### Introduction

In 2001, the Veterans Health Administration (VHA) created a national system of comprehensive care centers to serve Veteran patients with Parkinson’s disease (PD) and other movement disorders. Veterans anywhere in the country could be referred to these 6 Parkinson’s Disease Research, Education, & Clinical Centers (PADRECCs), which brought together expert multi-disciplinary teams to provide a full spectrum of treatment, ranging from pharmacologic therapies to chemodenervation (neurotoxin) treatment to neuromodulation using deep brain stimulation devices. PADRECCs partnered with clinicians across the VHA system to create a Consortium Network to broaden the availability of comprehensive PD care.

Over the past decade, the PADRECCs have developed, individually and collaboratively, innovative programs focused on clinical care, research and education.

### Clinical Care

Collectively, the various PADRECC sites have developed a standardized approach for comprehensive patient evaluation and management which is in the process of being implemented at all sites. PADRECC-wide evaluation of newly released medications, for example, lead to consistent availability of these treatments across the VHA.

### Research

Collaboration in the VA Cooperative Study on Deep Brain Stimulation (DBS) with the Cooperative Study Project 468 (CSP#468) brought standardized protocols for evaluating patients for this treatment and a consistent approach to clinical management. More recently, PADRECC-wide procedures for the delivery of telemedicine consultations have been created. At all PADRECCs, patients referred from anywhere in the nation have access to the full complement of modern treatments, innovative investigational therapies, and care delivered by multi-disciplinary teams to address medical and psychosocial needs. PADRECC Consortium Network linking the six PADRECCs to dozens of regional VA specialty clinics (hub and spoke model of care) ensured even easier access of specialty care to Veterans.
Selected research highlights from the various PADRECC programs include:

- The Houston PADRECC research portfolio includes work focused on differential effects of two deep brain stimulation sites on motor, autonomic and neuropsychological aspects of PD, utility of diffusion tensor imaging (DTI) in PD, research on novel methodology to improve gait and balance in PD, sleep architecture and sleep disorders, and studies focused on energy expenditure in patients with PD. Additionally, the center is involved in high yield projects focusing on self management, quality of lives of the patients and caregivers; and PD Veteran epidemiological studies. The Houston PADRECC has also investigated medication administration patterns among hospitalized patients with PD. Observational studies are ongoing to determine the effects of neurotoxins on cervical dystonia.

- The Philadelphia PADRECC conducts research aimed at understanding the basic mechanisms of PD by examining the neuropathological changes in the brain of deceased patients, and has been a leader in the investigation of neuropsychiatric symptoms of this disorder. The center is actively involved in the development of biomarkers for PD including olfactory dysfunction and in the quantitative assessment of motor function. Philadelphia PADRECC researchers are conducting Health Services research with respect to improving health care access by utilizing telemedicine and related technologies. Additionally, they are conducting clinical trials for the management of non-motor symptoms of PD as well as the investigation of alternative therapies.

- The Northwest PADRECC is engaged in research on prevention and treatment of dyskinesia and cognitive impairment in PD. Additionally, they are studying gait and balance disorders. Research on dyskinesia, balance and gait involves the development of new methods for evaluating these common and challenging problems in Parkinson's disease, as well as evaluation of candidate treatments using these novel assessment modalities. Their research on cognitive disorders involves genetics and biomarker work in coordination with the NIH-funded Pacific Northwest Udall Center.

- The Southeast/Richmond PADRECC research includes utilizing state of the art eye tracking to accurately diagnose different movement disorders. Specifically, this includes verifying the utility of eye tracking for diagnosing PD preclinically in those predisposed to develop PD as well as developing related software for general use. Their neurosurgical techniques related research includes developing frameless DBS surgical approaches, and using an intra-operative O-arm CT scanner to more accurately guide DBS placement. Studies are underway utilizing navigated brain stimulation (NBS) to assess its utility in, for example, non-invasive treatment of chronic pain and speech dysfunction in PD. Non-pharmacological approaches including the use of an electrically powered stationary bicycle (Theracycle) to study the impact of forced exercise in PD. In collaboration with Virginia Commonwealth University, an investigational drug is being tested that could provide neuroprotection and slow the progression of PD. VA Merit Award supported studies include investigating the pathophysiology of basal ganglia related movement disorders in experimental rodent models with the ultimate goal of developing improved therapies.

- The San Francisco PADRECC research portfolio includes work focused on optimization of outcomes from DBS treatment, advanced MRI-based imaging techniques, and development of innovative methods to quantify parkinsonian motor function. Also, investigations evaluating new therapeutic approaches for neuroprotection, symptomatic treatment, and the assessment of caregiver educational approaches are being undertaken.

- The Southwest PADRECC (West LA) Health services researchers have developed quality indicators for PD, conducted a chart review of patients at VA Los Angeles to identify gaps in care, and are currently conducting a randomized controlled study to evaluate a nurse-led care management intervention.
Southwest PADRECC (West LA) cont…
Basic science research includes investigation into the causes of PD such as mechanisms of pesticide toxicity and gene-environment interactions, testing new drugs in a zebrafish model, and studying molecular mechanisms underlying selective neuronal degeneration. Clinical research projects include studying the effect of DBS on non-motor functions, pursuing gene therapy, and cell-based therapy, evaluating SPECT scanning for early PD diagnosis, evaluating novel classes of drugs for treatment of advanced motor fluctuations, as well as studying the cortical physiology of dystonia.

Education
During the past decade, substantial PADRECC-wide educational outreach has taken place for patients and their caregivers. Educational programs were delivered via the PADRECC websites, live and recorded streaming video conferences, printed materials, newsletters, and in-person dialogue. Additionally, all PADRECC sites host well-attended support groups tailored to a variety of constituencies such as, younger patients, family members, caregivers, DBS patients, and patients with advanced disease, etc.

The PADRECCs have collaborated on a variety of educational programs for VA and community clinicians. PADRECCs sponsor weekly and monthly conferences targeting local and regional health care providers. National broadcasts deliver education to VA providers across the system, and a series of biannual conferences have provided attendees with updates on the latest scientific and clinical advances in the field. Through sponsorship by the VHA Office of Academic Affiliations, the PADRECCs have developed robust clinical fellowship programs in movement disorders, with dozens of fellows training in various PADRECCs and their academic affiliates. Subsequently, many of these fellows have joined VA facilities to continue caring for the Veterans.

National VA PD Consortium
In 2003, the PADRECCs established the National VA Parkinson’s Disease Consortium to broaden the impact of their mission and to encourage the delivery of “leading edge” PD care across the collective VA Healthcare System. The highlight of this initiative was the creation of the Consortium Center Network, which encompasses a hub and spoke model of care between the 6 PADRECCs and 51 dedicated movement disorder clinics housed at various VA facilities across the VA healthcare system. The PADRECCs and Consortium clinicians work in partnership to ensure convenient access to specialized care for all Veterans affected by PD and related movement disorders. The PADRECCs maintain the momentum of the Consortium initiative through national educational offerings, training opportunities, peer collaboration and mentorship.

Conclusions
A decade ago, the Veterans Health Administration embarked on a unique effort to develop specialized centers to provide expert care to the Veterans with Parkinson’s disease and other movement disorders. Over that period, the PADRECCs and their collaborators at the Consortium Centers have created a network of programs that deliver comprehensive medical care and conduct collaborative and site-based research. Additionally, they provide high quality education to patients, their caregivers, healthcare providers, and clinical trainees. We know of no other effort in the world that matches the scope, depth, and comprehensive approach to PD care that operates in such an integrated and collaborative manner.

For additional information on the PADRECCs and National VA PD Consortium, please visit www.parkinsons.va.gov.

PD PEARLS
Deep Brain Stimulation Criteria to Consider for PD
- Medication refractory symptoms
- At least a 30% improvement to L-Dopa
- Little or none cognitive dysfunction.
Formal consensus criteria for Dementia in Parkinson’s disease (PDD) have only recently been proposed.\(^1,2\) Several studies note that milder cognitive impairment may be present even in early Parkinson’s disease (PD), and progress with time, causing early functional impairment and decreased quality of life.\(^3\) At some point in their disease progression, PD patients may develop some cognitive impairment that does not fully meet criteria for dementia. Adapting the concept of mild cognitive impairment (MCI) from the dementia literature (particularly from Alzheimer’s disease),\(^4\) over the last several years, researchers in PD have begun a movement to define MCI in PD (abbreviated as PD-MCI).\(^5\) MCI by definition refers to mild cognitive abnormalities beyond those expected for age, but that still allow for normal daily function.

An important new publication by a Movement Disorders Society Task Force addresses the characteristics and frequency of PD-MCI based on a comprehensive literature review.\(^6\) Despite screening hundreds of articles, the nine-member Task Force found only eight studies that met their predefined inclusion criteria for review. These studies were mostly cross-sectional studies, reflecting the relative paucity of rigorously designed studies involving substantial numbers of patients. The individual studies varied in their definition of PD-MCI and dementia, cognitive domains assessed, neuropsychological tests used, the populations studied, and study design. However, taken together, these studies consistently demonstrated that PD-MCI appears to be common, occurring on average in 26.7% of PD patients without dementia. The frequency of PD-MCI correlated with longer disease duration, more significant disease severity, later onset of PD, lower educational levels, and higher patient age. As one might predict based on the typical cognitive impairment patterns already recognized in PD,\(^1\) primarily amnestic forms of MCI (i.e., predominantly affecting memory) were less common than deficits in non-amnestic cognitive domains (i.e., affecting visuospatial, executive function, and attentional domains). The cognitive profile of PD-MCI appears heterogeneous, with deficits seen in a number of cognitive domains. Demonstrated impairment in a single domain was more common than multi-domain impairment. The two longitudinal studies included in the publication showed that PD-MCI patients progressed to dementia in a short period of time, implying that MCI is likely a risk factor for dementia. Formal diagnostic strategies will be proposed in a future publication by the task force.

Future exploration of this relatively uncharted topic will yield important discoveries about the characteristic and pathophysiology of PD-MCI. As part of the Veterans Health Care System, members of the VA PADRECC/Consortium Network are in an ideal position to contribute to the further refinement and development of our understanding of the spectrum of cognitive impairment in PD. Future studies could utilize the large VA patient databases to investigate possible risk factors and clinical co-morbidities of cognitive impairment in PD. Prospective studies following a large cohort of PD patients at multiple PADRECC/Consortium Centers may provide a more accurate assessment of the pattern of PD-MCI and PDD in Veterans. Studies to determine whether these patterns are different from non-Veteran or non-VA patients, more clearly identify PD-MCI subtype profiles, provide validation of upcoming proposed PD-MCI criteria, and ultimately identify a subpopulation of patients that may benefit from more intense interventions to delay the onset of PDD.
Characterizing Midld Cognitive Impairment in Parkinson’s disease: A Work in Progress  by Dr. Bradon Barton

References


RESEARCH FOCUS
National Institute of Neurological Disorders and Stroke (NINDS) Clinical Trials

As of February 16, 2012 the NINDS PD trials seeking participants are:

Biomarkers of Risk of PD

Adults who have particular risk factors for developing PD such as a strong family history of the disease, a known genetic abnormality associated with PD, loss of a sense of smell (which is very common in PD), a particular type of sleep disorder called REM behavior disorder, or persistent, consistent orthostatic hypotension. Individuals who do not have PD risk factors are also being recruited for the control group.

Pioglitazone in Early PD

The NIH Exploratory Trials in Parkinson’s Disease (NET-PD) is conducting a clinical trial of pioglitazone in people with early PD. The purpose of this study is to determine if pioglitazone is safe, tolerated, and effective in slowing the progression of PD symptoms. The study will also examine potential biological characteristics, or biomarkers, for PD. Pioglitazone is an FDA-approved medication for treatment of type II diabetes, however it is currently not approved for PD treatment. Early research suggests pioglitazone may help to slow the progression of PD.

More information can be found at:  http://www.ninds.nih.gov/disorders/parkinsons_disease/parkinsons_disease.htm#Clinical_trials
Adults with chronic illness who take an active role in learning about their condition and managing its every day challenges may help themselves be better equipped to cope with it and have improved health outcomes.\(^1\)\(^6\) Parkinson’s disease (PD) is a slowly progressive neurological disorder that deteriorates over a course of 10-25 years and affects many dimensions of life. In addition to its physical challenges, PD presents social, spiritual, emotional, psychological and financial struggles. PD is prominent in the older population and is frequently one of their several co-morbidities, which complicates PD management. As a result, difficulties experienced by these individuals may include coordination of medical care, management of multiple medications, and aggravation of one condition or new side/adverse events caused by treatment of another. Thus involving Veterans with PD in effective daily self-management of their chronic neurological disease by empowering them to take responsibility to resolve day-to-day problems may improve their health outcomes and quality of life.

Treatment of chronic illness has traditionally followed the medical model and prescriptive actions provided by health care professionals. In addition, patient education is often provided with a focus on information and technical skills. However, research has demonstrated that education affected patient knowledge but not their self-care behavior or improvement in health.\(^3\)\(^9\)\(^10\)

The purpose of this article is to introduce the concept of self-management support, defined by the Institute of Medicine as “the systematic provision of education and supportive interventions by the health care system to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support”.\(^7\) It is important to note that patient self-management support programs (SMP) have been shown to help adults with chronic conditions such as diabetes and arthritis to develop skills in managing their health and in living healthier lives.\(^1\)\(^6\)\(^9\) SMPs have found that improved behavior increases patient self-efficacy and knowledge that leads to better disease control, which in turn should lead to improved patient outcomes and quality of life as well as lower resource utilization and ultimately reduced health care cost. SMP’s primary objective is to change people’s behavior in order to improve health outcomes. Key features in self-management techniques include supportive coaching, interactive learning, and goal setting. The self-management participant brainstorms and problem solves while sharing and receiving feedback from lay leaders and other participants for the purpose of enhancing their confidence (self-efficacy) in managing their disease.\(^3\)\(^4\)\(^11\)\(^15\)

The theoretical framework for many chronic disease SMPs has been self-efficacy from the social cognitive theory, the chronic care model (CCM), and Lorig’s work at Stanford University. Physical or psychosocial manifestations present a common set of challenges to the person and their families. They are dealing with symptoms, disability, emotional impact of the disease, complex medication regimens, and difficult lifestyle adjustments without adequate support from medical care to be effective self-managers of their illness.\(^1\) The CCM predicts that improvement in its six interrelated components: 1) health care organization, 2) community resources, 3) self-management support, 4) clinical information systems, 5) delivery system redesign, and 6) decision support, produce more informed and activated patients. Clinical practice teams are better prepared and proactive, they communicate and collaborate more effectively with each other to improve outcomes such as the patient’s health and functional outcomes.\(^1\)\(^4\)\(^5\)

There are multiple variations of SMPs of which Lorig’s Chronic Disease Self-Management Program (CDSMP) is the most widely known and evidence-based SMP. In the CDSMP, two peer facilitators who have a chronic illness themselves facilitate the
who have a chronic illness themselves, facilitate the group in a highly scripted, standardized program (in person or web-based discussion boards) for 2 ½ hours a week for six weeks.

Each session uses didactics and group discussion/interaction to teach strategies on managing common chronic health problems and engaging in healthy behaviors. Topics include the use of: 1) cognitive symptom management techniques to deal with frustration, depression, fatigue and anger (guided relaxation and distraction); 2) physical symptom management; 3) physical exercise; 4) use of medications and community resources; 5) fatigue and sleep management; 6) effective communication with family, health providers and friends; 7) benefits of proper nutrition; 8) strategies to evaluate new treatments; 9) partnering with health care providers; and 10) health related problem solving and decision making to make informed choices.8

Parkinson’s disease-focused SMPs are limited except for the Patient Education for People with Parkinson’s Disease and their Carers (EduPark), an eight-session education program developed within an interdisciplinary team consortium, comprised of research centers in seven European countries.16,17 This SMP was based on empirical evidence of effective strategies for managing psychological distress and social impact. When implemented and evaluated, EduPark improved patient self-reported psychosocial problems and quality of life, and caregiver mood.16–18 Lorig’s research also had similar findings and demonstrated that health care costs decreased by 20%.3,5,6

In summary, SMPs for chronic diseases have been found to be low-cost, evidence-based interventions that improve self-management skills and health status, and reduce the need for more costly medical care. Self-management programs may offer an alternative low-cost approach for supporting persons with PD, their families and caregivers. It improves health outcomes and quality of life while helping ease associated financial and psychosocial burdens.

References

Consumer health information on Parkinson’s Disease (PD) is at your fingertips through our Veterans Health Care Intranet. The Krames On-Demand provides a series of one or two page patient education handouts, called HealthSheets™, at least 13 HealthSheet topics relate to PD. Once only available in print form, the HealthSheets are now electronic resources that can be loaded onto your computer desktop as an easy “go to” source for additional patient health information. Although not a substitute for individualized patient education, they can supplement your face-to-face education information provided during the office visit.

**PD DISEASE**

**Treating Parkinson’s Disease: An Overview.**

* Most appropriate for early diagnosed individuals.

**Common Symptoms of Parkinson’s Disease.**

* Defines the most common symptoms of PD: tremor, rigidity, bradykinesia, and balance problems.

**Understanding Parkinson’s Disease.**

* Defines PD, elaborates on the changes in the brain, and describes the common symptoms. Diagnosis and the differentiation between PD and Parkinsonism are also addressed.

**MEDICATION & SURGERY**

**Parkinson’s Disease: Tips for Taking Medications.**

* Covers the basic essentials for optimizing medication effectiveness: timing, staying on tract (specific tips such as using a pillbox, taking all medication, dietary considerations, keeping a list, etc.), and coping with side effects. Important signs and symptoms to report are also included.

**Parkinson’s Disease: Understanding Your Medications.**

* Provides a chart of the types of medications by category, examples of the medications per category, and briefly describes their mechanism of action.

**Surgery for Parkinson’s Disease.**

* Provides a brief description of surgical options.

**FUNCTION & SAFETY**

**Getting Around with Parkinson’s Disease.**

* Includes clearly written instructions with illustrations of how to adjust walking/turning, getting up/sitting down, and getting out of bed.

**Parkinson’s Disease: Managing Day to Day.**

* Illustrates and discusses specific techniques to improve the safety and efficiency of everyday tasks, functions, and activities: dressing, bathing/grooming, eating/drinking, constipation, communicating, sleeping, and sexual activity.

**Exercises You Can Do for Parkinson’s Disease.**

* Illustrates and describes stretches and exercises to keep muscles loose and flexible.

**Parkinson’s Disease: Home Safety.**

* Describes helpful tips for modifying the home for prevention of falls. An illustration of a modified bathroom is especially useful.

*** Available in both English & Spanish ***
Due to the chronic and progressive nature of Parkinson's disease, it is likely that a person with this diagnosis will require the assistance of another at some point during the disease process. Consequently, family caregivers become an integral member of the care team, being most familiar with their loved one's medications, treatment and overall needs. Family caregivers provide care, comfort and security to their loved ones often while balancing commitments to their families, occupations and own well being. The caregiver role is demanding and responsibilities vary throughout the disease trajectory.

The PADRECCs recognize the complex role of family caregivers and offer an array of caregiver focused programs such as support groups, educational programs and resource fairs. The intention of these programs are to provide caregivers with the information and support necessary to successfully care for their loved one as well as offer an opportunity for peer support from those on a similar journey.

To learn more about the programs offered at your local PADRECC, visit the National PADRECC and Consortium website at www.parkinsons.va.gov or call 1-800-949-1001 x 5769

Additionally, the newly established VA Caregiver Support Program was developed to provide caregivers of eligible Veterans with a wide range of services.

To learn more visit: www.caregiver.va.gov or call Caregiver Support Line: 1-855-260-3274

### RESEARCH FOCUS

**Match to Clinical Trials on Fox Trial: Register today and be part of the answer to Parkinson’s disease**

When you participate in research, you give something money can’t buy. Fox Trial Finder opens the door to your opportunity to make a priceless contribution in the search for a cure. Parkinson’s patients and their loved ones are eager to play an active role in finding the cure, and dozens of new clinical trials are launched each year. Yet challenges identifying participants too often mean that these studies finish late — or never really get started.

Today, 80 percent of trials fail to recruit enough volunteers within planned timelines. This slows research progress and deters funders from investing in Parkinson’s research. It is estimated that only 1 in 10 people with Parkinson’s participate in clinical trials. Yet in spite of the challenges, we know that this low participation rate belies the Parkinson’s community’s significant interest in stepping up.

Fox Trial Finder makes it easy for patients and their loved ones to find personalized potential trial matches based on specific individual criteria (i.e. location and medical history). You can connect with trial teams to learn more about participating, and stay alerted to future potential matches that arise as new trials start recruiting.

Our goal is to end 2012 with 10,000 registered volunteers willing to participate in research. To get there, we must continue to spread the word about this need – and opportunity – for the PD community. Join the effort to speed breakthroughs today by visiting Fox Trial Finder and creating your profile. The power of Fox Trial Finder grows with every new profile completed, so share Fox Trial Finder with family, friends, and members of your community. Thank you for being part of the answer.

For more information email support@foxtrialfinder.org
Southeast PADRECC

Dr. Mark Baron (r), Director of Southeast PADRECC with Bio-Med Engineering PhD student Deepak Kumbhare at his laboratory.

Dr. Baron’s VA Merit Award supports laboratory studies that investigate the pathophysiology of basal ganglia related movement disorders in experimental rodent models. The ultimate goal of his studies is to develop improved therapies.

Way to go... RESEARCH TEAM!

Southwest PADRECC

Dr. Vickrey is Professor of Neurology at the David Geffen School of Medicine at UCLA and her health services research includes the evaluation of health outcomes, the evaluation of health care systems and the delivery of care to patients with neurologic diseases.

Barbara Vickrey, MD, MPH, Director of Research for Southwest PADRECC, has been elected to the Institute of Medicine (IOM) of the National Academies of Sciences.

Congratulations DR. VICKREY!
Established in 2000, The Movement Disorder (MD) Clinic at the Lexington VAMC is staffed by a physician, a nurse practitioner, and a pharmacist. These professionals provide subspecialty consultations, patient selection and management services for DBS surgery, and botulinum toxin injections. Dr. John T. Slevin, is the MD Clinic Medical Director, he is affiliated with the University of Kentucky Medical Center and Director of Clinical Research for the UKMC Morris K. Udall Parkinson’s Disease Research Center of Excellence. Dr. Slevin is the PI or a Co-PI on three industry and one NIH-sponsored clinical/translational studies that are currently recruiting subjects.

To refer patients for medical care or to enroll in research at the VA MD Clinic in Lexington, KY please

Contact: 859-281-4920 (VAMC Movement Disorders Clinic)

Recent Publications from the Lexington VAMC Consortium are:


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**Calendar of Events**

**April 21-28, 2012**

*American Academy of Neurology Annual Conference*

New Orleans, LA

http://www.aan.com/go/am12

**May 19, 2012**

*Davis Phinney Foundation Event*

The Victory Summit (for people living with PD)

http://www.davisphinneyfoundation.org/

Southeast PADRECC is a partner for this event.

**July 12, 2012**

*EES/PADRECC Movement Disorder Series*

Rehab Issues in PD

http://www.parkinsons.va.gov

**May 10, 2012**

*EES/PADRECC Movement Disorders*

Pharmacy and Therapeutics

http://www.parkinsons.va.gov

**June 17-21, 2012**

*16th International Congress of Parkinson’s Disease and Movement Disorders*

Dublin, Ireland

http://www.movementdisorders.org/congress/congress12/

**September 13-14, 2012**

*National VA PD Consortium West Coast Conference*

Location and venue TBD—SAVE THE DATE!
### PADRECC Centers:

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<th>City, State</th>
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<tr>
<td>Houston</td>
<td>Michael E. DeBakey VAMC</td>
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<td>San Francisco</td>
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<td>415-379-5530</td>
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### PADRECC and Consortium Centers

[Map of PADRECC and Consortium Centers]

**PADRECC Service Areas**
- Portland/Seattle
- San Francisco
- West Los Angeles
- Houston

**Richmond**
- Richmond
- Richmond/Philadelphia Overlap

**Philadelphia**
- Philadelphia

**PADRECC**
- Consortium Centers