The Curse of Stigma campaign is growing, and we'd love to have you join us as a partner! This documentary film sheds light on the challenges faced by individuals living with epilepsy in Africa. It aims to spark meaningful conversations and drive social change by addressing the stigma surrounding epilepsy and advocating for closing the global epilepsy treatment gap.

In 2024, the film was officially released and widely viewed via exclusive screenings. Highlights included:

- Acceptance into 15 film festivals
- Winner of "best documentary short" at the Hollywood Boulevard Festival
- Invitation to screen at the American Epilepsy Society meeting in L.A.

As we move into 2025, the BAND Foundation and Whitten Newman Foundation (film co-producers) are excited to partner with the International Bureau for Epilepsy (IBE) on the launch of the ***Curse of Stigma Impact Campaign*****.** The goals of the campaign are to create awareness of the global epilepsy treatment gap and to raise funds to support African communities in need. ***By joining as a partner, you can help promote this campaign and amplify its messages – through social media, by hosting a film screening event, or by donating to the campaign. We'll also add your logo to our website.***

To launch this campaign, we have created a **"Watch Party Toolkit"** that supplies tools, messages and information to inspire and engage audiences. With **International Epilepsy Day approaching on February 10th**, we hope that this day (or others) might create an opportunity for you to galvanize your audiences in support of global epilepsy and the Curse of Stigma Impact Campaign.

The Watch Party Toolkit has everything you need to create a successful in-person or virtual event. It includes:

- The Curse of Stigma award winning documentary film on the website (https://thecurseofstigma.org/)
- A Discussion and Resource Guide
- Sample Social Media Posts to promote the event across your platforms
- Curse of Stigma Impact Campaign One-Pager

Thank you for your help in raising awareness about global disparities in epilepsy care and treatment by sharing the Curse of Stigma documentary film and its accompanying resources. If you have any questions please contact Alison Kukla, alison@thecurseofstigma.org.

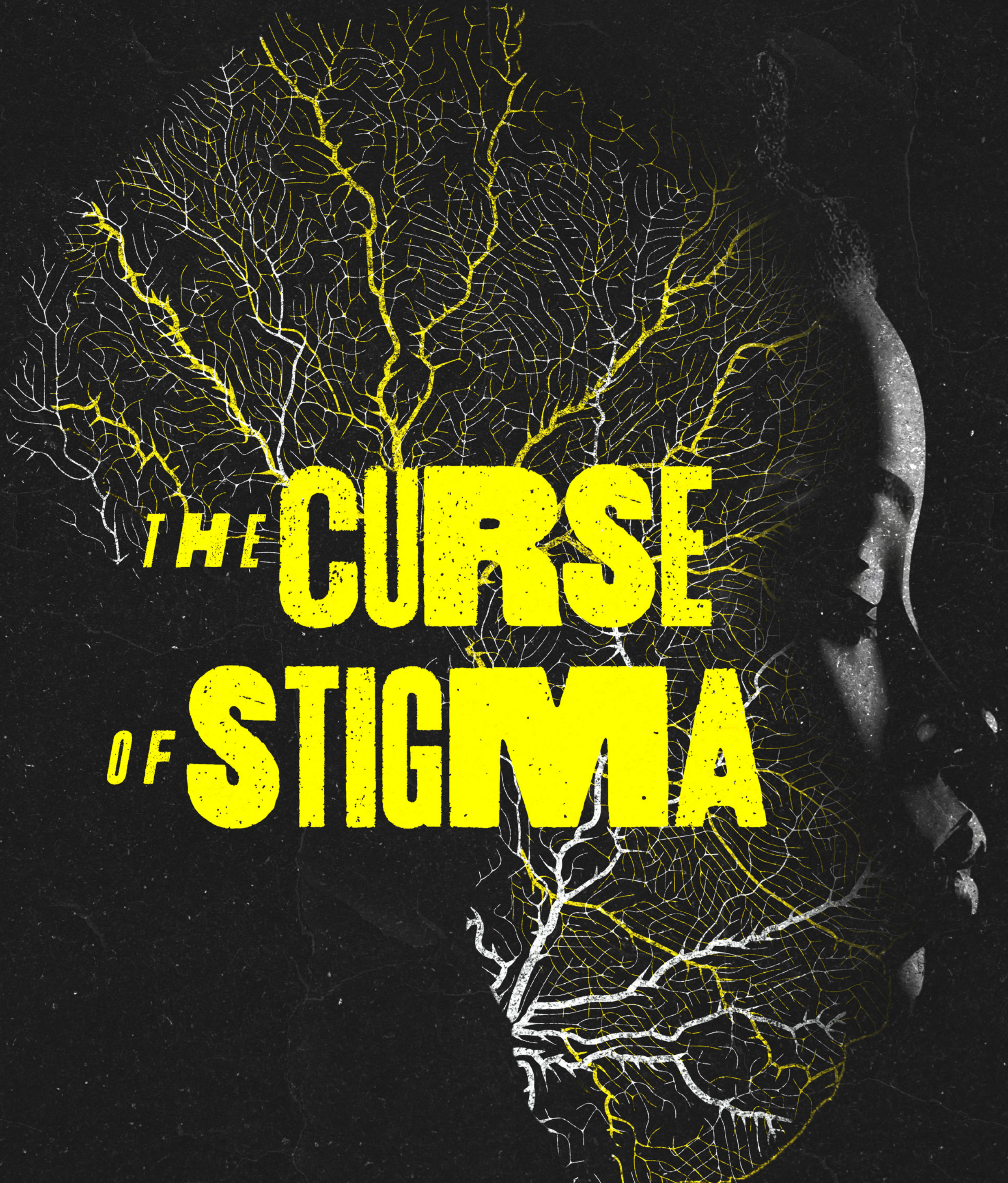
Together, we can ensure that "The Curse of Stigma" has a lasting impact on audiences and people with epilepsy worldwide.

Warm regards,

Gardiner Lapham, BAND Foundation
Hannah Whitten,
Whitten Newman Foundation
Donna Walsh, IBE

Watch Party Toolkit
Table of Contents

DISCUSSION & RESOURCE GUIDE



THE CURSE OF STIGMA

African Stories of Epilepsy

HOW TO USE THIS GUIDE

This guide is designed to help you navigate and utilize the film ***The Curse of Stigma*** effectively. It offers structured support for pre-and post-screening activities, classroom discussions, event inclusion, and other community engagements. Here's how to get the most out of it:

1. **Film Overview:** Start with the Film Overview to understand the key themes and participants in the documentary.
2. **Featured Participants:** Familiarize yourself with the individuals whose stories are highlighted in the film to better connect with their experiences.
3. **Letters from Producers and Partners:** Read these letters to gain insights into the motivations behind the film and its broader impact goals.
4. **Themes in the Film:** Explore the thematic breakdown to understand the issues addressed, such as understanding epilepsy, promoting human rights, and overcoming stigma.
5. **Discussion Questions:** Use these questions to spark conversations around the film's themes. Questions are tailored to different audiences to facilitate meaningful exchange.
6. **Learn More and Take Action:** Dive into additional resources to expand your knowledge, combat stigma, support advocacy efforts and take action.

Following these steps will enable you to engage with the film and contribute to the ongoing conversation about epilepsy awareness and advocacy.

The Curse of Stigma is a powerful and intimate documentary film that tells the story of Kenyan families living with epilepsy and the pain, isolation, and harm they have suffered due to discrimination and deeply embedded cultural beliefs. Their ultimate understanding of epilepsy as a treatable condition leads them to better health and brighter futures. By telling their truth, and the truth about epilepsy, they overcome shame – the ultimate curse of epilepsy stigma.

A preview of the film premiered at the 2023 International Epilepsy Congress in Dublin, Ireland, and will be featured at select international film festivals in 2024 & 2025. This film is brought to you by two US-based nonprofits: The BAND Foundation and the Whitten-Newman Foundation, in partnership with the International Bureau for Epilepsy (IBE).

Stay Connected:
Facebook: The Curse of Stigma
X/Twitter: @curseofstigma
LinkedIn: The Curse of Stigma
Instagram: @thecurseofstigma
Website: thecurseofstigma.org

FILM OVERVIEW

FEATURED PARTICIPANTS

Cate

"Epilepsy is not about witchcraft. It's not about curses. It's a sickness just like any other. …We need to embrace people with epilepsy because they're people like…just like the rest."- **Cate**

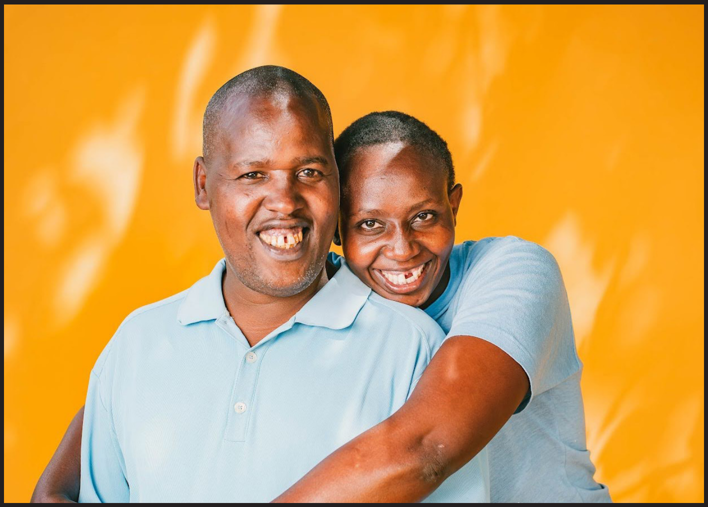
Ramskie

"Epilepsy takes a piece of yourself. The lie that epilepsy tells you is that no one is going to accept you...We need to tell our story with our voices." - **Ramskie**

Dorcas & Lucy

"A lot of people lack knowledge. Some said that she was bewitched and I told them 'no'. This is a condition and it is treatable." - **Lucy**

Kimani & Nancy



"Epilepsy has been forgotten. Because the society feels, [if] it is not my son, it is not my daughter, then I don't care." - **Kimani**

"Self-acceptance is key, and to seek out and take the medication that doctors advise."
- **Nancy**

Action Amos

Most people continue to live in the shadows because of shame and fear. And that's why the numbers we can discuss are an underestimation." - **Action Amos**
VP, IBE Africa Region

Patrick Ngeche

We have demonstrated that epilepsy is treatable. We can manage epilepsy at the lowest cost.
- **Patrick Ngeche*, CEO, K.A.W.E***

" We should love children with epilepsy... They're children, and they should not fear anything. Because if you fear, you will not be able to deal with the situation." - *Lucy*

LETTER FROM THE EXECUTIVE PRODUCERS

Much about epilepsy is surprising and misunderstood. Many people living with epilepsy could easily and affordably be treated but are not. Persistent misconceptions, at all levels of society, have kept these people in the shadows. "***The Curse of Stigma***" seeks to tell their story, stir conversation, and spark action towards the World Health Organization's 2031 epilepsy goals.

Epilepsy affects more than 50 million people worldwide - 80% of whom live in low-income countries. Despite this high prevalence, epilepsy is often absent from national and global public health agendas.

As a common brain disease characterized by recurring seizures, epilepsy can lead to disability and premature death. **People living with epilepsy are 3 times more likely to die early than people without epilepsy. Two-thirds of them could be treated with affordable medications (for as little as $5/year, according to the WHO).** However, these potentially life-saving solutions are unavailable in many parts of the world. Strikingly, 80% of Africans living with epilepsy are untreated. There are many reasons for this so-called "treatment gap," among them untrained healthcare providers and inconsistent drug supply. But perhaps most alarmingly, **a vast number of people cannot access treatment because of misconceptions surrounding the disease.**

In all parts of the world and to varying degrees, people with epilepsy endure stigma, discrimination, and, in the worst cases, human rights abuses. "***The Curse of Stigma***" shines a light on these uncomfortable truths by sharing the personal stories of several Kenyans living with epilepsy. Their initial fears and those of their family, friends, and caregivers—e.g., that epilepsy is contagious or the work of spirits—compound their suffering. However, once they learn that epilepsy is a medical condition and treatable like other diseases, they can advocate for better care and choose to tell their stories to help others.

We have a shared experience of epilepsy loss that led us to become accidental filmmakers. While our stories ended in personal tragedy, they also forced us to confront epilepsy up close. They galvanized us to try to reduce the needless suffering that millions with this disease endure. At its core, this film is an opportunity to make epilepsy understood—to close the treatment gap and realize the 2031 WHO targets.

Cate in "***The Curse of Stigma***" is right when she says, **"Epilepsy is not about witchcraft, it is a condition like any other."** So too is Action Amos of the International Bureau for Epilepsy (IBE) when he says, **"Now is the time to get on board."** We are grateful to all who so bravely participated in this film and to the two organizations that made it possible - the Kenya Association for the Welfare of People with Epilepsy (KAWE) and the IBE. Thank you for viewing this film and joining us, Cate, Action, and so many others on this urgent journey to end the curse of stigma. Please check out the thecurseofstigma.org to learn more and to support anti-stigma efforts in Africa.

With hope and gratitude,
Hannah Whitten & Gardiner Lapham
Co-producers, The Curse of Stigma


Hannah Whitten


Gardiner Lapham

WHITTEN-NEWMAN FOUNDATION

BAND FOUNDATION


OFFLOAD

LETTER FROM THE INTERNATIONAL BUREAU FOR EPILEPSY

We are honored to partner on ***The Curse of Stigma***, a documentary that profoundly captures the lived experiences of individuals with epilepsy in Kenya. This film aligns with our vision to achieve a transformational social change for people worldwide, by empowering and amplifying the voices of people with lived experience.

The Curse of Stigma provides an intimate look at the challenges faced by people with epilepsy, featuring the personal stories of several individuals in Nairobi, Kenya. These stories highlight the profound impact of cultural beliefs and misconceptions on their lives. By sharing their journeys, the film demonstrates how **understanding epilepsy as a treatable condition can lead to better health outcomes and brighter futures.**

Our colleague Action Amos (Coordinator, IBE Africa Region) featured in the film, plays a crucial role in showcasing the ongoing efforts to support people with epilepsy in the region. The film's focus on real-life experiences and grassroots advocacy aligns perfectly with our goals. We believe that by amplifying these voices, we can foster a deeper understanding and spark meaningful conversations that lead to action.

Our partnership on this film reflects our commitment to improving the quality of life for those living with epilepsy. We aim to leverage the power of storytelling to educate, inspire, and mobilize communities and stakeholders worldwide. Together, we can make significant strides toward achieving the global targets contained within the World Health Organization's Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders 2022-2031. You can read more about this plan later in the discussion guide.

We invite you to join us in this important endeavor. By watching and sharing ***The Curse of Stigma***, you are helping to shed light on a critical health issue and contributing to a future where epilepsy is universally understood and treated without stigma.

If you're feeling inspired to take further action, why not check out our toolkits created to empower advocates in Africa to advocate for, and raise awareness of, epilepsy.

- Our Advocate's Toolkit for Making Epilepsy a Priority in Africa is for those seeking guidance, ideas, or inspiration as they develop advocacy projects around epilepsy. The various modules can be used both as a step-by-step guide to lead you through a brand new advocacy planning process or as a reference or set of stand-alone resources that can be used when opportunities arise in the context of existing epilepsy advocacy work.

- Our IBE Africa Stigma Toolkit offers comprehensive strategies to combat epilepsy stigma through awareness campaigns, community engagement, and advocacy efforts. This toolkit is instrumental in enhancing understanding and support for individuals living with epilepsy across Africa.

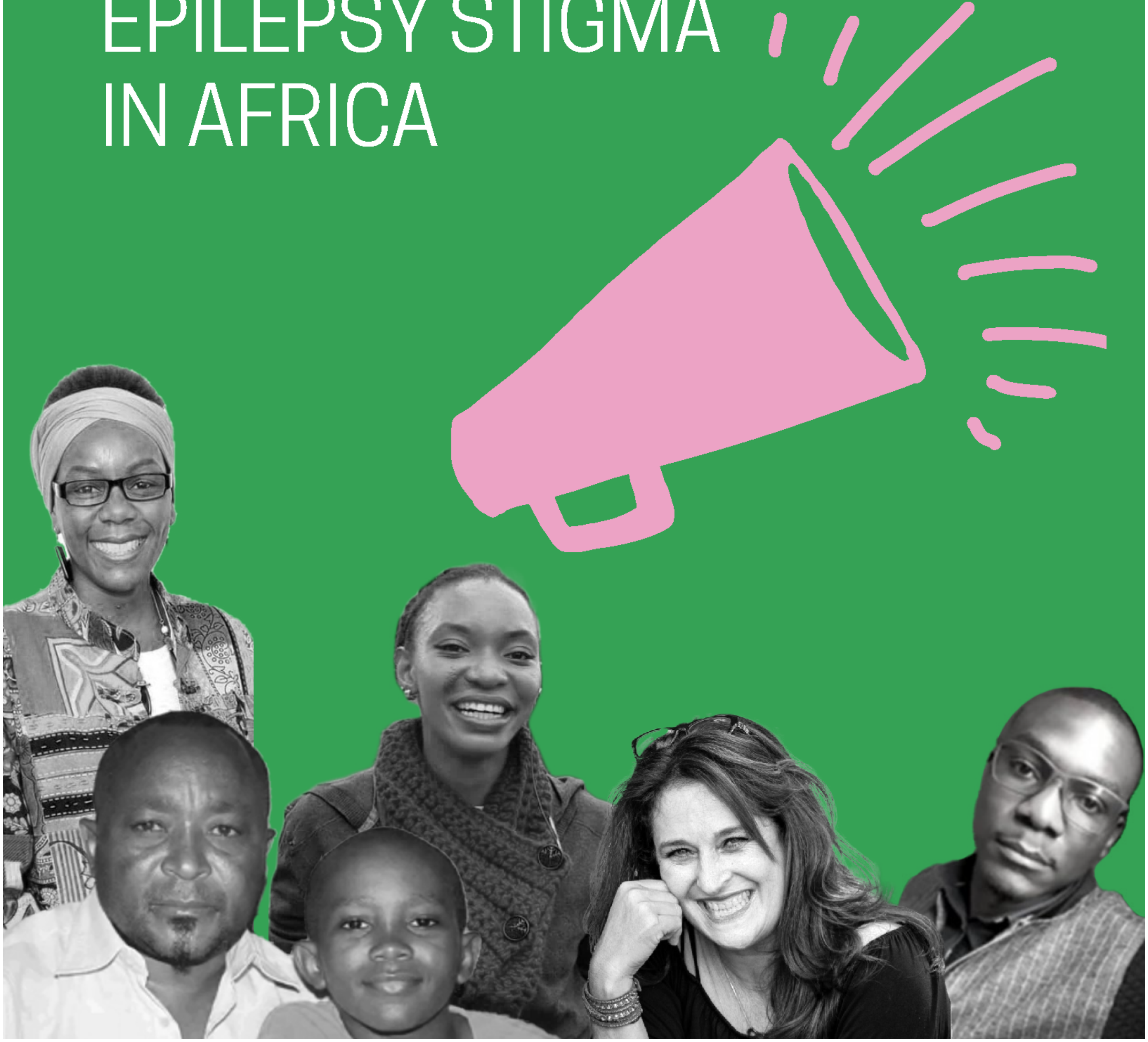
Thank you for your support and for joining us on this urgent journey to end the stigma surrounding epilepsy.

Sincerely,
Donna Walsh, CEO
International Bureau for Epilepsy (IBE)
Follow IBE on Twitter/X, Instagram, LinkedIn, Facebook, & YouTube

IBE International Bureau for Epilepsy

Advocate's Toolkit

FOR REDUCING EPILEPSY STIGMA IN AFRICA



GET INVOLVED

Follow the campaign on social media.

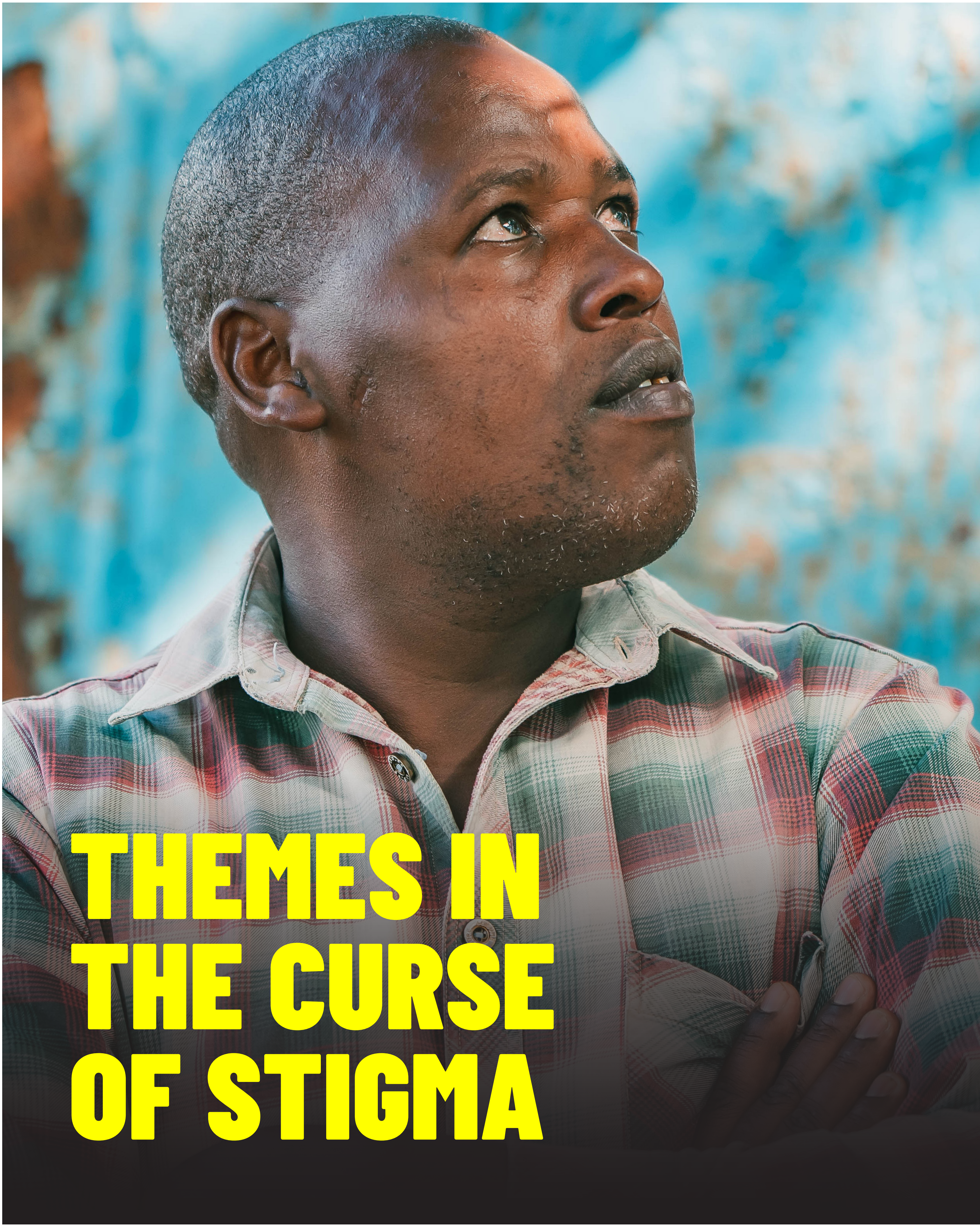
Join the campaign and receive updates on screenings and festivals.

Donate to The Curse of Stigma Campaign and help advocates in Africa to end stigma and close the epilepsy treatment gap.

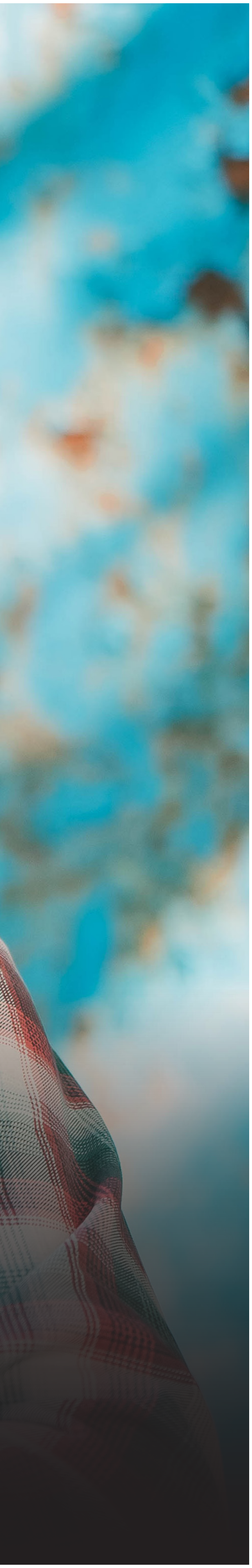
Campaign Funds
Our campaign aims to raise funds for the International Bureau for Epilepsy to support anti-stigma efforts in select African countries.

- A portion of the funds will support local initiatives through a small grants fund, empowering community-led efforts to combat stigma.
- A portion of the funds will be directed towards promoting the film across Africa, facilitating crucial policy meetings, educational screenings, and engaging with the media to amplify our message.

**All film production and campaign strategy costs were underwritten by the BAND and Whitten-Newman Foundations.*



THEMES IN THE CURSE OF STIGMA



The Curse of Stigma explores several profound themes throughout the film:

Understanding Epilepsy

The film provides an in-depth look at the lives of individuals with epilepsy in Nairobi, Kenya, shedding light on their myriad of challenges. It addresses widespread societal and cultural misconceptions that lead to stigma, discrimination, and poor health. Through touching personal stories, the film portrays the transformative journey of individuals and their families who come to understand epilepsy as a treatable condition and in doing so inspire other people living with epilepsy to seek out treatment. Furthermore, the film underscores the public health burden of this disease which, although treatable for many, has been neglected.

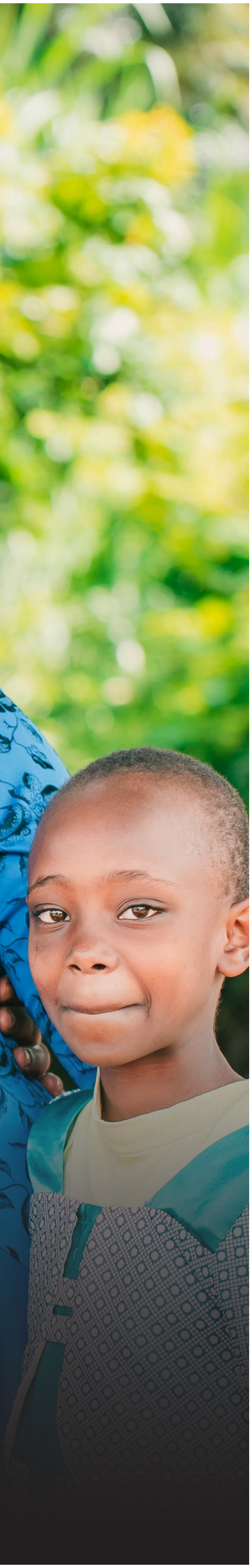
Promoting Human Rights and Advocacy

The film highlights the severe human rights violations experienced by individuals with epilepsy due to entrenched societal stigma. It explores how this stigma affects various aspects of life, including relationships, safety, access to education, employment opportunities, and healthcare. By highlighting personal stories, such as that of young student Dorcas, "The Curse of Stigma" emphasizes the critical need for advocacy and increased global awareness to support marginalized communities and uphold their human rights.

Overcoming Stigma

The film showcases the courage and resilience of individuals living with epilepsy, inspiring viewers to take action against stigma within their communities and countries. The personal stories of these individuals and their families demonstrate the power of advocacy and community support in overcoming societal barriers. The film encourages individuals to use their platforms and voices in various settings to challenge misconceptions and promote understanding of epilepsy. It also highlights specific actions communities can take to create a more inclusive environment and emphasizes the role of educational initiatives and awareness campaigns in fostering societal change and countering harmful stereotypes.

AN OVERVIEW OF EPILEPSY



Epilepsy - A General Global Overview

Epilepsy is a chronic neurological disorder that affects about 1% of the global population, with estimates ranging from 50-70 million people affected worldwide. It is characterized by recurring seizures caused by abnormal electrical activity in the brain. It has many causes (e.g. genetic, traumatic brain injury, infection, prenatal injury, to name a few) and 25% of cases in Africa could be prevented. Despite its prevalence, epilepsy is often misunderstood and stigmatized, particularly in low- and middle-income countries where 80% of those affected reside.

Common and Serious

Epilepsy is not just a medical condition but also a significant public health concern due to its high prevalence and the severe impact it can have on individuals and their families. Seizures can vary in severity and frequency, affecting people's ability to work, drive, and participate in daily activities. The condition is also associated with a higher risk of premature death, with people with epilepsy being 2-3 times more likely to die early than the general population.

Treatable Condition

Epilepsy is often treatable with medication, which can control seizures for up to 70% of patients. Remarkably, these medications can be very affordable, costing as little as US$5 per year. However, the reality is starkly different in low-income countries, where more than 75% of people with epilepsy do not receive the necessary treatment. This lack of access to medication and care is a significant barrier to managing the condition effectively.

Significant Treatment Gap

The treatment gap for epilepsy is primarily driven by stigma and a lack of access to quality healthcare. Misconceptions about epilepsy, such as the belief that it is contagious or caused by supernatural forces, exacerbate the stigma and discrimination faced by those with the condition. Additionally, there is often a shortage of trained healthcare providers and inconsistent drug supply, further hindering effective treatment. Bridging this treatment gap requires concerted efforts to raise awareness, improve healthcare infrastructure, and ensure the availability of affordable medication.

Key Statistics

- **Global Prevalence:** According to the World Health Organization, epilepsy affects more than 50 million worldwide, though higher estimates of up to 70 million exist.

- **Geographical Disparity:** 80% of people with epilepsy live in low- and middle-income countries.

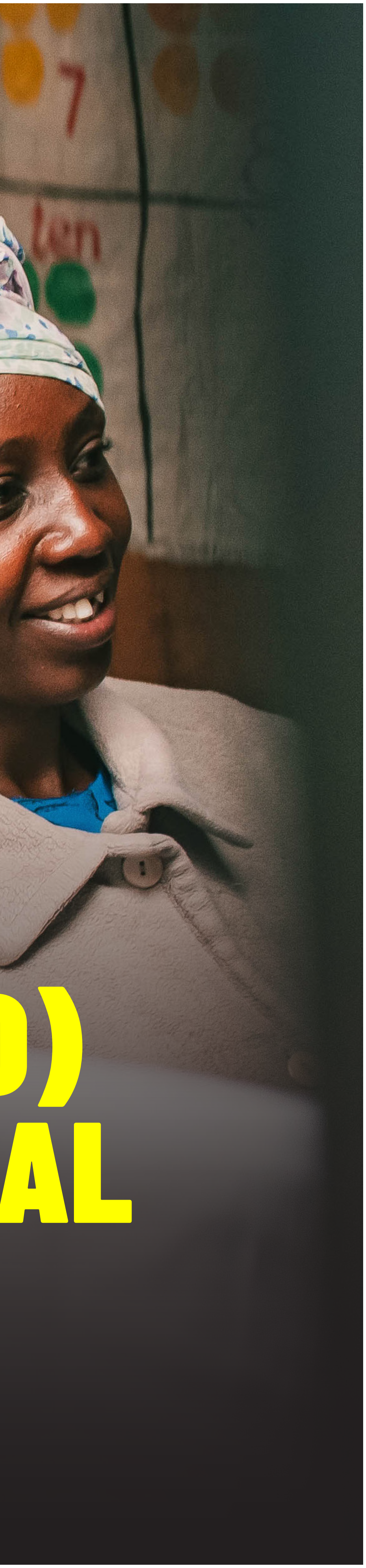
- **Treatment Accessibility:** Three-quarters of individuals with epilepsy in low-income countries do not receive proper treatment.

- **Treatment effectiveness:** Up to 70% of people living with epilepsy could have their seizures controlled with medications that cost as little as USD$5/year.

- **Mortality Risk:** People with epilepsy are 3 times more likely to die prematurely than the general population.

Sources:
WHO Epilepsy Fact Sheet
International League Against Epilepsy (ILAE)

WORLD HEALTH ORGANIZATION’S (WHO INTERSECTORAL GLOB ACTION PLAN ON EPILEPSY (IGAP)



The World Health Organization's (WHO) Intersectoral Global Action Plan (IGAP) for Epilepsy and Other Neurological Disorders, is a global agreement that was passed by 192 Member States of the World Health Assembly, including the U.S. It strives, by 2031, to close the epilepsy treatment gap.

Why Now?

The IGAP presents a timely opportunity to elevate epilepsy on the global health agenda. With its passage in 2021, the plan's framework provides a structured roadmap for nations to follow, making it a pivotal moment to push for change and at long last improve the quality of life for people with epilepsy.

Key Actions from IGAP:

1. **Raise Policy Prioritization and Strengthen Governance**
    a. Advocacy for epilepsy to be recognized as a public health priority.
    b. Strengthening governance structures to support comprehensive epilepsy care.

2. **Provide Effective Diagnosis, Treatment, and Care**
    a. Ensuring access to accurate diagnosis and effective treatment options.
    b. Establishing care pathways that integrate epilepsy treatment into general health services.

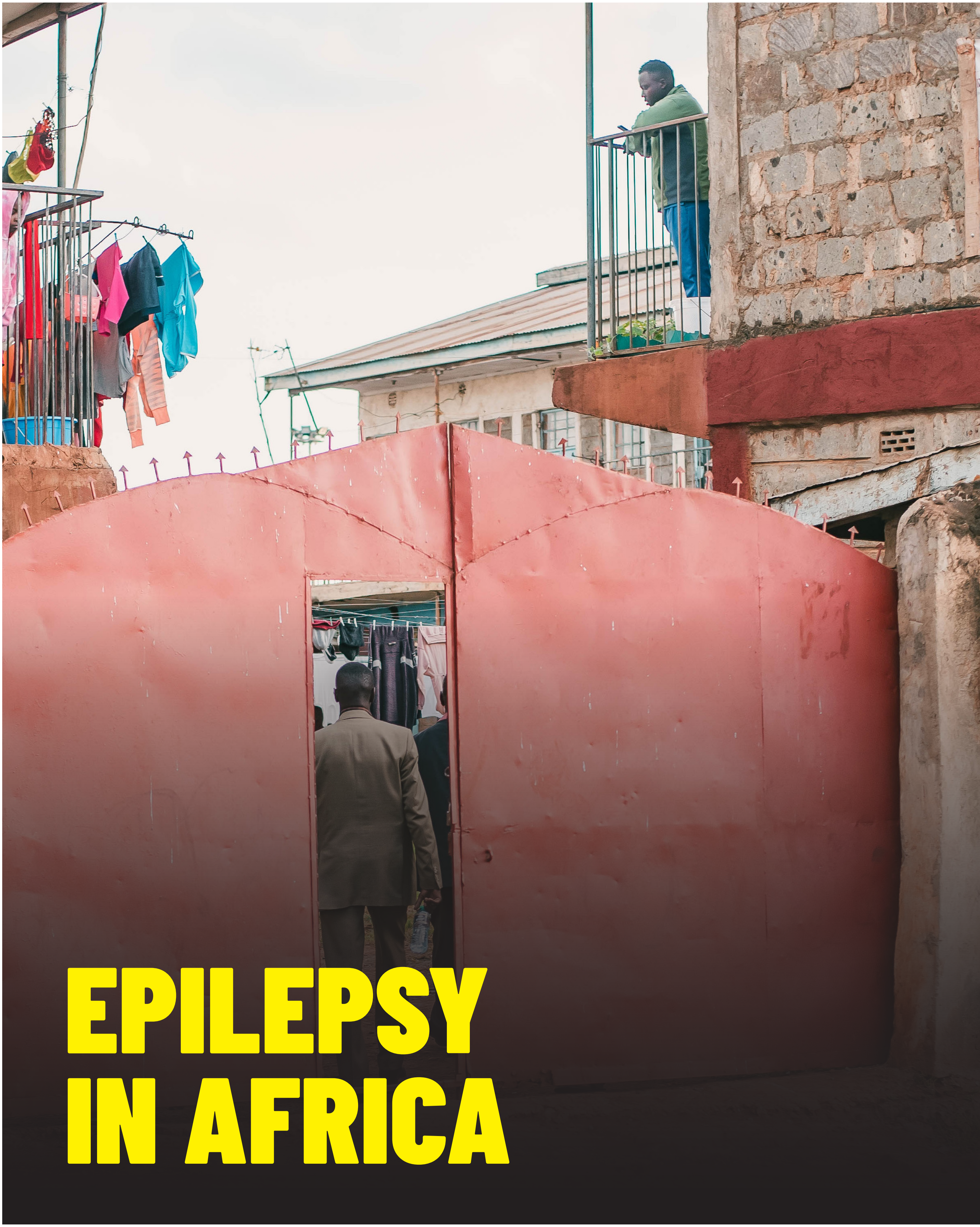
3. **Implement Promotion and Prevention Strategies**
    a. Developing public health campaigns to raise awareness about epilepsy.
    b. Promoting preventive measures to reduce the incidence of epilepsy where possible.

4. **Foster Research, Innovation, and Strengthen Information Systems**
    a. Encouraging research and innovation to develop new treatments and improve existing ones.
    b. Enhancing information systems to track and monitor epilepsy care and outcomes.

5. **Strengthen the Public Health Approach to Epilepsy**
    a. Integrating epilepsy care into broader public health initiatives.
    b. Ensuring that epilepsy is included in national health plans and policies.

Goals:
The International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) champion the following targets to achieve IGAP by 2031.

Sources:
WHO IGAP
International League Against Epilepsy
International Bureau for Epilepsy
(IBE): IGAP Unpacked



EPILEPSY IN AFRICA

Epilepsy stigma has existed since ancient times and continues to be a significant barrier to care and social acceptance. Despite some improvement in attitudes, a lack of awareness persists globally, particularly in parts of Africa where epilepsy is still often misunderstood. People with epilepsy in these regions are sometimes thought to be contagious, bewitched, or unworthy, which severely impacts their lives in multiple ways.

Impact on Various Aspects of Life

Marriage and Social Exclusion:

- In many African communities, epilepsy is seen as a curse or bad omen, leading to social rejection. This stigma can affect marriage prospects, with individuals often deemed unsuitable for marriage due to misconceptions about the condition.

- People with epilepsy frequently face isolation and exclusion from community activities. This social ostracism is fueled by myths and misinformation about the disease.

Employment and Education:

- Stigma and discrimination can lead to significant employment barriers.
  - Employers may be reluctant to hire individuals with epilepsy due to unfounded fears about their reliability and safety.

- As shown in the film with Dorcas' story, children with epilepsy are at risk of being denied access to education.
  - Schools & teachers are often ill-equipped to handle seizures, and the associated stigma can lead to bullying and exclusion from educational opportunities.

Mental Health and Human Rights:

- The stigma surrounding epilepsy contributes to mental health issues such as anxiety, depression, and low self-esteem.
  - The fear of social rejection and discrimination can lead to severe psychological distress.

- Stigmatization often leads to violations of basic human rights, including the right to healthcare, education, and employment. In some cases, individuals with epilepsy are subject to inhumane treatment and exclusion from their community.

Access to Treatment:

- In Africa, the epilepsy treatment gap is significant. An estimated 80% of people with epilepsy in the region do not receive the necessary treatment. In Kenya, for example, only about 20% of individuals with epilepsy have access to appropriate medical care.

- There is a shortage of trained healthcare providers who can diagnose and treat epilepsy.
  - This lack of expertise contributes to the treatment gap and perpetuates the cycle of stigma and inadequate care.

Kenya-Specific Statistics

- There are 2 million Kenyans living with epilepsy (source).

- Studies show that in Kenya, epilepsy is often associated with witchcraft and supernatural forces. This belief significantly impacts the willingness of individuals to seek medical help.

- Organizations like the Kenya Association for the Welfare of People with Epilepsy (KAWE) (shown in the film) are working to combat stigma through education and advocacy, aiming to demystify epilepsy and promote understanding of it as a medical condition.

Sources:
WHO Epilepsy Fact Sheet
International Bureau for Epilepsy (IBE)
Kenya Association for the Welfare of People with Epilepsy (KAWE)

DISCUSSION QUESTIONS

PEOPLE LIVING WITH EPILEPSY & CAREGIVERS

This section is dedicated to those who experience the daily realities of living with epilepsy. These questions focus on understanding personal experiences and promoting supportive environments:

Personal Stories and Challenges

1. How do the personal stories in ***The Curse of Stigma*** illuminate challenges faced by people with epilepsy in Kenya and across Africa?
2. What are some of the challenges of living with epilepsy that you or your family face?

Misconceptions and Daily Impact

1. What common misconceptions about epilepsy are highlighted in the film, and how do these misconceptions impact the daily lives of those affected?
2. Have you or your loved ones encountered misconceptions about epilepsy, and how have they affected your lives?

Transformation Through Understanding

1. How does the film portray the transformation in the lives of individuals once they understand epilepsy as a treatable condition?
2. How has knowledge about epilepsy changed your perspective or the approach to managing epilepsy in your life or the life of a loved one?

HEALTHCARE PROVIDERS

This section is crafted for healthcare providers, including epileptologists, neurologists, general practitioners, nurses, etc. It emphasizes their crucial role in addressing stigma, improving patient support, and collaborating with communities to enhance epilepsy awareness and care.

Role in Addressing Stigma

1. How does the film highlight the role of healthcare providers in addressing the stigma surrounding epilepsy?
2. Reflecting on your practice, what actions can you take to help reduce stigma for your patients with epilepsy?

Improving Support

1. What was surprising in the film about access to medical care?
2. Consider your current practices. What are the barriers to care that your patients face?

Community Collaboration

1. In the film, how did the medical communities work to dispel myths and get people into care?
2. What are some practical steps you can take to engage with your community and promote accurate information about epilepsy?

EPILEPSY ADVOCATES

This section is designed for individuals and organizations that focus on awareness and policy change, similar to the organizations showcased in this guide and film. It emphasizes the importance of leveraging personal stories to promote awareness and drive meaningful change in the support and treatment of people living with epilepsy.

Importance of Advocacy

1. How do the personal stories in the film demonstrate the importance of advocacy in overcoming epilepsy stigma?
2. Reflect on your experiences; how have advocacy efforts made a difference in your community or for individuals with epilepsy?

Policy Changes Needed

1. What policy changes are needed to improve the lives of individuals with epilepsy, as highlighted in the film?
2. Based on your knowledge, what specific changes would you advocate for to enhance the support and treatment of people with epilepsy - in your neighborhood, around the country, or the world?

Leveraging the Film

1. How can advocates like you working on epilepsy-related causes leverage this film to promote epilepsy awareness and drive change?
2. What strategies can you implement to use the film as a tool in your advocacy work to educate and influence policymakers, funders, the public, etc?

GENERAL PUBLIC + HEALTH & EDUCATION ORGANIZATIONS

This section is for the general public, as well as organizations focused on educational initiatives, community outreach, and support programs for epilepsy awareness and treatment. It is designed to raise awareness, dispel myths, and educate about epilepsy. Organizations that do not currently focus on epilepsy can use these resources to educate their communities about the condition.

Educational Impact

1. How does The Curse of Stigma help to educate the general public about the realities of living with epilepsy?
2. Reflect on your community or organization; how can you utilize the film to enhance understanding and awareness of epilepsy?

Dispelling Myths

1. What myths and misconceptions about epilepsy does the film dispel, and how can these be further addressed in educational programs?
2. Have you encountered any similar misconceptions in your community, and what strategies could you implement to address them?

Creating Inclusive Environments

1. What specific actions can the general public take to create a more inclusive and supportive environment for people with epilepsy?
2. What steps can you or your organization take to foster inclusivity and support for individuals with epilepsy in your community or educational programs?

GLOBAL HEALTH ORGANIZATIONS/FUNDERS

This section is aimed at global health organizations and funders, focusing on exploring ways to integrate epilepsy into global health initiatives, funding strategies, and partnerships to improve epilepsy care and support worldwide. It emphasizes the importance of addressing epilepsy in low-resource settings through strategic funding and collaboration.

Highlighting Global Health Challenges

1. How does the film highlight the global health challenges associated with epilepsy, particularly in low-resource settings?
2. Reflecting on your experience, how does epilepsy as a public health problem compare to other issues?

Funding Strategies

1. The film seeks to launch a campaign to raise funding for anti-stigma efforts in Africa. Can you think of ways to support the campaign goals?
2. Based on your expertise, what innovative funding approaches could be implemented to enhance epilepsy care globally?

Partnerships with Local Communities

1. How can global health organizations partner with local communities to enhance epilepsy care and support?
2. What successful partnerships have you seen or participated in that could serve as models for improving epilepsy care?

Considering Funding for Epilepsy

1. Do you see opportunities to integrate epilepsy care into existing primary health care programs?
2. Did watching this film influence your perspective on the need for expanded funding for epilepsy initiatives, and if so, how?


The Misunderstood

Learn More

Explore these resources to deepen your understanding of the issue and identify additional ways to get involved.

Global Resources

- World Health Organization (WHO) Epilepsy Fact Sheet
- International Bureau for Epilepsy (IBE):
  - Advocate’s Toolkit for Reducing Epilepsy Stigma in Africa
  - Global Epilepsy Needs Study (GENS)
- International League Against Epilepsy (ILAE)
- World Federation of Neurology (WFN)

US/North America Resources

- Centers for Disease Control and Prevention (CDC)
- National Institutes of Health (NIH)
- CURE Epilepsy
- Epilepsy Foundation
- American Epilepsy Society
- Epilepsy Alliance America
- Purple Day
- Healthline: "12 Celebrities with Epilepsy"

GLOSSARY

Epilepsy	A neurological disorder characterized by recurring, unprovoked seizures.
Seizure	A sudden surge of electrical activity in the brain.
Neurological Disorder	Disorders affecting the nervous system, including epilepsy.
Recurring Seizures	Multiple seizure events happening over time.
Disability	A physical or mental condition limiting a person's movements, senses, or activities.
Stigma	A mark of disgrace associated with a particular condition.
Treatment Gap	The difference between those needing treatment for epilepsy and those receiving it.
Intersectoral Global Action Plan (IGAP)	The World Health Organization (WHO’s) plan to improve care for neurological disorders, including epilepsy.
Community Health Workers	Individuals trained to provide basic health services and education in their communities.

IMPACT CAMPAIGN ALLIES

IBE International Bureau for Epilepsy

KAWE
KOMESHA KIFAFA

CURE EPILEPSY

AES
AMERICAN EPILEPSY SOCIETY

ROW | One World. One Standard.

EPILEPSY FOUNDATION

ILAE International League Against Epilepsy

World Health Organization

epilepsy ALLIANCE AMERICA

Purple Day - March 26
www.purpleday.org

Sample Social Media Posts

To assist with promotion of your *The Curse of Stigma* film watch party, please see the sample social media posts below. The social media posts are general in nature and touch upon the themes in the movie – understanding epilepsy, protecting human rights and advocacy, and overcoming stigma.

All Social Media Graphics can be found HERE.
*If you have any problems accessing the files, please contact Alison Kukla (alison@thecurseofstigma.org).

	**FB/IG/LinkedIn:** Epilepsy stigma has existed since ancient times and persists in various degrees throughout the world. Join us at (insert screening details) for a documentary film screening, featuring The Curse of Stigma Film, followed by an expert panel discussion. **http://thecurseofstigma.org**
	X: Epilepsy stigma has existed since ancient times and persists in various degrees throughout the world. Join us at (insert screening details) for a documentary film screening, featuring The Curse of Stigma Film, followed by an expert panel discussion.
	**FB/IG/LinkedIn:** Epilepsy stigma has existed since ancient times and persists in various degrees throughout the world. Join us for the screening of The Curse of Stigma Film and a discussion at (insert screening details). **http://thecurseofstigma.org**

	X: Epilepsy stigma has existed since ancient times and persists in various degrees throughout the world. Join us for the screening of The Curse of Stigma Film and a discussion at (insert screening details). http://thecurseofstigma.org
	**FB/IG/LinkedIn:** The Whitten-Newman Foundation and BAND Foundation is proud to partner with IBE to present The Curse of Stigma Documentary Film to raise awareness about stigma worldwide. Join us at (insert screening details) for a film screening, featuring The Curse of Stigma Film, followed by a panel discussion. http://thecurseofstigma.org
	X: The Whitten-Newman Foundation and BAND Foundation is proud to partner with IBE to present The Curse of Stigma Documentary Film to raise awareness about stigma worldwide. Join us at (insert screening details) for a film screening, featuring The Curse of Stigma Film, followed by a discussion.
	**FB/IG/LinkedIn:** The Curse of Stigma Film reveals the experiences of African families living with epilepsy, illustrating the profound impact of cultural misconceptions and stigma. Join us at (insert screening details), for a film screening and a discussion. http://thecurseofstigma.org
	X: The Curse of Stigma Film reveals the experiences of African families living with epilepsy, illustrating the profound impact of cultural misconceptions and stigma. Join us at (insert screening details), for a film screening and a discussion.

Advocacy
for Impact

IBE International Bureau
for Epilepsy

AFRICA REGION

50 million

Steps Against Stigma 2025

FUNDRAISING PARTNER

In 2025, IBE will partner with the BAND and Whitten-Newman Foundations to raise funds through our #50MillionSteps campaign.

Proceeds raised will directly support the **IBE Advocacy for Impact Fund**, which channels resources back into the African region to tackle stigma and improve the lives of people with epilepsy.

Built on the powerful message of the Curse of Stigma documentary film, this fund empowers local IBE chapters to create meaningful change through advocacy, awareness, and community-based projects.

WHITTEN-NEWMAN FOUNDATION

THE CURSE OF STIGMA

BAND FOUNDATION

Why fundraise?

This year, we're asking our chapters in Africa, and globally, to go beyond raising awareness by incorporating fundraising into their #50MillionSteps campaign activities. Funds raised will directly support the IBE Advocacy for Impact Fund, empowering local epilepsy organisations to:

- Launch media campaigns to combat stigma.
- Organise community dialogues to build understanding.
- Facilitate training workshops for epilepsy stakeholders.
- Advocate for better epilepsy services and policies.

Together, we can improve the lives of people with epilepsy by reducing stigma and fostering political and social change, in alignment with the IGAP objectives.

How can you get involved?

- Incorporate fundraising into your chapter's #50MillionSteps initiatives (think sponsorships, donation drives, and creative local campaigns).
- Share the message of the Curse of Stigma documentary film to inspire action, and encourage donations to the IBE Advocacy for Impact Fund.
- Leverage this opportunity to strengthen epilepsy awareness and support in your community.

For more information and to donate, visit thecurseofstigma.org or 50millionsteps.org