

# Sickle In Africa

## Newsletter Issue 1 – Dec 2017

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### Editorial

This is the inaugural issue of *Sickle In Africa*, a bi-annual Newsletter for the Sickle Africa Data Coordinating Center (SADaCC), Sickle Pan African Research Consortium (SPARCO) and the Sickle Pan-African Network (SPAN). *Sickle In Africa* aims to keep members and stakeholders aware of progress, achievements and upcoming events within SADaCC, SPARCO, SPAN and other partners such as SickleGenAfrica. A brief background to SADaCC and SPARCO is given in the next paragraph.

Sickle Cell Disease (SCD) is most common in individuals from or with ancestry from sub-Saharan Africa; South or Central America (particularly Panama), Caribbean islands, Mediterranean countries (Greece, Turkey, and Italy), India and Saudi Arabia. Sub-Saharan Africa carries the largest SCD burden, this region contributes approximately 64% of live SCD births globally. Despite Sub-Saharan African countries being the hardest hit by SCD, they lack proper management strategies for SCD mainly due to a failure to implement national control systems and lack of funding and resources allocated to research<sup>1</sup>. Most of the progress on the pathophysiology of SCD has been established in high income countries in Europe and the United States of America, where the prevalence of SCD is much lower. To this end, the NIH recently funded the establishment of SPARCO which is coordinated from a hub in Tanzania. SPARCO aims to develop research capacity for SCD through a multidimensional approach which addresses infrastructure; education & training, provision of longitudinal research data; the translation of research into practise and the inclusion of new African sites through SPAN<sup>1</sup>. To facilitate data standardization, integration and coordination across the three SPARCO sites in Tanzania, Ghana and Nigeria, NIH concurrently funded SADaCC<sup>1</sup>.

This newsletter will be an informal reporting tool of our milestones to various stakeholders including the funders and for our own internal recording keeping. This issue has sections briefly described below which we hope will be regular features of our newsletter. **Featured Articles:** This section will highlight newsworthy events happening at the various SPARCO sites, SADaCC, SPAN and other stakeholders. **Behind the Scenes:** This will highlight personnel profiles from across the consortia. **Brag Board:** Awards, promotions, achievements and publications from any of the consortia members. **Working Groups:** A significant portion of the SPARCO and SADaCC activities are led and implemented through working groups. In each issue of *Sickle In Africa* working groups will outline achievements, lessons and plans for the next reporting period. The working groups are: **Skills; Clinical Guidelines; Database & Research.**

We welcome feedback and suggestions to improve this newsletter. We look forward to your continued support, articles and input.

Best Regards,  
SADaCC and SPARCO Hub

<sup>1</sup>Makani, J. et al., 2017. Sickle cell disease: tipping the balance of genomic research to catalyse discoveries in Africa. *Lancet* (London, England), 389(10087), pp.2355–2358. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/28635598> [Accessed October 25, 2017].

## Featured Articles

### **1<sup>st</sup> SADaCC and SPARCO Consortium Meeting**

#### *SADaCC Core & SPARCO Hub*

The first SADaCC and SPARCO Consortium meeting was held in Dar es Salaam, Tanzania and was attended by 30 participants with one participant joining remotely from the US via Skype (whenever the network allowed). The main aim of this 1st SADaCC & SPARCO consortium meeting was optimization of SPARCO and SADaCC implementation plans with the following objectives: a) To review and adjust the project's milestones and work-plans based on feedback from representatives from all collaborating sites; b) To collect baseline data and conduct a formative assessment of the current status of each site and use this data to adapt the project plan accordingly and for future evaluations; c) To initiate sustainability plans.



***Participants of the 1<sup>st</sup> SPARCO & SADaCC Consortium Meeting, Dar es Salaam, Tanzania, 3-4 December 2017***

The NIH, like most funders, requires potential grantees to submit comprehensive proposals with detailed work-plans. However, such proposals are prone to biases and weaknesses which although unintended, may decrease the suitability of the implementation plans to the project sites or needs. Implementation plans are traditionally drafted by a few select lead authors mainly to meet grant funding deadlines, which leaves limited time to gather input from other key stakeholders or set realistic milestones. In addition, such implementation plans may contain outdated milestones since there is usually a lag between submission of grant applications and project initiation.

**Day 1:** 3rd November. An overview of the SADaCC and SPARCO projects were presented. Stakeholders with initiatives which the projects could learn from also presented their work, this included RED II (Anna Barbara, Brazil), H3ABioNet (Nicola Mulder, South Africa), Cancer Research Institute in Genoa (Luccio Luzzatto, Tanzania) and the University of Cape Town, Clinical Research Center (Delva Shamley and Annemie Stewart, South Africa). The working sub-groups discussed their deliverables and presented these to the group.

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**Participants during sessions.**

**Day 2:** The 3rd of November saw key research and activities relevant to SPARCO and SAdACC presented and discussed. These included a review of Sickle Cell Disease Registries (Vicky Nembaware), Data management and SPARCO Data Elements (Raphael Sangeda), Data Sharing & Consent (Syntia Nchangwi), Standards of Care (Kwaku Ohene-Frempong), Planning Research (Andre Pascal), Training and Symposiums (Obiageli Nnodu). Various discussions around sustainability, branding and governance issues were also initiated. Solomon Ofori-Acquah also gave an inaugural presentation on SickleGenAfrica.

**Feedback:** Thanks to the planning team which was made up of members from SAdACC and the SPARCO hub. Gabby Emjedi went an extra mile by staying awake on the last day to say farewell to all the guests. It was also great having local administrative and IT support from Frank Makundi. A big thank you to Mario Jonas for managing the presentations. Based on the evaluation form circulated after the meeting, participants were satisfied with the logistics and planning of the meeting. Most requested that the meeting be at least 3 or 4 days instead of the 2 days. Other suggestions included asking the presenters to send outlines of their talks before the meeting to the organisers to make ensure that the meeting objectives were met. Most participants enjoyed the social event which was held at the end of the meeting.

### **SPARCO Nigeria Site: Conducts Hemo Type SC™ Trial**

**Obiageli Nnodu**

HemoTypeSC™, is a novel rapid point of care test that uses a lateral flow immunoassay method to detect the presence of HbA, HbS, and HbC with monoclonal antibodies that have very low limits of detection for HbA, HbS, and HbC antigens. These antibodies are blind to HbF, and so even newborns with elevated HbF and low levels of HbA or HbS will be accurately diagnosed. Developed by Silver Lake Corporation, California, USA, HemoTypeSC™ was designed to cater for limited-resource settings and is therefore rapid and affordable. The SPARCO Nigeria Site coordinated an implementation trial of this diagnostic test by Silver Lake Corporation in primary health care centres in the six geopolitical regions across Nigeria.

## **SPARCO Nigeria Site Contributing SCD in the World Health Organization Package of Essential Non-Communicable Disease Interventions for Primary Health Care (WHO PEN)**

**Obiageli Nnodu**

Members of the SPARCO Nigeria Site were part of a team of experts who met to include SCD in the World Health Organization Package of Essential Non-Communicable Diseases Interventions for Primary Health Care (WHO PEN). The inclusion of SCD in WHO PEN is an important development because it includes newborn screening and interventions for screen detected babies. This expert meeting happened in Abuja, Nigeria.



***Participants of the Experts Meeting in Abuja who included SCD in the WHO Package of Essential Non-Communicable Diseases Interventions for Primary Health Care (WHO PEN) in Nigeria***

## **SADaCC Co-Facilitating Launch of First SCD Support Group in South Africa**

***Nakita Laing, Ambroise Wonkam***

SADaCC in collaboration with the Genetic Counselling Department at the University of Cape Town recently hosted the Hughes family and their friends from the United States of America on the 13th and 14th of November 2017. The entourage included Mr. Hassan and Mrs. TaLana Hughes, their eldest daughter Hasana, son Hassan, daughter Tianha. Tianha was also accompanied by her friend India. Tianha is living with Sickle Cell Disease (SCD) and is a Child Ambassador of SCD in the United States. She promotes awareness of the disease where 1 in 13 babies born to people of African descent has SCD. TaLana is also an advocate for families affected by SCD and together with Tianha aim to foster a community-based network for people and their families who are affected. The "Make a wish" foundation in the USA sponsored the trip for Tianha and her family as Tianha's wish was to visit Cape Town and meet other SCD patients and their families. Nakita, a Genetic Counsellor tasked with planning this visit under the supervision of Prof Wonkam put together a two-day schedule for the Hughes Family.

Nakita together with the Genetic Counsellors took this opportunity to bring together SCD patients and their families to launch a support group for SCD patients and their families in

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Cape Town. On the first day, Prof Wonkam opened the session with a presentation of ongoing SCD research in his group. This presentation was followed by the SCD patients and families then shared their experiences of living with SCD. The second day was held at the Red Cross Children's hospital. The families of pediatric SCD patients were encouraged and motivated by meeting adult patients. While a formal support group is yet to be established, a Whatsapp group for consenting SCD patients and their families based in Cape Town was created as a result of these meetings.



*SCD patients and Prof Ambrose Wonkam meeting the Hughes Family.*

### **SPARCO Tanzania Site: Launch of Sickle Cell Disease Health Passport**

*Furahini Tluway*

The Sickle Cell Disease Health Passport was developed with the aim of empowering patients to have ownership of their medical records. The passport contains patients' socio-demographic information as well as records of hospital visits. The passport was developed in collaboration with Tanzania Sickle Cell Disease Patient Community, led by Arafa Salim. The passport has been adopted by the Ministry of Health as a National document. It was officially launched on the 19<sup>th</sup> of June 2017 as part of the World Sickle Cell Day commemorations, held in Dar es Salaam, Tanzania. The distribution of the passport has started in Dar es Salaam regional Hospitals.



*Launch of the SCD passport*

## **Behind the Scenes**

### **SADaCC PI and Co-Investigator**



**Prof. Wonkam, Ambroise**  
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Prof Ambroise Wonkam is a specialist medical geneticist, in the Division of Human Genetics, Faculty of Health Sciences, University of Cape Town (UCT), South Africa. After MD training at 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 highly reputable genetics department in Geneva (Switzerland). He subsequently practiced medical genetics in both European and African contexts. His research interests are reflected in more than 100 peer-reviewed publications, in molecular, clinical, educational and ethical aspects of medical and human genetics. His research focuses on: 1) Psychosocial Burden and Genomics modifiers of Sickle Cell Disease (SCD); 2) Genetics of hearing loss, and 3) Ethical and educational Issues in human genetics in Africa. He is member of the steering committee of the H3Africa consortium, leading specifically the NIH/NHGRI funded SCD project. He was recently awarded an NIH/NHLBI grant worth 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 secretary 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 Genetic Medicine Collaborative (G2MC).

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**Prof Mulder, Nicola**  
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Prof Mulder heads the Computational Biology Division (CBIO) at UCT. She 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 European Bioinformatics Institute (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 group, 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.

## **SPARCO PI and Co-PIs**



**Prof Makani, Julie**  
SPARCO PI  
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Julie Makani is Associate Professor in the Department of Haematology and Blood Transfusion at Muhimbili University of Health and Allied Sciences (MUHAS) the main clinical, academic and research centre in Tanzania. Tanzania has recognised sickle cell disease (SCD), as a major public health problem and it has been included as a priority condition in the national strategy for Non-Communicable Diseases in the Ministry of Health. With global partnerships, Muhimbili has developed a systematic framework for comprehensive research that is integrated into healthcare, advocacy and education. With prospective surveillance (2004 – 2016) of over 5,000 SCD patients; this is one of the largest single-center, SCD research programs in the world. Scientific themes include clinical research, biomedical research (including genomics) and public health [including ethics, social/behavioral science, population health and health policy]. The aim is to use SCD as a model to establish scientific and healthcare solutions in Africa that are locally relevant and globally significant. Julie trained in Medicine (Tanzania) and Internal Medicine (UK), and completed her PhD in clinical epidemiology of SCD. She is a consultant physician at Muhimbili National Hospital <http://www.mnh.or.tz/>, and honorary visiting research fellow in the Nuffield department of clinical medicine, University of Oxford [www.ndm.ox.ac.uk/researcher/juliemakani](http://www.ndm.ox.ac.uk/researcher/juliemakani). She has held a Commonwealth Scholarship for post graduate studies in London and training (2003) and intermediate fellowships (2011) from the Wellcome Trust and Tutu Leadership Fellowship (2009) [www.alinstitute.org](http://www.alinstitute.org). She received the 2011 Royal Society Pfizer Award for her work in using anaemia in SCD as a model of translating genetic research into health benefit <http://www.youtube.com/watch?v=sd17odE1YLs>. She is a Fellow of Royal College of Physicians of United Kingdom and Tanzania Academy of Sciences.

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**Prof Nnodu, Obiageli**  
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*University of Abuja, Abuja, Nigeria.*

Prof. Obiageli Nnodu is Professor of Haematology and Blood Transfusion, Director, Centre for Sickle Cell Disease Research and Training University of Abuja (CESRTA), Honorary Consultant Haematologist, University of Abuja Teaching Hospital Gwagwalada, Abuja, Nigeria and Country PI for the Sickle Pan African Research Consortium (SPARCO). She graduated in 1982 and obtained the Fellowship of the West African College of Physicians in 1992. Thereafter she received the United Kingdom Chevening Scholarship, World Pathology Foundation Fellowship, and several UICC Fellowships for early detection and diagnosis and cancer prevention at Imperial college of Medicine, London, Karolinska Hospital, Stockholm, Sweden, University hospital, Lund and the National Cancer Institute, Bethesda, USA. In 2010, she helped articulate a strategy for the control of sickle cell disease (SCD) in Nigeria and became a founding member of Sickle CHARTA. As Vice Chair of the Nigerian Sickle Cell Support Society (which works with the government and professional groups for the control of SCD in Nigeria), she is responsible for most of the in-country activities of the Network. She serves on technical committees for the government on non-communicable diseases and has completed a number of national assignments related to SCD. She has NIH- funded clinical trial trainings and experience in the following clinical trials: Clexane, Cutenox AKBM094-H as Co-PI, PI and National -PI respectively. Professor Nnodu possesses significant strategic planning and capacity building skills and has coordinated a number of multi disciplinary, multi-institutional and community based research projects including the DFID funded DeLPHE Project. She is a member of the American Society of Hematology African Newborn Screening and Early Intervention Consortium and is a Site Lead for H3Africa SickleGenAfrica Consortium.



**Dr Paintsil, Vivian**  
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*KNUST, Ghana*

Dr (Mrs.) Vivian Paintsil is a Specialist Paediatrician at the Child Health Directorate of the Komfo Anokye Teaching Hospital. She has been taking care of children with sickle cell for the past 13 years. Her work involves clinical care of paediatric sickle cell patients at the Komfo Anokye Teaching Hospital which is a tertiary referral center in Ghana. She is in charge of training at the sickle cell clinic. She has gained extensive experience in undergraduate and postgraduate teaching and in clinical research. She was involved in the Newborn Screening for SCD patients in Kumasi. She is currently the Principal Investigator in the longitudinal study 'Organ damage in sickle cell disease study' in which children from birth to 15 years are monitored closely and all acute illness.

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**Prof. Osei-Akoto, Alex**

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Prof. Alex Osei-Akoto is an Associate Professor in the Department of Child Health at the School of Medical Sciences of the Kwame Nkrumah University of Science and Technology and an Honorary Consultant Paediatrician at the Child Health Directorate of the Komfo Anokye Teaching Hospital, in Kumasi. He has worked in the Sickle cell clinical program in the hospital since 1993 and has contributed to the success of the Newborn Screening program in the hospital since 1995. He coordinates the clinical services at the Paediatric sickle cell clinic of the Kumasi Centre for Sickle Cell Disease (KC-SCD) at the Komfo Anokye Teaching Hospital, a tertiary referral center in Ghana. He has been involved in the training of both undergraduate students and paediatric residents in the hospital. He has been involved in many clinical research works in the department in sickle cell as well as in Malaria and was part of the Malaria vaccine Trial study team at the Agogo Trial Site. He graduated from the Kwame Nkrumah University of Science School of Medical Sciences and went on to obtain the Fellowship in Paediatrics of the West African College of Physicians. He has served on some technical committees for the Ministry of Health and Ghana Health Service. He is a member of the American Society of Hematology African Newborn Screening and Early Intervention Consortium



**Dr Balandya, Emmanuel**

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*MUHAS, Dar es Salaam, Tanzania*

Emmanuel Balandya MD, PhD is a physician-scientist with medical, doctoral and post-doctoral training. He obtained his MD at the University of Dar-es-salaam in Tanzania in 2005. Since 2007, he has been faculty at the School of Medicine, Muhimbili University of Health and Allied Sciences (MUHAS) in Tanzania. He was awarded the prestigious NIH AITRP-Fogarty Fellowship in 2008 to pursue Doctor of Philosophy (PhD) studies at Dartmouth College in the United States and graduated in 2012. He subsequently joined the Center for Virology and Vaccine Research, Beth Israel Deaconess Medical Center, Harvard Medical School as a post-doctoral research fellow between 2012-2014. With a Fogarty Global Health Fellowship supported by the National Heart, Lung and Blood Institute (NHLBI), Fogarty and the University of California Global Health Institute (UCGHI) he returned to MUHAS and focused his research on the role played by T and B lymphocytes in the immunity of children with sickle cell anemia in Tanzania. Dr. Balandya has a solid background in immunology, vaccinology and advanced biomedical physiology, and has

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contributed in the fields of mucosal immunology, primary HIV transmission, HIV vaccine development and immunity in sickle cell anemia. He is currently the Tanzanian PI for SPARCO and Acting Director, Directorate of Postgraduate studies at MUHAS.

### Working Groups

SPARCO has five working groups that have a clear mandate and deliverables based on their focus areas. These groups include: **Management:** Chair-Furahini Tluway; **Standards of Care:** Chair-Kwaku Ohene-Frempong; **Database Development and Registry:** Chair-Raphael Sangeda; **Skills development:** Chair-Obiageli Nnodu and **Research planning:** Chair-Julie Makani. During this first quarter, the working groups reviewed and adjusted their deliverables. The 1<sup>st</sup> SPARCO & SADaCC consortium meeting was a great opportunity for the Chairs to meet working group members and discuss work plans face to face. In the next edition, the working groups will give detailed outlines of their plans, activities, lessons and achievements.

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This Brag Board features news in brief from various sites as a way to celebrate achievements from across the consortium and beyond.

Area	Announcements
Recruitment of Core Staff	<ul style="list-style-type: none"> <li>SADaCC is yet to recruit a Database Manager, Developer.</li> <li>A Data Coordinator was recently recruited for the GHANA SPARCO site – Mr Isaac Nyanor, welcome onboard Isaac!</li> <li>Dr Hezekiah Isa was recently recruited as Site Coordinator for Nigeria.</li> </ul>
Career Progressions	<ul style="list-style-type: none"> <li>Abel Makubi from the Tanzania SPARCO site was promoted to a hospital Executive Director of Bugando Referral Hospital.</li> <li>Magdalena Lyimo also from the Tanzania SPARCO site was recently appointed to head the national Blood Transfusion Services (NBTS)</li> </ul>
Training	<ul style="list-style-type: none"> <li>Mario Jonas from SADaCC recently attended a week-long R short course at Stellenbosch University.</li> <li>Drs. Maxwell Nwegbu and Toyin Babalola from SPARCO Nigeria Site attended the 2017 NIBR Global Health Fellowship facilitated by Professor Funmi Olopade</li> <li>Prof Kwaku Ohene-Frempong connected SADaCC and SPARCO to the 2018 NIBR Global Health Fellowship Program. Selection will happen in 2018.</li> </ul>
Presentations	<ul style="list-style-type: none"> <li>Professor Obiageli Nnodu presented SPARCO and SPAN at the Nigerian SCD Network Conference in August 2017</li> <li>Prof Ambroise Wonkam presented SADaCC at the African Society of Human Genetics Meeting in Cairo – November 2017</li> </ul>
Achievements and Awards	<ul style="list-style-type: none"> <li>Prof Ambroise Wonkam was given a recognition award for his contribution to the African Society of Human Genetics in Cairo.</li> <li>Prof Ambroise Wonkam is now an Associate Editor of the American Journal of Medical Genetics.</li> </ul>
Networking Engagements &	<ul style="list-style-type: none"> <li>SADaCC helped facilitate the establishment of a Sickle Cell support group in Cape Town, South Africa.</li> <li>Prof Julie Makani organized an informal meeting with ASH and HOSA members at the American Association of Hematology Conference–December, 2017 to introduce SADaCC and SPAN.</li> </ul>