PARKINSON'S DISEASE SYSTEM OF CARE

1. SUMMARY OF MAJOR CHANGES: This directive:

a. Updates responsibilities in paragraph 2 for the Assistant Under Secretary for Health for Clinical Services and National Parkinson's Disease Research, Education and Clinical Centers (PADRECC) Director, and adds responsibilities for the Neurology National Program Executive Director, PADRECC Directors, Veterans Integrated Services Network Director, Department of Veterans Affairs (VA) medical facility Director, VA medical facility Chief of Staff or Associate Director of Patient Care Services and Regional Parkinson's and Movement Disorder Center Director.

b. Removes former Appendix A, PADRECCs and Appendix B, Consortium Sites. This information is in the Parkinson's Disease Program and Clinical Guide located at <u>https://rebrand.ly/NPO-Parkinsons-Guide</u>.

c. Adds Appendix A, Designation of VA Medical Facilities.

2. RELATED ISSUES: VHA Directive 1215, Standards for Veterans Health Administration Centers of Excellence, dated February 14, 2017; and VHA Directive 1159, VHA Specialty Care Program Office and National Programs, dated March 9, 2022.

3. POLICY OWNER: The National Neurology Program (11SPEC15) within the Specialty Care Program Office is responsible for the content of this directive. Questions may be addressed to the Neurology National Program Executive Director at <u>VHA11SPEC15N2@va.gov</u>.

4. RESCISSIONS: VHA Directive 1420, Parkinson's Disease System of Care, dated January 18, 2019, is rescinded.

5. RECERTIFICATION: This Veterans Health Administration (VHA) directive is scheduled for recertification on or before the last working day of August 2029. This VHA directive will continue to serve as national VHA policy until it is recertified or rescinded.

6. IMPLEMENTATION SCHEDULE: This directive is effective 6 months after publication.

BY DIRECTION OF THE OFFICE OF THE UNDER SECRETARY FOR HEALTH:

/s/ Erica M. Scavella, MD, FACP, FACHE Assistant Under Secretary for Health for Clinical Services/CMO

NOTE: All references herein to VA and VHA documents incorporate by reference subsequent VA and VHA documents on the same or similar subject matter.

DISTRIBUTION: Emailed to the VHA Publications Distribution List on August 30, 2024.

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PARKINSON'S DISEASE SYSTEM OF CARE

1. POLICY

It is Veterans Health Administration (VHA) policy that all eligible Veterans have access to high-quality, Veteran-centered, comprehensive and interdisciplinary care for Parkinson's Disease (PD) and related disorders and can be referred to Parkinson's Disease Research, Education and Clinical Centers (PADRECCs) or Regional Parkinson's and Movement Disorder Centers (RPMDCs) via inter-facility consult. **AUTHORITY:** 38 U.S.C. § 7329.

2. RESPONSIBILITIES

a. <u>Under Secretary for Health.</u> The Under Secretary for Health is responsible for ensuring overall VHA compliance with this directive.

b. <u>Assistant Under Secretary for Health for Clinical Services/Chief Medical</u> <u>Officer.</u> The Assistant Under Secretary for Health for Clinical Services/Chief Medical Officer is responsible for:

(1) Supporting the Specialty Care Program Office (SCPO) with implementation and oversight of this directive.

(2) Collaborating with the Assistant Under Secretary for Health for Patient Care Services to support program offices within Patient Care Services with implementation of this directive.

c. <u>Assistant Under Secretary for Health for Patient Care Services/Chief Nursing</u> <u>Officer.</u> The Assistant Under Secretary for Health for Patient Care Services/Chief Nursing Officer is responsible for:

(1) Supporting the program offices within Patient Care Services with implementation of this directive.

(2) Collaborating with the Assistant Under Secretary for Health for Clinical Services to support implementation of this directive.

d. <u>Assistant Under Secretary for Health for Operations.</u> The Assistant Under Secretary for Health for Operations is responsible for:

(1) Communicating the contents of this directive to each of the Veterans Integrated Services Networks (VISNs).

(2) Assisting VISN Directors to resolve implementation and compliance challenges in all Department of Veterans Affairs (VA) medical facilities within that VISN.

(3) Providing oversight of VISNs to ensure compliance with this directive and its effectiveness.

e. <u>Chief Officer, Specialty Care Program Office.</u> The Chief Officer, SCPO is responsible for supporting the Neurology National Program Executive Director (NPED) in executing their responsibilities as outlined in this directive.

f. <u>Neurology National Program Executive Director.</u> The Neurology NPED is responsible for:

(1) Supporting implementation of and compliance with this directive through collaboration with VISN Directors and the National PADRECC Director.

(2) Supporting the National PADRECC Director in developing a plan to establish, collect and assess national performance data for quality improvement for PD care across VHA.

(3) Collaborating with the National PADRECC Director to designate PADRECC sites within VHA and to select PADRECC Directors.

(4) Providing concurrence on designations by VISN Directors of at least one RPMDC per VISN. **NOTE:** This responsibility is delegated to the National PADRECC Director.

(5) Collaborating with the Executive Director, Office of Rehabilitation and Prosthetics Services on PD-related rehabilitation and prosthetics initiatives.

(6) Appointing the National PADRECC Director with VA medical facility Director concurrence via competitive application process.

g. <u>National Parkinson's Disease Research, Education and Clinical Center</u> <u>Director.</u> *NOTE:* National PADRECC Director is appointed by the Neurology NPED via competitive application. The VA medical facility Director must concur with the application. The National PADRECC Director position must be filled by a physician (i.e., a neurologist with specialty fellowship training and at least 5 years of experience in the management of patients with movement disorders) who has served as a PADRECC Director for at least 5 years and who can serve the given VA medical facility through a part-time (at least 5/8ths) or a full-time appointment consistent with VHA Directive 1065(1), Productivity and Staffing Guidance for Specialty Provider Group Practice, dated December 22, 2020. The National PADRECC Director is responsible for:

(1) Providing guidance to the Neurology NPED on issues that affect health care of Veterans with PD and related disorders, including but not limited to identifying advances in PD care, gaps in care and providing expertise and education to VA health care providers, Veterans and caregivers.

(2) Serving as a subject matter expert to Neurology NPED, VISN leadership and VA medical facilities to support implementation and compliance with this directive.

(3) Establishing, collecting and assessing national performance and quality data for PD across VHA with collaboration from the Neurology NPED to ensure PADRECC sites

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within VHA provide high-quality, Veteran-centered comprehensive and interdisciplinary care.

(4) In collaboration with the Neurology NPED, designating PADRECC sites within VHA and selecting PADRECC Directors.

(5) Collaborating with VISN Directors, the Neurology NPED and PADRECC Directors to designate at least one RPMDC per VISN to ensure appropriate Veteran access to and geographical distribution of comprehensive movement disorders care.

(6) Serving as the PD communication liaison to PADRECC Directors, VISN Directors and VA medical facility Directors.

(7) Promoting patient-centered, informatics-based approaches to PD specialist access including telehealth, e-consults and other e-connected modalities.

(8) Coordinating with PADRECC Directors and RPMDC Directors to ensure that all VA medical facilities have consultation access to appropriate movement disorders expertise (e.g., via active inter-facility consults).

(9) Updating the PD Program and Clinical Guide at least annually. The PD Program and Clinical Guide is a document developed by the PADRECCs to inform clinicians of treatment options for Veterans with PD and related disorders. This document does not prescribe mandatory clinical practices but provides expert opinion on best clinical practices. *NOTE:* To review this guide, please refer to <u>https://rebrand.ly/NPO-Parkinsons-Guide</u>.

h. <u>Veteran Integrated Services Network Director.</u> The VISN Director is responsible for:

(1) Ensuring that all VA medical facilities within the VISN comply with this directive, based on their designation as a PADRECC or RPMDC, and if barriers to compliance are identified, informing the Chief Officer, SCPO, the National PADRECC Director and the Neurology NPED to develop a VISN action plan.

(2) Designating at least one RPMDC per VISN, in collaboration with the Neurology NPED and National PADRECC Director.

(3) Collaborating with PADRECC Directors to ensure that all VA medical facilities in the PADRECC catchment area have consultation access to the PADRECC (e.g., active inter-facility consults).

(4) Collaborating with the VA medical facility Director, VA medical facility Chief of Staff (CoS) and Associate Director for Patient Care Services (ADPCS) to ensure selfdirected care for Veterans with PD and related disorders is coordinated in accordance with VHA Directive 1310(1), Medical Management of Enrolled Veterans Receiving Self-Directed Care from External Health Care Providers, dated October 4, 2021. i. <u>Parkinson's Disease Research, Education and Clinical Care Director.</u> NOTE: PADRECCs continue to be selected by the Neurology NPED via competitive application from VA medical facilities that qualify for PADRECC designation. Applications propose a PADRECC Director. The VA medical facility Director must concur with the application (and thus appointment of the PADRECC Director if the application is selected). If the PADRECC Director appointed via the initial selection process cannot continue in that role, the new PADRECC Director is appointed by the VA medical facility Director in collaboration with the VA medical facility CoS after concurrence by the Neurology NPED. The PADRECC Director position must be filled by a physician (i.e., a neurologist with specialty fellowship training or greater than 3 years of experience in the management of patients with movement disorders), who may serve the given VA medical facility through a part-time or full-time appointment consistent with VHA Directive 1065(1). The PADRECC Director is responsible for:

(1) Serving as the subject matter expert to the National PADRECC Director, VISN leadership and VA medical facility leadership on issues that affect health care of Veterans with PD and related disorders, including but not limited to identifying advances in PD care, gaps in care and providing expertise and education to VA health care providers, Veterans and caregivers.

(2) Supporting the National PADRECC Director in promoting patient-centered, informatics-based approaches to PD specialist access including telehealth, e-consults and other e-connected modalities.

(3) Collaborating with VISN Directors, the Neurology NPED and National PADRECC Director to designate at least one RPMDC per VISN to ensure appropriate Veteran access to and geographical distribution of comprehensive movement disorders care.

(4) Collaborating with VISN Directors to ensure that all VA medical facilities in the PADRECC catchment area have consultation access to the PADRECC (e.g., active inter-facility consults).

(5) Leading, coordinating and overseeing all clinical and administrative aspects of the PADRECC, including the PADRECC Multidisciplinary Care Team. **NOTE:** Due to the complex nature of providing high-quality and Veteran-centered comprehensive care to Veterans with PD and related disorders, standard performance and productivity metrics for individual health care providers may not be achievable.

(6) Developing and maintaining processes, standard operating procedures, knowledge and skills to ensure that Veterans with PD and related disorders receive comprehensive, high-quality multidisciplinary care, including:

(a) Surgical program for Deep Brain Stimulation (DBS) therapy.

(b) Post-operative care of Veterans with DBS therapy including stimulator programming and adjustment.

(c) Chemodenervation and Botox therapy for the management of dystonia and other movement disorders.

j. VA Medical Facility Director. The VA medical facility Director is responsible for:

(1) Ensuring overall VA medical facility compliance with this directive, informing the VISN Director and developing a corrective action plan if non-compliance is identified.

(2) Ensuring that VA medical facility staff providing care to Veterans with PD and related disorders or suspected of having PD have referral options to a RPMDC or PADRECC (e.g., active inter-facility consults, community care) as outlined in the PD Program and Clinical Guide located at <u>https://rebrand.ly/NPO-Parkinsons-Guide</u>.

(3) Ensuring that necessary medical equipment, supplies and subspecialty care are provided to eligible Veterans with PD and related disorders.

(4) Collaborating with the VISN Director and VA medical facility CoS or ADPCS to ensure that self-directed care for Veterans with PD and related disorders is coordinated in accordance with VHA Directive 1310(1).

(5) For VA medical facilities designated as a PADRECC, ensuring the availability of space, administrative support and essential staff (e.g., PADRECC Multidisciplinary Care Team) needed to deliver comprehensive inpatient and outpatient care for Veterans with PD and related disorders including a surgical program for DBS therapy. See Appendix A for VA medical facility designation information. **NOTE:** The PADRECC Multidisciplinary Care Team is a multidisciplinary group of VA health care providers who provide specialty services for Veterans with PD and related disorders. All staff may serve the given VA medical facility (part-time or full-time) consistent with VHA Directive 1065(1). In some circumstances, PADRECC Multidisciplinary Care Team members may participate by telehealth. The PADRECC Multidisciplinary Care Team is led by the PADRECC Director or Assistant Director for Clinical Care and must include a Registered Nurse or Physician Assistant or Advanced Practiced Registered Nurse, a Psychiatrist, Social Worker, Psychologist, Physical Therapist, Occupational Therapist and Speech-Language Pathologist. Other VA health care providers whose services are frequently needed for comprehensive care of Veterans with PD and related disorders are involved in clinical care as Veteran needs and local availability dictates (e.g., Clinical Pharmacist Practitioner, Whole Health and Palliative Medicine/Hospice Care provider, Recreational Therapist, Creative Arts Therapist, Assistive Technology Specialist). Dedicated administrative support is recommended. For detailed information on the designation and scope of RPMDCs refer to the PD Program and Clinical Guide at https://rebrand.ly/NPO-Parkinsons-Guide.

(6) Designating a RPMDC Director in collaboration with the VA medical facility CoS or ADPCS and National PADRECC Director for VA medical facilities designated as a RPMDC.

(7) For VA medical facilities designated as an RPMDC, ensuring the space, administrative support and essential staff (e.g., RPMDC Multidisciplinary Care Team)

needed to deliver comprehensive inpatient and outpatient care for Veterans with PD and related disorders is available. See Appendix A for VA medical facility designation information. NOTE: The RPMDC Multidisciplinary Care Team is a group of VA health care providers who provide specialty services for Veterans with PD and related disorders. All staff may serve the given VA medical facility (part-time or full-time) consistent with VHA Directive 1065(1). In some circumstances, RPMDC Team members may participate by telehealth. The RPMDC Team is led by the RPMDC Director and must include a Registered Nurse or Physician Assistant or Advanced Practiced Registered Nurse, Psychiatrist, Social Worker, Psychologist, Physical Therapist, Occupational Therapist and a Speech-Language Pathologist. Other VA health care providers whose services are frequently needed for comprehensive care of Veterans with PD and related disorders are involved in clinical care as Veteran needs and local availability dictates (e.g., Clinical Pharmacist Practitioner, Whole Health and Palliative Medicine/Hospice Care provider, Recreational Therapist, Creative Arts Therapist, Assistive Technology Specialist). Dedicated administrative support is recommended. For detailed information on the designation and scope of RPMDCs refer to the PD Program and Clinical Guide at https://rebrand.lv/NPO-Parkinsons-Guide.

k. VA Medical Facility Chief of Staff or VA Medical Facility Associate Director of Patient Care Services. The VA medical facility CoS or ADPCS, depending on the VA medical facility, is responsible for:

(1) Collaborating with the VA medical facility Director to designate an RPMDC Director if the VA medical facility is designated as an RPMDC. See paragraph 2.j.7. **NOTE:** Due to the difficulty recruiting and retaining physicians with specialty training in movement disorders, a qualified RPMDC Director may become unavailable. If this occurs, the VA medical facility CoS or ADPCS must notify the National PADRECC Director and an Interim RPMDC Director (without movement disorders expertise) can be appointed by the CoS or ADPCS for up to 2 years with a signed agreement outlining virtual back-up. When this option is not available, RPMDCs must be placed on inactive status.

(2) Notifying the VA medical facility Director of challenges complying with this directive and the PD system of care.

(3) Collaborating with the VISN Director and VA medical facility Director to ensure self-directed care for Veterans with PD and related disorders is coordinated in accordance with VHA Directive 1310(1).

I. <u>Regional Parkinson's and Movement Disorder Center Director.</u> *NOTE:* The position of RPMDC Director is appointed by the VA medical facility Director in collaboration with the CoS or ADPCS and must be filled by a physician (i.e., a neurologist with specialty fellowship training or substantial experience (greater than 3 years) in the management of patients with movement disorders), who may serve the given VA medical facility through a part-time or full-time appointment consistent with VHA Directive 1065(1). The RPMDC Director is responsible for:

(1) Leading, coordinating and overseeing all clinical and administrative aspects of the RPMDC. **NOTE:** Due to the complex nature of providing high-quality and Veterancentered comprehensive care to Veterans with PD and related disorders, standard performance and productivity metrics may not be achievable.

(2) Developing and maintaining processes and standard operating procedures, knowledge and skills to ensure that Veterans with PD and related disorders receive comprehensive, high-quality multidisciplinary care, including:

(a) Chemodenervation and Botox therapy for the management of dystonia and other movement disorders.

(b) Post-operative care of Veterans with deep brain stimulation therapy including stimulator programming and adjustment.

(3) Being available as a consultative and referral source for local VA health care providers for the management of Veterans with PD or movement disorders.

(4) Communicating with the VA medical facility CoS or ADPCS and the National PADRECC Director if they are no longer able to perform the duties of the RPMDC Director.

(5) Working with the PADRECC Directors to identify Veterans with PD and related disorders within their catchment area.

(6) Leading the RPDMC Team and ensuring the RPMDC Team:

(a) Receives and reviews movement disorders consults.

(b) Participates in PADRECC and National VA PD education, training, meetings and other activities related to PD.

3. TRAINING

There are no formal training requirements associated with this directive. For information about the National VA PD education, training, meetings and other activities related to PD, refer to <u>https://rebrand.ly/NPO-Parkinsons-Guide</u>.

4. RECORDS MANAGEMENT

All records regardless of format (for example, paper, electronic, electronic systems), created by this directive must be managed as required by the National Archives and Records Administration (NARA) approved records schedules found in VHA Records Control Schedule 10-1. Questions regarding any aspect of records management can be addressed to the appropriate Records Officer.

5. BACKGROUND

a. PD is a progressive neurological disease with no known cure. Approximately 110,000 Veterans currently have this diagnosis. PD is presumed to be service connected when a Veteran has been exposed to certain herbicide agents (e.g., Agent Orange), or to contaminants in the water supply at the Marine Corps Base Camp Lejeune or had as a secondary service connection to moderate to severe Traumatic Brain Injury.

b. The progressive nature and variable symptoms of PD require a multidisciplinary approach to the care of Veterans with PD and related disorders. The multidisciplinary team consists of neurologists, neurosurgeons, Physician Assistants, Advanced Practice Registered Nurses, psychiatrists, physiatrists, psychologists, nurses, social workers, rehabilitation therapists (speech, physical, occupational, kinesio), pharmacists, chaplains and other allied health professionals who care for Veterans with PD and related disorders along with their primary care physicians. This multidisciplinary team may be entirely located at a VA medical facility or accessed through the PD System of Care. **NOTE:** Find detailed description in the PD Program and Clinical Guide at <u>https://rebrand.ly/NPO-Parkinsons-Guide</u>.

c. To address the unique needs of Veterans with PD and related disorders, VHA established PADRECCS to coordinate clinical care, education and research. Host VA medical facilities were selected by a peer review committee from a national pool of applications and were made permanent by the Veteran's Benefits, Healthcare and Information Technology Act of 2006 (PL 109-461-Dec 22, 2006). The legislation directed VA to establish at least six PADRECCs and requires that PADRECCs coordinate education, clinical and research activities and to jointly develop a consortium of providers with interest in treating PD to ensure better access to state-of-the-art diagnosis, care and education. There are currently six PADRECCs which are located in Philadelphia, Richmond, Houston, West Los Angeles, San Francisco and Portland/Seattle VA medical facilities.

d. Given the size of the population of Veterans with PD and related disorders seeking treatment in VA and their distribution across the country, it is feasible to provide access to high-quality subspecialty care through a hub and spoke network of at least six regional PADRECCs, at least one designated RPMDC in each VISN. **NOTE:** *PADRECC and Regional Site locations can be found at:* <u>https://www.parkinsons.va.gov/care.asp</u>.

(1) RPMDCs are PADRECC-designated VA multidisciplinary movement disorder clinics that serve as a VISN resource for PD specialty consultation and education; and extend the reach of specialty care for PD and related disorders to Veterans who cannot travel to a PADRECC. RPMDCs are designated VA movement disorder clinics (see paragraph 2.i.(6)) that provide specialty care including but not limited to chemodenervation therapy for movement disorders, post-operative management of Veterans with deep brain stimulation (including stimulator programming). **NOTE:**

Specific designation criteria can be found in the PD Program and Clinical Guide at <u>https://rebrand.ly/NPO-Parkinsons-Guide</u>.

(2) Veterans evaluated by a neurologist and have been diagnosed with PD or related disorder may be referred to one of the PADRECCs, RPMDCs, or community care facilities as needed for PD specialty care evaluations.

(3) Primary care and, in some cases, non-PD specialty care (e.g., physical therapy, speech therapy) is provided at locally accessible VA medical facilities within specified referral areas and at community care facilities. **NOTE:** For additional information, see <u>https://rebrand.ly/NPO-Parkinsons-Guide</u>.

6. DEFINITIONS

Parkinson's Disease and Related Disorders. PD is a progressive disease of the nervous system marked by some combination of tremor, slow movement, rigidity and problems with gait and balance. Other non-motor symptoms including cognitive impairment/dementia, mood disorders, psychosis, sensory disorders, autonomic disorders and sleep disorders may also be present. Determining the diagnosis of PD versus other causes of Parkinsonism (e.g., drug induced Parkinsonism, vascular Parkinsonism, progressive supranuclear palsy, multi-system atrophy, corticobasal degeneration, dementia with Lewy bodies.) is based on recent diagnosis criteria for PD published by the Movement Disorders Society. Movement disorders are clinical syndromes affecting the timing and coordination of movement, resulting in hyperkinetic symptoms or hypokinetic symptoms. *NOTE: For more information, please see Movement Disorder Society Diagnostic Criteria for PD at https://onlinelibrary.wiley.com/doi/full/10.1002/mds.26424.*

7. REFERENCES

a. 38 U.S.C § 7329.

b. VHA Directive 1065(1), Productivity and Staffing Guidance for Specialty Provider Group Practice, dated December 22, 2020.

c. VHA Directive 1310(1), Medical Management of Enrolled Veterans Receiving Self-Directed Care from External Health Care Providers, dated October 4, 2021.

d. Movement Disorder Society Diagnostic Criteria for PD. https://onlinelibrary.wiley.com/doi/full/10.1002/mds.26424.

e. PADRECC and Regional Sites. https://www.parkinsons.va.gov/care.asp.

f. PD Program and Clinical Guide. <u>https://rebrand.ly/NPO-Parkinsons-Guide</u>.

DESIGNATION OF VA MEDICAL FACILITIES

DESIGNATION	National Parkinson's Disease Research, Education and Clinical Center (PADRECC)	Regional Parkinson's and Movement Disorder Center (RPMDC)	Parkinson's Disease Research, Education and Clinical Center Associated Sites (PAS)		
Neurologist with fellowship or specialty training in movement disorders.	Required	Required	Optional		
Neurologist with interest in movement disorders and PD-specific continuing education and training.	Not applicable	Not applicable	Required		
Comprehensive Inpatient Specialty Care					
Comprehensive inpatient specialty care including surgical program for deep brain stimulation therapy.	Required	Optional	Optional		
Comprehensive Outpatient Specialty Care					
Post-operative care including deep brain stimulator programming and adjustment.	Required	Required	Optional		
Chemodenervation therapy including for dystonia, sialorrhea, spasticity.	Required	Required	Optional		
Multidisciplinary team including Registered Nurse or Physician Assistant or Advanced Practice Registered Nurse, Psychiatry, Social Worker, Psychologist, Physical Therapist or Kinesiotherapist, Occupational Therapist and Speech- Language Pathologist.	Required	Required	Optional		
Multidisciplinary team including Clinical Pharmacist Practitioner, Whole Health and Palliative Medicine/Hospice Care, Recreational Therapist, Creative Arts Therapist, Assistive Technology Specialist.	Optional	Optional	Optional		