

Summary report: Sickle Cell Disease Awareness Day

On 12 January 2025 we were invited by The Healing Church of God in Christ (THCOGIC) Community, based at the Emmanuel Church on Harrow Road, London to deliver a health information talk on sickle cell disease.

Background and development of the session

This was the first in-person health awareness session held in collaboration with the THCOGIC Community as part of their fundraising event, which takes place every other year. Previous sessions with THCOGIC were held online as part of their online Round Table sessions on Friday evenings for which we identified speakers on health-related topics prioritised by the THCOGIC Community to raise awareness through online community engagement sessions. The collaboration started as a two-part session focused on dementia ([‘What is dementia?’](#) June 2023 and [‘Management of dementia following diagnosis’](#) August 2023), and sessions on [stroke](#) (March 2024), [bowel cancer](#) (July 2024), and [multiple myeloma](#) (September 2024).

The speakers at this session were:

- Dr Steven Okoli, Consultant Haematologist, Imperial College Healthcare NHS Trust; Clinical Lecturer, Imperial College London delivered a talk on sickle cell disease
- Minister Kay from the congregation shared her personal experience of living with sickle cell
- Dr Rutendo Muzambi, Research Associate in Health Inequalities, Imperial College London hosted a stall showcasing current and future research on sickle cell disease

Prior to the session, a planning meeting was held online with Community Leaders from THCOGIC, which was attended by the session speakers and Naomi Asantewa-Sechereh (PERC) to finalise the session outline.

Attendees:

Approximately 40 people joined the fundraising event at the Emmanuel Church.

The audience is cross-generational and the session was attended by individuals, families and carers.

Promotion for the information session was led by THCOGIC who developed a flyer (page 2) which was disseminated across the THCOGIC network.

Next Steps

The community confirmed they would be keen to support future events and would provide feedback on this session in due course.

Format and aims of the session:

The session started with key members of THCOGIC community welcoming the speakers and highlighting to attendees why this session was important. As this is a Church community, an opening prayer and reading took place before the main presentation started.

Dr Okoli's talk covered the below content:

- What is sickle cell disease?
- Global distribution of sickle cell disease
- Why is sickle cell disease persistent?
- Genetics of sickle cell disease and how it is inherited.
- Impact on the individual
- Features of pain crises
- Psychological impact of sickle cell disease
- Sickle cell disease survival over time
- Current treatment and new treatments for sickle cell disease

The Healing Church of God in Christ
THCOGIC
Paddington

SICKLE CELL DISEASE
Awareness Day

Sunday 12th January 2025 - 1pm - 3pm

Dr Steven Okoli
Consultant in red cell haematology
At the NHS Trust since April 2021

Minister Kay
Speaking as a person
living with sickle cell

You're cordially invited to hear a Doctor giving the facts about **Sickle Cell Disease** and views from a person **living with the disease**.
Followed by a question and answer session with a light buffet

Join us in the sanctuary
Emmanuel Parish Church
389 Harrow Road, Paddington, W9 3HA

Questions were invited after the talk, which are listed below.

- Is there a cutoff for giving blood as a donor? For example, like the Anthony Nolan Trust for bone marrow.
- Has education for healthcare professionals changed now so that they have a better understanding of sickle cell disease?
- What is the difference between sickle cell disease and thalassemia?
- How is someone diagnosed with sickle cell disease? Is it self-diagnostic? How do you know if you have the trait?
- What defines someone as a carrier of the sickle cell trait, or someone with sickle cell disease?
- If you have sickle cell trait, will you have sickle cell-shaped red blood cells?
- Once a person has been cured of sickle cell disease, do they still have the trait and can they still pass it on?
- How does the stem cell treatment for sickle cell disease work?
- If you have high blood pressure, can you still donate blood?
- If a baby is diagnosed with sickle cell disease in the womb, can their chromosomes be altered?
- As a teacher, what is the best way to support children in my class with sickle cell disease?