



Welcome to our

VIRTUAL SUPPORT GROUP MEETING



Virtual Support Group Agenda

- Welcome
- 2024 Recap and 2025 plan
- Highlight from Partners
- Open forum



Transforming Parkinson's Care in Africa (TraPCAf)

Transforming Parkinson's Care in Africa (TraPCAf) is a multi-site grant funded by the UK-based National Institute for Health and Care Research (NIHR). The overall aim of the grant is to transform the landscape of Parkinson's care and treatment in Africa through research in Egypt, Ethiopia, Ghana, Kenya, Nigeria, South Africa, and Tanzania.

The project's key research questions involve (1) understanding the burden of Parkinson's across Africa; investigating ways to (2) improve diagnosis rates, (3) provide affordable and sustainable treatment through a clinical trial of *Mucuna Pruriens*, and (4) improve the quality of disease management; (5) establishing genetic and environmental links to Parkinson's (e.g., related to diet, heavy metals and pesticides); and (6) understanding the lived experience of people with Parkinson's and their caregivers.

The research team will be working closely with Parkinson's Africa and partners, who will be supporting the community engagement and involvement work throughout the 4-year grant. This work involving Parkinson's Africa has already helped shape the research questions and will continue to ensure that the work is guided by people with lived experience on the ground and that the research has real impact. One important aim of the grant is to establish support groups in each of the study sites, and the team will be drawing on the expertise of PMD Alliance and the Universal Support Group Guide being developed through the PD Avengers Wellness Committee.

Virtual Support Groups 2024

























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Download
Presentation
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Jan 11, 2024

Parkinson's

Watch Presenta-

About

Feb 8, 2024

Medication

management

Watch Presenta-

tion

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Presentation

Apr 25, 2024 May 9, 2024 Exercise and **Emotional** movement well-being Watch Watch Presentation Presentation Passcode: \$? Passcode: 5z1=GM ATm&8Nra Download Download Presentation Presentation Slide Slide

<u>Slide</u> **24**

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Mar 14, 2024

PD Motor

Symptoms

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Watch Presenta-

Apr 11, 2024

Non-motor

symptoms

Passcode:

tion

Watch Presenta-

August 8, 2024

Nutrition & Diet

Watch Presentation

Passcode: 4KG!*Y!M

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October 24, 2024

Presentation

Slide

Advocacy in Action

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Passcode: I*07d*MD

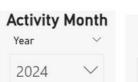
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Virtual Support Groups Attendance 2024





Virtual Support Group Data





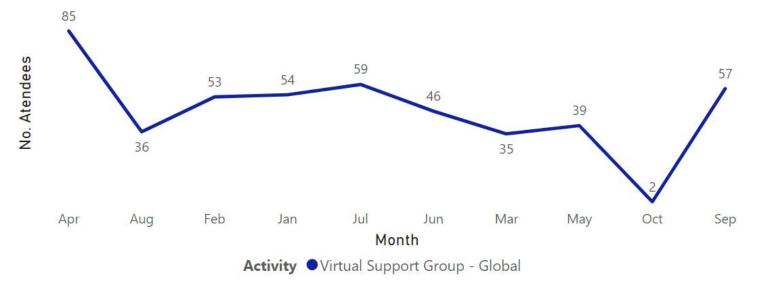


No. Activities

Countries 15

No.

| Month | | Australia | Canada | DR Congo | Egypt | Ethiopia | Gambia | Ghana | Kenya | Nigeria | South Africa | Tanzania | Uganda | UK | USA | Zimbabwe | Total |
|-------|-----|-----------|--------|----------|-------|----------|--------|-------|-------|---------|--------------|----------|--------|----|-----|----------|-------|
| Apr | 48 | 1 | 1 | | 3 | 1 | 2 | 4 | 18 | 19 | | 1 | | 4 | | | 102 |
| Aug | 8 | | | | | | 1 | 5 | 8 | 10 | 2 | | | 2 | 2 | | 38 |
| Feb | 29 | | | | 1 | 1 | | 3 | 9 | 5 | | | 2 | 4 | | | 54 |
| Jan | 23 | | | | 1 | 1 | | 2 | 13 | 7 | 3 | | 1 | 4 | | | 55 |
| Jul | 23 | | | | 1 | | | 4 | 11 | 11 | 3 | 1 | | 4 | 1 | | 59 |
| Jun | 7 | | | 1 | 2 | 2 | 1 | 5 | 14 | 3 | 3 | 4 | | 3 | 2 | | 47 |
| Mar | 10 | | | | 2 | | 1 | 2 | 13 | 9 | | 1 | 1 | 1 | | | 40 |
| May | 11 | | | | | 2 | 1 | 1 | 10 | 10 | | 1 | 1 | 2 | | | 39 |
| Oct | 1 | | | | | | | | 1 | | | | | | | | 2 |
| Sep | 14 | | | | 1 | | | 14 | 6 | 12 | 1 | | | 6 | 2 | 1 | 57 |
| Total | 174 | 1 | 1 | 1 | 11 | 7 | 6 | 40 | 103 | 86 | 12 | 8 | 5 | 30 | 7 | 1 | 493 |





2024 SCHEDULE

- About Parkinson's & Diagnosis 11th Jan 2024 Team Ghana
- Medication management 8th Feb 2024 Team Nigeria, Abuja
- Motor Symptoms of PD 14th March 2024 Team Kenya, Nairobi
- Non-motor Symptoms of PD 11th April 2024 Team Kenya, Mombasa
- Exercise and movement 25th April 2024 Team Egypt
- Emotional well-being 9th May 2024 Team Nigeria and Team Kenya
- Caregiver support 13th June 2024 Team Ghana
- Communication and speech 11th July 2024 Team South Africa
- Nutrition and diet 8th Aug 2024 Team Ghana
- Free session/Recap 12th Sept 2024
- Advocacy in action 24th Oct 2024 Team Ghana

Virtual Support Group Sessions 2025

To ensure interactive and engaging sessions, the Virtual Support Sessions will focus on addressing questions and facilitating discussions related to the specific topic of concern.

- We will revisit the same topics as 2024 but adopt a more collaborative approach.
- Presentations will be shared ahead of the VSG, and participants will be invited to submit up to three questions for discussion on each topic.
- During the VSG, the focus will be on addressing the submitted questions and facilitating any additional discussions.

Register for the VSG: bit.ly/PAVSGM

Ghana











Kenya (Kilifi)









Kenya (Mombasa)









Kenya (Nairobi)









Nigeria (Lagos)





We signed a memorandum of Understanding (MOU) with the esteemed Nigerian Institute of Medical Research (NIMR). (January).



We premiered our first documentary featuring 3 members of ADPF sharing their experience with Parkinson's Disease. (jUNE).



We premiered our first documentary featuring 3 members of ADPF sharing their experience with Parkinson's Disease. (June).



ADPF'S 2024 JOURNEY IN PICTURES



A group photograph of all attendees at the 2nd edition of the #Move4PD awareness walk. (May).



Guests at the 2nd edition of the Parkinson's Disease Symposium themed "Educating, Engaging and Empathizing: Building a Supportive Ecosystem for Parkinson's Awareness and Care". (April).



Warriors engaging in a Walking Football block session ahead of the Walking Football Tournament (October).



UNLOCKING PARKINSON'S CAF



Navigating the Challenges and Opportunities within the

Parkinson's Healthcare System in Nigeria

Professor Njideka Okubadejo presenting her teaching at the Webinar held in celebration of World Parkinson's Disease day. (April).



John Akinola, Senior Programs Manager, teaching the Warriors and Caregivers during our monthly Support group session. (February).



ADPF members at the 2nd edition of the Walking Football for Parkinson's Disease Tournament held in partnership with Parkinson's Africa. (November).

Tanzania







Egypt







Ethiopia







South Africa











Register with VSG and Contacts

Register for the VSG: bit.ly/PAVSGM

Key Contacts:

Rachel or Team Africa: teamafrica@parkinsonsafrica.org

Dr Tash Fothergill-Misbah: tash.fothergill-misbah@newcastle.ac.uk

Tania Park: tania@parkinsonsafrica.org

Your space to share ideas and ask questions





Thankyou



















