

PADRECC

NEWS

Volume 9 Number I Summer 2011

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

Research Happenings at Southeast PADRECC

Dystonia Research

Congratulations to PADRECC Director Mark Baron, MD who received a Veterans Affairs Merit Review in 2011! The process to receive this VA grant is highly competitive and only 20% of those who apply are selected. Dr. Baron now has a research laboratory at the McGuire Research Institute to study dystonia. Dystonia is the third most common movement disorder and is characterized by ineffective twisting movements and contorted postures. Pathophysiology of dystonia remains poorly understood. As a result, no therapies have ever been introduced specifically to



I to r: Dr. Mark Baron with his lab staff: Deepak Kumbhare, VCU Bio Med Engineering PhD Student; Nancy L. Smith, LVT, Research Technician.

treat dystonia effectively. The lab will systematically investigate pathological alterations in discharge patterned activity of brain cells that are likely to be the key to understanding dystonia, and the role of the basal ganglia in normal and abnormal motor control.

Forced Exercise with Theracyle

Dr. Abu Qutubuddin, PADRECC's Associate Director of Rehabilitation, is currently conducting a feasibility study regarding forced exercise using an electrically powered stationary bicycle, called a Theracycle. Recent anecdotal reports have suggested that bicycling at certain intensity may improve symptoms of Parkinson's Disease (PD). Since PD patients are sometimes unable to maintain the required higher rate of pedal speed, the electrically powered pedals "force" the patient to meet a certain level of effort.

Continue on pg 5



Practical Pointers by Peggy Roberge, RN, Clinical Coordinator, Southeast PADRECC **HYDRATION** Proper hydration is paramount anytime for a PD patient, but becomes even more of an issue during the summer. With PD, a person's loss of

body fluid is three times higher than the norm. The effort to perform a task, as well as tremors and bradykinesia contribute to fluid loss. Proper hydration will help with the metabolism of medication & food, avoid constipation and decrease urinary tract infections (UTIs). The PD patient's intake of water should be 12-16 ounces of water with each dose of medication. Patients who are diabetic should get 1-2 sports drinks in daily. If you are having problems with choking or difficulty swallowing, talk to your physician. There are many interventions that can be ordered or taught to help overcome this problem.

DOSING OF MEDICATIONS Time of dosing is very important. It is even more of a challenge when you have issues with memory or are very active. There are many ways to alert you that it is time to medicate: I. Program your cell phone. 2. Set alarm clock. 3. Set wrist watch to beep. 4. Obtain medication pill box that can be programmed to alarm or vibrate. The vibrating pill box is great when there is a hearing deficit. Patient compliance is fundamental for continued overall function when you have a PD diagnosis. Ask to see some examples of pill reminder products when you come for your PADRECC clinic visit. Call I-800-549-0095 for a catalog of ideas or check the website www.epill.com. An occupational therapist can also be consulted to help you find an appropriate pill reminder system, and teach you how to use it.

Inside this issue:

SE PADRECC Staff & Clinic Services	2
Eligibility/Enrollment for VA Healthcare	3
VA Network of Care for PD	4
Research Happenings at Southeast PADRECC	5
In & Around Movement Disorder Community	6
Richmond Parkinson's Dance Project	7-8
Parkinson's Specific Exercise Programs	9
Parkinson's Educational Programs	10
DBS Corner	10
National & Regional Organizations/Centers	11
Support Groups	12



Southeast PADRECC Staff

Mark Baron, MD Director Southeast PADRECC Neurologist Movement Disorder Specialist



Kathryn Holloway, MD Director, PADRECC Neurosurgical Services Neurosurgeon



Movement Disorder Specialist

Will Maragos, MD Chief, Neurology McGuire VAMC Neurologist

Abu Qutubuddin, MD **Associate Director PADRECC Rehabilitation** Physiatrist



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

Multidisciplinary Team Vanessa Rowlett Program Support Assistant William Carne, PhD **Psychologist** George Gitchel, MS Health Science Research Specialist Miriam Hirsch, MS, RN Neurosurgical Nurse Coordinator Lynn Klanchar, RN, MS Associate Director of Education Cathy McGrady Administrative Officer

Peggy Roberge, RN Clinic Nurse Coordinator

PADRECC Clinic Services

For Veterans with Movement Disorders including Parkinson's Disease (PD), Essential Tremor (ET), and atypical parkinsonian disorders

- New, follow up, and telemedicine visits
- Multidisciplinary Approach—assessment/treatment/education by:
 - -Medical Doctors: Neurologist, Movement Disorder Specialist, Neurosurgeon & Rehabilitation specialties
 - -Registered Nurses: Clinical, Neurosurgical, & Education
 - -Neuropsychologist
- 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 (see page 10) Palliative care and hospice care referrals
- Educational materials, Caregiver resources
- Support groups, exercise group, and educational events
- Clinical trials/research studies



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-II0 Phone (804) 675-5931

How do I get an appointment?

- The PADRECC main clinic number is (804) 675-5931. To receive treatment at the PADRECC Clinic, you must be a Veteran who is enrolled in VA Health Care. Call Veterans Health Benefits Service Center I-877-222-VETS (8387) to learn about enroll-ment. Once enrolled, your primary care doctor will refer you to the PADRECC Clinic. 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

Some research projects and clinical trials recruit from the community in addition to PADRECC patients. Non-Veterans and nonenrolled Veterans may meet the criteria for participation. Inquire at the PADRECC.

PADRECC PD Support Group meets 4th Thursday of the month from 1-3pm in Room 2K 113/115 at McGuire VAMC. You do not have to be a Veteran or enrolled in VA Health Care to attend. Call (804) 675-6952 for information.





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.
- **Priority Groups:** After your application is processed, you will be assigned a priority group from 1-8. VA made the difficult decision to stop enrolling new priority group 8 (high income) Veterans in 2003 to ensure the availability of health care to veterans in priority groups 1-7 (those with service connected conditions, special authority, low income, and special health care needs). New regulations went into effect in 2009 to relax income restrictions on enrollment for health benefits. Contact the health benefits office If you applied and were assigned priority group 8 before January 1, 2009 to see if you are now eligible.
- 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.



CAREGIVER SUPPORT LINE
1-855-260-3274

Caregiver M-F 8:00am - 11:00 pm ET and Sat 10:30 am - 6:00 pm ET

Learn more about the support services the VA offers Family Caregivers on line at www.caregiver.va.gov



Internet Access to VA Health Care

Help with MyHealtheVet available at McGuire VAMC, Room 1B-217 call 675-5312 or ask at a PADRECC visit.

New! Secure Messaging a web-based messaging system through MyHealtheVet. It allows patients to communicate with their VA health care team about non-urgent, health information in a private & safe computer environment.

Reduces the need for telephone calls!

AGENT ORANGE (AO) & PARKINSON'S DISEASE (PD)

VA presumes Veteran's Parkinson's Disease is related to their exposure to AO or other herbicides during military service.

VA's final regulation recognizing this association took effect October 30, 2010. Vietnam-era Veterans exposed to herbicides do not have to prove a connection between their PD & military service to be eligible to receive VA benefits.

Toll-free Helpline: 1-800-749-8387, press 3

AO Registry Exam: 675-5000 ext 4665 (McGuire VAMC)

Health Care: 1-877-222-8387

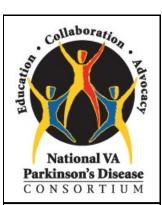
Disability Compensation & Non-Health Care Benefits:

1-800-827-1000

AO Website: (VA Office of Public Health & Environmental Hazards) www.publichealth.va.gov/exposures/agentorange



Veterans Affairs Network of Care for Parkinson's Disease



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-ofthe-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

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) Marian 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

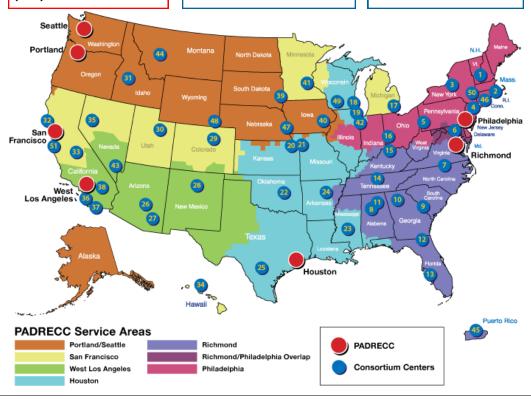
Lexington, KY (VISN 9) John Slevin, MD (859) 281-4920

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



Volume 9 Number I (Summer 2011)





Theracycle with Raed Alramadhani, Research Assistant

Research Happenings at Southeast PADRECC

continued from page 1

Forced Exercise with Theracyle

PD patients who meet certain criteria are randomly assigned to either an exercise or control group. Exercise group members participate for eight weeks in a twice weekly Theracycle session lasting approximately 30 minutes. In this session, participants pedal at a pre-determined rate via the electrically powered bicycle. Participants take a number of pre and post test to examine PD symptoms, finger speed, balance and perception of quality of life. Dr. Qutubuddin hopes to examine if any measurable beneficial effects occur in these areas as well as determining if larger scale studies of this nature will prove practical.

Eye Tracker Research

PADRECC Southeast continues to enroll patients in a large study that is researching the specific eye movements of patients with various movement disorders. Currently there are 560 patients enrolled, and we are continually looking for more. Preliminary results suggest the ability to accurately differentiate all of the "typical" movement disorders with a very high accuracy. Additionally, data suggest the ability to predict many of these disorders (especially PD) possibly many years before any outward symptoms are noticed.



Eye Tracker equipment

We encourage patients to consider enrollment in the study and are most interested in recording patients diagnosed with REM sleep behavior disorder, more atypical disorders (e.g. MSA, CBGD, PSP), and patients that are currently using apomorphine or Apokyn. For any questions, more information about the study or enrollment, contact George Gitchel, MS, Research Health Science Specialist at (804) 675-6300.

Neurosurgery Research

Intraoperative O-Arm Guidance During Frameless Stereotactic Placement of Deep Brain Stimulators

This study involves research aimed at improving the placement of brain leads or electrodes during deep brain stimulation (DBS) surgery. The effectiveness of the DBS procedure depends on the accurate placement of these lead (s) in a part of the brain that is no longer working properly. The placement of the lead is typically not known for sure until after the surgery is over, and a computerized tomography (CT) scan has been obtained and analyzed.

The purpose of this research is to determine whether or not images from an intra-operative (during surgery) "O-arm" CT scanner can be used to accurately determine where the DBS lead has been placed during surgery while the patient is still in the operating room.

Repetitive Transcranial Magnetic Stimulation for the improvement of speech in Parkinson's Disease

Hunter Holmes McGuire Veterans Affairs Medical Center in Richmond, VA is the first VAMC to utilize navigated brain stimulation (NBS) for assessment of brain functioning, specifically in the area of the primary motor cortex, as well as to study its effectiveness in treating conditions such as chronic pain and Parkinson's disease (PD).

NBS involves the use of strong transcranial magnetic field pulses that penetrate the skull, non-invasively. The stimulation causes a flow of energy into brain tissue which stimulates brain cells within a defined area. The NBS system utilizes MRI images as well as EMG responses to determine within 2 millimeters where to direct the magnetic pulses in the brain.

Cooperative Studies Program (CSP) #468-F Long Term Study of Deep Brain Stimulation for Parkinson's Disease: A Longitudinal Follow-Up Study of the VA/NINDS CSP #468 Cohort

The National Institutes of Neurological Disorders and Stroke (NINDS) and the Department of Veterans Affairs (VA) teamed up to study the effectiveness of best medical management compared to deep brain stimulation (DBS) surgery for the treatment of PD and to compare the safety and effectiveness of two brain targets, the subthalamic nucleus (STN) and globus pallidus (GPi). The original study has provided a wealth of information about DBS and these findings have been reported in the New England Journal of Medicine and the Journal of the American Medical Association.

continued on page 10



In and Around the Movement Disorder Community

Parkinson's Disease Community Education Day - an annual Richmond event!

2010 Event Summary: Over 275 people from Virginia and nearby states came to Holiday Inn Select Koger South Conference Center on Oct 16, 2010 for a day of learning about the many aspects of PD, and to network with peers & professionals in a supportive environment. PADRECC, APDA Richmond Metro Chapter, APDA I&R Center at UVa, and VCU PD Center worked together to bring the education day to the Virginia Parkinson's community. Miriam Hirsch, RN kicked things off with an early bird, pre-conference seminar on PD 101. Local Movement Disorder Specialists included Fred Wooten, MD and Tiffini Voss, MD from UVa, Jim Bennett, MD, Director of VCU Parkinson's Disease Center, and Will Maragos, MD, representing both VCU and McGuire VAMC. Several national experts on Parkinson's Disease were featured: Susan Imke, RN, MS, a Nurse Practitioner from Texas, and author of *The Comfort of Home: Parkinson's Disease Edition—An Illustrated Step-by-Step Guide for Caregivers* gave a humorous, yet practical talk called "Family Caregiving: Choices and Challenges". Judy Cameron, PhD, from the University of Pittsburgh spoke on the "Neuroprotective Effects of Exercise in PD". David Zid, a personal trainer and Parkinson's Exercise Specialist from Columbus, OH, got the audience moving with exercises from his Parkinson's specific training program called "Delay the Disease".

Please join us for the upcoming PD COMMUNITY EDUCATION DAY OCTOBER 22, 2011

NEW LOCATION this year - SHERATON RICHMOND PARK SOUTH
Online registration link at Richmond Metro APDA Chapter website www.parkinsonrichmond.com
See page 10 for more information

Essential Tremor Seminar held at McGuire

March is Essential Tremor Awareness Month and "Reasons for Hope", a half-day education session for people affected by Essential Tremor (ET) was held on March 12, 2011 at McGuire VAMC. This was the 2nd year for the program which was sponsored by PADRECC and the International Essential Tremor (IETF) Support Group based in Richmond. Featured speaker Mark Baron, MD, Director of Southeast PADRECC addressed clinical updates and surgical treatment. He was assisted by a support group member who recently underwent DBS surgery for successful treatment of his tremor. George Gitchel, MS, Research Science Specialist from PADRECC presented eye tracker research, which appears to help differentiate between movement disorder types. Sarah Lageman, PhD, VCU PD Center spoke on "Living Life to the Fullest".



Cecil Tune (I) and Dr. Mark Baron (r)

Tentative date for the next ET "REASONS FOR HOPE" Seminar is MARCH10, 2012.

Richmond Essential Tremor Support Group 3rd Tuesday of each month at 6:30 PM

Meeting Location:
Our Lady of Hope
13700 North Gayton Rd.
Henrico, VA 23233
upcoming meetings/speakers:
Aug 16 (Sarah Lageman, PhD)
Sep 20 (Dr. John O'Bannon, MD)

Contact: **Diana Campbell, Support Group Leader** Phone: **(804) 556-2345**

email:

RichmondVA@yahoo.com





What is an ET support group?

- An informal, self-managed, self-help group. Not a therapy group or 12-step program. It is run by and for people who have ET or who have a family member or friend who has ET.
- A place to be you. A place where people feel welcome & accepted, can talk openly, & can exchange ideas about the challenges of living with ET. A place where privacy & confidentiality are respected.
- A source of information and practical suggestions about ET and the IETF. Not a substitute for medical treatment or for personal or health counseling.
- A circle of friends. A place to talk, laugh, and empathize about life with ET with people who will listen, laugh, and empathize too.
- As unique as its members. The interests and capabilities of support group members vary greatly and change over time.



Richmond Parkinson's Dance Project Promotes Mobility, Creativity and Balance for those with PD By Terri Woods, daughter of dancer, Jiggs Fowler

Sometimes people can get frustrated, discouraged and at times hopeless with everyday life. I've been there once or twice myself. But be encouraged. There are those out there who can definitely put a positive spin on life and circumstances if we are lucky enough to find them.



Veronica Braun with Jiggs Fowler

Fortunately there is that person, that organization, and that place in Chesterfield County.

Veronica Braun, dance instructor and part owner of Simply Ballroom Dance Studio off of Hull Street Road, brings to those with Parkinson's Disease (PD) the opportunity to have some time to be just who they are with whatever level of movement they have and to DANCE. They are people who are there to have fun, laugh, meet friends and enjoy the music. There are no expectations individually or as a group, yet there isn't one I've seen there who didn't give it 110% effort in both categories.

This local pilot program began in January 2011 and has been successful since day one. Veronica displays amazing encouragement, leadership and a caring attitude in each class she leads. She also shares her knowledge of various music types and dances with different tempos and rhythms to the class, so it's easy to see why the program is such a success. This program brings together the mind, body movement and balance which are some of the major things that PD effects. Through the use of music, stretching, mobility exercises and dancing to slow and moderately fast tempos, it is used as therapy for the PD patient and it is just fun. As a caregiver, I watch my father who has PD go through movements and exercise that I never dreamed of only a few months ago. There are spouses, caregivers and family members that come and most participate in this as well. As I look at it, it's a win-win situation for everyone. The volunteers at the studio who work with Veronica on Richmond Parkinson's Dance Project are wonderful.

It's time.... participants in the class start to arrive, some have mobility challenges and other problems, but then they see their classmates, Veronica and the volunteers from the studio who help with the class and they are all ready for the class to begin. At first everyone sits in a chair in a big circle and they are all welcomed. Then (without music) Veronica starts demonstrating the first seated routine. As you look around the room you see each eye focused on her every move and her every word explaining each movement. There is explanation of posture for breathing, balance and the rhythm of the music that will be used for that particular routine. All are invited to join in and go through the routine (still no music). Once everyone has gone through it, the music starts and the whole atmosphere in the room changes and there is a different feel to the routine.



They're successful, they're doing what she's doing and they're having a great time. Everyone is participating. All are acknowledged for their success and it's on to the next routine. The auditory and visual means of learning works well. She continues to talk about similarities in music, dance and how they were developed through history.

continued on page 8



Richmond Parkinson's Dance Project Information

Where: Simply Ballroom Dance Studio, 3549 Courthouse Rd., Richmond, VA 23236

When: Wednesdays from 11 a.m. until noon

Cost: The class is free and open to the public. You do not have to have Parkinson's to participate. Caregivers, friends, and family are welcome.

RSVP: For more information or to reserve a spot in class, please contact Veronica Braun, (804)276-3343 or email dance@simplyballroomva.com.



Richmond Parkinson's Dance Project continued from page 7



After a few sitting routines and exercises, they stand behind the chairs and do more challenging exercises and dance routines to music. It is clear they are focusing on the music as well as the movement. Already most are displaying movement that is more fluid and they are more confident.

For the last part of the class, the chairs are moved to the side of the room and men are lined up on one side and the women on the other. Veronica introduces a dance and goes through each step. Some of the dances they have done are the rumba, tango, fox trot and swing. She demonstrates the movements and shows them how to count the rhythms (no music yet). The men

go first this time, learning each move by following her lead. As Veronica teaches them, her lighthearted and caring attitude makes each person want to be successful....and they are. Next she works with the women and the same attitude is evident. Now everyone gets a partner and she starts the music. They start counting and begin dancing.

WOW! They are dancing!

I watch as I see those who had a real mobility issue now doing the fox trot with a partner, no one is watching, they are just dancing and enjoying it. The mind is exercising and so is the body. The two are working together once again. It is truly amazing!



My heart goes out to those who are living with this disease, but I'm here to tell you that this program brings a type of therapy and exercise to those with PD that works both mind and body and has a positive impact on the heart and soul as well.

Veronica is so generous to give of her time and talent to this project. Veronica's inspiration and passion for working with those with PD is from her father who had Parkinson's for many years. He had a very aggressive version of the disease that included dementia, called MSA (Multiple System Atrophy). Veronica found out about

the program when she found an article in a magazine about retired dancers and what they did when they retired from performing. One of the dancers featured in

the article was a ballet dancer who retired from the Houston Ballet. She was now teaching Dance for PD®. Veronica's parents live in Texas and her father's neurologist was in Houston. She contacted them and arranged a meeting with the neurologist and her parents and after the appointment they went to the class. At the time Veronica's father was in a wheelchair most of the time with limited movement, mostly shuffling. But by the end of the class, he was walking with big steps up and down the floor and swinging his arms in time to "New York New York". She said "It was amazing"!

Veronica spoke with the Social Worker and the instructor of the class and they told her about a training class for Dance for PD®. When she returned home, she contacted Lynn Klanchar RN, MS, PADRECC Southeast Associate Director of Education for McGuire VAMC and together they

traveled to Brooklyn, NY for the training by the Mark Morris Dance Group and Brooklyn Parkinson Group. Veronica stated, "After we came back, Lynn arranged for me to do a demo of the class at a few of their events and she was instrumental in publicizing the class to the local PD community. If it weren't for her, we would not have a class". Since then, Veronica has attended another training course in Brooklyn and in the fall she will be going to Charlotte, NC with one of her teacher-trainees as well as other dance instructors for more Dance for PD® training.

For more information on Dance for PD® go to www.danceforpd.org



Why Dance For Parkinson's?

- Dancing is joyful, especially to upbeat music
- Dancing is a social activity
- Dancing is excellent exercise.
- A dance class provides a complete workout.
- Dancing stretches, strengthens, and relaxes muscles.
- Dancing is first and foremost, a mental activity.
- Dancing involves the brain as well as the body to control movement. The brain gets a complete workout too.
- Dancing makes use of the senses. Conscious use of vision, hearing, and touch make moving easier for persons with PD, just as it does for dancers.



Parkinson's Specific Exercise Programs

Local classes in Richmond area

Now 2 YMCA locations! Exercise for People Living with PD

John Rolfe Family YMCA 2244 John Rolfe Parkway Richmond, VA 23233

Tuesdays & Thursdays I I am - I 2 noon

call (804) 360-8767 Monica Atnip, Wellness Director Keith Overstreet, Instructor



Member: \$30 per 6 week session Community Member: \$60 per 6 week session



Sept 13 through Oct 20, 2011 Chickahominy Family YMCA 5401 Whiteside Road Sandston, VA 23150

> Tuesdays & Thursdays 12:30 – 1:30pm

call (804) 737-9632 ext 311
Tricia Wright, Wellness Coordinator

PADRECC Exercise Class

Sitter & Barfoot Veterans Care Center Community Room

1601 Broad Rock Blvd.

(on campus of McGuire VAMC)

Fridays from 11am - 12noon

Doctor's approval required.

call Lynn Klanchar (804) 675-6952









"Passing the sigh", a voice exercise at the PADRECC Friday class

Richmond Parkinson's Dance Project

Simply Ballroom Dance Studio 3549 Courthouse Road, Richmond, VA 23236

Wednesdays from 11am - 12noon

call Veronica Braun (804) 276-3343 or dance@simplyballroomva.com

(See article on page 7-8)

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Exercise Helpline Toll Free Number: 888-606-1688 or email: rehab@bu.edu

The Center for Neurorehabilitation at Boston University has established the National Resource Center for Rehabilitation with support from the American Parkinson's Disease Association, Inc. (APDA). Callers can speak with a licensed PT that can answer questions about exercise. Healthcare professionals may find the helpline useful too. Call anytime on Monday through Friday from 9am to 3pm or email your questions.



Parkinson Specific Training (for Professionals) The Parkinson's Wellness Recovery (PWR!) Project

• PWR! Clinician Training: November 5-6, 2011

(for Physical Therapists, Occupational Therapists, PTA's, COTA's) 1.4 CEUs

PWR! Fitness Training: November 7-8. 2011

PWR! Moves™and PWR! Circuit Training (for Personal Trainers, Group Fitness Instructors) 1.2 CEC's



Instructor: Becky Farley, PhD, MS, PT Location: John Rolfe Family YMCA, Richmond, VA More information or to register: www.nfnw.org

VCU Parkinson's Disease Center

Parkinson's Educational Programs

Sep 14, 2011 SSI/SSDI Workshop & Sep 27, 2011 Young Onset PD Focus Group Richmond, VA VCU PD Center Fall Seminars www.parkinsons.vcu.edu (804) 828-3747

Oct 14-16, 2011 Atlanta, GA Southeastern PD Conference

Northwest Georgia Parkinson Disease Association www.gaparkinsons.org

October 22, 2011 Richmond, VA Annual Parkinson's Community Education Day at Sheraton Richmond Park South "Achieving Balance in Body & Mind"

- New in 2011!
 - * Online registration link at www.parkinsonrichmond.com
 - * New location at Sheraton Richmond Park South
 - * PDF Quilt Project panel will be on display
- Cost is \$20/person
- Grant funding from Teva Neuroscience and Medtronic
- Contact these organizations for registration information:
 - *APDA Richmond Metro Chapter (Kathy Morton) (804) 730-1336
 - *APDA I & R Center (Susan Dietrich) (434) 982-4482
 - *PADRECC (Lynn Klanchar) (804) 675-6952 or Miriam Hirsch (804) 675-6284
 - *VCU Parkinson's Disease Center (Andrea Perseghin) (804) 828-3747

Speakers at Richmond PD Community Day October 22, 2011

Sheryl Jedlinski & Jean Burns,

PD advocates and www.pdplan4life.org website creators "Living Well is a Balancing Act"

Diane Huss, Physical Therapist, UVa "Fitness, Flexibility and Finesse: How "Fysical Therapy can Help"

Peter MacGregor Davison

Motivational Speaker & YOPD "Four Dimensions of Living Well"

Plus local Movement Disorder Specialists: **Dr. Matthew Boyce, Dr. Fred Wooten, Dr. James Bennett, Dr. Mark Baron** and Neurosurgeon, **Dr. Kathryn Holloway**

May 5, 2012 Richmond, VA Victory Summit™ by Davis Phinney Foundation

 Save the Date! The Victory Summit[™] is a national series of symposia focusing on the things people living with PD can do today to improve the quality of their lives.

 Learn more about Davis Phinney Foundation & the Victory Summit[™] at www.davisphinneyfoundation.org





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

Questions about or considering DBS? contact:

Miriam Hirsch, MS, RN at PADRECC (804) 675-6284 or Holley Stone, RN at VCU (804) 828-5235



Miriam L. Hirsch, MS, RN, PADRECC Neurosurgery Nurse Coordinator, maps a patient's motor cortex using a handheld coil. The mapping helps identify specific regions in the brain by eliciting responses from specific muscles.

continued from page 5

Longitudinal Follow-Up Study of the VA/NINDS CSP #468 Cohort

A five-year continuation study is now underway and involves subjects who participated in the original trial. During this trial we will examine whether or not the motor benefits of DBS persist and if the brain target makes a difference. Long-term function and quality of life of subjects is also being examined and what clinical features, if any, predict long-term outcome. Information about long-term performance of the DBS devices, including durability, explantation rate, replacement frequency, and changes in stimulation parameters will be collected and analyzed.



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

PD Trials 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

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 (704) 248-3722 www.parkinsonassociation.org

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

VCU PD Center, Richmond, VA (804) 828-3747 www.parkinsons.vcu.edu

PADRECC. Richmond VAMC (804) 675-5931 www.parkinsons.va.gov

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 Specialty Designated Centers 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

Support Groups for PD and ET in Virginia/West Virginia

Please call the contact person for details about each meeting. APDA I&R office (434) 243-5422 maintains the most up-to-date list.

PARKINSON'S DISEASE Annandale: 2nd Wed @ 6:30pm, PFNCA (703) 287-8729.

Arlington: 2nd Tues @ 2pm, PFNCA (703) 287-8729

Ashburn/Loudoun: Ist Tues @ Ipm, Gary Heinberg (703) 404-5563

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

Centreville/Chantilly: 4th Sat @ 10am, PFNCA (703)287-8729.

Charlottesville: 2nd Mon @ 2pm, Susan Dietrich (434) 982-4482. Young Onset meeting, Debra Pressman (434) 996-1718.

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

Eastern Shore/Onancock: Last Mon @ 5pm, Betty Arnsey (757) 787-3310.

<u>Fairfax:</u> 3rd Thurs @ 2pm, PFNCA (703) 891-0821.

Falls Church: Each Thurs @ 10:15am, Leon Paparella (202) 966-4450. Carepartners group each Tues @ 11am, PFNCA (703) 891-0821.

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

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

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

<u>Hampton</u>: Ist Tues @ 3pm, Susie Garrison (757) 827-2170.

Harrisonburg: 3rd Sat @ Ipm, Eva Showalter (540) 879-9743.

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

<u>Lynchburg:</u> 3rd Tues @ 2pm, Jimmy White (434) 239-2373.

Newport News: 3rd Wed @ Ipm, Cynthia Dowd (757) 886-6381. 4th Wed @ 7pm, Sandy Snapp (757) 534-5408.

Norfolk, Virginia Beach, East Chesapeake: 1st Wed @10am, Zelia Graham (757) 271-5969.

N. Neck/Middle Peninsula: 2nd Wed @ Ipm and Carepartners group 1st Mon @ 10:30 am, Rita DePew (804) 435-9553.

Richmond: Ist Tues @ 7pm Circle Center, 4900 W. Marshall Street Ann Spinks (804) 355-5717. 3rd Sun @ 2pm, Health South, 5700 Fitzhugh Avenue. Kathy Morton (804) 730-1336. 4th Thurs @ Ipm, PADRECC, McGuire VAMC Room 2K113/115, Lynn Klanchar (804) 675-6952.

Roanoke: 3rd Tues @ 2pm, Eric Anderson (540) 721-1994. Young Onset, 1st Sat @ 10am Melissa Johnson (540) 312-5202.

Suffolk, Chesapeake, Portsmouth: 1st Sat @ Ipm, Barb Voelkel (757) 538-0655.

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

Winchester: 2nd Tues @ Ilam, Sharon Wilson (304) 258-0496 West Virginia (Bluefield): 1st Mon at 2pm, Alice Pujari (304) 327-5434.

ESSENTIAL TREMOR
Charlottesville: 2nd Thurs,
John Watterson (434) 973-2510

<u>Lexington</u>: Mary Barker (540) 463-7269.

Lynchburg: Terry Houck (434) 525-6085.

N. Neck/Middle Peninsula: Quarterly on Sat @ 10am, Steph Jewell sjewell@nnwifi.com

Richmond: 3rd Tues @ 6:30pm, Diana Campbell ET.RichmondVA@yahoo.com or (804) 556-2345. Daytime group, Peter Muller (804) 754-4455.

Roanoke: Mike Hopkins (540) 721-2087.

International Essential Tremor Foundation (IETF) www.essentialtremor.org Community Ambassadors: Peter Muller (703) 543-8131 Preston Boggess (540) 651-6777



Volume 9 Number I Summer 2011

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