

### Meeting Information

**Science Summit at the United Nations General Assembly (UNGA)**  
**Sickle Cell Disease: Gene Therapy to Improve Health and Cure Disease**  
**Date: Thursday, 21 September 2023. 930am – 1230pm EDT**  
**Venue: Dar-es-Salaam, New York, London, Bangui**

#### Introduction

Achieving the Sustainable Development Goals (SDGs) for health in many countries in Africa will include addressing sickle cell disease (SCD), a chronic non-communicable disorder (NCD). Africa is the epicenter of the disease burden: an estimated 80% of patients live in Africa and more than 300,000 new babies with SCD are born on the continent each year. Historically, health systems in many regions have been ill-equipped to provide optimal preventative and therapeutic healthcare over the life-course of patients with SCD. The result has been high rates of mortality and severe morbidity beginning in early childhood. In this context, the current era of scientific innovation holds promise for helping patients, health workers, policy makers, and other stakeholders to make a sustained impact on population health as it relates to SCD.

Some of the most significant advances in science have been in genomics with the completion of the Human Genome Project in 2003 and Gene Editing, with recognition of the latter by the Nobel Prize in 2020 to Jennifer Doudna and Emmanuelle Charpentier. The translation of genomic science to improve health has resulted in clinical trials with cure of sickle cell disease using gene therapy. This has led to an increase in investment and interest from key stakeholders, particularly the patient community, as well as discussion to ensure equity and access to these interventions, as well as integration within the existing interventions and health systems.

Tanzania convened a sickle cell Session in 2022 at the Science Summit at UNGA [click this link for more details](#). For 2023, this Thematic Session will focus on four areas: (1) State of health of Sickle Cell Disease at national, regional, and global level. (2) Progress in Science and Technology with impact on improving health and curing sickle cell disease. (3) Partnerships in health and science to integrate and leverage progress in different sectors. (4) science policy and science investment that is required to ensure universal access to research and health. The focus will be on sickle cell disease. The main goal is to develop strategies to improve health in sickle cell disease through the generation and application of scientific knowledge.

Tanzania Academy of Sciences <https://www.taas-online.or.tz/> will convene this thematic session. Partners will include African Leadership Institute (AfLI) <https://alainstitute.org/>, Muhimbili University of Health & Allied Sciences (MUHAS) <https://www.muhas.ac.tz/>, SickleInAfrica <https://www.sickleinafrica.org/>. Other partners will include Institut Pasteur de Bangui <https://pasteur-banqui.org/>, Tanzania UK Health Diaspora Alliance (TUHEDA). Government of Tanzania: Embassy of Tanzania to USA and Permanent Representative to the United Nations, Ministries: Foreign Affairs, Health, Education, Science & Technology.

The event speakers will feature national and global leaders in SCD-focused biomedical research, and health. The event will serve to educate a diverse audience of stakeholders on current research efforts underway and to foster dialogue that will inform strategies for accelerating SCD-focused science, promoting development of research infrastructure through partnership with global partners, and assuring sustainability of science in improving health of SCD in Africa and globally.

## Tanzania Academy of Sciences

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### Objectives

The session will:

- Educate stakeholders on state of Sickle Cell Disease with regards to health. This session will provide an overview of the public health magnitude of disease and outline the progress made at global, regional and national level. With both immediate and long-term implications for improving health outcomes.
- Outline the significant progress in science and technology in genomics, gene editing and gene therapy. This session will provide examples of how these advances have launched tremendous potential in, not only improving health, but curing diseases.
- Discuss successful partnerships in science and technology which have transformed health. This session will recommend pragmatic approaches to multi-sectoral and cross-sectoral collaboration that will maximize the quantity and quality of research to address SCD in Africa with an emphasis on conducting research in Africa.
- Recommend Policy and Investment strategies that will facilitate universal access to existing and new technologies.  
Outline how the output of basic biomedical science, including the elucidation of genetic underpinnings of disease, will translate to improved health care. Showcase current efforts to discover definitive gene therapy cures for SCD and explore the anticipated enablers and barriers to achieving widespread access for patients in Africa.

### Target audience

Multi-disciplinary stakeholders that are utilizing science and technology to improve health in Sickle Cell Disease. Integrated efforts are ongoing at country, regional, and global level. Participants are anticipated to include patient advocates, healthcare providers, policy makers & other government officials, researchers, Industry, NGOs, philanthropies, and multilateral health and research organizations.

### Date

15 August 2023

### Organising committee

Tanzania Academy of Sciences (TAAS). <https://www.taas-online.or.tz/>

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