

Parkinson's Foundation Center of Excellence at CCLRCBH & PF's Global Care Network

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Cleveland Clinic

KEEP MEMORY ALIVE
 Supporting the Mission of Cleveland Clinic Lou Ruvo Center for Brain Health
 ALZHEIMER'S | HUNTINGTON'S | PARKINSON'S
 MULTIPLE SYSTEM ATROPHY | MULTIPLE SCLEROSIS

OUTLINE

- Introduction to Parkinson's Foundation (PF), their "Global Care Network" and Centers of Excellence (CoE)
- The benefits of the PF CoE designation
- The Cleveland Clinic Lou Ruvo Center of Brain Health's (CCLRCBH's) Parkinson's and Movement Disorder Program's activities that qualified as a PF CoE

The Parkinson's Foundation

National Parkinson's Foundation
Est. 1957
Miami, FL

Parkinson's Disease Foundation
Est. 1957
New York, NY

Parkinson's Foundation

Mission: To make life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson's community.

Strategic Goals

Care: Ensuring better outcomes and improving the standard of care for everyone with Parkinson's.

Research: Further understanding of Parkinson's so that advances are made toward better therapies and ultimately a cure.

Education and Empowerment: Reach all people with PD so that they have the information and tools necessary to live the best lives possible.

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Global Care Network: Background

- The Parkinson's Foundation (PF) has recognized the top Parkinson's Disease (PD) treatment centers for over 20 years
- Provide high-quality, patient-centered, multidisciplinary care
- Utilize an expert team of medical, nursing, and allied health professionals to address the complex symptoms and challenges that people with PD experience
- Engage in professional education and community outreach to increase PD awareness, knowledge, resources and services in the broader community
- Active in a variety of research activities to improve the lives of everyone with PD and for future generations

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Global Care Network: Transition

Centers of Excellence (COE) Network
1985 - 2022

Global Care Network (GCN)
2022 - Present

Centers of Excellence (COE) Network:
 Closes the gap between those diagnosed with PD and those receiving comprehensive and quality care, information, and support.
 Fosters the sharing and implementation of "best practices."
 Develops targeted research to extend knowledge base in PD and innovative models of education, service and outreach.

Global Care Network (GCN):
 Creates more opportunities for people with PD to access high-quality care while also providing health professionals the chance to advance and share their knowledge.
 Broadens the Foundation's footprint of care settings.
 Recognizes Centers that are providing excellent care within a broad geographic region.

Parkinson's Foundation CENTER OF EXCELLENCE

Global Care Network

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Global Care Network Overview

Serves over 300,000 people living with Movement Disorders

Global Care Network

- Network of Excellence (6)
Fresco[®] Parkinson Institute
- Centers of Excellence (51)
Parkinson's Foundation CENTER OF EXCELLENCE
- Comprehensive Care Centers (6)
Parkinson's Foundation COMPREHENSIVE CARE CENTER

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Network of Excellence (NOE)

New care designation as of 2022.

The Fresco Network in Italy is comprised of multiple, independent medical sites that together provide high-quality, patient-centered and multi-disciplinary care to people with Parkinson's disease (PD) within a specific country or region.

Demonstrates exemplary care, innovative research, a commitment to medical professional training and educating the community of people with and affected by Parkinson's.

As of 2022, there are 6 medical centers that comprise the Fresco Network.

- Moroggia-Pelascini Hospital
- Villa Margherita
- Policlinico di Milan
- Santa Maria della Misericordia Hospital
- Santa Chiara Hospital
- San Martino Hospital

Fresco[®]
Parkinson
Institute

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Center of Excellence (COE)

Recognizes medical facilities with specialized, multi-disciplinary teams providing evidence-based PD care.

Each center is required to meet rigorous care, professional training, research, community education and outreach criteria.

As of 2022, there are 51 COEs in the GCN.

- 37 located in the U.S.
- 14 located internationally



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Designation Criteria



Care



Education



Community Outreach



Research

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Care

Care must be **coordinated, comprehensive** and provided by an **interdisciplinary team**

Provide **expert care across the full spectrum of patient issues**, including motor, non-motor (particularly neuropsychiatric and cognitive symptoms)

Provide all people with Parkinson's **equal access to services**



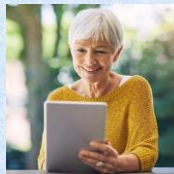
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Education

Provided at the center for:

- Health care professionals
- People with PD
- Care partners

- Ensure that clinicians are knowledgeable about all evidence-based treatments for Parkinson's Disease
- Educational events for people with PD and families, to provide current information about Parkinson's disease (such as an annual symposia or lunch and learn programs)
- Provide resources - such as newsletters, fact sheets, etc.



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Community Outreach

Provided outside of the Center for:

- Healthcare professionals
- People with PD
- Care Partners

Facilitation of community events

Provide resources for alternative wellness programs, support groups, exercise programs, etc.

Provision of disease-specific community provider education and training



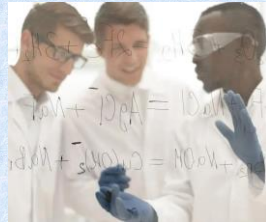
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Research

Centers must:

Conduct research relevant to Parkinson's

Publish findings from this research in peer-reviewed journals



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U.S. COEs - 2022

- | | |
|--|--|
| <ul style="list-style-type: none"> AZ—Barrow Neurological Institute CA—University of Southern California CA—University of California, San Francisco CA—University of California, San Diego Movement Disorder Center CO—University of Colorado Movement Disorders Center DC—Medstar Georgetown University Hospital FL—University of Florida Center for Movement Disorders and Neurorestoration FL—University of Miami FL—University of South Florida Parkinson's Disease and Movement Disorders Center GA—Medical College of Georgia, Augusta University GA—Emory University IA—University of Iowa IL—Northwestern University Movement Disorders Center IL—Rush University Medical Center IN—Indiana University School of Medicine KS—University of Kansas Medical Center MD—Johns Hopkins Parkinson's Disease and Movement Disorders Center MA—Massachusetts General Hospital MA—Beth Israel Deaconess Medical Center | <ul style="list-style-type: none"> MN—Struthers Parkinson's Center NH—Dartmouth Hitchcock Medical Center NY—Mount Sinai Beth Israel NY—Columbia University Irving Medical Center NY—Marlene and Paolo Fresco Institute for Parkinson's and Movement Disorders at NYU Langone Medical Center NY—University of Rochester Medical Center NC—Duke Health Movement Disorders Center NC—University of North Carolina at Chapel Hill School of Medicine NY—Columbia Center for Brain Health OH—Cleveland Clinic Center for Neurological Restoration OR—Oregon Health and Science University Parkinson Center PA—University of Pennsylvania Movement Disorder Center PA—Jefferson Health's Comprehensive Parkinson's Disease and Movement Disorder Center SC—Medical University of South Carolina TN—Vanderbilt University Medical Center TX—Baylor College of Medicine UT—University of Utah VA—Virginia Commonwealth University |
|--|--|

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International COEs – 2022

- | | |
|---|---|
| <p>Australia
Victorian Comprehensive Parkinson's Program</p> <p>Canada
McGill Parkinson Program
University of Western Ontario, London Health Sciences Centre
University of Calgary
University of Alberta
Pacific Parkinson's Research Centre, University of British Columbia
Toronto Western Hospital Movement Disorders Center</p> <p>Germany
Philipps University</p> <p>Israel
Tel Aviv Sourasky Medical Center</p> | <p>Netherlands
Nijmegen Parkinson Center</p> <p>Singapore
Singapore National Neuroscience Institute</p> <p>Taiwan
National Taiwan University Hospital, Center for Parkinson & Movement Disorders</p> <p>United Kingdom
Kings College Hospital
Derby Hospitals NHS Foundation Trust and The University of Nottingham</p> |
|---|---|

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Comprehensive Care Centers (CCC)

New care designation as of 2022.

Charged to meet the same criteria as a COE, but participation in clinical research is not a requirement.

As of 2022, there are 6 CCCs in the network.

- AR—University of Arkansas Medical Sciences
- CT—Hartford HealthCare
- HI—Queens Medical Center (Honolulu)
- LA—Ochsner Neuroscience Institute
- MI—Spectrum Health
- TN—University of Tennessee Medical Center



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Global Care Network Review Process



To be considered for designation, Centers must undergo a comprehensive application process



Once designated, Centers must complete annual reports



Centers must apply for re-designation every 5 years which also includes an in-person site review

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Global Care Network Presence - 2022



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Global Care Network Statistics – 2022

of Patients Seen in Global Care Network

Total Number of Movement Disorder Patients seen: 274,934

of Health Care Professionals in Global Care Network

Movement Disorder Specialists: 434
 Neurologists (non-movement): 218
 Physical therapists: 216
 Neuropsychologists: 190
 Nurses: 179
 Speech language pathologists: 124
 Occupational therapists: 123
 Neurosurgeons: 121
 Social Workers: 83
 Psychiatrists: 68
 Nurse practitioners: 66
 Physician assistants: 31



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The Benefits of COE Designation



A universally recognized landmark for excellence in PD/MD

- Improves our standing in applying to become a site for competitive/high impact/high profile clinical trials
- Excellence-based other networks and foundations with their own CoE designation process consider PF COE/GCN designation NIH, MJFF grant applications involving patient research projects consider it
- Patients locally and regionally recognize PF COE designation as a guarantee of excellence, a token of ultimate care quality

Networking, career building for the entire team

- As opposed to professional provider/physician centered, PF is multidisciplinary, allied professional TEAM centered, providing unmatched access and opportunity to any team member to find career defining projects, directors, initiatives with potential national and international impact
- Its annual "Center Leadership Conference" is a true PD/PPF "family" event, with coordinators, nurses, other allied health professionals coming together, sharing notes, setting up collaborative projects, building lifelong relationships

Funding opportunities with access restricted to PF COE/GCN sites

- Scientific grant applications – usually pilot, single site, or data analysis/epidemiological research – great opportunity for junior team members, students, allied health professionals, as well as seasoned investigators (depending on the RFA)
- Non-research quality improvement projects – generally modest funding, but still a great experience

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Our PF COE (GCN) Application History

ZM, having served 10+ years as (then) National Parkinson Foundation (NPF) COE Director at JHU, when recruited to join CCLRCBSH in 2017, immediately set in motion the application process, working with Pete Schmidt then CFO of NPF, in charge of COE network, successfully identifying a donor to fund the addition of a COE outside of the usual application cycle

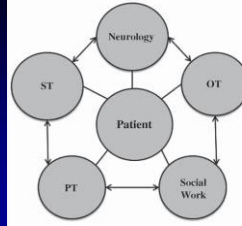
ZM shared the news with CNR Director HF, himself a former NPF COE Director (at UF Gainesville) before joining CCF. A plan to apply for COE together was forged between the 2, with the previously unseen novel model of a 2-site COE, divided by thousands of miles – a new model afforded by CCF's unique multi-state geographical presence. The proposed COE would become the 1st in state for both OH and NV.

After ZM led the initial steps (like writing the LOI, serving as the primary applicant and contact), the NPF-PDF merger finalized during the application process. This caused major reshuffling of leadership, including departure of Pete Schmidt and new leaders appointed to the COE application process. Supported by our OH counterpart site, PF downgraded CCF Nevada's role to be a satellite to the COE awarded to CCF OH, after our plaque was unveiled.

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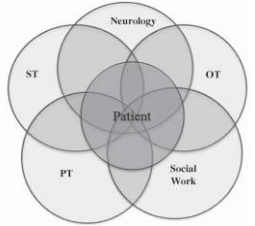


Multidisciplinary Model



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Interdisciplinary Model



The integrative care of Parkinson's disease: a systematic review. <https://doi.org/10.1016/j.parkpdis.2019.04.002>

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Implementation of an Integrative Holistic Healthcare Model for People Living with Parkinson's Disease

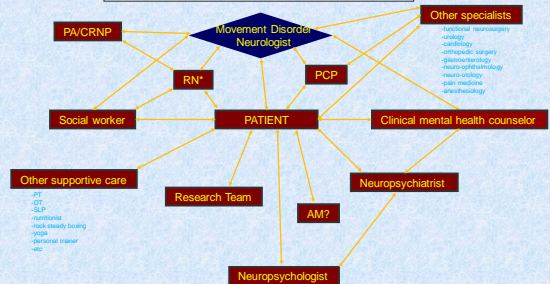


Implementation of an Integrative Holistic Healthcare Model for People Living with Parkinson's Disease. <https://doi.org/10.1016/j.parkpdis.2019.04.002>. <https://doi.org/10.1016/j.parkpdis.2019.04.002>. Published: 18 May 2019

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Multi-Disciplinary Care in PD

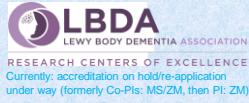


*Depending on the model, RPA may also take the role of patient education, research coordinator, and care help beyond the PDNE model

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COMMITMENT TO QUALITY: PD & Movement Disorders @CCLRCBH

Multiple recognitions as a Center of Excellence



HDSA CoE: application under way (Dr. Oguh)

Clinical Domain: PD & Movement Disorders at the CCLRCBH



Providers
Clinics: no wait
DBS, BoNT, HD,
Ataxia, virtual,
general movement

PT, OT, SLP

Rehab

Behavioral medicine

Social work, mental health therapy, music therapy

Additional services:

- Nursing
- Patient education
- Library
- Outreach
- Research
- Imaging
- Neuropsychology
- Neuropsychiatry
- Genetics counseling

ZM Parkinson's Foundation CoE at CCLRCBH

PD & MOVEMENT DISORDER SECTION/CLINIC

Zoltan Mari, MD FAAN
Division Director

Odirachi Oguh, MD
DBS & Advanced Therapies Clinic

PD/MD Clinic: Our 3 movement disorder providers all have full clinics that are exclusively dedicated to movement disorder patients. They are headed by 3 movement disorder MDS: Janet Najcus Paack, RN, Stephanie Goffine, RN, & Roy Doston, RN. We also have 4 wonderful MAs: Angeli, Chely, Christa, & Jessica!

Dina Abbasov, NP-C

Jenny Nguyen, DNP

SEPARATE SPECIAL FOCUS/THEMED CLINICS

- DBS & ADVANCE THERAPIES
- INJECTION CLINIC/DYSTONIA CLINIC
- ATAXIA CLINIC
- HUNTINGTON DISEASE CLINIC

THE INTER-DISCIPLINARY TEAM PARTICIPATING IN THE PF COE

Dr. Zoltan Mari, MD FAAN, Division Director

Dr. Odirachi Oguh, MD DBS & Advanced Therapies Clinic

Dr. Dina Abbasov, NP-C

Dr. Jenny Nguyen, DNP

Dr. Virendra Mishra, Dietmar Cordes

Dr. Brach Poston

Dr. Jeff Kinney, Boris Decourt

What is Deep Brain Stimulation?

Deep brain stimulation (DBS) involves a surgical procedure to place stimulation electrodes into the deep structures of the brain – the thalamus for essential tremor or dystonia, subthalamic nucleus for Parkinson's disease or dystonia. The electrodes are connected by wires to a computer device called an implantable pulse generator (IPG) implanted under the skin of the chest just below the collarbone.

Once activated, the device delivers continuous electrical pulses to the target areas to modify the dysfunctional brain circuitry that was responsible for motor symptoms of the disease.

How effective is DBS surgery?

DBS surgery is FDA approved and is the most effective surgical treatment for essential tremor, dystonia, and Parkinson's disease (PD). In some patients, medication reduction is possible. DBS can improve quality of movement, and ultimately reduce PD. The total number of properly placed contacts determines a patient's movement. Patients with the most placed contacts receive the most benefit. DBS is highly effective when the medication is not working.

What are the risks?

A comprehensive evaluation will be performed to make sure you are a good candidate. One of the most important criteria is to have had an adequate trial of medication for the condition. Surgery is not recommended if medication use adequately controls the disease. A good candidate must be healthy enough to tolerate surgery and not have any significant uncontrolled medical conditions that may increase the risk of surgery. This may include heart disease, diabetes, and high blood pressure. You will also have to have a good understanding of the risks and benefits of surgery.

What are the outcomes?

Deep brain stimulation has many advantages, including:

- DBS can greatly improve quality of life by reducing motor and non-motor symptoms.
- It does not damage brain tissue.
- DBS is reversible. The stimulation can be turned off if the medication can be tolerated.
- Most individuals are able to significantly reduce their medication following DBS surgery.
- The electrical stimulation can be easily adjusted over time to optimize the individual's motor symptoms. This can be done at the Cleveland Clinic. This can be done at the Cleveland Clinic. This can be done at the Cleveland Clinic.

Deep Brain Stimulation at Cleveland Clinic

Surgery in Cleveland, Outpatient care in Las Vegas.

Research Domain: PD & Movement Disorders at the CCLRCBH

Imaging
Dr. Virendra Mishra, Dietmar Cordes

Basic Science
Dr. Jeff Kinney, Boris Decourt

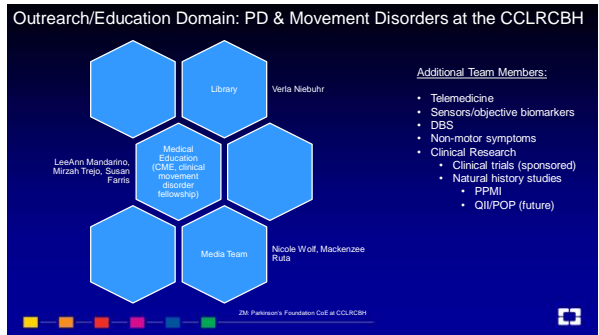
Neurophysiology
Dr. Brach Poston

Additional Research:

- Telemedicine
- Sensors/objective biomarkers
- DBS
- Non-motor symptoms
- Clinical Research
 - Clinical trials (sponsored)
 - Natural history studies
 - PPMI
 - QILFOP (future)

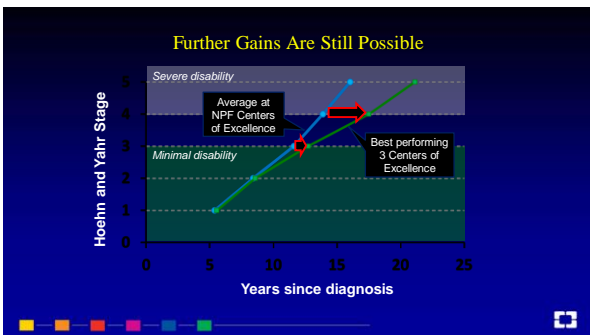
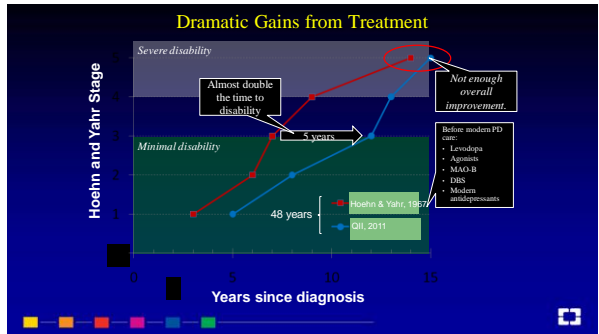
ZM Parkinson's Foundation CoE at CCLRCBH

LeeAnn Mandarino, Mirzah Trejo, Susan Ferris, ... [Bibliography text continues with numerous references]



It Would Not Be Possible To Dream Big without Larry and Camille

- LRCBH founded by Mr. Larry Ruvo
- Larry is a leader in LV and beyond
- Larry is key to the philanthropy of the LRCBH
- Larry is enormously supportive and grateful to CCF and has been always supportive of our efforts in the area of PD and movement disorders
- The work of Larry and Camille inspires us all





 **Cleveland Clinic**

Every life deserves world class care.

