**ELSI Friday Forum**

**Friday, May 10, 2024 12-1 PM ET US**

**Session Title:**

***Patients as Partners in Sickle Cell Disease Research in Africa: Ethos, Challenges and Lessons Learned***

**Date and time:** Friday, May 10, 2024 | 12pm ET US / 9am PT US

**Moderator:** Tabia Henry Akintobi, PhD, MPH

**Speakers:**

* Ms Arafa Salim Said, Founder, Sickle Cell Disease Patients Community of Tanzania,
* Ms Nabeelah Peerbhai, Executive Director, Sickle South Africa Support Group
* Ms Nchangwi Syntia Munung, Bioethics Researcher, University of Cape Town

**CERA Representative:** Maya Sabatello, LLB, PhD

**Biographies**

**Moderator:** Tabia Henry Akintobi, PhD, MPH

**Tabia Henry Akintobi, PhD, MPH** is Professor and Chair of Community Health at Morehouse School of Medicine (MSM). She is a globally sought health equity champion and social behavioral scientist, leading, or collaborating in the implementation of translational research and participatory evaluations that address health disparities and advance community or population health transformation. She also serves as Principal Investigator of the Morehouse School of Medicine Prevention Research Center, MSM’s institutionally designated community-based participatory research center. She is an extensively published contributor to the peer reviewed literature and co-author of texts including *The Morehouse Model: How School of Medicine, Revolutionized Community Engagement and Health Equity* and the *Principles of Community Engagement Primer*. As Associate Dean for Community Engagement, she advances efforts to promote and strengthen effective community-campus partnerships. Her work is guided by training in public health social epidemiology, social marketing, community-based participatory research, and evaluation.

***Link to Dr. Akintobi’s Biography:*** <https://www.msm.edu/about_us/FacultyDirectory/CommunityHealthPreventiveMedicine/TabiaAkintobi/index.php>

**Panelist:** Ms Arafa Salim Said

Ms Arafa Salim Said is the Founder and Executive Director of the Sickle Cell Disease Patient Community of Tanzania, an organization whose objective is to spread the word to the community and give hope to other patients living with Sickle Cell Disease. Through her advcacy project he has worked closely with SCD research projects to support engagement. She has received training in genetic counseling.

***Link to Ms Said’s Biography:*** <https://www.onescdvoice.com/people/arafa-salim-said/>

**Panelist:** Ms Nabeelah Peerbhai

Ms Nabeelah Peerbhai is a Genetic Counseling Intern at the University of Cape Town, South Africa. She holds an undergraduate qualification in Biochemistry and Psychology and completed her Honors in Human Genetics at the University of Witwatersrand. In addition to her academic qualifications, she is actively involved in patient advocacy with Rare Diseases SA and the Sickle Cell SA support group.

***Link to Ms Peerbhai’s Biography***: <https://www.ichg2023.com/ms-nabeelah-peerbhai/>

**Panelist:** MsNchangwi Syntia Munung

Nchangwi Syntia Munung is a Bioethics Researcher at the Faculty of Health Sciences, University of Cape Town, South Africa. Nchangwi is interested in ethical and social issues in health research. She is currently involved in research related to the equitable governance of global health research consortia. Key areas: Justice, fairness and equity in health research.

***Link to Ms Munung’s Biography:*** <https://www.sickleinafrica.org/article/84>

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