PD Awareness Day Trip to National Marine Corps Museum

By Lynn Klanchar, RN, MS, Southeast PADRECC, Associate Director of Education

The Parkinson’s Disease Research, Education and Clinical Center (PADRECC) Southeast Support Group at McGuire VAMC made a trip on April 11th to the National Museum of the Marine Corps in Quantico, Virginia. This date is the worldwide Parkinson’s disease (PD) awareness day and marks the birthday of Dr. James Parkinson for whom the disease is named.

The idea began when a support group member attended the dedication of The National Museum of the Marine Corps in November 2006. After the ceremony, he brought the program booklet to support group and shared about it. Since the group is made up of many veterans, military experiences are often recalled, along with discussions about day to day issues that people with PD face.

The group began brainstorming about how we could visit the museum together. It was decided that spring would be a good time to plan the excursion.

The idea was pitched in February at the quarterly Voluntary services meeting at McGuire VAMC. Several Veterans Services Organizations (VSOs) came forward to offer assistance. VFW Post 1503, Military Order of the Cootie (MOC) in Dale City, VA offered lunch and a personal tour by Colonel Larry Britton, Marine Corps (Retired), a docent at the museum. Delpha Martin and the MOC Ladies Auxiliary helped serve the lunch, socialized with our group, and provided snacks for the bus ride home. Dale McIntosh from VFW Ladies Auxiliary in Virginia arranged a discount on the local James River bus lines. Our group of 36 was very appreciative of the generous donations provided by the VSO’s.

Field trip participants included veterans with PD (7 who served in the Marine Corps), spouses, caregivers, and several staff members. The museum was breathtaking and an incredible monument to the history of the Marine Corps. It was a user-friendly place for our PD group, built to handle wheelchairs. Some veterans did experience strong memories from viewing the realistic exhibits, but the power of group support proved to be a real help for those who needed it.

This fun outing on PD Awareness Day helped demonstrate that social outings go on in spite of disease. The day reminded us to be grateful to the Marine Corps, and for all military members who have served both past and present. Thank you USMC. Semper Fi! Ooh rah!

Expiratory Muscle Strength Training for Parkinson’s Disease

Michelle Troche, MA, and Christine Sapienza, PhD
Department of Communicative Disorders
Brain Rehabilitation Research Center, Malcolm Randall VAMC

While much attention to the deficits caused by Parkinson’s disease deal with its impact on walking and balance, PD can also affect other critical functions such as respiration (breathing), phonation (voice production), resonance (richness of voice), articulation (clarity of speech), cough and swallow. The same types of disrupted movements that affect the arm and leg muscles, resulting in slower, less accurate, more rigid, weaker or uncoordinated actions of the muscles, also cause disruptions to breathing, voice, speech, cough and swallowing. Many of the same muscles that are also used to produce voice and speech are utilized for eating and swallowing, particularly those that control the functions of the lips, tongue, palate, pharynx and larynx. The physical changes to these muscles can affect a person’s ability to chew and swallow in an efficient and safe way. Certain foods of different thicknesses and amounts can result in greater swallowing problems. For example, thin liquids (continued on pg 3)}
Medications used to Treat Parkinson’s Disease
by Peggy Roberge, RN, Southeast PADRECC Clinical Nurse Coordinator

Medications used for treating Parkinson’s disease (PD) are aimed at replenishing or enhancing dopamine. Levodopa and dopamine agonists are the main medications used for PD. They are considered first line drugs. Levodopa is used in the brain to produce the chemical dopamine. These drugs are known to us as Sinemet IR (instant release) or Sinemet CR, SA or ER (controlled released, sustained action, or extended release) and Parcopa, a dispersible Sinemet.

Dopamine agonists mimic dopamine and thus do not have to be converted into dopamine. Trade names for these are Requip, Mirapex and Pergolide, Parlodel and Apokyn. Pergolide however, was recently removed from the market due to increase in patients having cardiac issue with their valves.

Medications used in conjunction with Sinemet and dopamine agonists either alter or enhance effect. The names of these drugs are Amantadine, Cogentin, and Artane which help with tremor. Comtan and Tasmar are used to enhance the effect of Sinemet or dopamine agonist. Tasmar is used with caution due to the potential for it becoming toxic to the liver. Parkinson patients on Tasmar will have their blood checked frequently to monitor any adverse effects. Other meds frequently used are selegiline and now on the market are Azilect and Zelapar which are usually given as first line drugs in patients with mild PD symptoms.

As you can see we still do not have enough medications to help with all of the symptoms that come with PD. But we do have several drugs that are coming on the market such as: Neupro, a dopamine agonist in the form of a patch and a longer lasting type of Sinemet that has even a longer extended release than the Sinemet CR.

Drugs are in the pipeline which are still investigational and will be delivered via an implantable pump either subcutaneous, intraventricular or intestinal. They are still in phase 1 or 2 testing and have yet to be named, but are showing some promise of better medication delivery. Other drugs and procedures in the investigational phase such as fetal implant, growth factor, hormones, gene therapy and antioxidants may prove to be neuroprotective, meaning slowing down the progression of the disease. These are all in the future and hopefully in the next 5-10 years will show benefit and will be another avenue to treat Parkinson’s disease.
Other swallow symptoms reported by patients include:

- Slow rate of eating
- Fatigue during eating
- Food "sticking" in the throat
- Coughing or choking on food or liquid
- Excessive saliva and drooling
- Difficulty swallowing pills
- Difficulty initiating swallowing
- Unexplained weight loss
- Change in dietary habits
- Longer meal times
- Recurrent pneumonia
- Nasal regurgitation (liquid or food out of the nose)

Expiratory Muscle Strength Training (continued from pg. 1)

(e.g. water) often cause more episodes of choking while more solid foods can be difficult to move from the front of the mouth to the back.

These documented changes occur in all stages of PD and can negatively impact health and quality of life. Often, patients are unaware of the subtle changes they are experiencing in their swallowing function. However, these subtle changes are usually evidence of neurological dysfunction and will likely lead to worse symptoms in the future. Therefore, patients, caregivers, and physicians should pay careful attention to these symptoms. Early intervention may result in better response to therapy and could alter the trajectory of the disease process over time. Early intervention is important because the severity of the swallow problem increases, more foreign material can enter the airway leading to an increased incidence of aspiration. Aspiration pneumonia is often cited as the number one cause of death in patients with PD (Fernandez & Lapane, 2002; Gorell, Johnson, & Rybicki, 1994; Hoehn & Yahr, 1967; Scheirmeier, Schafer, Schafer, Greulich, & Schlafke, 2001; Shill & Stacy, 1998; Singer, 1992).

Currently, clinicians have few behavioral techniques to treat the swallowing dysfunction associated with PD and little evidence to support their use. Swallow therapies include strategies to compensate for difficulties. These include diet modification (i.e. thickened liquids and pureed diets) or changes to posture when eating. With these types of modifications, the focus is not on changing the active process of swallowing but rather changing extrinsic factors that make the swallow simpler. Some therapy techniques actively work on changing the process of the swallow. These interventions alter the mechanics of the swallow, targeting the muscles and their coordination. Unfortunately, several of these techniques do not provide a mechanism for the clinician to define the degree to which the muscle is working and the implementation can be difficult with some patients struggling with complex steps.

We have been using a therapy technique called expiratory muscle strength training (EMST) to study whether muscle strengthening can improve functions like breathing, cough, voice/speech and swallow. EMST utilizes a device that helps the muscles involved with these swallowing functions become active, and the intended result is to combat the slow, rigid and weak musculature associated with PD.

The technique uses an experimental pressure threshold device to accomplish the strength training. Figure 1 shows a photograph of the device. The device requires patients to develop an expiratory pressure while blowing forcefully. It uses a pressure threshold relief valve and is calibrated up to a pressure range of 150 cmH₂O and the pressure load can be varied as the strength of the muscles improves. This is similar to increasing the weight you are lifting during exercise, as the muscle gets stronger. We determine strength improvement by measuring a parameter called maximum expiratory pressure, as well as by monitoring the activity of the muscles we are interested in, like the muscles involved in swallowing and breathing. Using a device with a pressure threshold relief valve prevents the user from varying their airflow rate, which can result in lower training effect.

The device shown in Figure 1 is currently patent-pending and was invented by several researchers at the University of Florida. There is an ongoing treatment study in which patients with PD use the device at home for 5 weeks, 5 days a week. Patients are trained on how to use the device by a licensed speech pathologist and they train with the device for approximately 20 minutes per day. One goal of this study is to determine how the device’s training affects the safety and efficiency of swallowing in patients with PD, and additionally how the training impacts the quality of life with reference to swallow.

We have evidence to support that our expiratory-based therapy program will likely have a rehabilitative effect on the swallow mechanism as it increases the activity of the submental muscles in the neck (Wheeler, Chiara, & Sapienza, in press). Recently, using techniques that allow us to see the swallow process as it happens (videofluoroscopy) and track how much the muscles are working during the use of the device (electromyography) we have discovered that the therapy makes the hyoid bone elevate. The movement of the hyoid bone during swallowing is very important because it helps close off the respiratory airway protecting it from foreign material traveling the wrong way, and helping to open the sphincter of the esophagus (stomach tube) which then allows food to enter the stomach. Improving the extent of hyoid movement should in theory improve swallow efficiency. Figure 2 shows the muscle activation of the submental muscle group acquired using surface EMG (a measurement of muscle movement) and simply demonstrates that the muscle activation is higher than that which occurs during a normal dry or wet swallow. Activation of the muscles is also higher when the device is set at a higher setting, like that shown for EMST use at 75% versus EMST use at 25%.

Finally, we are aware that when discontinuation of a therapy occurs, the effects of the training may also disappear. This is called detraining and is particularly relevant when strength training therapy protocols are stopped. We are currently examining the detraining effect associated with discontinuation of the EMST device in those with PD to determine if there is a loss in improvement associated with discontinuing our training and if so, how much of the positive effect remains.

When studied in healthy participants we found that strength decreased by approximately 10% after 8 weeks of not using the device. It is our opinion that this information is very important to share with clinicians and all types of patients, as it is quite reasonable to conclude that a maintenance program with the device will be necessary so that detraining does not occur over time. The effects of detraining can occur with any therapy program and functional improvements gained by an intervention may be lost.

Interestingly, many of our patients do not want to return the device to us after the experimental therapy discontinues. Patients report that they find the training easy to complete and that it does...
Caregivers Bill of Rights:  *I have the right…*

from Caregiving: Helping an Aged Loved One by Jo Horne, AARP Books, 1985

1. To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my relative.
2. To seek help from others even though by relatives may object. I recognize the limits of my own endurance and strength.
3. To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.
4. To get angry, be depressed, and express other difficult feelings occasionally.
5. To reject any attempts by my relative (either conscious or unconscious) to manipulate me through guilt, and/or depression.
6. To receive consideration, affection, forgiveness, and acceptance for what I do from my loved one for as long as I offer these qualities in return.
7. To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.
8. To protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.
9. To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting Caregivers.

References:


Delay the Disease - a New Exercise Book and DVD
by Jackie Russell, RN, BSN, CNOR

Parkinson’s disease (PD) remains, for the most part, a mystery of medical science. Research continues, but at the present time the primary treatment modality is medication directed at minimizing the symptoms. It is not a condition you choose, but once diagnosed, PD does have the capacity to cause you to reassess your priorities and make lifestyle choices that can affect the path of the disease.

An emerging reality is the positive effect of exercise on the course of this disease. An exercise agenda may offer stimulation to the various neurological pathways, increasing the capacity to counteract the progression of symptoms. An exercise plan can provide a sense of purpose and direction, offering the opportunity to improve stability, strength, flexibility, and management of tremor. When your ability to move improves, so does your feeling of accomplishment and sense of achievement. Scientific evidence has proven that not only can motor function improve with exercise, but mood and a “feeling of well being” is clearly related to routine activity. More importantly, it shows that you may have Parkinson’s disease, but it does not have you. No matter how long you have been diagnosed with Parkinson’s disease, it’s not too late to start, and it’s never too early.

David Zid, from Columbus, Ohio, has designed a Parkinson’s - specific exercise routine. Zid is an ACE, APG certified personal trainer that has always had an interest in training the older adult. He is extremely excited about his latest project. In collaboration with Thomas H. Mallory, M.D., (a retired orthopedic surgeon from Columbus who has PD) and Jackie Russell (a local nurse with a special interest in the disease) he has authored a book detailing this PD fitness plan. It is a colorful, user-friendly guide to a daily fitness regimen directed at all levels of PD. The title of the book is Delay the Disease – Exercise and Parkinson’s Disease. The manual can be purchased by visiting the website www.delaythedisease.com. A portion of the proceeds will benefit the Madden Parkinson’s Center of Excellence at The Ohio State University. Additionally, Zid has created a companion DVD that is also available for purchase on the website.

Get started on a fitness plan today and see the results for yourself. The challenge presented to the individual with PD is to never give up. A new attitude filled with vigor, enthusiasm and sense of optimism will commence each day as you realize there is an opportunity to modify the progression of this condition. Keep moving, stay positive. Contact Jackie at run1176@aol.com

DBS Corner FAQ’s (frequently asked questions)

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

Q. I’m interested in deep brain stimulation (DBS). How do I start researching this as a treatment option?
A. There are many sources of information about DBS including, but not limited to, Medtronic Neurological, Inc., (www.medtronic.com) the makers of the device, as well as several national nonprofit Parkinson’s disease groups such as the American Parkinson Disease Association (APDA), National Parkinson Foundation (NPF), Parkinson Disease Foundation (PDF) and the PADRECC network. These numbers and websites can be found on pages 6-7. You should also discuss your interest in learning more about DBS with your treating physician. Neurosurgical nurses can provide information too. In the Richmond and Southeast area, veterans can contact Miriam Hirsch at the McGuire VAMC (804) 675-6284. Tammy Searles, RN is the neurosurgical nurse at Virginia Commonwealth University (VCU) Medical Center (804) 828-5235.

Q. Will I need to take PD medications after having surgery?
A. The goal of DBS surgery is to improve one’s level of functioning by reducing the severity of the Parkinson’s disease symptoms, the fluctuations in these symptoms and any drug-induced side effects such as dyskinesia. For some, the Parkinson’s disease medications may be reduced as a result of the surgery and for others, they may be increased. Careful and ongoing monitoring of the effects of the medications and stimulation is important in determining what the most appropriate treatment is. As Parkinson’s disease progresses however, these treatments will need to be adjusted accordingly.

Exercise Class
“Moving to agility, balance and joy”
at Southeast PADRECC
McGuire VAMC
Richmond
every Friday
11 am - 12 noon
Inquire when you visit the clinic or call (804) 675-6952 for more information

“Life is like riding a bicycle.
To keep your balance you must keep moving”
Albert Einstein (1879-1955)
German born American physicist who developed the theory of relativity. Nobel Prize for Physics

Deep brain stimulators are implanted on one or both sides of the brain with connecting wires and batteries.
**PADRECC Support Group**

Where: Hunter Holmes McGuire VAMC, Room 2K-113/115 1201 Broad Rock Blvd., Richmond, VA 23249

When: 4th Thursday at 1-3pm
Contact: Lynn Klanchar (804) 675-6952
Format: Speaker, plus group discussion for PWP & caregivers

Aug 23  Sleep Disorders in PD & Sleep Hygiene Anna Hristova, MD, Movement Disorders Specialist, Southeast PADRECC, McGuire VAMC

Sep 27  Therapeutic Value of Animals/Pet Therapy Cara Carlson, Recreational Therapist, McGuire VAMC

Oct 25  Well Spouse Association Nancy Jarrell, Richmond Well Spouse Support Group, Henrico Doctors’ Hospital

Nov 29* Coping with Dementia in PD Mary Ann Johnson, MA, Alzheimer’s Association, Greater Richmond

Dec 20* Holiday Party featuring creative arts by support group members * alternate Thursday

**National Organizations & Regional Groups**

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

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

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

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

**Parkinson Association of the Carolinas** (704) 248-3722  www.parkinsonassociation.org

**Parkinson Foundation of the National Capital Area** (703) 891-0821  www.parkinsonfoundation.org

**Richmond Metro Chapter APDA**  www.parkinsonrichmond.com

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

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

**Support Groups in Virginia**

**Please Note:** This list is not all inclusive. New groups are always forming and places/contacts may change. Contact Susan Dietrich at the APDA I & R Center of Virginia (434) 982-4482 for the most up-to-date list for Virginia.

It’s always a good idea to call the contact and verify the meeting especially if it is your first time.

Richmond: 4th Thurs at 1pm PADRECC, McGuire VAMC Contact: Lynn Klanchar (804) 675-6952

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

Richmond: 1st Tues at 7pm (Discussion) Circle Center, Broad St, Methodist Home. Contact: Ann Spinks (804) 355-5717

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

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

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

**How to Find a PD Support Group**

Although Southeast PADRECC is based in Richmond, Virginia, it serves not only Virginia, but West Virginia, Tennessee, Kentucky, North & South Carolina, Georgia, Alabama, Mississippi, Florida, and Puerto Rico.

There are many regional, independent, and non-profit Parkinson’s organizations that maintain support group lists, and offer many other services such as educational materials and conferences.

American Parkinson Disease Association (APDA), National Parkinson Foundation (NPF), Parkinson’s Disease Foundation (PDF), and Parkinson Action Network (PAN) are good places to start. Some areas have regional PD organizations. See the websites and phone numbers posted below.

APDA has Information & Referral (I&R) Centers that serve specific geographic areas. I&R Centers that serve the Southeast US are listed below.

Most of these organizations have newsletters, booklets and educational offerings. Check them out. You may want to consider joining and or being put on their mailing list.

**APDA I & R Centers in the Southeast**

Atlanta GA: (404) 728-6552

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

Charlottesville VA:  (434) 982-4482

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

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

Jacksonville FL: (904) 953-7030

Memphis TN: (901) 516-0677

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

Pompano Beach FL: (800) 825-2732

St. Petersburg FL: (727) 898-2732

Reno, NV: (888) 838-6256 ext 1715 or (775) 328-1715

A center dedicated to serving armed forces veterans

Glenbrook IL: (847) 657-5787 or (800) 223-9776

A center dedicated to young onset PD

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

**New Fredericksburg:** last Tues at 1030 am  Contact: Earlene Haney (540) 371-7334

**Young Onset Support** Contact: Cheryl Majeske (804) 932-3846  cherylmajeske@hotmail.com
The National VA Parkinson’s Disease Consortium was established in 2003 as a means to broaden the impact of the Parkinson’s Disease Research Education and Clinical Centers (PADRECCs) and encourage modern Parkinson’s disease care across the collective VA Healthcare System. Together the PADRECCs and the Consortium Centers create a hub and spoke model of care, allowing effective and convenient services to all veterans regardless of locality. The concept of a “Consortium Center Network” was devised in 2006 and there are now 41 Consortium Centers established across the country.

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

**PADRECC Network**

**Philadelphia** (215) 823-5934
**Southeast/Richmond** (804) 675-5931
**Houston** (713) 794-7841
**Portland/Seattle** (503) 721-1091 or (206) 277-4560
**San Francisco** (415) 379-5530
**West Los Angeles** (310) 478-3711 x48001

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**Welcome Drs. Kasturi & Skoblar**

We are pleased to welcome a new Fellow, Gopi Kasturi,, MD and new Associate Director of Research, Barry Skoblar, PsyD.

**Dr. Kasturi** is a movement disorders & research fellow at SE PADRECC with interests in Parkinson’s disease, geriatric rehabilitation, osteoporosis, and integrative medicine. He attended the Armed Forces Medical College (MBBS) in Pune, India, and did his residency in Physical Medicine and Rehabilitation at the William Beaumont Hospital, Royal Oak, Michigan.

**Dr. Skoblar** will be coordinating and facilitating all levels of research at SE PADRECC. He earned his Doctorate in Clinical Psychology at Florida Tech. He interned at Little Rock VAMC, and was a behavioral neurology and neuropsychology fellow at Gainesville VAMC/University of Florida (UF). Most recently he worked as a research fellow at UF’s Cognitive Neuroscience Lab studying the cognitive and emotional aspects of PD. His professional interests are PD, memory and cognition, dementia, and healthy aging.

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**Southeast PADRECC Staff**

**Barry Skoblar, PsyD**
Associate Director of Research

**Lynn Klanchar, RN, MS**
Associate Director of Education

**Peggy Roberge, RN**
Clinic Nurse Coordinator

**Miriam Hirsch, MS, RN**
Neurosurgical Nurse Coordinator

**Abu Qutubuddin, MD**
Physical Medicine &Rehabilitation

**Gopi Kasturi, MD, Fellow**

**William Carne, PhD, Psychologist**

**Cathy McGrady**
Administrative Officer

**Odetta Semple, Program Support Assistant**

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**Dr. Gopi Kasturi**

**Dr. Barry Skoblar**
Eligibility/Enrollment for VA Healthcare

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

How do I apply?
First step to enrollment is completing a Veterans Affairs (VA) health care benefits application. Call (877) 222-8387 for an application to be sent to you or go to www.va.gov and download an application or complete it on-line. During enrollment, veterans are assigned priority groups VA uses to balance demand with resources. Changes in available resources may reduce the number of priority groups VA can enroll. If this occurs, VA will publicize the changes and notify the affected enrollees.

How do I get an appointment?
Once enrolled, you or your VA doctor can make a referral to Southeast PADRECC at (804) 675-5931.

PADRECC Clinic and other services: interdiscipli- nary assessment and treatment, clinical trials, physician consultation, medical management, surgical interventions, neuropsychological services, physical and occupational therapy, speech therapy, nursing services, caregiver resources, educational materials, community education programs and support.

A Telemedicine Clinic is also available for veterans with Parkinson’s disease living in the Southeastern region of the US who cannot easily travel to Richmond for an appointment.

Research Opportunities at Southeast PADRECC are available to veterans & non-veterans diagnosed with PD. You do not need to be a veteran or enrolled to participate in some research. You are welcome to call and inquire about current studies that are being conducted.