



VA PADRECC CONNECTIONS



National Parkinson's Disease Research, Education and Clinical Centers Newsletter
Houston, Philadelphia, Northwest (Portland/Seattle), Southeast (Richmond), San Francisco, Southwest (West LA)
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The National VA Parkinson's Disease Consortium: Intensifying the Realm of Specialty Care Across the Nation

Rebecca Martine, APRN, CS, BC, Chairperson

Over the past 2 years, the VA Healthcare System and Parkinson's Disease Research, Education and Clinical Centers (PADRECCs) have devised an innovative model of healthcare delivery for chronic disease in the veteran population. This effort has been reinforced with the development of the National VA Parkinson's Disease Consortium. The Consortium is designed to network nationally dispersed clinicians with expertise and/or interest in the fields of Parkinson's disease and related movement disorders. It serves as the foundation for collaboration and development in the areas of clinical expertise, scientific research, and educational outreach. Consortium members are offered the opportunity to cooperate with PADRECC experts in the delivery of specialized care throughout the VA system.

The Consortium commenced with a national conference in Miami, Florida from April 23-25, 2003 titled "Novel Concepts and Management Strategies in Parkinson's Disease." Approximately 75 VA clinicians selected from the allocated PADRECC service areas were invited to attend the conference as Consortium charter members. The six PADRECC directors presented a series of lectures focused on modern management and treatment modalities. Participants were also invited to share in the development of future Consortium en-

deavors during focus group meetings. In addition, the Consortium Advisory Committee was formed with a representative from each PADRECC facility and a representative from each PADRECC service area.

To date, the Consortium is comprised of approximately 150 multidisciplinary clinicians. Subcommittees were recently launched during the first Advisory Committee meeting in Philadelphia, Pennsylvania on September 3, 2003. Incorporated subcommittees include Communication, Scientific Research, Patient Education, Annual Conference and Telemedicine Services. These subcommittees will serve as channels for collective interests and the development of notable contributions.

The Consortium is anticipated to mature into an influential society that will better serve the veteran population afflicted by Parkinson's disease and associated disorders. It will also continue to promote the recognition of VA clinicians as leaders in the areas of research, education and most importantly, clinical care. The PADRECC Directors are excited about the many possibilities that lie on the horizon with the establishment and impact of the National VA Parkinson's Disease Consortium. Together, they will allow for continued advancement across the spectrum of PD care. (*For information on Consortium membership, see page 5.*)



PADRECC Associate Directors of Education: Front row, L to R: Ruth Tsukuda, MPH, Miriam Hirsch, MS, RN. Back row, L to R: Becky Martine, APRN, CS, BC, Naomi Nelson, PhD, RN, Marilyn Trail, MOT, BCN, Eric Cheng, MD and Gary Abrams, MD.

PADRECC Clinical Demonstration Projects

Parkinson's disease (PD) is a chronic condition that impacts physical and mental health. New, and sometimes highly technological and expensive therapies, show promise and may require access to specialists having expertise in PD care. There has been a lack of data on what are ideal models for delivering high quality care for PD and other movement disorders inside or outside of the VA, and there have been few integrated net-

work models for providing highly specialized care across geographic regions within the VA for any condition.

Thus, when the six PADRECCs were established nationwide in February 2001, each PADRECC was charged with implementing one or more clinical demonstration programs. The purpose was "to provide an environment for evaluation of new models of health care delivery for veterans with PD

and movement disorders." It was envisioned that these programs would serve as a core component for training, education, and research in PD and movement disorders in the VA.

In this newsletter, we report the achievements each PADRECC has made over the past two years in establishing their clinical program innovations to improve the care of veterans nationwide. B. Vickrey, MD

Philadelphia PADRECC: The Neuropsychiatric Complications of PD

by Lisette Bunting-Perry, MScN, RN, CCRC, Assistant Clinical Director and Gretchen Glenn, LSW, Philadelphia PADRECC

In 1817, James Parkinson included a reference to the mood changes caused by the illness that bears his name today. However, until recently little attention has been made to the non-motor features of Parkinson's disease (PD). Neuropsychiatric complications, such as depression, anxiety, dementia, and psychosis are among the most problematic and challenging manifestations of PD. The neuropsychiatric components of Parkinson's disease can be a direct result of physiological changes in the brain, as well as adverse effects from pharmacological therapy. It has been estimated that 40% of Parkinson's disease patients suffer from depression, 40% from anxiety, 20% from dementia, and 20% from psychosis. These difficult and disturbing symptoms not only concern patients but also family members, who commonly experience caregiver burden.

In the original grant proposal for the Philadelphia PADRECC, neuropsychiatric complications of Parkinson's disease were targeted as a key focus of the clinical program.

Daniel Weintraub, MD and Paul Moberg, PhD have joined the Philadelphia PADRECC staff to provide clinical diagnosis, treatment, and medication management as well as, education and support to veterans and their family members.

Dr. Weintraub is a board certified

Geriatric Psychiatrist who has evaluated over two hundred PADRECC patients. Through research-focused evaluations, he found that one-third (34%) of patients seen in the PA-



Matthew B. Stern, MD, Director
Philadelphia PADRECC

DRECC met criteria for a depressive disorder and two-thirds (65%) of them were not currently receiving antidepressant treatment. Approximately one-quarter (23%) of all patients seen were taking an antidepressant, but almost half (47%) of them still met criteria for a depressive disorder. His evaluation and assessment of patients have led him to develop

and conduct several investigative research projects to further explore and develop treatment modalities for treating patients who suffer from depression, dementia, and psychosis.

Dr. Paul Moberg is a Neuropsychologist and is available for clinical consultation if a patient is felt to have a cognitive impairment. Dr. Moberg has assessed well over half of the PADRECC patients. Once the tests are completed and scored, Dr. Moberg makes recommendations to the PADRECC treatment team, the patient, and his/her caregiver on steps that should be taken to improve the patient's quality of life as well as his/her safety in the home environment.

Lastly, both Dr. Weintraub and Dr. Moberg have presented at numerous professional conferences across the county on the neuropsychiatric components of Parkinson's disease and are scheduled to be speakers on the PADRECC/GEC/EES teleconference broadcast. They are also co-authoring a National Parkinson Foundation Handbook called: Parkinson's Disease: Mind, Mood, and Memory. Dr. Weintraub and Dr. Moberg's clinical and research contributions to the Philadelphia VA PADRECC have allowed our veterans to receive state-of-the-art care that examines every aspect of their disease with the goal of improving their overall quality of life.

SW PADRECC: Improving Access to PD Specialty Care for Veterans Across the Southwestern US

by Barbara G. Vickrey, MD, MPH, Associate Director of Research, SW (West LA) PADRECC

The goals of the clinical demonstration program of the Southwest (SW) PADRECC are to improve the quality of care for veterans with Parkinson's Disease and related movement disorders (PDRMD) and to increase their access to specialists, to Parkinson's Disease (PD) treatments, and to clinical research trials.

To accomplish this, we created and/or expanded a network of specialized clinics for PDRMD at 8 VA medical centers spanning 2 VISNs in the southwestern US. One or more neurologists with special interest or specialized training in PDRMD were identified and recruited to lead each site's clinic. Establishment of the SW PADRECC network required the cooperation of each medical center's director, department of medicine and/or neurology leadership, and key clinic managers.

Since the SW PADRECC's inception, new movement disorder clinics led by neurologists have been established at VISN 18's New Mexico Veteran Affairs Health Care System in Albuquerque (Jill Marjama-Lyons, MD), Carl T. Hayden VA Medical Center in Phoenix (William Lawrence, MD), the Southern Arizona VA Healthcare System in Tucson (Scott Sherman, MD, PhD), and at VISN 22's Long Beach VA (John Ringman, MD) and Las Vegas VA (Shanker Dixit, MD). Movement disorder clinics at VISN 22's Greater Los Angeles VA (Indu Subramanian, MD; Zeba Vanek, MD; Adrian Handforth, MD), Loma Linda VA (Dorothee Cole, MD), and San Diego VA (Evelyn Tecoma, MD, PhD, and Clifford Shults, MD) have more than doubled their capacity.

Over 1700 visits were made by PD patients to a SW PADRECC pro-

vider between April 1, 2001 and May 1, 2003. Access to evaluation for a VA-sponsored clinical trial of surgical therapy for PD (performed by Antonio DeSalles, MD, PhD, neurosurgeon for the SW PADRECC) and to movement disorder subspecialists was provided to three dozen veterans referred from network sites to the Greater Los Angeles (GLA) VA. Additional access via telephone and email to other neurological specialists



*Jeff Bronstein, MD, PhD, Director
Southwest PADRECC*

at the GLA VA is also available to our network neurologists.

As a tertiary care center, the GLA VA is the home institution for 3 movement disorder specialist neurologists and 2 fellow neurologists receiving advanced training. To enhance educational and clinical care across network sites and to expand training opportunities for neurologists who lead PADRECC network clinics, a collaborative, *on-site*, out-

patient-centered education program was created. At least monthly, one of our PADRECC movement disorder specialists at the GLA VA travels to each network clinic led by a general neurologist, to teach and to share in patient care. Similarly, at least monthly, each fellow in our program travels to a site that has a movement disorder specialist, to learn from other subspecialists and to share in patient care across the network.

PADRECC network neurologists and fellows participate in joint educational activities including monthly teleconference calls using CD-ROMs to provide video case presentations and an annual education symposium that includes allied health professionals. We distribute selected teaching videos, textbooks, and patient educational materials across the network. A plan to establish patient support groups at sites where these are not readily available to veterans with PD is underway.

Future goals of the SW PADRECC's clinical demonstration program are to identify areas of PD care where there is room for continued improvement and, with the PADRECC neurologists now in place to serve as local champions, to plan specific projects to measure and further improve the quality of PD care within the network.

The National VA Parkinson's Disease Consortium is designed to network nationally dispersed clinicians with expertise and/or interest in the fields of Parkinson's Disease and related movement disorders.

Houston PADRECC: Enhancing Clinical Care through Educational and Support Programs

by Eugene C. Lai, MD, PhD, Director and Marilyn Trail, MOT, Co-Associate Director of Education, Houston PADRECC

One of the goals of the Houston PADRECC's clinical demonstration project is to enhance the treatment and services we provide veterans with Parkinson's disease (PD) and their families through our educational and support programs.

Our PADRECC quarterly symposiums, attended by over 100 veterans, their families, and community participants provide information on all aspects of Parkinson's disease, including diagnosis, medications, speech, cognition, physical therapy, and motor complications. Speakers include faculty from PADRECC, Baylor College of Medicine, and Texas Woman's University. A panel of experts is available for a question and answer session on PD topics.

We hold monthly educational support group meetings for veterans with PD and their families and/or caregivers. These small group sessions provide opportunities for learning and discussion of issues affecting quality of life. They also afford the ongoing opportunity for veterans and their families to discuss challenges imposed by Parkinson's disease that affect activities of daily living, diet, mobility, and social involvement. Health care providers with expertise on these topics frequently attend to facilitate the exchange of information and ideas.

A patient educator is available at PADRECC clinics. She consults with patients and their families, provides written educational materials, and arranges for them to view videos relevant to their expressed concerns. Our PADRECC clinical staff travel to other communities within our area of responsibility, VISNs 12, 15, 16,

and 17, to present programs on Parkinson's disease to local support groups and VA facilities. We provide educational materials published by the national PD organizations and produce and distribute PADRECC publications, including newsletters and special bulletins, to veterans, their families, health care professionals, and the interested public. The Houston PADRECC website (www.va.gov/PADRECC_Houston) allows us to post our programs, resources, activities, and announcements online and reach a wider audience.

To further improve clinical care, we are looking for other innovative approaches. We are currently investigating the efficacy of a tele-health intervention program to reinforce patient education and enhance medication compliance. Effects on patients' quality of life and health

status will also be assessed. Another study involves patient quality of life and caregiver stress in 100 pairs of PD patients and their caregivers. The data will allow us to learn more about their concerns and needs. It will also help us develop an interactive computer-based quality of life measurement tool for persons with PD.

The Houston PADRECC will continue to work in cooperation with community PD support groups and professional organizations to develop additional programs and self-evaluations to ensure continuous quality improvement and patient satisfaction.

visit our website

www.va.gov/padrec/



Pictured L to R: Eugene C. Lai, MD, PhD, Director, Houston PADRECC, John Booss, MD, National Director of Neurology, and Vincent Calabrese, MD, Director, SE (Richmond) PADRECC, pause for a picture at the National VA Parkinson's Disease Consortium Conference, Miami, Florida, April 23-25, 2003.

SE PADRECC: Bringing Specialty Care to Veterans with PD Through Telemedicine Technology

by Miriam Hirsch, MS, RN, Associate Director of Education, SE (Richmond) PADRECC

The Southeast PADRECC telemedicine clinic offers expert clinical care by neurologists and clinical staff specialized in the treatment and management of movement disorders such as Parkinson's disease. The Southeast PADRECC also offers a monthly telemedicine clinic. Telecommunication technology brings medical care and education to patients and families at distant locations. The consultation takes place through a live, interactive telecommunication link between the remote site (the closest Veteran's Affairs Medical Center [VAMC] to the patient) and the Hunter Holmes McGuire VAMC in Richmond, VA.

The PADRECC Parkinson's specialist conducts a detailed assessment and suggests treatment. However, the implementation of care is the responsibility of the local healthcare provider. Healthcare providers in remote areas also benefit by having access to colleagues for consultation and educational programming. The telemedicine clinic, in which both new and follow-up patients are evaluated, has also been used by the PADRECC neurologists and neurosurgeon to pre-screen candidates for deep brain stimulation.

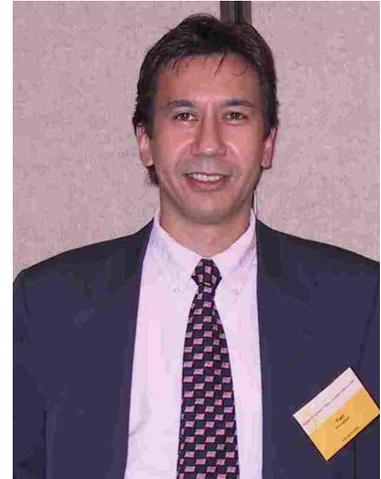
A nurse, prior to the telemedicine appointment, gathers information about signs and symptoms as well as a medication list. On the day of the evaluation, the neurologist conducts an in-depth interview with the patient and family. A neurological examination is performed to assess movement, balance, and motor function. The referring physician is encouraged to participate in the examination and to discuss recommendations for treatment and management.

There are many benefits of using telemedicine technology to evaluate veterans with PD, particularly in remote areas where fewer services are available and where traveling to a major medical center is difficult. Since November 2002, we have scheduled 18 telemedicine clinic appointments. We have evaluated patients from four VAMCs in our catchment area including Beckley and Huntington VAMCs located in West Virginia, Salisbury VAMC in North Carolina, and Birmingham VAMC in Alabama. These clinic visits have saved our veterans approximately 50 hours of travel time and 3,100 miles and \$900.00 in travel reimbursement by the VA.

We use top-of-the-line equipment in our clinic and will continue to do so as technical advances in networking capabilities are made. The system that is currently used allows the PADRECC clinician to control the remote camera and provides clear audio and visual transmission. The Southeast PADRECC purchased the unit for our VAMC, and other clinical departments have access to it.

Telemedicine is a powerful tool that has successfully established a connection to cost-effective, specialized care for veterans with PD, their families, and healthcare providers. Despite its advantages, telemedicine is not a substitute for a complete "in-person" neurological examination.

For more information about this program, call Miriam Hirsch, MS, RN, SE PADRECC Associate Director of Education and Telemedicine Clinic Coordinator at (804) 675-6952 or toll-free (800) 784-8381 ext. 6952 or by e-mail Miriam.Hirsch@med.va.gov.



Yuri Romaniuk, National PADRECC Coordinator, played an active role at the National VA PD Consortium Conference, Miami, FL.

***For further information on the
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You may access the Consortium
Membership application on the
PADRECC webpage.

www.va.gov/PADRECC

San Francisco PADRECC Clinical Demonstration Program: Refining Surgical Intervention

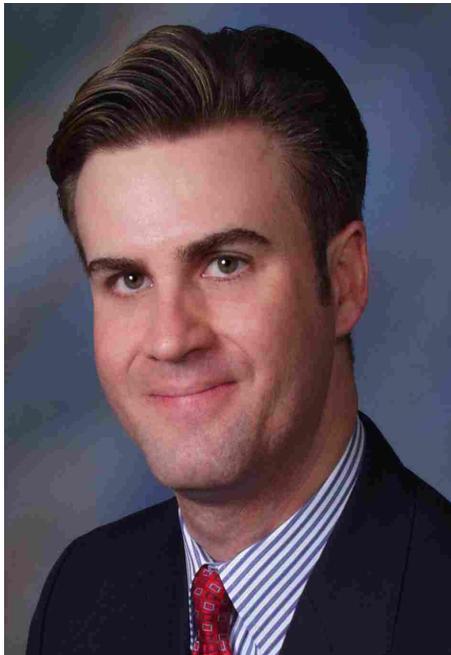
by Lorraine Anzaldo, Program Manager and William J. Marks, Jr., MD, Director, San Francisco PADRECC

Before the development of the PADRECCs, deep brain stimulation (DBS) was a new and promising technique performed at the San Francisco VAMC. DBS therapy for veterans with Parkinson's disease (PD) with disabling symptoms inadequately controlled by medication continues to be the focus of the San Francisco Clinical Demonstration Program. Goals include (1) to concurrently expand DBS and other state-of-the-art treatments to a larger number of patients, while reducing wait time for surgery and, with the creation of the six-PADRECC system, reorient our focus on outreach to veterans in our region; (2) to develop data collection systems for the evaluation of PD patients; and (3) to develop a PD Consultation Service to provide timely diagnostic and treatment recommendations to referring healthcare providers.

Since 1997, the San Francisco VA Center for Parkinson's Disease & Movement Disorders had provided comprehensive care for veterans with PD, with a focus on surgical treatments. We had a six-month backlog due to high demand. We are pleased to report patients no longer have lengthy wait times and can be scheduled for surgery within a short period. Outreach extends throughout our VISN and beyond, with 489 PD patients followed (338 referred for evaluation from other VA facilities). The positive outcomes, both in service and patient response, help us measure and celebrate a greater quality of life for our veteran patients with PD.

To meet our goal of technical data collection, the San Francisco

PADRECC collaborated with database designers for the development of our DBS Research and Analysis System (DBSRAS). The database includes critical details regarding surgery, medication, stimulator programming, demographics, and outcome testing data for hundreds of patients. The sophisticated system produces reports comparing pre- and postoperative results, which are used to optimize stimulator lead location, stimulator programming, and medi-



*William J. Marks, Jr., MD, Director
San Francisco PADRECC*

cation treatment programs. In FY 2003, members of the San Francisco PADRECC published 12 papers/abstracts on technical approaches to DBS, lead location, and outcomes. With experience gained through DBSRAS, San Francisco assumed responsibility for the technical design and implementation of the PA-

DRECC National VA Parkinson's Disease Registry, to be implemented at all PADRECCs at the close of FY 2003. This clinical and demographic data on all PADRECC PD patients will assist clinicians in understanding the disease and enable the Veterans Health Administration to plan care nationally.

Video teleconferencing has increased communication with referring VA clinicians who confer with our PADRECC consultants on preliminary PD evaluations. This technology also minimizes travel stress and expense to our patients. The "face-to-face" patient, local physician, and DBS consultant interaction can be intimate, compassionate, and communicative, which is as important to our patients and their families as positive therapeutic outcomes. Innovations include the recording of interviews and attachment to patient records and consulting for challenging DBS programming issues. In addition, an electronic CPRS referral system was developed, guiding clinicians on the types of movement disorders patients that are appropriate candidates for referral to the PADRECC. As an assistant to remote providers, an Electronic Clinical Warning System has been implemented; the system flags progress notes to indicate the patient has a deep brain stimulator implanted and provides contact numbers for questions about DBS. This useful system, developed at the San Francisco PADRECC, will be presented for national implementation.

NW PADRECC Gait and Balance Project

by John G. Nutt, MD, Director, and Ruth Ann Tsukuda, MPH, Associate Director of Education, NW (Portland/Seattle) PADRECC

People with movement disorders are particularly prone to difficulties with balance and walking, which stem from many different causes. The emergence of these problems during the course of a disease marks the transition of the disorder from a “damned nuisance” to a disabling condition with a corresponding decline in the quality of life.

The Northwest PADRECC Gait and Balance Project is addressing these concerns by developing a systematic approach to assessing and managing the falls and gait disturbances common in Parkinson’s disease. The program provides patients with education, physical therapy, and the development of individualized treatment approaches to increase mobility and minimize falling. In addition, a Gait and Balance Disorders clinic operates concurrently with the PADRECC Movement Disorder clinics to facilitate patients being seen in both clinics on the same day, thus increasing collaboration among the neurology staff, physical therapists, and the veteran.

The number of balance impairments underlying parkinsonian disorders is large and calls for specific treatment strategies. However, physical therapy for gait disorders and falls has historically focused on whatever abnormality is most prominent when the patient is seen, without consideration of the variety of ways gait and balance can be disturbed in parkinsonism. There has been no systematic manner to assess and treat balance problems specific to parkinsonism such as slowed movement, periodic inability to move, and changes in sensory awareness.

The initial efforts of the Gait and

Balance Project have focused on developing a 30-minute assessment which identifies a variety of underlying gait and balance impairments that can be addressed by different medical and physical therapy strategies, and on developing a method to assess the effects of therapy on the patient’s quality of life. Currently, efforts are being made to identify specific rehabilitation strategies to apply to each impairment underlying balance problems associated with parkinsonism to help patients improve their functional abilities.

The Northwest PADRECC’s Gait and Balance Project offers benefits to both patients and clinicians. Improved treatment approaches are developed through collaboration between movement disorder specialists and physical therapists. The Project assists patients by concurrently providing care by these specialists, alleviating the need for additional clinic visits. In addition, patients gain a better awareness of their disease process and develop an improved ability to manage their mobility limitations.

Finally, health care professionals are developing practical clinical approaches that will benefit patient care while increasing knowledge of complex disease processes.

Teleconference

**A PADRECC/EES/GEC
video training program for
VA staff and the community**

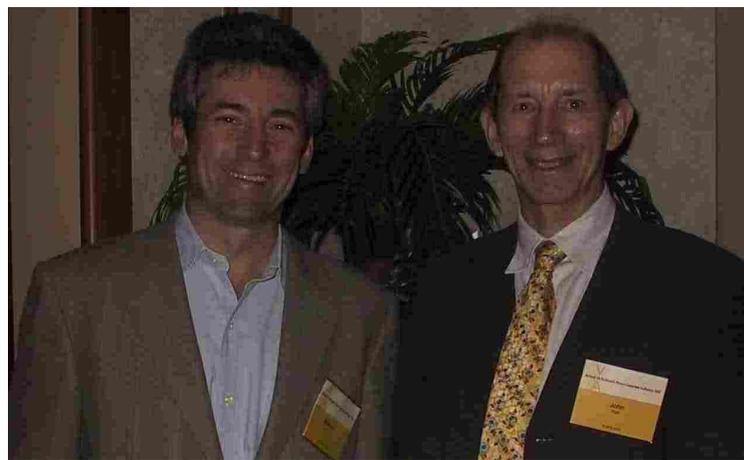
Understanding and Managing

Parkinson’s Disease

November 12, 2003

**12 Noon to 3:00 pm EST
(Re-broadcast Dec 3, 10 & 17)**

**For more information contact
Miriam Hirsch, MS, RN, Associate
Director of Education, SE
PADRECC at 804-675-6952 and
see our PADRECC website
www.va.gov/PADRECC**



Pictured L to R: Matthew B. Stern, MD, Director, Philadelphia PADRECC and John G. Nutt, MD, Director, N W (Portland/Seattle) PADRECC, Co-Chaired the National VA PD Consortium Conference in Miami, FL, April 23-25, 2003.

PADRECC Activities

Houston PADRECC	
9/18/03	PADRECC Patient/Family Forum
1/13/04	PADRECC Patient/Family Forum
Philadelphia PADRECC	
9/02/03	Host Nat. VA PD Consortium-Advisory Committee
11/14/03	Fall Prevention Fair
Southeast (Richmond) PADRECC	
11/19/03	Patient/Family Program: Surgical Intervention
6/04	PD Update 2004: Patient/Family Symposium
Southwest (West Los Angeles) PADRECC	
10/9/03	2nd Annual PD Symposium & Awareness Walk Albuquerque, NM
San Francisco PADRECC	
9/3/03	Lee Silverman Voice Treatment Certification Course
National Projects	PD Registry, National VA PD Consortium, PADRECC/GEC PD Education Evaluation Tool

Nationwide PADRECCS

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