



# ADEKUNLE DESALU PARKINSON'S FOUNDATION

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

Rasheda Ali 2005

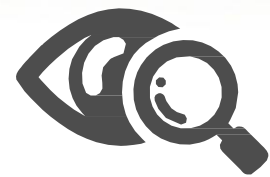


## ADEWUNMI DESALU PARKINSON'S FOUNDATION

**A**dewunmi Desalu Parkinson's Foundation (ADPF) is a non-governmental, not-for-profit organisation registered with the Corporate Affairs Commission (IT166351) to support people living with Parkinson's disease (PD), their care partners and their families.

PD is a degenerative condition of the brain associated with motor symptoms (slow movement, tremors, rigidity and walking imbalance) and a range of non-motor complications (cognitive impairment, mental health disorders, pain and other sensory disturbances). Motor impairments, involuntary movements and painful muscle contractions 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.

ADPF offers a seamless route to diagnosis, medication, rehabilitation and social support at no cost to people living with or impacted by PD in Nigeria; and provides inspiration, tools and a positive environment to enable people with PD live better everyday. Until there is a cure for PD, ADPF shall continue to lead the way in providing care and resources that improve quality of life, first within Nigeria and then on the continent.



#### VISION

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



**Dr Adewunmi Desalu**

## OUR STORY

**D**r. Adewunmi Desalu was a famous engineer and mathematician renowned for developments in the fields of science, electronics and space. He is known for two patents and a long career in the General Electric's stable.

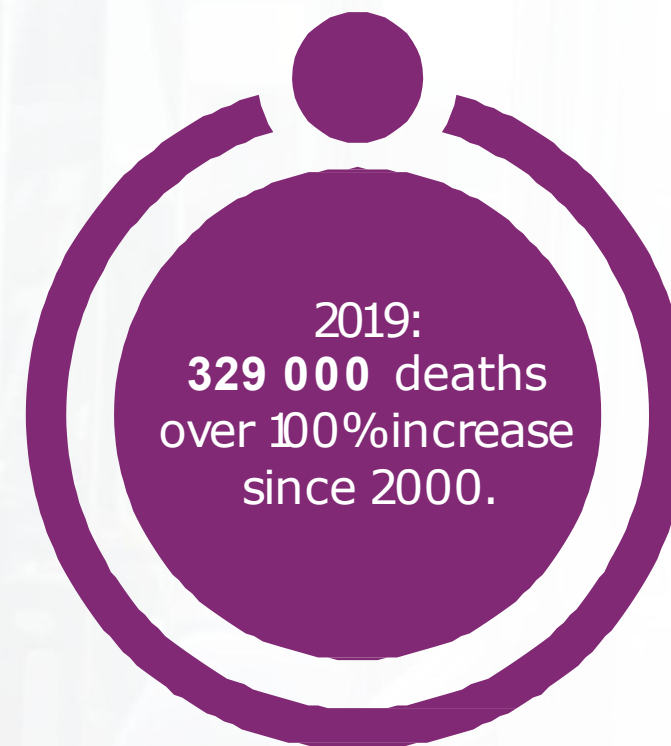
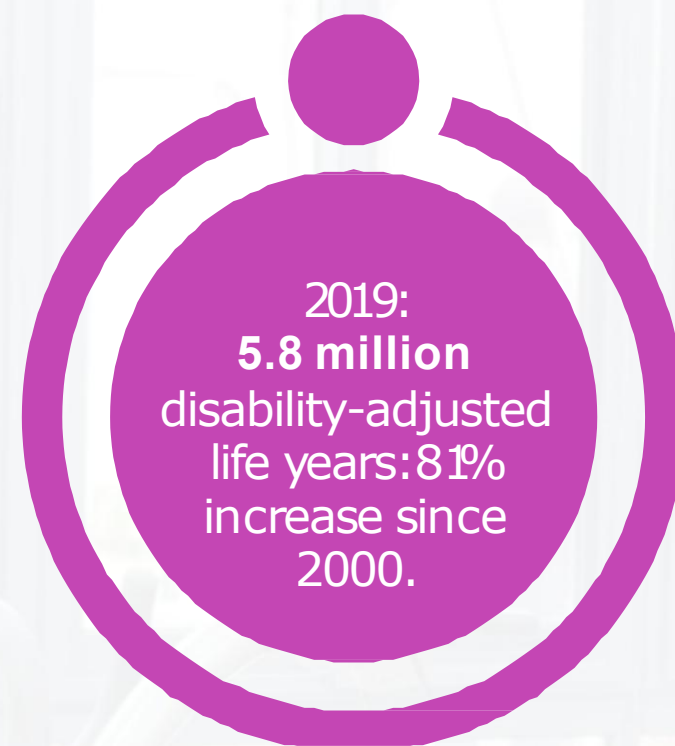
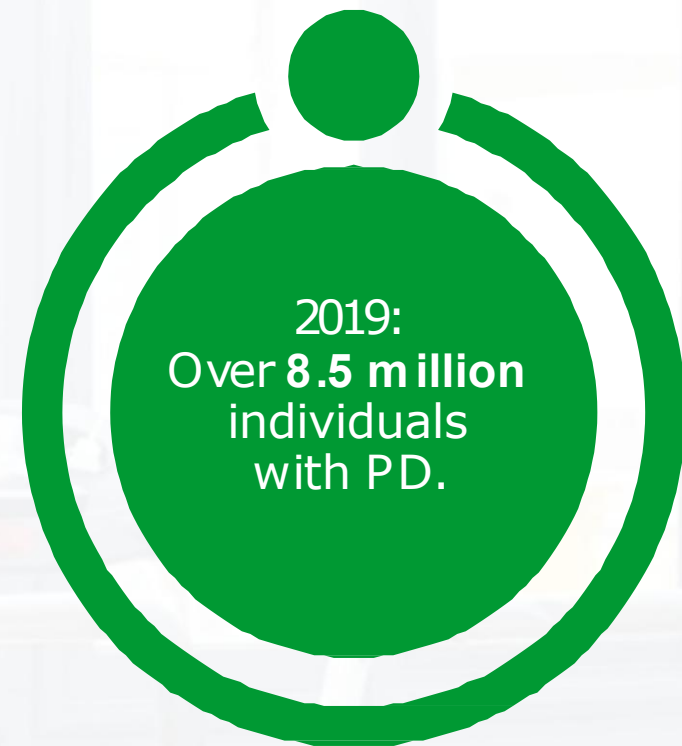
Dr. Adewunmi Desalu's power was compromised for nearly ten years by Parkinson's Disease, yet he stood and fought the disease with all the strength he had. He showed courage in the face of challenges that he had no control over, choosing instead to exercise full control over how he accepted his fate and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

## PROBLEM STATEMENT: WHY THE FOCUS ON PD?

### GLOBAL ESTIMATES



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*(World Health Organization Parkinson's Disease Fact Sheet: June 13, 2022).*

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### NIGERIA

Approximately **5.25 million** Nigerians are above 65 years and at risk for developing PD. (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 PD 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 SDG3 aims to ensure healthy lives and promote well-being for all at all ages. With ADPF'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.





# TEN MONTHS AT A GLANCE



**06**

## Diagnosis Referrals

Referrals from ADPF to Lagos University Teaching Hospital (LUTH) to establish PD diagnosis by a neurologist



**14**

## Assessments by Physio-therapist

Comprehensive assessments of PwPs by ADPF Physiotherapist to design treatment Plan and slow down the progression of the disease



**13**

## Custom Treatment Plans Being Implemented Weekly

Physio and other exercise regimens in active execution by ADPF physiotherapist and support staff at least once weekly



**30**

## Weeks of Physio Sessions

Weeks during which the ADPF centre has been open to PwPs to come in to implement their custom Treatment Plans.



**183**

## Individual Physio Sessions

Over Seventy individual Physiotherapy and exercise sessions undertaken by PwPs at the Centre since June 20, 2022

*"I'll hold your hand, so you won't fall"* ————— Rasheda Ali 2005



# REVOLVING PROGRAMS

## MEDICATION ASSISTANCE PROGRAM

To facilitate access to medication at no cost to PwPs.



## AWARENESS & ADVOCACY

To educate the public PD through trainings, sensitization outreaches. To erase the stigma and influence public health Policy.



## HOSPITAL REFERRAL

For diagnosis by a Neurologist, to confirm or rule out PD



## ASSESSMENT BY PHYSIOTHERAPIST

To measure the impact of PD on movement, function and safety



## PHYSIOTHERAPY

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



## ROCK STEADY BOXING

To improve agility, coordination, and balance



## DANCE THERAPY

For improved balance and gait function



## HANDWRITING CLASSES

To combat Micrographia and improve legibility



## SOCIAL SUPPORT GROUPS

A safe space for connections, questions, emotional support and practical advice.



## SPEECH THERAPY

To help maintain as many communication skills as possible



# 2023 PROJECTS

## EDUCATION



### Research: Understanding Parkinson's Disease Awareness in Nigeria

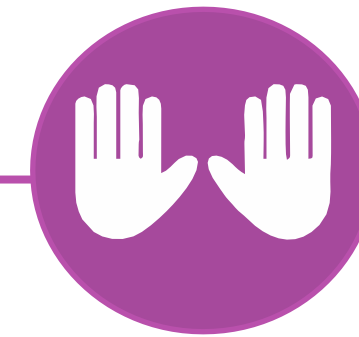
In Nigeria, there is a lack of data on PD awareness. This research will identify:

1. Current PD awareness;
2. Knowledge gaps and barriers;
3. Effective education strategies;
4. The effect of PD education on diagnosis and management of the disease.



### Walk 4 Parkinson's

A walk to raise awareness about Parkinson's disease (PD) and the challenges that people with the condition face.



### Shakes and Freezes

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

Artworks created by PwPs as part of their treatment plan will also be on display.

# 2023 PROJECTS

## EDUCATION



### Punch Out Parkinson's Disease

A boxing exercise event to raise awareness on the importance of boxing as an exercise that helps to keep the symptoms of Parkinson's in check



### Parkinson's Disease Radio Drama Series

A four-part radio program that tells fictional stories about people living with Parkinson's disease; focusing on their 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 ADPF 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.

# 2023 PROJECTS

## CARE



### Teletherapy and Telemedicine Program

Our Telemedicine & Teletherapy Program uses electronic communication and information technologies to provide care services to PWPs.

We are able to deliver the rehabilitative therapies that we offer at our Centre to anyone unable to visit in person - whether because of distance or mobility challenges.

In addition, we are able to connect them with specialist care, which is a challenge in Nigeria due to manpower limitations.

This Program makes care accessible and convenient; improves communication and coordination between PWPs and health workers; enables the easy storage and sharing of medical records, test results, and other information; and reduces expenses incurred visiting healthcare facilities.



### Medication Assistance

Our Medication Assistance Program provides medication to individuals living with Parkinson's disease who are unable to afford their medication.

ADPF partners with suppliers of Parkinson's medication to provide them at no cost to program participants. This program will also serve to provide current data on Parkinson's disease medication usage and expenses.

We also educate program participants about the importance of taking medication as prescribed.



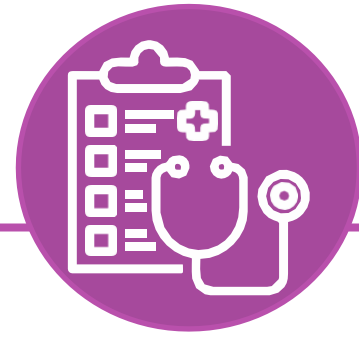
### Research to investigate alternative treatments for Parkinson's disease in Nigeria

Current treatments for Parkinson's disease include medications and surgery, but there is no cure yet.

The primary objective of this research is to investigate alternative or indigenous, yet efficacious treatments for Parkinson's disease in Nigeria, and potentially find a cure.

# 2023 PROJECTS

## CARE



### PD Care Training for Healthcare Workers

Training courses designed to help healthcare professionals understand how to care for people with Parkinson's disease, develop interprofessional care plans and cooperate for optimal service delivery.



### PD Diagnosis Training for Healthcare Providers

Training courses offering essential diagnosis information to healthcare professionals who are not experts in Parkinson's disease, enabling them to identify symptoms and promptly refer people to neurologists for proper diagnosis.

# 2023 PROJECTS

## SUPPORT



### Caregiver Support Program

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



### Support Groups

Many Parkinson's patients and caregivers may benefit from connecting with others who are going through similar experiences.

Support groups provide a space for individuals to share their feelings, ask questions, and learn from each other.

This program will enable the establishment and running of nodes of support groups wherever there are clusters of Parkinson's patients.

The intended model will enable segmentation by age, gender or needs (e.g. Caregivers can be separate from PWP) for greater impact.

# ADPF FACILITY



**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 JOURNEY IN PICTURES



Cross-section of participants in ADPF Awareness Walk - June 11, 2022



Channels TV coverage of Walk 4 PD - the Awareness Walk organised in honour of Col. Guy Deacon



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.



ADPF 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 PD



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



ADPF Stakeholder Engagement - Meeting to discuss collaboration with LUTH for Neurology Consultations and Referrals



An ADPF member being guided through physiotherapy in our low-impact gym



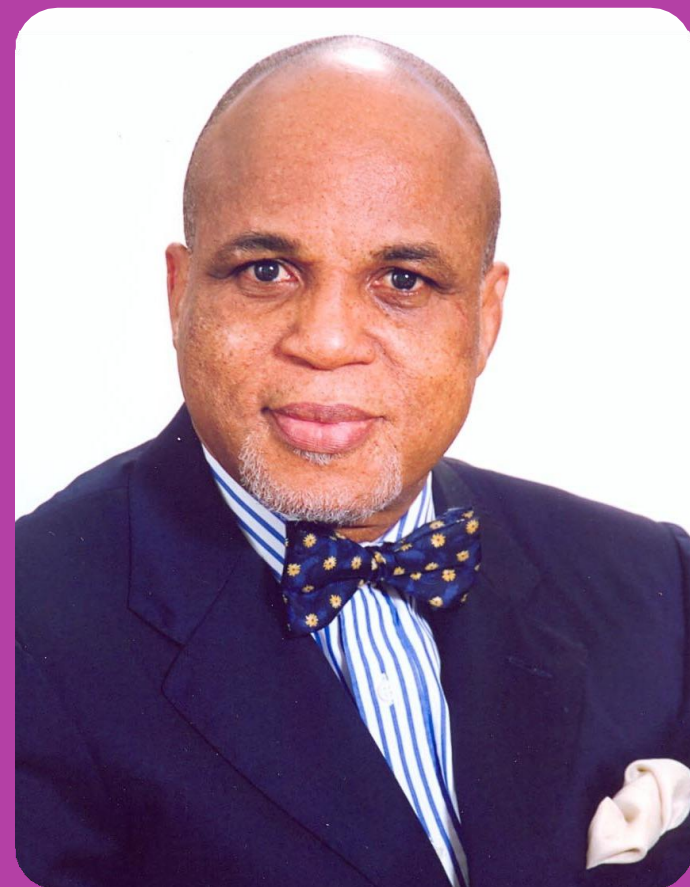
ADPF member undergoing her physiotherapy session, as exercise has been proven to slow down the progression of PD



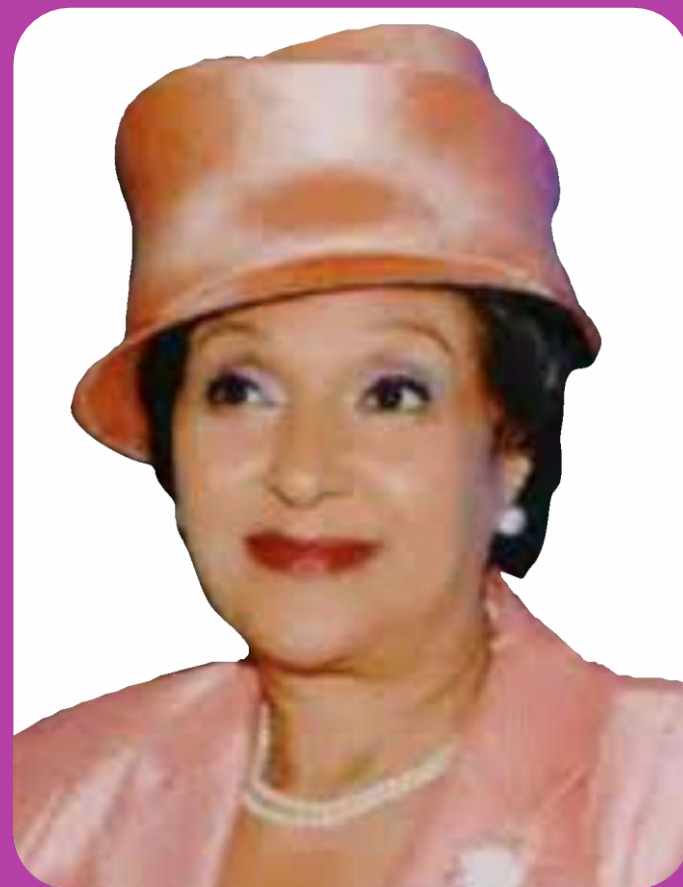
An ADPF member, his caregiver and the physiotherapist in a session



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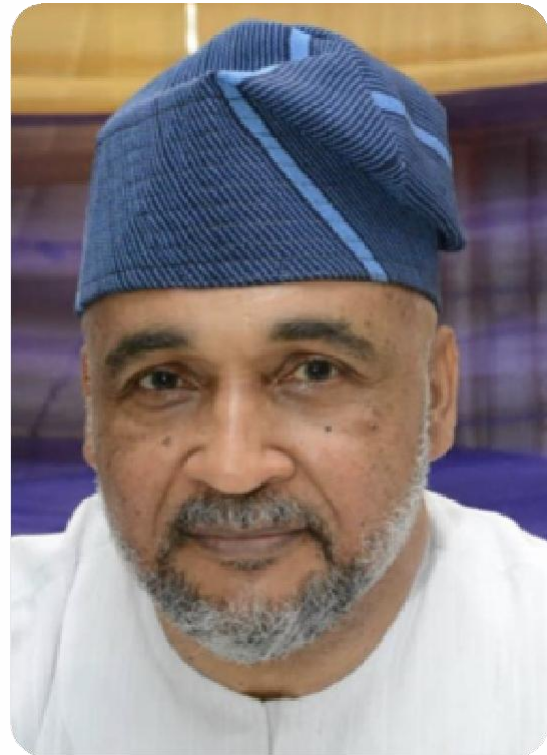


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