World Parkinson Coalition Leadership Forum 2021  
Presentation summary from June 2021

PDMDS Case Study Presentation and team members  
Maria Baretto, PhD, Natasha Fothergill-Misbah, PhD, Helen Mwithiga

Overview  
This case study was presented about a community-based multi-disciplinary model of care implemented in India by the Parkinson’s Disease and Movement Disorder Society of India (PDMDS), that is being replicated in Kenya. PDMDS’s vision is to build a Parkinson’s community at each support centre, offering education, activities, and therapy that encourages sharing and the development of social and psychological support for People with Parkinson’s (PwPs) and their families. Because both India and Kenya are developing countries with similar challenges, it is expected that the program can be replicated in Kenya.

About Parkinson’s Disease and Movement Disorder Society  
PDMDS consists of 62 Parkinson’s support centres in 13 regions of India. All services are community-based. This means:
- All programs and services are **taken to the people** and made accessible within the community — i.e., at a community school, religious building, or community space. This creates a greater sense of well-being because they are not offered in a clinical setting.
- Facilitators are **hired from the community**
  - HCPs, care partners, those seeking training in the field, etc.
- Materials, programs, and implementation strategies are **contextualized based on each community’s socioeconomic, religious, and cultural considerations**. This had a significant impact on engagement and sustained interest.

Other Key Takeaways from PDMDS  
- **Assessment and training of facilitators** posed an unexpected challenge, requiring the development of training models for many different categories of prospective facilitators.
- The most effective and sustainable programs **focused on the practical implications** of its content — i.e., the impact the information may have on the participant’s quality of life.
  - Physiotherapy classes focusing on daily activity
  - Speech classes focusing on how to better communicate with loved ones and in social situations
- **Care partner, caregiver, and family involvement** proved key to the program’s success. Facilitators encouraged family participation and offered content focusing on their needs.
The Kenya Program
The Kenya program, implemented through the Africa Parkinson’s Disease Foundation (APDF), is supported by the Edmond J. Safra Foundation, with special thanks for support from Max Coslov, Program Director. Because of the foundation’s support, PDMDS and Africa Parkinson’s Disease Foundation. With support from. were able to take the first steps toward replication of the one-year pilot project.

The Indian team will be responsible for:
- Management of the project
- Analyzing available resources in Kenya
- Designing and implementing training modules for the team
- Developing sessions and resource materials
- Financial management

The Kenya team will be responsible for:
- Assisting with identification of community resources
- Selection of venues
- Implementation and documentation of the program

Both teams will be responsible for developing the final project report.

APDF Program Outline
- The program will be offered in Mombasa
- In-person weekly and bi-weekly 90-minute sessions
- Offered over a 10-month period
- Effectiveness will be assessed via:
  - analysis of program implementation
  - comparisons of pre and post qualitative and quantitative measures — i.e., improvement of quality of life

Progress to date:
- Held an initial meeting
- Facilitators are identified
- Assessment and development of training modules has been initiated

Questions for the Group Leading this Pilot Project?
Contact Maria Barretto, PhD at alfmaria88@gmail.com

Questions for the WPC?
Contact Elizabeth Pollard at eli@worldpdcoalition.org

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