

GUIDANCE COUNCIL
A New Day for Children with Sickle Cell Disease

Mrs. Joy Phumaphi is a distinguished global health leader whose decades of service have been dedicated to advancing public health in Africa and enhancing global health security. Her work, spanning key health priorities, including malaria, Neglected Tropical Diseases, Reproductive, Maternal, Child, and Adolescent Health, nutrition, pandemic preparedness and response, and the intersections of gender and climate change with health, aims to transform Africa's healthcare landscape by improving accessibility, equity, and the response to emerging health threats that significantly affect millions of Africans and the global community. She is an instrumental voice in championing the strengthening of health systems, health financing, and pandemic preparedness, paving the way for Africa to achieve its own health transformations, asserting that a healthy Africa is essential for the continent's development, peace, and stability.



Joy serves as the Executive Secretary of the African Leaders Malaria Alliance (ALMA), a groundbreaking coalition of African Union Heads of State and Government working to eliminate malaria in Africa by 2030. She leads the ALMA Secretariat in supporting the Heads of State and Government's agenda to drive accountability and action for results, public and private domestic resource mobilization for malaria, Neglected Tropical Diseases, and other priorities in Africa's health development agenda.

Joy has been at the forefront of working with the Africa CDC and other global health entities to concretize mechanisms for global health security and ensure Africa takes a leading role in redefining the global health architecture.

She joined the World Health Organization (WHO) as the Assistant Director-General for Family and Community Health. She also served as Vice President for Human Development at the World Bank where she oversaw a dramatic expansion of the network evaluation programme, introduction of health results-based financing, growth in the World Bank's contribution to basic education, and the Network's extensive role in expansion of social protection programs during the 2007/8 Global Food and Financial crises.

In her extensive portfolio, she has co-chaired the United Nations (UN) Secretary-General's Independent Accountability Panel for Every Woman, Every Child, Every Adolescent, and has been a member of the UN High-Level Panel on Global Response to Health Crises. Additionally, she has served as a member of the UN Reference Group on Economics, and as a UN Commissioner on HIV/AIDS and Governance. Her most recent role was as Interim co-CEO of the Clinton Health Access Initiative. Joy continues to contribute her expertise on the boards of several international organizations and serves as an advisor to multiple global health initiatives, including, Children's Investment Fund Foundation; African Comprehensive HIV/AIDS Partnership; Medicines for Malaria Venture, Save the Children, and as an advisor for Hilleman Laboratories at the Wellcome Trust, the Gates Foundation Malaria Program, the Harvard Health Ministerial Leadership program, the Uppsala Health Summit, Aspen Institute's AMP Health's Leadership Council and Board, as well as blue orange, and the Clinton Health Access Initiative.

She is a distinguished African American Institute Fellow and holds a Bachelor of Commerce from the University of Botswana and a Master's in Finance, Accounting, and Decision Sciences from Miami University in the US.

Dr. Matshidiso Moeti was the first woman Director of the WHO Africa Regional office which she led until 2023 and transformed it into an accountable and results driven organisation.

She bolstered WHO Africa's capacity to improve health security, universal health coverage and supporting countries in the implementation of Sustainable Development Goal 3, i.e., ensuring healthy lives and promoting well-being for all at all ages. Dr Moeti is a public health expert, with more than 38 years of experience.



She joined WHO's Africa Regional Office in 1999 and served as Deputy Regional Director, Assistant Regional Director, Director of Noncommunicable Diseases, WHO Representative for Malawi, Coordinator of the Inter-Country Support Team for the South and East African countries and Regional Advisor for HIV/AIDS. She is renowned for having successfully spearheaded increased access to antiretroviral drugs by HIV-infected persons in Africa. Prior to joining WHO, she worked with UNAIDS as a Team Leader of the Africa and Middle East Desk in Geneva (1997-1999); with UNICEF as a Regional Health Advisor for East and Southern Africa; and with Botswana's Ministry of Health as a Clinician and Public Health Specialist.

Dr Moeti holds a medical degree from the Royal Free Hospital School of Medicine and a Master's degree in public health (Community Health for Developing Countries) from the University of London and the London School of Hygiene and Tropical Medicine.

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His Excellency Dr. Jean Kaseya is the Director General of the Africa Centres for Disease Control and Prevention (Africa CDC) having been appointed by the African Union Heads of State and Government during the 36th Summit in February 2023. Dr. Kaseya is a medical doctor with advanced degrees in Epidemiology and Community Health, and 25 years of expertise in public health.

As the Director-General of Africa-CDC, Dr. Kaseya oversees the organization's political, strategic, and technical functions. At the forefront of his agenda is his commitment to advancing a transformative "New Deal" for Africa's health, which entails establishing innovative and sustainable financing mechanisms, enhancing robust governance structures, cultivating technical expertise, strengthening health systems, and efficient response to health crises.

Before assuming his role as Director General of Africa CDC, Dr. Kaseya had a distinguished career, at the national level in Democratic Republic of Congo and internationally. He led the National Expanded Programme on Immunization and grassroots level health programs. He has led initiatives with UNICEF, GAVI, Clinton Health Access Initiative, and the World Health Organization.



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Dr. Sharif K. Tusubira is a person living with sickle cell disease who is renowned for promoting sickle cell awareness and advocacy across Africa. Sharif grew up in Katanga, one of the most impoverished slums in Kampala Uganda, where he developed a passion for community service.

In 2011, after experiencing a heartbreaking incident of discrimination because of being a person with sickle cell disease, Sharif became a fervent advocate for people with the disease.

He is co-founder of Sickle Cell Network Uganda and the Pan African Sickle Cell Federation – both of which brought together numerous community-based sickle cell advocacy associations to form a common voice. Sharif served as the first Executive Director of the Uganda Sickle Cell Rescue Foundation where he created the first sickle cell counselor training program. He also founded Sickle Cell Network Uganda, which runs the biggest sickle cell virtual chat room offering real time support to families affected by sickle cell in Uganda. He has mentored many leaders of sickle cell disease advocacy groups in Africa. He is a board member at the Uriel E. Owens Sickle Cell Disease Association of the Midwest, based in Kansas City, USA.



Sharif has been honored as one of the “100 Leaders of Impact” by the Global Thinkers Forum and received the “International Sickle Cell Advocate of the Year 2020” award. He was also a Mandela Washington Fellow, selected among the top 1,000 leaders in Africa by the U.S Dept of State out of 30,000 applicants across Africa under the Young African Leaders Initiative.

Dr. Tusubira is an archery enthusiast, having competed on the Uganda National team, enjoys hiking, and spends most his weekends biking with his two kids and wife.

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Mrs. Verónica Arroyave is the Vice President of Corporate Responsibility and Global Philanthropy at Baxter Healthcare (Chicago, IL) and the Executive Director of the Baxter Foundation. As a native of Columbia with a strong background in global health, she advances Baxter's healthcare mission by building global philanthropic partnerships to increase access to healthcare, developing the next generation of STEM innovators and helping create resilient communities.



Verónica has held several leadership and advisory roles in the corporate, government, and non-profit sectors catalyzing global health partnerships and collaborations. She previously served as Senior Director of Global Community Relations and Senior Director of Global Health Programs at Baxter. Prior to joining Baxter, Verónica was Director of Corporate Responsibility at AbbVie Foundation where she advanced the company's global philanthropic investments in the areas of oncology, hepatitis C, neglected tropical diseases, and health system strengthening. She launched eleven signature initiatives.

She holds a master's degree from Tulane University's School of Public Health & Tropical Medicine and a doctorate from Virginia Tech's School of Public and International Affairs.

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Mr. John Damonti was the President of the Bristol Myers Squibb Foundation as well as Vice President of Corporate Philanthropy and Patient Assistance at the Bristol Myers Squibb Company until he retired in 2024.

John has more than 30 years of experience working in the areas of health policy, government affairs and corporate social responsibility. He received his undergraduate degree from Bowling Green State University and a Master of Social Work degree from Fordham University in 1985. In 2007 he was awarded an Honorary Doctorate degree from Fordham University.



John has been a philanthropic advisor for Texas Children's global pediatric HIV for over twenty-five years, and more recently for the Global HOPE program for cancer and blood diseases.

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Ambassador Jimmy Kolker is a veteran in global health and diplomacy. He retired in January 2017 as Assistant Secretary for Global Affairs at the United States Department of Health and Human Services. In this role, Kolker was the Department's chief health diplomat, representing the United States at the World Health Organization and as alternate Board Member of the Global Fund to Fight AIDS, Tuberculosis and Malaria.

Ambassador Kolker had a 30-year diplomatic career with the US Department of State where he served as the US Ambassador to Burkina Faso (1999-2002) and to Uganda (2002-2005). From 2005-2007, he was Deputy Global AIDS Coordinator in the Office of the US Global AIDS Coordinator, leading the implementation of the President's Emergency Plan for AIDS Relief (PEPFAR). Ambassador Kolker was Deputy Chief of Mission at US embassies in Denmark and Botswana.



From 2007-2011, Ambassador Kolker was Chief of the AIDS Section at UNICEF's New York headquarters. During this time, he led UNICEF's work on HIV/AIDS, focusing on preventing mother-to-child-transmission of HIV, pediatric treatment, prevention among adolescents and young people, and protection for children and families affected by AIDS.

Ambassador Kolker holds a Master's in Public Administration from Harvard Kennedy School and a B.A. magna cum laude from Carleton College in Minnesota. He was a Thomas J. Watson Foundation Fellow (1970-1971). He speaks French, Swedish, and Portuguese.

Mrs. Mary Gregory is a twenty-six-year Bachelor of Law graduate at Tanzania School of Law and a person living with sickle cell disease. Mary's journey with sickle cell disease typifies the trials, tribulations, and resilience of people with the disease in Africa. Mary describes her life as "me vs. sickle cell disease."



She was eight months old when she was diagnosed with sickle cell disease, after months of hospital visits with swelling of her feet and hands without an explanation. When she was eventually diagnosed at a specialist hospital, there was no specific treatment offered. Her family put her on a stringent diet of bean soup, hibiscus and beetroot juice, in addition to frequent doses of aspirin.

She suffered frequent pain crises resulting in missing school for at least a week every month for most of her elementary and middle school life. She was often offered the option to repeat grades in school but preferred to push forward – sometimes taking exams while in a pain crisis.

In 2015, she had a painful crisis that barely relented for three months. This is when she consulted a doctor who started her on hydroxyurea. She has occasional, mild painful crises since then. Her priority now is to support her 12-year-old brother who is having more severe sickle cell disease. She also participates in advocacy activities community based

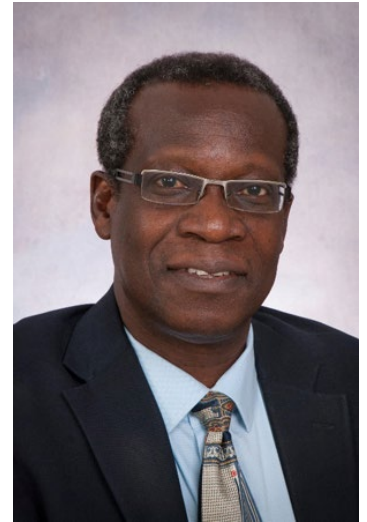
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Dr. Isaac Odame is Professor of Pediatrics and Head of Hematology at University of Toronto, Canada. He is also the President of the World Coalition for Sickle Cell Disease, Medical Director of the Global Sickle Cell Disease Network and the Centre for Global Child Health at The Hospital for Sick Children – Toronto. He is a fellow of the Royal College of Paediatrics and Child Health, the Royal College of Physicians, and the Royal College of Pathologists, all of Canada. He is native of Ghana, West Africa.

Dr. Odame is a career-long leader in building enduring collaborations between clinicians, scientists, and global agencies worldwide to further research and advance care of people with sickle cell disease, particularly in low-income countries.

He founded The World Coalition for Sickle Cell Disease, which provides a multi-stakeholder and cross-sectoral platform to enhance coordination of efforts to control sickle cell disease on a global scale. The Coalition convenes national governments, international development agencies, financial institutions, foundations, healthcare providers, patient groups, medical organizations, pharmaceutical companies, and other private sector entities, each contributing unique insights and capabilities to the cause.



Professor Obiageli Eunice Nnodu is a Nigerian Professor of Haematology and Blood Transfusion, specializing in sickle cell disease. She is the Director of the Centre of Excellence for Sickle Cell Disease Research and Training at the University of Abuja, Nigeria.

She is also the National Coordinator for the American Society of Hematology Consortium for Newborn Screening in Africa for Sickle Cell Disease. Prof. Nnodu was troubled by the unconscionable deaths of children with sickle cell disease in Nigeria, which compelled her to switch and devote her career to the disease from her earlier focus on cancer care.



She is the Nigeria principal investigator for the Sickle Pan African Research Consortium, a multi-site consortium working to develop an infrastructure for sickle cell disease research, health care, education, and training in Africa. In this role, Prof. Nnodu's team has recruited nearly 7,000 patients into research database – providing data-based evidence for best practices in sickle cell disease in the African context. With her leadership, the Consortium has developed guidelines for standardized care of patients with sickle cell disease in primary health care settings, district hospitals, and tertiary hospitals.

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Professor Nelson Sewankambo is a leader in medical education, research, and translating research into policy in the context of Africa's health systems. He is Emeritus Professor of Medicine and former Principal of Makerere University College of Health Sciences, a position he took up after serving as Dean of Makerere University Medical School for 11 years. He has served at the US Institute of Medicine as an External Associate member since 2012. He has led many health workforce development and research initiatives across Africa in collaboration with North American and European institutions with focus on translating evidence-based interventions into largescale clinical practice and health policy.



He spearheaded the development of the Regional East African Community Health (REACH)-Policy Initiative to bolster research and programmatic work related to knowledge translation for policy and action. He also coordinates the International Chairs Initiative focusing on the evaluation of knowledge translations platforms.

He has worked closely with Dr. Joseph Lubega, the Director of Texas Children's Global HOPE to establish pediatric cancer and hematology specialist training programs in Africa. He is also a co-principal investigator with Dr. Joseph Lubega on a US National Institutes of Health-sponsored project that has successfully developed a novel mobile phone app for information management and coordination of population-wide point-of-care infant screening for sickle cell disease in the African context.

His work to strengthen health systems in Africa through workforce development and research has been recognized by many preeminent awards including the Grand Silver Medal of Karolinska Institutet Sweden, Fellow of The Academy of Sciences for the Developing World, Member of the Advisory Committee of the Consortium of Universities for Global Health, Honorary Doctoral Degrees from Johns Hopkins University, Baltimore Maryland and McMaster University Canada.