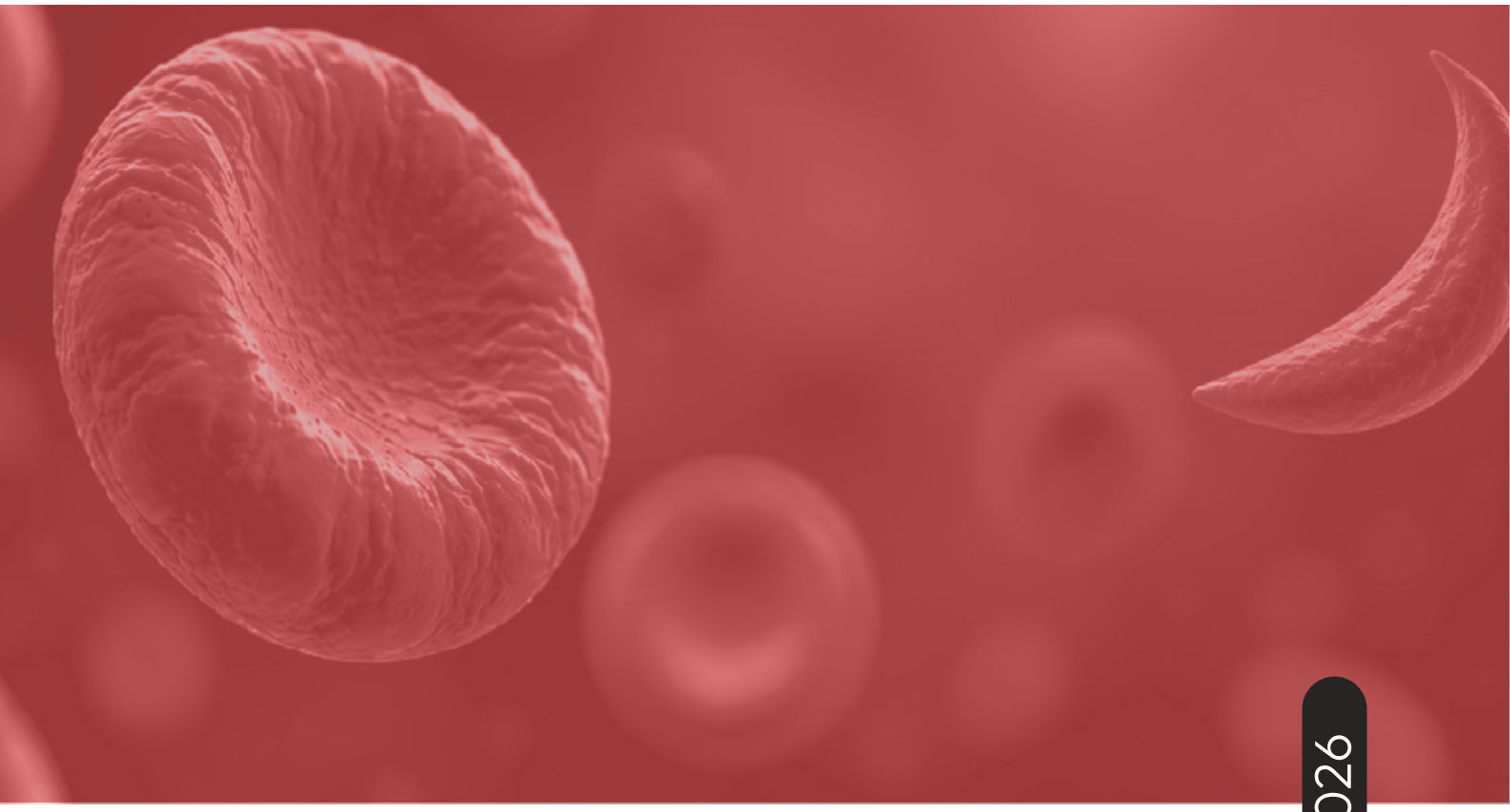
SCIENTIFIC SYMPOSIUM ON

SICKLE CELL DISEASE.

HOSTED BY: JOINT CLINICAL RESEARCH CENTRE AT GOLDEN TULIP HOTEL, KAMPALA UGANDA.



16 June 2026

SYMPOSUIM PROCEEDINGS.

PARTNERS:

JCRC Joint Clinical Research Centre

imara Sickle Cell Framework

CLINTON HEALTH ACCESS INITIATIVE

TERUMO BLOOD AND CELL TECHNOLOGIES

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Editorial Preface.

This symposium proceedings captures the scientific deliberations, research presentations, and consensus outcomes of the Sickle Cell Disease Scientific Symposium held on June 16, 2026, at the Golden Tulip Hotel, Kampala.

The symposium served as a key pre-commemoration event ahead of World Sickle Cell Day 2026. It brought together researchers, clinicians, policymakers, patient advocates, and implementing partners to review Uganda's progress in SCD management and chart a path forward.

The proceedings document the presentations, panel discussions, and key consensus points that emerged from the four sessions: Basic Science and Epidemiology, SCD Treatment Advances, Testing and Care Programs, and the Cure Agenda. The symposium's findings provide a strong evidence base for accelerating Uganda's national SCD response.

We extend our sincere gratitude to all presenters, panelists, and participants who contributed to the success of this landmark event.

Dr. Francis Ssali.

Chairman, Scientific Symposium
Deputy Executive Director, Joint Clinical Research Centre.

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ACKNOWLEDGEMENTS.

The symposium organizers gratefully acknowledge the Clinton Health Access Initiative (CHAI) for their generous financial contribution, which was instrumental in making the symposium a success and enabling the participation of leading experts and the wide dissemination of critical scientific evidence.

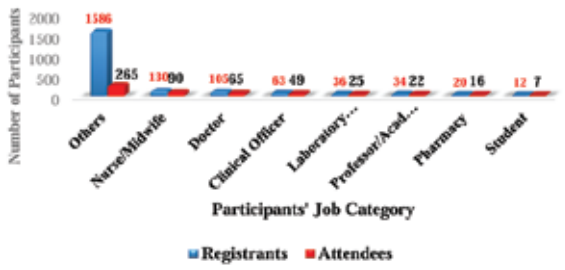
We also extend our sincere gratitude to Terumo Blood & Cell Technologies for catalyzing the IMARA Programme, under which funding was provided for pre-World Sickle Cell Day activities, including this symposium. The IMARA Program's commitment to strengthening sickle cell care in Uganda and the region is deeply valued.

Additional thanks go to the Ministry of Health, Joint Clinical Research Centre (JCRC), Baylor Uganda, and all partners who contributed to the success of this landmark event.

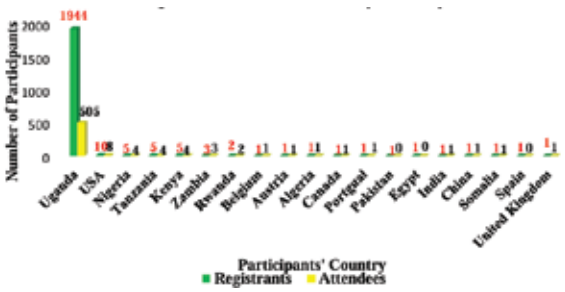
1.0 Executive Summary

The Sickle Cell Scientific Symposium convened on 16 June 2026 as a pre-commemoration event ahead of World Sickle Cell Day. Organised by the Joint Clinical Research Centre (JCRC) with the Ministry of Health, the Clinton Health Access Initiative (CHAI), and partners, the hybrid symposium recorded 1,986 registrations, 539 unique virtual viewers, and 53 in-person attendees from Uganda, Kenya, Tanzania, and beyond. The symposium reviewed Uganda's progress in SCD epidemiology, treatment, diagnostics, and policy, and generated consensus on accelerating the national response through universal newborn screening, hydroxyurea at maximum tolerated dose, decentralised comprehensive care, and strategic preparation for curative therapies.

Registration &Attendance by Job Category.



Registration & Attendance by Country.



Attendance Overview.

The symposium attracted a wide and diverse audience, reflecting the growing interest and commitment to SCD among various stakeholders.

Metric	Number
Total Registrations	1,986
Physical Attendance	53
Virtual Attendance (Unique Zoom Viewers)	539
Total Attendance	592



Key Observations:

- The high number of registrations (1,986) indicates strong demand and interest in SCD scientific discourse not only regionally but also globally.
- The virtual platform enabled participation from a broad geographic audience, including attendees from Kenya, Tanzania, and various regions within Uganda as well as other countries across Africa and beyond, demonstrating the global relevance of Uganda's SCD efforts.
- The hybrid format proved effective in maximizing reach and engagement, and is recommended for future symposia.

2.0 Chairperson's Note



It is my great pleasure to welcome you to the proceedings of this Scientific Symposium on Sickle Cell Disease (SCD). I warmly acknowledge and welcome all participants joining us in person and virtually, and I am particularly pleased to recognize the leading experts, researchers, clinicians, patient advocates, policymakers, implementing partners, and other stakeholders from Uganda and across the region who have come together around a shared commitment to advancing the SCD response.

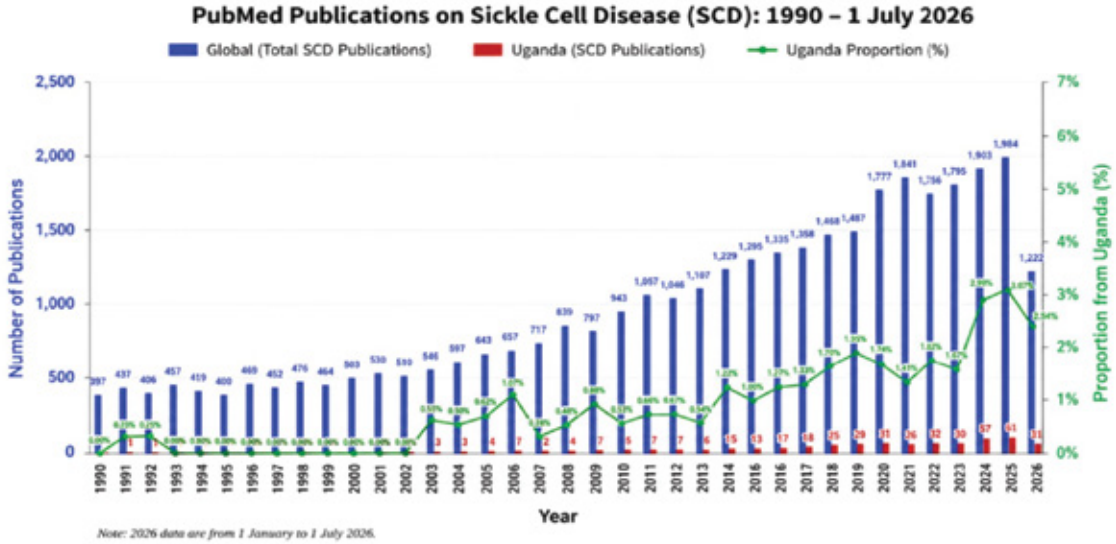
This Symposium represents much more than a pre-event to the national commemoration of World Sickle Cell Day. It is an important scientific platform and a critical part of the national response to SCD. The evidence, experiences, innovations, and perspectives shared here provide the scientific foundation upon which stronger policies, better services, and more effective interventions can be built.

Over the past several years, Uganda has made important progress in its response to SCD. We have moved beyond simply recognizing SCD as a significant public health challenge towards generating evidence, strengthening systems, testing new approaches, and identifying interventions that can be taken to scale. This progress has been driven by collaboration among government, academia, healthcare providers, researchers, communities, people living with SCD, civil society, development partners, and the private sector.

In addition, the growing body of scientific publications on SCD in Uganda reflects increasing research engagement, investment in evidence generation, and collaboration among researchers and institutions. Historically, the 1990s and early 2000s saw paucity of sickle cell disease literature; however, recent trends indicate that this research gap is actively being bridged (see graph).

Yet, significant challenges remain. SCD continues to affect individuals, families, and communities, with consequences extending beyond health to education, livelihoods, household finances, and quality of life. The scale and complexity of the challenge require us to continually examine what works, identify gaps, learn from implementation, and translate scientific evidence into practical solutions that can reach every person who needs them.

This Symposium therefore provides an opportunity not only to present research findings, but also to interrogate evidence, exchange experiences, challenge existing approaches, and identify opportunities for innovation and collaboration. I encourage all participants to engage openly and constructively in these discussions, recognizing that the value of a scientific meeting lies not only in the quality of the presentations, but also in the conversations and partnerships that emerge from them.



I wish to express my sincere appreciation to the Ministry of Health for its leadership and stewardship of the national SCD response, and to CHAI and all our partners for their continued technical, financial, and institutional support. I also commend the researchers, clinicians, programme teams, patient advocates, communities, and organizers whose commitment and hard work have made this Symposium possible.

The deliberations captured in these proceedings are intended to contribute to a stronger evidence base for Uganda's SCD response and to inform the national conversations and commitments surrounding the commemoration of World Sickle Cell Day on 19 June in Jinja.

As we reflect on the evidence presented and the progress made, let us remain focused on the ultimate objective: ensuring that people at risk of, living with, or affected by SCD can access timely diagnosis, quality care, appropriate treatment, adequate blood services, and the support they need to live healthy and

I commend all contributors to this Symposium and invite every stakeholder to carry forward the knowledge, partnerships, and commitments generated here. Together, we can transform evidence into action and build a more coordinated, equitable, and sustainable national response to sickle cell disease.

Dr. Francis Ssali
Deputy Executive Director, Joint Clinical Research Centre (JCRC) Chairman, Scientific Symposium

3.0 Official Opening.



Delivered by: The Director General of Health Services (DG) – Dr. Charles Olaro

The Director General officially opened the symposium, framing it as a critical pre-activity leading to World Sickle Cell Day on June 19, 2026. He congratulated the organizers and acknowledged the heavy burden of SCD in Uganda, noting that over 20,000 children are born with the condition annually, contributing significantly to under-5 mortality.

The DG highlighted Uganda's leadership in SCD science and policy within the East African region. He commended the progress made, including the establishment of the national newborn screening program, the development of national treatment guidelines, and the growing body of research evidence. He emphasized that the symposium was the "scientific engine" behind the national commitment, essential for transitioning newborn screening from a pilot to a national mandatory policy and for advancing local gene therapy readiness

The DG issued a call to action to researchers and clinicians to be bold in their findings and rigorous in their recommendations. To partners and implementing organizations, he stressed the need for sustainable financing, laboratory strengthening, and equitable access to new and advanced therapies. He underscored that the symposium should produce clear recommendations on scaling newborn screening nationally, reducing barriers to hydroxyurea and transfusion support, and advancing local gene therapy readiness.

He concluded by officially declaring the World Sickle Cell Day 2026 Scientific Symposium open, wishing all participants productive and impactful deliberations.

4.0 Symposium Proceedings.

KEYNOTE ADDRESS:

THE BURDEN AND FUTURE OF SCD IN UGANDA (Dr. Phillip Kasirye)

- Dr. Kasirye framed SCD as a persistent public health challenge: sub-Saharan Africa carries 80% of the global burden, with 300,000 babies born annually and 20,000–25,000 in Uganda alone. Uganda's gene prevalence is 13.3%, with 8 districts exceeding 20%. The national response has evolved from the Mulago clinic (1968) to universal mandatory newborn screening (February 2026) and parliamentary recognition (March 2026). Current programmes include CONSA (~30,000 newborns tested), SPARCO (5,655 enrolled), SCALE (83% retention in Kayunga), IMARA (launched 2026), and local hydroxyurea production. However, care remains centralised, only 35% of PHC workers are confident in SCD management, and hydroxyurea supply can be interrupted.



Dr. Phillip Kasirye the Keynote speaker discussing The Burden and Future of SCD in Uganda.

Keynote message: *Uganda has the evidence and tools to transform SCD outcomes universal newborn screening, hydroxyurea, and decentralised care but implementation lags. The priority is political commitment, sustainable financing, and systematic scale-up from specialised centres to every district.Uganda has the evidence and tools to transform SCD outcomes universal newborn screening, hydroxyurea, and decentralised care but implementation lags. The priority is political commitment, sustainable financing, and systematic scale-up from specialised centres to every district.*

Session 1: Basic Science and Epidemiology Research.

Moderated by Dr. Deogratias Munube

SPARCO UGANDA REGISTRY (Prof. Sarah Kiguli)

This session established the current epidemiological landscape and scientific infrastructure.

- Prof. Kiguli presented the SPARCO-Uganda Registry, a centralised electronic haemoglobinopathy database established to improve SCD outcomes through evidence-based care, research, and training. As of May 2026, 11,776 patients were enrolled across five sites Mulago (7,029), Jinja (1,873), Mbale (1,725), Lira (971), and Pallisa (178). The cohort is 51.4% female, with ages from 3 months to 64 years; the largest age group is 6–12 years (36%). Site retention ranges from 43% to 60%. The registry addresses high rates of stroke (6.8%), neurocognitive deficits (21.5%), and acute chest syndrome (22.7%), alongside low newborn screening and hydroxyurea use. It supports student and consortium research, advocacy, planning, and serves as a guide for a national registry.



Prof. Sarah Kiguli highlighting about The SPARCO (Sickle Cell Pan African Consortium) registry

Keynote message: *The SPARCO-Uganda Registry successfully launched a national sickle cell disease platform, enrolling over 11,700 patients across five sites. This initiative enhances clinical care, research, professional training, advocacy, and data-driven health-system planning.*

HEALTH STATUS OF UGANDAN CHILDREN IDENTIFIED THROUGH NEWBORN SCREENING (Dr. Charles Kiyaga)

Dr. Kiyaga presented the first national mapping of three erythrocyte genetic mutations — HbS, $-\alpha^{3.7}$ deletional α-thalassaemia, and the G6PD G202T allele — across all 122 districts of Uganda, and their effect on survival in children with SCD. A total of 12,009 babies (0–6 months) were sampled nationally. Prevalence findings: HbAS 11.0%, HbSS 0.5%; α-thalassaemia −α/−α 9.4%; G6PD G202T male deficiency 10.4%. All three mutations follow malaria distribution patterns. Survival analysis found no significant association between α-thalassaemia genotype and age group, but G6PD G202T conferred a statistically significant survival disadvantage among male children with SCD (p=0.04).



Keynote message: *This is the first national mapping of HbS, α-thalassaemia, and G6PD deficiency in Uganda. α-thalassaemia shows no survival benefit in children with SCD, while G6PD G202T confers a survival disadvantage among males. The Ministry of Health should include G6PD testing in newborn screening and SCD care packages.*

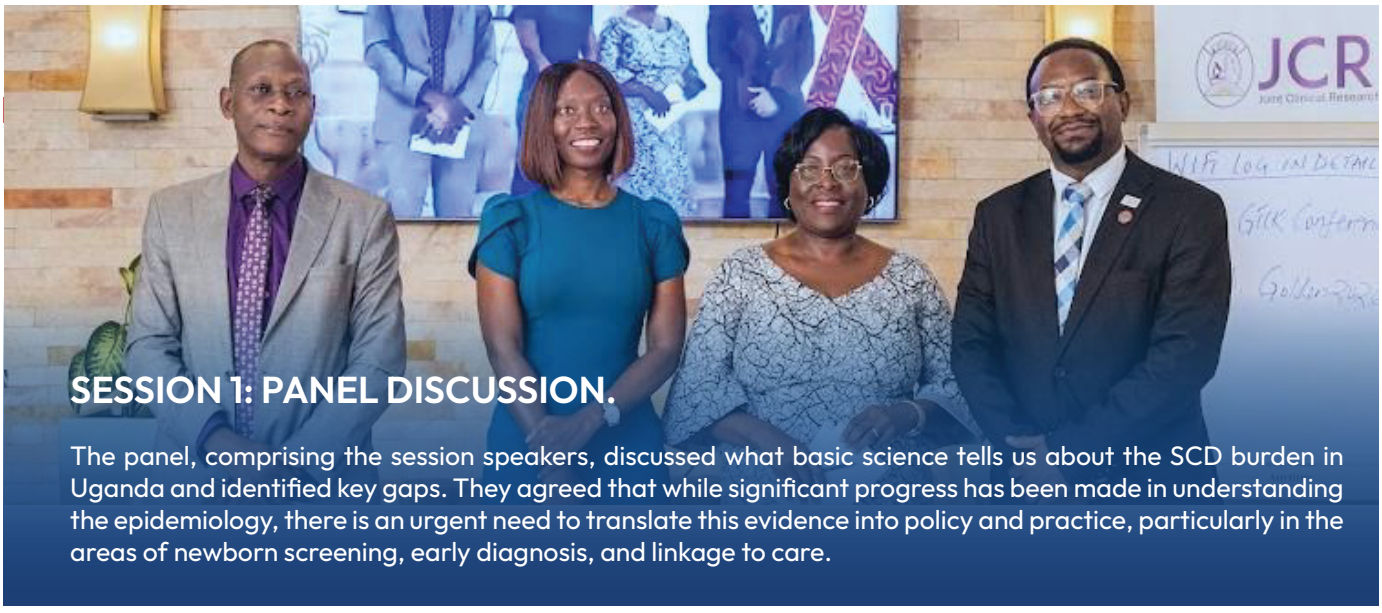
AI-ENHANCED IMAGE ANALYSIS FOR POC SCD SCREENING (Dr. Anne Akullo)

- Dr. Akullo presented a novel AI-powered SCD screening information management and communication system (SIMCS) designed to enable community-wide point-of-care screening and care coordination. The four-module smartphone app (ID, Assay, Education, e-Passport) classifies sickle cell genotypes (AA, AS, SS) from commercially available POC tests (HemoTypeSC and Sickle SCAN) using computer vision and deep learning. Results showed 99.1% mean average precision, 99.6% precision, and 99.3% recall across all genotype classifications, with a 37% reduction in diagnostic time and 28% improvement in accuracy. All children diagnosed with SCD were linked to care. A full cluster-randomised trial using Sickle SCAN is underway to evaluate performance in rural settings.



Dr. Anna Akullo presenting on a novel AI-powered smartphone application developed to interpret point-of-care (POC) SCD test results.

Keynote message: *AI-enhanced POC screening achieves >99% accuracy, cuts diagnostic time by 37%, and ensures linkage to care. The Ministry of Health should integrate this tool into the national newborn screening programme to accelerate early diagnosis at lower-level health units.*



SESSION 1: PANEL DISCUSSION.

The panel, comprising the session speakers, discussed what basic science tells us about the SCD burden in Uganda and identified key gaps. They agreed that while significant progress has been made in understanding the epidemiology, there is an urgent need to translate this evidence into policy and practice, particularly in the areas of newborn screening, early diagnosis, and linkage to care.

Session 2: SCD Treatment Advances in Uganda.

Moderated by Dr. Anne Akullo

ADAPT TRIAL: PK-GUIDED HYDROXY-UREA DOSING (Dr. Ruth Namazzi)

- Dr. Namazzi presented baseline feasibility results from the ADAPT trial, a prospective study evaluating hydroxyurea's impact on transfusion rates and the feasibility of pharmacokinetic (PK)-guided dosing for children with SCA in Jinja. The trial enrolled 106 children (1–10 years, HbSS). All participants completed PK testing; 78% received an individualised PK-guided dose, and 38% of generated doses were within the protocol-defined range (15–35 mg/kg/day). Key clinical outcomes included a 43% reduction in transfusion use over 12 months (IRR 0.57, p=0.011), with higher HbF responses in the PK-guided group (34.2% vs 27.6%, p=0.018) and equivalent toxicity rates. Challenges included accurate serum hydroxyurea measurement via portable HPLC and hydroxyurea degradation.



Dr. Ruth Namazzi presenting the ADAPT trial

Keynote message: *Hydroxyurea significantly reduces transfusion needs in Ugandan children with SCA. While PK-guided dosing is feasible, it is technically demanding; standard weight-based dosing should remain the national standard while PK capacity is developed.*

10-YEAR SAFETY & EFFICACY OF HYDROXYUREA (Dr. Robert Opoka)

Dr. Opoka presented 10-year outcomes from the NOHARM studies (2014–2026), in which 174 of 207 enrolled children (84%) remain on hydroxyurea at a mean of 10.1 years and 28.9 mg/kg/day. Haemoglobin rose from 7.5 to 8.6 g/dL and HbF from 13.9% to ~26%. At maximum tolerated dose (MTD) versus fixed dose, hospitalisations fell by 81%, transfusions by 54%, serious adverse events by 63%, and deaths by 69%. Cohort mortality was 8.7% versus 43.3% in the natural history of SCA in Africa. Dose-limiting toxicities occurred at 0.2/person-year with no increase at MTD; growth and Tanner staging were normal. Only 2 strokes occurred over 1,861 patient-years.



Dr. Robert Opoka discussing 10-year Safety & Efficacy of Hydroxyurea

Keynote message: *Ten years of Ugandan evidence proves hydroxyurea at MTD (25–30 mg/kg/day) is safe and highly effective reducing deaths by 69% and hospitalisations by 81% with minimal toxicity. The Ministry of Health should adopt MTD hydroxyurea as national standard of care and ensure uninterrupted supply.*

BRAIN INJURY AND NEUROCOGNITIVE PROTECTION IN PEDIATRIC SCA (Dr. Deogratias Munube & Dr. Richard Idro)

- Dr. Munube and Dr. Idro presented findings from the Brain Safe Study series (2016–2025), demonstrating that cerebrovascular injury in Ugandan children with SCA is common, frequently silent, and detectable through imaging and blood biomarkers. In a cross-sectional survey of 265 children, 21.5% had abnormal results on at least one of three tests; among 81 who underwent MRI/MRA, 67.9% had infarcts and/or arterial stenoses — often undetectable by clinical testing. Children with SCA performed significantly worse than unaffected siblings in spelling, mathematical computation, and word reading. Blood neurofilament light chain (NfL) was significantly higher in children with MRI-detected infarcts ($p<0.001$). The Brain Safe II hydroxyurea trial ($n=270$) showed TCD normalisation increased from 73.1% to 90.2% at 18 months, with a 2.6-fold reduction in neurocognitive impairment ($p=0.005$).

Keynote message: *Over two-thirds of Ugandan children with SCA have silent cerebrovascular injury, and hydroxyurea normalises TCD velocities in 90% while reducing neurocognitive impairment 2.6-fold. The Ministry of Health should introduce national neurocognitive screening guidelines and expand TCD screening to all SCD care centres.impairment 2.6-fold. The Ministry of Health should introduce national neurocognitive screening guidelines and expand TCD screening to all SCD care centres.*



Dr. Deogratias Munube *Dr. Richard Idro*

ZINC FOR INFECTION PREVENTION (ZIPS-2 TRIAL) (Dr. Ruth Namazzi)

- Dr. Namazzi presented findings on infection prevention in pediatric SCD. Infections account for 20–40% of deaths; 95% of sick visits and 69% of hospitalisations in a Ugandan cohort were infection-related. Encapsulated bacteria predominate due to splenic dysfunction. The CHEMCHA trial ($n=724$) showed weekly DP reduced clinical malaria from 43.7 to 8.8 per 100 person-years (IRR 0.20, $p<0.0001$) and malaria hospitalisations by 71%. The ZIPS-2 trial (20 mg daily zinc) showed a 38% reduction in all-cause infections. Hydroxyurea was associated with a 60% reduction in severe or invasive infections (IRR 0.40, $p<0.001$).

Keynote message: *IInfections are a leading cause of death in children with SCD. DP malaria prophylaxis reduces malaria by 80%, hydroxyurea reduces severe infections by 60%, and zinc at 20 mg daily reduces all-cause infections by 38%. The Ministry of Health should adopt these interventions as standard SCD care.*

ADVANCES IN THE BLOOD BANK (Mr. Ezra Musisi, UBTS)

- Mr. Musisi presented UBTS's transformation and its critical role in SCD care. The service operates 9 regional blood banks, 9 collection centres, and 26 mobile teams, serving 600+ facilities, and is fully government-funded since 2016. In FY 2024/25, 393,972 units were collected and 342,397 issued a 50% increase since FY 2020/21 against a target of 480,000 units for FY 2026/27. Despite progress, a >30% unmet gap persists. SCD drives 30–55% of paediatric blood use; 80% of SCD hospitalisations need transfusion; alloimmunisation rate is 6.1–8.5%. Technological advances include automated serology (Alinity i), nucleic acid testing (Cobas 6800), automated blood grouping (Immucor NEO), and digital traceability (BSIS).

Keynote message: *UBTS has moved from manual testing to fully automated serology, NAT, and blood grouping — meaning Uganda can now offer safer blood, not just available blood. The Ministry of Health should prioritise SCD patients in blood allocation and invest in paediatric packs and leuco-reduced components.*



Mr. Ezra Musisi, presenting Advances in the Uganda Blood Bank Services.

HIBISCUS 2 TRIAL
(Dr. Diana Rutebarika)

Dr. Rutebarika presented the HIBISCUS 2 trial, a global Phase 3 randomised, double-blinded, placebo-controlled study evaluating etavopivat in adolescents and adults with SCD. Uganda will host three trial sites JCRC, Jinja Regional Hospital, and Mulago Hospital sponsored by Novo Nordisk. Etavopivat, an oral pyruvate kinase-R activator, improves RBC health by reducing sickling and haemolysis. Earlier HIBISCUS data showed a 27% reduction in vaso-occlusive crises and a 48.7% haemoglobin response rate versus 7.2% for placebo. Participants receive etavopivat 400 mg or placebo daily for 52 weeks, followed by 52 weeks of open-label etavopivat. Challenges include participant fatigue, multiple blood draws, and ethical concerns about placebo.



Dr. Diana Rutebarika presenting on the upcoming "Hibiscus 2" trial

Keynote message: *HIBISCUS 2 brings a new oral therapy to Uganda for adolescents and adults with SCD. The Ministry of Health should support regulatory approval, plan for post-trial access, and ensure trial infrastructure at all three sites.*



Red cell exchange procedure at JCRC.

RED CELL EXCHANGE
(Dr. Francis Ssali)

Dr. Ssali presented JCRC's experience with red cell exchange (RBX) as an adjunctive therapy for severe SCD complications. More than 90% of individuals with SCD require transfusion in their lifetime. At JCRC through May 2026, 319 procedures were performed for recurrent vaso-occlusive crises (102), acute chest syndrome (73), stroke prevention (85), acute stroke (30), chronic leg ulcers (12), and other indications. Among 131 patients evaluated, 87 underwent antibody screening; 13 (15%) had transfusion allo-antibodies, 11 with SCD. Antibody patterns included multiple specificities (Anti-K, Anti-E, Anti-c, Anti-Jkb, Anti-S). Nearly all acquired antibodies during past top-up transfusions.

Keynote message: *Red cell exchange is a feasible, life-saving procedure for severe SCD complications at JCRC. Alloimmunisation is common (15%), underscoring the urgent need for routine antibody screening and safer transfusion practices, including leuco-reduced packed cells and extended blood grouping.*



Session 3: Testing, Care Programs & Policy

Moderated by Dr. Charles Kiyaga

CONSA CONSORTIUM
(Mr. Ssenjovu Benjamin)

- Mr. Ssenjovu presented the Consortium on Newborn Screening in Africa (CONSA) project, a multi-country initiative (Ghana, Kenya, Liberia, Nigeria, Tanzania, Uganda, Zambia) establishing newborn screening and early therapeutic interventions. In Uganda, 27,694 babies were screened: 4,628 (16.7%) with sickle cell trait and 435 (1.6%) with SCD. Jinja screened 14,497 (SCT 17.1%; SCD 1.6%) and Lira 13,158 (SCT 16.3%; SCD 1.5%). Only 26 children are on hydroxyurea. Clinical retention: 238 at first visit, 160 at second, 479 at third, and 474 attending more than three routine visits. Challenges include uncovered entry points.

Keynote message: *CONSA has screened nearly 28,000 babies in Uganda, identifying 435 with SCD and 4,628 with trait. However, only 26 children are on hydroxyurea screening is working; linkage to treatment is lagging. The Ministry of Health must integrate newborn screening into all maternal and child health entry points and ensure every diagnosed child is started on hydroxyurea.*



Mr. Ssenjovu Benjamin presenting Consortium on Newborn Screening in Africa (CONSA) project

COMMUNITY HEALTH WORKERS TRAINING (Mr. Bukenya Ivan)

Mr. Bukenya presented the Community Health Worker Initiative, launched in August 2025 in Lira and Jinja to reduce loss-to-follow-up among babies diagnosed with SCD through CONSA. A total of 180 CHEWs/CHWs were trained across both sites, with Nurse Coordinators and Assistant Nurse Coordinators selected at each site. Regional training of Nurse Coordinators was conducted in April 2026. Follow-up outcomes: 33 first home visits conducted (Jinja 29; Lira 4) and 96 babies brought back into care (Jinja 58; Lira 38). At Jinja, 74 are active enrolled, 163 lost, 58 brought back; at Lira, 35 active, 163 lost, 38 brought back. Challenges include missing phone numbers, address changes, and lack of funds for home visits.

Keynote message: *The CHW model works 96 babies brought back into care within months. The Ministry of Health should scale it nationally and fund it sustainably to ensure no diagnosed child is lost to follow-up.*

THE ECONOMIC BURDEN AMONG CHILDREN WITH SICKLE CELL ANEMIA IN EASTERN AND SOUTHERN AFRICA
(By: Perez Ochanda)

Mr. Ochanda presented findings from a household cost-of-illness study nested within the CHEMCHA trial (Uganda and Malawi). A total of 723 children (437 Uganda; 286 Malawi) aged 6 months–15 years with HbSS were recruited from Jinja and Kitgum (Uganda) and Blantyre and Lilongwe (Malawi). Annual median household costs were $638 in Uganda and $387 in Malawi. In Uganda, direct medical costs accounted for 38%, direct non-medical 31%, and indirect 31%; drugs were the main cost driver. In Malawi, indirect costs dominated at 55%. Poorest households consistently faced the highest catastrophic health expenditure at all thresholds. Concentration indices showed pro-rich distribution: −0.23 (Uganda) and −0.12

Keynote message: *Families in Uganda spend a median of $638 per year caring for a child with SCA a catastrophic burden for the poorest households. Malaria prevention and hydroxyurea access are not just clinical interventions they are economic imperatives. The Ministry of Health should include SCD services in national insurance schemes and expand social protection.*

SCALE PROGRAMME
(Dr. Angella Mirembe)

Dr. Mirembe presented the SCALE Programme, a Ministry of Health initiative launched in October 2024 at Kayunga Regional Referral Hospital, demonstrating successful integration of SCD care into primary health services. Baseline challenges included care clustered at tertiary centres, <40% newborn screening coverage, and frequent hydroxyurea/penicillin stockouts. From November 2024 to March 2026, 17,745 patients were screened across all entry points; 13.5% were carriers (HbAS) and 2.7% had SCD (HbSS: 439). All 439 confirmed cases were linked to comprehensive care. Treatment uptake: hydroxyurea 94% at KRRH and 93% across all sites; penicillin V 97% at KRRH and 86% across all sites. Combined registration reached 2,734 with 2,261 active (83% retention). A total of 263 health workers were trained across 12 facilities.



Dr. Angella Mirembe presenting the SCALE Program in Kayunga district

Keynote message: *The SCALE Programme proves that decentralised, integrated SCD care is achievable at scale. In just 17 months, 17,745 patients were screened, 439 linked to care, and 93% hydroxyurea uptake achieved with 83% retention across 10 facilities. The Ministry of Health should roll out this model nationally.*

COMMUNITY MOBILIZATION AND PATIENT ADVOCACY

(Mr. Isaac Okello)

Mr. Okello presented the Sickle Cell Alliance Uganda (SCAU), a national umbrella uniting 18+ member organisations patients, caregivers, clinicians, researchers, and CSOs as one voice for advocacy, education, screening, care, and policy. The Alliance's 8-pillar framework spans awareness, screening, early diagnosis, referral, treatment, advocacy, psychosocial support, and policy change. Policy priorities include universal newborn screening, hydroxyurea access, affordable diagnostics, comprehensive care, school and workplace inclusion, and sustainable financing.



Mr. Isaac Okello, Director Sickle Cell Alliance Uganda

Keynote message: *Persistent stigma, low awareness, and weak referral systems continue to delay diagnosis and undermine care. SCAU provides a unified civil society platform that government, health sector, researchers, and partners must engage as a full stakeholder in the national SCD response.*

IMARA PROGRAMME

(Dr. Nathan Mulure)

Dr. Mulure presented the IMARA Sickle Cell Framework a multi-country initiative (Uganda, Kenya, Côte d'Ivoire) designed to move SCD care from fragmentation to integrated impact. SCD is a leading cause of child mortality in Africa (~400,000 newborns/year; 5.7M people living with SCD; 30 years shorter life expectancy), yet lacks its own WHO category. The framework, developed by 39 experts across 3 African countries, integrates care across primary interventions (awareness, screening, early linkage), secondary interventions (diagnostics, blood management, routine care), tertiary interventions (complication management), and cross-cutting engagements (data management, healthcare financing, programme management). It comprises 10 activity areas and is built on horizontal integration into existing health systems.

Keynote message: *IMARA offers Africa's first expert-validated, integrated SCD care framework spanning primary, secondary, and tertiary levels. The Ministry of Health should adopt it as the national SCD care model, establish a programme management office, and leverage public-private-donor partnerships for sustainable financing.*



Dr. Nathan Mulure presenting the IMARA Program

Session 4: The Cure Agenda

Moderated by Dr. Ssali Francis



Dr. Cissy Kityo delivers an insightful presentation on gene therapy updates

UPDATE ON GENE THERAPY
(Dr. Cissy Kityo)

Dr. Kityo presented the case for advancing gene therapy for SCD in sub-Saharan Africa, where >75% of global cases occur yet the region is largely excluded from gene therapy research. Approximately 8 million people live with SCD worldwide, with ~500,000 new cases annually. Gene therapy clinical trials are concentrated in the US (63.3%), UK (8.5%), Germany (3.5%), and China (3.2%); Africa has had very few. FDA-approved therapies cost over $2.5 million per patient. Dr. Kityo co-founded the Global Gene Therapy Initiative (GGTI) and is establishing the African Centre of Excellence for Gene Therapy (ACE-Gene) at JCRC, with the foundation stone laid by H.E. the President of Uganda in October 2023. The immediate goal is a bone marrow transplant unit; the long-term goal is in-vivo gene therapy.

Keynote message: *Africa bears >75% of the global SCD burden but is largely excluded from gene therapy research. JCRC's ACE-Gene initiative is building the infrastructure for affordable, locally relevant gene therapy. The Ministry of Health should support a national advanced therapies roadmap and regulatory readiness.*

GENE THERAPY: ONGOING WORK IN UGANDA
(Dr. Lois Bayigga)

Dr. Bayigga presented her research on developing a cost-effective, minimal manufacturing workflow for ex-vivo gene therapy in Uganda. Cord blood offers advantages over adult peripheral blood stem cells: no donor risk, non-invasive collection, more primitive cells, higher proliferative capacity, and better availability in LMICs. CD34+ yield from cord blood was 2.94% versus 2.12% from RBC exchange waste ($p<0.001$). Magnetically assisted transduction (MAT) was significantly superior to culture-based transduction ($p<0.01$), with advantages including reduced manufacturing time, lower reagent cost, and maintained cell viability. Alternative vector approaches (COCAL, measles virus pseudotypes) show promise for eliminating the need for pre-stimulation.

Keynote message: *Uganda has the scientific capability to manufacture gene therapy locally using cord blood and red cell exchange waste. The Ministry of Health should invest in infrastructure, training, and regulatory systems to move from bench to bedside.*



Dr. Lois Bayigga discussing Ongoing Gene Therapy Work in Uganda

ADVANCED THERAPY IN AFRICA
(Prof. Julie Makani - Online)



Prof. Makani presented Tanzania's integrated approach to SCD, spanning public health, research, and advanced therapies. Tanzania has successfully transplanted 30 patients with SCD using HLA-matched sibling donors at Benjamin Mkapa Hospital. The Sickle Cell Disease Advanced Therapy Programme (SCD-ATP) at MUHAS, initiated in 2021, identified 157 patients eligible for advanced therapies; 22 received exchange blood transfusion, and HLA typing was conducted on 127 family members. The SickleInAfrica registry now has >13,000 participants (targeting 34,000 by end of 2026) across seven African countries. Tanzania has developed Target Product Profiles (TPPs) to guide future gene therapy development. Prof. Makani emphasised that advanced therapies must be built on a strong public health base.

Keynote message: *Tanzania proves that Africa can deliver advanced therapies for SCD 30 bone marrow transplants completed and a registry of >13,000 participants. Uganda should learn from this model: build on public health foundations, engage patients, develop regulatory readiness, and partner globally.*

SESSION 4: PANEL DISCUSSION.

Bone Marrow Transplant for Sickle Cell Disease in Uganda

Dr. Kityo presented the establishment of Uganda's first Bone Marrow Transplant (BMT) Centre at JCRC, launched in partnership with Rotary Clubs of Uganda and Pearl Bank Uganda. Families requiring BMT have historically travelled abroad at costs of UGX 150–250 million. JCRC and partners have invested $1.35 million in remodelling inpatient units into international-standard clean rooms, training clinical staff, conducting 147 HLA typings through partnership with DKMS Germany, and establishing a dedicated post-transplant care clinic currently managing 16 patients who underwent transplants abroad. An additional $4 million is required to fully equip, staff, and operate the centre. The centre will serve patients with SCD, blood cancers, and other

Keynote message: *Uganda is building its first Bone Marrow Transplant Centre — a transformative step toward curative care for SCD and blood cancers. The Ministry of Health should prioritise government funding, support regulatory frameworks, and integrate BMT into the national SCD care strategy.*



5.0 KEY CONSENSUS

The symposium generated strong consensus on the following key messages for the Ministry of Health and Government of Uganda

1. SCD constitutes a major public health challenge requiring urgent national attention.

It must be integrated into broader strategies for child survival, non-communicable diseases, maternal and child health, and universal health coverage.

2. There is sufficient scientific evidence to support immediate scale-up of proven interventions.

Universal newborn screening, hydroxyurea at maximum tolerated dose, and comprehensive decentralised care should be implemented at scale without further delay.

3. Universal newborn screening is critical for reducing childhood mortality.

To reduce childhood Mortality associated with SCD. Universal newborn screening should be transitioned from a pilot to a fully mandatory national Program.

4. Hydroxyurea at maximum tolerated dose (25–30 mg/kg/day) is the cornerstone for SCD treatment.

This requires guaranteed uninterrupted national procurement, inclusion in all essential medicines packages, expanded prescribing authority, and sustainable financing through local production.



Physical attendance at the Symposium

5. Comprehensive SCD care should be integrated into primary healthcare.

Trained primary healthcare workers should safely manage uncomplicated SCD, with task-sharing approaches increasing coverage, and strengthened referral networks connecting communities to specialised care.

6. Brain complications of SCD are under-recognised, and are leading causes of disability and mortality in SCD.

National neurocognitive screening guidelines, expanded transcranial Doppler screening, universal penicillin prophylaxis, strengthened malaria prevention, and enhanced vaccination coverage are urgently needed.

7. Access to blood transfusion is an essential component of SCD management.

SCD patients should be prioritised in blood allocation systems, with strengthened regional exchange transfusion centres, routine antibody screening, and adoption of leuco-reduced and extended-matched blood components.

8. SCD has a major impact on population health and development.

It requires inclusion in national insurance schemes, expanded social protection, mobilisation of domestic financing, and multi-sectoral engagement beyond the health sector.

9. Bone marrow transplantation and gene therapy represent a cure for high risk SCD.

Strategic preparation must begin immediately through the establishment of the national Bone Marrow Transplant Centre at JCRC, development of a national advanced therapies roadmap, building genomic medicine capacity, strengthening regulatory frameworks, and fostering global partnerships for technology transfer and affordable access.

6.0 STRATEGIC PRIORITIES FOR 2026–2030

Priority Area	Key Action	Lead Agency	Timeline	Alignment with Consensus
Universal Newborn Screening	National scale-up using point-of-care testing, integrated within maternal, newborn and child health services, with mandatory linkage-to-care pathways	MoH	2026–2030	Consensus 2, 3
Universal Hydroxyurea Access	Guaranteed national procurement and distribution, inclusion in all essential medicines packages, subsidised treatment costs, and expanded prescribing authority	MOH/NMS	2026–2030	Consensus 2, 4
Decentralised Comprehensive Care	Establishment of SCD clinics in all regional referral hospitals, expansion to district hospitals, and integration into primary healthcare with national standards of care and strengthened referral networks	MOH	2026–2029	Consensus 2, 5
Strengthened Blood Services	Prioritisation of SCD patients in blood allocation systems, expansion of regional exchange transfusion centres, increased component preparation capacity, and strengthened haemovigilance systems	UBTS/ MOH	2026–2030	Consensus 7
Brain Health and Stroke Prevention	Introduction of national neurocognitive screening guidelines, expanded transcranial Doppler screening, strengthened stroke prevention strategies, and integration of developmental assessment into routine care	MOH/ Academic Institutions	2027–2030	Consensus 6
Infection Prevention	Universal penicillin prophylaxis, strengthened malaria prevention, enhanced vaccination coverage, and improved antimicrobial stewardship	MOH	2027–2030	Consensus 6

Priority Area	Key Action	Lead Agency	Timeline	Alignment with Consensus
Registry and Surveillance Strengthening	Sustained national registry, integration of registry data into planning, and expansion of implementation science	MOH/ SPARCO	2026–2028	Consensus 1, 2
Sustainable Financing	Inclusion of SCD services in national insurance schemes, expanded social protection, periodic cost-effectiveness analyses, and mobilisation of domestic financing	MOH/MoF	2026–2030	Consensus 8
Research and Innovation	Sustained Uganda's participation in global trials, strengthened pharmacovigilance, increased domestic research funding, and promotion of multicentre collaboration	MOH/ Researchers	2026–2030	Consensus 2, 9
Future Readiness for Advanced Therapies	Development of a national advanced therapies roadmap, building genomic medicine capacity, strengthening regulatory frameworks, and participation in continental initiatives	MOH/ Researchers	2026–2030	Consensus 9



9.0 Conclusion

Uganda stands at a pivotal moment in the fight against sickle cell disease. The country has generated world-class evidence through research, built strong partnerships, established screening and treatment platforms, and demonstrated the effectiveness of comprehensive care. The challenge now is not whether interventions work, but how rapidly they can be scaled equitably and sustainably. The symposium calls upon the Ministry of Health, Parliament, development partners, civil society, researchers, healthcare workers, and affected communities to unite behind a National Sickle Cell Disease Acceleration Strategy capable of reducing mortality by at least 50% by 2035, preventing disability, improving quality of life, and positioning Uganda as a continental leader in SCD prevention, care, research, innovation, and cure.

5.0 Appendix

List of Presentations

1	The Burden and Future of SCD in Uganda — Dr. Phillip Kasirye
2	SPARCO-Uganda Registry — Prof. Sarah Kiguli
3	Newborn Screening & Genetic Epidemiology — Dr. Charles Kiyaga
4	AI-Enhanced Image Analysis for POC SCD Screening — Dr. Anne Akullo
5	ADAPT Trial: PK-Guided Hydroxyurea Dosing — Dr. Ruth Namazzi
6	NOHARM Studies: 10-Year Safety & Efficacy of Hydroxyurea — Dr. Robert Opoka
7	Brain Injury and Neurocognitive Protection — Dr. Deogratias Munube & Dr. Richard Idro
8	Zinc for Infection Prevention (ZIPS-2) — Dr. Ruth Namazzi
9	Advances in the Blood Bank — Mr. Ezra Musisi
10	HIBISCUS 2 Trial: Etavopivat — Dr. Diana Rutebarika
11	Red Cell Exchange — Dr. Francis Ssali
12	CONSA Project — Mr. Ssenjovu Benjamin
13	Community Health Worker Initiative — Mr. Bukenya Ivan
14	Economic Burden of SCD — Ms. Perez Ochanda
15	SCALE Programme — Dr. Angella Mirembe
16	Community Mobilization and Patient Advocacy — Mr. Isaac Okello
17	IMARA Programme — Dr. Nathan Mulure
18	Update on Gene Therapy — Dr. Cissy Kityo
19	Gene Therapy: Ongoing Work in Uganda — Dr. Lois Bayigga
20	Advanced Therapy in Africa — Prof. Julie Makani
21	Bone Marrow Transplant for SCD in Uganda — Dr. Cissy Kityo

SYMPOSIUM SCHEDULE.

Time	Session/ Presentation	Presenter/Affiliation
08:00-0900	Registration and Poster set-up	
09:00-09:35	Opening/ Session	Moderator: Dr. Francis Kanyike
09:00-09:05	Welcome Remarks	Dr. Ssali Francis (DED, JCRC)
09:05-09:15	Official Opening	Director General, MOH
09:15-09:35	Key note: The Burden and Future of SCD in Uganda	Dr. Phillip Kasirye
09:35-10:35	**Session 1**: Basic Science and Epidemiology Research	Moderator: Dr. Deogratias Munube
09:35-09:45	SPARCo Uganda Registry: 5,655 patients and lessons learned	Prof Kiguli / Makerere University
09:50-10:00	Health status of Ugandan children identified through newborn screening (SCD & HIV)	Dr. Charles Kiyaga
10:05-10:15	AI-enhanced image analysis for point-of-care SCD screening in Uganda	Dr. Anne Akullo / Dr. Deogratias Munube
10:15-10:25	Panel Discussion: What does basic science tell us about SCD burden in Uganda? Where are the gaps?	All speakers
10:25-10:35	Break & Exhibition View	
10:35-12:55	**Session 2**: SCD Treatment advances in Uganda	Moderator: Dr. Anne Akullo
10:35-10:45	ADAPT Trial: PK-guided hydroxyurea dosing for children in Uganda (106 participants, 100% completed PK testing)	Dr. Ruth Namazzi / Global Health Uganda
10:50-11:00	10-year safety & efficacy of Hydroxyurea in Ugandan children	Dr. Robert Opoka
11:05-11:15	Prospective HU impact on cerebral MRI (30-month trial)	Dr. Richard Idro / Dr. Deogratias Munube
11:20-11:30	Economic burden & catastrophic expenditures for SCD households	Carol Kamya (Makerere)
11:35-11:45	Zinc for Infection Prevention in SCA (ZIPS-2 trial)	Dr. Ruth Namazzi / Global Health Uganda
11:50-12:00	FACTS Study: Burden of SCD on pediatric blood transfusion	Dr. Ruth Namazzi / Dr. Robert Opoka
12:05-12:15	Advances in the Blood Bank	Dr. Kyeyune / Ezra
12:20-12:30	Hibiscus 2 Trial (Trial-in-Progress): Etavopivat for SCD	Uganda Site Lead (Local PI)
12:35-12:45	Red Cell Exchange: JCRC's experience and lessons for regional expansion	Dr. Ssali / JCRC
12:45-12:55	Panel Discussion, What treatments are working in Uganda what are the barriers to access?	
12:55-13:55	Lunch Break & Exhibition view	
13:55-15:20	**Session 3**: Testing, Care Programs & Policy	Moderator: Dr. Charles Kiyaga
13:55-14:05	National Newborn Screening Programme: Launch, implementation, and early lessons	Dr. Miriam Ajambo / MOH
14:10-14:20	ASH/CONSAA Consortium: Newborn screening progress in Africa	Dr. Charles Kiyaga
14:25-14:35	Community Health Worker training for SCD education	CPHL team
14:40-14:50	SCALE Programme (Kayunga): Strengthening SCD care at district level	Dr. Dithan Kiragga / Baylor Uganda
14:55-15:05	Sickle Cell Alliance Uganda: Community mobilization and patient advocacy	Mr. Isaac Okello / Raising Hope
15:10-15:20	IMARA Programme: Comprehensive SCD care pathway in Jinja	Dr. Nathan
15:20-15:30	Panel Discussion	All speakers
15:30-16:55	Session 4: The Cure Agenda	Moderator: Dr. Francis Ssali
15:30-15:45	Update on Gene therapy	Dr. Cissy/ JCRC
15:50-16:00	Gene Therapy, Ongoing work in Uganda, (Rubaga study)	Dr. Lois Bayigga / JCRC
16:05-16:15	CRISPR-based cure for SCD: A test of equity in public health genomics	Dr. Gerald Mboowa (Makerere)
16:20-16:30	Bone marrow transplant for sickle cell disease in Uganda	Dr Ssali
16:35-16:50	Bone marrow transplant for sickle cell disease in Tanzania	Dr Makani
16:50-17:00	Panel Discussion	
17:00-17:10	Poster and Exhibition	Guided tour for dignitaries
17:10-17:20	Closing Remarks & Vote of Thanks	Dr. Cissy Kityo (ED, JCRC)

ORGANIZING COMMITTEE



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SCIENTIFIC SYMPOSIUM ON

SICKLE CELL DISEASE.

SYMPOSUIM PROCEEDINGS.

16 June 2026