



Global Action Network for Sickle Cell
and Other Inherited Blood Disorders

The Global Action Network of Sickle Cell & Other Inherited Blood Disorders (GANSID) Launches

April 6th, 2023: Dover, Delaware, USA and Toronto, Canada

A new international organization incorporating all benign inherited blood disorders has launched. The Global Action Network of Sickle Cell & Other Inherited Blood Disorders, or GANSID for short, aims to foster cross-disease collaborations to advance advocacy efforts that improve outcomes for people living with sickle cell and other inherited blood disorders no matter where they live.

The objective is to galvanize the attention of public health policy decision-makers and governments around the world.

Benign Inherited Blood Disorders not limited to- Sickle Cell Disease (SCD), Hemophilia, Fanconi Anaemia, Thalassemia, and Aplastic Anaemia know no geographical or racial boundaries; oftentimes they exert a heavy toll on the physical, mental and financial resources of affected individuals and families.

GANSID was created by global benign Inherited Blood Disorders patient advocacy leaders who saw an opportunity to unite forces across benign Inherited Blood Disorders patient communities, and harness the power of their collective voice to better the needs of people impacted by benign Inherited Blood Disorders around the globe.

The organization will bring together patient organizations, health care providers, health organizations, professional and academic societies, and industry partners that serve people impacted by sickle cell disease and other inherited, non-malignant blood disorders.

Dr. Isaac Odame, Medical Director, Global Sickle Cell Network

Sickle cell disease (SCD) is associated with high mortality and significant morbidity, particularly in low and middle-income countries that shoulder the heaviest disease burden. However, health systems in these countries have not prioritized SCD highly enough to tackle this major health problem acknowledged by the World Health Organization. A global collaborative initiative such as GANSID will be a needed resource to embolden civil society and empower patient organizations to lobby their governments to move SCD high on their agenda.

Alain Baumann, CEO, World Hemophilia Federation

Collaborating with initiatives like GANSID is aligned with the WFH goals of working with different organizations to find innovative ways to both support and advocate for the global bleeding disorders community.

Lanre Tunji-Ajayi, M.S.M, CEO, Global Action Network

Many organizations serving people impacted by benign inherited blood disorders lack the necessary training and mentorship to undertake effective government advocacy on behalf of the people they serve. This is especially true in many parts of the Global South, where there are scarce financial resources and limited capacity despite having the highest proportion of individuals and families needing support.

The GANSID will empower these grassroots organizations and embrace cross-disease advocacy to help them build the capacity to pursue public policy changes that will improve the quality of care for all people living with inherited blood disorders.

The GANSID's inaugural Board Members representing different regions of the world include:

1. [Dr. Adletti Inati](#), Professor of Clinical Medicine at the Gilbert and Rose-Marie Chagoury School of Medicine, Lebanese American University, Lebanon;
2. [Dr. Donnell Ivy](#), Director of Community Programs with the Association of Black Cardiologists, Inc (ABC) and Vice Chief Medical Officer for the Sickle Cell Disease Association of America (SCDAA), USA;
3. [Mr. Ewakat Suwantaraj](#), a Hemophilia patient/advocate, and Board member, World Hemophilia Federation, Thailand;
4. [Dr. Kibet Shikuku](#), Hematopathologist, University of Nairobi and President, Kenya Hemophilia Association (KHA), Kenya;
5. [Dr. Marimilia Pita](#), Pediatric Hematologist/ Oncologist, University of Campina, Brazil and President/ Chief Executive Officer of the Lua Vermelha-a sickle cell disease patient association, Brazil;
6. [Dr. Sandra Newton](#), a Clinical and School Psychologist in Supervised Practice with a longstanding interest in advocacy for children, youth, and adults affected by sickle cell disease, Canada;
7. [Mr. Riyad Elbard](#), President, Thalassemia Foundation of Canada and Treasurer, Thalassemia International Federation, Canada;
8. [Vinita Srivastava](#), Health Adviser, Ministry of Tribal Affairs, India.

Ways to Join the GANSID Movement

1. Patient organizations, [click here](#)
2. HCP orgs., professional and academic societies, and industry partners, [click here](#)
3. Individuals with specialized skills set seeking to volunteer, [click here](#)

To learn more about GANSID, visit: www.inheritedblooddisorders.world

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