Eye Tremors May be Early Sign of Parkinson’s

A test that measures eye movements may become a powerful biomarker for Parkinson’s disease. This exciting research was published online on April 9, 2012 in the Archives of Neurology. The journal article, “Pervasive Ocular Tremor in Patients with Parkinson Disease” is the research of George T. Gitchel, MS; Mark S. Baron, MD (both are PADRECC staff) and Paul A. Wetzel, PhD (Virginia Commonwealth University). The study shows that people with Parkinson’s exhibit tremors of the eye, while people without Parkinson’s do not. The researchers used advanced eye tracking equipment to monitor the eye movements of 112 people with PD and 60 people who were controls (same age but without PD). They studied eye movements both during fixation - when subjects are told to hold their eyes still and simply focus on a central point, and then during saccades - when subjects react quickly to a moving dot and redirect their gaze. During the test, all 112 people with PD had unstable gazes or eye tremors. Their eyes moved even while they were attempting to hold them still. Only two of the 60 people without a diagnosis (the controls) demonstrated this instability. One of the two control subjects with eye tremors demonstrated symptoms of PD during a follow-up visit a year later suggesting this test can predict PD.

Brain Stimulation for Parkinson’s Offers Improvement in Symptoms Over Three Years

Department of Veterans Affairs
Office of Public Affairs
News Release June 21, 2012
WASHINGTON - Patients with Parkinson’s disease who undergo deep brain stimulation (DBS) - a treatment in which a pacemaker-like device sends pulses to electrodes implanted in the brain can expect stable improvement in muscle symptoms for at least three years, according to a Department of Veterans Affairs study appearing in the most recent issue of the journal Neurology.

“VA was a proud partner with the National Institutes of Health in this research,” said Secretary of Veterans Affairs Eric K. Shinseki. “Our research on Parkinson’s helps ensure we continue to provide the best care possible for Veterans with this debilitating disease.”

VA cares for some 60,000 Veterans with the condition. In DBS, surgeons implant electrodes in the brain and run thin wires under the skin to a pacemaker-like device. Electrical pulses from the battery-operated device jam the brain signals that cause muscle-related symptoms. Thousands of Americans have seen successful results from the procedure since it was first introduced in the late 1990’s. But questions have remained about which stimulation site in the brain yields better outcomes, and over how many years do the gains persist.

Initial results from the study appeared in 2009 in the Journal of the American Medical Association. (continue on page 4)
Southeast PADRECC Doctors and Staff

Mark Baron, MD  
Director Southeast PADRECC  
Neurologist  
Movement Disorder Specialist

Will Maragos, MD, PhD  
Chief, Neurology McGuire VAMC  
Neurologist  
Movement Disorder Specialist

Kathryn Holloway, MD  
Chief, Neurosurgery McGuire VAMC  
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Physiatrist

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William Carne, PhD  
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George Gitchel, MS  
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Neurosurgical Nurse Coordinator

Lynn Klanchar, RN, MS  
Associate Director of Education

Cathy McGrady  
Administrative Officer

Peggy Roberge, RN  
Clinic Nurse Coordinator

Multidisciplinary Team

Southeast PADRECC - A Center of Excellence for Movement Disorders

PADRECC treats all types of movement disorders such as Parkinson’s Disease (PD), Essential Tremor (ET), Dystonia, and Atypical Parkinsonian Disorders.

- New, follow up visits and clinical video tele-health (CVT) consults
- Multidisciplinary Approach—assessment/treatment/education by: MDs: Neurologist, Movement Disorder Specialist, Neurosurgeon, Rehabilitation; Neuropsychologist, RNs
- Rehabilitation evaluation and referrals to PT, OT, Speech and Social Work
- Medications and medical management
- Neuropsychological assessment of cognitive and emotional status
- Deep Brain Stimulation (DBS) surgery and programming
- Palliative care and hospice care referrals
- Educational materials/events, caregiver resources, support & exercise group
- Clinical trials/research studies

How do I get an appointment at PADRECC Clinic?
- To receive treatment at the PADRECC Clinic, you must be a Veteran enrolled in VA Health Care. If you are already enrolled, ask your primary care doctor to consult (make a referral) to the PADRECC Clinic. VA doctors must order an electronic referral entitled “Movement Disorders/Parkinsons/PADRECC”. Referrals from outside the Richmond/VISN 6 area require an inter-facility consult (IFC).
- To apply for VA Health care or determine if you are a Veteran eligible for enrollment:
  * Call Veterans Health Benefits Service Center 1-877-222-VETS (8387)
  * Go to www.va.gov. Look up Health Benefits and how to apply
  * Call (804) 675-5611. The Eligibility/Health Benefits Enrollment Office at McGuire VAMC is located in Room 1B-232.

Research Opportunities: Some research projects and clinical trials recruit from the community in addition to PADRECC patients. Non-veterans and non-enrolled Veterans may also meet the criteria for participation. See page 10 for more information.

Support Group: PADRECC sponsors a PD Support Group the 4th Thursday of the month at McGuire VAMC. The meeting is open to the community. You do not have to be a Veteran or enrolled in VA Health Care to attend. Call (804) 675-6952.
The year was 1817. Nearly 200 years ago, James Monroe was sworn into office as the 5th U.S. President and Dr. James Parkinson astutely described and wrote an essay about a condition he termed “The Shaking Palsy”. To honor Dr. Parkinson’s contribution to medicine, this condition eventually would be named Parkinson’s disease. Today, I would argue that we should instead refer to this malady as Parkinson’s diseases.

Until close to the end of the 20th century, we could only speculate as to the origin of this disease or these diseases. But in the 1990’s, the alpha-synuclein gene was discovered to be tied to Parkinson’s diseases. Although abnormalities of the alpha-synuclein gene are particularly rare, its discovery proved for the first time that Parkinson’s diseases could be caused by inherited genetic defects; that is, an abnormality in the genetic make-up we receive from our parents.

Ever since the break though discovery of the alpha-synuclein gene, there has been an explosion of genetic defects linked to Parkinson’s diseases. Each of these defects leads to the gradual death of dopamine cells in the brain in common, but very different ways.

While environmental factors certainly play a role, the various genes identified so far can account for close to 10% of all cases of Parkinson’s diseases. To clarify that these are really many different disorders. I propose the terminology Parkinson’s diseases. All lead to the degeneration of dopamine cells and ultimately cause what Dr. Parkinson described as “The Shaking Palsy”. Today we would not refer to it as a “palsy”, but rather a slowness and stuttering of gait.

As we approach the 200 year mark of Dr. Parkinson’s famous essay, expect more advances in understanding these Parkinson’s diseases, improved treatments, and the ultimate hope: a cure.

Hospitalization and PD:
Being admitted to the hospital can be a challenge for people with PD. Be prepared whether it is an emergency or planned:
1. Bring “Critical Information for Caring for the Parkinson Patient” paperwork with you. This will give staff a list of your medication and dosing times. It also helps educate them about PD and understand on-off time.
2. Inform PADRECC or your neurology clinic if you are admitted to the hospital. Give hospital staff the name & number of your specialist to help open the lines of communication.
3. Bring all your medication in their bottles, so medication can be verified.
4. If you have DBS, make sure the hospital is aware.

Hydration:
This is paramount during the summer and especially with the extreme heat!
1. Drink 12-16 ounces of water 4-5 times a day.
2. Drink 1-2 sports drinks daily(16 ounces) as long as you are not diabetic.
3. Avoid coffee, tea and sodas as they will increase fluid loss.

Proper hydration helps with metabolism of medication and food, helps constipation and increase energy.

Train Your Brain:
Before going to bed at night, write down a list of things you will be doing the next day in a journal. Next morning try to recall those things you wrote without looking at the journal first. Then look up the missing ones if any. This practice will teach your brain to do exercise and help your memory not to fade away quickly.

Voice Exercise:
Make loud sounds with the vowels. A E I O U
Exaggerate your facial expressions as you say the letter. Feel the movements of your mouth and lips.

Daily Morning Stretching:
Wait 45 minutes after the first dose of your medication. Then do 3-5 minutes of gentle stretching.

Walking in Place:
Stand in place and do at least 5-10 minutes daily of stationary walking. This will keep your quadriceps and gluteus muscles strong and improve your balance and ambulation.
Dr. Kathryn Holloway, PADRECC neurosurgeon, currently has an article in press involving the use of the O-arm, a portable, computerized tomography (CT) scanner during deep brain stimulation (DBS) surgery. The purpose of the study was to determine how accurate and reliable the O-arm CT images were compared to traditional CT images. O-arm images were taken throughout the surgical procedure to see where the DBS brain penetrations had been made and whether or not their locations matched Dr. Holloway’s intended targets. The study found that the O-arm scanner can be readily incorporated into the DBS procedure. It provides efficient and accurate registration and can be used to assess DBS lead location before the conclusion of the DBS surgery. This study titled “A quantitative assessment of the accuracy and reliability of O-arm images for deep brain stimulation surgery” was supported by an investigator initiated grant from Medtronic and institutional support from the PADRECC at Hunter Holmes McGuire VAMC & Virginia Commonwealth University Medical Center, Parkinson’s Disease and Movement Disorders Center. For more information about the study, please contact Miriam Hirsch, R.N. at (804) 675-6284.

A follow-up report in the New England Journal of Medicine in 2010, using data from 24 months of follow-up, showed that similar results could be obtained from either of the two brain sites targeted in DBS.

The new report is based on 36 months of follow-up on 159 patients from the original group. It extends the previous findings: DBS produced marked improvements in motor (movement-related) function. The gains lasted over three years and did not differ by brain site.

Patients, on average, gained four to five hours a day free of troubling motor symptoms such as shaking, slowed movement, or stiffness. The effects were greatest at six months and leveled off slightly by three years.

According to VA Chief Research and Development Officer Joel Kupersmith, MD, “This rigorously conducted clinical trial offers valuable guidance for doctors and patients in VA and throughout the world. As our Veteran population and the general U.S. population grow older, this research and future studies on Parkinson’s will play an important role in helping us optimize care.”

The research took place at several VA and university medical centers and was supported by VA’s Cooperative Studies Program (CSP) and the National Institute of Neurological Disorders and Stroke (NINDS), part of the National Institutes of Health (NIH). The maker of the devices used in DBS, Medtronic Neurological, helped fund the research but did not play a role in designing the study or analyzing the results.

VA, which has the largest integrated health care system in the country, also has one of the largest medical research programs. This year, approximately 3,400 researchers will work on more than 2,300 projects with nearly $1.9 billion in funding.

For more information on VA research, visit www.research.va.gov.

The research article “Randomized trial of deep brain stimulation for Parkinson disease: Thirty-six month outcomes” was published in the July 3, 2012 issue of the journal Neurology. Frances M. Weaver, PhD, Hines VA Hospital, Hines, IL was the lead author along with many co-authors including Dr. Kathryn Holloway, MD, Chief of Neurosurgery, McGuire VAMC, and Neurosurgeon for PADRECC Southeast and VCU Medical Center.

The VA hospitals and university medical centers that took part in this important study were the six PADRECCs and their affiliated university medical centers. This includes PADRECC Richmond/ Southeast at McGuire VAMC and Virginia Commonwealth University (VCU) Medical Center. To learn more about PADRECC (Parkinson’s Disease Research, Education, and Clinical Center) and VA network of care for Veterans with movement disorders, go to the website: www.parkinsons.va.gov
Upcoming Events in the Community

OCTOBER 13, 2012 - Richmond, VA @ Sheraton Richmond Park South Hotel
Parkinson’s Disease Community Education Day

- Samuel Goldman, MD, The Parkinson’s Institute, Sunnyvale, CA “Genes, Environment and PD: the search for causes”
- Mary Spremulli, Speech Pathologist, Voice Aerobics™ “A Whole Body Approach to Strengthening the Voice”
- Paul Short, PhD, Columbia, MD; “The Parkinson Coach” for APDA National YO Center “Parkinson’s is a Family Disease”
- Tim Ford, VCU Chaplain “Spiritual Growth in the Face of Illness”
- Charles F. Bryan, Jr., PhD, Richmond Mover & Shaker “How I Fight My PD Demon”

Hosted by:
Register ON-LINE at: http://tinyurl.com/2012PDday

or
Contact any committee members for a paper registration:
Kathy Morton - APDA (804) 261-5201
Susan Dietrich - APDA (434) 982-4482
Lynn Klanchar - PADRECC (804) 675-6952
Andrea Perseghin - VCU (804) 828-3747

Supported by Educational Grant funding from

OCTOBER 12 – 14, 2012 - Atlanta, GA @ Sheraton Gateway Hotel
7th Annual Southeastern PD Conference

Hosted by National Parkinson Foundation Georgia
(formerly the Georgia Parkinson’s Association)
Contact: NPF Georgia (706) 413-3264

MARCH 3, 2013 - Richmond, VA
Essential Tremor Seminar

Hosted by Richmond IETF Support Group, PADRECC, VCU Parkinson’s & Movement Disorders Center
Contact: Diana Campbell (804) 556-2345 or Lynn Klanchar (804) 675-6952

APRIL 13, 2013 - Virginia Beach, VA @ 31st Street Oceanfront Park
Walk 2013 for Parkinson’s Research

Hosted by Hampton Roads Chapter APDA www.hrparksons.com
Contact: Chair, Ann Perkins (757) 495-3062 or info@hrparksons.com

OCTOBER 1 - 4, 2013 - Montreal, Canada
3rd World Parkinson Congress for physicians, scientists, nurses, rehab professionals, policy advocates, care partners, family members and people with Parkinson’s disease - a worldwide dialogue to expedite the discovery of a cure and best treatment practices. Registration will open January 2013 on the WPC website.
Contact: www.worldpdcongress.org

OCTOBER 12, 2013 - Richmond, VA @ Holiday Inn Koger Center
Parkinson’s Disease Community Education Day

Hosted by APDA Richmond, APDA I&R Center at UVA, PADRECC Southeast, & VCU Parkinson’s & Movement Disorders Center
Scenes from the Movement Community

Parkinson’s Disease Community Education Day held October 22, 2011
At Sheraton Richmond Park South Hotel
A PADRECC joint venture with APDA, VCU and UVa

Cheryl Majeske with PDF Parkinson’s Quilt Project panel

Sheryl Jedlinski & Jean Burns, creators of PD Plan 4 Life www.pdplan4life.org

Alan Showalter with motivational speaker Peter Davison

Rita & Jay DePew and Angela & Carl Robb clowning around

Exercise break with Keith Overstreet, instructor from the John Rolfe YMCA class

PADRECC Support Group Holiday Party held December 8, 2011
Multipurpose Room at McGuire VAMC

Juanita sings. Peggy, Vanessa & Heather dance?

Lou & Charlotte Cunningham

Always a lot of food, entertainment, fun and games! Don’t miss this year’s party which will be held Thursday, December 13, 2012

Doug & Gloria Pace cut the rug
Scenes from the Movement Community

Parkinson’s Awareness Month Walk at Virginia Beach on April 14, 2012

Aerial shot: Hampton Roads APDA Chapter Parkinson’s Walk 2012 at Neptune Park, 31st Street and Atlantic Avenue, Virginia Beach, VA. PADRECC staff member Peggy Roberge, RN emceed at the event. Picture courtesy of Ann Perkins, APDA Hampton Roads Walk chairman.

May 19, 2012 at Richmond Convention Center
Victory Summit - A symposium of the Davis Phinney Foundation
www.davisphinneyfoundation.org
Southeast PADRECC was a local partner for the event along with VCU and APDA

Veteran Ron Kessler accepts the Davis Phinney Foundation “Local Hero” award, which is given to someone who epitomizes the philosophy of living well with PD. Ron is flanked by Lynn Klanchar (l) and Kathy Morton (r).

Practicing laughter yoga

The Victory Salute to celebrate moments of victory
New Resources

Two new items from PADRECC!

☆ The DVD called “My Parkinson's Story”
Produced in conjunction with Veterans Health Administration Employee Education System (EES). The DVD provides information about common concerns related to PD. Each of the 8 segments on this disk explores a specific issue from the perspective of the patient, his or her family and the health care team. Specific topics include: DBS, Depression, Early or Young Onset PD, Agent Orange, Falls, Genetics, Memory & Thinking Problems, and Sleep Problems. Each segment is approximately 8 minutes long.
To obtain a DVD, call PADRECC (804) 675-6952.

☆ Patient Education Facts Sheets
6 topics related to PD are explained on a 2 page tri-fold format: Motor Symptoms, Medications, Exercise & Physical Activity, Non-Motor Symptoms, Fall Prevention, and Agent Orange. Look for these brochures in the clinic literature rack or download them from www.parkinsons.va.gov/patients.asp

Be Prepared in case of Hospitalization!
The National Parkinson Foundation (NPF) has a new resource called the “AWARE IN CARE” Kit. It is filled with useful tools and information to help the person with Parkinson’s advocate for their self during a hospital admission—whether it be planned or an emergency. The kit includes a bag for carrying your medications, a hospital action plan, a medical alert ID bracelet and wallet card, a form to list your medications, fact sheets about PD and contraindicated medications, and reminder slips to share with hospital staff that say “I need my PD medications on time, every time”. You can order the kit from NPF by going to this website: www.awareincare.org

Attention PADRECC patients—ask your health care team to order you (through VA Prosthetics department) a personalized medical ID bracelet that alerts others about your DBS implant or PD, ET or other conditions.

Richmond area Parkinson’s Specific Exercise Programs

John Rolfe Family YMCA
2244 John Rolfe Parkway
Richmond, VA 23233
call (804) 360-8767
Tuesdays & Thursdays
11am – 12noon

Offered at 2 YMCA locations
YMCA Members: $30 per 6 week session
Community Member: $60 per 6 week session

Chickahominy Family YMCA
5401 Whiteside Road
Sandston, VA 23150
call (804) 737-9632 ext 311
Tuesdays & Thursdays
12:30 – 1:30pm

Sitting & Exercise Class
Sitter & Barfoot Veterans Care Center
1601 Broad Rock Blvd.
(on campus of McGuire VAMC)
Fridays from 11am - 12noon
No cost. Doctor’s approval required.
call Lynn Klanchar (804) 675-6952
Sponsored by PADRECC

Richmond Parkinson’s Dance Project
Simply Ballroom Dance Studio
3549 Courthouse Road, Richmond, VA 23236
Wednesdays from 11am - 12noon
No cost
call Veronica Braun (804) 276-3343 or
dance@simplyballroomva.com

SE PADRECC News
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.

- **Priority Groups:** After your application is processed, you will be assigned a priority group from 1 through 8. In 2003, VA stopped enrolling priority group 8 Veterans (those with high income/non service connected conditions). This was to ensure the availability of health care to Veterans in priority groups 1 through 7 (those with service connected conditions, special authority, low income, and special health care needs). In 2009, some new regulations went into effect to relax income restrictions. If you were assigned priority group 8 before January 1, 2009, contact the health benefits office and see if you are now eligible for health benefits. Veterans with Parkinson’s disease that are assigned priority group 8 should ask for a catastrophic disability evaluation. Due to the progressive nature of the disease, they may qualify for care.

- **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.

Eligibility/Health Benefits Enrollment Office at McGuire VAMC is located on the first floor, Room 1B-232. Call (804) 675-5611 or (804) 675-6675. McGuire VAMC main number (804) 675-5000.

**AGENT ORANGE & PARKINSON'S DISEASE**

VA presumes a Veteran’s Parkinson’s disease (PD) is related to their exposure to Agent Orange (AO) or other herbicides during military service.

Vietnam Veterans exposed to AO who now have PD do not have to prove a connection to be eligible for VA benefits. This rule took effect October 30, 2010. The process to obtain benefits is not automatic. Veterans must apply for health care and disability compensation.

Agent Orange Website: www.publichealth.va.gov/exposures/agentorange
Special Health Issues Helpline: 1-800-749-8387

Disability Compensation & Pension (C&P) Office:
Agent Orange Registry:
McGuire VAMC, Room 1A-112
Call (804) 675-5000 ext 4665

Health Care: 1-877-222-8387
VA Benefits: 1-800-827-1000
eBenefits: www.ebenefits.va.gov

Department of Veterans Affairs: www.va.gov

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**My HealtheVet** is VA’s award-winning online Personal Health Record (PHR)
* Anywhere, anytime Internet Access to VA Health Care
* Gateway to web-based tools that empower Veterans
* **Online services** such as **VA Prescription Refills** and **Communication** with doctors

Secure Messaging through My HealtheVet
* Is **not** considered email
* Secure, two-way electronic communication
* Web-based and encrypted
* Veterans communicate with their VA health care team about non-urgent, health matters in a private & safe computer environment
* **Reduces the need for telephone calls!**

Need Help with My HealtheVet or Secure Messaging?
call (804) 675-5312, stop by Room 1B-217 at McGuire VAMC, or ask at your next PADRECC visit
Research Opportunities at PADRECC Southeast, McGuire VAMC

Eye Movement Research
This large study is researching the specific eye movements in people with various movement disorders. Preliminary results suggest the ability to accurately differentiate all of the typical movement disorders (e.g., PD, ET). Eligibility criteria: movement disorder patients; special interest in recording the eye movements of patients with REM sleep behavior disorder, atypical disorders (e.g., MSA, CBGD, PSP), and those using the drug apomorphine (Apokyn); open to non-veterans as well as Veterans. Contact George Gitchel, MS, Research Health Science Specialist (804) 675-6300.

Safety and Tolerability of R (+) Pramipexole in PD
R (+) PPMX or Pramipexole is an experimental neuroprotective drug. The purpose of the study is to determine how well patients can tolerate the medication, not to see if it improves the symptoms of PD or if it slows the progression. The study medication has been tested in people with amyotrophic lateral sclerosis (ALS or Lou Gehrig’s disease) with excellent safety results. Study participants will be required to take increasing doses of R (+) PPMX by mouth over a 28-week, eight visit period. Eligibility criteria: confirmed diagnosis of PD; mild to moderate symptoms; positive therapeutic response to anti-PD medications; on stable doses of all medications for at least 3 months prior to entry into the study; ages 30-80. open to non-veterans as well as Veterans.  Contact Miriam L. Hirsch, M.S., R.N., CCRC, Study Nurse Coordinator at (804) 675-6284.

Repetitive Transcranial Magnetic Stimulation (rTMS)
A new research study is underway at the Southeast PADRECC studying the effectiveness of repetitive transcranial magnetic stimulation (rTMS) on speech in people with Parkinson’s disease (PD). rTMS uses strong magnets to stimulate brain cells. The magnetic pulses pass through the skin, skull and brain using a handheld device that rests on the surface of the scalp with no surgical incisions necessary. For this study, rTMS will be used to stimulate the part of the brain that controls the muscles in the mouth. Dr. Kathryn Holloway, the primary investigator for this trial, hopes that stimulation in this part of the brain will improve speech in people with PD. This study is open Veterans only. For more information about this study, please call the study coordinator, Miriam Hirsch, M.S., R.N., CCRC, at (804) 675-6284.

Requip XL in Early and Advanced PD
This is a fixed dose, dose response study of ropinirole prolonged release in patients with early stage PD, and also as an adjunctive treatment to L-Dopa in patients with advanced PD. To learn more, contact Peggy Roberge, RN, study coordinator at PADRECC (804) 675-5931.

NATIONAL Research News

PDtrials.org website closed on July 3, 2012. Below are several other websites that can help guide you -- or match you -- to Parkinson’s studies that may be of interest to you, and/or help you understand clinical research and suggest ways in which you can play an important role in advancing clinical research in Parkinson’s.

Fox Trial Finder (FTF) www.foxtrialfinder.org
Michael J. Fox Foundation for Parkinson's Research
FTF is a new Web tool created in 2011 in an effort to speed recruitment in clinical trials. FTF specifically matches volunteers with trials looking for people like them and facilitates the connection with the researchers, making it much easier for volunteers to find and act on suitable opportunities.

ClinicalTrials.gov www.clinicaltrials.gov
National Institutes of Health
This website offers a registry of federally and privately supported clinical trials conducted in the United States and around the world.

NIH Clinical Research Trials and You
www.nih.gov/health/clinicaltrials
National Institutes of Health
NIH Clinical Research Trials and You is an online resource to help people learn more about clinical trials, why they matter and how to participate.

Parkinson’s Advocates in Research
www.pdf.org/pair
Parkinson’s Disease Foundation
Parkinson’s Advocates in Research is dedicated to bringing educated community voices to important issues in Parkinson’s research by offering in-person trainings and an online course that provides people with Parkinson’s and care partners with the scientific knowledge and leadership skills needed to influence research and speed the development of new treatments.
The six Parkinson’s Disease Research Education and Clinical Centers (PADRECCs) were established in 2001 as centers of excellence for Veterans with PD or other movement disorders. The National VA Parkinson’s Disease Consortium was designed in 2003 to broaden the PADRECC’s reach.

Consortium Centers were then established to offer specialized movement disorder care in more areas of the country. Currently there are 51 centers representing every VISN. The centers are run by movement disorder specialists or doctors with an interest in PD. The 6 PADRECCs plus 51 Consortium Centers together provide convenience and state-of-the-art care to Veterans with movement disorders regardless of where they live. If a Veteran is unable to access services at a PADRECC, the nearest Consortium Center may be an option.

For more info, go to www.parkinsons.va.gov
Support Groups in Virginia - for various Movement Disorders

Please Note: This is a partial list. Contact the person listed prior to attending your first meeting.

**ATYPICAL DISORDERS**
Society for Progressive Supranuclear Palsy
www.sps.org
Online meetings for PSP, CBD, MSA and related brain diseases.

**DYSTONIA**
Dystonia Medical Research Foundation
www.dystonia-foundation.org

**ESSENTIAL TREMOR**
International Essential Tremor Foundation (IETF)
www.essentialtremor.org
(888) 387-3667

HopeNET - a guiding light for those affected by Essential Tremor www.thehopenet.org

**Central Virginia:**
Carol Wines (804) 746-3667

**ESSENTIAL TREMOR**
International Essential Tremor Foundation (IETF)
www.essentialtremor.org
(888) 387-3667

**DYSPHONIA**
National Spasmodic Dysphonia Association
www.dysphonia.org

**Hampton Roads Chapter APDA**
www.hrparkinsons.com

**RICHMOND METRO CHAPTER**
www.parkinson-richmond.com

**CENTRAL VIRGINIA**
Carol Wines (804) 746-3667

**HopeNET** - a guiding light for those affected by Essential Tremor www.thehopenet.org

**Charlottesville:**
2nd Thurs @ 4pm, John Watterson (434) 973-2510.

**Copper Hill:**
Dr. Preston Boggess (540) 651-6777.

**Falls Church:**
2nd Thurs @ 7:30pm, Peter Muller (703) 543-8131.

**Herndon:**
Clayton Bourges (703) 863-4086.

**Kilmarnock:**
meets quarterly, Steph Jewell (804)435-2589.

**Landstown/Leesburg:**
Eleanor Foley (703) 858-5346.

**Lexington:**
1st Fri @ 10:30am, Mary Barker (540) 463-7269.

**Richmond:**
3rd Mon @ 10:30am, Peter Muller (804) 754-4455.

**Roanoke:**
Mike Hopkins (540) 721-2087.

**PARKINSON’S DISEASE**
APDA I & R (434) 243-5422
maintains the most up-to-date list for Parkinson’s Disease.

**Richmond Metro Chapter APDA**
http://www.parkinsonrichmond.com

**Hampton Roads Chapter APDA**
http://www.hrparkinsons.com

**Parkinson Foundation of the National Capital Area (PFNCA)**
meetings in NOVA & DC Metro
http://www.parkinsonfoundation.org

**Bedford:**
2nd Thurs @ 2:30pm, Dave or Meg Ballard (540) 586-1406.

**Bluefield (West Virginia):**
2nd Tues @ 2pm, Jean Brown (276) 322-5715.

**Charlottesville:**
2nd Mon @ 1:30pm, Susan Dietrich (434) 982-4482.

**Chesapeake, Portsmouth, and Suffolk:**
1st Sat @ 1pm, Pat & Steve Yaros (757) 489-4302.

**Danville:**
1st Wed @ 2pm, Jay or Ruth Whitt (434) 792-2067.

**Eastern Shore/Onancock:**
Last Mon @ 3pm, Betty Aramesy (757) 787-3310.

**Farmville:**
4th Wed @ 5:30pm, Glenda Stone (434) 390-9839.

**Fishersville:**
1st Sat @ 2pm, Keith Shank (540) 255-1847.

**Fredericksburg:**
last Wed @ 10:30am, Jim & Earline Haney (540) 371-7334.

**Front Royal:**
1st Wed @ 1pm, Lee Mangene (540) 868-8838.

**Mariners:**
2nd Sat @ 1pm,

**Hampton:**
1st Tues @ 3pm, Susie Garrison (757) 827-2170.

**Harrisonburg:**
3rd Sat @ 1pm, Eva Showalter (540) 828-5212.

**Hillside:**
2nd Wed @ 10am, Mary Cox (276) 728-3703.

**Loudoun:**
1st Tues @ 1:30pm, Gary Heinberg (703) 404-0563.

**Lynchburg:**
3rd Tues @ 2pm, Jimmy White (434) 239-2373.

**New River Valley/Blacksburg:**
3rd Wed @ 2:30pm, Rick Richardson (540) 951-0040.

**Newport News:**
3rd Wed @ 1pm, Cynthia Dowd (757) 886-6381.

**Norfolk:**
4th Wed @ 7pm, Sandy Snapp (757) 534-5408.

**N. Neck/Middle Peninsula:**
2nd Wed @ 1pm and Carepartners group 1st Mon @ 10:30 am.

**Richmond:**
1st Sat @ 1pm, Pat & Steve Yaros (757) 489-4302.

**Williamsburg:**
2nd Mon @ 1:30pm, Joan Byrne (757) 898-6674.

**Winchester:**
2nd Tues @ 11am, Sharon Wilson (304) 258-0496.

**YOUNG PARKINSON’S**
Charlottesville: Debra Pressman (434) 996-1718.

**Richmond:**
4th Sun @ 2pm, Church Office of St. Paul Lutheran Church, Mechanicsville, Andrea Perseghin (804) 828-3747.

**Virginia Beach:**
1st & 3rd Sat @ 10am, Bob Johnson (757) 961-8564.

Please report address changes, additions or deletions to the mailing list to the editor, Lynn Klanchar, RN, MS, Associate Director of Education, Southeast PADRECC. Phone (804) 675-6952, email: lynn.klanchar@va.gov

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PADRECC NEWS

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