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# ANNUAL REPORT

[haemocare.org.ng](http://haemocare.org.ng)

# HAEMOPHILIA FOUNDATION OF NIGERIA

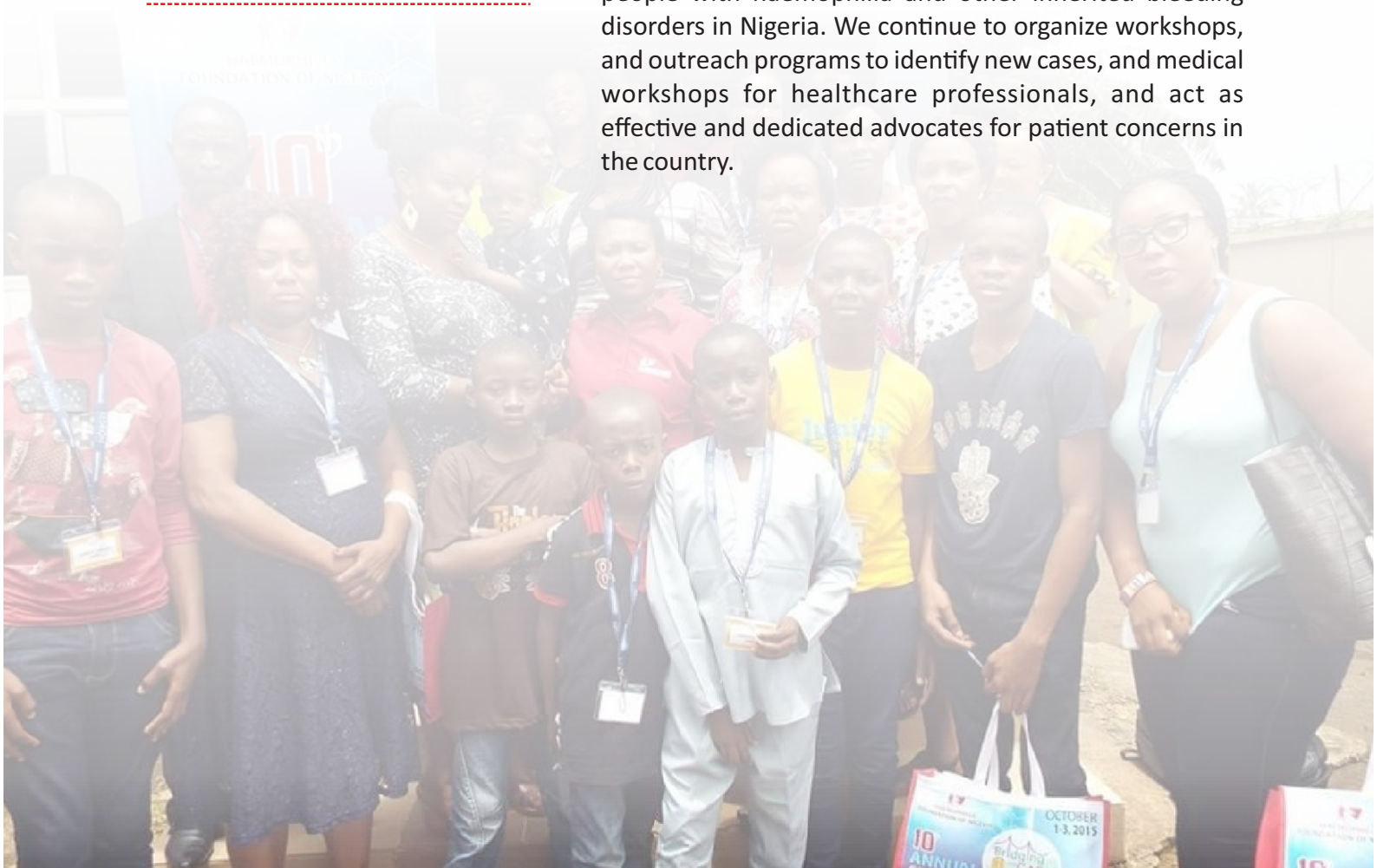
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*HFN is resolved to continue to be a go-to for persons with bleeding disorders to ensure that have access to care and management.*

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Founded on April 17, 2005, we work to ensure that every person living with bleeding disorders (haemophilia, von Willebrands disease (VWD), rare factor deficiencies, and women with bleeding disorders have access to diagnosis, treatment, and care. Our partners, donors, and volunteers also believe in this, and we thank them for their continuous support to help us achieve our goal.

In Nigeria, 96% of persons with haemophilia are still undiagnosed, while for VWD more than 99% are undiagnosed. Those who are diagnosed still receive inadequate levels of care. HFN continues to be a voice for people with haemophilia and other inherited bleeding disorders in Nigeria. We continue to organize workshops, and outreach programs to identify new cases, and medical workshops for healthcare professionals, and act as effective and dedicated advocates for patient concerns in the country.



# OUR VISION, MISSION & STRATEGIC PLAN

*Our vision is to see that persons with bleeding disorders live a normal life.*

*Our mission is to SUPPORT, EDUCATE and ADVOCATE for persons with bleeding disorders to have access to RIGHT and PROMPT treatment.*

## HFN STRATEGIC IMPERATIVES: 2020-2024

*To enable us achieve our vision of enabling persons with bleeding disorders live a normal life, our Strategic Plan for 2020-2024 focuses on tackling current challenges facing our community.*

### 1 AWARENESS AND OUTREACH

Continuous education of our communities and healthcare providers.

### 2 ADVOCACY

Partnership with vital stakeholders for better care and services for persons living with bleeding disorders.

### 3 TREATMENT AND MANAGEMENT

Provision of more treatment products, services and healthcare providers.

### 4 FINANCE & FUNDING

Getting financial support from government, corporate & private businesses as well as individuals.

### 5 ORGANIZATIONAL DEVELOPMENT

Continuous development of members of the organization to enable them serve the bleeding disorders community better.

### 6 GOVERNMENT

Partner with Government (Federal & States) to improve Health and Quality of Life for persons living with bleeding disorders.



Review & Finalization of the Nigerian National Policy and Strategic Plan of Action on Non-Communicable Diseases, 2021

# HFN PRESIDENT/ED MESSAGE

In the year 2022, we continued to work with healthcare professionals, governments and other partners to improve access to care and quality of life. This has allowed for our activities to be better tailored to our community's need.

Patient identification has remained top priority for us and we have continued to carry out outreach programs to enable us identify new patients and close the gap. In the year through our various activities, we identified 35 new patients.

Knowing that Nigeria is a country that is huge in size, families face the challenge of having to travel more than 3 hours to reach their Treatment Centres. We decided to have more centres established to reduce the burden and also shorten the treatment time.

Under the WFH PACT program in 2022, we continued to work closing with government. This engagement lead to WFH submitting a draft MOU with the Federal Ministry of Health. This document is under review and will soon be signed. The signing of this document will be a boost to us and it will move us closer to achieving of vision.

As we continue to put in efforts, we hope that by the time we bring to a close our current strategic plan in 2024; we will reach our strategic goal indicators.



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*Thanks to the great dedication of our executives, partners, healthcare providers, and volunteers, HFN was able to support patients and families in 2022. We believe that together we can make persons with bleeding disorders live a normal life*

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# TREATMENT SUPPORT

The biggest challenge to care and management for people with bleeding disorders in Nigeria is the lack of access to treatment products. This can be linked to the fact that these medications are not being purchased by government and too expensive for individuals living to condition to afford themselves.

Since its inception, the Haemophilia Foundation of Nigeria has been the only source by which persons living with bleeding disorders access this life saving medications. As a National Member Organization (NMO) of the World Federation of Federation (WFH), HFN has depended on donations of treatment products from the WFH.

WFH is leading the change to reduce the lack of access in developing countries by providing consistent and predictable donations of these medications through its Humanitarian Aid Program. This program has made it possible for people with bleeding disorders in Nigeria to have continued access to treatment for emergencies, acute bleeds, corrective surgeries and also prophylaxis for young children.

Another organization Save One Life Inc, has also supported us with donations especially for von Willebrands patients.

In 2021, Nigeria was enrolled unto the Emicizumab program. 56 patients are in this program to date. This medication has been defined as a “game changer” with the positive testimonies received from both patients and treating physicians.

HFN will continue to advocate for government to begin purchase of treatment products, as donations cannot last forever.

## Factor Concentrates

### 2004-2021

Millions IUs Distributed **38+**

States Reached **24+**

Bleeds Treated **20,000+**

### 2022

Millions IUs Distributed **4+**

States Reached **28+**

Bleeds Treated **1,000+**



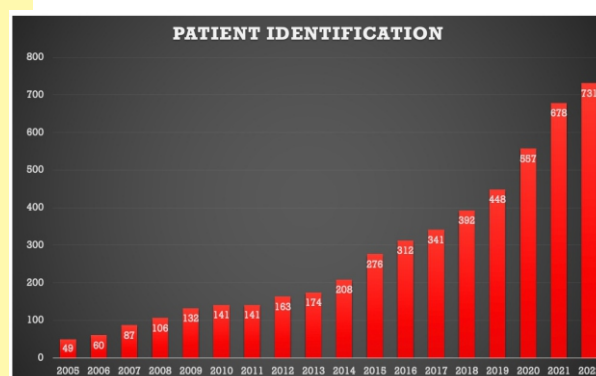
# PATIENT IDENTIFICATION

The Haemophilia Foundation of Nigeria maintains a bleeding disorder registry that serves as a platform for the Haemophilia Treatment Centres (HTCs) across the country to present and collect uniform and standardized patient data. This data is used to guide clinical practice and improve care for those affected. As an organization with at least 15 HTCs in government hospitals and medical practitioners in fields applicable to the care and management of people with bleeding disorders, HFN recognizes the importance of collecting and analyzing data as the essential first step in improving care.

Over the last decade, there has been a concerted effort to improve patient identification in bleeding disorders in Nigeria. This has involved increasing awareness among healthcare professionals and the general public, establishing diagnostic and treatment centres, and providing education and support to patients and their families.

HFN is committed to leading the cause of uniting treatment centres and healthcare professionals in delivering data-driven initiatives aimed at advocating for, creating awareness of, and strengthening our capacity to diagnose and improve the infrastructure necessary to address the challenges facing people with bleeding disorders in Nigeria.

*An estimated 1 in 1,000 people worldwide live with a bleeding disorder*



**97%** *STILL*  
*UNDIAGNOSED*



# PROGRAMS

HFN has a variety of programs and activities for our community. These includes a yearly camp for children between the ages of 10-17 called Camp Infusion. It's main objective is to teach self-infusion, so as to build more independence and self-esteem. The Red Heart workshop is for women and girls with bleeding disorders, as well as mothers and spouses of persons with bleeding disorders.

The Stand-Up and Stand-Out Camps are also organized for different age groups. Stand-Up for 18-25 years while Stand-Out is for 26 and above.

The National Bleeding Disorders Week, is observed every 3rd week of November to raise awareness for persons living with haemophilia and other bleeding disorders in Nigeria.

Our National Conference is the largest gathering for bleeding disorders in Nigeria. This event brings together persons living with bleeding disorders, healthcare providers, government agencies and the public to discuss current issues, possible solutions and generally bond with each other as a community.





# HTCs REPORT

13

HTCs Reported

7

HTCs on WFH WBDR  
(World Bleeding Disorders Registry)

3

HTCs on WFH IEQAS  
(International External Quality  
Assessment Scheme)

10

HTCs with multidisciplinary team

4

HTCs with dedicated coagulation labs

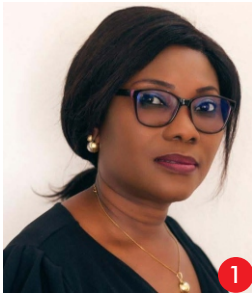
The Haemophilia Foundation of Nigeria (HFN) is leading efforts to change the narrative of the management of bleeding disorders in Nigeria. One such area is in making sure persons with bleeding disorders are managed at a dedicated hospital called a Haemophilia Treatment Centre (HTC). These centres in most developed countries are stand-alone hospitals. For a start, HFN currently domiciles its HTCs at the Department of Haematology and Blood Transfusions of Teaching Hospitals or Federal Medical Centres. We currently have 15 such centres.

In 2022, 13 HTCs report was received by HFN with 674 persons with bleeding disorders enrolled in these centres. 658 males and 16 females. 583 with Haemophilia A, 48 with Haemophilia B, 23 with Von Willebrands Disease, and 23 with an unknown diagnosis. 3 new inhibitor cases.

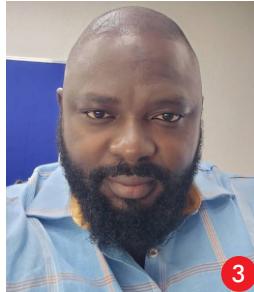
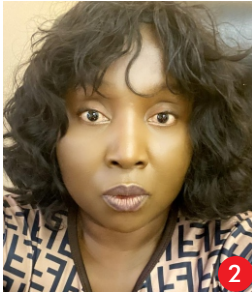
In the area of treatment, 149 persons are on primary prophylaxis. 447 joint bleeds, 11 ICH, 30 GI bleeds were reported managed. 5 reported deaths and 58 patients lost to follow-up.

68 persons were recommended for physiotherapy out of which 54 carried out the session. According to the reports, 21 persons are needing synovectomy, and 13 need joint replacements.

21 persons are having psycho-social concerns.

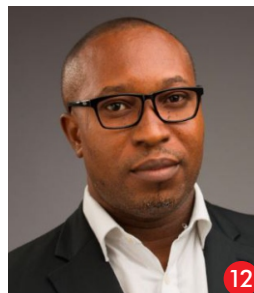
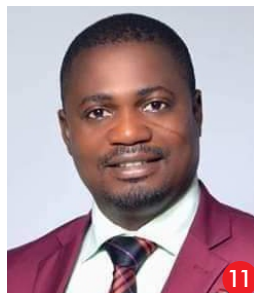
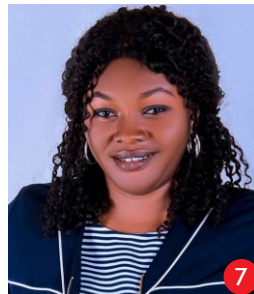
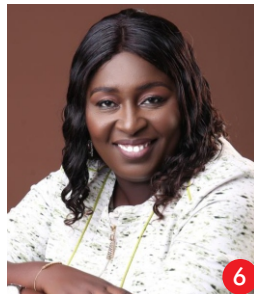
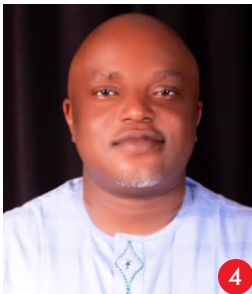


# HFN NATIONAL EXECUTIVE MEMBERS



*We rely on the HFN National Executive Council, HFN Staff, and volunteers to help bring our shared vision to life.*

*We have an extensive number of individuals who share the HFN's vision of ensuring people with bleeding disorders live normal lives.*



1. **Megan Adediran**  
President/Executive Director  
Northwest Chapter

2. **Dr. Theresa Nwagha**  
Vice-President Medical  
Southeast Chapter

3. **Idris Aderinto**  
Vice-President Finance  
South-south Chapter

4. **Innocent Ikpetha**  
Vice-President Programs  
North-central Chapter

5. **Prof. Titi Adeyemo**  
Medical Member  
Southwest Chapter

6. **Dr. Christiana Udo**  
Medical Member  
North-central Chapter

7. **Josephine Okpe**  
Coordinator  
Southeast Chapter

8. **Hafsata Baba-Koki**  
Coordinator  
Northwest Chapter

9. **Gladys Njoku**  
Coordinator  
South-south Chapter

10. **Usman Sabo**  
Coordinator  
Northeast Chapter

11. **Akuza Gajere**  
Coordinator  
North-central Chapter

12. **Anyachi Ezendu**  
Coordinator  
Southwest Chapter

13. **Benjamin Onoje**  
Youth Coordinator  
North-central Chapter

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