



NEWS

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Winter 2007

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

PADRECC Holiday Party Features Creative Arts Plus a Visit from Santa

Over 60 people showed up for the annual PADRECC Southeast patient/family holiday party on December 14th at the McGuire VAMC Multipurpose Room.

The party had a little bit of everything, and lots of surprises for the guests! An extensive luncheon buffet was available featuring deli sandwiches, meatballs and cocktail shrimp. We were able to do this thanks to generous contributions made to the PADRECC SE General Post Fund and the work of PADRECC staff and volunteers who planned, shopped and prepared the main menu.

Lots of homemade desserts and side dishes were

provided by participants and their spouses. Seconds were allowed and no one went home hungry!

Party events included an ornament exchange and door prizes. A dozen people took up the offer to bring samples of the arts and crafts they do to showcase at the party and to discuss their work with others. It was a grand opportunity to see how people are able to rise above the impact of Parkinson's disease to produce beautiful works of art. The therapeutic value of such creativity and the joy it brings in sharing with others was readily apparent. We are looking forward to doing more of this at future support group



Neurology resident Dr. Garbee as Santa

meetings.

The party was not over until Santa made an appearance and the group joined in for some spirited Christmas caroling along with piano accompaniment.

The last big surprise was a white poinsettia for each to take home! These were donated to the McGuire Voluntary Services who generously passed them on to our group.

All I know is that next year's party will be a tough act to follow!

Arts at the Party.....

- Piano playing
- Fine art oil painting
- Writing: books/ stories
- Cartooning
- Marquetry
- Ornamental lights in glass bottles
- Photography
- Woodwork & crafts
- Scherenschnitte (cut paper art)



Photography & Scherenschnitte

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PADRECC Bill Signed into Law

In a flurry of activity just before the holidays, legislation to preserve the Parkinson's Disease Research, Education, and Clinical Centers (PADRECCs) passed the House and the Senate. It was signed by the President into Public Law No: 109-144 on 21 December, 2006. The original bill, HR 6342, was introduced to the House in early Decem-

ber. It had been worked on for months by Parkinson Action Network (PAN) advocates and other PD organizations when it was learned that the centers' existence was in jeopardy. The passage of this bill honors the work of retiring Congressman Lane Evans, a founder and co-chair of the Congressional Working Group on Parkinson's Dis-

ease. This vital legislation ensures that the PADRECC centers at VA Medical Centers in Richmond, Houston, Philadelphia, West Los Angeles, Portland/Seattle and San Francisco continue to provide state-of-the-art clinical care and outreach to veterans with PD. For more information about PAN call (800) 850-4726 or go to www.parkinsonsaction.org.



Southeast PADRECC Staff

Mark Baron, MD

*Director, PADRECC Southeast
Neurologist, Movement Disorder Specialist*

Kathryn Holloway, MD

Neurosurgeon, Neurosurgical Director

Anna Hristova, MD

*Neurologist, Movement Disorder Specialist
Associate Director of Patient Care Services*

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
and Rehabilitation Physician**

William Carne, PhD, Psychologist

Cathy McGrady, Administrative Officer

Odetta Semple, Program Support Assistant

Vanessa Banks, Program Support Assistant

Our team of caring and qualified professionals consist of full-time, part-time, government, contract, and fee-basis employees. Many staff have academic affiliations at Virginia Commonwealth University (VCU) Medical Center.



*Southeast PADRECC Staff:(left to right) Front row: A. Qutubuddin, A. Hristova, K. Holloway, M. Baron
Back row: L. Klanchar, P. Roberge, C. McGrady, V. Banks, W. Carne, M. Hirsch.*



Neuropsychology Service at Southeast PADRECC by Patrick Armistead-Jehle, Ph.D.

Patients being treated at the Southeast PADRECC may wonder why an initial appointment and on-going assessment with a neuropsychologist are part of their care. After all, Parkinson's Disease (PD) is primarily a motor disorder, right? While this is true, clinical data now demonstrates that a percentage of individuals diagnosed with PD will experience related symptoms that can best be identified by a trained mental health professional. These symptoms generally fall into two categories: emotional and cognitive.

According to the National Parkinson's Foundation the prevalence of depression in PD is between 20-40%. Further, between 40-90% of individuals diagnosed with PD experience clinically significant depression in their lifetime. The National Institute of Mental Health further reports that a similar percentage of PD patients will experience some sort of anxiety disorder. We all feel blue from time to time, or have periods of nervousness and tension. However, in some PD patients, these feelings can take on a much more severe quality that ultimately compromises daily functioning. The PADRECC neuropsychologist is in the best position to properly diagnose any such condition and make the referrals necessary for the treatment and support of you or your loved one.

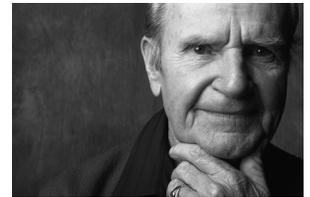
A subset of PD patients can experience memory decline that, at its worse, could result in a diagnosis of dementia. Dementia is not simply forgetting where you placed your house keys or failing to pick up milk while at the grocery store. Rather dementia is a much more severe clinical syndrome marked by significant cognitive deficits not only in memory, but also language skills, reasoning and judgment, and/or the ability to recognize familiar objects through one or more of the five senses.

According to the National Parkinson's Foundation approximately 30% of PD patients will meet diagnostic criteria for dementia during their disease course. In general, there is a 10-15 year gap between the diagnosis of PD and the emergence of dementia in those that will develop it. (Please keep in mind this is an average and varies by individual patient.) Not all types of dementia initially present themselves in the same way. PD patients who begin to have cognitive difficulties may experience a different profile of symptoms than patients diagnosed with other conditions that cause dementia, such as Alzheimer's disease or strokes. In general, PD patients are more likely to notice initial deficits in attention, motivation and emotionality. They may also show early symptoms of depression, clumsiness, irritability or apathy.

The PADRECC neuropsychologist will screen for cognitive abilities and continue to monitor any changes over time. Should more comprehensive testing appear necessary, it will be completed at the PADRECC clinic or a referral will be made. Based on test results, the neuropsychologist can make many recommendations to include suggestions for improving activities in daily living and/or increasing home safety, selected readings to help address any areas of deficit, or further consultation with your neurologist for possible medication adjustments.

The PADRECC neuropsychologist is here to improve your care, assist your caregiver and ultimately help assure a comprehensive approach to your treatment.

The neuropsychologist can make many recommendations to include suggestions for improving activities in daily living and/or increasing home safety, selected readings to help address any areas of deficit, or further consultation with your neurologist for possible medication adjustments.



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Parkinson's Disease Community Education Day

October 7th, 2006 was a very rainy autumn day. But over 160 people came together for the Annual Parkinson's Disease Community Education Day at Holiday Inn Select, Koger South Conference Room in Richmond Virginia. The whole day was filled with learning, sharing and supporting each other in a festive atmosphere. People living with PD, their friends and family members, as well as professionals with expertise in Parkinson's disease came together at this conference. Miriam Hirsch, RN presented "Parkinson's Disease 101" for those who have been newly diagnosed. Dr. Fred Wooten from the University of Virginia (U.Va.) gave a stimulating talk on the spectrum of symptoms that occur in PD related to Lewy body pathology. These symptoms are different than the motor problems of PD that are caused by a dopamine deficiency problem in the substantia nigra. Keynote speaker was a dietician, Jackie Nielsen from Colorado, a protégé of Kathrynne Holden who has written many books and articles about nutrition and Parkinson's disease.

After a delicious lunch and the raffling of many door prizes, Dr. Anna Hristova from the PADRECC spoke on complementary medicine research in PD. The conference closed with a choice of two seminars by speakers from U.Va. Dr. Laura Lee presented on the Role of Exercise, and Scott Wylie, PhD gave the group tips on living well with a chronic disease. He walked the audience through a coping exercise and used humor to explain that coping was somewhere between moping and hoping! **Mark your calendars: Next PD Community Education Day is Oct 6, 2007.**



APDA and PADRECC Partnership



This annual community outreach event is sponsored by Southeast Parkinson's Disease Research, Education, and Clinical Center (PADRECC) and the American Parkinson's Disease Association (APDA). Representatives from the APDA Richmond Metro Chapter and the Information and Referral Center at University of Virginia in Charlottesville come together with PADRECC staff to plan the agenda and a timeline months in advance. Staff and group members volunteer their time to make it happen. Many activities beforehand lead up to the big day such as: writing a contract with a conference center, arranging for speakers, obtaining door prizes, mailing brochures, putting conference packets together, and handling registration forms. On the day of the event, some folks come early to set up, decorate tables, and stay late to take down. It is a wonderful experience, both the planning and execution of this fun day for people with PD and their families. Thanks to all who helped bring this together!



Locals Cycle Indoor El Tour for APDA

Eight cyclists from Virginia participated in the first "Indoor" *El Tour de Tucson* on Saturday, November 18, 2006. The participants included people with PD, spouses and friends of those with the disease, and health care professionals! Five people came to the McGuire VAMC on a Saturday and rode stationary bicycles together. Three others (including 2 veterans!) rode their own exercise bicycles at home. The goal was at least 10 minutes

and the Virginia group all rode 30-45 minutes. They earned a handsome medal after sending in proof of the ride. The outdoor *El Tour de Tucson* is a fundraising event in its 24th year. People come from all over the country to bicycle up to 100 miles around Tucson, Arizona. This year, a new event was added called "LeMond Fitness Indoor El Tour" for the benefit of the Arizona Chapter of the APDA. An individual benefactor sponsored an "AZ-



APDA Away" team so other APDA chapters and Centers around the country could get involved. The Virginia APDA I & R Center in Charlottesville put the word out. Southeast PADRECC and APDA Richmond Metro responded with a great showing!



Indoor El Tour participants at McGuire VAMC: top photo: D. Cruise and S. Cruise (l to r), bottom photo, C. Majeske and T. Greenlee (l to r). Thanks to the Kinesthesiology (KT) department for allowing the use of their indoor cycling equipment!

How to Find a Support Group in the Southeast US

Recommended Service Areas for PADRECCs



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 offer information and support group lists. Ameri-

Southeast PADRECC is based in Richmond, Virginia. It serves not only Virginia, but West

can Parkinson Disease Association (APDA) is a good place to start. Log-on to their main APDA website at: www.apdaparkinson.org or call the toll free number (800) 223-2732. You may also call the nearest APDA Information & Referral (I&R) Center or other sources listed below.

These organizations have literature such as newsletters and booklets and educational offerings. Some have on-line discussion forums. Most of the material is free. Check them out. You may want to consider being put on their mailing lists.

APDA Information & Referral Centers

Atlanta GA: (404) 728-6552
 Birmingham AL: (205) 833-4940 or (205) 934-9100
 Charlottesville VA: (434) 982-4482
 Durham NC: (919) 681-2033 or (919) 668-2938
 Hot Springs AR: (501) 321-2811 or (501) 922-4976
 Jacksonville FL: (904) 953-7030
 Memphis TN: (901) 516-0677
 Nashville TN: (615) 342-4635 or (800) 493-2842
 Pompano Beach FL: (800) 825-2732
 St. Petersburg FL: (727) 898-2732

Regional Support Groups & Other Sources

Parkinson Association of the Carolinas

(704) 248-3722 www.parkinsonassociation.org

Parkinson Foundation of the National Capital Area

(703) 891-0821 www.parkinsonfoundation.org

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

National Parkinson Foundation (NPF)

(800) 327-4545 www.parkinson.org



PADRECC Support Group — 2007 Schedule



Jan 25 Visual Impairments in Parkinson's Disease/Eye Movement Study Paul A. Wetzel, PhD, Department of Biomedical Engineering, VCU/IMCV Campus

Feb 22 Well Spouse Association-Support for Spousal Caregivers Mottos: When one is sick or disabled, two need help. You are not alone! Kathy Jarrell, Richmond Well Spouse Support Group, Henrico Doctors' Hospital

Mar 22 What is Palliative Care? Implications for People with PD Catherine Kelso, MD, Medical Director, Hospice and Palliative Care Ruchir Shah, MD, Geriatric Fellow, McGuire VAMC

Apr 26 Normal Aging Changes Marian L. Baxter, MS, MA, RN, CRRN, McGuire VAMC

May 24 Voice, Speech and Swallowing Issues in PD Mari Hayashi, PhD, CCP/SLP, CJW Medical Center, Johnston-Willis Campus

"Moving to agility, balance and joy"

Jun 28 Deep Brain Stimulation Miriam Hirsch, MS, RN, Neurosurgical Nurse, Southeast PADRECC, McGuire VAMC

Future dates: **Jul 26, Aug 23, Sep 27, Oct 25, Nov 29*, Dec 20***

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

When: 1-3 pm usually 4th Thursday of the month (* alternate week)

Contact: Lynn Klanchar (804) 675-6952

PD Support Groups in Virginia

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

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

Richmond: 4th Thurs – 1 pm
PADRECC, McGuire VA Medical Center
Contact: Lynn Klanchar (804) 675-6952

Richmond Metro Chapter APDA
www.parkinsonrichmond.com

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

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

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

APDA I & R Center of Virginia
Contact: Susan Dietrich (434) 982-4462

Virginia Beach & Chesapeake:
Contact: Hampton Roads Area Chapter APDA
www.hrparkinsons.com

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

* please note: list is not all inclusive. If you know of another support group that you would like listed, please contact the editor.

New PD Support Group at Atlanta VAMC

by Bettye Robinson, RN, MSN

The Atlanta VA Medical Center is located in Decatur, Georgia, just northeast of Atlanta, and services veterans from Georgia and surrounding states. Atlanta is fortunate to have two movement disorder specialists (Dr. Garrett Alexander and Dr. Marion Evatt) on staff that specialize in Parkinson's Disease (PD). The clinic is now a designated National VA PD Consortium Center.

The idea of starting a Parkinson's support group began one year ago because of the increasing number of patients diagnosed with PD. PADRECC and the local Parkinson's Association were contacted for information and assistance. Medical Administration was very instrumental in providing the Neurology Service with a list of patients with the diagnosis of Parkinson's disease. A questionnaire was developed to see if there was interest among our Veteran

population in starting a support group. In April 2006 we held our first support group with one couple in attendance. Today we have 20 or more couples involved in our support group and each month we are growing.

Our support group provides education, and support for our patients with PD and their families. We typically have invited speakers that provide expertise in specific areas of interest to our Parkinson's patients and their families. We also provide patient advice and information about outside resources.

The support group meets the first Tuesday of each month in the Veterans Learning Center at 1:00 PM. For additional information please contact Bettye Robinson, RN at 404-321-6111 ext. 7121 or Connetta Sam, RN at 404-321-6111 ext. 7227.



Is Deep Brain Stimulation Right for You?

By Kathryn Holloway, MD & Miriam Hirsch, MS, RN

In approximately 75% of people with Parkinson's disease, the medications used to control symptoms become less effective. Some patients may experience too little or too much movement. Others may not respond at all to the medications and/or may develop neuropsychiatric complications such as hallucinations. When the regimen of existing medications and the various rehabilitation strategies become less effective in managing symptoms, surgical intervention can be considered.

Such an intervention is deep brain stimulation (DBS). This is a surgical intervention used to treat movement disorders such as essential tremor, Parkinson's disease and dystonia. It received approval from the Food and Drug Administration (FDA) to treat essential tremor and tremor in Parkinson's disease in July 1997 and for advanced motor symptoms of Parkinson's disease in January 2002. It is currently approved for the treatment of dystonia through a "humanitarian device exemption."

The *subthalamic nucleus* (STN) and the *globus pallidus* (GPi) are two locations in the brain that are targeted in the DBS procedure for the treatment of Parkinson's disease. DBS administers a well-controlled electrical current into the target area(s). This electrical current functions as an "off switch" by disrupting abnormal brain signals responsible for the abnormal physical movement. This disruption helps restore more normal activity in the brain enabling more controlled movement. DBS does not involve destruction of brain tissue, and its effects are reversible and adjustable. It is now preferred over the *thalamotomy* or *pallidotomy*, two surgical techniques that involve the actual destruction of the brain cells that are "misfiring."

The effectiveness of the DBS procedure depends on accurate placement of the brain lead(s) or wire (s). Electrical impulses generated from an implanted battery pass through the lead and into the target area. The target areas, or nuclei, are quite small, approximately the size of a grape. However, the optimal area within these structures is approximately the size of a grain of rice! Special imaging techniques and the placement of a metal, stereotactic head frame to the patient's skull help to guide the positioning of the leads. Certain areas of the brain have a characteristic sound. Microelectrode recording (MER) is conducted during surgery and involves "listening" to the brain cells to identify these specific areas. The patient is awake during this and other portions of the surgery and becomes an important member of the team. The patient helps in determining whether beneficial effects occur when the stimulation is applied during surgery. DBS surgery is time consuming, usually lasting three to four hours per side of the brain being operated on.

The most common complaints from patients include back and neck pain and fatigue. These complaints occasionally can become so disabling that the patient has a difficult time participating in the surgery and/or requests to have the surgery prematurely stopped. The traditional approach to DBS surgery involves attaching a large, metal halo device to the patient's skull and securing it to the surgical table. The frame's effectiveness has been proved during several decades of use. However, the negative aspects of the frame are that it creates complete immobilization of the patient's head and neck and it obscures the patient's line of vision.

A Frameless Approach to DBS

In an effort to simplify the DBS procedure and enable greater patient comfort and participation during surgery, neurosurgeons at Virginia Commonwealth University (VCU), Cleveland Clinic and Tulsa, Oklahoma worked with Image Guided Neurologics Inc. (IGN) to develop a frameless stereotaxy technique. In this technique, the heavy frame has been replaced with five small bone screws and the *NexFrame*, a disposable guidance device. This new device does not require that the head and neck be kept in a fixed position and the patient can move or adjust his/her position if needed. Importantly, the accuracy of the frameless and framed techniques has been found to be equal (J. Neurosurg/Volume 103/September 2005). Frameless DBS is offered in Virginia at VCU Medical Center and McGuire VA Medical Center in Richmond, VA and is performed by Dr. Kathryn Holloway.

In August 2005, Medtronic Neurological, the world-wide leader in DBS therapy, acquired IGN and the *NexFrame* technology. The implications of DBS therapy are far-reaching not only in the treatment of movement disorders but for disorders such as epilepsy and depression. DBS and this new frameless option offer much promise for those suffering from Parkinson's disease that is refractory to medical therapies.



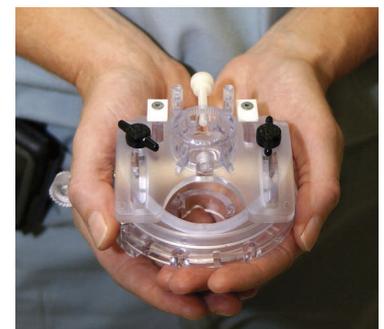
Kathryn L. Holloway, MD, Neurosurgical Director, SE PADRECC; Professor, VCU Dept of Neurosurgery



Miriam L. Hirsch, MS, RN
Neurosurgical Nurse Coordinator,
SE PADRECC

NEED MORE INFORMATION about Frameless DBS ?

Veterans: please call Miriam Hirsch, at SE PADRECC
(804) 675-6284
At VCU Medical Center in
Richmond: call Tammy
Searles, RN, neurosurgical
nurse at (804) 828-5235.



Frameless device for DBS



Parkinson's Disease Research Education & Clinical Center Southeast
Neurology Service #127 Room 2C-114
Hunter Holmes McGuire VAMC
1201 Broad Rock Boulevard
Richmond, Virginia 23249

Phone: 804-675-5931
Toll-free: 800-784-8381 ext 5931
Fax: 804-675-5939
Web: www.va.gov/netsix-padrecc
or www.parkinsons.va.gov

PADRECC NEWS

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National VA Parkinson's Disease Consortium Center Network

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

PADRECC Network:

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

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: interdisciplinary assessment and treatment, clinical trials, physician consultation, medical management, surgical interventions, neuropsychological services, physical and occupational therapy, speech therapy, nursing services, caregiver resources, educational materials, community education 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.



Southeast PD Consortium Network

Nine Consortium Centers are located at VAMCs in the Southeast region. Directors and referral numbers are also listed.

Atlanta (Decatur), GA

(VISN 7)
Dr. Garrett Alexander (404) 321-6111 x 7121

Augusta, GA (VISN 7)

Dr. John Morgan (706) 721-1115

Birmingham, AL (VISN 7)

Dr. Anthony Nicholas (205) 933-8101 x4734

Durham, NC (VISN 6)

Dr. Burton Scott (919) 286-0411 x15611

Gainesville, FL (VISN 8)

Dr. Frank Skidmore (352) 374-6058

Lexington, KY (VISN 9)

Dr. John Slevin (859) 281-4920

Nashville, TN (VISN 9)

Dr. Thomas Davis
(615) 327-4751 x5244

Tampa, FL (VISN 8)

Dr. Theresa Zesiewicz
(813) 972-7633

Tuscaloosa, AL (VISN 7)

Dr. Fernando Franco
(205) 545-2976

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