Specialty Care for More Veterans via PADRECC’s Expanding Telehealth Program

by Jackie Johnson, BSN, RN

It is estimated that the rate of Parkinson’s disease (PD) in the U.S. will double over the next 20 years. Our veteran population is aging along with the U.S. population. With the aging process comes a rise in PD and other movement disorders. To help meet the needs of veterans with movement disorders who live in rural areas or a far distance from Richmond, the Southeast/Richmond Parkinson’s Disease Research Education and Clinical Center (PADRECC) is expanding its virtual reach! As a VA Center of Excellence, we were chosen as one of seven pilot sites for the Telehealth Integrated Neurology Project by Veterans Affairs Central Office (VACO).

Expanding Capacity
Our PADRECC has expanded its Telehealth clinic availability from two days a week to five. Currently we are serving over 48 veterans per month with tele-health appointments, increasing the total number of telehealth visits by 134% in the first 5 months of 2014. The target goal is to double the number of Veterans served by telehealth over the next six months. Continued on page 3

DBS Surgical Expertise & Research Efforts Driven by Dr. Holloway’s Leadership

by Miriam Hirsch, MS, RN, CCRC

Over 400 Deep Brain Stimulation (DBS) surgeries have been performed since 1997 by Dr. Kathryn Holloway, an implanting surgeon, current Chief of Neurosurgery at McGuire VAMC. She has directed neurosurgical services at the Southeast PADRECC for the past 13 years, providing improved functioning and a restored sense of hope to hundreds of veterans with medically refractory Parkinson's Disease. Continued on page 2
movement disorders such as Parkinson’s disease (PD) and essential tremor (ET). In addition, she and her interdisciplinary clinical and research team are involved in numerous research projects aimed at improving the DBS technique and our understanding of the procedure.

The Richmond/Southeast PADRECC and Virginia Commonwealth University Medical Center are two of twelve centers that participate in the CSP #468 Study: A comparison of Best Medical Therapy to Deep Brain Stimulation of Subthalamic Nucleus and Globus Pallidus for the Treatment of Parkinson’s Disease. Dr. Holloway is the primary investigator and implanting surgeon for both of these study sites. The CSP 468 project is the largest multicenter trial examining the different brain targets for DBS in Parkinson’s disease. The data that has been and continues to be generated has contributed to a better understanding of DBS and the long-term effects of this treatment modality.

Other research interests of Holloway and her team include the development of improved frameless methods for DBS placement, the use of brain imaging technologies during DBS surgery, the creation of a mapping system or “GPS” to help improve surgical accuracy and outcome and the exploration of sub-regions of efficacy within DBS brain targets or the brain’s “sweet spots.” Dr. Holloway is also interested in the potential for DBS for the treatment of other brain disorders such as dementia and severe depression.

For more information about the Richmond/Southeast PADRECC DBS program, please call (804) 675-6284.

PADRECC Clinic Services
A Center of Excellence for Movement Disorders
Diagnosis and treatment for all types of movement disorders including Parkinson’s disease (PD), essential tremor (ET), dystonia, and atypical parkinsonian disorders.

- New, follow up visits and clinical video telehealth (CVT) consults
- Multidisciplinary Approach with Movement Disorder Specialists
- 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 and exercise groups
- Clinical trials/research studies

How do I get an appointment at PADRECC Clinic?
- To receive treatment, you must be a Veteran enrolled in VA Health Care. Your primary care doctor can consult the PADRECC Clinic by electronic referral entitled “Movement Disorders/Parkinsons/PADRECC OUTPT”. Referrals from beyond VISN 6 area require an inter-facility consult (IFC).
- To apply for enrollment in VA Health care or determine if you are eligible:
  * Call Veterans Health Benefits Service Center 1-877-222-VETS (8387) or go to www.va.gov. Look up Health Benefits and how to apply
  * In Richmond, Call (804) 675-5611 or (804) 675-6660. Enrollment Office for Eligibility/Health Benefits at McGuire VAMC is located in Room 1B-100/1B-232.

Research Opportunities: Some PADRECC research projects and clinical trials recruit non-veterans from the local community in addition to PADRECC patients. See page 10 for a list of current research opportunities.

Education and Support Group: PADRECC sponsors a monthly Parkinson’s group on the 4th Thursday at McGuire VAMC. The educational component is broadcast using V-tel (video telebroadcast) to Community Based Outpatient Clinics (CBOC) in Charlottesville, Fredericksburg and Emporia. Call (804) 675-6952.

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We consult via telehealth with over 32 Veterans Affairs Medical Centers (VAMCs) and Community Based Outpatient Clinics (CBOCs). This effort has brought quality specialty care to distant and rural veterans, while minimizing their travel burden to Richmond. One of the keys of success for our PADRECC telehealth providers is that each provider has telehealth capacity at their desk. The ready availability of technology allows for the expanded scheduling and timely access to care for the veterans.

Richmond/Southeast PADRECC receives referrals from VHA providers in the Southeast states including Virginia, West Virginia, Maryland, DC, North Carolina, South Carolina, Tennessee, Kentucky, Georgia, Alabama, Florida, and Puerto Rico. Because of our unique services we can treat patients from all over the east coast. For outlying VA providers and veterans who are dealing with a puzzling movement disorder or need support or treatment, we can provide individualized and comprehensive telehealth services for even the most remote veterans.

Consult Richmond/Southeast PADRECC using an inter-facility consult (IFC) through CPRS. The consult title is: Movement Disorder/Parkinsons/PADRECC OUTPT*. Or call (804) 675-5000, extension 3314 or 3749 for assistance.

Dr. Jessica Lehosit, DO is the new Neurologist, Movement Disorder Specialist, and Associate Director of Clinical Care at Richmond/Southeast PADRECC. She earned her Doctor of Osteopathic Medicine degree from Touro University in San Francisco. She did her medical school internship and neurology residency at Virginia Commonwealth University in Richmond, VA.

Marie Bradley, RN, MSN, FNP is the new PADRECC Telehealth Nurse Practitioner at Richmond/Southeast PADRECC. She is a graduate of the Virginia Commonwealth University MSN/APN program in Richmond, VA. Marie has been a Nurse Practitioner since 2001 and brings a solid knowledge of the Veterans Health Administration, plus 8 years of neurosurgery experience.

Welcome two new Telehealth Clinical Coordinators for Richmond/Southeast PADRECC Jackie Johnson, BSN, RN (left) and Mark Lawson, RN (right).

**NEW CLINICAL STAFF TO SUPPORT THE MISSION**

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**TELEHEALTH, VIRTUAL CARE, and EDUCATION at PADRECC Southeast/Richmond**

**Telehealth or CVT (Clinical Video Telehealth):** A live, secure, two-way interactive video telecommunication link between the movement disorder specialist in Richmond and the veteran at the VAMC or CBOC where he/she is enrolled. Telehealth minimizes the expense and burden of travel time to Richmond.

- **Telehealth general consults for movement disorders:** We provide diagnosis, evaluation, and treatment recommendations for tremor, gait, or other symptoms of movement disorders and assistance with best medical therapy.
- **Deep Brain Stimulation (DBS) surgery screening:** Initial assessment and education for possible surgery. DBS is used for the treatments of essential tremor, Parkinson’s disease, torticollis, and dystonia. Surgery is considered when significant symptoms persist (i.e. poorly controlled tremor, dyskinesia, motor fluctuations, or poor “off” time) despite best medical therapy.
- **DBS programming follow up:** Remote DBS programming via Telehealth, including staff education regarding the DBS device and programming.
- **Botox/neurotoxin therapy screening:** Evaluation of movement disorder related symptoms such as dystonia, muscle spasms, and sialorrhea for possible treatment with neurotoxins.

**SCAN-ECHO (Specialty Care Access Network):** Starting in the fall of 2014 we will be providing continuing education for clinicians via didactic and case studies presentations by our movement specialists.

**Veteran Group Education:** Monthly PD education/support group presentations are broadcast from Richmond using video teleconferencing (V-Tel) to CBOCs in Charlottesville, Emporia and Fredericksburg. More V-Tel sites are being planned.
RV A Offers a Variety of Exercise Options if you have PD

By Lynn Klanchar, RN, MS

Anti-parkinson medications are the cornerstone of treatment for Parkinson’s disease and the medicine helps control the motor symptoms. But medicine is not enough! Adding a plan for exercise and regular physical activity will keep you independent longer and provide long term benefits.

Here in Richmond, Virginia (RVA) we are fortunate to have a variety of exercise options available through community based programs. New programs are popping up all around the area and established programs are thriving. People with Parkinson’s and other movement disorders have discovered that exercising together in groups is fun! It’s easier to stay motivated when you exercise with others. In addition to the physical benefits, people are making new friendships and experience built-in emotional and social support.

Non-profit based Project Yoga Richmond (PYR), and PYR Ambassador Sarah Humphries, ERYT-200, graciously offered a series of introductory classes for people with movement disorders at their studio during the months of April, May, and June 2014. Sarah also teaches an ongoing gentle yoga class that she calls EnJOYoga most Saturdays at 10:30am. She guarantees that this class is appropriate for people with MS, PD, ET, and other movement disorders. Contact Sarah with your questions at (804) 840-4881 or email at sarah.humphries@verizon.net.

Sheltering Arms at the Bon Air Center recently introduced a Parkinson’s Wellness Recovery or PWR! class. PWR! is about intervention, enrichment, education and empowerment of those living with Parkinson’s disease (PD). The class is comprised of two components: group exercises that can be done seated or standing and circuit training in the fitness center. Instructor Eric Mays is committed to the philosophy that exercise is a first line of defense and that exercise may slow deterioration in people with PD. Class is offered in a 6-week session on Tuesdays and Thursdays from 11:30am-12:30pm. Contact (804) 764-5275 to register or Eric Mays (804) 764-5288 for more information.
The Richmond Parkinson’s Dance Project at Simply Ballroom Dance Studio is based on the premise that professionally trained dancers are movement experts whose knowledge is useful to persons with PD. Dancers know about stretching and strengthening muscles, and about balance and rhythm.

This program integrates movement from modern, ballet, folk, tap, improvisation, and ballroom dance. PD specific concerns of balance, flexibility, coordination, isolation and depression are addressed in a social environment that emphasizes dancing rather than therapy.

The class is taught by Veronica Braun and Diane Bates of Simply Ballroom Dance Studio, and Patty Mochary of the Richmond Ballet. All received training from the founders of the original program, Dance for PD at the Mark Morris Dance Center in Brooklyn, NY.

Classes are free and held every Wednesday from 11am-12pm. Call (804) 276-3343, email dance@simplyballroomva.com or go to the web: www.richmondparkinsonsdanceproject.com

The PADRECC Movement Class has been available every Friday morning from 11am-12pm for many years through a partnership with the Sitter & Barfoot Veterans Care Center (SBVCC). SBVCC is a nursing home for veterans that is run by the state of Virginia, located on Broad Rock Boulevard near McGuire VAMC.

This group has a regular following of residents from SBVCC with parkinsonism, and others from the PD community. Spouses and family members are welcome. The group practices a variety of exercises including singing and voice, stretching and yoga moves, dancing, BIG movements, and more.

Contact is Lynn Klanchar (804) 675-6952.

Calling all PD and ET road cyclists

Avid cyclists Cheryl and Tim, two VCU Parkinson’s and Movement Disorder Center patients, are organizing group bicycle rides with other cyclists who have Parkinson’s or a movement disorder. Participants should be able to ride a 14mph pace for two hours on country roads just outside Richmond.

Contact Tim at jtimthornton@yahoo.com for further information.
The John Rolfe Family YMCA in Richmond’s West End of Richmond recognized a need for Parkinson’s specific exercise classes in the PD community years ago. This class continues to flourish under the direction of Monica Newsome, Program Director, Membership & Wellness. A team approach is employed with four certified personal trainers: Sandy Lawson, Andy Thorrson, Heidi Schmidt, and Sandi Price. A variety of exercise formats including circuit training, free weights, TRX, Tai Chi, and voice strengthening are taught. Focus is on increasing strength, flexibility, endurance, balance and coordination.

Exercise Classes for People Living with Parkinson’s are offered Mondays, Tuesdays, and Thursdays from 11am-12pm. Participants choose a 2 or 3 day option for each 6 week session. Call (804) 360-8767 or email newsomem@ymcarichmond.org

Explore what is available in the community where you live. Ask your neurologist, inquire at your local PD support group, gym, YMCA, dance studio, or parks and recreation department.

Many Parkinson’s organizations offer free booklets and DVDs. PADRECC developed an exercise and physical activity leaflet and a short video on exercise that is available at www.parkinsons.va.gov.

PADRECC maintains a list of exercise resources and would be happy to help you explore classes in your area or help you research your specific needs. Contact (804) 675-6952 if you need assistance.

Make a lifelong commitment to exercise. Develop a daily routine and stay active. If you have been recently diagnosed, talk to your doctor about your current exercise plan or how to get started. If you are already active, ask how you can improve your level of fitness even more. If you have been diagnosed for a while and not exercising, consult a rehabilitation doctor or a physical therapist to help you take that first step. Remember, it’s never too late to start.
To Drive or Not To Drive: The Plague of Parkinson’s

Submitted by veteran, Ron Kessler

At the completion of my annual physical, my long-time family doctor surprised me with his recommendation that I should turn in my driver’s license. He said I had lost some strength in my legs and occasionally was troubled by leg spasms, tremors, and uneven balance. He suggested that such symptoms (probably related to my Parkinson’s) could cause significant delays in response time which would be critical when reacting to situations often encountered in operating a car. He added my age as an additional consideration due to typical weakening of vision and peripheral sensing.

My wife added that I had increasingly chosen not to drive at night or under foggy weather circumstances because I could not see as well as I felt I should. I agreed with the points being made, although I was beginning to feel that being candid and honest was avoiding the full story. My record was not one that supported taking my driver’s license away from me.

I began to feel that one of my vital freedoms was being threatened. I had not scratched a car in 40-50 years let alone been involved in a serious accident. I had not been charged with a moving violation. I drove almost daily often providing a lift for family and friends. My wife and I had made lengthy trips adding up to hundreds of miles while initiating and participating in Parkinson's exercise programs during the twenty-eight years since my diagnosis was confirmed. By my own choice, I had done less of our driving, two main exceptions being when my wife was hospitalized for extended periods.

I consulted with an outstanding specialist in Movement Disorders who had treated me, including my medical administration, for my entire experience with Parkinson’s. The advice regarding potentials from symptoms was the same as from my family doctor. I still felt that the “what if” approach was not giving a true picture of my typical behavior when operating a vehicle. However, I agreed to an extensive test by an independent laboratory that had been certified by the State Department of Motor Vehicles.

Using proven objective computerized tools and motor highway driving, an overall assessment would be made by the lab experts in driving safety. Their conclusion was that I should not be permitted to drive at this time.

I was offered another comprehensive test like this one by a different lab, but felt it would add little additional information that would give a more positive answer to my question regarding the continuation of my driver’s license. My answer was that I would turn over my driver’s license. The main influence on my decision came from something that my wife raised as a question: how would I feel if an accident occurred which might be due to my Parkinson’s?

Perhaps I will decide to take another test allowable by the state or perhaps changes will be made in the form of better guidelines defining what is considered unsafe. Maybe there will be technological improvements that will affect safety? This is all speculation, however. In the foreseeable future, the answer for a person with Parkinson's is to restrict driving available based on objective testing techniques. Apparently, I am one such person.

Author’s note: In February 2013, on my 80th birthday, I voluntarily turned in my driver’s license although I could have submitted it for renewal.

more about driving on page 8
Driving

continued from page 7

Resources about driving & Parkinson’s disease:

Short Video:
“My Parkinson Story—Driving” – this 9 minute video produced by the Veterans Administration provides information about PD and driving from the perspective of the veteran, his family and health care professionals involved in his treatment. Made on location at a National PADRECC with a real veteran and PADRECC staff.

Watch it on the web at: www.parkinsons.va.gov. Click on tab “For Veterans and Families”. Look for the section called “My Parkinson’s Story” and pick “Driving” or
Watch on YouTube at: www.youtube.com and search with keywords “driving, Parkinson’s disease, Veterans affairs” or
Scan this QR code with your phone or device ………………………..

Fact Sheets:


Am I safe to drive with PD?
Many people with PD do drive, usually in the earlier stages or when symptoms are well controlled. Realistically, there may come a time when you can no longer drive safely and you need to plan ahead for this possibility.

Parkinson Conference Scene

⇒ September 13, 2014 (Saturday 9:30am-2pm) Parkinson Disease Symposium hosted by Fishersville PD Support Group, Fishersville, VA. Contact Keith Shank (540) 255-1847 or Joyce Huddle (540) 943-2229.
⇒ September 13, 2014 (Saturday 9:30am-1pm) Parkinson’s Symposium: Care for Parkinson’s—Caring for you, Charlotte, NC. Hosted by Parkinson Association of the Carolinas. Call (866) 903-PARK (7275).
⇒ September 14, 2014 (Sunday, 8:30am) Walk Off Parkinson’s, Nationals Park, Washington DC. Walk & fundraising program by Parkinson Foundation of the National Capital Area. Register: www.walkoffpd.org or (703) 734-1017.
⇒ October 11, 2014 (Saturday, 8am-3:30pm) Annual Parkinson’s Disease Community Education Day, Glen Allen, VA. Hosted by PADRECC, VCU PDMC, APDA Richmond Metro Chapter & APDA I&R Center at UVa. Register: http://tinyurl.com/2014PDday or by phone: (804) 261-5201. See ad on back page of this newsletter.
⇒ October 17, 2014 (Friday, 7-9pm) Milestones and Horizons, CurePSP -Foundation for PSP/CBD and Related Brain Diseases event), Baltimore, MD. RSVP: psp.org/milestones or (800) 457-4777 x5665.
⇒ November 8, 2014 (Saturday) Movement Disorder Symposium - Johns Hopkins Medicine, BWI Airport Marriott Hotel, Linthicum Heights, MD. Contact Bailey Vernon (410) 616-2811 or bvernon1@jhmi.edu.
⇒ November 15, 2014 (Saturday) The Victory Summit, Davis Phinney Foundation for Parkinson’s, Greenville, SC http://www.davisphinneyfoundation.org/victory-summit/upcoming-victory-summits/victory-summit-upstate-sc/.
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. Together, the 6 PADRECCs and over 50 Consortium Centers 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
A Variety of Research Opportunities at Southeast/Richmond PADRECC

Eye Movement Research
Enrollment in the eye movement study is now well over one thousand subjects, and data strongly support the ability to differentially diagnose movement disorders, or even combinations of neurological disorders such as patients with both Parkinson’s disease and essential tremor. The study has produced two manuscripts recently. On Sept. 3, 2013, Tremor and Other Hyperkinetic Movements published “Slowed saccades and increased square wave jerks in essential tremor”. On March 30, 2014, Parkinsonism and Related Disorders published “Experimental support that ocular tremor in Parkinson’s disease does not originate from head movement”. A poster was presented at the 18th International Congress of Parkinson's Disease and Movement Disorders in Stockholm, Sweden in June 2014 outlining “Distinct Eye Movement Abnormalities in Vascular Parkinsonism”. This study is enrolling movement disorder patients with special interest in patients with REM sleep behavior disorder, atypical disorders (e.g., MSA, CBGD, PSP), and those using the drug Apokyn (apomorphine). Open to veterans and non-veterans. Contact George Gitchel, MS, Research Specialist (804) 675-6300.

Repetitive Transcranial Magnetic Stimulation (rTMS)
This study is underway, investigating the possibility of improving speech in patients with Parkinson’s disease using repetitive transcranial magnetic stimulation (rTMS). rTMS uses strong magnets to stimulate the part of the brain that controls the muscles in the mouth. The study is enrolling patients with moderately impaired speech and involves rTMS every day for a week, with assessment of speech before, immediately after, and three months post treatment. The study is sham controlled, double-blinded, and seeks to enroll approximately 20 patients. Study is open to veterans only. Contact Miriam Hirsch, MS., RN, CCRC, study coordinator at (804) 675-6284.

Clinical Trial for Chronic Constipation
This multicenter study funded by the Parkinson’s Study Group will investigate the effects of RM-131 on chronic constipation in Parkinson’s disease. The investigational drug is a daily subcutaneous injection, which may or may not be effective in helping symptoms of chronic constipation in PD. This study is not yet open for enrollment. Contact George Gitchel, MS, Research Specialist (804) 675-6300.

Resources for Research

ClinicalTrials.gov
www.clinicaltrials.gov
A service of the U.S. National Institutes of Health
This website is a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world.

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

Fox Trial Finder
www.foxftrialfinder.org
Michael J. Fox Foundation for Parkinson's Research
Fox Trial Finder was created to help increase the flow of willing participants (both people with Parkinson’s and control participants who do not have Parkinson’s) into the trials that need them, accelerating the Parkinson’s drug development process. Fox Trial Finder will match registrants to the trials that are best suited to their specific traits.

Parkinson's Advocates in Research (PAIR) www.pdf.org/pair
Parkinson's Disease Foundation
PAIR is dedicated to bringing together the people who live with Parkinson’s and the people who are developing new treatments. Through in-person trainings and an online course, PAIR provides people touched by Parkinson’s with the knowledge and skills needed to pair up with scientists and health professionals.
Southeast/Richmond PADRECC Clinicians

Mark Baron, MD
PADRECC Director
Neurologist
Movement Disorder Specialist

Jessica Lehosit, DO
PADRECC
Associate Director of Clinical Care
Neurologist
Movement Disorder Specialist

Abu Qutubuddin, MD, MBBS
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Kathryn Holloway MD
Chief, Neurosurgery, McGuire VAMC
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Chief, Neurology, McGuire VAMC
Neurologist
Movement Disorder Specialist

Marie Bradley, RN, MSN, FNP
PADRECC Telehealth
Nurse Practitioner

Multidisciplinary Team

William Carne, PhD
Psychologist

George Gitchel, MS
Health Science Research Specialist

Miriam Hirsch MS, RN, CCRC
Neurosurgical Nurse Coordinator

Jackie Johnson, BSN, RN
Telehealth DBS Coordinator

Lynn Klanchar, RN, MS
Associate Director of Education

Mark Lawson, RN
Telehealth Coordinator

Contact Us

Appointments/Main Office:
(804) 675-5931  Fax: (804) 675-5939

Consults:
“MOVEMENT DISORDER/PARKINSONS/PADRECC OUTPT”
Request a traditional appointment, a CVT (telehealth) appointment, or an E-consult using this inter-facility consult (IFC).

Administration: (804) 675-5690

Education: (804) 675-6952

Deep Brain Stimulation (DBS):
(804) 675-6284

Telehealth: (804) 675-5000 x3314

Telehealth/DBS: (804) 675-5000 x3749
PADRECC hosts this event together with VCU Parkinson’s and Movement Center, American Parkinson Disease Association (APDA) Richmond Metro Chapter, and the APDA Information & Referral Center at University of Virginia. To register, go to [http://tinyurl.com/2014PDday](http://tinyurl.com/2014PDday) or contact Kathy Morton (804) 261-5201.