



VA PADRECC CONNECTIONS



National Parkinson's Disease Research, Education and Clinical Centers Newsletter
Houston, Philadelphia, Northwest (Portland/Seattle), Southeast (Richmond), San Francisco, Southwest (West Los Angeles)
Vol. 4, No. 1, Summer 2005

National VA Parkinson's Disease Consortium Acquires New Members and Partners with Other Organizations

Yuri Romaniuk, National Coordinator, VA Parkinson's Disease Consortium

The National VA Parkinson's Disease Consortium was established in 2003 to broaden the impact of the six Parkinson Disease Research, Education and Clinical Centers and to encourage progressive PD care across the VA healthcare system. The Consortium continues to press for national endorsement and support from VA Central Office (VACO) and external organizations. Achievements include:

- In March 2005, VACO named the Philadelphia PADRECC the "National VA Parkinson's Disease (PD) Consortium Coordinating Center." VACO reassigned National PADRECC Coordinator, Yuri Romaniuk, to the Philadelphia PADRECC to assist with the coordination of the Consortium.
- The Consortium recently hosted an exhibit at the American Academy of Neurology 57th Annual Meeting in Miami. Over 20 VA clinicians registered as new members of the Consortium and countless organizations became familiar with our mission.
- The Consortium and PADRECCs are currently in negotiations with the National Parkinson Foundation, Inc. (NPF) to amplify the relationship outlined in the 1999 NPF/VA Memorandum of Understanding. If successful, this

collaborative agreement will promote joint programs and initiatives for the Consortium and NPF.

- Since its inception, the Consortium has recruited over 200 members, including movement disorder specialists, neurologists, neurosurgeons, geriatricians, internists, nurses, and allied health professionals.
- In February 2005, the Consortium launched its independent website www.vapdconsortium.org. This site includes member and specialist directories, annual goals and objectives, and pertinent information. We plan to enhance this site by adding web-based CME programs and other educational resources in the near future. ***Important Note:** The Consortium website address will be changing to www.parkinsons.va.gov. This is expected to be effective by June 2005. Subsequently and for a limited time, you will be re-directed to the new site from the www.vapdconsortium.org site.
- The Consortium Research Subcommittee is currently compiling a database of research interests and pro-

jects of all members. This database will be posted on the Consortium website in an effort to promote collaboration, multi-center trials, patient recruitment and funding opportunities.

- The Consortium Executive Committee continues to explore opportunities to fund national programs and meetings. Recently the Consortium broadened its scope by becoming an organizational partner with the World Parkinson Congress, Inc., an organization dedicated to providing an international forum on PD research and practice. The Consortium will be joining a list of other non-profit and professional organizations worldwide in the effort to combat the influences of PD amid an aging population, to help build awareness about PD, and to increase collaborative efforts to find a cure. Consortium membership is free. VA clinicians can register by downloading an application at www.vapdconsortium.org* or by con-



Portland VA speech-language pathologists present information at NW PADRECC PD Health Fair.

PADRECC SE: A Successful Multi-disciplinary Clinic

David X. Cifu, MD, Associate Director of Patient Care Services, PADRECC SE

PADRECC Southeast (SE) is proving itself successful as a model multi-disciplinary care clinic. This model incorporates Parkinson's disease (PD) specialists from neurology, physical medicine and rehabilitation, psychology, neurosurgery, nursing, physical therapy, speech-language pathology, and occupational therapy into a single outpatient clinical setting. Evaluation of longitudinal Unified Parkinson's Disease Rating Scale (UPDRS Part III Motor Examination) data from 49 consecutive individuals with PD managed at the SE PADRECC reveals that 74% of pa-

tients had the same or improved physical functioning at their follow-up evaluations at 12, 24 and 36 months. This is an impressive finding when the "gold standard" for individuals with PD (based on the research of the collaborative Parkinson's Study Group) is to experience a slight annual decline in functioning, even when appropriately treated with medications. The 26% of patients who had a decline over these 1-3 year follow-ups did better than expected based upon these "historic controls."

Importantly, even when comparing the overall neurological status of

all PADRECC patients studied, this research demonstrates an average improvement of their neurological examinations over the follow-up periods. Findings suggest that the multidisciplinary approach to care, which has been so successful in managing the needs of individuals with other neurological disorders, may also be the optimal model of care for individuals with PD.

Future research may identify specific aspects of this treatment model that are most effective, but most likely it is the integration of the multiple facets that is key.



SE PADRECC: Front row L to R: A.Qutubuddin, MD, M.Barron, MD (Acting Director), P.Roberge, RN; Middle: L.Klanchar, RN,MS, K.Massey-Makhoul, RN; Back: B.Carne, PhD, E.Carter-Hawkins, R.Brown, MS, C. McGrady, H. Green, P. Marcinko, FACHE, T. McGuirk, D.Cifu, MD

SF PADRECC: L to R: W.Marks (Director), J.Funk, IT, F.Lopez, N.Vanderlinden, RN, E.Lanier, RN, MS, J.Ostrem, MD, S.Heath, RN, MS, S.Khandhar, MD



Houston PADRECC: Front Row L to R: N.Nelson, PhD, L. Fincher, RN, B. Wade, F.Atassi, MD, MPH, M.Trail, MOT, BCN; Back: M. York, PhD, S. Moore, BA, G.Hou, MD, PhD, E.Lai, MD, PhD (Director), A. Sarwar, MD, Constance Ward, MSN, RNC



Release of "Parkinson's Disease: Mind, Mood & Memory" Handbook

Rebecca Martine, APRN, CS, BC, Associate Director of Education, Philadelphia PADRECC

The Philadelphia PADRECC proudly announces the release of "Parkinson's Disease: Mind, Mood & Memory." This educational handbook was produced by the Philadelphia team and published by the National Parkinson Foundation, Inc. It will be distributed free to patients, caregivers, and providers throughout the United States and international communities. "Mind, Mood & Memory" is the first of its kind to provide lay education on the neuropsychiatric aspects of PD.

Did You Know?

- Approximately **50%** of people with PD will develop some form of **depression**
- As many as **40%** will develop **anxiety**
- Approximately **50%** will develop some form of **cognitive impairment** and up to **30%** will be diagnosed with full-blown **dementia**
- As many as **40%** will experience **psychosis** during the course of their illness

PADRECCs Establish National Registry

Eric Cheng, MD, MS, Associate Director of Education, Southwest (West Los Angeles) PADRECC

In 2001, The Parkinson's Disease Research, Education, and Clinical Center (PADRECC) grants were awarded to the six Veterans Affairs Medical Centers. Central Office directed the PADRECCs to create a registry of patients seen by PADRECC providers, and by 2002, each of the Centers had created their own local database of patients.

In 2003 we formed a national committee comprised of staff from each PADRECC to decide what set of information should be collected from all the Centers to create a single national registry. They convened by telephone on a biweekly basis. Due to technical difficulties, the committee decided to adapt a web-based database already in use by the San Francisco (SF) PADRECC to meet na-

tional registry needs.

The national registry contains information on patient demographics and diagnosis. If the patient has been given the diagnosis of idiopathic PD, then information on the severity of disease is collected through Hoehn and Yahr Staging of Parkinson's Disease, Unified Parkinson Disease Rating Scale (UPDRS), and Schwab and England Activities of Daily Living Scale. Information is also being collected on the prescription of medications used to treat PD symptoms.

Each of the six PADRECCs faced their own set of local challenges to participate in the national PADRECC registry. The local PADRECC databases differed so that some may have collected similar information as the national registry, but other Centers

collected different sets of information and needed to establish procedures to collect the data. Local institutional review board (IRB) decisions on the research status of the registry and the need for written informed consent have also varied. In addition, the ability to transfer information from existing PADRECC databases to the national registry has varied according to the structure of the local PADRECC database. We gradually overcame these problems. As of April, 2005, there have been 3,288 patients enrolled in the national PADRECC registry, of which 1,677 have the diagnosis of idiopathic PD.

For additional information, contact Lori Anzaldo, SF PADRECC at 415-221-4810 extension 2485.



Philadelphia PADRECC psychiatrist Dan Weintraub, MD talks with PD veteran patients and families at the Philadelphia VA "Mind, Mood, and Memory Education Fair."

visit our website
www.va.gov/padrecc

Research News

Naomi Nelson, PhD, Co-Associate Director of Education
Houston, PADRECC

Rivastigmine and PD Dementia

Over 400 PD patients completed a placebo-controlled study testing rivastigmine (Exelon) for PD dementia. Although changes were modest, patients treated with 3-12 mg daily of rivastigmine showed statistically significant improvement on memory, concentration, and behavioral changes. Changes are similar to those reported for Alzheimer's disease. <<http://nejm.org/cgi/content/abstract/351/24/2509>>

Mutation in LRRK2 Gene is Associated with Late-Onset PD

Researchers have recently discovered that a novel mutation in the leucine-rich repeat kinase 2 (LRRK2) gene caused PD in several North American and European

families. The disease-causing Gly2019Ser mutation is the 1st time a genetic cause has been associated with typical, late-onset PD. DNA sequencing of the LRRK2 gene led to the discovery that 22 of 42 family members of PD patients also carry the mutated gene. Seven were already diagnosed with PD. The mutation was absent in 2,000 healthy controls. Age of PD onset varied, but older patients exhibited more symptoms. The team of neuroscientists (Mayo Clinic, Jacksonville, FL) believes a single LRRK2 mutation could be responsible for up to 5% of PD cases. They say this discovery helps identify typical PD cases before symptoms are manifested. Further exploration of the cellular role of the LRRK2 gene and its mutation, Gly2019Ser, together with clinical trials of kinase inhibitors, are ongoing. **Am J Hum Genet 2005 76(4)672-80.**

PADRECC Activities

Nationwide PADRECCs

Houston PADRECC	
8/26/05	PADRECC Patient/Family Education Support Group
9/9/05	PADRECC Patient/Family Forum
Philadelphia PADRECC	
9/16/05	3rd Annual PADRECC/MIRECC Symposium
12/2/05	PD Research Update for Patients and Families
Portland/Seattle (Northwest) PADRECC	
8/12/05	VTel Conference Series
9/28/05	VTel Conference Series
Southeast (Richmond) PADRECC	
8/28/05	Patient/Caregiver Support Group
10/05	PADRECC/APDA Fall Symposium
San Francisco PADRECC	
8/4/05	SF PADRECC VTel Series: DBS Cases
8/11-12/05	Focus Group on Activa Deep Brain Stimulation
Southwest (West Los Angeles) PADRECC	
8/19/05	Monthly Case Conference Journal Club
9/9/05	Monthly Case Conference Journal Club

PADRECC Richmond/SE Director Retires

Lynn Klanchar, RN, MS, Associate Director of Education,
SE PADRECC

PADRECC staff helped Dr. Vincent Calabrese celebrate his retirement in February. It was an occasion to honor his career and thank him for his dedication to the treatment of Parkinson's disease. Dr. Calabrese served as SE PADRECC's director since its inception. A physician for 40 years, he is board certified in Neurology and a Fellow of the American Academy of Neurology.

Dr. Calabrese was involved in the initial clinical trials for levodopa. In the early 80's, he pioneered movement disorder clinics at Medical College of Virginia (MCV) and McGuire Veterans Hospital in Richmond.

He is most proud of being involved in bringing state of the art PD care to the veteran population and helping to establish clinical care guidelines. He says more work needs to be done to disseminate delivery of key PD care processes in the VA and other health systems. The SE PADRECC will truly miss Dr. Calabrese. Fortunately, he will continue to serve as an Advisory Board member for the PADRECC.

"Parkinson's Disease Mind, Mood & Memory"

for copies contact Dianne Gross at the National
Parkinson Foundation, Inc.
dgross@parkinson.org or 305-243-3881

Central Office, West Haven, CT

John Booss, MD, National Director of Neurology, VHA
VA CT Healthcare System 203-932-5711
www.va.gov/padrec/

Houston PADRECC

Eugene C. Lai, MD, PhD, Director 713-794- 7841
http://www.va.gov/padrec_houston/

Philadelphia PADRECC

Matthew B. Stern, MD, Director 888-959-2323
http://www.padrec.org

Northwest (Portland/Seattle) PADRECC

John G. Nutt, MD, Director 503-721-1091

Southeast (Richmond) PADRECC

Mark Baron, MD, Acting Director 804-675-5931
http://www.va.gov/netsix-padrec

San Francisco PADRECC

William J. Marks, Jr., MD, Director 415-379-5530
http://www.sf.med.va.gov/padrec

Southwest (West Los Angeles) PADRECC

Jeff Bronstein, MD, PhD, Director 310-268-3975
http://swpadrec.medsch.ucla.edu/

Newsletter Editor

Marilyn Trail, Co-Associate Director of Education
Houston PADRECC marilyn.trail@med.va.gov



On February 22-26, 2006, representatives from all sectors of the international Parkinson's community will convene for the first time at the World Parkinson Congress (WPC) in Washington, DC. More than 3,000 researchers, patients, and caregivers will participate in this 4-day event on latest developments in Parkinson's disease. The mission is to expedite the discovery of a cure and showcase best treatment practices.

The program will include coursework for CME and CEU credits.

The PADRECCs and Consortium are Organizational Partners with the WPC. Registration and program information are forthcoming. To receive email updates, visit www.worldpdcongress.org/reg_housing/reg_info.cfm.

The abstract submission deadline has been extended to August 1 through September 21, 2005.

Abstract submission information can be found on the website. (For questions contact Eli Pollard at info@worldpdcongress.org)