It is not caused by another neurological condition or the side effect of a medication.

ET usually affects the hands, but it may also affect the head and neck, face, jaw, tongue, voice, the trunk and, rarely, the legs and feet. The tremor may be a rhythmic “back-and-forth” or “to-and-fro” movement. Severity of the tremors can vary greatly. Some people experience tremor only in certain positions – this is called *postural tremor*. Tremor that worsens while writing or eating is called *kinetic or action-specific tremor*. Most people with ET have both postural and kinetic tremor.

The Cause

Essential tremor is due to abnormal communication between certain areas of the brain, including the cerebellum, thalamus and brain stem. In the majority of people with ET, the tremor seems to be inherited as an autosomal dominant trait. This means that each child of a parent with ET has approximately a 50% chance of inheriting a gene that causes ET. However, not everyone who inherits a gene develops symptoms. Some people have ET and do not have a family history of tremor, suggesting the possibility of other causes. Researchers have already located two genes that predispose to ET and are currently trying to locate others. However, at this time, there is no generic test for ET. Identifying genes may allow scientists to find a cure.

Treatments

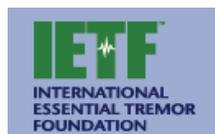
If you have mild ET, you may not need treatment. With adequate knowledge, many people learn ways to live well with ET.

The main medications used to treat ET are propranolol (Inderal) and primidone (Mysoline). If your tremor is not well controlled by a beta-blocker or by primidone alone, you may experience better results when you take both medicines together. If combination therapy is not helpful, your doctor may then recommend one of the benzodiazepines such as clonazepam (Klonopin), diazepam (Valium), alprazolam (Xanax) or lorazepam (Ativan). Other drugs may be used too that include emerging treatments such as topiramate (Topamax) and gabapentin (Neurontin), along with miscellaneous agents such as mirtazapine (Remeron), moderate use of alcohol, or injections of Botulinum toxin into muscles. All medications have side effects so become aware and ask questions of your physician and pharmacist. Finding the correct medicine is often a trial and error process that takes time and patience.

If treatment with medications is not effective and ET is very disabling or is putting your livelihood at risk, your doctor may suggest a surgical technique, such as thalamotomy or thalamic stimulation (Activa tremor control therapy).

Community Ambassadors are professional volunteers who serve as liaisons between the IETF and the community. **Peter Muller** and **Preston Boggess** are assigned to the VA, WV, DC, and MD area and have been instrumental in getting support groups off the ground. If you are interested in starting a support group, contact Preston at (540) 651-6777 or pboggess@swva.net and Peter at (703) 543-8131 or solutionspmm@peoplepc.com

International Essential Tremor Foundation
PO Box 14005
Lenexa, Kansas 66285-4005
(913) 341-3880
Toll Free (888) 387-3667
Email: staff@essentialtremor.org
Web: www.essentialtremor.org



The IETF works globally to provide patient support, educate the healthcare community about ET, fund research into its cause and cure and increase awareness and understanding about the disorder. Founded in 1988, this charitable, not-for-profit organization's members include patients and their families, health care providers, educators and volunteers who support the mission and efforts of the IETF.

International Essential Tremor Foundation Hope through research, awareness and support

Some of IETF Services include: “Tremor Talk”, a quarterly newsletter, and outreach to the community via Community Ambassadors. **ET Support Groups** are informal, self-managed, self-help groups. People are welcome and accepted, and willing to talk openly and exchange ideas. Support groups are a source of practical suggestions about living with ET, and a circle of friends where privacy and confidentiality are respected.

**ET Groups in Virginia
Richmond**
Contact: Diana Campbell
(804) 556-2345

Lexington
Leader: Mary Barker
(540) 463-7269

Lynchburg
Leader: Terry Houck
(434) 525-6085

Roanoke
Leader: “Mike” Hopkins
(540) 721-2087



Worldwide Education and Awareness

www.wemove.org is the Internet's most comprehensive resource for movement disorder information—the *hub of movement disorder activities on the Web.*

FOR PATIENTS AND FAMILIES

We Move's goal is to make early diagnosis, up-to-date treatment, and patient support a reality for all people living with movement disorders. If you are a person affected by a movement disorder, visit the Web site for:

- Understandable disease information
- A glossary of movement disorder terms
- International support group listing
- Discussion forums and chat rooms
- Pediatric movement disorder information, including "Ask the Experts" and Parent-to-Parent Discussion Forum
- Searchable pediatric treatment center database

You can register for your own personal edition of *E-MOVE*, the free electronic news clipping service that delivers timely synopses of developments in movement disorders...directly to your desktop. Email: wemove@wemove.org or phone: **(800) 437-6682**.

- ATAXIA
- BRADYKINESIA
- CHOREOATHETOSIS
- CORTICOBASAL DEGENERATION
- DYSKINESIAS
- DYSTONIA
- ESSENTIAL TREMOR
- HEREDITARY SPASTIC PARAPLEGIA
- HUNTINGTON'S DISEASE
- MULTIPLE SYSTEM ATROPHY
- MYOCLONUS
- PARKINSON'S DISEASE
- PROGRESSIVE SUBPRANUCLEAR PALSY
- RESTLESS LEG SYNDROME
- RETT SYNDROME
- SPASTICITY
- SYDENHAM'S CHOREA
- TICS
- TOURETTE'S SYNDROME
- TREMOR
- WILSON DISEASE

The **Life in Motion** campaign brings together over 40 patient advocacy organizations, foundations, and professional societies committed to raising awareness about movement disorders, emphasizing the importance of early diagnosis, and illustrating available treatment options. Campaign initiatives include media outreach, public service announcement, community outreach, and the creation of the *Life in Motion*



Resource Center. For detailed information about specific movement disorders, the brochure "Managing Your Life in Motion: A Guide for Patients with Movement Disorders, their Families, and Caregivers", and other valuable resources, visit the *Life in Motion* Resource Center.

Life in Motion Resource Center
www.life-in-motion.org
or call toll-free: **(866) 546-3136**

For the healthcare professional:
WE MOVE also hosts the Movement Disorders Virtual University (MDVU) at www.mdvu.org

Restless Leg Syndrome (RLS)



1610 14th St. NW Suite 300
Rochester, MN 55901
Phone: **(507) 287-6465**
Web: www.rls.org

RLS is a disruptive neurologic disorder that affects up to 10% of the population. RLS results in an irresistible urge to move the legs which is often accompanied by unusual or unpleasant sensations in the legs. Because it most often occurs in the evening, it can

severely disrupt sleep and reduce quality of life. Currently there is no cure for RLS, but there are many non-pharmaceutical and pharmaceutical therapies that help ease RLS symptoms. In addition to medication, you and your doctor can:

- Check for a vitamin or iron deficiency

- Look at medications, habits, & activities that make your RLS worse
- Find an exercise schedule that helps
- Discuss eliminating alcohol & caffeine
- Look at diet to assure it is healthy & balanced
- Implement a program of good sleep habits

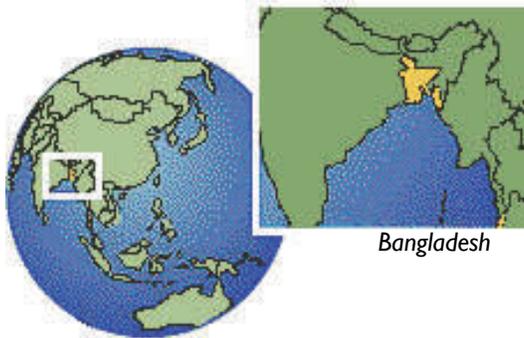


PADRECC Docs Teach Internationally for a Multicultural Experience



Dr. Qutubuddin lecturing at Medical College

In March, 2008 Dr. Abu Qutubuddin made a visit to his alma mater Chittagong Medical College and Bangabhandu Medical College in Dhaka, Bangladesh. He spoke to faculty, medical students and post graduate students on “Physical Medicine and Rehabilitation, Parkinson’s Disease and other Movement Disorders”.



Bangladesh

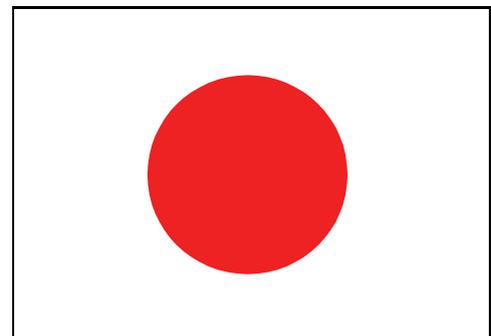


Dr. Qutubuddin performing an assessment in Bangladesh.

In May, 2008, Dr. Mark Baron traveled to Matsumoto, Japan as a Visiting Professor at Aizawa Hospital. He taught a course to the medical residents and was guest lecturer at Neurosurgical Rounds presenting on “Electrophysiological Correlates of Movement Disorders”. Dr. Baron was honored for his contribution to the residency training program at Aizawa Hospital by Takao Aizawa, MD, PdD, and CEO. Dr. Aizawa is 3rd generation to run the medical facility founded by his grandfather as a clinic.



Dr. Baron (front row, 2nd from right) with residents at Aizawa Hospital in Matsumoto, Japan





New tulip designed by woman with Parkinson's gaining grassroots support to become national symbol

By Sheryl Jedlinski,* Co-founder pdplan4life.com

A new tulip is popping up in gardens across the country, just in time for Parkinson's awareness month. The tulip — a red flower with distinctive leaves shaped like the letters “p” and “d” — was designed by a young onset person with Parkinson's (PWP) from Washington state — Karen Painter. Grassroots support for making her tulip the national symbol for Parkinson's awareness is growing.

“After staring at a pink breast cancer ribbon in a store window, it dawned on me that people with Parkinson's also need a nationally recognized symbol for awareness,” she recalls.

True the red tulip has been associated with Parkinson's awareness since 1980 when a Dutch horticulturalist who had PD developed a red and white tulip and named it “Dr. James Parkinson.” More than 25 years later, however, there is no single recognized red tulip design.

When Jean Burns, co-founder of pdplan4life.com, saw the tulip her new friend Karen had doodled on a napkin, she was “immediately struck by the unique and beautiful design. Of all the tulips I have seen used for PD awareness, this one stands apart from the rest.”

Jean and Karen believe that Karen's tulip design can do for Parkinson's awareness what the pink ribbon has done for breast cancer. They hope that the established Parkinson's organizations will recognize this potential and use Karen's tulip emblem in their materials alongside their official logos.

“We have a dream that Karen's stylized tulip will become the symbol not for one Parkinson's organization or event, but for the Parkinson's community nationwide,” Jean says. “It will serve as a reminder that we all must work together to find a cure for the millions of people living with Parkinson's disease.”

Jean and Karen's campaign is not about financial gain or fame. They simply want to do something positive for others living with Parkinson's. To get the ball rolling, Jean had Karen's design copyrighted for her and then wrote a successful grant application which funded the creation of several thousand lapel pins based on Karen's design. Jean followed this up with a grassroots letter-writing campaign to introduce the design to people with Parkinson's and their local PD organizations. Karen sent her own “mission” letter to her friends and family and collected enough money to buy hundreds of buttons featuring her tulip logo.

At the same time Jean created a new page (www.pdtulip.com) on the pdplan4life Web site enabling people to easily download the tulip graphic in a variety of sizes for use on their print materials and slide shows.

“We were able to get my PD tulip in front of thousands of PWP,” Karen says. “The groundswell of support for this design has far exceeded my expectations.”

“I'm hearing from people all across the nation that they love the design, and they are requesting computer graphics of it to use on printed materials,” Jean says. “The dream Karen and I share is coming true.”

Parkinson disease knows no social, ethnic, economic or geographic boundaries. Some 60,000 new cases are diagnosed each year in the United States alone. While the condition usually develops after the age of 65, 15% of those diagnosed are under 50.

For more information, contact:

Karen@pdtulip.com

Jean@pdtulip.com

To order tulip pins, contact Wes Bourne, Sales & Graphics Consultant, at “Pin Depot Lapel Pins”. Reference JEAN BURNS when you call 1(800)-803-2879 (toll free) or email info@pindepot.com. Tulip pins come in 1.0” and 1.5” sizes and cost about \$3.00 each when purchased in quantities of 100.



* article reprinted with permission from the author



Virginia PD Support Group Highlights

PLEASE NOTE: This list is only a sampling and is not a complete list of Virginia PD support groups.

New groups are always forming and places/contacts may change. Call the contact and verify the meeting especially if it is your first time.

Download the entire list from the SE PADRECC website at www.parkinsons.va.gov

Richmond: usually 4th Thurs at 1pm (speaker & discussion), McGuire VAMC, PADRECC. 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, Broad St, Methodist Home. Contact: Ann Spinks (804) 355-5717

Richmond: Young Onset Support
Contact: Cheryl Majeske (804) 932-3846
cherylmajeske@hotmail.com

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

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

Northern Neck/Middle Peninsula: 3rd Wed at 2pm & 1st Mon at 10:30 am (care partners group), Rappahannock Westminster Canterbury. Contact: Rita DePew (804) 435-9553

Hampton: 1st Tues at 2pm, Sentara Careplex. Contact: Susie Garrison (757) 727-7296

Norfolk: Young Onset Group - 1st Sun at 3pm, 1st Baptist Church of Norfolk, Rm 308. Contact: Ann Perkins (757) 486-5677.

Fishersville: 1st Sat at 2pm, 1275 Goose Creek Road, Blue Ridge Church of Christ. Contact: Keith Shank (540) 248-5004 pdgrp4u@yahoo.com

Fredericksburg: New day & location - last Wed at 1030am, The Disability Resource Center, 409 Progress Street. Contact: Earline Haney (540) 371-7334. Also has information about caregiver only gatherings.

Hampton Roads Area (Norfolk, Chesapeake, Virginia Beach, Newport News, Hampton, Kilmarnock) Multiple meetings. Contact: APDA Hampton Roads Chapter (757) 495-3062.

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

Charlottesville: Care Partners Friday at 10am (following the regular Monday meeting), Meadows Presbyterian Church. Contact: Barbara Morin (434) 973-7721.

SE PADRECC
Richmond
McGuire
VAMC



Upcoming Support Group Dates/Topics

July 24: Lee Silverman Voice Treatment
Fern Stillerman Cohen, MEd, CCC-SLP, LSVT certified
Aug 21: Healthy Living & PD Management
Ruth Meyer, Med, RKT
Sept 25: Tips to Keep Moving - Physical Therapy
Christie Walmsley, PT
Oct 30: Nutrition & PD
Jerri Zacko, RD,
Nov: to be determined
Dec 11: Holiday Party held in multipurpose room

Parkinson's Disease Community Education Days in Virginia

The annual Parkinson's Disease Community Education Day sponsored by the Richmond Metro Chapter of APDA, the APDA I&R Center of Charlottesville and the Southeast Parkinson's Disease Research Education and Clinical Center (PADRECC) was held on Thursday, October 4, 2007 at the Central Virginia Community College in Bedford, VA and again on Saturday, October 6, 2007 at the Holiday Inn Select Koger Center in Richmond, VA.

Approximately 250 people attended the conferences and the keynote speaker for both was Mr. John Argue, author of "Parkinson's Disease & The Art of Moving." He demonstrated movement and speech techniques to assist Parkinsonians with such activities as turning over in bed, getting in and out of chairs and cars, walking and maintaining speech.

Dr. Frederick Wooten, from the University of Virginia, discussed "Parkinson's Disease in the Post-levodopa/dopamine Era" and Dr. Abu Qutubuddin, from the Southeast PADRECC, spoke on "The Importance of Balance and Fall Prevention." Miriam Hirsch presented "Parkinson's Disease 101" and Rachel Schmidt, from the American Hospice Foundation, presented information about hospice while Paula Peaden, from Parker, Pollard & Brown, informed the group about estate planning and elder law.

The 2008 conference is scheduled for Saturday, October 11 at the Holiday Inn Select, Koger Center in Richmond, VA. Registration forms will be available in August and will be mailed to those on the PADRECC mailing list. Call (804) 675-6952 if you need one.



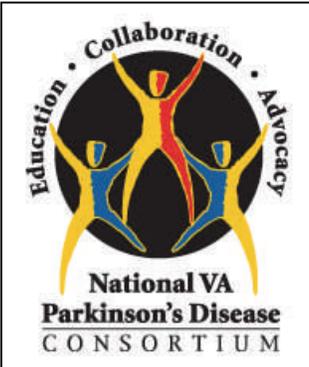
Dr. Fred Wooten talking to Meg & Dave Ballard at the registration table in Bedford.



John Argue autographing his book "PD and the Art of Moving" for a participant at the Richmond event.



National VA Parkinson's Disease Consortium Center Network



The National VA Parkinson's Disease Consortium was established in 2003 as a means to broaden the impact of the Parkinson's Disease Research Education and Clinical Centers (PADRECCs) and encourage modern Parkinson's disease care across the collective VA Healthcare System.

The concept of a "Consortium Center Network" was devised in 2006. Today, there are 47 Consortium Centers established across the country, representing every VISN.

Together the PADRECCs and the Consortium Centers create a hub and spoke model of care, allowing effective and convenient services to all veterans regardless of locality.

Veterans who cannot access direct services to PADRECC facility can receive specialized care at the closest Consortium Center in their region.

PADRECC Network

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 or
(206) 277-4560

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 VA PD Consortium Center Network Directors



Atlanta (Decatur), GA

(VISN 7)
Marion Evatt, MD
(404) 321-6111 x 7121

Augusta, GA

(VISN 7)
John Morgan, MD, PhD
(706) 733-0188 x2415

Birmingham, AL

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

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(VISN 6)
Burton Scott, MD
(919) 286-0411 x15611

Gainesville, FL

(VISN 8)
Frank Skidmore, MD
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Lexington, KY

(VISN 9)
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(VISN 8)
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Tuscaloosa, AL

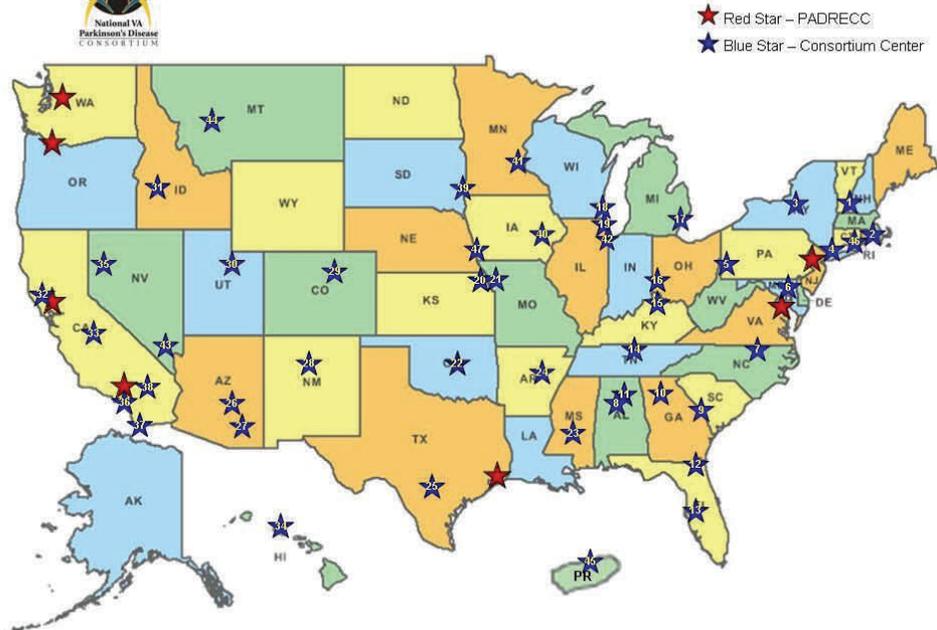
(VISN 7)
Fernando Franco, MD
(205) 554-2000 x4136

San Juan, Puerto Rico

(VISN 8)
Ana Vidal-Cardona, MD
(787) 641-7582



National VA PD Consortium Center Network





Southeast Parkinson's Disease Research
Education & Clinical Center (PADRECC)
Hunter Holmes McGuire VAMC (652/127)
1201 Broad Rock Boulevard
Richmond, Virginia 23249

Phone: 804-675-5931

Toll-free: 800-784-8381 ext 5931

Fax: 804-675-5939

Web: www.va.gov/netsix-padrecc

or

www.parkinsons.va.gov

PADRECC NEWS

Please report address changes or contact us if you would like to be added to the mailing list. Submissions are welcome and will be considered for publication.

Please send to the editor: Lynn Klanchar, RN, MS, Associate Director of Education, Southeast PADRECC by email: lynn.klanchar@va.gov or phone (804) 675-6952.

Eligibility/Enrollment for VA Healthcare

Who is eligible for PADRECC?

Veterans who received an honorable discharge from any branch of the service & served on Active Duty during war or Peacetime & meet eligibility requirements for VA health care benefits.

How do I apply?

First step is being enrolled for Veterans Affairs (VA) health care benefits. If not already enrolled, go to the Health Benefits Office of a VA hospital to apply, or call **(877) 222-8387** for an application. You can complete an on-line application at www.va.gov. During enrollment, veterans are assigned priority groups to determine co-pays. Changes

in available resources may reduce the number of priority groups VA can enroll. If this occurs, VA will publicize the changes and notify the affected enrollees.

How do I get an appointment?

Once enrolled, your VA doctor can write a consult and make a referral to Southeast PADRECC. Call **(804) 675-5931** to schedule an appointment.

PADRECC Clinic and other services: 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, and support groups. Veterans who live in the Southeast, and are unable to travel to Richmond, may be seen through our **Telemedicine Clinic**, if their home VAMC has telemedicine connection capability.

Research Opportunities at Southeast PADRECC are available to veterans and sometimes non-veterans diagnosed with PD or other movement disorders. Some projects recruit from the community and do not require you to be a veteran. Inquire at the PADRECC if you are interested in current studies.



Hunter Holmes McGuire
Veterans Affairs Medical Center
Richmond, Virginia