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U.S. Department  
of Veterans Affairs

# Epilepsy Centers of Excellence

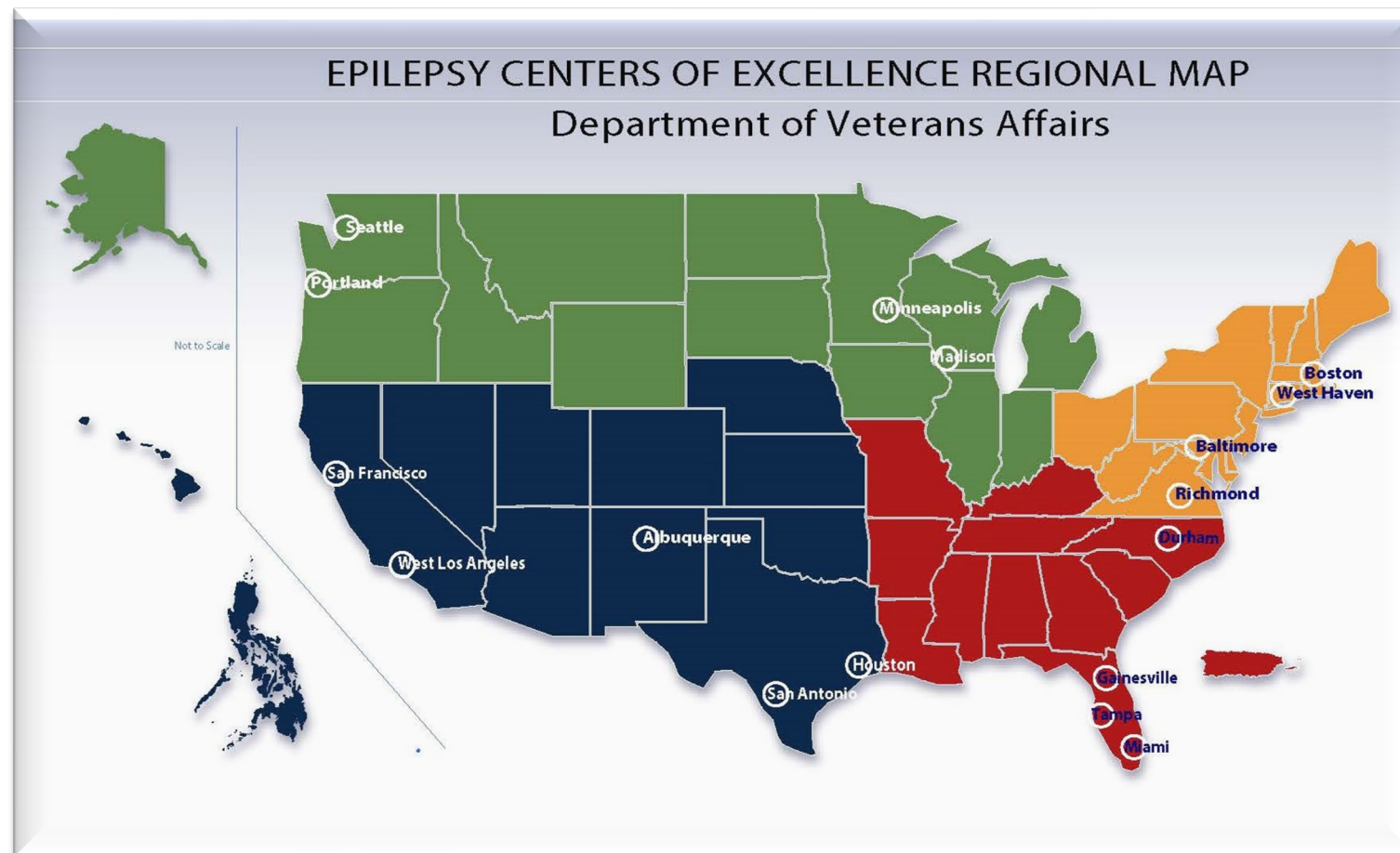
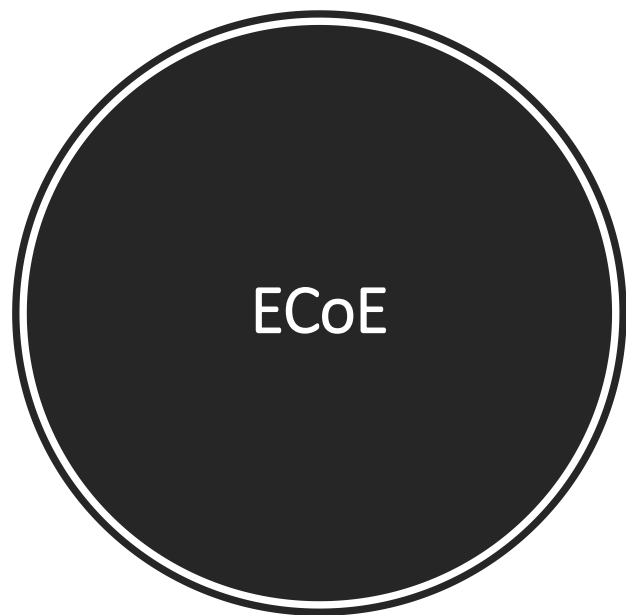
Alan Towne, M.D., M.P.H.

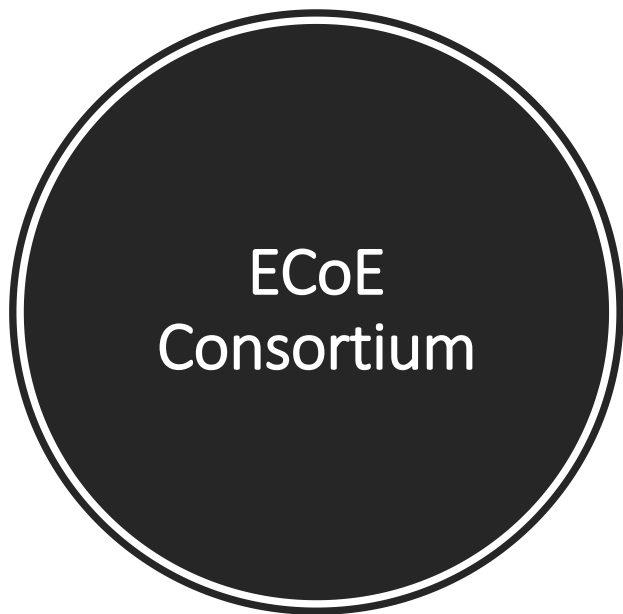
ECoE National Clinical Director, Department of Veterans Affairs  
Professor of Neurology, Community Health, Physical Medicine  
And Rehabilitation, Virginia Commonwealth University,  
Richmond, VA



# Background

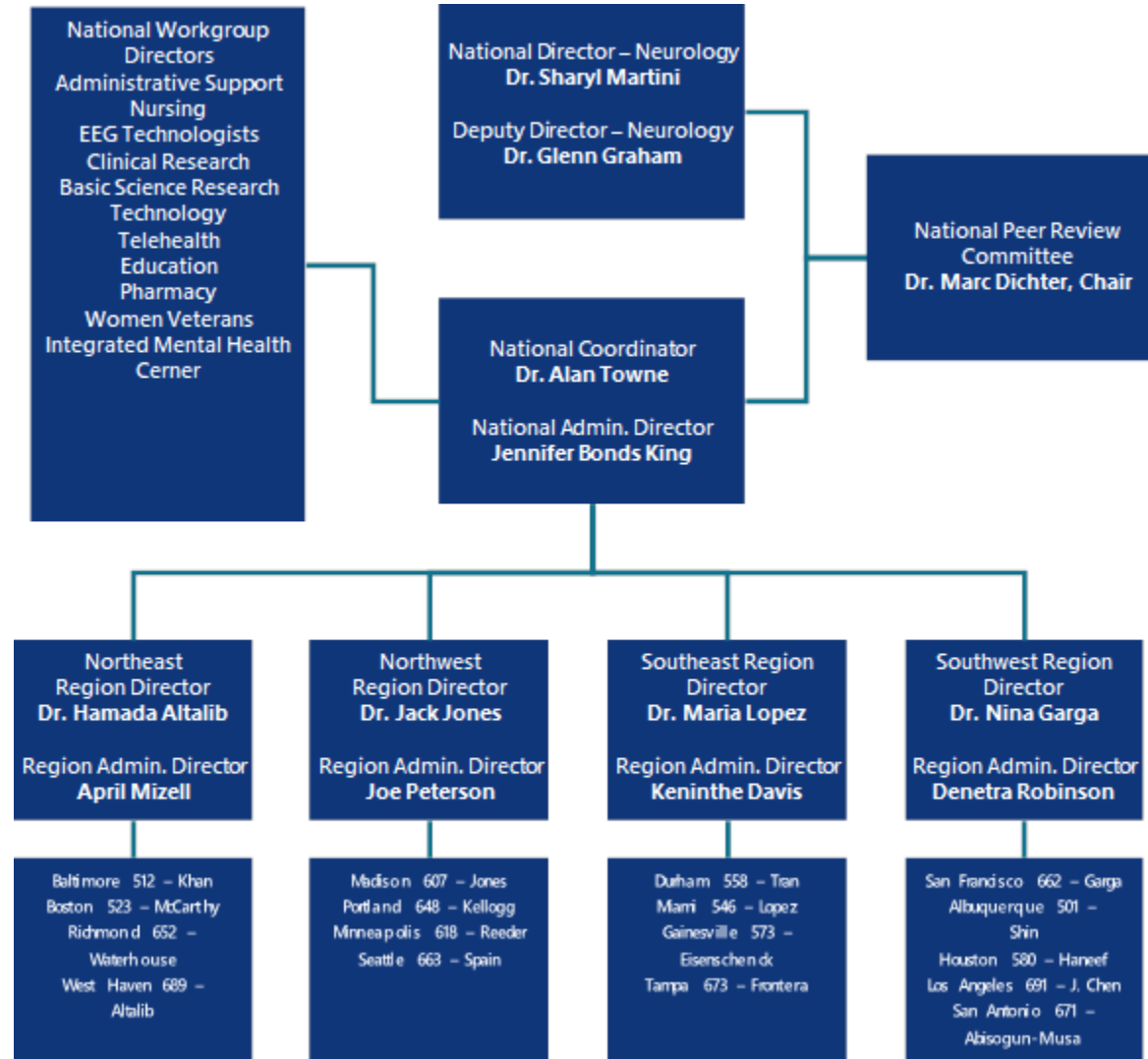
The Epilepsy Centers of Excellence (ECOE) were established in response to the “Veterans’ Mental Health and Other Care Improvements Act of 2008” (P.L. 110-387§ 404). In that law, an ECOE was defined as “a health care facility that has (or in the foreseeable future can develop) the necessary capacity to function as a center of excellence in research, education, and clinical care activities in the diagnosis and treatment of epilepsy.



[illegible]



# Epilepsy Centers of Excellence Organization Chart (Current)





# GOALS

Our primary goal is to optimize the care of veterans with epilepsy and other seizure disorders across the nation. To achieve this goal:

- we must address the unique needs and comorbidities of the Veteran population with epilepsy and other seizure disorders
- Ensure that all enrolled Veterans have access to high quality comprehensive epilepsy care, including care of non-epileptic seizures
- Improve veteran access to diagnostic EEG testing via ECOE Hub-Spoke referrals, TeleEEG networks, home based EEG systems, and other emerging technologies
- Provide epilepsy education venues for all VA Healthcare providers and caregivers
- Implement national standards for the comprehensive health care of Veterans with epilepsy and other seizure disorders
- Provide expertise and make recommendations to National Director of Neurology Services and the VACO/VHA leadership regarding the comprehensive health care of Veterans with epilepsy and other seizure disorders

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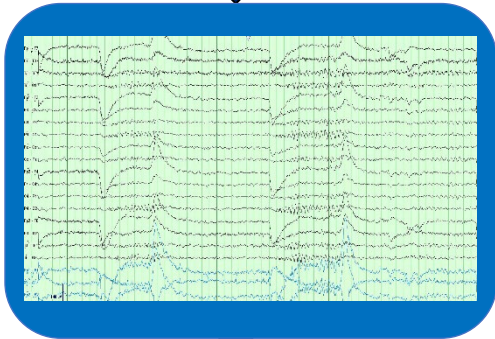
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Epilepsy Centers  
of Excellence

Expand the tele-EEG  
platform; focus on rural  
and ICU access

Clinical

# ECoE Tele-EEG Initiative



## TeleEEG: Store and Forward EEG

Routine Outpatient

Inpatient EEG

Video EEG

Ambulatory 24hr EEG +/- Video

## TeleEEG: Synchronous: Continuous Monitoring

Inpatient Video EEG

ICU EEG

## Home Based EEG: Continuous Monitoring

## Rapid EEG Devices



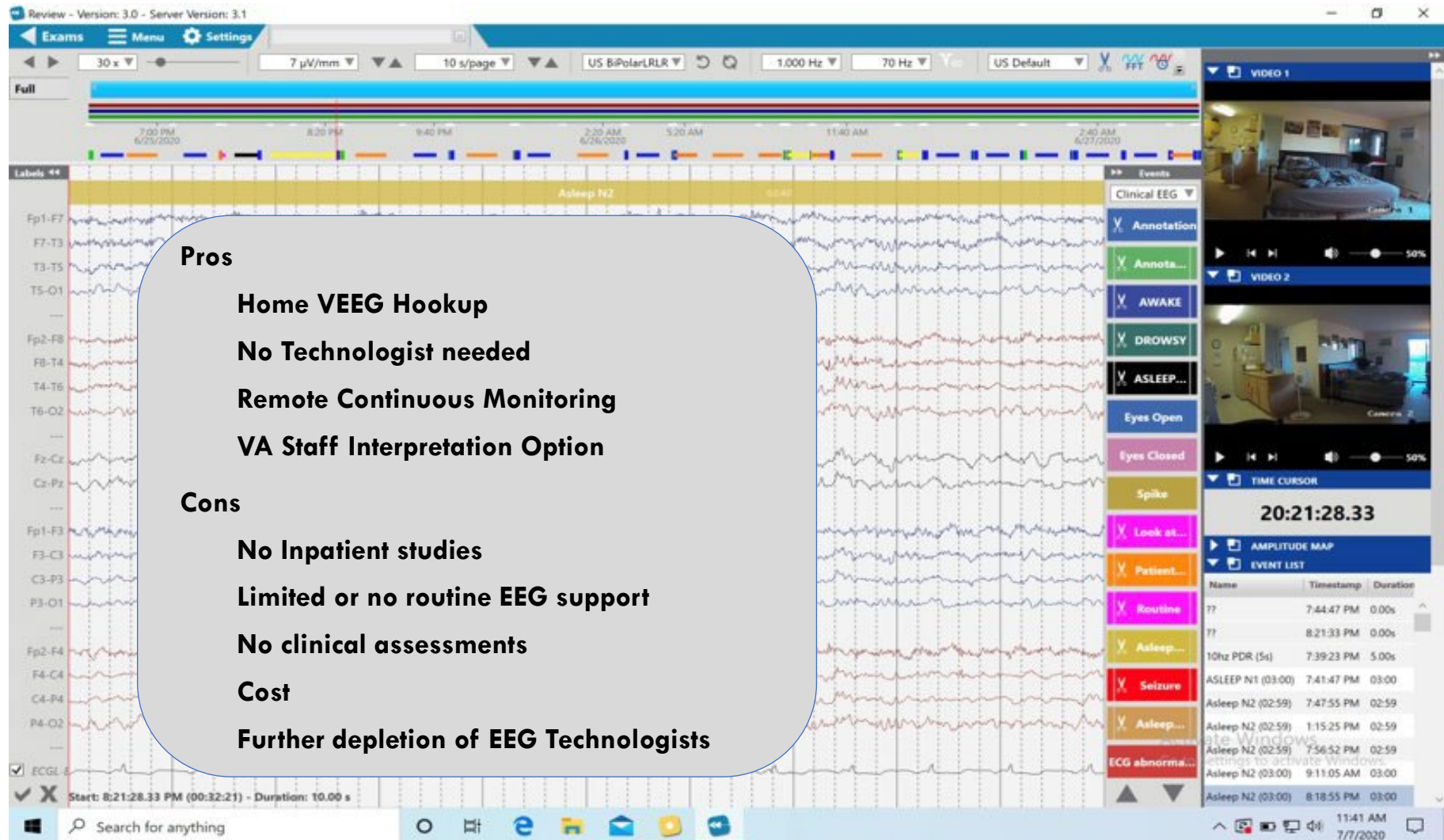
# HOME BASED EEG

## Active Vendors:

Stratus Alliance

NeuroTech

Corticare



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VA Mind Brain Program  
(MBP)

Clinical

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**MBP**

- Treatment of patients with ES and PNES
- Clinical Manuals for NBT for other neuropsychiatric disorders: Functional Movement Disorder manual, Functional Cognitive Disorder manual
- Coordination/recruitment of patients for seizure counselors-in-training
- Twice monthly clinical peer supervision meeting
- Facilitated VA National Library access to Oxford University Press, Treatments That Work series

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**Clinical**

- **Tele-Epilepsy/EEG  
Integration**
- **Tele-Neurology/ECOE  
partnership**



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Education

# Workgroup Mission

- Mission: to provide education and resources to veterans and those involved in the care of veterans with epilepsy
- In recent years, the Education Committee has provided webinars, TMS courses, and a series of brief YouTube videos, called Veterans and Epilepsy: Basic Training
- Brochures, an epilepsy manual, and other published resources are available on the ECoE website

VA » Health Care » Epilepsy Centers of Excellence (ECoE) » Patient/Caregiver Education


## Epilepsy Centers of Excellence (ECoE)

▼ Epilepsy Centers of Excellence (ECoE)

- Epilepsy ECoE - Home
- Symptoms, Causes, Treatments
- ▶ About the ECoEs
- Epilepsy Care Near You
- ▼ Education
  - Patient Education
  - Provider Education
  - Nursing Education
- News
- ▶ Patient Resources
  - Epilepsy Awareness Month
  - Employment/Education Opportunities

Patient/Caregiver Education

### Veterans & Epilepsy - Basic Training



Watch on YouTube

### Provider Education

#### TMS - Clinical Webinars

Item No.	Date of Training	Time of Training (ET)	Direct Item Link
42698	11/04/2020	12:00 PM	<a href="#">Responsive Neurostimulation (RNS) Programming in Epilepsy</a>
43226	12/92/2020	12:00 PM	<a href="#">PNES in the EMU Epilepsy</a>
44033	04/21/2021	12:00 PM	<a href="#">Common statistical mistakes in clinical research</a>
44383	05/12/2021	12:00 PM	<a href="#">Epilepsy Imaging</a>
44750	06/09/2021	12:00 PM	<a href="#">Women Veterans with Epilepsy: Beyond Seizure Control - 1</a>
44750	06/16/2021	12:00 PM	<a href="#">Women Veterans with Epilepsy: Beyond Seizure Control - 2</a>

#### Adobe Connect - Clinical Webinars

- Status Epilepticus - Sally Mathias, MD. - May 6, 2020 - <http://va-eerc-ees.adobeconnect.com/pwu0x6txb7kl/>
- First Time Seizure Comprehensive Approach to Evaluation and Management – Hoyjin Suh, MD - October 3, 2019 - : [First Time Seizure: Comprehensive Approach to Evaluation and Management](#)
- Management of Antiepileptics and Their Side Effects – Hoyjin Suh, PharmD - September 5, 2019 - <http://va-eerc-ees.adobeconnect.com/pc4r538est8x/>
- Epilepsy Through the Lifespan – Denise Riley, ARNP - July 10, 2019 - <http://va-eerc-ees.adobeconnect.com/pn4a2os1hx06/>
- Anti-Epilepsy Drug: Focus on Drug Interactions – June 5, 2019 – Sunita Dergalust -: <http://va-eerc-ees.adobeconnect.com/pn57takx5bby/>
- Sudden Unexpected Death in Epilepsy - November 7, 2018 - Tung Tran, MD - : <http://va-eerc-ees.adobeconnect.com/pdgua4ifluj2/>

### Epilepsy Manual for Clinicians

# Current and Past Programs

- Educational programs/series (All programs are open to all)
  - Hope In Epilepsy Series: For patients and caregivers.
    - Increased attendance to >35 per seminar.
    - Creation of local site/s for live patient attendance and facilitate participation.
  - For primary care and general neurology:
    - Series of 4 topics identified by a smaller committee of general neurologists as important
  - Journal Club For Epilepsy Experts
    - Epilepsy Guidelines publications and discussion from the VA Epilepsy centers perspective.
  - Grand Rounds for Epilepsy Experts
    - Veteran epilepsy disease specific topics for state of the art that may lead to research collaborations.
- Educational materials
  - Update and growth: website, videos, printed materials, pharmacy, textbook
- Education outreach
  - Purple Day
  - Anita Kauffman Foundation
- Training of students, residents and fellows
- 156 epilepsy/clinical neurophysiology fellows trained over the past 5 years



## Hope In Epilepsy Series

Hosted by the VA Epilepsy Centers of Excellence

**Antiseizure Medications: Why and How Can I Remember to Take My Medications?**

**Presenters: Sunita Dergalust, PharmD  
and Hyojin Suh, PharmD**

Patient/Caregiver Audio/Video Conference Series

**September 8, 2022, Thursday 9am Pacific/12pm Eastern**

Target Audience: Patients and Caregivers

Webinar/Online Meeting

RSVP: to [winaona.finley@va.gov](mailto:winaona.finley@va.gov)

Use below link to connect:

[Click here to join the meeting](#)

Audio: +1 872-701-0185 Conference ID: 825034251#

### UPCOMING MEETINGS:

October 13, 2022: Dr. Alfred Frontera: TBI and Epilepsy

November 10, 2022: Dr. Kathy Tortorice: Antiseizure Medication Side Effects

December 8, 2022: Dr. Kristen Mordecai: How Can a Neuropsychologist Help a Patient with Epilepsy?

Introducing a **NEW** Provider Webinar Series  
Hosted by the VA Epilepsy Centers of Excellence

Accredited for CMEs

JAIPCE, ACCME, ACCME-NP, ACPE, ANCC

## ACUTE SEIZURE MANAGEMENT

The primary target audience includes all physicians, nurses, pharmacists, and other healthcare workers who care for epilepsy patients!

[Click each title below to get to the link for the webinar](#)

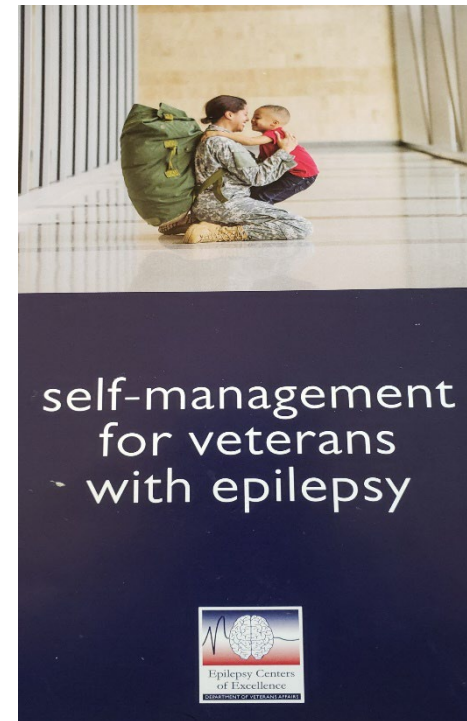
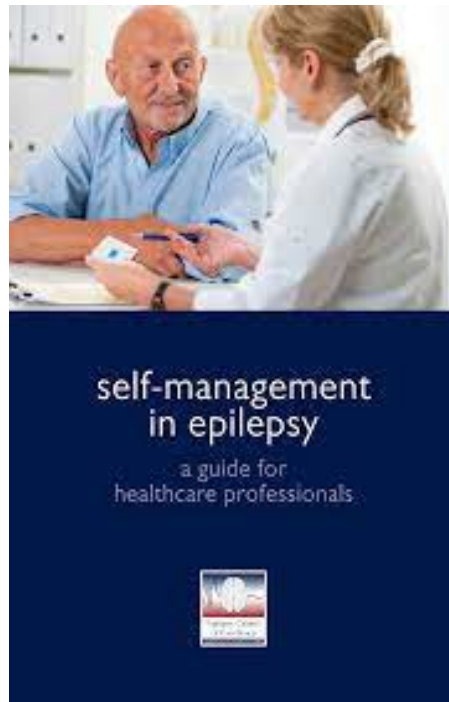
\* For BREAKOUT sessions, "Ask the Epileptologist Session" or "Meet the Regional Epileptologist", register in TMS before the session.

Date	PST	EST	Titles	Speakers
Friday 10/7/22	09:00 am	12:00 pm	<a href="#">Status Epilepticus and Antiseizure Medications (ASMs)</a> * with "Ask the	Dr. James Way-Young Chen
Wed 11/16/22	10:00 am	1:00 pm	Case based Discussions for Acute seizure Management and "Meet the Regional Epileptologist live breakout sessions *	Dr. Zulfi Haneef
Wed 12/07/22	09:00 am	12:00 pm	Driving Guidelines for Seizure Patients	Dr. Stephan Eisenschenk
Wed 01/18 /23	09:00 am	12:00 pm	First seizure management and guidelines	Dr. Omar Khan



**Please Join us for CMEs  
Virtual Education!**

# The Nursing Workgroup has meticulously updated two major educational pamphlets



Update/Revise two major educational tools from our previous nursing workgroup, Self Management for Veterans for the healthcare provider from 2015 and for Veterans with epilepsy from 2017.





# EEG Technologists Education

- VA Cross training initiatives (Polysomnography to EEG)
- Exploring SkillBridge
- Reach out to VA employees interested in EEG training
- ASET Core Curriculum
- EEG Tech continuing education

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**Research**

- Clinical Research
- Basic Science

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# Research

- Drug resistant epilepsy
- Women's health and epilepsy
- Cellular mechanisms and channelopathies that contribute to epilepsy
- Traumatic brain injury with a focus on post-traumatic epilepsy (PTE) and its comorbidities.
- Neuronal and network mechanisms contributing to epilepsy in human tissue
- EMU database
- PTE biomarkers
- Home-Based Technologies to Improve Diagnosis in Veterans with Epilepsy
- Epidemiology of Epilepsy and Traumatic Brain Injury
- Effectiveness of Tele-EEG



# Neurology Chiefs Survey

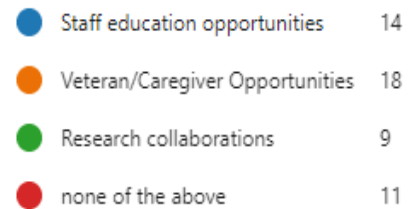
9. Does your staff use subspecialty clinical consultations for the **EPILEPSY CENTERS OF EXCELLENCE**?

[More Details](#)



11. Which other **EPILEPSY CENTERS OF EXCELLENCE** resources does your staff use? (select all that apply)

[More Details](#)





# Epilepsy Centers of Excellence (ECoE)

▼ Epilepsy Centers of Excellence (ECoE)

- Epilepsy ECoE - Home
- Symptoms, Causes, Treatments
- ▶ About the ECoEs
- Epilepsy Care Near You
- ▶ Education
- News
- ▶ Patient Resources
- Epilepsy Awareness Month
- Employment/Education Opportunities

▶ More Health Care

QUICK LINKS

Hospital Locator

Go

Health Programs

Protect Your Health

A-Z Health Topics

 **Veterans Crisis Line**  
DIAL 988 then **PRESS 1**

 **My healthvet**  
My Health, My Care: 24/7 <sup>Online</sup> Access to VA



Caregivers Support Services

Through VA's Caregiver Support Program, family caregivers have access to a menu of supports and services.

[Learn more >](#)

Education

Caregivers Support

Epilepsy Care Near You

Epilepsy Centers of Excellence (ECoE)

MISSION

*Improve the health and well-being of Veteran patients with epilepsy and other seizure disorders through the integration of clinical care, outreach, research, and education.*

OVERVIEW OF EPILEPSY CENTERS of EXCELLENCE (ECoE)

The VA Epilepsy Centers of Excellence (ECoE) is a network of 17 sites that provide comprehensive epilepsy evaluation and care for Veterans with seizure disorders. To improve the care of Veterans nationwide, ECoE partner's with a consortium of VA physicians, nurses, therapists, pharmacists and other allied healthcare providers with interest and expertise in improving the health and well-being of Veteran patients with epilepsy.



VA's Epilepsy Centers for Excellence

 VA's Epilepsy Centers for Excellence

Watch later Share



**CHRISTOPHER RANSOM, MD, PhD**  
EPILEPSY CENTERS OF EXCELLENCE

Watch on  YouTube

• <https://www.epilepsy.va.gov>

# Contact Information

## Northwest Sites

① <b>Madison</b>	William S. Middleton Memorial VA	(608) 256-1901 x17728
② <b>Minneapolis</b>	Minneapolis VAMC	(612) 467-2047
③ <b>Portland</b>	Portland VAMC	(503) 220-8262 x58334
④ <b>Seattle</b>	Puget Sound HCS	(206) 764-2021

\*States Covered: Alaska, Idaho, Illinois, Indiana, Iowa, Michigan, Minnesota, Montana, North Dakota, Oregon, South Dakota, Washington, Wisconsin, and Wyoming.

## Southwest Sites

⑤ <b>Albuquerque</b>	New Mexico VA HCS	(505) 265-1711 x2752
⑥ <b>Houston</b>	Michael E. DeBakey VAMC	(713) 794-8835
⑦ <b>San Francisco</b>	San Francisco VAMC	(415) 379-5599
⑧ <b>West Los Angeles</b>	Greater Los Angeles HCS	(310) 268-3595
⑨ <b>San Antonio</b>	Audie L. Murphy VA Hospital	(210) 617-5300 x14372

\*States Covered: Arizona, California, Colorado, Hawaii, Kansas, Nebraska, Nevada, New Mexico, Oklahoma, Texas, Utah, and Philippines

## Northeast Sites

⑩ <b>Richmond</b>	Central Virginia VA HCS	(804) 675-5000 x2531
⑪ <b>Baltimore</b>	VA Maryland HCS	(410) 605-7414
⑫ <b>West Haven</b>	VA Connecticut HCS	(203) 932-5711 x4724
⑬ <b>Boston</b>	VA Boston HCS	(857) 364-4750

\*States Covered: Connecticut, Delaware, Maine, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Ohio, Pennsylvania, Rhode Island, Vermont, Virginia, West Virginia, and District of Columbia

## Southeast Sites

⑭ <b>Durham</b>	Durham VAMC	(919) 416-5982
⑮ <b>Miami</b>	Miami VAHCS	(305) 575-3192
⑯ <b>Gainesville</b>	Malcom Randall VAMC	(352) 548-6058
⑰ <b>Tampa</b>	James A. Haley VAMC	(813) 972-7633

\*States Covered: Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, Missouri, North Carolina, South Carolina, Tennessee, and Puerto Rico

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# Overview of the VHA Headache Centers of Excellence Program

October 7<sup>th</sup>, 2022



**Jason J. Sico, MD, MHS, FAAN, FACP, FANA, FAHA**  
National Director, Headache Centers of Excellence (HCoE),  
Veterans Health Administration  
Director, HCoE Research and Evaluation Center  
Associate Professor of Neurology and Internal Medicine



@JSico\_MD



# DISCLOSURES & ACKNOWLEDGEMENTS

## Grant support :

- VA HSR&D Investigator Initiated Research Award - Addressing Sleep Apnea Post-Stroke (ASAP; IIR 16-211)
- VA Headache Centers of Excellence Research and Evaluation Center (HCoE REC) Partnered Award
- VA Implementation Research Pilot - TelemEdiciNe-bAsed CognItive TherapY (TENACITY; IRP 20-002)

## Acknowledgements:

- The views expressed in this plenary are those of the presenter and do not necessarily represent the views of the Department of Veterans Affairs



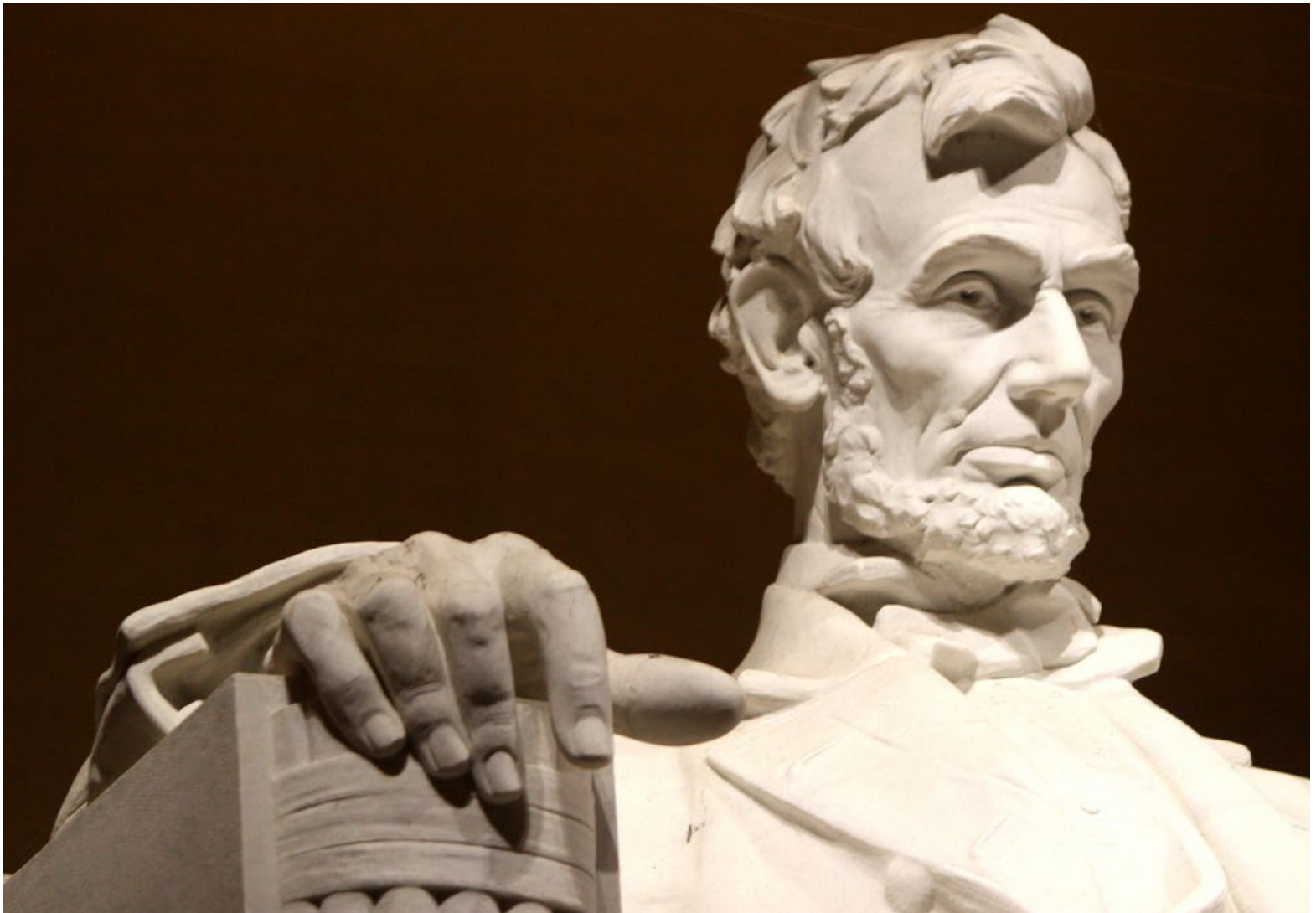
# Outline

- Provide an overview of Headache and headache data within the Veterans Health Administration
- Highlight the past, present, and future of the HCoE Program
- What the HCoE can do for you ...





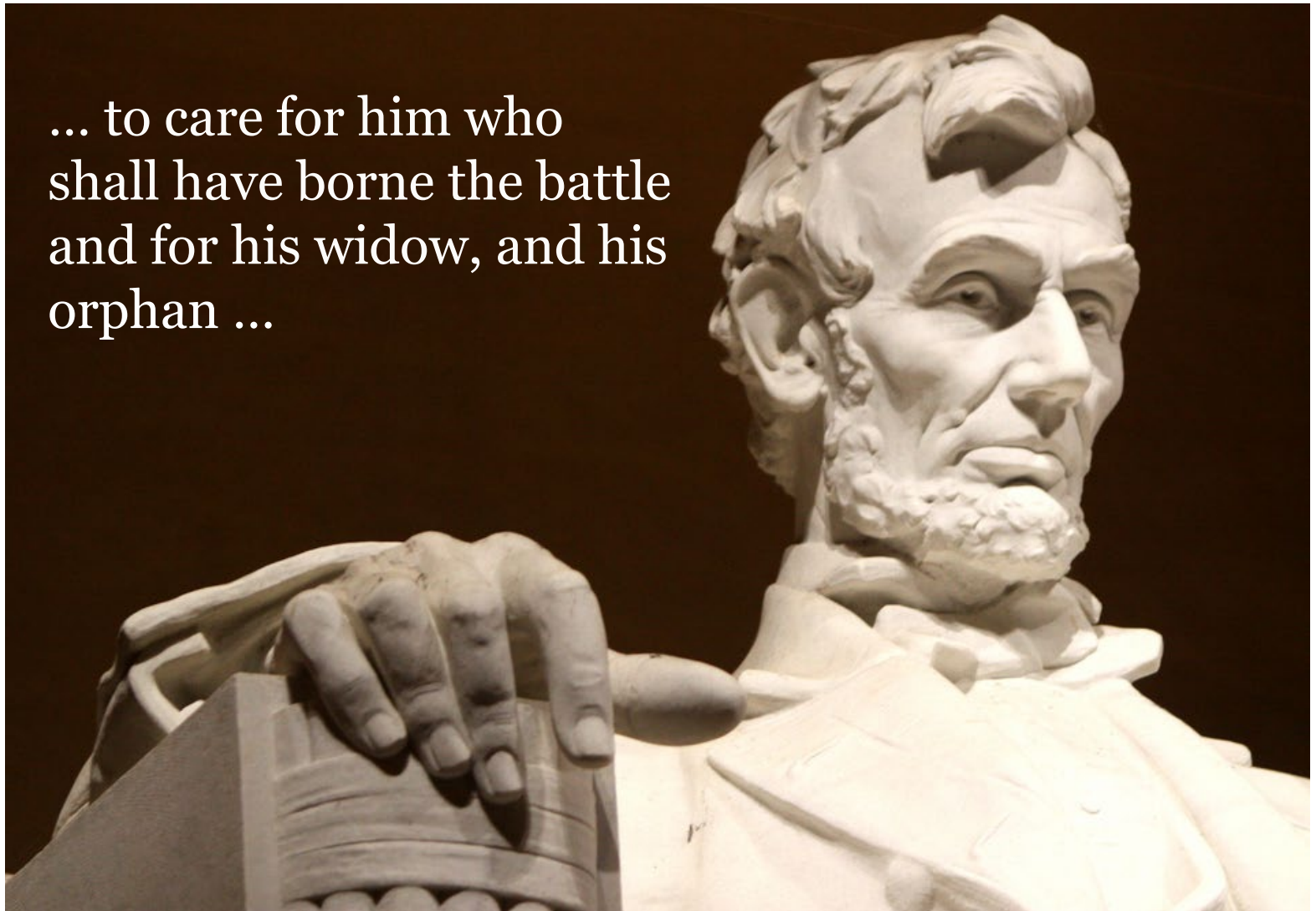
# OVERVIEW OF THE VETERANS HEALTH ADMINISTRATION





# OVERVIEW OF THE VETERANS HEALTH ADMINISTRATION

... to care for him who  
shall have borne the battle  
and for his widow, and his  
orphan ...







# Our Veterans





# OVERVIEW OF THE VETERANS HEALTH ADMINISTRATION

- In 2019, 19 million Veterans living in the US <sup>1</sup>
  - 90.6% men; 81.4% white
  - More than half were 65 years or older
  - 7% of the US population are Veterans
  - More than half of Veterans use VHA for healthcare
- Serves more than 9 million Veterans each year <sup>2</sup>
- Largest Healthcare System in the US <sup>2</sup>
  - 171 VHA Medical Centers
  - 1,112 outpatient clinics
  - 1 EHR

1. [www.census.gov](http://www.census.gov)

2. [www.va.gov/health](http://www.va.gov/health)



# Headache Care within the Veterans Health Administration

9.7 million

Individual visits to a VHA-based provider for headache treatment between October 1, 2007 and September 30, 2020.



# Headache Care within the Veterans Health Administration

1,745,960





# Headache Care within the Veterans Health Administration

1,745,960

Number of Veterans diagnosed and treated within the Veterans Health Administration for headache between October 1, 2007 and September 30, 2021.



# Headache Care within the Veterans Health Administration

1,745,960

Number of Veterans diagnosed and treated within the Veterans Health Administration for headache between October 1, 2007 and September 30, 2021.

14% of all Veterans receiving care in VHA have at least one headache disorder



# Headache Care within the Veterans Health Administration

1,745,960

Number of Veterans diagnosed and treated within the Veterans Health Administration for headache between October 1, 2007 and September 30, 2021.

46% have at least one mental health condition



# Headache Care within the Veterans Health Administration

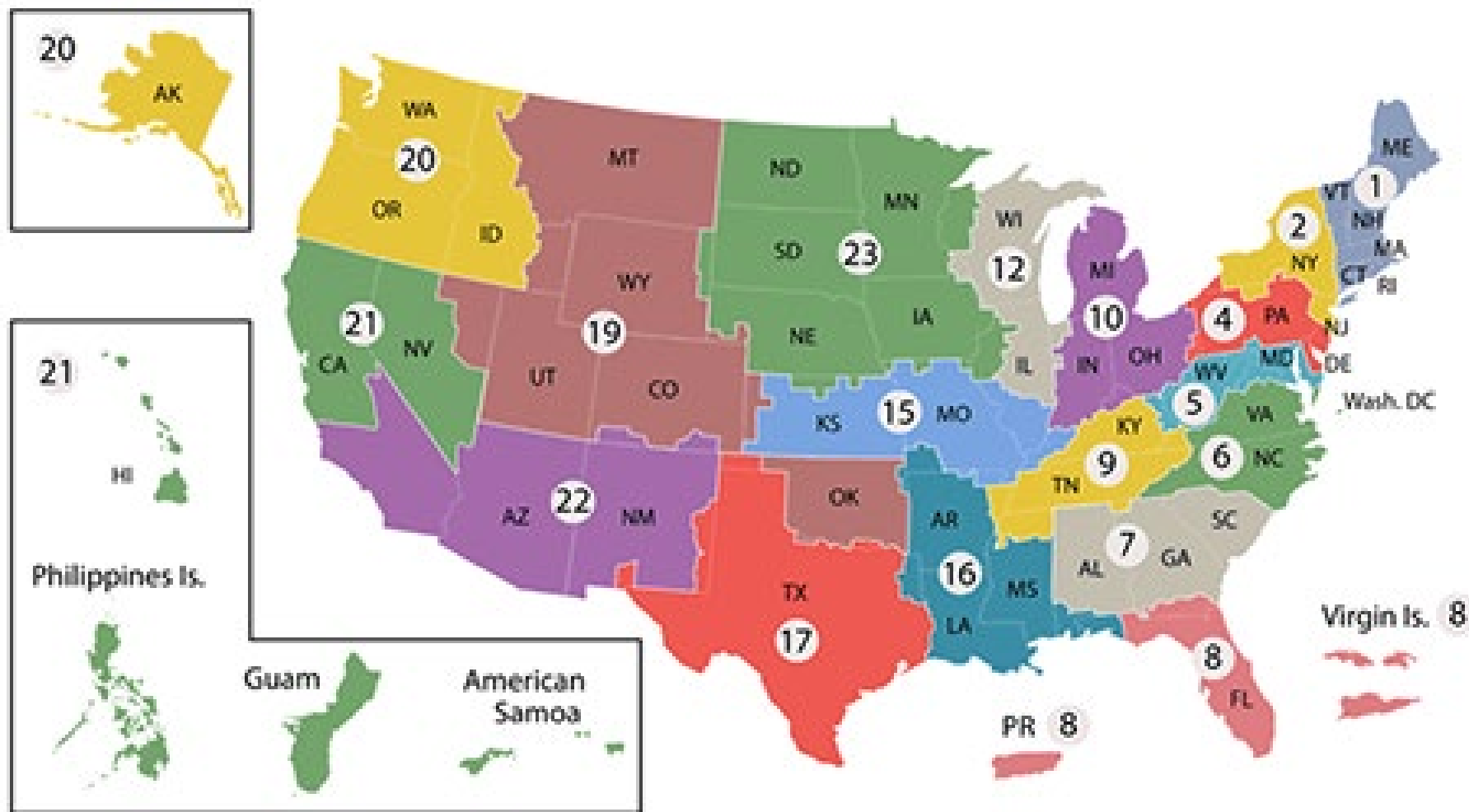
1,745,960

Number of Veterans diagnosed and treated within the Veterans Health Administration for headache between October 1, 2007 and September 30, 2021.

65% have at least one other  
non-headache pain condition

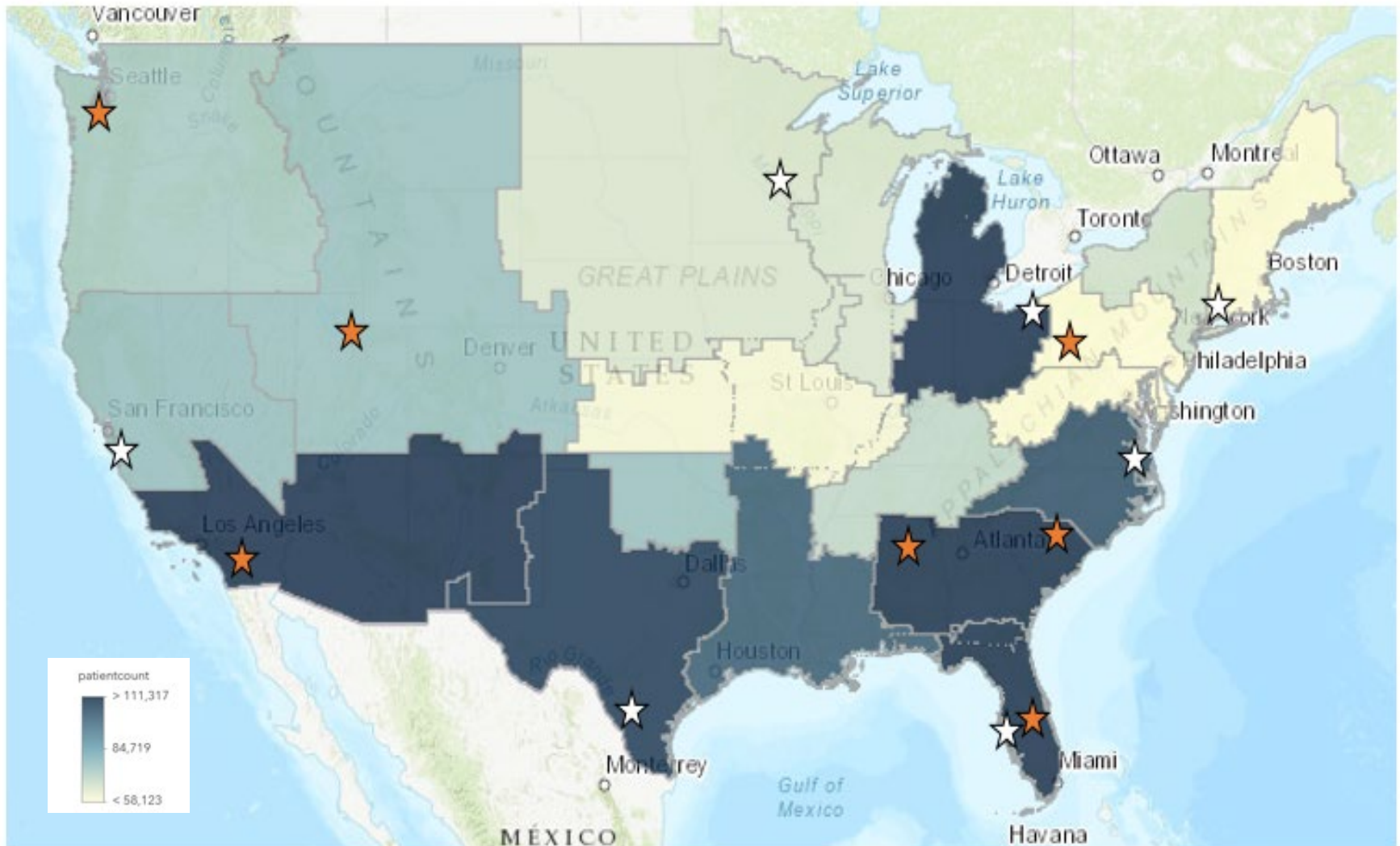


# Headache Care within the Veterans Health Administration





# Headache Care within the Veterans Health Administration





# VHA Headache Centers of Excellence

## MILITARY CONSTRUCTION, VETERANS AFFAIRS, AND RELATED AGENCIES APPROPRIATION BILL, 2018

*Headache Disorders Centers of Excellence.*—The Committee recognizes that over 350,000 veterans sustained traumatic brain injury [TBI] during the Global War on Terror and that chronic migraine/post-traumatic headache is the signature symptom of TBI. The Committee is concerned that veterans with chronic migraine/post-traumatic headache often do not receive specialty care, and that only three VA-affiliated physicians are certified with training in Headache Medicine by the United Council for Neurological Subspecialties. The Committee recognizes the importance of VA centers of excellence and the need for VA Headache Centers of Excellence. The Committee provides \$10,000,000 for the creation of at least five headache centers to be placed at the existing sites for polytrauma and traumatic brain injury [TBI] or at locations that the Secretary sees fit.



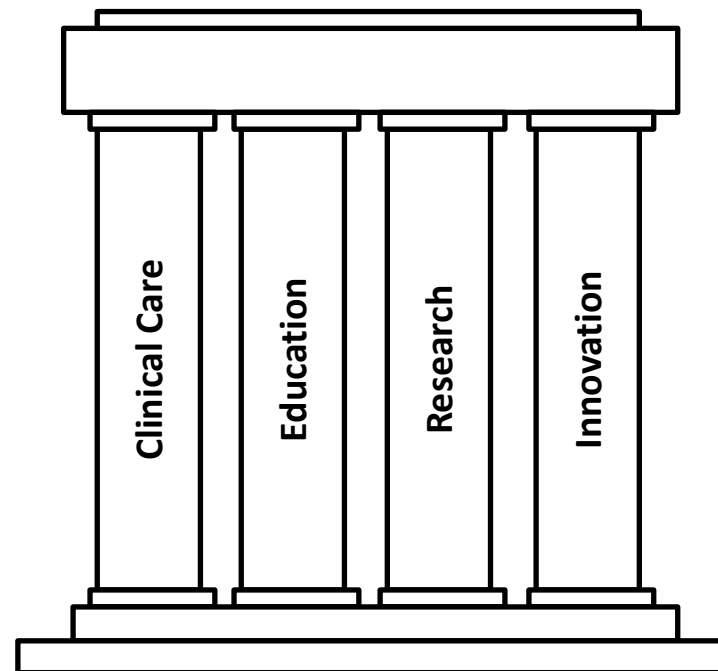
# VHA Headache Centers of Excellence

Department of Veterans Affairs  
Veterans Health Administration  
Washington, DC 20420

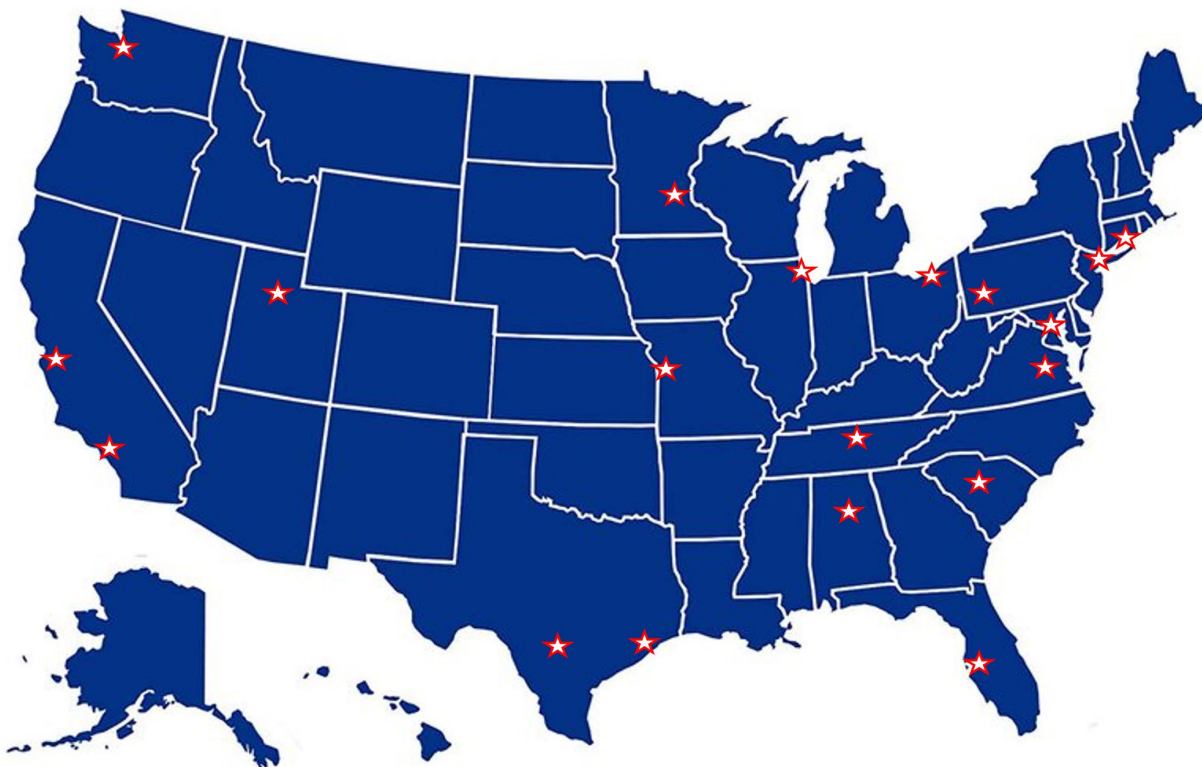
VHA DIRECTIVE 1215  
Transmittal Sheet  
February 14, 2017

## STANDARDS FOR VETERANS HEALTH ADMINISTRATION CENTERS OF EXCELLENCE

- 1. REASON FOR ISSUE:** This Veterans Health Administration (VHA) directive provides policy and direction for establishing standards and guidelines for VHA Centers of Excellence (COE) and ensuring that VHA COE meet those standards.
- 2. SUMMARY OF CONTENT:** This new directive establishes standards for the creation and continuation of VHA COE.
- 3. RELATED ISSUES:** None.
- 4. RESPONSIBLE OFFICE:** The VHA Chief of Staff (10B) is responsible for content of this VHA directive. Questions should be addressed to the Office of the Chief of Staff at 202-461-7016.
- 5. RECERTIFICATION:** This VHA directive is scheduled for recertification on or before the last working day of February 2022. This VHA directive will continue to serve as national VHA policy until it is recertified or rescinded.



# VHA Headache Centers of Excellence



## Nineteen VHA HCoE's

Palo Alto, CA  
Seattle, WA  
Los Angeles, CA  
Salt Lake City, UT  
San Antonio, TX  
Houston, TX  
Kansas City, MO  
Minneapolis, MN  
Chicago, IL  
Birmingham, AL  
Nashville, TN  
Cleveland, OH  
Tampa, FL  
Charleston, SC  
Pittsburgh, PA  
Richmond, VA  
Washington, DC  
New York City, NY  
West Haven, CT



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# HCoE – As a Clinical Partner



# HCOE CLINICAL PROGRAMS

## Growing Faculty at the University Affiliate

Site for learners to care for those who have served our country

- Healthcare system with a unique business model
- Interdisciplinary clinics
- Telehealth

## Fellowship Opportunities

- Training site for University-based fellowship programs
- Advanced fellowships within VHA ([Advanced Fellowships - Office of Academic Affiliations](#))



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# HCoE – As an Educational Partner





# VA/DoD Clinical Practice Guidelines

## THE PRIMARY CARE MANAGEMENT OF HEADACHE



<https://www.healthquality.va.gov/guidelines/pain/headache/>



# VA/DOD HEADACHE CLINICAL PRACTICE GUIDELINES PROVIDER AND PATIENT RESOURCES


## About the CPG

The guideline is formatted as a single clinical algorithm and 27 evidence-based recommendations:

[Questions about the Headache Guideline](#)

## Guideline Links


[Headache Full Guideline \(2020\)](#) 


[Headache Provider Summary \(2020\)](#) 


[Headache Pocket Card \(2020\)](#) 

## Patient Provider Tools

[Headache Patient Summary \(2020\)](#) 

[Headache Diagnosis Coding Tool \(2021\)](#) 

[Headache Patient 7 Day Diary \(2021\)](#) 

[Headache Patient 3 Months Diary \(2021\)](#) 

[Types of Headache Handout \(2021\)](#) 


## Related Guidelines

[Concussion-mTBI](#)

[Posttraumatic Stress Disorder \(PTSD\)](#)

[Opioid Therapy \(OT\) for Chronic Pain](#)

## Webinars

[Introduction to the New VA/DOD CPG: The Primary Care Management of Headache Webinar \(2020\)](#) 

## Headache in Peer Reviewed Publications

[Synopsis of the 2020 Headache CPG \(2022\)](#)

<https://www.healthquality.va.gov/guidelines/pain/headache/>



# HEADACHE CENTERS OF EXCELLENCE LECTURE MONTHLY SERIES

**Access outside of VA:** The Headache Centers of Excellence Monthly Series is available for all Non-VA attendees through VHA TRAIN.

-Create or access an account at  
<https://vha.train.org/vha/welcome>

-Search for the HCoE monthly webinars by utilizing the COURSE CATALOG to search keywords “Headache Evaluation and Management.”

-After locating the course, click the course title link & the **green Register** button.



EMPLOYEE EDUCATION SYSTEM  
**VHA TRAIN**

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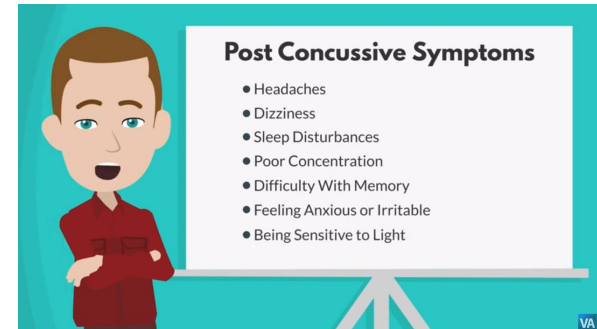


# HEADACHE CENTERS OF EXCELLENCE 'QUICK DRAW VIDEOS'

## Health Psychology for Headache – YouTube



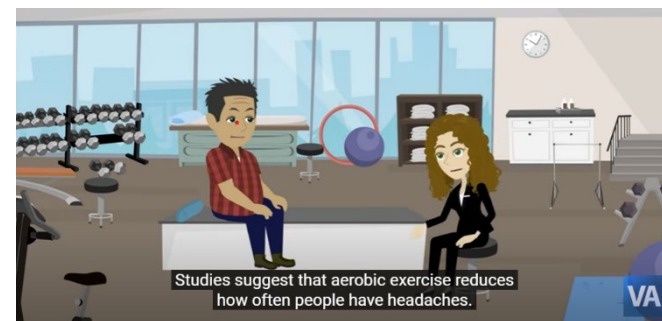
## Post-Traumatic Headache - YouTube



## Nutrition & Headache - YouTube



## Exercise for Headache (Video) - YouTube



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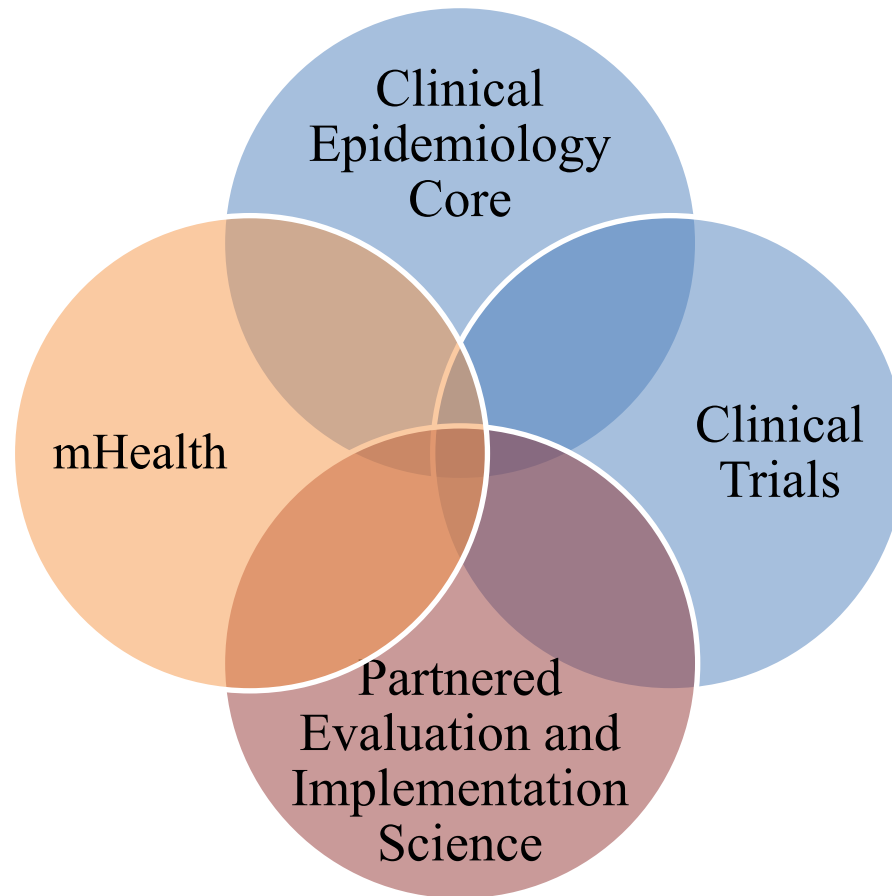
U.S. Department  
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# HCoE – As a Research Partner





# HCoE Research, Evaluation, Education, Engagement Activities Center for Headache (RE<sub>3</sub>ACH)







Jason.Sico@va.gov

 @JSico\_MD



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# Multiple Sclerosis Centers of Excellence

Jodie K. Haselkorn, MD, MPH, Director MSCOE West

Michelle Cameron, Co-Director MSCOE West

Mitchell Wallin, MD, MPH Director MSCoE East



- Who are we?
- Where are we?
- What do we do?
- How can we be helpful to you?
- How to contact us?



# Multiple Sclerosis Centers of Excellence



**VA Portland Health Care System  
Portland, OR**



**VA Puget Sound Health Care System  
Seattle, WA**



**DC VA Medical Center  
Washington, DC**



**VA Maryland Health Care System  
Baltimore, MD**



# MSCoE Staff

## East

Mitchell Wallin, MD, MPH	Director
Angela Young, MBA	Administrative Officer
Kenith Walker	Program Support Assistant
Heidi Maloni, NP, PhD	Assoc. Director Clinical Care
Francesca Bagnato, MD, PhD	Assoc. Director Research

## West

Jodie Haselkorn, MD, MPH	Director
Michelle Cameron, MD, PT, MCR	Co-Director
Rebecca Spain, MD, MSPH	Assoc. Director Clinical Care
Lindsey Wooliscroft, MD	Assoc. Director Research
Steven Leipertz, PhD	Assoc. Director Informatics
Aaron Turner, PhD, ABPP (RP)	Assoc. Co-Director R&D
Vijayshree Yadav, MD, MCR	Assist. Director Clinical Care/ Fellowship Director
Lynda Hillman, DNP, ARNP	National Clinical Nursing Director
Jaimie Henry, MPA	Program Specialist
Lani Pitofsky	Administrative Specialist





## MSCoE Mission

- *Further the understanding of multiple sclerosis (MS) and its impact on Veterans*
- *Ensure access to effective treatments to help manage MS and its associated symptoms*



# VA National Goals

- Undersecretary for Heath's VA-wide anchors
  - Access = Timeliness
  - Outcomes
  - Advocacy
  - Excellence

"If we don't get the first 2 right, the other 2 don't matter."



# Multiple Sclerosis Centers of Excellence

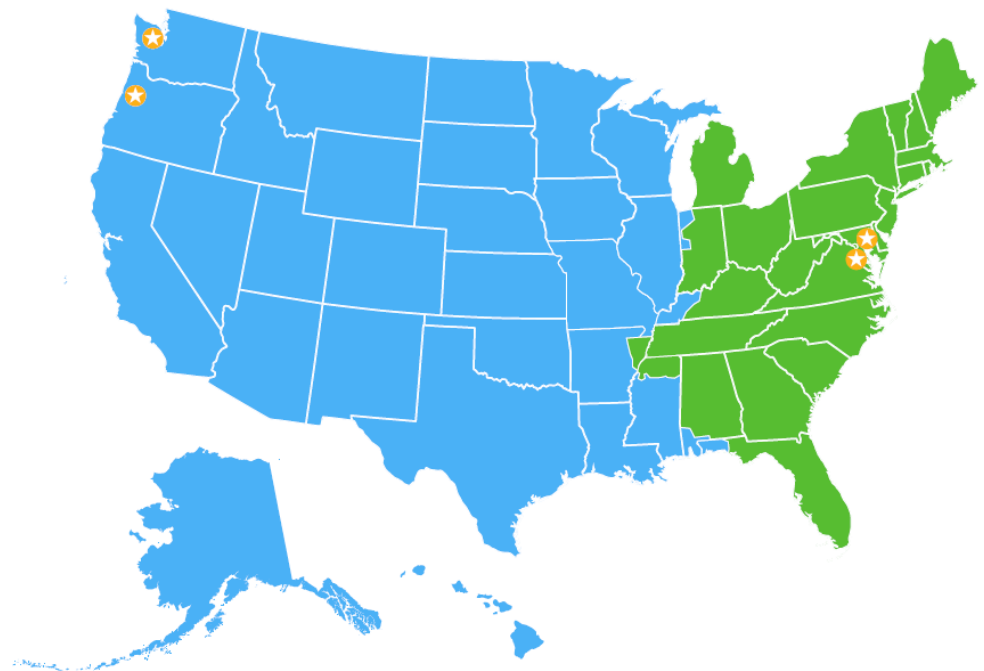
**MSCoE West:** Puget Sound, WA and Portland, OR

**MSCoE East:** Baltimore, MD and Washington, DC

**Veteran Total FY22:** 19,806 Veterans with MS enrolled in VA

**MSCoE Total FTE = 14**

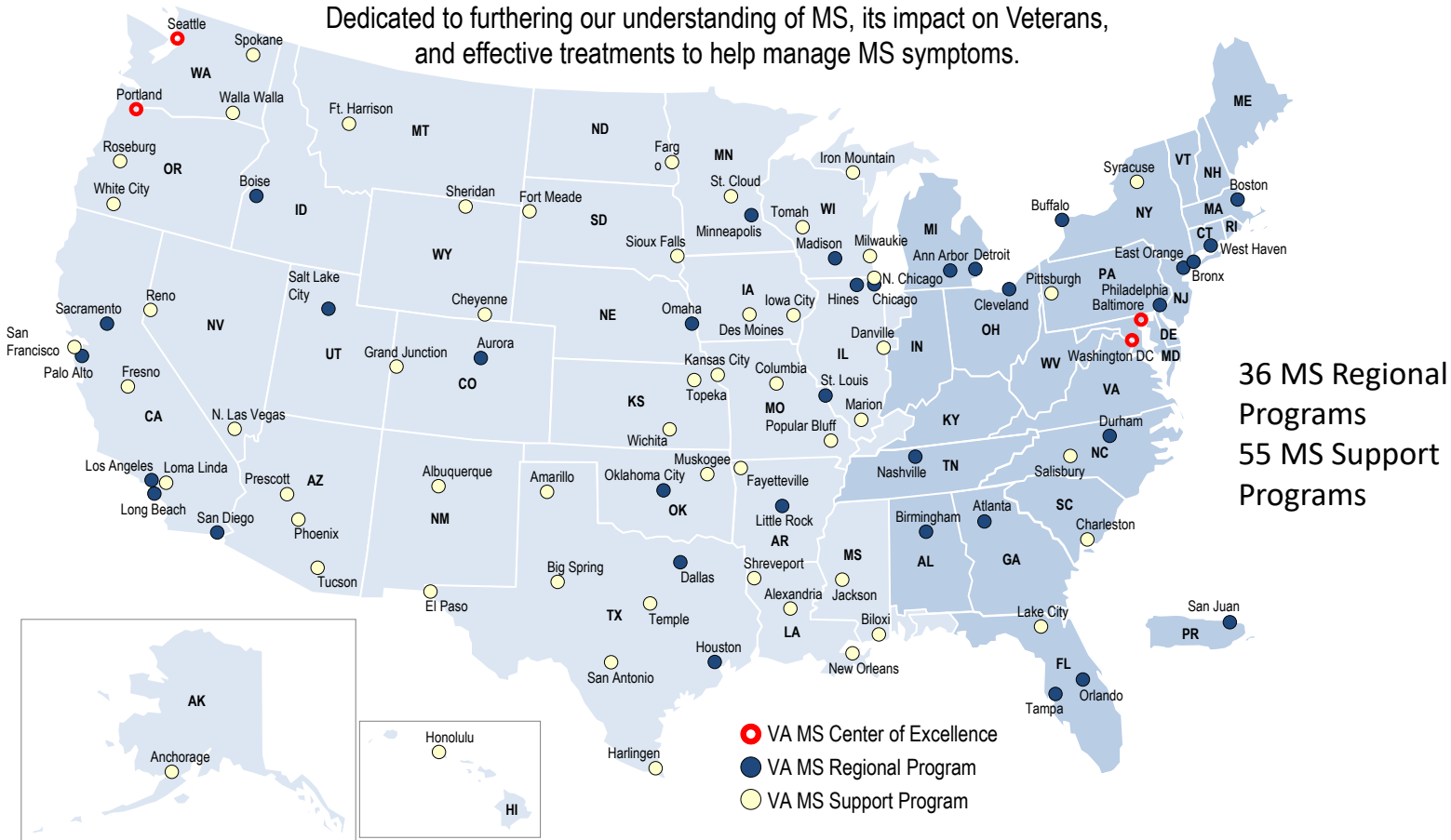
**FY22 MScOE Budget = \$2,560,789**





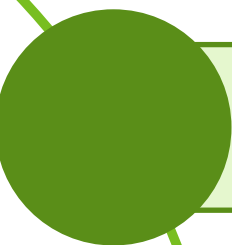
## VA MS Centers of Excellence – West & East

Dedicated to furthering our understanding of MS, its impact on Veterans,  
and effective treatments to help manage MS symptoms.

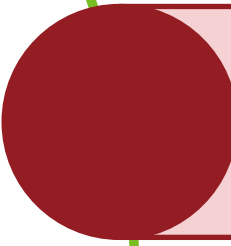




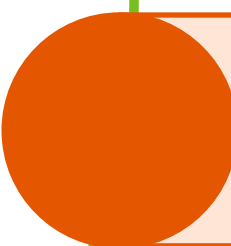
# MSCoE Four Functional Cores



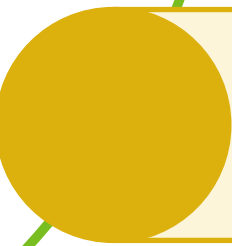
**Clinical Care:** Improve clinical services for Veterans with MS by fostering an integrated network of health services within the entire VHA.



**Research & Development:** Conduct, disseminate and apply research relevant to health needs of Veterans with MS.



**Education & Training:** Provide a national program of MS education for VA health care providers, Veterans and caregivers.



**Informatics:** Employ informatics and telemedicine technology to enhance MS healthcare delivery.





# VA MSCoE Clinical Care

- **Guides and provides content for education** of providers, Veterans and Caregivers
- **Requests and interprets data pulls** and analysis by informatics (e.g. number of Veterans with MS, number of encounters, DMT use, specialty care)
- **Works with Pharmacy Benefits Management (PBM)** on Criteria for Use and Drug Monographs for DMTs
- **Performs e-consults** (via VIRS) for Regional and Support Programs
- Guided by VHA Directive 1011.06: MS System of Care
  - Program Guide: MS System of Care Procedures
  - Consensus Statement: Relapse and Disease Management



# FY21 Demographics of Veterans with MS Diagnosis in the VA

Demographic Variable	Entire VA	Percent of Total
N (number of patients)	19,806	
Male	14,940	73.4%
Female	4,866	24.6%
Average Age (Male)	66	
Average Age (Female)	57	
Caucasian	14,376	77.2%
Black	3,752	20.1%
Asian	64	0.3%
American Indian or Alaskan Native	121	0.6%
Pacific Islanders and Native Hawaiians	135	0.7%
Multiple Ethnicities	180	1.0%
Rural	6,465	32.6%
Operation Enduring Freedom/ Operation Iraqi Freedom (OEF/OIF)	1,429	7.2%

*Data source: CDW tables describing patient by station and related tables.*



Medication Name	FY19	FY20	FY21	FY22 (9/26/22)
Teriflunomide	468	562	611	620
Glatiramer Acetate <b>GENERIC</b>	1,914	1,707	1,561	1,362
Interferon Beta-1a	1,131	979	836	708
Interferon Beta-1b	270	226	195	162
Peginterferon Beta-1a	43	41		
Dimethyl Fumarate <b>GENERIC</b>	2,084	1,973	1,967	1,832
Diroximel fumarate		3	26	35
Fingolimod ( <b>GENERIC</b> )	477	453	419	396
Ozanimod		2	9	19
Ponesimod			1	1
Siponimod	2	22	37	59
Cladribine	14	9	15	18
Ofatumumab			31	74
<b>Unique prescriptions for oral &amp; injectable DMT</b>	<b>6,389</b>	<b>5,968</b>	<b>5,662</b>	<b>5,194</b>
Alemtuzumab	27	51		
Natalizumab ( <b>BIOSIMILAR</b> )	335	270	217	190
Ocrelizumab	651	1,098	1,279	1,489
Rituximab <b>BIOSIMILAR</b>	407	525	512	514
<b>Unique prescriptions for Infusion DMT</b>	<b>1,420</b>	<b>1,944</b>	<b>2,008</b>	<b>2,193</b>
<b>Total Unique prescriptions for DMT</b>	<b>7,809</b>	<b>7,912</b>	<b>7,670</b>	<b>7,387</b>

## DMT Utilization FY22 through September

Veterans on DMT: 7387/18,763= ~39%

Top DMT: B cell therapy: 2,003  
 Fumarates : 1,867  
 Glatiramer: 1,362

On high efficacy DMT: 2,267 (31%)



Opportunity for cost savings

1. Generics
2. Right drug/Right time



# Quality Indicators:

## VA Central Office directed MSCoE Initiative

FY22: Quality Insights audited a random sample of charts nationally. 1006 charts were included for QI MS documentation & coding of 3 measures

1. >90% : MS diagnosis
2. 49% : MS subtype
3. 71% : Discussion of DMT

FY 22: Partnered with **EDUCATION**

- Presentations at regional and national meetings (CMSC, PVA)
- E-letters, website

FY23 goal: Increase adoption by 25%

- **EDUCATION**
- Reassessment FY23Q2-3



The healthcare improvement experts.



# Establishing MScOE Interfacility Consults

VA health care providers of Veterans with MS, who have clinical questions for an MS expert, may request a remote consult from the Multiple Sclerosis Centers of Excellence (MScOE). When appropriate, requesting providers from MS Support Programs will be connected to their nearest MS Regional Program to facilitate regional communication.

1. Use an MS interfacility consult system if already available at your VA facility.
2. If not, send an encrypted Outlook email to [lani.pitofsky@va.gov](mailto:lani.pitofsky@va.gov) with the consult question and minimum identifiers necessary to identify the Veteran.
3. Your request will be sent to the appropriate MScOE clinical staff.
4. As possible, the MScOE clinical staff will review the medical chart remotely. MScOE staff will arrange a telephone call with the requesting VA health care provider as necessary.
5. The consult response will be sent via encrypted Outlook email to the requesting VA health care provider.
6. The requesting VA health care provider must copy and paste the email consult response into a telephone encounter in the Veteran's electronic medical record. This is necessary to ensure proper documentation and communication with the other providers for the Veteran.





# 50 Research Publications FY22

Cohen J, **Cameron MH**, Goldman MD, Goodman AD, Miller AE, Rollins A, Llorens L, Patni R, Elfon R, Johnson R. A phase 3, double-blind, placebo-controlled efficacy and safety study of ADS-5102 (amantadine) extended-release capsules in people with multiple sclerosis and walking impairment. *Multiple Sclerosis Journal*. 2022; 28(5):817-830.

O'Neal MA, Zecavati N, Yu M, **Spain R**, Friedenber SM, El Husseni N, Torres-Russotto DR, Feliciano B, Spears R, and Baca C. Effects of fragmentation and the case for greater cohesion in neurologic care delivery. *Neurology* 2022;98(4):146-153.

**Vandenbark, A. A.**, Meza-Romero, R., Wiedrick, J., Gerstner, G., Seifert, H., Kent, G., ... & Offner, H. (2022). "Near Cure" treatment of severe acute EAE in MIF-1-deficient female and male mice with a bifunctional MHCII-derived molecular construct. *Cellular Immunology*, 378, 104561.

Clarke MA, Archer D, Yoon K, Oguz I, Smith SA, Xu J, Cutter G, **Bagnato F**. White matter tracts that overlap with the thalamus and the putamen are protected against multiple sclerosis pathology. *Mult Scler Relat Disord*. 2022 Jan;57:103430. doi: 10.1016/j.msard.2021.103430. Epub 2021 Dec 3. PMID: 34922252.

Bebo B, Cintina I, LaRocca N, Ritter L, Talente B, Hartung D, Ngorsuraches S, **Wallin M**, Yang G. The Economic Burden of Multiple Sclerosis in the United States: Estimate of Direct and Indirect Costs. *Neurology*. 2022 May 3;98(18):e1810-e1817

Mizell R, Chen H, Lambe J, Saidha S, **Harrison DM**. Association of retinal atrophy with cortical lesions and leptomeningeal enhancement in multiple sclerosis on 7T MRI. *Mult Scler*. 2022 Mar;28(3):393-405.



# Conference Presentations

Wagner J, **Cameron M**, Bethoux F, Field-Fote E, Lenderking W, Zaiser E, Cutts K, Steinerman J. (2021, October). Spasticity experience in adults with multiple sclerosis: An integrated conceptual model. Presented platform at Consortium of MS Centers annual meeting, Orlando, FL.

**Knowles, L. M., Hugos, C. L., Cameron, M. H., Haselkorn, J. K., Bourdette, D. N. & Turner, A. P.** (2022, February). Treatment improvements in depressive symptoms are associated with sustained improvements in fatigue impact in adults with multiple sclerosis. Poster presentation at the Annual Rehabilitation Psychology Conference, Online due to COVID-19. \*\* Recipient of Trainee Poster Award

Clarke M, Cheek R, Clarke R, McKnight C, Derwenskus J, Eaton J, Fan R, Ye F, Rogers B, O'Grady K, Smith S, **Bagnato F**. Paramagnetic rims in treatment naïve persons at the time of multiple sclerosis diagnosis. American Academy of Neurology 73rd Annual Meeting, April 2022, Seattle, WA.

**Harel T, Wallin M.** Living with MS in the COVID-19 Era: Review and Case Discussion. PVA Dallas, TX.

Sowa G, Zamecnik C, Abdelhak A, Hauser S, **Wallin M**, Dandekar R, Green A, Wilson M. Disease-specific autoantibody biomarkers of multiple sclerosis are present years before disease onset. ECTRIMS 2022, October 2022, Amsterdam, NL.



# FY22 Educational Programs & Products

Title	Providers	Veterans	Caregivers
4 Veteran E-letters (8 articles, 4 Veteran stories)		x	x
12 Veteran Podcasts		x	
1 Veteran Collaborative Webinar (PVA, NMSS)		x	
1 Veteran Collaborative Virtual Conference (Can Do MS)		x	x
12 Provider E-letters (12 spotlight articles)	x		
17 CME Webinars with NMSS or VA ECHO	x		
1 Regional CME Virtual Conference	x		
8 OAA & NMSS Physician Fellows (2 graduated '22/4 continuing/2 new '22)	x		
1 NMSS Psychology Fellow (1 graduated '22)			
13 CMSC Annual Meeting Presentations	x		
7 PVA Summit Presentations	x		
MS Awareness Month Promotion	x	x	x
Website	x	x	x

See [www.va.gov/ms](http://www.va.gov/ms)



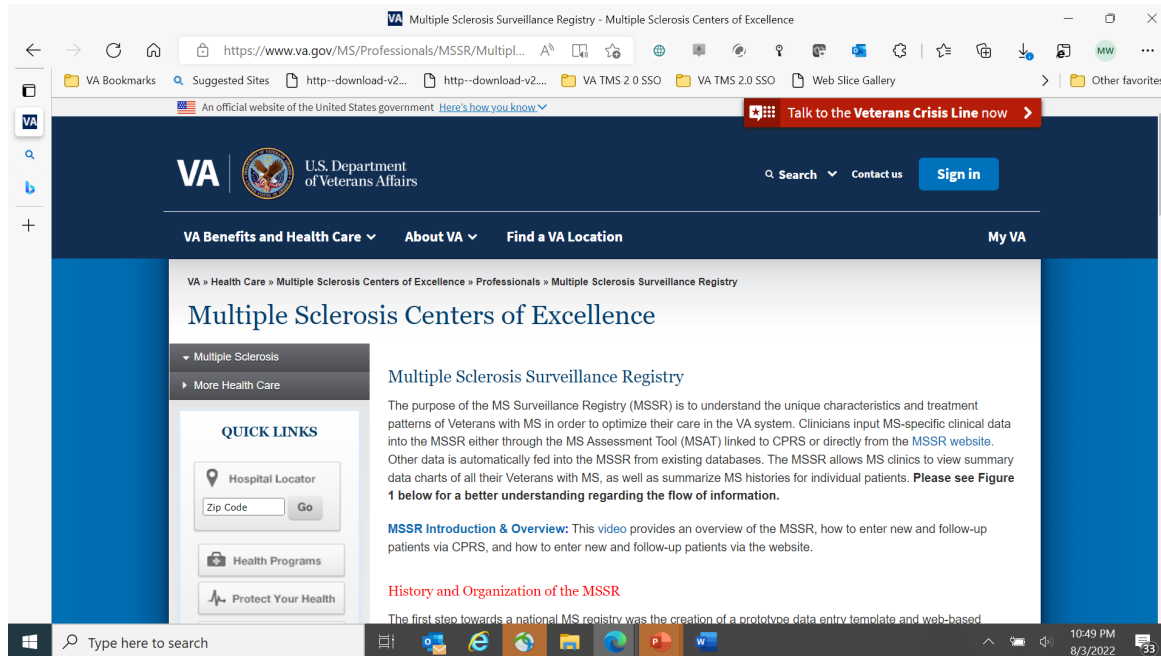
# Informatics & Telemedicine

- MScOE **Data Repository** (CDW) contains data on algorithm-defined MS cases and controls from 1998-present
- The MS **Surveillance Registry** is a provider-initiated registry that stores core demographic and clinical data related to MS and links these data to specific CDW fields
- **Neurology pyramid cube** provides real-time and historical data about Veterans receiving Neurology care for epilepsy, MS, and Parkinson's disease/movement disorders in the national VA system
- MS **Stop Code** (344) collects workload data that supports the continuity of Veteran care, resource allocation, and performance measurement
- MS **COVID Registry** estimates the COVID-19 incidence and explores its severity in Veterans with MS compared with the overall experience in VHA

Together, these data structures provide information regarding MS subtype, disability, utilization of DMTs, clinical utilization, administrative information, and data for research.



# MSSR Access and Tutorial



- Initial access to MSSR:
  - [william.culpepper@va.gov](mailto:william.culpepper@va.gov)
  - [mitchell.wallin@va.gov](mailto:mitchell.wallin@va.gov)
- Overview of the MSSR (video) on MSCoE website
- MS-COVID Registry linkage

[www.va.gov/ms](http://www.va.gov/ms)





- VHA Support Service Center (VSSC)  
<https://vssc.med.va.gov/VSSCMainApp/Defaulttrsg.aspx>
- Target Populations to Clinical Cohorts
- Multiple Sclerosis Definite

Name	SSN	OEOIF	Gender	DoB	Race	Service Connection
<u>Boop, Betty</u>	211-xx-2345	N	F	01/21/2001	WHITE	90%
<u>Rizzo, Ratso</u>	145-xx-4321	N	M	01/21/1942	WHITE	100%

Fiscal Year: FY21 VISN: All Facility: (V02) (630) New York Harbor HCS

Neuro Cohort	Uniques	Encounters	Rx Fills
<input checked="" type="checkbox"/> Multiple Sclerosis	127	8,912	847
Definite Multiple Sclerosis	124	8,553	821
Probable Multiple Sclerosis	3	359	26
Total	127	8,912	847

DEMOGRAPHICS					
SSN: 211-xx-2345 Age: 74 GENDER: M Date of Birth: 6/28/1847 Date of Death: Race: WHITE Ethnicity: Not Hispanic or Latino Marital Status: DIVORCED NOK: NOK Phone:	Address: Boop, Dog Lane, NYC Telephone: Rurality: RURAL Homeless: NO Housing Status: Homeless	Period Of Service: Vietnam Era Eligibility: SERVICE CONNECTED 50% to 100% SC%: 90% Priority: 1 Aid & Attendance: OEF-OIF-OND:	Last PC Visit: 12/2/2023 10:30:00 AM Clinic Name: HAR PC TM 2 (564GA)  Secure Msg User: NO Disruptive Behavior: NO High Risk Suicide: NO		
TEAM ASSIGNMENTS					
Team Type	Location	Team	Status	Provider Role	Provider Name
PRIMARY CARE	(V16) (564GA) Harrison, AR	VAR ZZZ	A	PRIMARY CARE PROVIDER	<u>XHEEZY, ELIZABETH O</u>
MENTAL HEALTH	(V22) (678) Tucson, AZ	BIG DOG	N/A	(MHTC) REGISTERED NURSE	<u>BILEN, CAROL A</u>



# MS and COVID 19 Demographic, Clinical Characteristics and Severe Clinical Outcomes

Sex Frequency (%)	Overall (N 282)	Not Hospitalized (n = 192)	Hospitalization (n = 90)	ICU and/or required ventilator support (n = 32)	Death (n = 12)
Female	71 (25%)	49 (26%)	22 (24%)	9 (28%)	1 (9%)
	Overall (N 282)	Not Hospitalized (n = 192)	Hospitalization (n = 90)	ICU and/or required ventilator support (n = 32)	Death (n = 12)
Age, Mean (SD), y	58.72 (13.41)	56.23 (13.26)	64.02 (12.18)	64.31 (10.97)	74.17(7.42)

Race	Overall (N 282)	Not Hospitalized (n = 192)	Hospitalization (n = 90)	ICU and/or required ventilator support (n = 32)	Death (n = 12)
White	198	130	68	25	11
Black	77	55	22	7	1
Asian	3	3	0	0	0
Native American	2	2	0	0	0
Other	2	2	0	0	0

US Census Region	Overall (N 282)	Not Hospitalized (n = 192)	Hospitalization (n = 90)	ICU and/or required ventilator support (n = 32)	Death (n = 12)
Continental	44`	24	20	7	4
Midwest	65	43	22	9	3
North Atlantic	61	48	13	6	3
Pacific	61	43	18	5	1
Southeast	51	34	17	5	1



# MS & Community Care Encounters FY21 & FY22

Location	FY21: # PwMS* Receiving CC ** Q1-Q4	FY21: # Enc <sup>§</sup> from PwMS Receiving CC	FY22: # PwMS Receiving CC Q1-Q3	FY22: # Enc. from PwMS Receiving CC
<b>TOTAL</b>	<b>2,993</b>	<b>149,946</b>	<b>2,583</b>	<b>44,320</b>
VISN 1	117	4,682	125	1,977
VISN 2	90	5,169	49	1,085
VISN 4	78	3,183	10	32
VISN 5	63	3,165	75	578
VISN 6	160	5,710	49	941
VISN 7	216	14,056	144	2,887
VISN 8	282	21,315	170	2,031
VISN 9	121	5,258	229	5,984
VISN 10	155	7,404	125	1,926
VISN 12	141	7,914	106	2,562
VISN 15	151	6,713	52	84
VISN 16	177	8,042	99	3,006
VISN 17	222	9,149	138	3,754
VISN 19	229	10,120	195	2,664
VISN 20	236	13,099	185	2,384
VISN 21	185	7,517	75	180
VISN 22	243	10,154	157	3,429
VISN 23	170	7,287	187	3,872

\*PwMS: patients with Multiple Sclerosis, \*\*CC: Office of Community Care Consults, §Enc.: Encounter



# Contacts

- MSAT entry questions/feedback: MSCoE-West: Dr. Rebecca Spain ([spainr@ohsu.edu](mailto:spainr@ohsu.edu), [Rebecca.spain@va.gov](mailto:Rebecca.spain@va.gov)) and MSCoE-East: Dr. Mitch Wallin ([mitchell.wallin@va.gov](mailto:mitchell.wallin@va.gov))
- MS-COVID-19 Data ([Steven.Leipertz@va.gov](mailto:Steven.Leipertz@va.gov))
- MSSR access requests: MSSR Business Owners
  - Dr. William Culpepper ([william.culpepper@va.gov](mailto:william.culpepper@va.gov)) or
  - Dr. Mitch Wallin ([mitchell.wallin@va.gov](mailto:mitchell.wallin@va.gov))

**VA**



U.S. Department  
of Veterans Affairs

# PADRECCS- Who are we & What do we do?

**Indu Subramanian MD**  
**Clinical Professor, UCLA Dept of Neurology**  
**SW PADRECC Director, GLA VA**





# PRE-MEETING SURVEY

- Lack of knowledge of how/when to refer and who/where we are
- We already have movement specialists- why do we need to interact with PADRECC?
- Helpful: clinical care help, handouts, websites, templates,
- Suggestions for Improvement: more education for staff, patients; Virtual annual patient symposium



# PARKINSON DISEASE

- Common- 1-2 in 100 people in an aging population
- Parkinson Pandemic- doubled in last 40 yrs, **doubling again in 20 yrs**
- Can affect all age groups form 20's to 90's
- Most common in 60 year old, men more than women
- May have genetic and environment contribution- **service connected with Agent Orange and Camp Lejeune**
- **Prisoner of War, Traumatic Brain Injury, PTSD** inc risk





# NON- MOTOR SYMPTOMS/MENTAL HEALTH

- Thinking- memory, daily life activities from cognitive issues
- Depression
- Anxiety
- Apathy-lack of motivation
- Impulse Control Ds
- Insomnia
- Psychosis





# MENTAL HEALTH GAPS PAPER 2021



Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

## Parkinsonism and Related Disorders

journal homepage: [www.elsevier.com/locate/parkreldis](https://www.elsevier.com/locate/parkreldis)

Point of view

**Mind the gap: Inequalities in mental health care and lack of social support in Parkinson disease**

Indu Subramanian<sup>a,b,\*</sup>, Jared T. Hinkle<sup>c</sup>, K. Ray Chaudhuri<sup>d,e</sup>, Zoltan Mari<sup>f</sup>, Hubert Fernandez<sup>g</sup>, Gregory M. Pontone<sup>h</sup>

<sup>a</sup> Dept of Neurology, David Geffen School of Medicine, UCLA, Los Angeles, CA, USA

<sup>b</sup> Southwest Parkinson's Disease Research, Education and Clinical Centers, Veterans Administration, Los Angeles, CA, USA

<sup>c</sup> Medical Scientist Training Program, Johns Hopkins School of Medicine, Baltimore, MD, USA

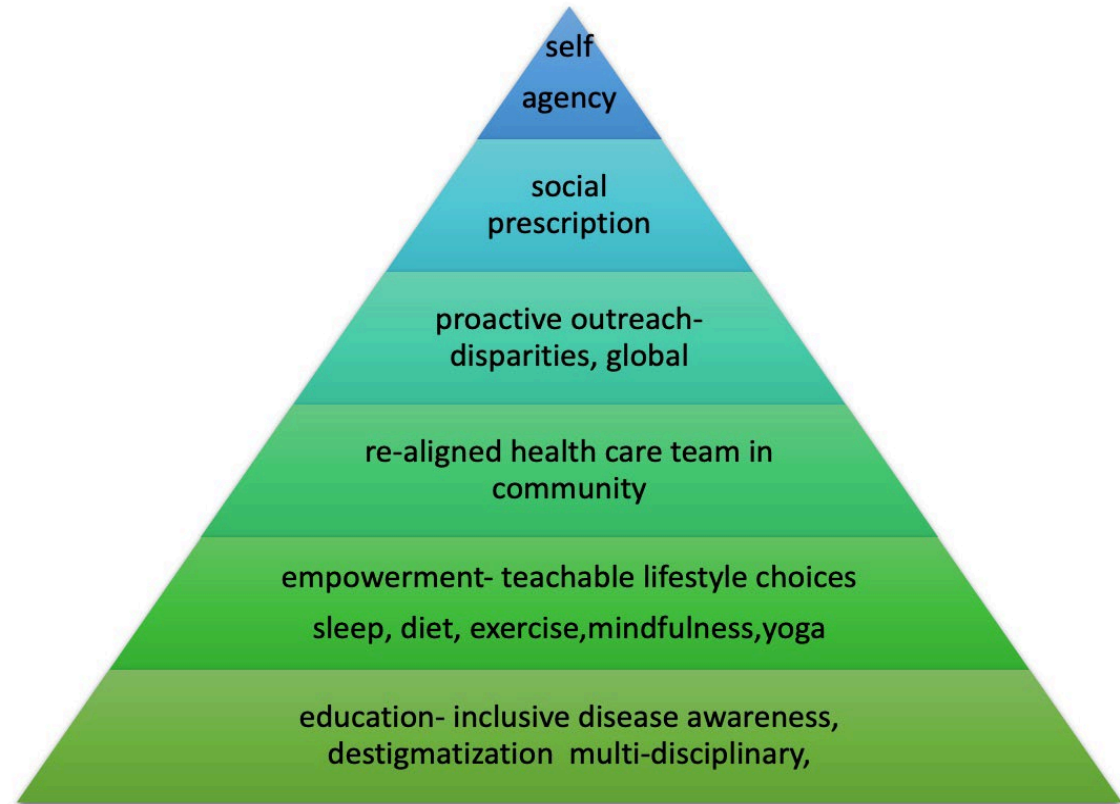
<sup>d</sup> Department of Neurosciences, Institute of Psychiatry, King's College London, London, UK

<sup>e</sup> Psychology & Neuroscience and Parkinson's Foundation Centre of Excellence, King's College Hospital, London, UK

<sup>f</sup> Parkinson's and Movement Disorders Program, Cleveland Clinic Lou Ruvo Center for Brain Health, Las Vegas, NV, USA

<sup>g</sup> Center for Neurological Restoration, Neurological Institute, Cleveland Clinic, Cleveland, OH, USA

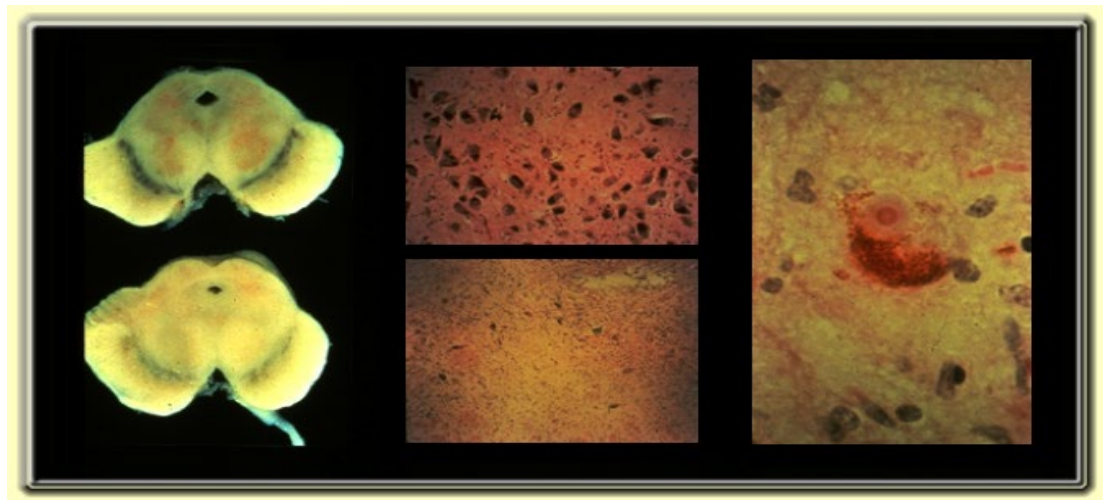
<sup>h</sup> Dept. of Neurology & Dept. of Psychiatry and Behavioral Sciences, Johns Hopkins School of Medicine, Baltimore, MD, USA





# WHY SEE A SPECIALIST?

- Diagnosis can be tricky
- It is clinical- no blood test or scan that diagnoses
- Accurate diagnosis if examined in hands of specialist







## TO ALL STAGES OF DISEASE

- Safety: Falls with broken hips
- Hallucinations: #1 reason for nursing home admission
- Swallow dysfunction: pneumonia
- **Service connection now includes Parkinson-plus disorders**
- Coordination of advanced care planning, palliative care and hospice care



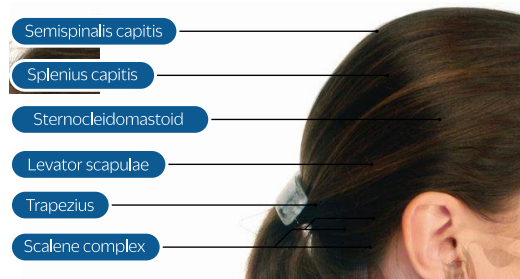
# PADRECCS

- Special formulary for medications/pill boxes- Rytary, Duopa, Pimavanserin, Inbrija, Gocovri,
- Physical, Occupational, Speech therapy,
- Durable Medical equipment- walkers
- Deep brain stimulation,
- Botulinum toxin,
- **Psychiatry**
- **Psychology**
- Integrative Medicine/Whole Health



# CLINIC: SUBSPECIALTY PROCEDURES

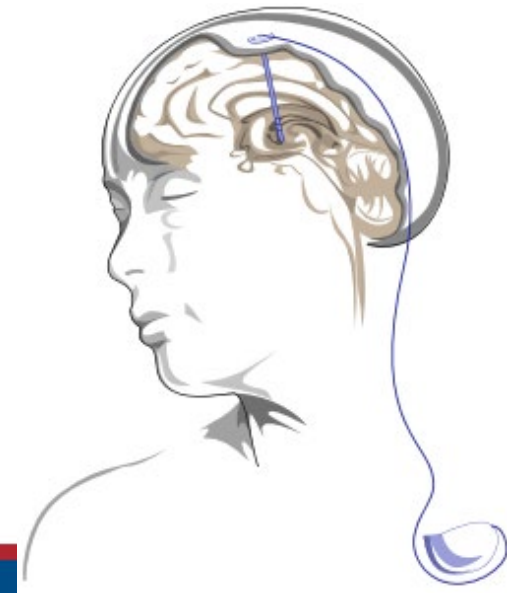
- **Botulinum toxin injections**
  - 1st line treatment for focal dystonia – blepharospasm, cervical dystonia, etc
  - Sialorrhea, a very common symptom in Parkinson's disease
  - Utilizing EMG guidance
  - Sharing expertise
    - Training fellows, educating pharmacy residents, neurology residents,
    - EES (Movement Disorders series)
    - Collaborate with PM&R





# CLINIC: SUBSPECIALTY PROCEDURES

- Deep Brain Stimulation
  - Referrals from across the US
  - Patients with essential tremor, Parkinson's disease, dystonia
    - Complex patients with disabling movement disorder symptoms that are refractory to medical management
  - Coordinate care with referring neurologist, neuropsychiatry, and neurosurgery
  - Perform intraoperative testing, initial & follow-up DBS programming
  - Manage and troubleshoot complications





# PADRECC WEBSITE

For Professionals

Consortium

PADRECCs

Contact Us

More Health Care

QUICK LINKS

Hospital Locator

Zip Code

Health Programs

Protect Your Health

A-Z Health Topics

Veterans Crisis Line

1-800-273-8255 PRESS 1

My healthvet

My Health, My Care. 24/7 Access to VA

eBenefits

My Gateway to Benefits Information

Home

Getting Care

For Veterans and Families

For Professionals

Contact Us

Appointments

Veterans with suspected movement disorders are typically referred to a PADRECC or a Consortium Center by a consult from their VA primary care provider or general neurologist. Please, see our [Getting Care](#) page for more information.

Parkinson's Disease and Military Exposures

Veterans diagnosed with Parkinson's disease who served in-country or on the inland waterways of Vietnam between January 9, 1962 and May 7, 1975 are presumed exposed to Agent Orange or other herbicides and are eligible for presumptive service-connection. To learn more, go to the [Agent Orange Parkinson's Disease website](#) or call 1-800-749-8387, the Special Health Issues Toll-Free Helpline.

VA intention:  
Camp Lejeune exposures and Parkinson's disease

[Click here for more information on Military Exposures](#)

Support Groups

Nationwide via telephone

**Parkinson's Telephone Education/Support Conference** 2016 schedule  
Meetings: 2nd Tuesday each Month; 10-11am PT, 11am-12noon MT, 12-1pm CT, 1-2pm ET

Location: call 1-800-767-1750 enter code

**Educational Resources**

**My Parkinson's Story**

A series of short videos prepared by the VA PADRECCs addressing various aspects of Parkinson's Disease.

**My Parkinson's Story on YouTube:** [My Parkinson's Story Videos](#)

Notice: When you click on a link provided below, you will be leaving the Department of Veterans Affairs Website. The VA does not endorse and is not responsible for the content of any of the links listed below. Please refer to the VA's official disclaimer at: <http://www.va.gov/disclaim.htm>

Deep Brain Stimulation, Depression, Early Parkinson's, Falls, Memory, Sleep, Environmental Exposure, Genetics, Advanced Parkinson's Disease, Impulsive Behaviors, The Caregiver, Driving, Exercise, Hospitalization, Medications, Speech and Swallowing, Atypical Parkinsonism, Dyskinesias, Pain, Visual Disturbances





- **PADRECC MISSION**

- To provide comprehensive, state-of-the-art **care** to assure the highest quality of life for Veterans afflicted with **Parkinson's disease** and related movement disorders; to advance **investigation** into the cause, treatment and cure for those disorders; and to enhance understanding of those disorders by developing **education** programs for practitioners, patients, and caregivers.



## • History

- The Parkinson's Disease Research, Education and Clinical Centers (PADRECCs) were established in 2001 and legally codified in 2006 by Title 38 United States Code (U.S.C.) 501, 7301(b), § 7329.
- **RFP expectations when formed**
  - Establish comprehensive, **multi-disciplinary clinics**, for the medical and surgical management of Parkinson's disease and related disorders
  - Participation in CSP #468
  - Develop investigator initiated research projects regarding PD and related disorders with ORD pilot project funding (funding never materialized)
  - Establish VA-based Clinical Movement Disorder Fellowships
  - Develop a national PD database

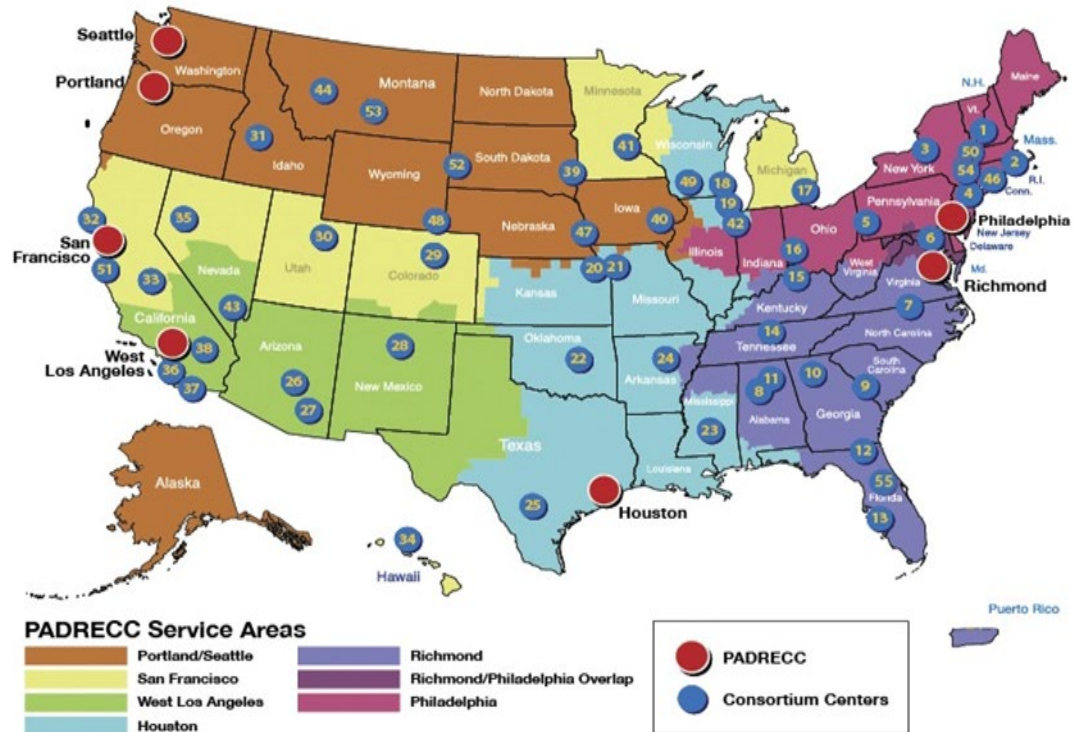


# **PARKINSON DISEASE RESEARCH, EDUCATION & CLINICAL CENTERS (PADRECCs)**

Philadelphia, PA	West Los Angeles, CA
Richmond, VA	San Francisco, CA
Houston, TX	Portland, OR/Seattle, WA

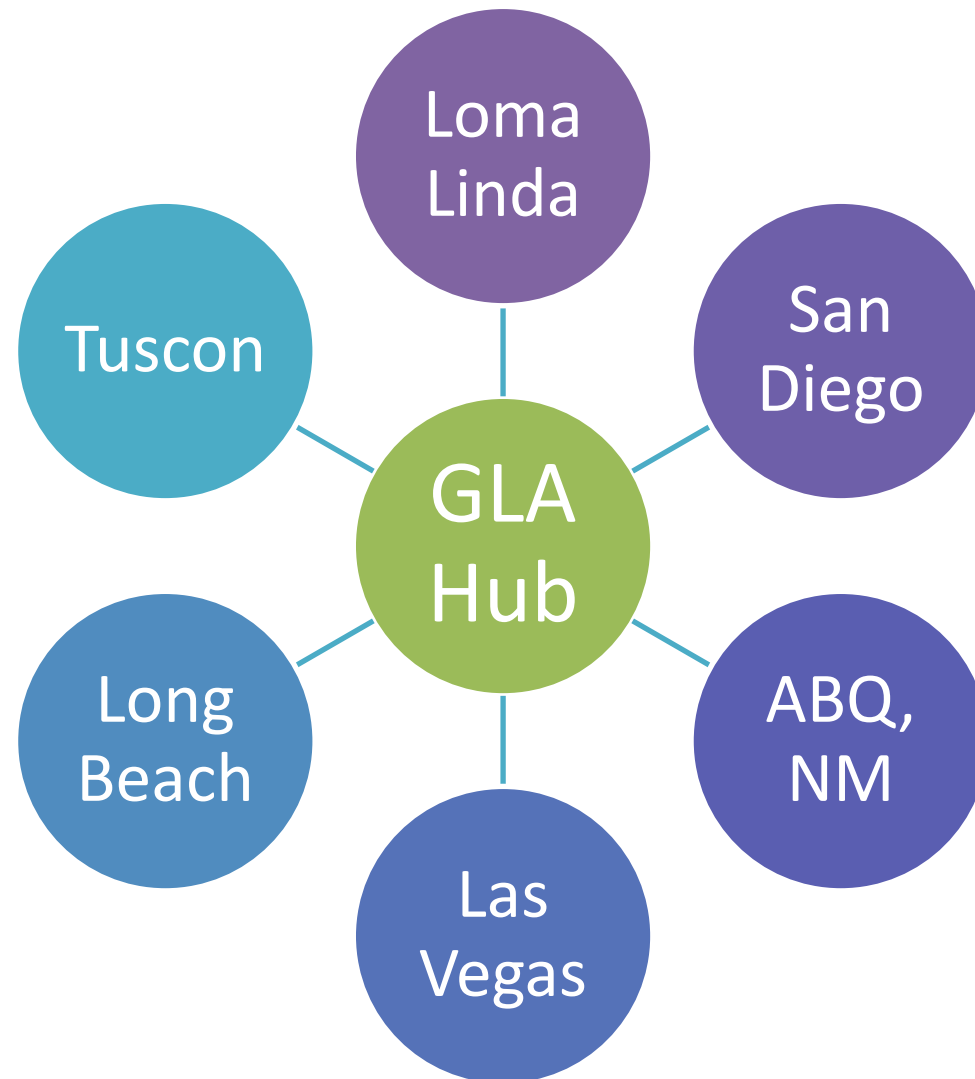


# PADRECCS & satellites- catchment area





# SW PADRECC-HUB AND SPOKE MODEL







parkinsons.va.gov

Home Getting Care For Veterans and Families For Professionals Contact Us

**PADRECC and Consortium Centers**

**The PADRECC and Consortium Center Network**  
is a nationwide hub and spoke model of care across the VA Healthcare System for veterans diagnosed with Parkinson's disease and other movement disorders.

**PADRECCs:**

- Designated VA Centers of Excellence
- Receive referrals across the VA Healthcare System
- Each serve a large geographic region

**Consortium Centers:**

- Regional specialty clinics for veterans unable to travel to a PADRECC
- Located in each of the 21 VISNs

**Getting Care — How to Make an Appointment**

1. Veteran must be enrolled in the VA healthcare system to receive care. Access and manage your VA benefits & health care at <https://www.va.gov>
2. Choose a PADRECC or Consortium Center to consult.
3. VA primary care provider or neurologist makes a referral to the PADRECC or Consortium Center using an inter-facility consult (IFC).
4. Follow up with the PADRECC or Consortium Center to schedule an appointment. (Please allow at least 72 hours after the IFC has been sent.)

**Call the PADRECC/Consortium Hotline at 1-800-949-1001 x205769 if you need assistance with this process.**

**PADRECC and Consortium Centers**  
To locate a PADRECC or Consortium Center view the map below and click on the pin in the area you are looking for. You will see the name, location and contact information for each PADRECC (red pin) or Consortium Center (blue pin) to your left. You may need to zoom in or out on the map to separate the pins.


**Learn what the PACT Act means for your VA benefits >>**

Health Programs  
Protect Your Health  
A-Z Health Topics

**Veterans Crisis Line**  
DIAL 988 then **PRESS 1**

**My healthvet**  
My Health, My Care: 24/7 Access to VA

**VA Health Care**  
Apply Now





Contact Us

More Health Care

QUICK LINKS

Hospital Locator

Health Programs

Protect Your Health

A-Z Health Topics

Veterans Crisis Line

DIAL 988 then PRESS 1

My healthvet

My Health, My Care: 24/7 Access to VA

Movement Disorder Series

The Movement Disorder Series-Webinars are designed to provide VHA healthcare professionals with current practice standards and emerging trends in the treatment of Parkinson's disease and other movement disorders. Continuing education credits are provided for live webinars. Click here for the [Movement Disorder series](#) page.

Free Patient Education Material

PADRECC clinicians and Consortium members can order bulk supply of FREE patient education resources from the PD non-profit community.

The Parkinson's Foundation (PF)

To order education resources directly from PF check out the [Ordering FREE Resources Instruction Sheet](#).

American Parkinson's Disease Foundation (APDA)

To order APDA education resources complete the [Resource Request Form](#) and email to the Consortium Coordinating Center.

Professional Education

Notice: When you click on a link provided below, you may be leaving the Department of Veterans Affairs Website. The VA does not endorse and is not responsible for the content of any of the links listed below. Please refer to the VA's official disclaimer at: <http://www.va.gov/disclaim.htm>

Parkinson's Foundation Digital Resources for VA Health Professionals Treating Veterans with Parkinson's Disease

PF offers a wide range of online training and education resources

Parkinson's Foundation Virtual Team Training Program: teaches medical professionals from

Referrals

VA primary care providers or neurologists can refer veterans with movement disorder related issues to a PADRECC or Consortium Center using an inter-facility consult (IFC).  
[Go to Getting Care](#)

Clinical Tools

Parkinson's Disease Quick Reference Guide for Initiating Therapy-Pocket Card

VHA Directive 1420 Parkinson's System of Care

VHA Directive 1420 Parkinson's System of Care

Parkinson's Disease Program and Clinical Guide

Clinical Indications for the Use of Dopaminergic Functional Imaging

Hoehn & Yahr Staging

Schwab & England

United Parkinson's Disease Rating Scale (UPDRS)

Patient Motor Diary

DBS in PD Fact Sheet

Montreal Cognitive Assessment (MoCA) -

Learn what the PACT Act means for your VA benefits >>

DATE

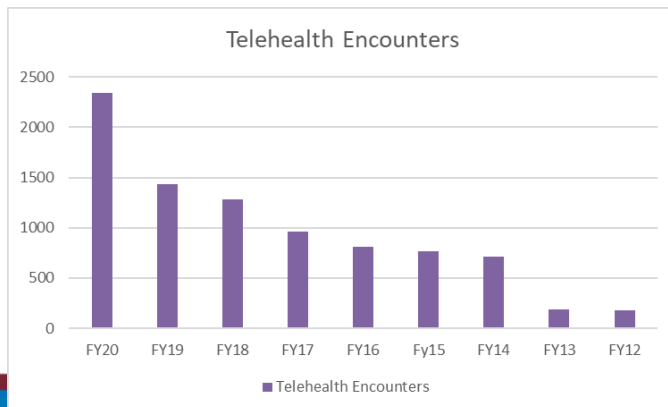
DOCUMENT TYPE/STATUS

18



## • Clinical Care

- Access to Multi-disciplinary State-of-the-art Care;  
improved QOL, survival for care by movement disorder specialists
- Integrative Medicine \*\* **Whole Health** \*\* Palliative Care\*\***Mental Health**\*\* **Pharmacy**
- Expansion of Connected Care; **Monthly meeting** of Clinical Care Committee
- **Telehealth** program established in 2003
- Development of National VA PD Consortium Network
  - Inclusion of Movement Disorders in the Clinical Care Registry in CPRS
  - VHA Directive 1420 Parkinson's Disease System of Care
  - Developed Parkinson's Disease Program and Clinical Guide



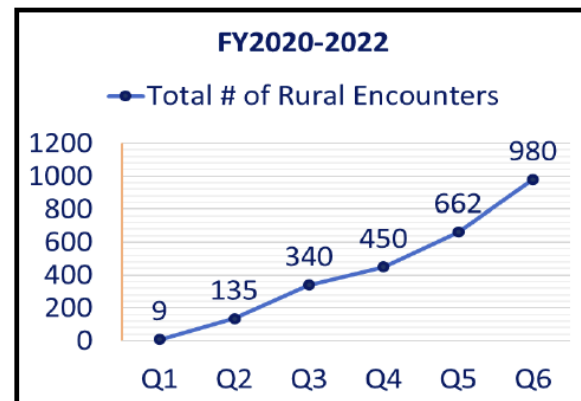
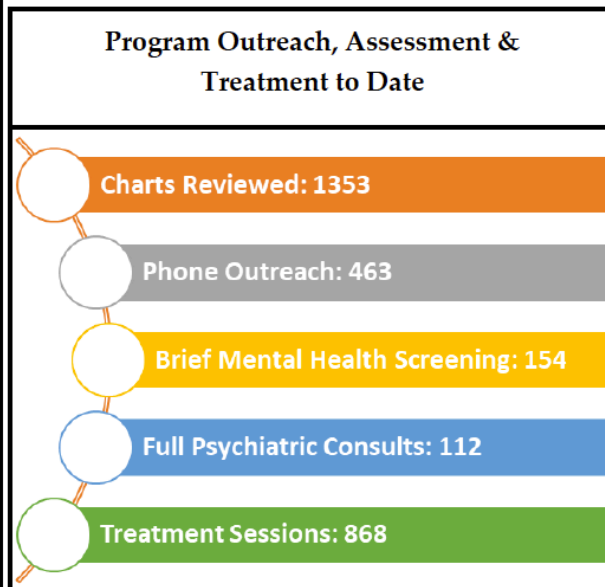
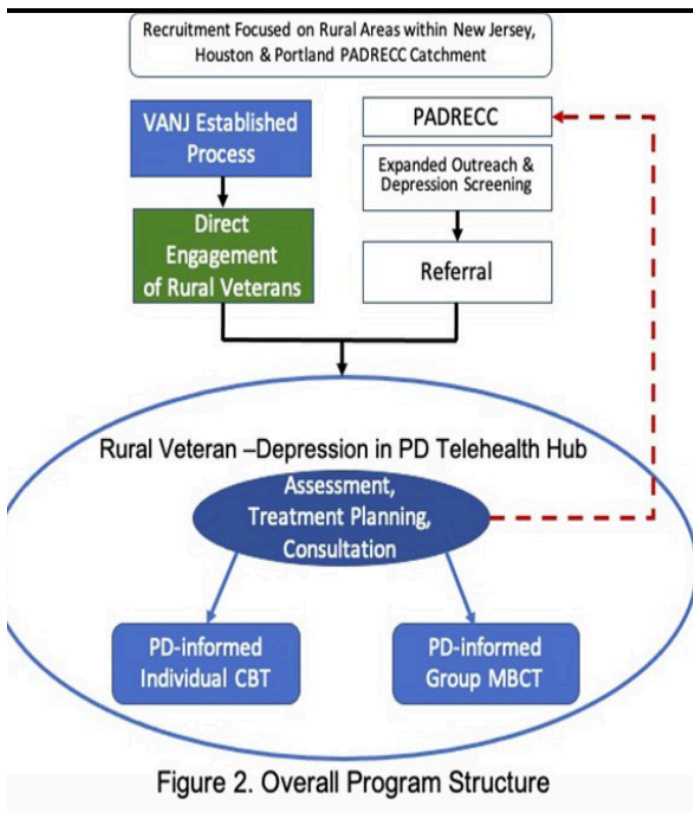


# CLINICAL INNOVATION

- The Southeast PADRECC :**Interdisciplinary Team (IDT) Clinic**. two Vets from 9-12 every :PT, OT, Speech, assistive technology, palliative care NP, PADRECC sleep neurologist and a PADRECC physician or NP. Team virtually meets to discuss and establish an integrated and complementary care plan tailored for each patient.
- The Southwest PADRECC: **VERA Reimbursement Change**: A success that has impacted care for every veteran with PD nationally- Spearheaded by Dr. Subramanian



# CBT IN PD DEPRESSION : DOBKIN- PORTLAND/HOUSTON



Please contact us for more information on the program or to discuss referrals:

Kristi Ketchum, LCSW- Program Coordinator

Joel Mack, MD- Site Psychiatrist

Susan O'Connor, RN- NW PADRECC Clinic Coordinator





- **VHA and Parkinson's Foundation entered into a Memorandum of Agreement on March 16, 2020.**
  - Improve the health, well-being and quality of life for Veteran's living with PD
  - Increase **access to PD related information for Veterans**, their care partners and healthcare providers by providing a wider array of relevant resources and support.



## PF National & Regional Events for Veterans, their families and community partners

### National Events

- Webinar-[Understanding Parkinson's Disease and Mental Health in the Veteran Community](#)
- Webinar-[Care Partner Town Hall: Care Partners of Veterans with Parkinson's Disease](#)

### Regional Events

- Webinar-[Veterans and Parkinson's: Mobility and Driving](#)
- In-person-[Veterans and Parkinson's: Exploring the Multidisciplinary Approach to Care](#)
- Webinar-[Veterans and Parkinson's: A Team Approach to Living Well](#)
- Webinar-[Environmental Exposures in Veterans with Parkinson's](#)
- Webinar-[Veterans and Parkinson's: What You Need to Know](#)

### Partner-produced content targeting Veterans and their families

- FAQ Guide: [Frequently Asked Questions: For Veterans with Parkinson's Disease and Their Care Partners](#)
- Vantage Point Guest Blog Posts:
  - \* [Webinar to Cover Impact Parkinson's Disease has on Mental Health](#)
  - \* [Parkinson's Disease Awareness: Answering 9 Most Popular Parkinson's Questions from Veterans](#)
- My PD Story: [Patrick Welch, PhD, Sgt. USMC \(ret\)](#)
- Updated Digital Resource Kits
  - \* [For Veterans with Parkinson's Disease and their Care Partners](#)
  - \* [For VA Health Professionals Treating Veterans with Parkinson's Disease](#)

## Trainings or protocols created through or as a result of the partnership

- **Updated Protocol:** VA Health Professionals can now call or email the Parkinson's Foundation Helpline to order their bulk materials for Veteran patients—living with PD and their care partners
- **Trainings:**
  - \* **Parkinson's Foundation Advance Team Training** for Alumni (of PF Team Training): Scholarship (BOGO) for VA clinicians (Aug. 2022)- 4 VA attendees
  - \* **Parkinson's Foundation Virtual Team Training-Spring 2022:** Scholarship (BOGO) for VA clinicians - 14 VA attendees
  - \* **Parkinson's Foundation Virtual Team Training-Fall 2021:** Scholarship (BOGO) for VA clinicians- 24 VA attendees
  - \* **Parkinson's Foundation 2022 In-Person Centers of Excellence Leadership Conference:** PADRECCs invited to attend, 7 PADRECC attendees (May 2022)
  - \* **Parkinson's Foundation 2021 Virtual Centers of Excellence Leadership Conference:** PADRECC and CC members invited to attend, 6 VA attendees

## Research or studies conducted through or as a result of partnership

- Richmond PADRECC participating in Palliative Care Research Project, "[Implementing Team-Based Outpatient Palliative Care in Parkinson Foundation Centers of Excellence](#)"
- Parkinson's Foundation Survey-[Understanding health care needs among Veterans with Parkinson's disease: A survey study](#)



# INPATIENT CARE-HOSPITAL PLAN FOR PD

The Parkinson's Foundation **Aware In Care** campaign aims to help people with Parkinson's get the best care possible during a hospital stay. For more information please visit [Parkinson.org/AwareInCare](http://Parkinson.org/AwareInCare) or call 1-800-4PD-INFO (473-4636).



Parkinson's Foundation



EDMOND J. SAFRA  
PHILANTHROPIC FOUNDATION

- Goal: promote awareness and advocacy to help make the hospital safer for patients with PD
- Research has shown that a majority of PD patients do not get their medications on time when they are hospitalized
- Dr. Keener serves on the Parkinson's Foundation Aware in Care Advisory Committee
- SW get alerted when our patients are admitted to the hospital so we can follow them in house along with pharmacy

## Providers' Quick Fact Sheet: Parkinson's Disease



**Please notify my Parkinson's Doctor that I have been admitted to the hospital**

### What is Parkinson's Disease?

Parkinson's disease (PD) is a chronic, progressive, neurological disorder associated with loss of dopamine-generating cells in the brain that results in multiple and often, complex symptoms. It is mainly associated with loss of motor control—tremor, stiffness, slowness of movement, and/or balance problems. However, non-motor symptoms are frequently present. Not every patient with PD has the same symptoms or response to medications. To date there is no known cause and no cure.

### Important Nursing/Clinical Care Considerations for the PD patient

- Patients with PD typically need their medications at specific times during the day. Please do not skip doses or postpone doses, unless ordered by a neurologist. To avoid serious side effects and/or help prevent an increase in debilitating motor symptoms, patients should receive their medications **on time, every time!**
- When ordering medications, please write specific times (i.e. 10:00am, 2:00pm, 6:00pm) as per the patient's home schedule, instead of frequency (i.e. three times a day).
- Do not stop Parkinson's medications abruptly.
- Resume medications immediately following procedures, unless vomiting or severely incapacitated.
- If an antipsychotic is necessary, use quetiapine (Seroquel) or clozapine (Clozaril).
- To treat nausea, use trimethoprim (Tigan) and ondansetron (Zofran).
- Be alert for swallowing problems.
- Do falls risk assessments and prevention.
- Ambulate as soon as medically safe. Patients may need assistance.
- If having trouble getting an EKG, EEG, or using a heart rate monitor, consider that the patient may have a deep brain stimulator. You may need the patient or family caregiver to turn the device off to avoid electrical interference. \*Remember to turn device back on as soon as possible!
- In the patient who has a deep brain stimulator, diathermy is contraindicated; MRI only if strict guidelines are followed. Contact manufacturer for guidelines.

### Contraindicated Medications

haloperidol (Haldol®)	prochlorperazine (Compazine®)
risperidone (Risperdal®)	promethazine (Phenergan®)
olanzapine (Zyprexa®)	metoclopramide (Reglan®)
aripiprazole (Abilify®)	meperidine (Demerol®) — do not mix with selegiline or rasagiline
ziprasidone (Geodon®)	

**Please notify my Parkinson's Doctor that I have been admitted to the hospital**

Prepared by Parkinson's Disease Research, Education, and Clinical Center (PADRECC).  
Adapted from: NPF Aware in Care Fact Sheet, Parkinson's Resources of Oregon and OHSU Parkinson Center "Critical Information for Caring for the PD Patient", and Parkinson Report (Summer 2007) "Five Frequently Asked Questions about Hospitalization".  
9/2013 For more information, go to [www.parkinsons.va.gov](http://www.parkinsons.va.gov)

Page 1 of 2



- **Research**

- Developed **PD Quality Care Indicators** adapted by AAN and Medicare
- CSP #468 **Deep brain stimulation** targeting and follow-up study of long term outcomes for DBS
- CSP #2015 “Multicenter, Randomized, Double-Blind Comparator Study of **Antipsychotics Pimavanserin and Quetiapine** for Parkinson’s Disease Psychosis (C-SAPP Study)”
  - \$19,000,000 thru January 2025; Kick Off meeting – Sept 2022
  - 24 Sites including Consortium Centers
- **Global Parkinson’s Genetics Program (GP2)** (Fox Foundation)- The five-year program is looking to identify PD genes is >150,000 volunteers around the world to further understand genetic risk factors of Parkinson’s Disease
- 138 publications in peer reviewed journals/ books, chapters (FY20)
- **Monthly meeting** of PADRECC/Consortium research interest group





## OTHER INNOVATIVE RESEARCH

- Philly: Developing Personalized Medicine Strategies to **Increase Physical Activity in Parkinson's Disease Through Digital Health**- DOD grant, Morley 1) use “**gamification**”— applying rules of games like point scoring—to increase physical activity in PD; 2) identify whether certain PD patients respond differently to gamification interventions; 3) use readily and commercially available digital health technologies to perform all study activities remotely and enable a “touchless” study.
- Richmond: nQ Medical remote monitoring pilot: The neuroQWERTY platform utilizes the **kinematics of typing on a laptop or smartphone** keyboard to determine **progression and/or severity of PD**, as well a medication efficacy and compliance. Collection of pilot data for validation of the technology.
- Portland: Scott, Gregory D, Lim, Miranda M, Drake, Matthew G, Woltjer, Randy, Quinn, Joseph F. **Onset of Gut and Genitourinary Prodromal Parkinson's Disease: A Study of 1.5 Million Veterans**. 3 May





# WOMEN IN PD-MOVEMENT DISORDERS 2022- SUBRAMANIAN, KEENER ET AL



## Menses

- Pre-menstrual worsening of symptoms
- Role of hormonal regulation, contraception
- Young-onset PD – impact on relationships, career, family planning



## Pregnancy

- Pre-conception counselling
- Maternal safety and wellbeing
- Teratogenicity of medications
- Guidance around childbirth
- Breastfeeding safety



## Perimenopause

- Worsening of symptoms
- Natural menopause vs surgical menopause (hysterectomy with or without oophorectomy)
- Timing and type of HRT (estrogen only vs combined estrogen-progesterone)



## Postmenopause

- Role of hormone replacement therapy
- Breast cancer
- Osteopenia/osteoporosis
- Pelvic floor dysfunction
- Transition in social roles (grandparent, retirement, bereavement)



## • Professional Education

- Strong Training Program (142 graduated **Fellows**, 100 resident/med student rotations per year; 101 Nurse educators trained (SAFRA Nursing Educator Training in PD program )
- 130 national/international lectures (FY20);
- 7 bi-annual National VA PD Consortium Conferences
- Movement Disorders CME Lecture Series (5 per year since 2009)
- **Monthly Journal Club**- From SW but national reach- international thought leaders as discussants
- Monthly video case conference calls
- Annual National Newsletter/Bimonthly (electronic) Transmitter Newsletter
- Parkinson's Disease Quick Reference Guide for Initiating **Therapy-Pocket Card**
- **Advanced Fellows:** two-year fellowship in advanced training in Movement Disorders, including procedures such as **deep brain stimulation programming** and **intraoperative assessment**, and **botulinum toxin injection**. Integrated **curriculum, milestones, evaluations and now a bootcamp** that aligns with AAN/SF Match Fellowship Directors Group (Aspen)
- Neurology Residents, Geriatrics, Geropsychiatry, Psychiatry, Pharmacy, Palliative Care, Psychology, PT, Nursing trainees



- Patient/ Caregiver Education
  - Patient:
    - My Parkinson's Story – **19 YouTube Videos** = 725,000 views (11.5.20)
    - 6 Education brochures and Education Essentials
    - Support Groups (local at each PADRECC and National Telephone Support Group)
    - PADRECC Hospitalization Kits
    - Outreach through **Parkinson Foundation** and other support group partnerships



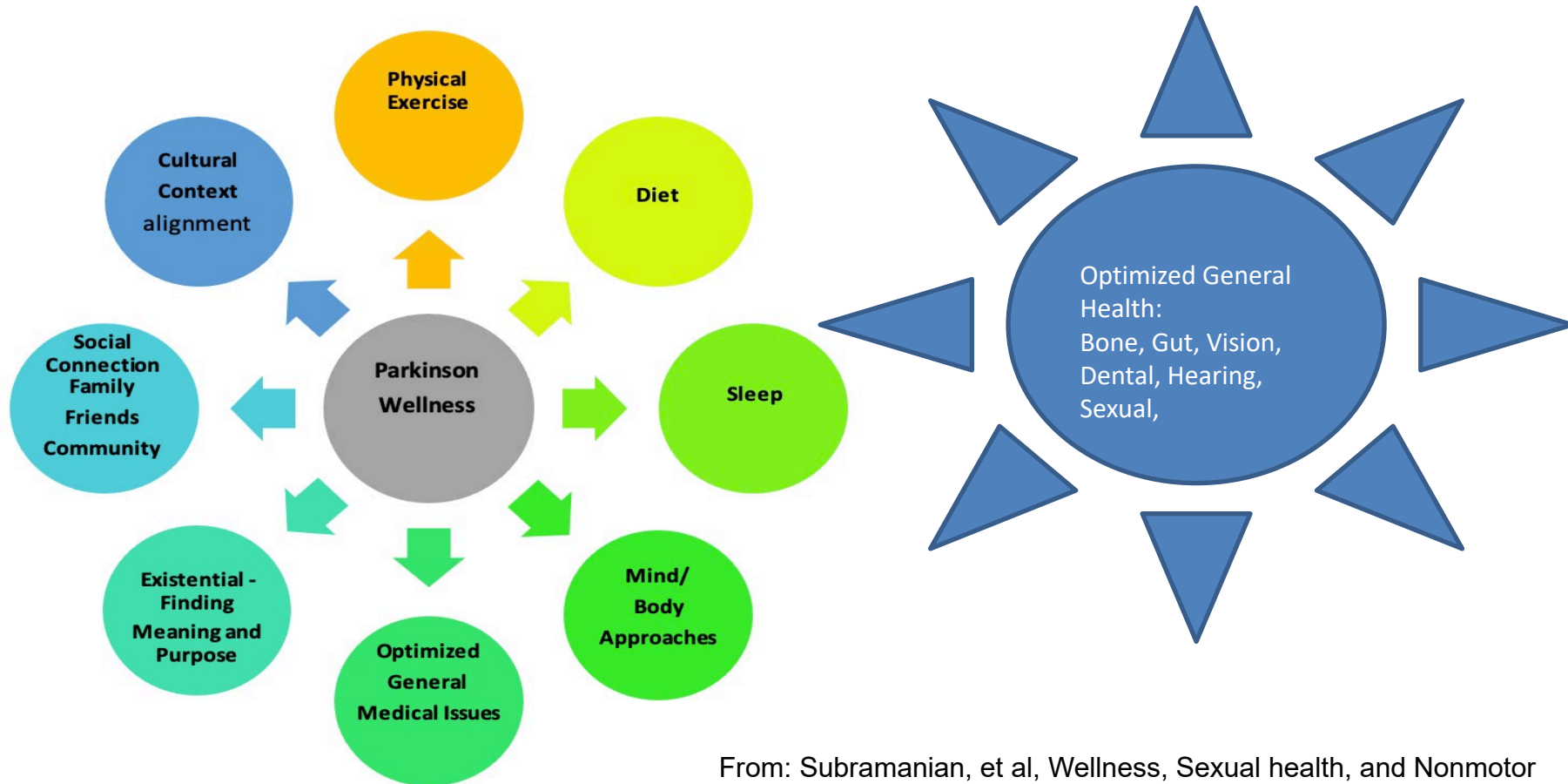
# WHOLE HEALTH







# Parkinson Disease Wellness Components



From: Subramanian, et al, Wellness, Sexual health, and Nonmotor Parkinson's, International Review of Neurobiology, 2022.



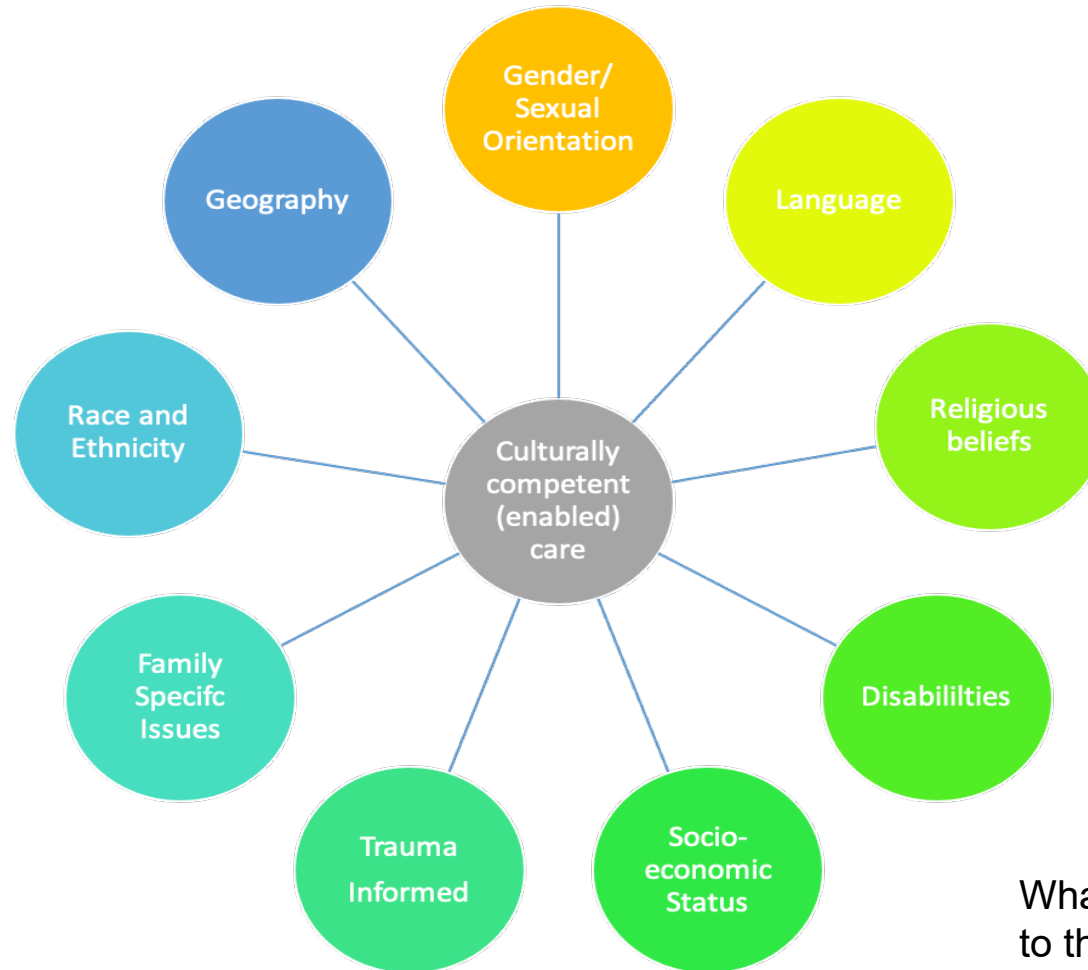


# WELLNESS ADVOCACY

- **The active pursuit of activities, choices and lifestyles that lead to a state of holistic health**
- Wellness is considered a conscious, self-directed and evolving process of achieving full potential. The person has **control**
- Wellness is multidimensional and **holistic**, encompassing lifestyle, mental and spiritual well-being, and the environment.
- Dr. Subramanian and Chaudhuri ( pioneer of non-motor issues in PD work) have recently had the **Wellness Taskforce at the Movement Disorders Society** launch



# CULTURAL CONTEXTUAL CARE

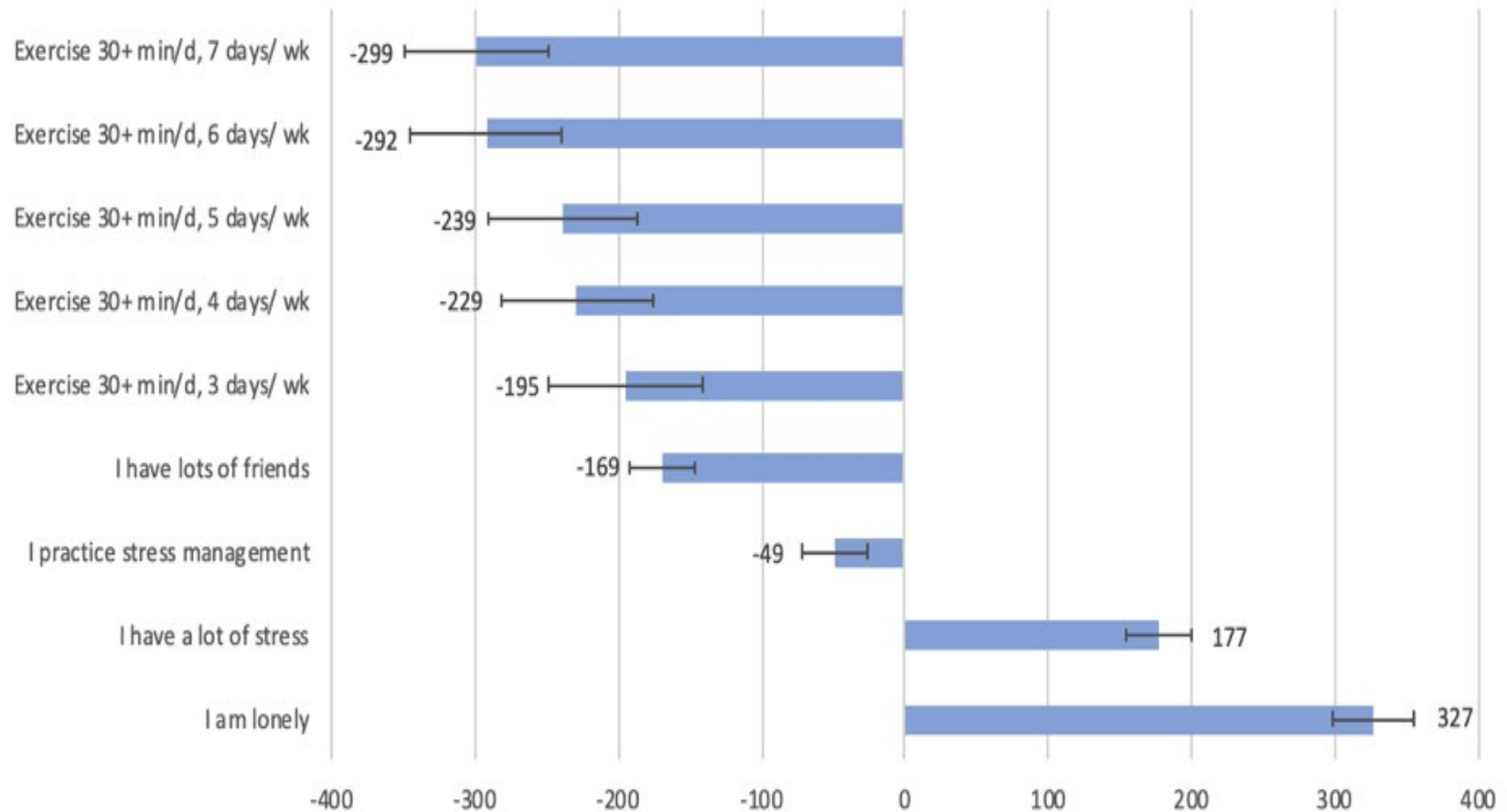


What do they bring  
to their disease?  
Trauma- informed  
Digital Divide

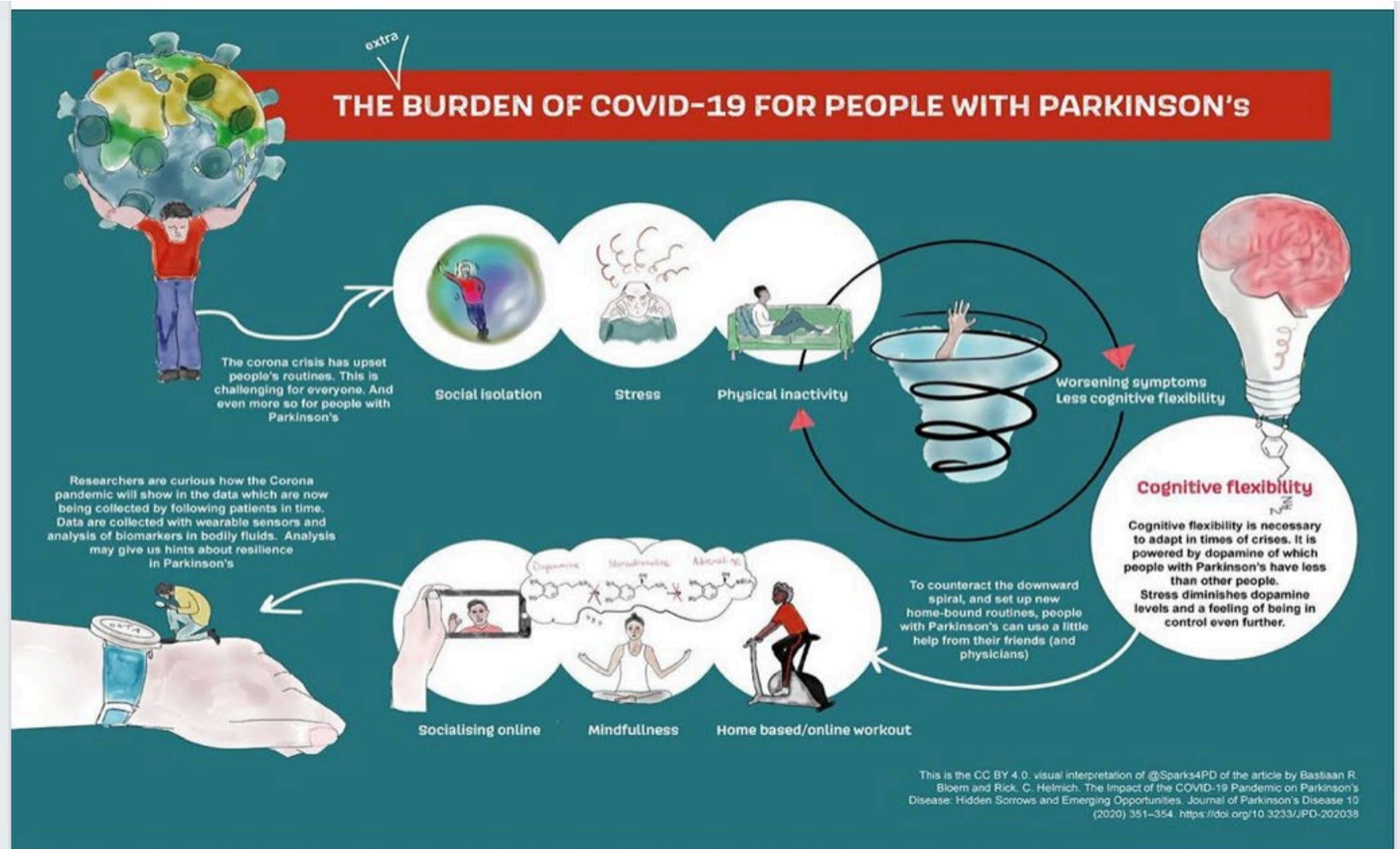
Subramanian/Chaudhuri et al  
Wellness 2022



# THE IMPACT OF LONELINESS IN PD



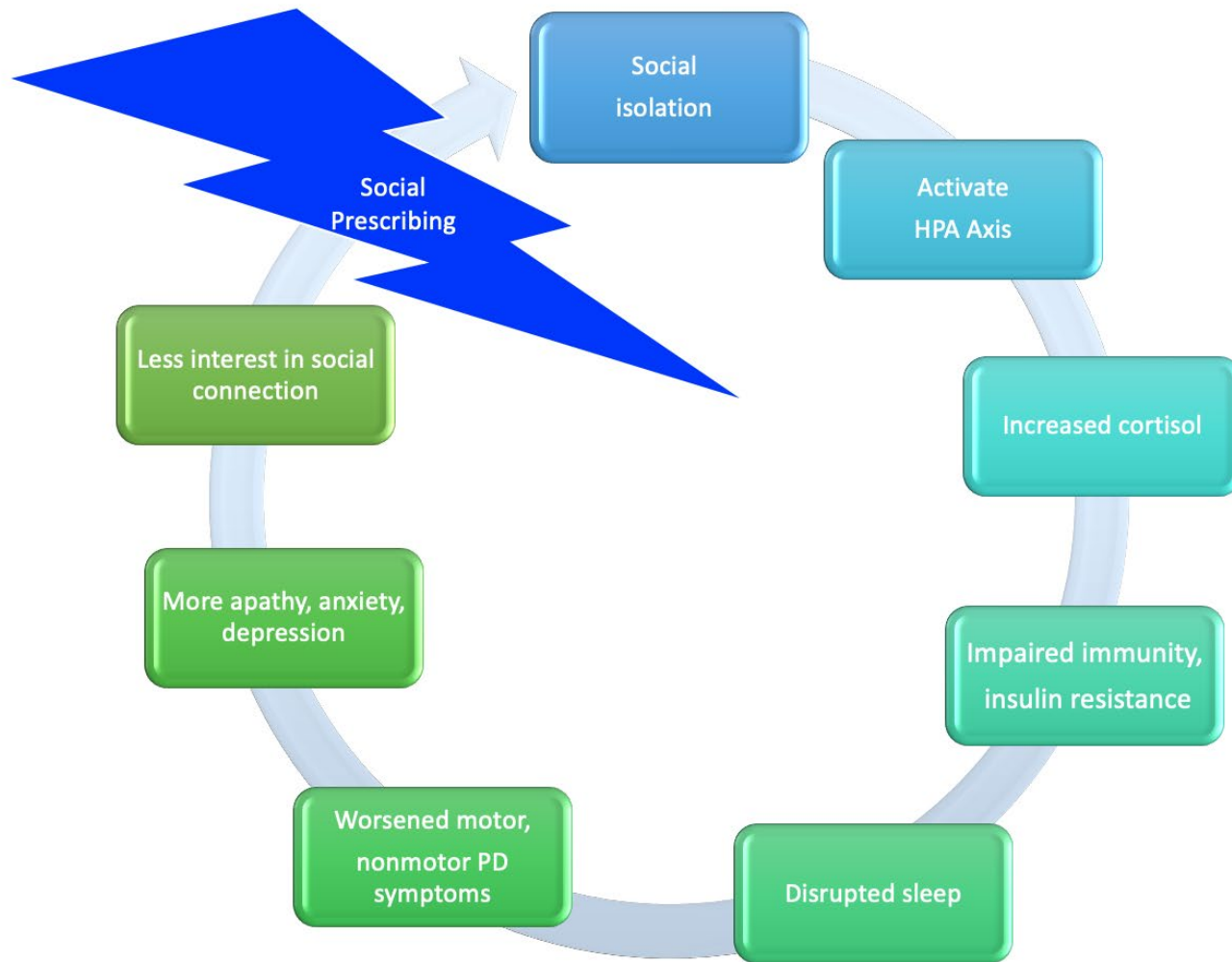
A Synergy of Pandemics:  
Subramanian I, Mischley L.  
NPJ Parkinson Dis. 2020







# THE CYCLE OF SOCIAL ISOLATION, STRESS AND PD SYMPTOMS: ROLE OF SOCIAL PRESCRIBING







# VA: COMPASSIONATE CONTACT CORPS-VAVS

- Referral from clinicians
- Fill out form with Private info
- Patients are **matched to volunteers**
- These volunteers used to come in person to the VA
- Can help volunteers as well with wellness
- Found 3 key questions about loneliness- would like to add to the survey
- Have been approached by AARP, Rotary



# SOCIAL PRESCRIBING-NYT ARTICLE

*The New York Times*

## Doctors Harness the Power of Human Connections

Social medicine programs, which often encourage patients to engage with other people, can help address dementia, isolation and more.



“I think it’s the way of the future,” “Social prescribing meets people in the community where they are, and links them to social support structures.”

Dr. Subramanian said she had seen the value of social group interactions for her

Parkinson’s patients:

“Loneliness is a big issue for them. Any way we can develop connections can help.”



# PATIENT EDUCATION: VIRTUAL SUPPORT GROUPS

Social Distancing & Resilience x +

← → ↺ 🏠

pmdalliance.org/social-distancing-coronavirus/

☆ 🔴 🔊 🔌 🗑️ 👤 ⋮

📱 Apps

📧 Gmail

📺 YouTube


📍 Maps

🔑 VA Access Gateway

📄 VA DigitalVA: Using C...


📖 Libby - Library

🕒 The Examined Life...



**PMD Alliance**

Parkinson & Movement Disorder Alliance



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Neuro Life Online® Programs

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Make An Impact

COVID-19

Recently Diagnosed?

← To COVID-19 Main Page

Past Events

All 2020 Programs →

Video Archive Page →

COVID Fatigue & PD – Social Connection as Medicine

Laurie Mischley, ND, PhD, MHP

Monday November 2nd

12-1 pm PT; 1-2 pm MT; 2-3 pm CT; 3-4 pm ET

[Register](#)

Driving and Road Safety for People with PD

Ergun Uc, MD

Friday November 6th

12-1 pm PT; 1-2 pm MT; 2-3 pm CT; 3-4 pm ET

[Register](#)

A Conversation with Rasheda Ali-Walsh

Rasheda Ali-Walsh

Monday, November 9th

12-1 pm PT; 1-2 pm MT; 2-3 pm CT; 3-4 pm ET

[Register](#)

Defining a Multidisciplinary Approach to PD

Suketu Khandhar, MD

Wednesday November 11th

12-1 pm PT; 1-2 pm MT; 2-3 pm CT; 3-4 pm ET

[Register](#)

Overcome PD Barriers & Stay Active: Strategies from a Physical Therapist



# PATIENT EDUCATION: BLOGS- PARKINSONSECRETS.COM

Social connection is a universal human need. We urge you to pick up the phone and reach out to someone who may have been forgotten and may be lonely or socially disconnected. It could be the only human contact that the person may have had in a long time and could make a world of difference.



This blog is brought to you by Michael S. Okun and Indu Subramanian.





## VA TEDX TALK → TEDX RIVER OAKS



[#TEDxRiverOaks](#) [#Parkinsons](#) [#SocialPrescribing](#)

TEDxRiverOaks Dr Indira Subramanian

TEDx Youtube Channel-  
Secret Sauce to Health: Finding Meaning through Connection





# TIPS FOR CLINICIANS:

**Table 3** Tips for clinicians.

- 
1. *Awareness*—Become more aware of the clinical importance of loneliness
  2. *Screening*—Ask patients about their social health (e.g., the three spheres of loneliness)
    - a. Ask, “Do you sometimes feel left out?”
    - b. Ask, “Do you sometimes feel isolated from others?”
  3. *Intervening*—Tailor the appropriate intervention for this specific patient taking into account their cultural context
    - a. Social Prescribing (e.g., virtual community groups, virtual exercise classes, and outdoor recreation activities)
    - b. Psychological Interventions (e.g., Mindfulness, CBT, ACT)
    - c. Wellness Strategies (e.g., diet, sleep, exercise, mind/body approaches)
-



## STRENGTHS OF OUR COE

- **Collaborative-** cutting across silos and disciplines to make a difference for our vets, Sister sites/ hub and spoke model of care, Interface with PF and other support groups, AAN/MDS liaison
- **Mental health collaboration and education-** Leaders in psychiatry, psychology, social work space
- **Multidisciplinary** model of clinical care- nursing, pharmacy, palliative care, geriatrics,
- **Pharmacy collaboration-** phone calls for compliance and note placed in chart one week before patient is seen by neuropharmD
- **Holistic/ Cultural Contextual-** whole health, mental health, DEI, mind-body approaches,
- **Innovative-** telehealth, wearable technology, social prescribing
- **Unique Skillsets-** integrative med, Educators, Diverse cultural backgrounds/ Spanish speaking, mindfulness/yoga teacher trained



# WHERE WE WANT TO GO:

- **Stabilize** support for PADRECCs and fill critical hires
- Use CSP #2015 to strengthen PADRECC/VA PD Consortium research enterprise for **translational research**
- Continue to **expand access** to state-of-the-art PD care by growing VA PD Consortium and expanding telehealth and **training** more trainees- there is a **severe shortage of movement neurologists** in the country and in the world
- **Partnering/Collaborating** with other COEs and across silos to innovate and improve care in areas such as **whole health, mental health, rural health,**