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9th SickleInAfrica Consortium Meeting (16 – 19 May 2023)

Introduction

It is a great pleasure to welcome you all to the 9th SickleInAfrica Consortium Meeting. SickleInAfrica has successfully conducted eight SickleInAfrica Consortium Meetings since 2017.

The NHLBI funded the establishment of a multinational Sickle Pan-African Research Consortium (SPARCO) which is supported by the Sickle Africa Data Coordinating Center (SADaCC) and the SPARCO Clinical Coordinating Center (CCC). The first phase of this grant focused mainly on research capacity development with an emphasis on establishing a patient disease registry. The second phase of this grant is focusing on implementing research studies that could change the quality of care and life for Sickle Cell Disease patients in Africa.

Main aim of the 9th SickleInAfrica Consortium Meeting: To optimize the implementation plans, impact and sustainability of the Newborn Screening and the Malaria Chemoprophylaxis cross-consortium research studies.

The objectives of this meeting include:

- review and adjust the research milestones and workplans.
- to strength coordination of research projects and the registry
- to initiate partnerships and sustainability plans through engagement with policymakers, potential commercial partners and patient support groups.

Summary of Meeting Activities

Day 1: Malaria Chemoprophylaxis Study (*Closed consortium sessions*)

Day 2: Newborn Screening Study (*Closed consortium sessions*)

Day 3: Stakeholder Engagement Day (*Open to all invited stakeholders*)

The SickleInAfrica Consortium is hosting a roundtable with policymakers, patient support groups and potential commercial partners to discuss potential partnerships. We hope by the end of the meeting, we will have:

- a) a draft outline of potential SickleInAfrica-Commercial agreements/partnerships.
- b) clear guidelines on how best policy makers could support research- and evidence-based practices resulting from the SickleInAfrica consortium.



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Policymakers: We kindly request that policymakers respond to the following questions in their brief presentations:

- a. How can they support obtaining of approvals for research implementation at SickleInAfrica sites?
- b. What would they need from the consortium to support scale up of interventions which will be guided by the current research projects/interventions?

Commercial Partners: We kindly request that the commercial partners respond to the following questions in their brief presentations:

- a) Describe a key product they have on offer (this will be guided by what was proposed by SickleInAfrica members/PIs).
- b) Describe what would be ideal win-win scenario for the companies, consortium and patients in a potential partnership or agreements.

Patient Support Groups: We kindly request that the patients support groups indicate:

- a. how they can best contribute to the ongoing research studies
- b. some of their key research priority areas which the consortium could address at scale in the future around New-born screening and Malaria Chemoprophylaxis.

Day 4: Wrap-Up and Way Forward (*Closed Consortium Meeting*)



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Day 1	16 May 2023	Welcome and Malaria Chemoprophylaxis Study	
Facilitator (s)	Time (CAT)	Title	Speaker
Prof Ambroise Wonkam & Prof Julie Makani	08:30 - 09:00	SickleInAfrica Video and Infographic Videos Playing Testing of sound for online	
	09:00 - 09:30	Welcome and Introductions	Prof Léon Tshilolo
	09:30 - 10:00	SADaCC (Data Coordination Plan)	Prof Ambroise Wonkam & Prof Nicola Mulder
	10:00 - 10:30	SPARCo CCC (Research Coordination Plans)	Prof Julie Makani & Dr Irene Minja
	10:30 - 11:00	Discussions	
	11:00 - 11:15	Tea-break	
	11:15 - 11:45	Malaria Chemoproxylaxis Study	Prof Aldiouma Guindo
	11:45 - 12:00	Tanzania - MCP	Prof Emmanuel Balandya
	12:00 - 12:15	Nigeria - MCP	Prof Obiageli Nnodu
	12:15 - 12:30	Uganda - MCP	Prof Sarah Kiguli
	12:30 - 12:45	Zimbabwe/ Zambia - MCP	Dr Patience Kuona
	12:45 - 13:00	Ghana - MCP	Prof Fred Sarfo
	13:00 - 13:15	Coordination of SickleInAfrica Research Projects	Prof Emmanuel Balandya
	13:15 - 13:30	Discussions	
	13:30 - 14:30	Lunchbreak	
14:30 - 15:30	MCP – Articles and Authorship Agreements		
Reflections and Discussions			
Prof Emmanuel Balandya	15:30 - 16:00	Tea-break	
	16:00 - 17:45	Sustainability - MCP Roundtable Engagements Contract Discussions, Possible Scale-Up	
	17:45 - 19:00	Steering Committee	



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Day 2	17 May 2023	New Born Screening Study	
Facilitator	Time (CAT)	Title	Speaker
Prof Nicola Mulder	08:00 - 08:30	SickleInAfrica Data Management/Analysis for NBS Studies	Prof Nicola Mulder
	08:30 - 09:00	SickleInAfrica Research Coordination for NBS Studies	Dr Siana Nkya & Dr Irene Minja
	09:00 - 09:30	NBS Study	Prof Obiageli Nnodu
	09:30 - 09:45	Ghana - NBS	Prof Fred Sarfo
	09:45 - 10:00	Tanzania - NBS	Prof Emmanuel Balandya
	10:15 - 10:30	Mali - NBS	Prof Aldiouma Guindo
	10:30 - 10:45	Uganda - NBS	Prof Sarah Kiguli
	10:45 - 11:00	Zimbabwe/ Zambia - NBS	Dr Patience Kuona
	11:00 - 11:30	On Tea-Break	
Dr Irene Minja	11:30 - 12:00	NBS – Articles and Authorship Agreements	
	12:00 - 13:00	Reflections and Discussions	
	13:00 - 14:00	Lunchbreak	
	14:00 - 14:30	Sustainability - NBS Roundtable Engagements Draft Contracts, Possible Scale-Up	
	15:10 - 15:30	Reflections and Discussions	
Prof Sarah Kiguli	15:20 - 15:30	Tea-Break	
	15:30 - 17:30	Data Management, Quality and Analysis Workshop for NBS	
	17:30 - 18:00	Wrap Up for the Day	



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Day 3	18 May 2023	Round Table with Key Stakeholders: Policy Makers, Commercial Companies and Patient Representatives	
Facilitator	Time (CAT)	Title	Speaker
Prof Léon Tshilolo	08:15 - 08:30	Welcome	Prof Léon Tshilolo
	08:30 - 09:00	SickleInAfrica Coordination and Data	Prof Ambroise Wonkam
	09:00 - 09:30	SickleInAfrica Research Coordination	Prof Julie Makani
	09:30 - 10:00	Newborn Screening Study	Prof Obiageli Nnodu
	10:00 - 10:30	Malaria Chemoprophylaxis	Prof Aldiouma Guindo
	10:30 - 11:00	Tea	
Prof Eligius Lyamuya	11:00 - 11:10	MCP	Fosun Pharmaceuticals
	11:10 - 11:20	Blood and Cell Technologies	TerumoBCT
	11:20 - 11:30	PCR Machines and Reagents	BGI
	11:30 - 11:40	Nanopore Sequencing	Oxford Nanopore
	11:40 - 11:50	HPLC Machines and Reagents	Trinity Biotech
	11:50 - 12:00	HemoType SC	SilverLake
	12:00 - 13:00	Discussions	
	13:00 - 14:00	Lunchbreak	
Prof Léon Tshilolo	14:00 - 14:15	SCD Policy in Ghana	Ghana
	14:15 - 14:30	SCD Policy in Mali	Mali
	14:30 - 14:45	SCD Policy in Nigeria	Nigeria
	14:45 - 15:00	SCD Policy in Tanzania	Tanzania
	15:00 - 15:15	Tea-break	
	15:15 - 15:30	SCD Policy in Uganda	Uganda
	15:30 - 15:45	SCD Policy in Zimbabwe	Zimbabwe
	15:45 - 16:00	SCD Policy in Zambia	Zambia
	16:00 - 16:15	SCD Policy in South Africa	South Africa
	16:15 - 16:30	Patient Support Group	Zambia/Zimbabwe
	16:30 - 17:30	Discussions & Wrap Up	
Dinner at the Boma			



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Day 4	19 May 2023	Way Forward	
Facilitator	Time (CAT)	Title	Speaker
Dr Patience Kuona & Prof Fred Sarfo	08:00 - 08:30	Recap from Stakeholder Engagements	Prof Léon Tshilolo
	08:30 - 09:00	Registry	DCC
	09:00 - 09:30	Standards of Care	CCC
	09:30 - 10:00	Pharmacogenomics + Discussions	Dr Patience Kuona
	10:30 - 11:00	Penicillin Chemoprophylaxis + Discussions	Prof Sarah Kiguli & Prof Bob Opoka
	11:00 - 11:30	Tea-break	
Prof Leon Tshilolo & Prof Fumni Olopade	11:30 - 12:00	Funding Opportunities	Dr Siana Nkya
	12:00 - 13:00	Way Forward and Close	Prof Ambroise Wonkam and Prof Julie Makani
	13:00 - 14:00	Lunchbreak	
	14:00 - 15:30	Optional Technical Meetings/Networking	DCC/CCC
	15:30 - 16:00	Tea-break	



SickleInAfrica Consortium Co-Chairs



Prof Leon Muepu Malaika
leon.tshilolo2012@gmail.com

Professor of Pediatrics and Haematology at Official University of Mbuji mayi (UOM) in DRC and Visitor at University of Kinshasa and University of Lubumbashi, DRC Director of Research in the Institut de Recherche Biomédicale et Drépanocytose associated to Monkole Hospital. Kinshasa, DRC. (since 2020) Paediatric haematologist in Centre Hospitalier Monkole (1998-2020) Expert of ITHANET-HVP

Global Globin Panel (since 2016) DRC leader Investigator of REACH-Realizing Effectiveness Across Continents with Hydroxyurea (since 2013) Co-Chair in SickleinAfrica Consortium. President and co-fondator of REDAC, a network of SCD Research in Central Africa. Member of the Académie de Médecine de France and the Académie Congolaise des Sciences (ACCOS).



Prof Olufunmilayo Olopade
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Prof. Olufunmilayo is the Walter L. Palmer Distinguished Service Professor of Medicine and Human Genetics, Dean for Global Health, and Director of the Center for Innovation in Global Health at the University of Chicago. Professor Olopade develops innovative strategies for comprehensive cancer risk assessment and prevention based on evolving understanding of genetic and nongenetic factors in individual patients, with a focus on women of African ancestry across the Diaspora.

She has received numerous honors and awards, including honorary degrees from North Central, Dominican, Bowdoin, and Princeton Universities; MacArthur Foundation Fellowship; Doris Duke Distinguished Clinical Scientist and Exceptional Mentor Award; American Cancer Society Clinical Research Professorship; Officer of the Order of the Niger Award; and the Franklin D. Roosevelt Freedom from Want Award. She is an elected member of the Association of American Physicians, National Academy of Medicine, American Academy of Arts and Sciences, and the American Philosophical Society, and currently serves on the board of directors for Susan G. Komen, Cancer IQ, Lyric Opera of Chicago, and MacArthur Foundation.

Principal Investigators



Prof. Ambroise Wonkam (Principal Investigator and Director, SADAaCC)

Prof Wonkam is a specialist medical geneticist, in the Division of Human Genetics, Faculty of Health Sciences, University of Cape Town, South Africa. After MD training from the Faculty of Medicine and Biomedical Sciences, University of Yaoundé I (Cameroon), he completed a thesis in Cell Biology in the department of Morphology, University of Geneva (Switzerland) and a PhD in Human Genetics (University of Cape Town, South Africa).

Other salient aspects of Prof Wonkam's background include his education as a medical geneticist at a



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highly reputable genetics department in Geneva (Switzerland). He subsequently practices medical genetics in both European and African contexts. His research interests are reflected in more than 100 peer-reviewed publications, which are in molecular, clinical, educational and ethical aspects of medical and human genetics. His research focuses on 1) Psycho-social Burden and Genomics modifiers of SCD, 2) Genetics of hearing loss, and 3) Ethical and educational Issues in human genetics in Africa. He is a member of the steering committee of H3Africa consortium, leading specifically the NIH/NHGRI funded SCD project.

In 2017 he was granted from NIH/NHLBI 3.7m USD, to establish a Sickle Africa Data Coordinating Centre (SADaCC), at the University of Cape Town that will work collaboratively with a sister consortium (Sickle Pan African Network, SPARCo) to develop various studies in Tanzania, Nigeria and Ghana. He was awarded the 2003 Denber-Pinard Prize for the best thesis from the Faculty of Medicine, University of Geneva, and won the very competitive Clinical Genetics Society International Award for 2014, from the British Society of Genetic Medicine.

Prof Wonkam is the current president of the African Society of Human Genetics, Board member of the International Federation of Human Genetics Societies, council member of Human Genome Organization, steering committee's member of the Global Genomic Medicine Collaborative (G2MC).



Prof. Nicola Mulder (Co-Principal Investigator, SADaCC)

Prof Mulder graduated with a BSc degree (*cum laude*) in Chemistry and Microbiology, and a first-class Honours degree in Microbiology, followed by a PhD in Medical Microbiology. She then spent over 8 years at the EBI in Cambridge, moving into the area of bioinformatics. At the EBI she was a Team Leader, responsible for the development of InterPro and the Gene Ontology Annotation Project. InterPro was one of the most heavily used Bioinformatics resources at the Institute.

At UCT, Prof Mulder works in the area of bioinformatics of infectious diseases, including pathogen and host genomics and biological networks, human variation and disease association studies. She heads the CBIO at UCT which consists of over 30 staff and students. The group provides bioinformatics support and training for postgraduate students and local researchers, and Prof Mulder convenes an Honours programme in Bioinformatics, and organises a South African national bioinformatics training course for postgraduate students. Internationally, Prof Mulder is involved in capacity development in Africa, as leader of a large NIH- funded consortium, H3ABioNet, to build a Pan-African Bioinformatics network for H3Africa.

Prof Mulder is also a member of the ELIXIR Scientific Advisory Board, which forms part of a major EU funded European initiative involving all the bioinformatics stakeholders in Europe and many others world- wide, and a founding member of the Global Organisation for Bioinformatics Learning, Education & Training (GOBLET). She is on the executive committee of the African Institute for Mathematical Sciences, as well as a number of review and advisory boards.



Prof. Julie Makani (Principal Investigator, SPARCo CCC)

Prof Julie Makani (MD, PhD, FRCP, FTAAS) is a Physician Scientist in the Department of Haematology and Blood Transfusion at Muhimbili University of Health and Allied Sciences (MUHAS) www.muhas.ac.tz, Tanzania has established one of the world's largest single-center study cohorts for sickle cell disease. She serves as Principal Investigator of the Sickle Cell program in MUHAS and Sickle Pan African Research Consortium (SPARCO) Clinical Coordinating Centre (CCC) within the SickleInAfrica network. Site Principal Investigator for MUHAS for H3ABioNet and Co- Principal Investigator SickleGenAfrica. The aim is to use

sickle cell disease as a model to establish scientific and healthcare solutions in Africa that are locally relevant and globally significant.

Professor Makani trained in Medicine (Tanzania), specialized in Internal Medicine (UK), and completed her PhD in clinical epidemiology of sickle cell disease (UK). She was a Wellcome Trust Research Fellow [2003 - 2009; 2012 - 2017], Tutu Leadership Fellow (2009) www.alinstitute.org and Honorary Visiting Research Fellow, University of Oxford (2003 - 2016). She received the 2011 Royal Society Africa Award ([View](#)) on the application of genomic research to improve health and find a cure for sickle cell disease. She is a Fellow of the Royal College of Physicians of UK and Fellow of the Tanzania Academy of Sciences.



Dr. Fred Sarfo (Principal Investigator, SPARCo Ghana)

Dr Sarfo is a researcher, a clinician and an educator. He practiced as a Neurologist from 2010 to date and holds 2 doctoral degrees in Epidemiology and Molecular Medicine from Durham University UK and the Kwame Nkrumah University of Science & Technology (KNUST) respectively. In 2010, he started a Neurology clinic at KATH in Kumasi where he led in providing services for a population of 12 million Ghanaians in the middle and northern sectors of the country as the only practicing

neurologist for this sector of Ghana. He is passionate about context-specific research as a way of fashioning out locally relevant solutions to the health challenges of my society. His research focus is on Stroke in the sub-Saharan African context.

Dr. Sarfo is currently the Kumasi site lead-Investigator on the SIREN (Systemic Investigative Research and Education Network) project which is the biggest study on stroke in sub-Saharan Africa investigating the traditional and emerging risk factors of stroke as well as characterizing the genetic markers of stroke. Understanding the incidence prevalence determinants and risk modifiers of stroke occurrence among individuals with Sickle Cell Disease has received little attention in Sub-Saharan Africa. Ghana SPARCO sites therefore seek to characterize the determinants etiologic subtypes outcomes and sequelae (functional status cognitive impairment quality of life) of incident and recurrent strokes across the lifespan of patients with SCD. This sub-aim is embedded in our overall goal of to establish a prospective cohort of 6 000 individuals living with SCD across the lifespan with a dual purpose of understanding the determinants of the protean manifestations of acute and chronic complications of SCD in a resource-limited setting while conducting implementation research to address " surmount & integrate the best resource-based standards of clinical care for SCD with a vision towards establishing hubs of excellence for research and care for SCD in Ghana.



Prof. Aldiouma Guindo (Principal Investigator, SPARCo Mali)

Prof Guindo is a Professor of Hematology at the University of Bamako, and in addition to the PharmD degree, he obtained a PhD from the University of London, did post-doctoral training in the NIAID Laboratory of Malaria and Vector Research under Dr Thomas E. Wellems. He is a member of French society of hematology and an allied member of American society of hematology. In his current role he leads all operations of the CRLD and serves as an advocate for sickle cell disease care, research and education to the national government.

He has a broad background in hematology, with specific training and expertise in red blood cell disorders and screening research and data analysis on sickle cell disease. His research includes sickle cell disease, G6PD deficiency and infections. The purpose of this grant is to improve the quality and duration of life of African people living with sickle cell disease.

Prof Guindo 's early publications directly addressed the afforded protection of sickle cell gene, hemoglobin C and G6PD deficiency against severe malaria and the mechanism by which that protection occurs. These publications found that sickle cell gene and HbC are associated with high protection against severe malaria by reducing infected erythrocytes cytoadherence to the vascular endothelium and the abnormal display of knobs on erythrocyte containing HbC. These results of natural protection against malaria have changed the design of any malaria vaccine trials. In addition to the contributions described above, with a team of collaborators, he directly documented the issue of the physiopathology of sickle cell disease, transfusion safety, infection in sickle cell disease and the referral values in hematology in Mali. These works allowed him to shed light on the field of research in hematology as well as in improving the quality of care.



Prof. Obiageli Nnodu (Principal Investigator, SPARCo Nigeria)

Prof Nnodu is Professor of Haematology and Blood Transfusion and Director, Centre of Excellence for Sickle Cell Disease Research and Training at University of Abuja ([CESRTA](#)), the National Coordinator of the American Society of Hematology Consortium for Newborn Screening in Africa (CONSA), the Nigerian Principal Investigator for SPARCO, Abuja Coordinator for SickleGenAfrica and Co-PI for the UK NIHR Patient centred management of sickle cell disease in Sub Saharan Africa.

Prof Nnodu is a UK Foreign Office Chevening Scholar. She has carried out many multi-institutional, multi-national research projects including a multilateral DFID DELPhe Project. She serves as expert on technical committees on non-communicable diseases with the Nigerian government and as consultant for international agencies including the WHO AFRO. Between 2018-2019, she carried out an assessment of the level of implementation of the WHO AFRO Strategy in SCD in sub Saharan Africa high burden countries and the findings highlighted the need for increased global funding for SCD. In partnership with Silver Lake Laboratories, she led a successful application for the inclusion of point of care tests for sickle cell disease in the essential diagnostics list of the WHO - EDL3.

Prof Nnodu is Chair of the largest network of SCD in Africa, the Sickle Cell Support Society of Nigeria and a Fellow of the Nigerian Academy of Medicine.



Prof. Emmanuel Balandya (Principal Investigator, SPARCo Tanzania)

Prof Balandya is a physician-scientist with expertise in biomedical sciences, encompassing Physiology, Haematology, Immunology and Vaccinology. He obtained his Medical Degree at University of Dar-es-Salaam (Tanzania), his Doctorate Degree at Dartmouth College (USA), and Post-doctoral fellowship at Harvard Medical School (USA). Following his return to Tanzania in 2014, he has researched on immunity and infection in Sickle Cell Disease (through the NIH-Fogarty/NHLBI/UCSF GloCal Fellowship) and is currently Principal Investigator (PI) for SPARCo Tanzania, a U01 grant funded by NHLBI with the goal to advance research as a strategy for improving health, advocacy and training for sickle cell disease in Tanzania as part of the larger SickleInAfrica Consortium.

He is also Co-Investigator on several ongoing health research and education capacity building projects. He is published and has presented his work at national and international platforms. Prof. Balandya is member of the Organizing Committees for the MUHAS Scientific Conference and National NCD Conference. Dr Balandya is Director of Postgraduate Studies at MUHAS, Board Member of Young Scientists Tanzania (YST), a nationwide Science Outreach Programme, and consults with the National Institute for Medical Research (NIMR) and Tanzania Commission for Universities (TCU) on matters related to health research and education.

Prof Balandya is a scientific reviewer for Tanzania Journal of Health Research (TJHR), Allergologia et Immunopathologia, Lancet Haematology, Journal of Community Genetics and PLOS ONE.



Prof. Sarah Kiguli (Principal Investigator, SPARCo Uganda)

Prof Kiguli (MBCHB, M.MED (MAK), MHPE (Maastricht)) is a Paediatrician and Health Profession Educationalist. She is the Principal Investigator of the NIH funded Sickle Pan-African Research Consortium (SPARCO) Uganda Project and the HEPI project: Health professions education and training for strengthening the health system and services in Uganda. She is a Professor and Past Head of Department of Paediatrics & Child Health, and Past Chairperson of the Teaching and Learning Committee of the Makerere University College of Health Sciences.

Prof Kiguli was a Council Member Makerere University, Representing Senate (2010-18).

She is a Fellow of the Foundation for the Advancement of International Medical Education and Research (FAIMER) Institute, President of the East African Health Professionals Educators (EAHPE) Association, Member, Uganda National Immunization Technical Advisory Group, Past Member of the Executive Committee of the Network-Towards Unity for Health (Network-TUFH) representing the Sub-Saharan Region, Women and Health Task Force of the Network-TUFH, and served as Global Faculty Advisor for the FAIMER Institute, and Faculty for the Southern Africa Foundation of Advancement of International Medical Education and Research (SAFRI) and sits on several National and International Boards.

In addition, she is a Founder Member of Women and Health: Together for the Future organization. Prof Kiguli is a Past President of the Association of Uganda Women Medical Doctors (2018-2020). She served in the same position for 4 years (2003-2007; 2028-2020). She is also a member of the Uganda Medical & Dental Practitioners Council.

During the last 20 years, she has focused on advancement of Health Professions Education, Paediatrics Clinical Research and Services. Her main research areas have included Emergency Paediatrics, Child Health, Childhood Tuberculosis, Sickle Cell Anaemia and Health Professions' Education. She has been involved in Clinical Trials involving Fluid Resuscitation, Blood Transfusion and Children's Oxygen Administration Strategies in severely sick children in low resource settings. She has more than 70 publications in peer reviewed journals.



Dr. Gwen Kandawasvika (Principal Investigator, SPARCo Zimbabwe)

Dr Kandawasvika (MD, PhD) is the Coordinator of the Paediatrics and Child Health program in the Child and Adolescent Health Unit, University of Zimbabwe, where she has taught and conducted research for the past 16 years. She is a paediatrician with research interests in, Sickle cell disease, paediatric HIV, nutrition, neurology, non-communicable diseases and climate change. She has published in peer reviewed journals and co-authored several book chapters. She has experience in the conduct of field studies having taken part in the SHINE (Sanitation Hygiene Infant Nutrition Efficacy) study in Zimbabwe investigating neurodevelopmental aspects of infants. Dr Kandawasvika is an executive member of the Zimbabwe Chapter of ILAE and the Paediatric Association of Zimbabwe.



Dr Patience Kuona (Principal Investigator, SPARCo Zimbabwe)

Dr Kuona is a Paediatrician and Senior Lecturer in the Unit of Adolescent and Child Health at University of Zimbabwe Faculty of Medicine (College of Health Sciences) where she has taught and researched for the past 11 years. Clinician with a passion for patient-centred care and has had a long-term interest in SCD care. Established the Harare SCD cohort at the SCD clinic at Parirenyatwa Teaching Hospital in 2018 recruiting over 115 children supported by the MEPI junior faculty program [D43TW010137]. She was an ICOHRTA/FIC/NIH research fellow in 2007-2008. She was awarded the Letten Foundation scholarship to complete her Doctorate in 2012-2015 at the University of Oslo. She was a scholar of the MEPI Junior Faculty award in 2016-2018. She was a co-investigator in the Better Health for the African Mother and Child (BHAMC) study, a cohort of 1050 mother-baby pairs where she performed various studies in malnutrition among HIV exposed and unexposed children.

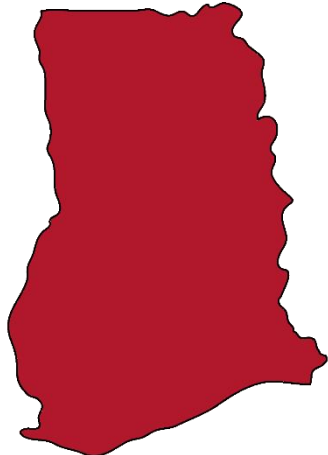
Dr Kuona is also an investigator in the UZ birth cohort study of perinatal HIV infection among 1,200 mother-baby pairs established in 2016. She acquired extensive outreach experience as the program lead of the "Lifesaving treatment of complicated severe acute malnutrition" project, a UNICEF-supported project on severe acute malnutrition implemented in 2019. Since 2016 she has served as a member of the National Health and Research Development Committee of the Medical Research Council of Zimbabwe.

She is a member of SIOP, the Paediatric Association of Zimbabwe (PAZ), the Zimbabwe Medical Association (ZIMA) Scientific committee and is in the National Validation Committee for elimination of maternal-to-child transmission of HIV and syphilis. She has completed a clinical fellowship in Paediatric



haematology oncology at Chris Hani Baragwanath Academic Hospital affiliated to the University of Witwatersrand (2020-2021) under the African Paediatric Fellowship Programme.

Attendees: Ghana



Dr Vivian Paintsil

vivpee@yahoo.com

Dr. Paintsil has over 21 years of Medical practice. She is a Senior Lecturer at the Department of Child Health, School of Medicine and Dentistry, Kwame Nkrumah University of Science and Technology (KNUST), Kumasi, Ghana and a Senior Specialist Paediatrician working at the Komfo Anokye Teaching Hospital (KATH) in Kumasi. She holds a Bachelor of Medicine and Surgery (MB ChB) from the School of Medical Sciences, KNUST and a postgraduate training in paediatrics from the West African College of Physician. She is a Fellow of the West Africa College of Physicians (Paediatrics) and the Ghana College of Physicians and Surgeons. She also holds a certificate in paediatric haem/oncology. Her work involves clinical care of paediatric cancer patients and others with haematological problems especially haemophilia and sickle cell disease at KATH. She has been involved with the newborn screening program for SCD in Kumasi. Over the last Fifteen years, she has gained extensive experience in undergraduate and postgraduate teaching and in research in Ghana. She is currently heading the Paediatric haem/oncology unit. She is involved with the SCD newborn screening project and the ORDISS project. She was the co-PI for SPARCO I for the Ghana site and in the SickleGen Africa project. She is also involved in ongoing clinical trials at KATH. She is the PI for the SIOP Wilms Tumour Africa Project at the Kumasi Site and part of the CANCaRe Africa consortium for paediatric oncology research and the medical oncology lead for the Kumasi City C/Can project



Mr Evans Xorse Amuzu

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Mr Xorse Amuzu is the Coordinator for the Ghana Sickle Pan-African Research Consortium (GHANA-SPARCO). He is a Health Research Officer with experience in managing hospital-based and community based observational and interventional studies. He currently coordinates SCD clinical research studies/trials in the Komfo Anokye Teaching Hospital. He also provides research design and management support to staff in their research projects and also training of other junior officers in research skills. Evans also has a special interest in Health Informatics and has designed and currently manages numerous databases being used in the collection of both cross-sectional and longitudinal studies cutting across several medical specialties.



Dr Eunice Agyeman Ahmed

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Dr. Ahmed is an adult haematologist working at the Komfo Anokye Teaching Hospital in Kumasi-Ghana. She did her medical training at Kwame Nkrumah University of Science and Technology, Kumasi, and her post-graduate training at the Ghana College Of Physicians and Surgeons in Accra. She has keen interest in sickle cell disease and blood transfusion. She strives to make a huge contribution to sickle cell disease care in Ghana and the whole of Africa. She loves to spend time with her family, playing tennis and sightseeing.



Dr Yaa Gyamfua Oppong-Mensah

lilquenda85@gmail.com

Yaa Gyamfua Oppong-Mensah, MD. MWACP, MGCPs, MBChB Pediatrician Specialist Current Institution: Komfo Anokye Teaching Hospital (KATH) Summary of Training and clinical interest Dr. Yaa Gyamfua Oppong-Mensah is a pediatrician with over eight years’ experience in working in child health. She has been working with the Komfo Anokye Hem-Oncology unit for the last four years and helps the unit to run the sickle cell clinic as well as the transition clinic for adolescents with sickle cell disease. She is currently pursuing a fellowship in General Pediatrics with a sub-specialization in Hem-Oncology. She earned her medical degree at the University of Ghana Medical School (UGMS) and her membership in pediatrics at the Komfo Anokye Teaching Hospital (KATH). She is member of the West African College of Physicians (MWACP) and also Ghana College of Physicians and Surgeons (MGCPs). She is also a fellow of the Sickle Pan-African Research Consortium (SPARCO II)-Ghana. She has devoted most of her practice to advocacy and education, empowering adolescents and up holding patient support groups. Her recent activities include being a facilitator at the SickKids-Ghana partnership with Ghana College of Nurses and Midwives training of health workers on sickle cell management. She is currently the Secretary of the Paediatric Society of Ghana, Ashanti-Chapter. Languages: English, French

Attendees: Mali



Dr Touré Boubacar Ali

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Physician at the Centre de Recherche et de Lutte contre la Drépanocytose. Head of consultation and hospitalization unit. Clinical manager of SPARCO Mali. Member of the Francophone African Society of Haematology and Malian Society of Haematology and Oncology.





Dr Sekou Kene

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Dr SEKOU KENE Clinical Hematology Responsible for the blood transfusion unit Responsible for transcranial doppler in sickle cell children Center for research and fight against sickle cell disease



Dr Yeya Dit Sadio Sarro

sadio@icermali.org

Coordinator of SickleInAfrica in Mali, Dr Sarro is an associate investigator at the Sickle cell disease centre in Bamako Mali (CRLD). As Pharmacist first and then Epidemiologist, he oversees data management in CRLD.

Dr Oumarou Tessougue

oumartessougue2013@yahoo.fr

Biologist Pharmacist

Attendees: Nigeria



Prof Maxwell Nwegbu

maxwell.nwegbu@uniabuja.edu.ng

Prof Nwegbu is a Professor of Chemical Pathology and the Head, Department of Chemical Pathology, College of Health Sciences, University of Abuja. He is also an honorary Consultant Chemical Pathologist, University of Abuja Teaching Hospital. An

alumnus of the College of Medicine, University of Nigeria, his post-graduate/specialist training was in laboratory medicine (Chemical Pathology sub-speciality), at University College Hospital, Ibadan, Oyo state, Nigeria. He is the recipient of the 2007 Awoonor-Reiner prize for best graduating Fellow (Laboratory Medicine), West African College of Physicians, Fellow of the Open Medical Institute, Austrian-American Foundation in Pathology and Global Health Fellow, Novartis Institute of Biomedical Research, Cambridge, Massachusetts. He leads the skills development working group in SPARC-NET and is currently the laboratory manager at the Centre of Excellence for Sickle Cell Disease Research and Training (CESRTA), University of Abuja. Prof Nwegbu is a coordinator of laboratory processes in a number of clinical trials and NIH grant-funded projects, as well as the North-Central Zonal coordinator of the Continuing -Professional Development/Medical Education (CPD/CME) of the Nigerian Medical Association.





Prof Samuel Asala

samuel.asala@yahoo.co.uk

Prof Asala is a Professor of Anatomy (Neuroscience and Forensic Anthropology). With 43 years of university teaching, research, and administrative experience in Nigeria, the United Kingdom, Japan, Zimbabwe, and South Africa. He was the Foundation Dean of the Faculty of Basic Medical Sciences and later Provost of the College of Health Sciences, University of Abuja. He was also the founding President of the Neuroscience Society of Nigeria, a subsidiary of the Society of Neuroscientists of Africa (SONA). His research experience began at the University of Sheffield where he obtained his PhD degree in Neuroanatomy in 1984. After a cumulative period of 7 years of teaching and research at the University of Medical and Dental Engineering, Tokyo, the University of Zimbabwe, and the University of the Witwatersrand he returned to Nigeria where he became the President and Fellow of the Anatomical Society of Nigeria and pioneered anatomy teaching and curriculum development in two Nigerian Universities. As Provost of the medical school, he provided significant support for the development of Sickle Cell research efforts and the ultimate establishment of the Centre for Sickle Cell Disease Research and Training (CESRTA) at the University of Abuja. He is currently serving on the Federative International Committee on the Support of Anatomy Professionals (FICSAP), a Committee of the International Federation of Associations of Anatomy (IFAA). He was recently appointed the Deputy Vice-Chancellor of the Abuja campus of the Margaret Lawrence University and Provost of the College of Medical Sciences of the University



Mr Ikechukwu Chianumba

reuben.chianumba@gmail.com

Mr Chianumba is very experienced and trained in the area of data management. Currently a postgraduate student in the department of Medical Biochemistry(M.Sc) University of Abuja, and a Big Data Research Fellow SPARCo Nigeria Hub. He has shown outstanding work ethics and dedication while handling the CONSA programme in the FCT. He is very proficient in the use of REDCap (Research Electronic Data Capture) online web application. He is also supporting other research activities ongoing in the Centre for Sickle Cell Disease Research and Training, University of Abuja (CESRTA), where his major responsibility involves data management



Professor Anazoeze Madu

anazoeze@gmail.com

"I have worked in the department of haematology and Immunology of the University of Nigeria teaching Hospital for the past 18 years, and have been involved in sickle cell research for the past 9 years. I have consistently been a Speaker/ Facilitator in the Haematology School, an annual update lecture series. I have also undertaken some hands-on laboratory research work of SNP analysis at the London Metropolitan University. I was part of the study on Omega-3 fatty acid trial in sickle cell and multi-modal therapy in sickle cell both carried out in the department. I have also carried and published some basic epidemiological research work showing the unique features of Nigerian sickle cell patients. I have also done some research work on use of interventional therapy (Omega 3) in sickle cell disease patients with intermediate cerebral vein flow velocity. I have been involved in the Sickle PanAfrican



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Research Consortium (SPARCO) UNTH Nigeria site recruitment and standard of care adoption in the last 4 years. These past research, collaboration and clinical work experience has armed me with the necessary capacity to work with SPARC-NET as a Site Lead for the University of Nigeria Teaching Hospital, Ituku Ozalla, Enugu State.”

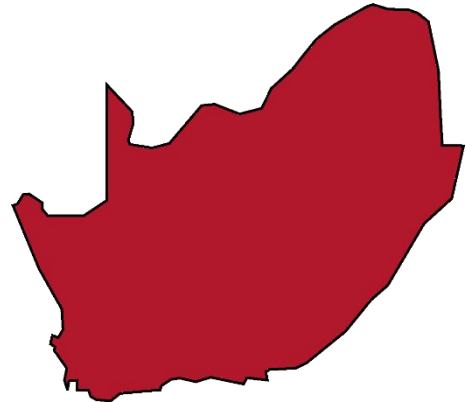
Dr Patrick Ohiani Moru
 morupatrick20@gmail.com

“...I’m a Medical Doctor and a Research Fellow at the Centre of Excellence for Sickle Cell Disease Research and Training (CESRTA) at the University of Abuja. I have certifications in Project Management (International Project), Integrated Disease Surveillance and Response (WHO AFRO), Leadership and Management in Global Health, and Human Clinical and Health Research Ethics. I also facilitate training, coordinating, and supporting ongoing Research projects and programs related to Sickle Cell Disease (SCD). Additionally, I play a crucial role in capacity building for SCD patients and caregivers, implementation of research protocols, and implementation of evidence-based health interventions for the management of SCD...”

Attendees: South Africa



Ms Paidamoyo Bodzo
 bdzpan001@myuct.ac.za
 Ms Bodzo is a junior health economist. She has an undergraduate degree in Economics and Statistics, an honours degree in Economics and is currently completing her Masters in Public Health specialising in Health Economics – all from UCT.



Mrs Jade Hotchkiss
 giant.plankton@gmail.com
 Jade Hotchkiss is the lead developer and curator for the Sickle Cell Disease Ontology (SCDO), amongst performing other tasks as an employee of the Sickle Africa Data Coordinating Centre (SADaCC), based at the University of Cape Town (UCT) in South Africa. She works remotely from her home in Kloof (KZN, South Africa) and travels for work as necessary. Her undergraduate background is in biochemistry and physiology. She has qualifications and work experience related to high school teaching and programming and research in the bioinformatics field. She also has work experience in software development quality control, documentation creation and editing, website development and maintenance, and graphic design. She is an avid learner of new skills, both professionally and as hobbies, and is interested in many different topics.



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Mr Mario Jonas
mario.jonas@uct.ac.za
Mr. Jonas' background in Bioinformatics, multi-disciplinary in nature, serves him well in supporting the research and functioning of SADaCC in particular and the SickleInAfrica Consortium in general. He finds satisfaction in enabling his colleagues to focus on their areas of expertise and he is passionate about capacity building and teaching.



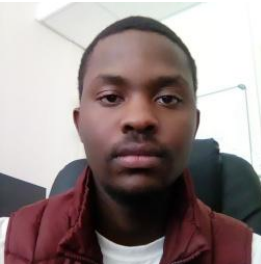
Ms Zimkita Magangana
kita.magangana@uct.ac.za
“..My name is Zimkita Magangana, I am an assistant administrator at the University of Cape Town, under the Human Genetics Division. I have an honours degree in Environmental Sciences from Walter Sisulu University...”



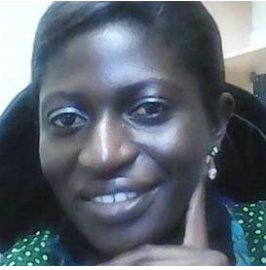
Mrs Teboho Malimabe
malimabeteboho@gmail.com
Mrs Malimabe is a research coordinator for SADaCC. She holds a Master of Science in Medicine (*cum laude*) from the University of the Witwatersrand, South Africa. She has previously worked as a Research Associate for Wits Research Institute For Malaria (WRIM) at the University of the Witwatersrand.



Dr Jack Morrice
jack.morrice@uct.ac.za
“...I am a data analyst for SADaCC. I support research projects across the consortium through consultation, hands-on analysis work, and the development of training materials and pipelines...”



Mr Wilson Mupfururirwa
mupfururirwawilson@gmail.com
Mr Mupfururirwa joined the SickleInAfrica Data Coordinating Centre (SADaCC) to assist with incorporating sustainable Data Management and information schemas/ or systems in their projects. His role is to find gaps in research which technology can fill. He is currently involved in implementing a mobile health application that will assist SCD management.



Dr Syntia Munung Nchangwi
nchangwisyntia@yahoo.com

Dr Nchangwi is interested in ethical and social issues in global health research.



Ms Chandre Oosterwyk
c.oosterwyk@gmail.com

Ms Oosterwyk received her BSc in Medical Bioscience and microbiology at the University of the Western Cape in 2018. In 2018 she completed her Honours degree in Human Genetics. Chandré recently completed her MSc (also in Human genetics) and is currently working as a laboratory technician for SADaCC.



Dr Kofi Anie (Consultant)
kofi.anie@nhs.net

Dr Anie is the Psychology Service Lead for children and adults with sickle cell disease and thalassaemia at London North West University Healthcare NHS Trust, affiliated with Imperial College London, and the Deputy Clinical Director of the West London Haemoglobinopathies Coordinating Centre, UK



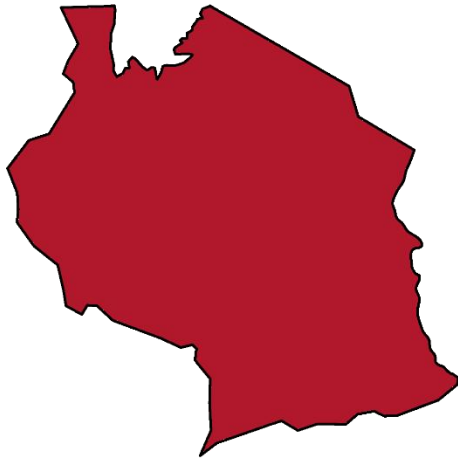
Dr Anie is a Fellow of the Royal Society of Medicine and Associate Fellow of the British Psychological Society. He has been involved in development of clinical guidelines and standards of care for sickle cell disease in the UK and Africa. Dr Anie is a collaborator on international initiatives including the West African Genetic Medicine Centre (WAGMC), the Ethics and Community Engagement Core Leader for the Sickle Cell Disease Genomics of Africa (SickleGenAfrica) Network, and SickleInAfrica Consultant. He was awarded with Member of the Order of the British Empire (MBE) for Services to People with Sickle Cell Disease and Thalassaemia in the 2017 Queen’s Birthday Honours.

Attendees: Tanzania



Dr Irene Minja
ikminja@blood.ac.tz

Dr. Minja is a Senior Lecturer in the Department of Restorative Dentistry at the Muhimbili University of Health and Allied Sciences. Her academic responsibilities include training of both undergraduate and postgraduate students. She is also a member of the Curriculum Committee, as well as Chair of Research and Publication Committee of the School of Dentistry. At University level, she is a coordinator of





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the Health Profession Educators? Group (HPEGs) and member of the Senate Research and Publication Committee, MUHAS. She has been involved in a number of research projects that have aimed to improve dental skills, treatment and outcomes in Tanzania. She developed an interest in sickle cell disease (SCD) due to the effects that the condition has on oral health. Currently, she is supervising a fellow in research to compare pulp blood flow in primary teeth in individuals with sickle cell disease and sickle cell trait with the aim of Improving Oral Care to people with Sickle Cell Disease in Dar es Salaam. Since 2018, she worked as the Skills Development Coordinator for the Sickle Pan-African Research Consortium (SPARCO) at Hub and Tanzania Site levels, to coordinate consortium efforts to develop curricula, organize and conduct short courses on sickle cell disease to healthcare workers and researchers with the aim of improving research skills and SCD care in Tanzania and across SSA. She is currently Co-PI and Skills Lead - SPARCO ? Clinical Coordinating Center, as well as Skills coordinator SPARCO ? Tanzania.



Dr Siana Nkya
snkyamtatiro@gmail.com

Dr Nkya is a Senior lecturer in the Department of Biochemistry, MUHAS. In 2015, Siana was involved in establishing a newborn screening programme for SCD. In 2018, Siana was nominated for the Women career scientists award Tanzania by Einstein Forum, She is a Fogarty Global Health Fellow (2016/2017) and an African Academy of Science affiliate (2018-2022) from Eastern Africa region. In 2018, Siana received inaugural ASH Global research award (2018-2020) and Early career fellowship (2019-2021) by the American Society of Hematology and the Organization for Women in Science for the Developing World, respectively, for conducting genomic research. Siana has also received the Emerging Global Leader Award, K43 from Fogarty, NIH. Due to her extensive research experience in sickle cell disease, Siana leads the research coordination for the SickleInAfrica consortium involving six African countries. Siana is a co-founder of the Tanzania Society of Human Genetics (TSHG) which was initiated in 2017. Dr Nkya has a background in Microbiology and Chemistry (BSc) and Molecular Biology (MSc). Siana has participated and led a number of Sickle Cell Disease (SCD) projects including the genetic research of SCD. The primary focus of her research has been the genetic determinants of fetal haemoglobin, a major SCD modifier. She established a genetic database of more than 1700 individuals with SCD and undertook the first Genome Wide Association Study (GWAS) analysis of an African population in collaboration with Wellcome Trust Sanger Institute. She then led the first next generation sequencing for individuals with extreme HbF levels. Her main areas of genetic research include diagnosis, disease modifying and monitoring, pharmacogenomics and gene based therapies.



Dr Ritah Mutagonda
rittdavisrida@yahoo.com

Dr. Mutagonda is a pharmacist and a lecturer for more than 10 years in the Department of Clinical Pharmacy and Pharmacology at the Muhimbili University of Health and Allied Sciences (MUHAS), Tanzania. She holds a PhD in Clinical Pharmacology and a Master?s degree in Pharmacology and Therapeutics from MUHAS through the Swedish International Development Cooperation Agency funding. Mutagonda?s research interests include the determination of the effectiveness and safety of the drugs used in the prevention and treatment of infectious diseases particularly malaria and HIV. She has expertise in pharmacokinetics, pharmacogenetics and pharmacodynamics studies. She has experience in cross-sectional, cohort and interventional study designs. She is a mentor and a research supervisor to



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postgraduate and undergraduate students and has co-authored several papers in peer-reviewed journals. She works as Malaria Chemoprophylaxis Study Lead for Sickle Pan Africa Research Consortium (SPARCO)-Tanzania.



Dr George Judicate Ndossi
judicategeorge@yahoo.com

Dr Judicate is a Medical doctor, Researcher and Lecturer passionate about improving the healthcare industry both locally and internationally, with demonstrated history of working in hospitals, research and teaching institutions. Proven ability in both hands-on and soft skills. Track record in working with donor-funded projects, grant applications, and publication of peer review journals.

Experienced team leader and ability to work independently and with people of diverse backgrounds to achieve intended outcomes.



Prof Paschal Ruggajo
prugajo@yahoo.com

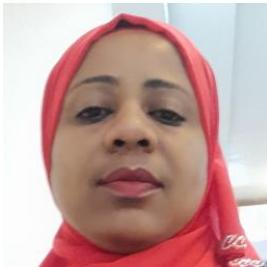
Prof Ruggajo is a seasoned Nephrologist and a pioneer in nephrology, nephropathology, kidney transplantation services and nephrology training program in Tanzania Mainland and Zanzibar. Dr Ruggajo has published his works in local, regional and international peer-reviewed scientific journals. His research interests include general nephrology, nephropathology, tropical nephrology, epidemiological outcomes, Developmental Origin of Health and Disease (DOHADs) Model, Sickle Cell Nephropathy, HIV & Kidney and Registry-based Studies. He is a Country Research Coordinator of the NIH/NHLBI-funded U01 HL156853 grant titled Sickle Pan African Research Consortium (SPARCO)-Tanzania, one of the independent awards in the larger SickleInAfrica Consortium involving Tanzania, Nigeria, Ghana, Mali, Uganda, Zimbabwe, Zambia and South Africa. In this domain, Prof Ruggajo exerts a laser-sharp focus on exploring the link between SCD and Kidney Diseases. Furthermore, he is an ardent community advocate against kidney diseases and sickle cell disease and an experienced member of the scientific committees in organizing local, regional and international. He is a frequent member and convener of various MoH Steering Committees for developing clinical guidelines, inspections, stewardship and quality assurance of health services in Tanzania. He is also a member of a number of local, regional and international medical & renal societies as well as the incumbent Vice President of the Nephrology Society of Tanzania (NESOT).



Dr Lulu Chirande
chirandelulu@yahoo.com

Dr. Chirande is a senior lecturer at Muhimbili University of Health and Allied Sciences (MUHAS) and a consultant Paediatric Hematologist and Oncologist at Muhimbili National Hospital (MNH). She is an educator and clinician with a passion to improve patient care through training and research. Dr. Lulu obtained her MD degree (2005) and MMED - Paediatrics and Child health (2011) from Muhimbili University of Health and Allied Sciences. In 2019 she completed two years of fellowship training in Paediatric Haematology and Oncology at Makerere University, Uganda in collaboration with the Global HOPE project of Baylor College of Medicine and Texas children hospital. She is the Director of the Global HOPE-MUHAS Paediatric Haematology and Oncology Program which aims at building capacity in the

management of children with cancer and blood disorders in Tanzania through sub-speciality training, supporting diagnostics and clinical care of patients as well as research. Dr. Lulu is the PI and National coordinator of the Consortium for Newborn Screening in Africa (CONSA), an American Society of Haematology (ASH) supported initiative for NBS in Sickle Cell Disease in Africa. Dr. Lulu also worked with SPARCO Tanzania and leads the NBS cross consortium study in Tanzania.



Dr Fadya Mohamed Hashimu

fadyashineni@hotmail.com

Dr Hashim is a Paediatrician, she holds Master of Medicine at University of Dodoma and Bachelor of Medicine and Bachelor of Surgery at International Medical and Technical University. She is a clinician working at the Sickle cell clinic in the Paediatric department at Mnazi Mmoja Hospital Zanzibar, Tanzania. She also works with Sickle Pan African Consortium (SPARCO Tanzania) as a clinician-Zanzibar satellite site.



Prof Eligius Francis Lyamuya

eligius_lyamuya@yahoo.com

Prof Lyamuya is a registered Medical Doctor in Tanzania since 1988 and an academic member of staff (currently a retired Professor of Microbiology and Immunology) at the Muhimbili University of Health and Allied Sciences (MUHAS). He obtained his MD and MMed (Microbiology) at the University of Dar es Salaam in 1985 and 1991, respectively and a PhD in Infectious Disease Control from the Karolinska Institute in Stockholm, Sweden in 2000. He is a Fellow of the Tanzania Academy of Sciences, and Fellow of the College of Pathologists of East, Central and Southern Africa and Editor in Chief of the Tanzania Medical Journal. He is passionately committed to academic and research mentorship of postgraduate students and junior faculty as well as promoting quality teaching and learning at MUHAS. Eligius is an active researcher, largely in the areas of HIV and other sexually transmitted infections; Immunology of infectious diseases; Molecular Epidemiology of bacterial pathogens; Antimicrobial chemotherapy; and promotion of research ethics. He is currently a Co-investigator in an ongoing HIV Vaccine trial; Co-investigator, Transforming Health Professions Education in Tanzania Project and MUHAS site PI Center for Innovation in Point-of-Care Technologies for HIV/AIDS at Northwestern University project. He has over 150 (119 PubMed accessible) scientific publications in peer-reviewed journals. He is an advisor for the SPARCO Tanzania



Ms Janeth Manongi

janethmanongi02@gmail.com

Ms Manongi is a program officer at the MUHAS Sickle Cell Programme and serves as the Head of Project Administration, Finance and Operations in Sickle Pan African Research Consortium (SPARCo) Clinical Coordinating Center (CCC). Janeth holds a Bachelor of International Relations and also possesses a Master's degree in Public Administration. She has over five years of experience in Human Resources, administrative activities, and project coordination. She has worked with Dar es Salaam Water and Sewerage Authority (DAWASA), Ando Roofing products, CRDB Bank Tanzania and is currently working with the MUHAS Sickle Cell Programme.



Ms Upendo Masamu

umasamu@blood.ac.tz

Ms. Masamu is a holder of Master of Statistics from the Katholieke Universiteit Leuven in Belgium and a Bachelor of Computer Science from University of Dar es Salaam. She works at Sickle Pan African Research Consortium (SPARCo) Clinical Coordinating Center Research and Data Coordinator at the Sickle Cell Program which is under the Department of Hematology of the Muhimbili University of Health and Allied Science (MUHAS). As research and data coordinator her main role includes coordinating all activities related to data and research implementation of center and consortium levels projects.



Ms Tunganega Matipa

tmatipa@blood.ac.tz

Ms. Matipa is a Business Administrator holding a Bachelor Degree of Business Administration (BBA) of Teofilo Kisanji University (TEKU). Ms. Tunganega currently serves as Admin & HR Officer for the Sickle Pan African Research Consortium (SPARCO) Tanzania at Sickle Cell Programme, Department of Haematology and Blood Transfusion, Muhimbili University of Health and Allied Sciences (MUHAS). In this position she contributes greatly to the project by Administration of daily project activities, handling all project Human Resource affairs to ensure positive working environment for project employees so as to increase their morale at work to attain project goals. She has experience in organizing events as she took part in the organizing committee of the 7th MUHAS University-wide Dissemination Symposium, which had great achievements including enhanced Hydroxyurea access to patients enrolled in all National Health Insurance Fund (NHIF) schemes. She contributes in project decision making as she takes part in all management meetings, Project Finance affairs including yearly project budget making as well as handling project petty cash for running daily project expenses. She also handles all project meetings including scheduling the meetings and sending reminders for the meetings to all project members.



Dr Bruno Mmbando

b.mmbando@yahoo.com

“...I am a Principal Research Scientist at the National Institute for Medical Research (NIMR) in Tanzania since June 2000, currently stationed at Tanga Centre. I also work with the Muhimbili Sickle Cell Programme (MSP) affiliated to the Muhimbili University of Health Sciences as a Statistician since 2012 as well as a visiting lecturer at the Kilimanjaro Christian Medical University College between 2002 and 2018. Some areas that I have worked on include malaria, HIV, Population studies, sickle cell disease, onchocerciasis and epilepsy. For the past 12 years I have been working partly with Muhimbili Sickle cell Programme looking at clinical epidemiology of patients with sickle cell disease. I am also a member of the Sickle Cell Pan-African Research Consortium, which working in seven Africa Countries. I am a Principal investigator a study assessing factors associated persistence of onchocerciasis and associated epilepsy in Mahenge area, Tanzania. Also, a co-Investigator in trials assessing the effectiveness of seasonal malaria chemoprophylaxis in children below five years, and assessing the impact of intermittent preventive treatment for malaria in school aged children in Tanzania. For the past 12 years, I provided mentorship for 15 (MSc and PhD) students of whom 13 have successfully completed their studies, while three are at



different stage of their studies. I have published over 87 publications in peer reviewed Journals...”

Attendees: Uganda



Dr Deogratias Munube
deomunube@gmail.com
 Dr Munube is a Consultant pediatrician/
 Paediatric Haematologist-Oncologist,
 Honorary Lecturer and PhD Fellow in the
 Department of Pediatrics and Child Health
 Mulago Hospital/Makerere University



Kampala. “...Over the last 8 years I have been involved in research in children with sickle cell disease evaluating children with stroke. I am currently completing my PhD in neurology with a focus on stroke in children with sickle cell anemia. My program is in under the larger MEPI-Neuro-linked NIH support for developing leaders in neurology in Uganda. In my project I am specifically looking at some risk factors for stroke in children with sickle cell anemia. I am currently in my final year of my project and want to use my experience gained to have a direct impact on this application. I have also completed a fellowship[training in Paediatric Haematology/Oncology under the Makerere University/Baylor College of Medicine HOPE program in East Africa. I am also a co-Investigator for BRAIN SAFE, with oversight responsibilities for the transcranial Doppler and clinical link to care in the SCA clinic. Currently I am undertaking a capacity building fellowship under the NURTURE grant of the College of Health Sciences. As part of my PhD training, I trained in Transcranial Doppler (TCD) recordings and have since undertaken additional training as part of the R21 capacity building program. Currently I am a Co-PI under the SPARCO Uganda program and lead on the Newborn Study under the consortium wide studies...”



Dr Ruth Namazzi
namazzi101@gmail.com
 Dr. Namazzi is a pediatrician and pediatric hematologist working at Makerere University College of Health Sciences/Mulago National Referral Hospital, Kampala,Uganda. My career goal is to reduce SCD morbidity and mortality through evidence based practices, research and training . I currently head the pediatric hematology and oncology fellowship training at Makerere University college of health Sciences and also give leadership to the SPARCO Uganda project.



Mrs Anna Namazzi
namazzianna78@yahoo.com
 Am called Anna Namazzi and I currently graduated with bachelors degree in human resource management at Makerere university business school. Am currently the project administrator for SPARCO Uganda I see myself attaining a masters in business administration five years from now with an aim of improving my administrative and project management skills.

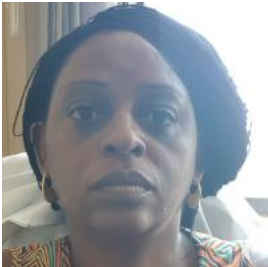


Mr Mike Nsubuga
nsubugamike021@gmail.com

Mr. Nsubuga is an IT Specialist at the African Centre of Excellence in Bioinformatics and Data-Intensive Sciences (ACE) within the Infectious Disease Institute (IDI) at Makerere University. He leads the software development branch of the ACE and is a specialist in Web, Mobile, and VR development. He is an IT consultant with IDEMS. International and has previously worked & undertaken training as a Fullstack developer at Stats4SD based in Reading, UK.

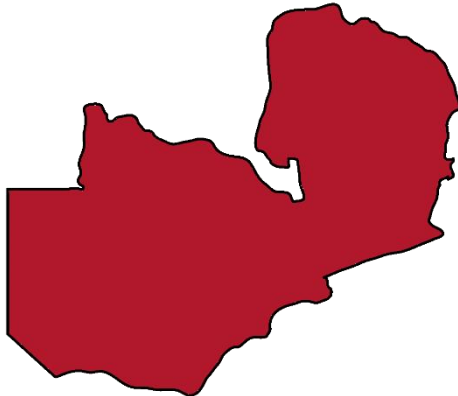
Mr Nsubuga is a graduate of Makerere University and holds a bachelor’s degree in Information Technology (First Class Honours), and an MSc Bioinformatics Fellow with EANBIT supported by FNIH under the H3Africa program. He has previously served as an IT consultant with the McKnight Foundation in Minnesota, US, and has keen interests in Bioinformatics tools and workflows, cloud computing, open-source computing, machine learning, and data science applications in biomedical research.

Attendees: Zambia



Dr Catherine Chunda Liyoka
catherinechunda@yahoo.co.uk

Consultant Paediatrician: Head of Paediatric Haematology Department at the University Teaching Hospitals-Childrens Hospitals; Honorary Lecturer at the University of Zambia and Apex Medical Universities, in the schools of Medicine; National Coordinator of Consortium for Newborn screening for SCD in Africa (CONSA); Chair of Taskforce for SCD in Zambia; CO-PI for SHAZ (SPARCO ZIMBABWE/ZAMBIA); PACT;TCD-COE.



Dr Natasha Mupeta Kaweme
tashkaweme@gmail.com

Dr. Natasha Kaweme (MBBS, MMED) is a specialist registrar in hematology at the University of Zambia Teaching Hospital with expertise in clinical hematology, hematology-pathology and conceptual training in genomics and genomic techniques. Natasha is an accomplished medical practitioner with over 9 years of experience. Natasha received her undergraduate training at Shanghai Jiao Tong University, School of Medicine and postgraduate training in Internal Medicine (Hematology) at Wuhan University. Her interest in research stems from the desire to resolve complex scientific questions and make a meaningful contribution to the lives of many. As a motivated and hardworking early career researcher her main objective is to understand the molecular and genomic aspects of leukemia and hemoglobinopathies, in particular sickle cell disease. Over the past year, Natasha underwent training in the application of Isoelectric Focusing, High-Performance Liquid Chromatography, and Agarose Hb electrophoresis for screening and diagnosing hemoglobinopathies. Among her achievements in her



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current role has been the development of training materials for the Gazelle device in qualitative and quantitative measurement of hemoglobin, facilitation of training, and coordinating outreach activities. Natasha has authored peer-reviewed articles and continues to broaden her research by exploring the molecular genomics of disease through advanced techniques such as DNA sequencing.



Mrs Cynthia Phiri
cynthiap900@gmail.com

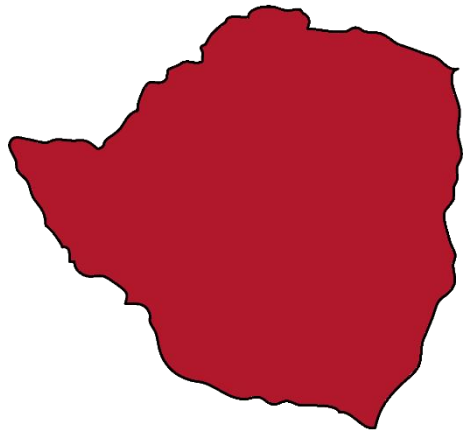
Cynthia Phiri is a versatile and motivated social scientist with a Bachelor of Arts degree in Sociology and Development Studies, 7 years' experience in data analysis, research, project management and monitoring and evaluation. Who takes pleasure in working on a variety of projects and solving innovative problems, and who is highly skilled at creating qualitative research questionnaires, running focus groups, and conducting in-depth interviews. She made a significant contribution to ensuring that people from less privileged backgrounds in Zambia had access to HIV treatments and took part in more cutting-edge health improvement initiatives. Cynthia Phiri is currently contributing to the sickle cell community through various roles on various projects such as the SickleIn Africa, CONSA newborn screening and Patient centred sickle cell disease management in Sub-Saharan Arica (PACT).

Attendees: Zimbabwe



Dr Takudzwa Chagumaira
takudzwamtisi@gmail.com

Dr Chagumaira is a Medical Research Scientist with more than ten years' experience in laboratory diagnostics, quality systems management, medical research, project management and coordination with cumulative expertise in setting up organisational systems and operational procedures. Her work has transitioned through full-time clinical laboratory practice, research and implementation science, culminating in her role as Project Coordinator within the University of Zimbabwe (UZ). Dr Chagumaira holds a BSc in Medical Laboratory Sciences and an MSc in Medical Microbiology from UZ, and a Masters in Public Health from Maseno University.



Prior to joining the university in 2015, she worked at the National Microbiology Reference Laboratory, Ministry of Health and Child Care, and she has significant experience in developing project protocols and implementation tools. Her main role in Sickle Hemoglobinopathy reseArch in Zimbabwe (SHAZ) to provide overall day-to-day management and ensure successful study implementation.



Dr Ian Ruredzo
imachingura@yahoo.co.uk

Senior Lecturer and current Chairman in the Department of Laboratory Diagnostic and Investigative Sciences, University of Zimbabwe. He teaches Clinical Biochemistry, his research interest is in Non-communicable diseases and Health Systems Strengthening. He is a founding member and current Chairman of the PublicHealth.Africa and Africa Consortium on Laboratory Systems Strengthening.

He is an Investigator in Sickle Haemoglobinopathy research in Zimbabwe.



Dr Lawson Takawira Chikara
chikaralaw@gmail.com

“...I am a 34 year old male specialist Paediatrician in Zimbabwe, currently working as a research fellow at SHAZ which is part of The Sickle in Africa consortium. I am passionate about research and publishing...”

Guests



Mrs Leda Sweerts
leda.sweerts@terumobct.com

“...I was born in South Africa and currently live in the Netherlands. I work for Terumo Blood and Cell Technologies. My role currently is a global strategic clinical marketing manager, and I have a particular focus on Sickle cell disease strategies globally. I am interested in connecting with external stakeholders who have also



involved Newborn screening programs in Africa to discuss initiatives currently underway in SSA. I look forward to attending the congress in person...”

Thank you everyone for your attendance and support

