2020-2025
Impact Report

Proof of Possibilities

5 Years. Many Voices. One Community

Zenebech
Care Partner, Ethiopia

EXECUTIVE SUMMARY

Over the past five years, Parkinson's Africa has grown from a small personal effort into a pan-African organisation working to close the gap between the rising number of Africans living with Parkinson's disease and the limited access to diagnosis, treatment, and support. We now work in nine countries and have reached more than 30,000 people through culturally relevant educational materials, research and advocacy partnerships, awareness campaigns, and support groups.

Our work has helped more people recognise symptoms earlier, seek help sooner, and feel less alone. Stories from across Africa highlight common challenges – late diagnosis, stigma, and difficulty accessing medication – but also show the hope, strength, and connection that come from shared support.

In the years ahead, we will continue to strengthen community-led services, expand our multilingual education work, improve access to clear information, and support local groups to grow. Our goal remains simple: no African should face Parkinson's alone.

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Section One

WHO WE ARE

Parkinson's Africa was founded on the belief, enshrined in Article 25 of the Universal Declaration of Human Rights, that everyone has the right to an adequate standard of living, including access to healthcare, support, and essential resources.

We exist to eliminate barriers to good health and well-being and to ensure access to healthcare, support, and essential resources for Africans affected by Parkinson's disease.

FOUNDER'S MESSAGE

OMOTOLA THOMAS
Founder / Trustee Chair

In November 2017, I wrote an open letter titled "Where Are You?" from a place of deep isolation and unanswered questions. Seventeen months into my Parkinson's diagnosis, I had yet to meet another African living with the condition. As a young Nigerian woman diagnosed with what was widely perceived to be an "old white man's disease," I struggled to make sense of a reality for which I had no frame of reference. Though surrounded by love and support, I felt profoundly alone.

At the same time, I was navigating growing tension between my cultural and religious beliefs and my medical reality – a space in which my diagnosis, and even my acceptance of it, sometimes felt like a spiritual failing. Where Are You? was both a cry for connection and an attempt to reach across a divide shaped by misunderstanding, stigma, and silence. For me, that divide threatened my psychological safety; for countless others, it threatened far more – access to relevant information, support, life-changing care, and the ability to live with dignity.

> **Over the past five years, we have evolved from a resource-constrained initiative into a pan-African organisation grounded in dignity, partnership, and strategic focus.**

Bridging that divide–what we now call the Parkinson's Chasm© – is why Parkinson's Africa exists.

Our early work was necessarily responsive – shaped by immediate need, limited resources, and the realities on the ground. Over time, we have gradually shifted from addressing individual gaps to intentionally constructing pathways across this Parkinson's Chasm. This report reflects that shift.

As you read through, you will see how our journey has unfolded – the lessons that have shaped us, the people we have walked alongside, and the moments that have quietly strengthened our resolve to do this work with honesty, intention, and care. You will also encounter stories that reflect the complexities and challenges inherent in a Parkinson's diagnosis, and the courage and resilience of those who navigate this journey daily. I hope these stories resonate with you and invite you to walk with us as we continue bridging the Parkinson's Chasm.

Today, we are no longer standing on one side of that chasm asking, "Where Are You?"

Instead, we are answering, "We are here."

To the people affected by Parkinson's, to local and international organisations, support groups, funders, partners, and every one of you who stands with us each day – thank you. Your trust and commitment continue to shape and strengthen this work across the continent.

OUR VISION

A future where every African affected by Parkinson’s disease has equitable access to the resources needed to make informed health decisions and lead fulfilled lives.

OUR MISSION

Transform the Parkinson’s disease landscape across Africa, community by community, into societies where those affected have access to quality healthcare, research, support, information, and educational resources.

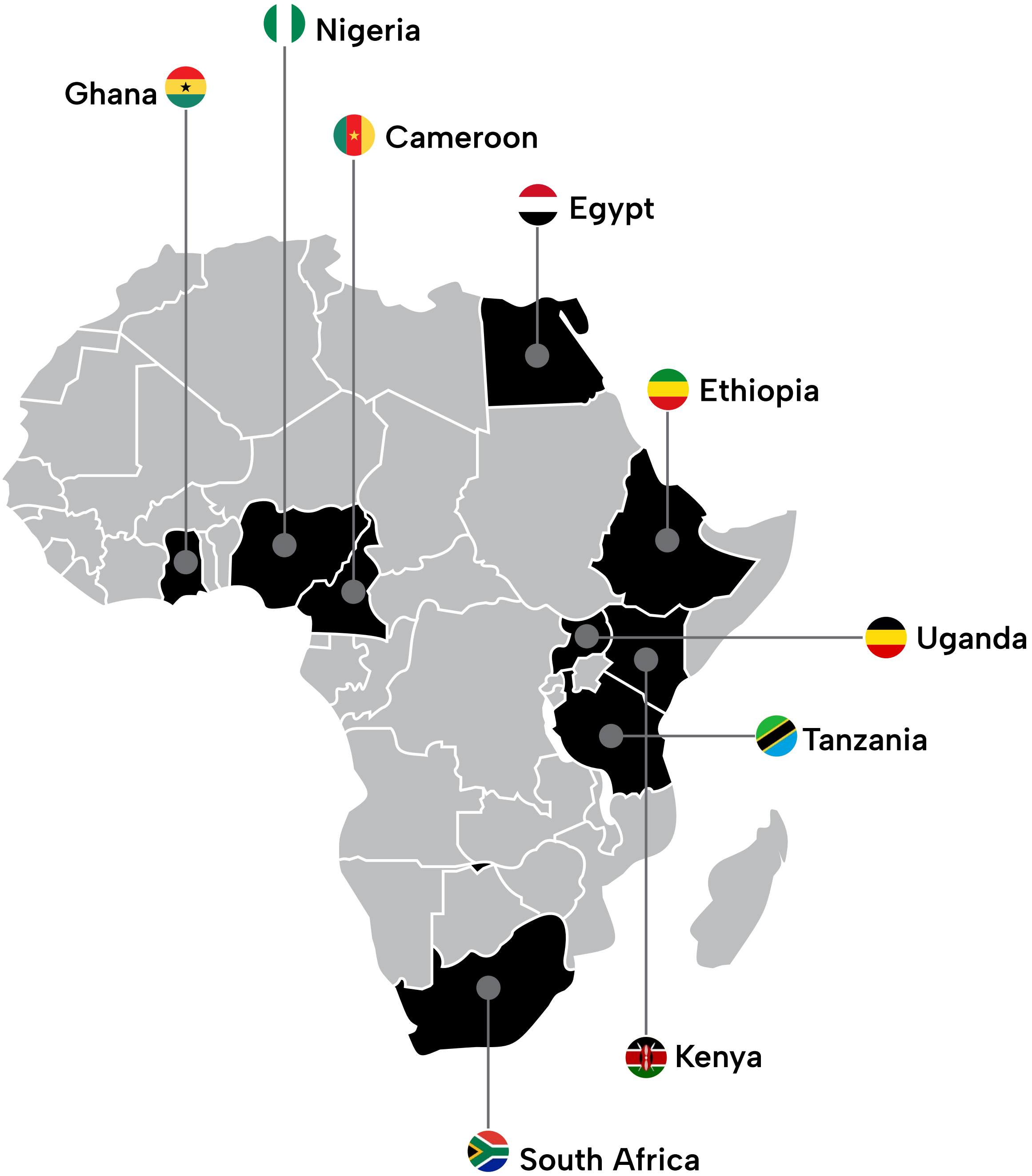
OUR FOUNDATIONAL **PILLARS**

- **Awareness**
- **Education**
- **Care**
- **Support**
- **Advocacy**

WHERE WE WORK

Parkinson's Africa works in partnership with local community engagement leads across the continent, empowering local voices and leveraging their deep-rooted expertise to adapt our support to unique regional needs. We currently collaborate across nine countries – building awareness, strengthening support systems, and improving access to care.

As we expand, our goal remains clear: to reach every African community affected by Parkinson's and ensure no one faces the condition alone.



OUR JOURNEY AND MILESTONES

Our journey has been shaped by the realities of Africans living with Parkinson's and the determination to ensure their experiences inform our approach and solutions. Over time, this commitment has grown into a network of programmes, partnerships, and community-led initiatives across multiple countries. Every milestone represents learning, collaboration, and the expanding visibility of Parkinson's disease in places where it was once overlooked. This timeline shows not just how far we have come but also how each step is laying the foundation for a future where every African affected by Parkinson's can access the care and support needed to thrive.

2009–2016

Search for diagnosis – lived experience that later shaped the organisation's purpose.

2016

Diagnosis confirmed – public advocacy and peer connection begin.

2016–2020

Informal network-building through volunteering, awareness efforts, and early advocacy.

July 2020

World Brain Day

First fundraising campaign launched and informal launch of Parkinson's Africa.

December 2020

UK charity registration completed – official launch of Parkinson's Africa.

January 2021

First external grant secured from the Farah Foundation, enabling initial medication support.

March 2021

Grant secured from UCL Global Engagement / Grand Challenges, supporting academic collaboration and health literacy engagement in collaboration with IPDGC-Africa.

April 2021

S.E.E. Health Literacy Campaign launched.

February–July 2022

The Janet Owens Legacy Fund establishes a partnership and commits to multi-year strategic support, providing critical organisational stability.

September 2022

TraPCAf project commences – Parkinson's Africa leads Community Engagement and Involvement within a major multi-year research collaboration funded by the National Institute for Health and Care Research (NIHR).

December 2022

Grant secured from Vitol, enabling the launch of the Walking Football for Parkinson's Disease (WFPD) initiative.

June 2023

First Walking Football for Parkinson's tournament held.

Nov. 2023–Present

Expansion of ongoing programmes: Walking Football, TraPCAf CEI activities, awareness campaigns, virtual support groups, and conference participation.

December 2023

Second grant secured from Vitol, sustaining the Walking Football initiative.

November 2024

Second Walking Football tournament held.

November 2025

Third Walking Football tournament held.

June 2025

LES Energy CSR partnership commences.

March 2026

First Annual Virtual Town Hall convened, and 5-Year Impact Report launched.

"Beyond what medication can answer, there is still the need for social support. You can't fully care for people living with Parkinson's disease without having associations and organisations that provide this type of support – they are indispensable."

Prof. Njideka Okubadejo

Professor of Neurology, College of Medicine, University of Lagos.

Pioneer Chair, Movement Disorder Society – Africa Section.

Section Two

OUR STRATEGY

Our strategy is grounded in the urgent need to address the growing gap between the rising prevalence of Parkinson's disease across Africa and the limited capacity of health systems to respond. To close this gap, we focus on strengthening community connection, expanding access to culturally relevant education, and supporting practical pathways to care. This approach ensures that the experiences of people living with Parkinson's continue to guide how solutions are designed and delivered across the continent.

The **Parkinson's Chasm©**

Removing Obstacles, **Creating Pathways**

Crossing the Parkinson's Chasm requires more than a single solution. While the bridge represents long-term routes to formal care, the ladders provide vital lifelines for those already within the chasm, offering a practical way back toward dignity. Above, the aerial car reflects the use of technology to overcome distance and access barriers.

THE PARKINSON'S **CHASM©**

Why We Must Build Fast

Parkinson's disease is now the fastest-growing neurological condition in the world, affecting more than 10 million people today and projected to double by 2040. Africa is not exempt from this rise; however, the region's healthcare systems, historically structured to combat infectious diseases, now face a disproportionate challenge in managing this rapid surge in chronic neurological needs.

For many across the continent, a Parkinson's diagnosis can feel like standing on one side of a gap you cannot cross. On the other side lies what every person deserves: good care, dignity, understanding, support, and clear information. But for millions of Africans, that gap remains painfully wide.

This wide and growing gap is what we call the **Parkinson's Chasm.**

On the near side of this gap, families face a set of barriers that make timely diagnosis and care almost impossible. These include:

Socio-cultural barriers	Stigma, fear, and spiritual interpretations of symptoms that delay help-seeking.
Health-system barriers	Severe shortages of specialists – often just one neurologist serving millions, compared with one per 20,000–50,000 people in higher-income regions–leading to frequent misdiagnosis and the reality that 40–60% of Africans living with Parkinson's are never formally diagnosed.
Economic and policy barriers	High treatment costs, poor insurance coverage, and limited inclusion of Parkinson's in national health systems.
Structural barriers	Long travel distances, unreliable transport, and limited access to mobility aids or digital tools.
Research and data gaps	Limited prevalence data and low African participation in global research efforts.

Together, these barriers widen the gap that defines the Parkinson's Chasm.

THE COST OF INACTION

When the chasm remains unbridged, people lose mobility, employment, and independence; sometimes, during their most productive years. Family members, often women, are forced to leave the workforce to provide full-time care, increasing the risk of long-term economic instability. Building fast matters because Parkinson's is a progressive condition; every year of delay results in a loss of function that cannot be regained.

OUR THEORY OF **CHANGE**

The CLIMB Framework

Our strategy is built around the urgent need to bridge the Parkinson's Chasm – the growing divide between the rising prevalence of the disease across Africa and the limited health–system capacity to respond.

To close this gap, we utilise our CLIMB framework to connect communities, listen to lived experiences, and provide culturally relevant education. By mobilising local leadership and building sustainable health–system pathways, we ensure our approach is impact–driven and shaped by those we serve. Our goal is to ensure that dignity, support, and knowledge are accessible to everyone living with Parkinson's across the continent.

Parkinson's Africa + Community Partners

Working in partnership to enable change

HOW WE CONTRIBUTE

Connect
Strengthen peer networks and create safe spaces for shared learning and mutual support.

Listen
Centre lived experience to guide our work, ensure relevance and challenge stigma.

Inform & Educate
Support research and provide clear, culturally relevant information that improves understanding and access to care.

Mobilise
Build local capacity and activate local and global partners to amplify African voices.

Build
Create sustainable pathways to diagnosis, treatment, and long–term support.

HOW CHANGE HAPPENS

Individual

- Reduced isolation.
- Increased confidence.
- Access to relevant practical information.

Community

- Stronger peer–led support groups.
- Improved local capacity and sustainability.

Ecosystem

- Stronger collaboration.
- Greater visibility of African–led knowledge.
- Increased inclusion of lived experience.

ULTIMATE IMPACT

Improved quality of life and wellbeing for Africans living with Parkinson's disease.

"Advancing Parkinson's care across Africa requires connected systems – where organisations, clinicians, researchers, and patient communities collaborate to close gaps and strengthen pathways to support."

Prof Ali S. Shalash

Professor of Neurology, Chair of Ain Shams Movement Disorders
Group Department of Neurology, Ain Shams University Cairo, Egypt
Chair of MDS-African Section

Section Three

OUR IMPACT

Harnessing The Power Of Programmes And Partnerships

IMPACT & FUNDING **HIGHLIGHTS**

Our journey shows that each step forward has strengthened our ability to reach more people, build stronger systems, and open new doors for Parkinson's care across Africa. The impact and fundraising highlights that follow reflect what can be achieved when communities, partners, and supporters unite under a shared purpose.

These numbers are not just measures of progress. They signal possibility and remind us that together, we can go further, reach more people, and create a future where Parkinson's support is within every African's reach.

15,500+
people reached across Africa since inception

4,800+
people engaged in community involvement activities

1,200+
people supported through virtual & in-person groups

1,300+
reached through Walking Football & wellness programmes

3,700+
reached through health-literacy materials

29,300+
digital downloads of health-literacy materials

08
major programme areas delivered across 9 countries

75+
partners, donors & collaborators engaged

6 Million+
people reached through media

£337,000
raised to date

OUR PROGRAMMES

Introduction

In our early years, our programmes and initiatives were deployed to address the pressing, everyday realities faced by Africans living with Parkinson's. From strengthening early recognition through health-literacy resources to expanding access to medication and building community-rooted support groups, we targeted urgent gaps across communities on the continent. These programmes, including our awareness campaigns and advocacy efforts, have reduced stigma, expanded knowledge, and brought vital support closer to individuals and families who had long been overlooked.

ADVOCACY

Influencing Policy and Elevating African Voices

Through speaking roles and panel sessions, we participated and contributed to global conversations aimed at improving care and access for Africans living with Parkinson's. Our advocacy efforts at local and international conferences, including the World Health Organisation (WHO), ensured that Parkinson's disease was recognised as a public health priority in Africa and drove change by:

- Representing African experiences in global forums
- Engaging policymakers to influence health priorities
- Supporting community-level advocacy that dismantles stigma

CARE
Expanding Access to Medication

While Parkinson's Africa does not directly provide clinical services or healthcare access, we work collaboratively with local partners, medical professionals, and organisations to address barriers to care. We collaborated with organisations such as the Farah Foundation and the World Parkinson's Program to provide vital medication to over 400 people with Parkinson's disease across Ghana, Nigeria, Uganda, and Cameroon.

EDUCATION
The S.E.E. Parkinson's Health Literacy Campaign

The Support, Educate, Empower (S.E.E.) campaign provided culturally relevant, accessible information about Parkinson's disease to communities across Africa. Funded by the University College London Grand Challenges and Global Engagement offices and in partnership with IPDGC-Africa, this collaboration produced trusted materials tailored to African contexts, including versions translated into 11 African languages.

To date, these resources have enabled thousands of individuals, families, and frontline health workers to recognise symptoms earlier, seek appropriate care, and understand the condition with greater confidence.

AWARENESS

Reducing Stigma and Increasing Early Recognition

We collaborated with local organisations and community leaders to deliver awareness campaigns that challenged misconceptions and promoted earlier diagnosis. These initiatives included marches, public events, educational sessions, and culturally appropriate messaging that directly spoke to the lived realities of African communities.

Our awareness work strengthened public understanding, empowered families to seek help, and created the supportive environments necessary for improved detection and care.


Ethiopia


Uganda


Ghana

We also contributed to global awareness efforts, supporting British Army veteran Guy Deacon's overland journey across Africa by coordinating media engagement and interviews with healthcare professionals and people living with Parkinson's to ensure African perspectives were reflected in international coverage. We also supported the global Spark the Night campaign led by the PD Avengers, amplifying calls for greater recognition of Parkinson's and improved support worldwide.


Nigeria


Kenya

SUPPORT GROUPS

Building Connection, Confidence, and Community

Support groups form the backbone of community resilience. From the ancient banks of Egypt to the vibrant communities of South Africa, we sponsored and helped to establish in-person support groups that offer culturally relevant education, physical therapy access, structured activities, and peer connection.

Our virtual support groups provided (and continue to provide) safe, welcoming spaces where individuals and carers connect across borders to share experiences, gain knowledge, and receive emotional reassurance. These groups improve quality of life by addressing mental, physical, and emotional needs, ensuring no one has to face Parkinson's alone.


Tanzania


THE WALKING FOOTBALL PARKINSON'S CUP


Audito


Champion Partner


Celebrates
World Parkinson's Day
Theme : EMPO RING LIVES,
QUA ARE FOR ALL
Partners


PARKINSON'S AFRICA


Select your session date
Select your session time


FanMilk
SYNERGY
LES
Vitol
RelianceHMO
PFL
THE WALKING FOOTBALL PARKINSON'S CUP


THE WALKING FOOTBALL PARKINSON'S TOURNAMENT


Partners
Parkinson's Africa


THE WALKING FOOTBALL PARKINSON'S TOURNAMENT


APRIL 11
WORLD
PARKINSON'


WORLD PARKINSON'S DAY


AFRICA Parkinson's Africa


THANK YOU!


asharami
THE WALKING FOOTBALL PARKINSON'S TOURNAMENT
HALOS


OMOTOLA
THOMAS
RESOURCE
CENTRE


PARKINSON'S AFRICA
GROUPE DE SOUTIEN AUX MALADES DE PARKINSON AU CAMEROUN
Journée mondiale Parkinson
VIVRE AVEC LA MALADIE DE PARKINSON
11 Avril
PARKINSON'S AFRICA


World Health Organization
World Health Organization


THE WALKING FOOTBALL PARKINSON'S CUP
THE WALKING FOOTBALL PARKINSON'S CUP
SPONSOR:
VitolFoundation


STRENGTH


RS • LUNCH


S DAY


IPDGC


WORLD PARKINSON'S DAY


THE WALKING FOOTBALL
THE WALKING FOOTBALL PARKINSON'S TOURNAMENT


THANK YOU!

WALKING FOOTBALL- STRONGER TOGETHER

Walking Football has become one of our most dynamic, unifying and transformational programmes. Over the past 3 years, this flagship programme has brought together individuals living with Parkinson's, care partners, health professionals, policymakers, and community members to promote movement, raise awareness, and challenge stigma.

Through major tournaments and community events, the programme:

- Educates the public about Parkinson's.
- Encourages physical well-being.
- Creates highly visible platforms for advocacy.
- Builds solidarity and joy within communities.

Walking Football shows what is possible when health promotion, community mobilisation, and partnership intersect through accessible, energising activities.

PARTNERSHIP IN ACTION

I have been involved in Parkinson's disease research in Africa for over 20 years. The main gaps in Parkinson's care across African contexts remain the diagnosis of Parkinson's in the first place, due to a lack of awareness in the general population, but also amongst healthcare professionals. Even when people are diagnosed, the main challenge is access to available and affordable drug treatment.

For Parkinson's research to be truly equitable, people with Parkinson's and their carers need to be involved in identifying the key research questions. Focus groups informed the TraPCAf Grant application.

One particularly important thing that arose was that people with Parkinson's would prefer to know the diagnosis, even though there are major challenges in getting affordable drug treatment.

For long-term change, publications can inform advocacy, but in-country support groups and the monthly online support group run by Parkinson's Africa, in conjunction with people with Parkinson's, help meet ongoing needs. Films can also have a major impact. Community engagement can inform research questions and improve clinical care pathways, for example, by advising about information and educational materials.

We need to develop a system, within local resource constraints, that improves diagnosis and care, including multidisciplinary team members such as physiotherapists. Diagnosis and management in primary care will be important, supported by tools such as the Jobaid (under development by WHO) for primary care for Parkinson's. An African-led model builds trust by accounting for local contexts, available resources, and issues such as stigma. Over the years, there has been more recognition of Parkinson's in African settings, particularly among healthcare professionals, supported by MDS initiatives, online communication, and training developed with local clinicians.

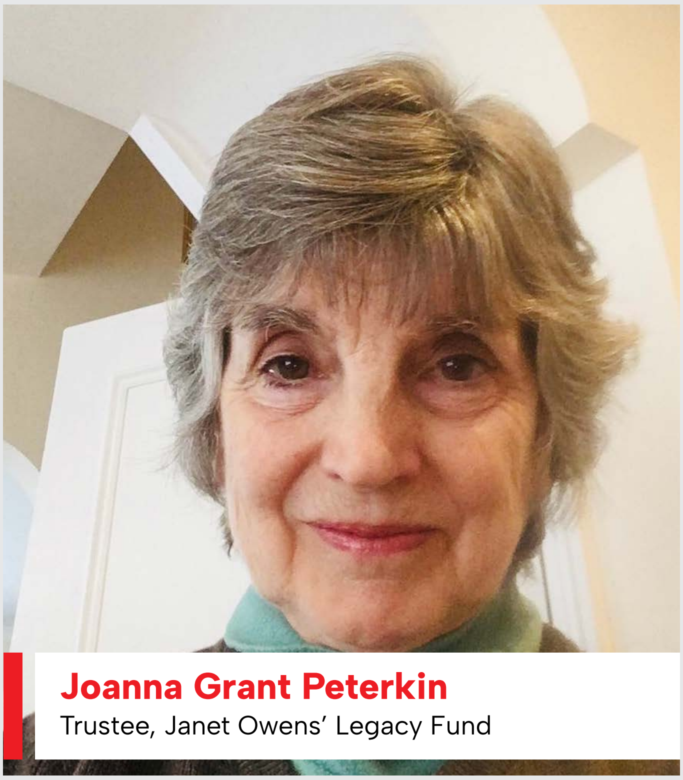
Professor Richard Walker
Consultant Physician and Honorary Professor of Ageing and International Health, Northumbria Healthcare NHS Foundation Trust/Newcastle University.

As Parkinson's Africa moves into a new phase, continuing support for online and in-country groups, advocacy for access to available and affordable drug treatment, and collaboration with organisations such as the WHO will help strengthen sustainable Parkinson's care systems. The original prevalence study also showed how many more people had not been diagnosed, and films such as 'Shaking Hands with the Devil' and 'Uhuru' have played an important role in raising awareness and showing the dramatic changes that drug treatment can make.

> ***A systems-based approach is important in African health contexts because the needs of people with Parkinson's are not being met adequately.***

STRATEGIC/CORE FUNDERS

Our strategic funders – including the immediate-past Janet Owens' Legacy Fund and our current partner, LES Energy Services – have played a vital role in sustaining and strengthening our mission.



Joanna Grant Peterkin
Trustee, Janet Owens' Legacy Fund

> As trustees of the Janet Owens Fund, when we met Omotola, we felt confident that Janet would approve of her dedication, hard work, warmth, communication skills and empathy, as well as the charity's core mission to improve understanding of Parkinson's in Africa. Our initial impression has been fully justified, and it has been a privilege to watch the charity's growth and to be excited about its future.

At LES, we believe that giving back to society is not just about donating funds but investing in a better future to bring hope. We couldn't have asked for a better partner than "Parkinson's Africa", who have been our vehicle to compassionately bring that hope through awareness, empowerment and community to our heroes.

It's oft' said that caregiving is erasure in the sense that you put your life on hold to show up for another; we want to remind you in the words of Mahatma Gandhi that "the best way to find yourself is to lose yourself in the service of others". So, to every caregiver and family of those living with Parkinson's- Your strength, sacrifice and resilience are inestimable.

We see you. We stand with you.

Oge Dan-Gogo
For **LES Energy Services**

Section Four

HUMAN STORIES

The work across our programmes and partner communities has revealed a simple truth: the most powerful drivers of change are the people living with Parkinson’s and the networks of care that surround them. This collection of impact stories is a testament not to an organisation, but to a shared commitment led by individuals, families, health workers, and community champions, who are reshaping what it means to live with Parkinson’s across Africa.

A SOLDIER'S NEW BATTLE

"I am a soldier," I told myself, brushing off the pain. "I have fought many battles. I have the strength to fight this, too."

I approached the illness with a soldier's mindset. I believed it was temporary– something I could overcome with willpower and medication. I placed my hope firmly in God and waited for the victory.

As the years passed, the tremors did not stop. I came to understand that Parkinson's disease is not a wound that heals, but a condition that persists. For years, I had fought visible enemies; now, I was fighting a silent one. Fear was not an option. My diagnosis brought a sorrow that challenged not only my physical body but also my faith in my own strength.

I suffered in silence until I discovered the Parkinson Patients Support Organisation Ethiopia (PPSOE).

For the first time, I saw that I was not fighting alone. That connection restored hope. This disease had many faces and many stories after all, and I was only one among them.

I now know that my story serves a larger purpose. I speak out because Parkinson's patients in Ethiopia remain deeply marginalised. Resources are scarce. The voices of patients are often unheard, and their struggles remain invisible to a society that frequently misunderstands neurological conditions.

Today, I live with my wife and hold on to my faith. I believe that God will one day bring a solution, and that science will discover a cure– not just for me, but for millions like me across the world.

My body may be weakened by Parkinson's, but my mind remains sharp. I am a soldier at heart. I remain devoted to God, country, and a future I still believe can be better.

Zewunde, K.
80 Years

TRUE PARTNERSHIPS POWER PROGRESS

Prior to our partnership, a significant knowledge gap existed at the primary care level, often resulting in missed or delayed diagnoses. There was also a profound absence of standardised, culturally relevant educational materials for both patients and providers. This resource constraint contributed to patient isolation and a fragmented care pathway.

Our collaborative health advocacy drive, which included producing and distributing the "Understanding Parkinson's" booklet, served as a cornerstone intervention. This resource provided a trusted, accessible reference that standardised foundational knowledge for community health workers and empowered patients and families. Coupled with targeted training, we have observed a marked improvement in early symptom recognition and more confident management by frontline staff, fostering a more informed and supportive ecosystem for patients.

Dr Vida Obese
Kumasi, Ghana – Founder/President of the Anidaso Parkinson's Disease Foundation

COMMITTED UNTIL CARE IS EQUAL

I was motivated to focus my physiotherapy expertise on Parkinson's disease because I realised that patients needed specialised care.

In my practice, training and awareness empower patients to take charge of their care and seek care from appropriate healthcare facilities, while ensuring access to medications remains a central focus of strong partnerships that also foster broader support systems that improve quality of life for people with Parkinson's.

Dr Mary Wetani Agoriwo
Accra, Ghana – PT. MSc. PhD / Coordinator, PD – Support Group, Ghana.

Access to specialist care is a fundamental right for every person, and the same must be extended to neurological care for persons with Parkinson's disease.

I hope our voices are louder to secure the government support needed for access to holistic care, including medical and rehabilitation services.

I hope that in the next five years, we will have significantly beaten the stigma peculiar to Africans affected by Parkinson's enough to encourage more persons with PD to identify with support groups, treatment and rehabilitative options that improve the quality of life.

There is no going back for me until I see people with Parkinson's disease in Ghana receive the best of care.

CHOOSING HOPE EVERY DAY

I'm a juvenile-onset Parkinson's disease warrior. I've lived with Parkinson's since my teenage years, but it took a long time to get a proper diagnosis.

When I received my diagnosis, I was devastated. I thought Parkinson's was something only older people experienced. At first, it felt like my life had been turned upside down. I imagined the end of my plans, goals, and dreams. I had hopes of getting married, moving countries, and building a career. With my diagnosis, it felt like everything was collapsing. It was terrifying because this is a chronic and progressive disease.

Even though the diagnosis shook me quite literally and figuratively, I was determined to live as fully as I could.

I am now heavily affiliated with the Parkinson's Support Group Kenya, which is also affiliated with Parkinson's Africa. Having a community, a place where people understand what you're going through and are willing to assist you to live as well as you can with a condition like Parkinson's disease, is so important. When you have a chronic lifelong situation that you're dealing with, it really helps to have the right support, even as care partners. Support Group meetings don't just support Parkinson's warriors; they support families and care partners. As they are supported, we are supported as well.

I hope that people understand that even as our bodies change, our minds, hopes, and dreams remain intact. We are still fully human and aspire to lead meaningful lives.

Although it took a while, I've learned that a Parkinson's diagnosis is not a death sentence.

I find hope in medical and technological advancements. Investments in research, congresses such as the World Parkinson Congress, and emerging therapies give me hope. I also hope for more government support in Kenya. While I hope for a cure one day, I am deeply grateful for organisations which make living with Parkinson's more manageable today.

Nduta M., 34 years
Nairobi, Kenya

WHEN PARKINSON'S **BECAME OURS**

I've been my father's caregiver since he was diagnosed with Parkinson's disease. Before I had any information about Parkinson's disease, it was very confusing and emotionally draining trying to understand what was happening to him.

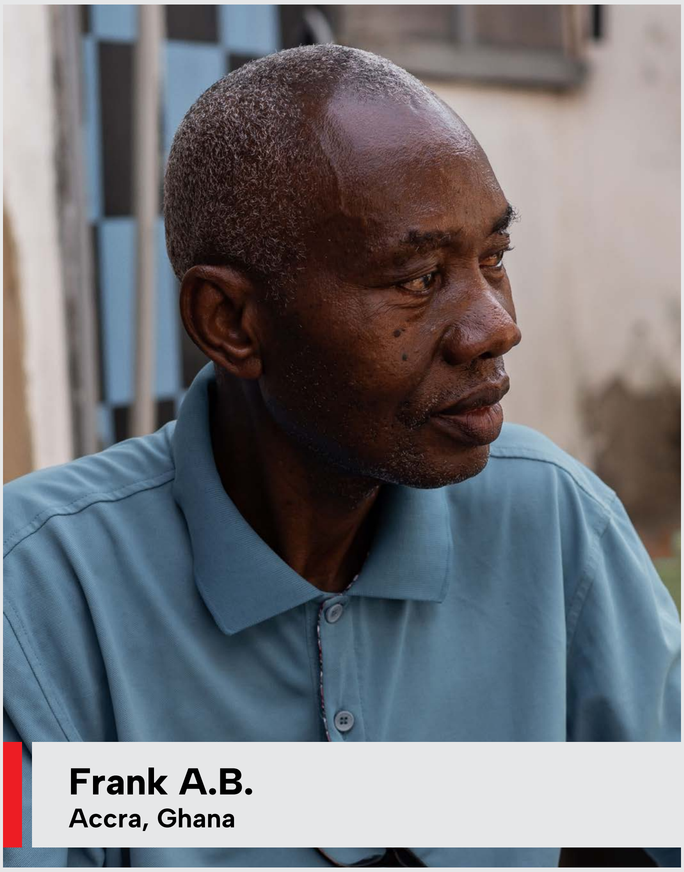
The emotional toll affected the quality of my education and how I interacted with people daily, as I felt like I needed to care for him mentally and physically.

Joining a support group changed everything for me. Listening to experts explain the condition and hearing other caregivers share their experiences gave me clarity and reassured me that I was not alone.

I now have a better understanding of Parkinson's disease and a more informed approach to how to live as his caregiver.

To continue with strength on this journey, I believe that every care partner needs emotional and mental support through private therapy sessions.

Angeline Otok
Kilifi, Kenya



Frank A.B.
Accra, Ghana

ACCESS AND **PARTNERSHIPS**

I was diagnosed in Ghana with Parkinson's disease. Before then, I had never heard of Parkinson's disease. I was told I would have to wait four months before seeing a specialist. At this point, gaining access was a bigger challenge than the cost. I just needed someone who could help me. When I eventually gained access, I faced the challenge of the cost of medication. With the introduction of partners supporting medication, the drugs that were once too expensive are now more accessible. My movement has improved, and many symptoms are better than before. I also joined the support group. Seeing people with the same condition helped me eliminate some fears and the superstitions around the disease. This was very important to me.

There are many vulnerable people in our area who need assistance. I hope more partnerships can help them, as they helped me.

WHEN COMMUNITY DISMANTLES STIGMA

On 11 April 2025, World Parkinson's Day, a community-based Sports and Fun Day took place in Soweto, a historic township in Johannesburg and home to millions of South Africans. This event, supported by Parkinson's Africa and delivered in partnership with the local non-profit, **Phila Sonke Wellness Initiative (PSWI),** formed part of a broader effort to raise awareness of Parkinson's disease in under-resourced urban communities and to strengthen access to local support.

On this day, nearly 120 community members participated in a range of accessible activities, including adapted physical games, wheelchair-accessible activities, and culturally familiar board games. These activities promoted participation, shared experience, and enjoyment, with the goal not being competition but visibility, inclusion, and connection.

For many, this marked the first time Parkinson's disease was spoken about openly in a community setting. By intentionally embedding Parkinson's awareness into an inclusive, disability-friendly Sports Day, this partnership enabled conversations in a familiar, welcoming environment. It was proof that Parkinson's disease does not preclude participation in community life.

Our work together has also enabled a broader programme of awareness and capacity-building activities in Soweto, including training healthcare and community workers in government clinics and at the Red Cross, equipping frontline staff with practical skills to identify possible signs of Parkinson's disease and confidently refer individuals to local support programmes.

Amy Harrison

Soweto, South Africa – Director, Phila Sonke Wellness Initiative, PSWI

To anyone newly diagnosed with Parkinson’s, a diagnosis can be frightening and overwhelming, but it is not the end of your life or who you are. Your life has great value, meaning, and possibility. With the right information, early care, support, and a community, many people with Parkinson’s continue to live full and dignified lives. You do not have to walk this journey alone.

Ask questions, involve your family, seek support, try to be as active as you have been, do not self-isolate and take a day at a time. I also do.

Brenda Mghendi
CEI Lead, Kilifi, Kenya.

Before receiving support in my community, I had no hope for my future. Now, I have some hope. I can think of things that I want to be. I have no idea where I would be today without medication. There are so many people in my village living with this disease who have no access to drugs or any kind of support. I hope that I continue to get this support and that others in my village can also receive medication and community support.

Mr Kingsley
Sawla Tuna Kalba District, Ghana.

Since its inception, the Adewunmi Desalu Parkinson’s Foundation (ADPF) has been Nigeria’s premier non-profit organisation addressing the significant gaps in awareness, diagnosis, psychosocial support, rehabilitative care, and community-based care for people living with Parkinson’s disease and their care partners.

From building life-changing support groups to restoring confidence through initiatives like Walking Football and Move4Parkinson’s Disease (Move4PD), our milestones demonstrate what is possible. Strategic collaborations have enabled us to expand access, strengthen services, and turn shared vision into measurable impact.

John Akinola
Head of Programmes, ADPF

Partnerships make meaningful local impact possible. It enables us to align grassroots community engagement with advocacy, evidence-based education, and shared lived experience.

Through our partnership, we have amplified awareness campaigns, strengthened caregiver and patient education, and ensured that the voices of people living with Parkinson’s in Kenya are represented regionally and beyond. Our partnership with PA has enabled us to build sustainable community structures rather than relying solely on informal networks.

Nadia Butt
Pharmacist, Caregiver, CEI Lead, Nairobi, Kenya.

Since starting our work with people living with Parkinson’s, we have made measurable progress on the urgent and critical challenges we set out to address. Our collaborative endeavours helped us build credibility, demonstrate results, and be seen.

As a result, we attracted additional partners, including a pharmaceutical company that joined us to support medication access after seeing the work being done on the ground.

As long as we continue to work together, we will reach more people and communities that have lived with little to no hope and felt invisible.

Stephen Acheampong
Neuroscience Nurse/CEI Lead, Sawla Tuna
Kalba District, Ghana.

Living with Parkinson’s in Nigeria is not just a health challenge. It is a fight for access and a continuous fight to be understood. Many people live undiagnosed, and even when diagnosed, a lot of people cannot afford medication.

Many are judged wrongly, but Parkinson’s is neither weakness nor laziness. It is not a death sentence. We need empathy. We need education and support systems that reach everyone.

Empress Omoijade
Lagos, Nigeria

DO SOMETHING

www.parkinsonsafrica.org/dosomething

Whether you are living with Parkinson's, supporting someone who is, working in health, funding solutions, or simply learning about Parkinson's for the first time, there is a role for you in closing the Parkinson's Chasm.

THE WALKING
FOOTBALL
PARKINSON'S CUP
PARKINSON'S AFRICA

Section Five

LESSONS LEARNED AND LOOKING AHEAD

What Five Years Taught Us: People, Systems, and Growth

ORGANISATIONAL GROWTH MOMENTS

Defining Our Mandate

One major turning point for us was clarifying our role in the wider ecosystem of care. As requests for medication, financial help, and daily support grew, we had to accept that Parkinson's Africa is not a humanitarian organisation and cannot fill systemic gaps alone. Setting clear boundaries allowed us to be compassionate and honest about what we could sustainably and ethically provide.

Holding Urgency and Sustainability in Tension

The needs around us are urgent, but urgency cannot drive every decision. Some requests were heartbreaking yet fell outside what we could responsibly deliver. We learned that safeguarding sustainability is a form of care – ensuring our support can endure rather than respond reactively.

Balancing Lived Experience with Governance

Lived experience remains central to our identity, but it cannot shoulder an organisation alone. As we grew, we strengthened systems and governance to support those whose personal journeys shape our mission. Clear roles, accountability, and institutional memory help prevent burnout and share responsibility, ensuring lived experience fuels the work without being overstretched.

Early Support During a Formative Period

Early grants and mentorship arrived when our systems were still forming. This support gave us space to build foundations, learn, and grow without constant crisis pressure – helping us transition from a passionate idea to a more resilient organisation.

SYSTEMIC INSIGHTS

Evidence as a Tool for Progress

Progress requires evidence. Without data, Parkinson's remains under-prioritised in health planning, and impact becomes harder to demonstrate with confidence. Yet numbers alone cannot capture the shifts we see every day — in confidence, connection, or willingness to seek care. True evidence must reflect both scale and depth, combining quantitative data with lived experience so we understand not just how many people we reach, but how meaningfully their lives change. This balanced approach helps us learn, adapt, and advocate more effectively for those we serve.

Remaining Connected to Those We Serve

Though we do not always work directly with beneficiaries, staying close to lived experience keeps our work grounded. Listening to people's stories ensures our approach remains human, thoughtful, and responsive.

Bridging the Awareness–Access Gap

We learned that awareness without access can create frustration. Persistent gaps – delayed diagnosis, unreliable medication supply – highlight the need for stronger referral pathways in our next phase.

The Power Dynamics of Partnership

Real change depends on trusted local partners. But partnerships carry power dynamics – funding and priority-setting often sit far from affected communities. Addressing this requires deliberate listening, shared control, and respect for local expertise.

NEXT STAGES OF GROWTH AND DEVELOPMENT

The next phase of Parkinson’s Africa is shaped as much by reflection as by ambition. The lessons of our first five years clarified not only what matters most, but how we must work if our impact is to be responsible, durable, and grounded in lived reality.

The following priorities are not promises or predictions, but guiding principles that will inform our decisions, partnerships, and trade-offs in the years ahead.

Strengthening Pathways Through Partnership

Our next phase centres on reinforcing pathways within constrained health systems, not replacing services or expanding beyond our mandate. Through partnership, we will prioritise coordination, stronger referral pathways, and supporting access where possible.

Our primary role remains that of connector, advocate, and amplifier – working with trusted local organisations and community leaders, while collaborating with regional and international professional bodies. This work will be guided by trust, clarity of role, mutual accountability, and careful attention to power and representation, ensuring that partnerships strengthen local capacity rather than overshadow it.

Deepening Organisational Foundations

As Parkinson’s Africa grows, strengthening our internal foundations remains essential. Lived experience will continue to guide our governance and operations, but always within structures that protect individuals and sustain the organisation over time. We will keep investing in shared leadership, institutional memory, and systems that support accountability and continuity. For us, growth is defined not by scale, but by the ability to remain focused, resilient, and responsive while navigating increasing complexity.

Practising Disciplined Growth

Immediate needs will remain visible and urgent, but responsible impact requires carefully balancing capacity, sustainability, and long-term responsibility. Our decisions will be shaped by what we can deliver ethically and well, recognising that choosing where not to act is often as important as deciding where to invest our effort. Disciplined growth ensures that our commitment to the community is consistent and enduring.

BRIDGING THE CHASM:
OUR STRATEGIC ROADMAP

The following strategic programmes translate our principles into action. Each is designed to strengthen practical pathways to care, connection, and dignity across the continent.

The Annual Virtual Townhall

Our annual Virtual Townhall creates a shared space for the African Parkinson's community and international partners to connect. What began as a search for visibility has become a recurring platform that amplifies lived experience, strengthens solidarity, and ensures African voices remain central within the global Parkinson's conversation.

By convening across borders, we reduce isolation and reinforce the message that no one should navigate this journey alone.

Local Groups Capacity and Sustainability

We will continue strengthening the capacity of local support groups with a focus on governance, leadership, and operational resilience. Our priority is to ensure that these groups are equipped to deliver consistent support and services while progressing towards sustainable, independent operation.

As capacity permits, we will extend this work to additional underserved communities through our developing Champions for Change model.

Champions for Change

Champions for Change is our structured community activation model designed to identify underserved Parkinson's communities and work alongside them to assess local needs, build awareness, and strengthen sustainable support systems. Through phased engagement and local capacity building, the model will empower community health workers, leaders, and advocates to drive change from within.

Inclusive Education and Language Expansion

Information must be accessible to be meaningful. We are expanding educational resources into audio, visual, and radio formats to reach people facing literacy or digital barriers, while strengthening multilingual support and exploring innovative translation options to better serve a pan-African community. Together, these efforts reflect our current strategic direction, shaped by learning, partnership, and a commitment to building sustainable pathways to care as our approach continues to evolve.

PATH – Parkinson's Africa Telephone Helpline

To address distance and specialist scarcity, we are developing PATH – Africa's first dedicated Parkinson's telephone helpline. Currently in the concept and partnership development phase, the initiative aims to provide psychosocial support and trusted signposting to appropriate medical advice and local services, offering people and carers in rural or isolated areas a direct and accessible point of connection.

Section Six

OUR LEADERSHIP, PEOPLE & PARTNERS

TRUSTEES

Dugie Young, MPA/MPP
Trustee/Treasurer

Ferdinard Okwor, FCA
Trustee

Omotola Thomas, MSc
Founder/Chair of Trustees

Pamela Gutmann, MBA
Trustee

Piers Mudd, MLitt
Trustee

STAFF

Ruth Ebe, MD
Charity Manager

Rachel Obinna, BSc
Operations Officer

Success Nwanedo, MA
Communications and Community Engagement Officer

PARKINSON'S AFRICA
SUPPORTERS & PARTNERS

CORE FUNDERS & STRATEGIC SUPPORTERS

- LES Les Energy Services Limited
- JANET OWENS LEGACY FUND
- TraPCAf Transforming Parkinson's Care in Africa NIHR
- Vitol Foundation
- Supported by UCL GLOBAL ENGAGEMENT GRAND CHALLENGES
- THE FARAH FOUNDATION

PARTNERS AND COLLABORATORS

- ADEWUNMI DESALU PARKINSON'S FOUNDATION
- iPDGC International Parkinson Disease Genomics Consortium • Africa
- PARKINSON'S ZA
- Parkinson Ethiopia Parkinson Patient Support Organization Ethiopia (PPSOE)
- PARKINSON'S SUPPORT GROUP CAMEROON NOS MISSIONS : SOUTENIR – INFORMER – ORIENTER
- ANIDASO PARKINSON DISEASE FOUNDATION
- BOKO
- PARKINSON'S DISEASE SUPPORT GROUP GHANA JOIN US TODAY! SUPPORT SELF HELP EMPATHETIC LISTENERS RELEVANT INFO & EXPERIENCE
- EGYPARKINSON'S RESOURCE CENTER
- PSGK PARKINSON'S SUPPORT GROUP OF KENYA
- KENYA PARKINSON'S CARE NETWORK Unite, Uplift, Empower
- PHILA SONKE WELLNESS INITIATIVE
- RICHARD NOVATI CATHOLIC HOSPITAL SOGAKOPE
- Inaref INSTITUT DE NEUROSCIENCES APPLIQUÉES ET DE REEDUCATION FONCTIONNELLE
- WAKA FOOTBALL ASSOCIATION NIGERIA
- COLLEGE OF MEDICINE of the University of Lagos
- ZEALOT&SHARK
- Newcastle University

COLLABORATORS AND SUPPORTERS

- World Parkinson Coalition
- WORLD PARKINSON'S PROGRAM
- CURE PARKINSON'S
- PD AVENGERS GLOBAL ALLIANCE TO END PARKINSON'S DISEASE
- StreSERT SERVICES LIMITED Stress-Free Enterprise Solutions
- AICO MULTISHIELD HEALTH CARE
- The Deacon Foundation Improving life with Parkinson's
- Parkinson's UK
- NIHR National Institute for Health Research
- parkinson's europe


Warrior

CONTACT US

parkinsonsafrica

parkinsonsafrica

Parkinson’s Africa

Parkinson’s Africa

hello@parkinsonsafrica.org
www.parkinsonsafrica.org