

"I'll hold your hand so you won't fall"





Dr. Adewunmi Desalu

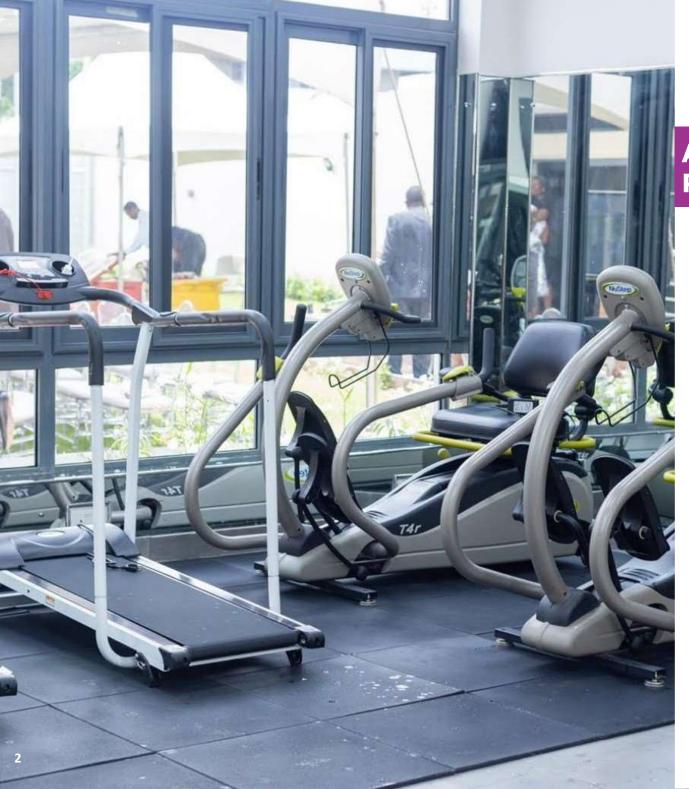
OUR STORY

r. Adewunmi Desalu was an exceptional engineer and mathematician renowned for developments in the fields of science, electronics and space. He is known for two patents & a long career with General Electrics.

Dr. Adewunmi Desalu's power was compromised for nearly ten years by Parkinson's Disease, yet he stood and fought the disease with all the strength he had. He showed courage in the face of challenges that he had no control over, choosing instead to exercise full control over how he accepted his fate and became a Parkinson's Warrior.

The Adewunmi Desalu Parkinson's Foundation (ADPF) will share this story of, and embody, the final ten percent of his life that defines his essence, the resilience, the power engineered by the discipline of yesteryears, which propelled him to fight to the final victory.

The Adewunmi Desalu Parkinson's Foundation (ADPF) was founded to honour his memory and seeks to encourage somebody living with Parkinson's disease, hold their hand so that they do not fall, encourage a caregiver and support a family caring for a loved one – as they journey along the same path that he and his family travelled.



ADEWUNMI DESALU PARKINSON'S FOUNDATION

dewunmi Desalu Parkinson's Foundation (ADPF) is a non-governmental, not-for-profit organisation registered with the Corporate Affairs Commission (Π166351) to support people living with Parkinson's disease (PD) in Nigeria, their care partners and their families.

Parkinson's disease is a degenerative condition of the brain associated with motor symptoms (slow movement, tremors, rigidity & walking imbalance) and a range of non-motor complications (cognitive impairment, mental health disorders, pain and other sensory disturbances).

Motor impairments, painful muscle contractions & involuntary movements contribute to limitations in speech, mobility and many areas of life. The cause of the disease remains unknown and, unfortunately, there is no cure yet.

Adewunmi Desalu Parkinson's Foundation offers a seamless route to diagnosis, medication, rehabilitation and social support at no cost to people living with or impacted by Parkinson's disease in Nigeria; and provides inspiration, tools and a positive environment to enable people with Parkinson's disease live better every day. We intend to continue to lead in providing care and resources that improve quality of life of people living with Parkinson's disease, first in Nigeria and then on the continent, until a cure is found.





VISION

"An Africa, in which all the people impacted by Parkinson's disease have a better quality of life through access to education, care and support."



MISSION

"The Adewunmi
Desalu Parkinson's Foundation
is committed to creating
awareness, building a community
and providing access to
education, care and support to
improve the physical and
emotional wellbeing of people
impacted by Parkinson's Disease."

OBJECTIVES

EDUCATION|| CARE || SUPPORT

- Ensure all people impacted by Parkinson's disease are aware of, and can access, available resources.
- Create and implement a country-wide education, advocacy, and communication campaign to increase awareness on Parkinson's disease and simplify the path to diagnosis.
- Remove barriers and create multiple pathways to access Parkinson's disease care.
- Provide evidence-based interventions to promote diagnosis, treatment and care for Parkinson's Disease.
- Create a network of support groups of Parkinson's disease heroes, caregivers, and families across Africa.
- Build caregiver capacity to cope and facilitate access to health, social, financial & legal support for people impacted by Parkinson's disease.

PROBLEM STATEMENT: WHY THE FOCUS ON PARKINSON'S DISEASE? GLOBAL ESTIMATES

2019: Over 8.5 million Individuals with Parkinson's disease.

2019: 5.8 million disabilityadjusted life years: 81% increase since 2000. 2019: 329,000 deaths over 100% increase since 2000. World Health Organization Parkinson's Disease Fact Sheet: June 13, 2022.

NIGERIA

More than 5 million Nigerians are above the age of 65 and at risk of developing Parkinson's disease. (*Parkinson's Disease in Nigeria. Oluwole, Helen 2018*).

Parkinson's disease has been a rare disorder for most of human history but according to the Global Burden of Disease study, neurological disorders are now the leading source of disability globally; and disability and death due to Parkinson's disease are increasing faster than for any other neurological disorder.

In June 2022, the World Health Organization launched a Technical Brief on Parkinson's disease, highlighting it as an urgent public health issue and stating crucial areas for action with a focus on low-and-middle-income countries (LMIC), including Nigeria. Research shows that cases of Parkinson's disease across Africa will rise significantly in the coming years and this Parkinson's disease pandemic will require heightened activism, focused planning and an innovative, deliberate approach.

The United Nations Sustainable Development Goal 3 (SDG3) aims to **ensure healthy lives** and **promote well-being for all at all ages.** With Adewunmi Desalu Parkinson's Foundation's focus on Parkinson's disease, we target an often-overlooked demographic - the elderly - thereby actively advancing the goal's objective for no one to be left out or overlooked.





YEAR 1APRIL 2022 TO APRIL 2023

"I'll hold your hand, so you won't fall"

Rasheda Ali 2005



ONE YEAR AT A GLANCE

At May 2023



One fully equipped Parkinson's disease rehabilitative care facility commissioned; doubling as a social hub for people with Parkinson's disease (PWPs), caregivers & family members - the Adewunmi Desalu Parkinson's Centre.



Diagnosis Referrals

Referrals from Adewunmi Desalu Parkinson's Foundation to Lagos University Teaching Hosp ital (LUTH) for Parkinso n's disease diagnosis by a neurologist.



Assessments by Physiotherapist

Comprehensive assessments of PwPs by Adewunmi Desalu Parkinson's Foundation consulting Physiotherapist to design treatment Plans and slow down the progression of the disease.



Members with Custom **Treatment Plans**

Physiotherapy and other exercise regimens actively implemented by consulting physiotherapist and support staff. At least one session per member delivered every week.



Weeks of Physical Therapy

Weeks during which the Adewunmi Desalu Parkinson's Centre has been open to PwPs to come in to implement their custom Treatment Plans.



Individual Physic al Therapy Sessions

Individual physical therapy and exercise sessions undertaken by people living with Parkinson's disease at Adewunmi Desalu Parkinson's Centre.



ONE YEAR AT A GLANCE

At May 2023



12

Support Groups

12 Support Group sessions hosted inperson in Surulere, Lagos, Nigeria and online across eight (8) African countries.



Health Workers Educated: World Parkinson's Day Webinar

44 Non-Specialist Healthcare Workers equipped to easily identify symptoms of Parkinson's Disease and facilitate prompt diagnosis.



120

1st Parkinson's Disease **Symposium**

Hosted the first Parkinson's Disease Symposium in Nigeria, convening 120 stakeholders in-person and online to address challenges in providing care and support to people with Parkinson's disease specific to the Nigerian context.



30

Press and **Media Features**

Achieved 30+ press and media features for Parkinson's disease awareness across television, radio, digital and print media.



Partnerships and Alliances

Secured seven (7) partnerships/al liances and affiliations with local and global Parkinson's disease stakeholder organizations for collaboration, knowledge exchange, Parkinson's disease research possibilities, improved credibility and influence

WHAT DO WE DO?



ADEWUNMI DESALU PARKINSON'S FOUNDATION

POEMUNMI DESCRIE

FINSON'S FOUNDARIO

REVOLVING PROGRAMS

MEDICATION ASSISTANCE PROGRAM

SOCIAL

To facilitate access to medication at no cost to PwPs.



AWARENESS & ADVOCACY

To educate the public on Parkinson's disease through trainings, sensitization outreaches, erase the stigma and influence public health policy



HOSPITAL REFERRAL For diagnosis by a

Neurologist, to confirm or rule out Parkinson's disease



HANDWRITING **CLASSES**

connections, questions,

SUPPORT GROUPS

emotional support

and practical advice.

A safe space for

To combat Micrographia and improve handwriting legibility



ASSESSMENT BY **PHYSIOTHERAPIST**

To measure the impact of Parkinson's disease on movement, function and safety



as possible



PHYSIOTHERAPY

To maintain or improve function, independence and quality of life.



For improved balance and gait **function**



ROCK STEADY BOXING

To improve agility, coordination, and balance



2023 - 2025 PROJECTS EDUCATION



An annual awareness and fundraising event that features different forms of movement (walking, cycling, dancing etc) to educate the public and garner support for Parkinson's disease (PD) and the peculiar challenges of people impacted by the condition.



Research: Understanding Parkinson's Disease Awareness in Nigeria

In Nigeria, there is a lack of data on Parkinson's disease awareness. This research will identify:

- Current Parkinson's disease awareness;
- Knowledge gaps and barriers;
- · Effective education strategies;
- The effect of Parkinson's disease education on diagnosis and management of the disease.



"Shakes and Freezes"

A Parkinson's disease awareness event and fundraiser in the form of an art exhibition.

Artworks created by people living with Parkinson's disease as part of their treatment regimen will also be on display.

2023 - 2025 PROJECTS EDUCATION



Parkinson's Disease Radio Drama Series

A six-part radio drama series in English and translated into local languages, telling short, fictional stories about people living with Parkinson's disease; focusing on challenges and experiences, as well as the impact that the condition has on their loved ones and their communities.



Digital Resource Bank

The 'Resources' section of the Adewunmi Desalu Parkinson's Foundation website is dedicated to offering up-to-date educational resources and information about Parkinson's disease, treatment options, best practices, support groups, innovations and research.



Punch Out Parkinson's Disease

A boxing mini-Tournament to raise awareness on the importance of boxing as an exercise that helps to keep symptoms of Parkinson's disease in check, improve balance, muscle control and gait.

2023 - 2025 PROJECTS CARE



Medication Asisstance Program

Our Medication Assistance Program provides free medication to individuals with Parkinson's disease who cannot afford it.

The Adewunmi Desalu Parkinson's Foundation partners with medication manufacturers and suppliers to offer this support.

The program also collects data on medication usage and expenses related to Parkinson's disease.

Additionally, we educate program participants about the importance of adhering to their prescribed medication.



Research: Alternative Parkinson's Disease Treatments

The primary focus of this research is to explore alternative or indigenous treatments for Parkinson's disease in Nigeria to discover effective solutions and potentially find a cure.

By integrating scientific research with indigenous knowledge and fostering collaboration between medical professionals and traditional healers, we can enhance our understanding and treatment of the disease.

While the existing treatments for Parkinson's disease involve medications and surgery, a definitive cure has not yet been found.



Teletherapy and Telemedicine Program

Our Telemedicine & Teletherapy Program aims to provide remote care services to PWPs using electronic communication and technology.

We will offer rehabilitative therapies from our Centre to individuals facing distance or mobility challenges.

We will also connect them with specialist care, overcoming manpower limitations in Nigeria.

This Program will improve healthcare access, enhance medical records, improve coordinated care and reduce logistical expenses for PWPs.

2023 - 2025 PROJECTS CARE



Parkinson's Disease Diagnosis Training for Healthcare Providers

Our Parkinson's Disease Diagnosis trainings offer essential diagnosis information to healthcare providers who are not experts in Parkinson's disease, enabling them to identify symptoms and promptly refer those who present possible symptoms to neurologists for proper diagnosis.



Parkinson's Disease Caregiver Training for Healthcare Providers

Our Parkinson's Disease Caregiver Trainings are designed to help healthcare providers understand how to care for people with Parkinson's disease, develop interprofessional care plans and cooperate for optimal service delivery.

2023 - 2025 PROJECTS SUPPORT



In-Person Support Groups

Our in-person support group for individuals living with Parkinson's disease and their caregivers physically connects them with others who understand their experiences; providing a safe space to express feelings, ask questions and learn from one another. We plan to expand to several locations, allowing for community close by.

Segmentation ensures tailored support for everyone involved.



Virtual Support Groups

The convenience of our virtual support group for people impacted by Parkinson's disease enables them connect with others from the comfort of their own homes,

Regardless of location, our online platform provides a secure space to share feelings, ask questions, and gain valuable insights from a community that understands the journey.



Caregiver Support Program

This program is designed to provide support and resources for caregivers of Parkinson's patients, such as respite care, mental health counseling, and financial empowerment.

HOW CAN YOU HELP?

Parkinson's disease presents and the gaps we have identified it is necessary to educate a wider audience and reach a larger number of people impacted by the disease with the help that they need.

"Help make a difference! Support a program today!"



ADEWUNMI DESALU PARKINSON'S CENTRE







Cross-section of Boxing Room for improved balance

Boxing balls

Consulting room for Physiotherapy







Library with Parkinson's educational resources

Fitness equipment

Low impact treadmills and recumbent elliptical bikes



Resource Centre for use by Parkinson's Researchers at no cost



Station gym

Low impact gym equipment and elliptical bike

OUR ORGANISATION'S JOURNEY IN PICTURES



Cross-section of participants in Adewunmi Desalu Parkinson's Foundation Awareness Walk -



Channels TV coverage of #Walk 4
Parkinson's disease - the Awareness
Walk organised in honour of Col. Guy



Stop the stigma. Stop the shame. Talking about Parkinson's on Nigeria Info FM



Parkinson's Awareness and sensitization visit to the Lagos State old people's Home, Yaba Lagos.



Adewunmi Desalu Parkinson's Foundation Awareness Campaign - Mrs. Morin Desalu, Mrs. Omotola Thomas and Col. Guy Deacon live on air with Yaw of Wazobia FM



Panel comprising people with Parkinson's disease and Caregivers sharing their journey and unique experience with Parkinson's



Parkinson's Awareness - Panel comprising people with Parkinson's disease and caregivers



Adewunmi Desalu Parkinson's Foundation Stakeholder Engagement - Meeting to discuss collaboration with LUTH for Neurology Consultations



An Adewunmi Desalu Parkinson's Foundation member being guided though physiotherapy in our low- impact gym



Adewunmi Desalu Parkinson's Foundation member undergoing her physiotherapy session, as exercise has been proven to slow down the progression of Parkinson's disease



PARKINSON'S AWARENESS & ADVOCACY: TELEVISION & RADIO



Oluyemisi Adedayo, Executive Director, Adewunmi Desalu Parkinson's Foundation on Arise TV discussing the global theme for World Parkinson's Day 2023, #Take6ForPD.



John Akinola, Senior Programs Manager, Adewunmi Desalu Parkinson's Foundation on Channels TV discussing the global theme for World Parkinson's Day 2023, #Take6ForPD.



John Akinola, Senior Programs Manager, on Wazobia TV raising Parkinson's disease awareness in a local dialect for Parkinson's Awareness Month



Member, Mrs. Ifeanyi, demonstrating Adewunmi Desalu Parkinson's Foundation's rehabilitative intervention for the Channels TV Special Report on World Parkinson's Day, 2023.



Executive Director, Oluyemisi Adedayo, on Arise TV discussing the global theme for World Parkinson's Day 2023, #Take6ForPD.



Senior Programs Manager, John Akinola, discussing Parkinson's disease alongside Rachel Agwu of Parkinson's Africa on Lagos Traffic Radio during Parkinson's Awareness Week

WEBINAR FOR HEALTHCARE PROFESSIONALS - WORLD PARKINSON'S DAY 2023



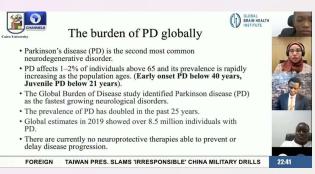
Webinar to educate non-specialist Healthcare Workers on identifying Parkinson's disease symptoms for prompt diagnosis on World Parkinson's Day, April 11, 2023



Dr. Shaimaa El-Jaafary, Consultant Neurologist and Professor of Neurology, breaking down the methodology for identifying Parkinson's disease.



Executive Diirector, Adewunmi Desalu Parkinson's Foundation, sharing the vision behind training healthcare workers to identify Parkinson's disease symptoms for faster diagnosis



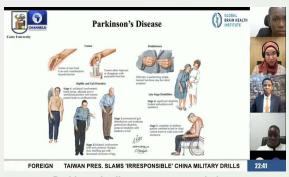
Establishing the global burden of Parkinson's disease and sharing statistics from clinical studies.



Dr. Adefemi Daniel, Medical Director, Evercare Hospital and Consultant Neurologist, educating healthcare professionals on multidisciplinary approach for Parkinson's disease management



Consulting Physiotherapist, Adewunmi Desalu Parkinson's Foundation, Abraham Adeogun describing the Adewunmi Desalu Parkinson's Foundation's integrated approach to rehabilitation



Parkinson's disease symptoms being vividly explained by the neurologist during the Webinar for Healthcare professionals



Channels TV Special Report on World Parkinson's Day Webinar for Healthcare Professionals



Programs Officer, Adewunmi Desalu Parkinson's Foundation, Tolu Oyenuga describing Member Management and Support

1ST PARKINSON'S DISEASE SYMPOSIUM



attendees to its 1st Parkinson's Disease Symposium, also the first Parkinson's Disease Symposium in Nigeria.



Dr. Ikechukwu Aganweze, Consultant Neurologist and Keynote Speaker at the 1st Parkinson's Disease Symposium, discussing the challenges of Parkinsons Disease Care & Management in Nigeria and possible solutions.



Ms. Oluyemisi Adedayo, Executive Director, Adewunmi Desalu Parkinson's Foundation highlighting the solutions the Foundation currently provides and calling for support and partnership on proposed projects and programs.



Panel Session during the 1st Parkinson's Disease Symposium, featuring PWPs, a caregiver, neurologist, physiotherapist, Ministry of Health representative, and representative of private sector health funder.



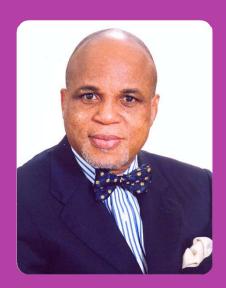
Cross-section of attendees at the 1st Parkinson's Disease Symposium of the Adewunmi Desalu Parkinson's Foundation to address challenges in providing care and support to people with Parkinson's disease.



Cross-section of in-person attendees during the 1st Parkinson's Disease Symposium with a total of 120 attendees combined, in-person and online.



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Chair,
Guardian Newspapers

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If you are a person living with Parkinson's disease (PwP), a member of a patient's family, a caregiver, a friend of a PwP, an individual or corporate body wanting to support our work, please contact:

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