



SICKLE GENE ACTION
FOUNDATION
EARLY ACTION SAVES LIVES

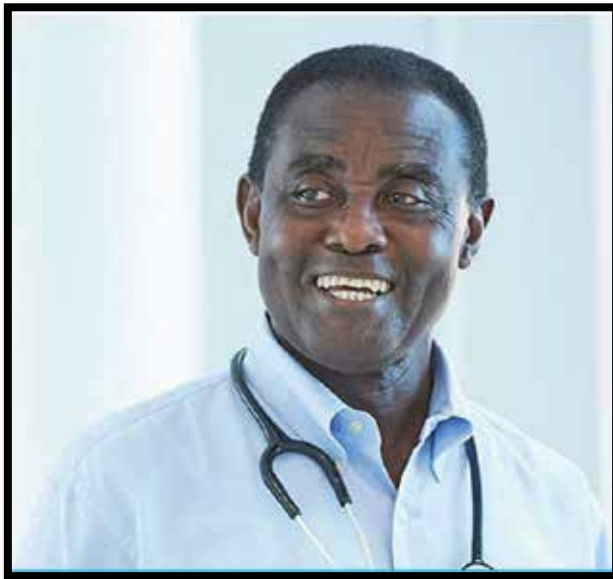
SGAF

Launch Ceremony

Order of Proceedings

3:00-3:20pm	Arrival of Guests
3:20-3:30pm	Opening prayer by Rev Mrs. Sylvia Fitti Royal House Chapel Int. Revival Temple,
3:30-3:45pm	Acknowledgment of Special Guests (All protocols observed)
3:45-4pm	Adowa Traditional Performance
4:05-4:15pm	Sickle Cell Disease Video featuring Dr. Kwaku Ohene-Frempong (KOF), John Dzido
4:15-4:30pm	Welcome Address by Awo Twumasi, Foundation Executive Director
4:30-4:45pm	Address by Dr. Yvonne Brew Experienced Pediatrician, Child Health Department of the Greater Accra Regional Hospital, with a special interest in children with chronic illnesses.
4:45-4:55pm	Poetry Recital/Adowa Traditional Performance
4:55-5:05pm	Address by Mrs. Mary Lamptey (National Coordinator New Born Screening)
5:05-5:15pm	Bridging Barriers to Healthcare Video Featuring Prof. Isaac Odame ISCC, Dr. Lutz Hegemann Novartis, Dr. Fola Egbujo Novartis et al
5:15pm-5:25pm	Address by Dr Kwabena Debrah Boakye BSC Human Biology, MBChB Medical officer at Department of Hematology, Komfo Anokye Teaching Hospital, Kumasi
5:25-5:30pm	Video Nana Opokuaa's story
5:30-5:45pm	SCD Highlights
5:45-5:55pm	Message from Advisory Board Member Ms. Afia Ohene-Frempong (Dr. Kwaku Ohene-Frempong KOF's Daughter)
5:55-6:30pm	Light Refreshments and Closing Remarks

OUR INSPIRATION



**Kwaku Ohene-Frempong, MD
1946-2022**

OUR INSPIRATION

In memoriam: Kwaku Ohene-Frempong (1946–2022)



Kwaku Ohene-Frempong, a leading figure in American hematology and a global authority on sickle cell disease (SCD), died of metastatic lung cancer on May 7, 2022, aged 76 years. He was affectionately known by his initials KOF.

Born in Kukurantumi, Ghana in 1946, KOF received his early education in Ghana where he excelled in academics, leadership, and sports – he was recruited to the national track and field team while in high school. These stellar achievements earned him admission to Yale University in 1966 through a competitive African scholarship program. KOF graduated with BSc in

Biology in 1970 and received his MD at the Yale University School of Medicine in 1975. His residency in pediatrics at New York Hospital- Cornell Medical Center was followed by a fellowship in pediatric hematology-oncology at the Children's Hospital of Philadelphia (CHOP). His first faculty position was at the Tulane University School of Medicine where he established and became the first Director of the Sickle Cell Center of Southern Louisiana. He returned to CHOP in 1986 and was named the Director of CHOP's Comprehensive Sickle Cell Center in 1988 and, for 20 years, led the center's growth and development into one of the largest and most comprehensive pediatric SCD programs in the United States.

KOF made major contributions to the field of SCD. He was involved in early studies to understand the fundamental mechanisms underlying Hb S polymerization and erythrocyte sickling. While at Tulane, he and his colleagues demonstrated the benefit of adenotonsillectomy in children with SCD diagnosed with obstructive sleep apnea syndrome (OSAS) and alveolar hypoventilation. The association of OSAS, adenotonsillar hypertrophy, and nocturnal hypoxemia with stroke in children with SCD has now been established. KOF led the writing committee of the Cooperative Study of SCD that reported on the prevalence and incidence of stroke in SCD in 1989, bringing attention to the high risk of stroke in SCD and forming the basis for subsequent studies to develop primary stroke prevention strategies. He was instrumental in originating the organization of the first multi-center trial of hydroxyurea therapy in children with SCD (HUG-KIDS) through the Comprehensive Sickle Cell Centers Program of the National Heart, Lung, and Blood Institute (NHLBI). Under his leadership, CHOP's Comprehensive Sickle Cell Program was a recipient of NHLBI funding for 18 continuous years. One of the most notable of the NHLBI grants was a pilot demonstration project from 1993 to 2008 that introduced newborn screening for SCD to Ghana, Africa's first. This project has served as a model for initiating similar programs in other countries in sub-Saharan Africa, enabling early interventions that have proven to be life-saving. Though Ghana and the rest of Africa are far from achieving universal newborn screening for SCD for newborns, KOF's work in Ghana has shed light on the enablers and barriers to the kind of health system strengthening needed to achieve this goal. His knowledge and expertise have been drawn upon by colleagues in Brazil, the Middle East, India, and Europe to help establish SCD treatment centers in their countries.

OUR INSPIRATION

In 2016, KOF retired from the University of Pennsylvania as an Emeritus Professor to devote more time to his role as President of the Sickle Cell Foundation of Ghana, which he had established in 2004, and as the Coordinator of the National Newborn Screening Program for SCD in Ghana. He championed a partnership between the Ghana government and Novartis that was launched in 2019 to improve SCD diagnosis and care including establishing new SCD centers and expanding affordable access to hydroxyurea therapy. Through these efforts, Ghana launched the listing of hydroxyurea for coverage under its national health insurance scheme in July 2022. A leader by example and keen collaborator, KOF was involved in several international initiatives focused on SCD in Africa including being a founding member of the Global SCD Network, SickleInAfrica Consortium, and the Ghana national coordinator of the American Society of Hematology Consortium for Newborn Screening in Africa.

KOF was a fierce champion and tireless advocate for people living with SCD; he himself has had a son with the disease. Devotion to the cause of SCD through advocacy, research, and education was for him more than a career but the essence of life itself. He served the Sickle Cell Disease Association of America as a chief medical officer and later as chair of the board of directors. He also chaired the Sickle Cell Advisory Committee of the National Institutes of Health and the National Advisory Board of the SCD and Newborn Screening Program of the Health Resources and Services Administration, US Department of Health and Human Services.

KOF has received numerous awards and honors in acknowledgment of his accomplishments. These include the William Mallory Award as the best scholar-athlete in 1970 and the inaugural recipient of the George H. W. Bush Lifetime of Leadership Award from Yale University. In 2008, Ghana's president inducted him into the Order of the Volta for his work in developing a newborn screening program for SCD, and in 2015, he received the Award for Medicine by the Millennium Excellence Foundation of Ghana. In 2020, he became the first civilian recipient of the United States Assistant Secretary of Health Exceptional Service Award in recognition of his exceptional contributions to the cause of public health and medicine. The American Society of Hematology honored KOF with the 2021 Henry M. Stratton Medal for lifetime achievement in clinical and translational hematology research.

KOF was known for his warmth, humility, and kindness. He has inspired and mentored many SCD clinicians and researchers in the US and around the world. Caring for his patients and their families was what he most valued and he devoted himself fully to their well-being. The US and the global SCD community have lost one of its most accomplished figures. To honor his legacy, we should double our efforts to continue his life's mission to advance the care and well-being of people living with SCD. He will be sorely missed by his family (his wife, Janet, daughter, Afia, two grandchildren, a sister, three brothers, and a host of cousins), as well as by patients, colleagues, and friends from all over the world.

ABOUT OUR EXECUTIVE DIRECTOR



Victoria Awo Twumasi-Nyarko
Executive Director

Victoria Awo Twumasi is an accomplished non-profit leader, as well as a business executive, with years of experience working in both the United States as well as in her home country of Ghana.

As a non-profit leader, Ms. Twumasi has been a health education trainer and steadfast advocate and spokesperson for people living with serious conditions and disabilities.

She is the mother of two children, the younger of whom is a Sickle Cell Warrior and Advocate.

She helped to establish the Sickle Association of at the Greater Accra Regional Hospital-Ridge Branch, the second largest hospital in the nation's capital

There, she has served as the President of the organization that advocates for 250 patients and their families. She is passionate about empowering and mentoring young up-and-coming leaders and raising awareness about the needs of people living in Ghana with Sickle Cell Disease. She is also a member of the Good Fellow Foundation in Ghana, a group that seeks to economically empower people with physical disabilities in Ghana. She is the volunteer Coordinator for the Ghana Chapter of the Ghana Advocacy Group (GAG) in Ghana, a nonprofit group of Ghanaians in the Diaspora who embark on socio-economic causes in Ghana. She is also a leading member of the Clean Ghana Army, an advocacy group that seeks to address the health and sanitation issues through awareness, education and organized cleanup efforts in Ghana.

While living in the U.S., Ms. Twumasi worked in Community Healthcare as the Worcester Massachusetts County Area Director for Program Development for Alternatives Unlimited, Inc. for 14 years. Alternatives Unlimited, a non-profit community health and human services provider for the Massachusetts Department of Mental Health, provides person-centered rehabilitative and community health support services to over 2,500 people living with various disabilities in Central and Western Massachusetts. Ms. Twumasi was recognized for her excellence in leadership by the Worcester Business Journal's 40 under Forty in 2011. She was also inducted into the Greater Worcester Community Foundation as a Corporator in 2011 where she served on the Grants and Scholarships Review and Outreach Committees for six years. Ms. Twumasi was acknowledged by the Worcester City Mayor O'Brien for her leadership efforts within the Worcester community in 2012. She has received various leadership awards over the years in her work with Non-Profit Management in Health and Human Services. She also served as a volunteer Executive Leader and Financial Secretary for the First Assembly of God Church Samaritans in Worcester Massachusetts, a mission she extended to Ghana.

In addition to her non-profit expertise, Ms. Twumasi is an entrepreneur. After 18 years in the U.S., she relocated to Ghana to run her family business as the CEO Palmer Group Real Estate in Ghana, West Africa, a company that specializes in lands, houses and buildings for homes, commercial and investment properties, farming, as well as sites for recreational facilities. She also owns a food outlet that offers catering services as well as opportunities for the training and employment for street vendors.

Ms. Twumasi holds Bachelor's Degrees in both Sociology and Business Administration and a Masters in Non-Profit Management and Leadership with a concentration in Community Health from Worcester State University in Massachusetts.

BOARD OF DIRECTORS



Prof. Eric Sampene-Donkor

Prof. Eric Sampene-Donkor is a Professor of Bacteriology and Global Health, and Head of the Department of Medical Microbiology, University of Ghana Medical School. He holds a PhD in Medical Microbiology from the London School of Hygiene and Tropical Medicine and a PhD in Public Health from the University of Iceland. He undertook postdoctoral studies in Microbial Genomics at the University of Cambridge. He has authored more than 130 peer-reviewed articles, 76 of which he was a lead or corresponding author. He has received many research grants and is currently the PI of a 5-year NIH grant, focused on unravelling the impact of vaccination on the population biology of pneumococcus with regard to children with sickle cell disease in Ghana.

In response to his FRCPATH award, Prof. Sampene-Donkor indicated that “this is testimony to the fact that research of UG faculty can compete with research anywhere in the world”. The FRCPATH award ceremony will take place in London early 2023.

The Royal College of Pathologists, UK, has recognised the research and scholarly works of Professor Eric Sampene-Donkor, awarding him Fellow of the Royal College of Pathologists (FRCPATH) in Medical Microbiology.

Having received a Royal Charter from Queen Elizabeth II in 1970, the Royal College of Pathologists is the UK’s recognised professional body for postgraduate medical training in the pathological sciences such as Medical Microbiology, Histopathology, Haematology and Immunology. FRCPATH is the highest award of the Royal College and the standard assessment of fitness to practice as a Consultant Pathologist in the UK and many other countries. Originally, FRCPATH is awarded to medical doctors, with the fellowship training taking about four years after specialisation. A couple of years ago, the Royal College decided to also award FRCPATH via a research track to both medical doctors and scientists who are making a sustained contribution in a defined area of pathology in any part of the world as evidenced by a strong publication record and several years of practice. In Ghana, Prof. Sampene-Donkor becomes the first to receive the FRCPATH award via the research track and also the first scientist to hold the award. Based on the strength of Prof. Eric Sampene-Donkor’s scholarship, the Royal College of Pathologists decided to award him FRCPATH via the expedited route of the College, which is reserved for outstanding candidates.

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Mr Kofi Amekudzi

As a dynamic, patriotic, insightful and results-oriented Pharmacist and Public Health Practitioner currently working with the International Labour Organization, a specialised UN Agency in Geneva, Switzerland, Kofi Amekudzi has experience which spans across health and development at the national and international levels.

Starting his career in Ghana as a Pharmaceutical Medical Representative, Kofi worked closely with medical doctors, pharmacists, nurses and other medical staff to ensure the availability of high quality medicines in Ghana. At the Ghana Social Marketing Foundation (GSMF), Kofi played a key role in the conceptualisation, design and implementation of national campaigns such as the Stop AIDS Love Life HIV campaign, the Life Choices Family Planning national campaign, among others in partnership with Johns Hopkins University, USAID, DFID and the Government of Ghana. As a consultant, Kofi worked across West Africa and was the executive producer of a World Bank-funded documentary on HIV across the Abidjan-Lagos corridor. Together with a team of consultants, Kofi helped draft the National Health Promotion Policy of the Federal Ministry of Health in Nigeria. Kofi also consulted for WHO, UNESCO, USAID and DFID among others.

At the University of Leeds in the UK, Kofi obtained a Masters in Public Health (MPH) and received the John Griffith and Ruth Griffith awards for outstanding academic work and a noticeable contribution to the development community.

At the International Labour Organization (ILO), Kofi currently works as a Specialist and provides global leadership for the ILO's engagement with the United Nations Joint Programme on HIV (UNAIDS) which comprises 11 United Nations Agencies including UNHCR, UNICEF, WFP, UNDP, UNFPA, UNODC, UN Women, ILO, UNESCO, WHO and the World Bank.

In his spare time, Kofi commits himself to advancing the course of Ghana and was nominated and elected the first president of the Ghanaian Community in Geneva between 2016 and 2019.

Kofi has considerable experience across the health and development domains both at the national and international levels and combines this knowledge and experience with a deep sense of affection for his country, Ghana.

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Dr. Vera Dansa Asante

Dr. Vera Dansa Asante holds a doctor of pharmacy degree from Virginia Commonwealth University/Medical College of Virginia. She has been in the Pharmaceutical industry for about 20 years now and currently the owner and CEO of Wellcheck Wholesale and Compounding Pharmacy an independent pharmacy in Tema Community 25. Dr. Asante is also the CEO of Pether Ghana Ltd an IT firm focusing on software development for the healthcare, insurance and agriculture in Africa. Dr. Asante is an APhA (American Pharmacists Association) board certified diabetes educator and immunizer (2004), she's also registered with the Center for Disease Control (CDC) as an international immunizations travel consulting specialist. Dr. Asante works with many non-profit organization such as Gold Coast Foundation (medical missionaries), Okyeame Foundation (Hepatitis awareness) and also the co-founder of Ghana Infants and Children Mortality Foundation – a non-profit to reduce infant, children and maternal mortality in Ghana. Most recently the project lead for a CPPA/TFHO project funded by USAID to train 400 pharmacists to become covid vaccine educators in second cycle and Tertiary Institutions. Currently she is the president for Ghanaian Pharmacist Association of North America Virginia chapter (GPhA -VA), a member of the Pharmaceutical Society of Ghana (PsgH) and Vice Chairperson for community practice pharmacy association CPPA. She's a member of the professional service committee for psgh, facilitator/trainer for pharmacist vaccination for the ghana college of pharmacists and chair for the digitalization committee of CPPA.



Roland Addo-Hammond

Passionate outcome-oriented Public Health enthusiast with an inspiring career in the development and implementation of programs with deep insights from conceptualization to scale, bridging gap between scientific, medical, patients and governmental communities especially in underserved population. A demonstrated experience includes leading global health integrated sustainable programs, a co-architect of Novartis' regional efforts in sub-Saharan Africa to address sickle cell disease under the Sickle Cell Flagship Program (with Memoranda of Understanding signed by governments of 4 countries focused on health systems strengthening and access- to- medicines to underserved populations and responsible for establishing Novartis' presence in Ghana (now the country's largest multi-national pharmaceutical company). Scientific background (pharmacist), MBA with two decades of global leadership experience in the pharmaceutical healthcare industry cutting across USA, Region Europe, Latin America, Asia and in sub- Saharan Africa, involving all aspects of developing and executing market access, operational excellence, innovative product launches, digital platform development to drive both branded and unbranded assets, establishing relationship with global medical experts and governments, ethics and risk management, and corporate responsibility initiatives. Recognized as an agile, resilient leader who inspires teams to think differently, challenge status quo while being results driven, build the right team for success to increase patient reach globally.

BOARD OF DIRECTORS



Mr Daniel Ampomah Opong

A results-driven and strategic professional with over 10 years of experience in media, marketing, and project management. Demonstrated success in implementing and leading integrated marketing campaigns, driving brand awareness, and delivering high-impact projects. Strong leadership and communication skills to effectively collaborate with cross-functional teams and stakeholders.

Media Expertise:

- Developed and executed comprehensive media strategies across traditional and digital platforms, resulting in increased brand visibility and customer engagement.
- Proficient in media planning, buying, and optimization, ensuring cost-effective and impactful media placements.
- Expertise in analyzing media trends and consumer insights to identify opportunities and drive advertising effectiveness.

Marketing Skills:

- Led marketing teams to develop and implement successful marketing campaigns, resulting in increased brand awareness and customer acquisition.
- Proficient in branding and positioning, creating compelling marketing messages and visual assets that resonate with target audiences.
- Demonstrated expertise in digital marketing techniques, including SEO, SEM, social media, email marketing, and content development.

Project Management:

- Proven track record of successfully managing complex projects from initiation to completion within tight timelines and budgets.
- Strong problem-solving and decision-making skills to effectively overcome challenges and ensure project delivery.
- Expertise in project planning, resource allocation, and risk management to achieve project objectives and stakeholder satisfaction.

Leadership and Communication:

- Skilled in leading and developing high-performing teams by providing clear direction, feedback, and mentorship.
- Excellent interpersonal and communication skills to build strong relationships with internal and external stakeholders.
- Proven ability to effectively present complex ideas and influence decision-making at all levels of the organization.

Overall, a highly experienced and versatile professional with a strong track record of success in media, marketing, and project management. Committed to driving growth, improving brand performance, and delivering exceptional results.

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Attorney Marian Acheampong

Marian Angela Kyei. Marian Angela Kyei is a lawyer of 20 years at the Ghana Bar and a development consultant. She is a product of the University of science and technology (first degree) now (knust) and the University of Ghana, Legon, Accra (postgraduate) and the Ghana School of Law. Work experience spans development work; communications and advocacy for the marginalized and vulnerable. Special interests include disability and social protection. She has served in various capacities including ; her role as the recent chairperson of the GJA Elections Adjudication Committee. She served also as a member of the Boards of Precevid and Vocational Training for Females (vtf). Marian has a passion for advocacy and charity work and supports initiatives through the Hand of God project that assists students in need. She has a number of networks and worked with state institutions; development agencies and private sector especially civil society. Marian is married with 2 children.



Collins Nuntwiri Nuamah

Mr. Collins Nuntwiri Nuamah is the Deputy Managing Director of the Ghana Water Company (GWCL) in charge of revenue mobilisation, taxes, and compliance.

Mr. Nuamah has over 19 years of experience in the area of Financial Management Services and Administration, Risk Analysis, Portfolio and Funds management, Tax Administration, Data management, etc.

He is currently a Ph.D. candidate at the prestigious Walden University, USA, pursuing Public Policy and Administration. He also holds a Bachelor of Commerce degree from the University of Cape Coast (1994-1998) Masters degree (MSC Banking & Finance) from Boston University, USA (2008-2010)

He also holds certificates in advertising, marketing, and public relations from the Ghana Institute of Journalism. (2001)

Mr. Nuamah is also the founder and president of Prudent Financial Services in Worcester, Massachusetts - a company that specialises in tax consulting, payroll services, and fund and investment management among other range of Financial consulting services.

He has also worked with reputable international organizations, including Bank of America, USA; Bose Corporation, USA; CVS Health, USA; BJ's Wholesale USA, CDH Financial Holdings, Ghana, among others.

BOARD OF DIRECTORS



Madam Mame Yaa Aboagye

Mame Yaa Aboagye is a mental health and wellness advocate, who recognizes that creating mental health awareness is crucial because mental health affects all persons regardless of age, sex, creed or economic standing.

She holds a Master's Degree in Business Administration and a Bachelor of Science Degree in Health Psychology from the University of Bedfordshire in the United Kingdom. She also attended Irwin College, UK and Achimota School.

Mame Yaa has multiple business interests spanning business consultancy, health education and pharmaceuticals.

She has a keen interest in literacy and the holistic development of children. She therefore started a Reading and After-school Club for children in 2011.

Her hobbies are cooking, ceramic art, gardening and travelling.



Mr Samuel Kwadjo
Agyapong Appenteng

Mr Samuel Kwadjo Agyapong Appenteng is an Engineer by profession. He is a successful Entrepreneur.

He gained in-depth industry and business leadership experience from 20 years of working as Technical Manager and General Manager at IIPIC. He co-founded the Joissam Group from 1996 and started operations from Ghana. The group has been operating in two African countries (Ghana and Gabon) and registered in 6 other countries.

He has co-founded Shedak Industries Ltd, Asdak MNK Ltd, Abokof AFK Ltd and Pan African Water Solutions Ghana Ltd (PAWS)

He is the Chairman of the Ghana Alternative Exchange (GAX) Committee of the Ghana Stock Exchange.

He is Director of Intravenous Infusions Plc

He is on the Advisory Board of the Water Resources Institute of the Council for Scientific and Industrial Research (CSIR)

He is the Chairman of IFS Capital Management Ltd

He is a Director of SIC-LIFE Company Ltd

He served on the National Council of the Association of Ghana Industries (AGI) for 19 years, rising from Eastern Regional Chairman (9 years) to National Treasurer (4 years) and the National Vice-President (6 years)

He served as Council Member for both Koforidua Technical University and the Methodist University College Ghana.

He is a member of the Seed Transformation Network (STN) of the Stanford University SEED program as well as a member of the Invest In Africa (IIA)-Africa Partnership Pool

Mr Samuel Kwadjo Agyapong Appenteng holds an MBA Finance and BSc. Chemical Engineering from University of Leicester, UK and also a graduate from KNUST, Kumasi. He is a corporate member of the Ghana Institution of Engineers, a fellow of the African Leadership Initiative West Africa and an affiliate of Aspen Institute of Colorado, USA.

ADVISORY BOARD

Mary Lamptey

National Coordinator Newborn Screening Coord
(New Board Screening)

Ms. Afia Ohene-Frempong

Licensed Social Worker, Sexual Health Educator,
Health Communications Professional and KOF's Daughter

Mr. Nana Osei Poku I

Engineer and Asantehene Advisor for the
Kumasi Sickle Cell Disease Center of Excellence

FOUNDATION STAFF

Mr. Theophilus Nyamadi,

Nurse, Foundation Organizer

Mrs. Matilda Offei-Akoto

Foundation Public Relations and Communications Officer

Mrs. Agnes Abutiata-Twumasi

Foundation Administrative Secretary

Our Mission (Goals)

- A. Early Detection**
Early detection of Sickle Cell Disease
- B. Treatment**
Expanded use of evidence-based therapies including affordable and accessible Hydroxyurea
- C. Stroke Prevention**
Expanded use of transcranial doppler technology to prevent stroke
- D. Psychosocial Support**
Expanded resources for psychosocial support for Sickle Cell Warriors and their families
- E. The Center of Excellence**
Accelerated completion of the Center for Sickle Cell and Blood in Kumasi on the land granted by Otumfuo Osei Tutu II in a sod-cutting ceremony on July 31, 2000.
- F. Treatment Guidelines**
National implementation of the SPARCo Standards of Care for Sickle Cell Disease in Sub-Saharan Africa
- G. National and International Collaboration**
Expanded national and international collaboration on the management and cure of sickle cell disease
- H. Recognition, Appreciation, and Support**
To shine a light on all of the good work being done by so many people to identify and treat children and adults born with sickle cell disease, and to recognize those who are working to provide and accessible cure.
- I. Problem Identification with Advocacy for Solutions**
To shine a light into the areas that need additional support and to advocate for and, when possible, provide that support.

Our Values

YES	NO
<ul style="list-style-type: none">✓ Cooperation✓ Collaboration✓ Collegiality✓ Commitment✓ Compassion	<ul style="list-style-type: none">✗ Competition

Our Request

Support our fundraising efforts both here in Ghana and abroad, so that we can join with others to:

- Help people understand what sickle gene and what sickle cell disease is and why it has special significance for Africans and for people of African descent.
- Ensure that we treat people who have sickle cell disease with understanding, respect and compassion – but not pity.
- Enable professionals, in all related fields, to provide the highest quality of care for the many people amongst us who have been born with sickle cell disease.
- Remove barriers to education and self-fulfillment.

HIGHLIGHTS

First day ... First Baby ... First Heel Stick



Courtesy of Mary E. Lamptey, RN National Newborn Screening Coordinator

**From the huge cities to the small villages,
Kof worked to get everyone the best care possible.**



Courtesy of Mary E. Lamptey, RN National Newborn Screening Coordinator

HIGHLIGHTS

His Vision for a Center for Excellence In Kumasi, Ghana



For Clinical Care, Workforce Development, and Research

His Vision for a Center for Excellence In Kumasi, Ghana



**Land Granted by Otumfuo Osei Tutu II
Sod-Cutting Ceremony Performed on July 31, 2000**



An Open Letter in Support of Sickle Cell Disease Communities

To the Sickle Cell Disease (SCD) communities, including warriors and caregivers.

We care about you.

We affirm that your lives are valuable.

We must do everything in our power to educate our communities and address the inequities that exist throughout the sickle cell disease care continuum.

Despite impacting millions of people worldwide and being the most common inherited blood disorder in the United States, many people are still unfamiliar with sickle cell disease. SCD is a chronic, debilitating condition that predominantly impacts those of Black and Hispanic descent and many demographics which have historically been overlooked by the health system. In the United States, one in 13 Black people and approximately one in 100 Hispanic people carry the gene for SCD. As a community, people with SCD experience worse health outcomes, with a life expectancy roughly 30 years shorter than the average American.

September is Sickle Cell Awareness Month, an opportunity to bring caregivers, advocates, and all those in the healthcare industry together to raise awareness of the disease, dispelling stigmas and highlighting the need for continued research for advanced treatments and better care for the SCD community. We start by raising public consciousness of the impact and the need for better education to ensure the medical community can detect sickle cell disease signs and symptoms. SCD is a complex, multifaceted disorder that presents differently in each person. However, the most consistent clinical feature of the disease is severe pain, which can occur anywhere in the body and last from several days to several weeks. And yet we acknowledge that sickle cell is more than pain—that it affects you every day, with or without pain, in a variety of ways.

As a part of America's Black health industry leaders, we recognize the medical community's role in racial justice and equity. We are calling on all Black and Hispanic communities to stand up as Champions for those impacted by SCD.

With no cure and limited treatment options, patients often head to the emergency department for care.

Several factors in emergency care present challenges for providing the best care to the sickle cell disease community. And bridging the educational gap and bias among HCPs is one of the first and most vital steps we can take to make a lasting, positive impact. There are currently limited HCPs trained specifically in SCD. Due to the varied and continuous complications associated with SCD, barriers to proper care are extensive—with people living with the disease experiencing the highest hospital return rate within 30 days compared to other health conditions. Those return visits can cause a series of added difficulties, including misconceptions of pain severity and concerns about opioid dependency. Delays in treatment can lead to dangerous outcomes and prolonged trauma.

Our healthcare system reflects the biases in our society. Racial inequities in care are evident in the SCD community, where patients are too often marginalized and dismissed while searching for the most basic medical care they need and deserve. While there are currently legislative efforts to establish programs focused on increased treatment and care for people living with SCD, incentivize more SCD-specialized HCPs, and provide widespread education on the disease, there is still much to be done to support progress and raise awareness of these initiatives.

We are dedicated to supporting the Black and Hispanic communities, and in partnership with Pfizer, we are committed to changing the future of care for the SCD community, bridging the education gap regarding SCD and the need for progress. As industry leaders, it is our responsibility to speak up for underserved communities and inspire change.

With our care,

Bert Bruce, US President, Rare Disease, Pfizer

Kim Smith-Whitley, MD, Advisor of Scientific & Clinical Affairs Global Chief Medical Affairs Officer for Patient Advocacy and External Collaboration, Pfizer; Board Member, Sickle Cell Disease Association of America (SCDAA)

Regina Hartfield, President and CEO, Sickle Cell Disease Association of America (SCDAA)

Jason Payne, MD, MSPH, FAAP, Assistant Professor—Pediatric Hematology/Oncology Morehouse School of Medicine

James G. Taylor, MD, Professor, Internal Medicine & Director, Center for Sickle Cell Disease, Howard University College of Medicine

Sacha Choupa, Medical Student, Sickle Cell Disease Researcher, Meharry Medical College

Torhiana Haydel, Student National Medical Association—Health Policy & Legislative Affairs Co-Chair

Karina Wang, Student National Medical Association—Health Policy & Legislative Affairs Co-Chair

Appreciation

Our gratitude goes out to so many people who have worked hard to help save lives and reduce preventable, pain and suffering, including but not limited to those in Ghana and in countries around the globe:

Government officials

Traditional leadership

Health professionals in all related fields of clinical care and research

Administrators

Support staffs

Maintenance staffs

Academic institutions

NGOs

Pharmaceutical companies

Medical device and supply companies

Professional associations

Faith communities

The Media

Families and caregivers

Sickle Cell Warriors

And all who donate to support these efforts

Signed,

[Redacted Signature]

Board Members

Sickle Gene Action Foundation of Ghana

