

Addressing Inequalities in Healthcare Spotlight on Sickle Cell Disease in Europe

Virtual Roundtable Event Summary



On 11 May 2021, a range of experts came together to discuss health inequalities and the specific challenges faced by patients with sickle cell disease (SCD) in Europe.

Organised by Global Blood Therapeutics (GBT), the event followed the publication of a white paper, *Overview of the sickle cell disease environment in select European countries*. The paper unearthed shocking truths regarding the health inequalities faced by these patients.

The following is a summary of that event. It focuses on the solutions to address these health inequalities in the hope of driving conversations advocating for tangible policy improvements for SCD patients.

SCD is a story of premature ageing and mortality...

Individuals with SCD produce sickle-shaped red blood cells. These rigid, sticky cells break apart easily, can slow or block blood flow and as a consequence reduced oxygen is delivered to parts of the body. Ultimately this leads **organ damage, failure and early death**. The disease **predominantly affects black and minority ethnic communities**. Real patient stories included:

- A little girl who had a stroke at the age of 3
- A patient who needed a hip replacement aged 40
- A child who had a splenectomy aged 6

“Sickle cell disease is a lot. It’s a roller coaster, it affects every single aspect of my life”

SCD patient - UK

Sickle cell disease and the impact of COVID-19

The pandemic has augmented the challenges faced by rare disease patients, exacerbating health inequalities. At a higher risk of death or serious illness from COVID-19, SCD patients have shielded for well over a year, creating concerns around job security, finances, loneliness, treatment interruptions and considerable psychological stress.

74.2% of SCD patients and their carers experienced an impact on their mental health due to social distancing and self-isolation

The realities of living with a rare disease

Over 30 million people across Europe live with debilitating and chronic rare diseases, including SCD. Data from EURORDIS revealed the challenges faced by rare disease patients with*:

40% reporting frequent depression compared to 11% of the general population

5-6% having access to transformative or curative treatment

50% spending over 2 hours a day on care-related tasks

*Recommendations from the Rare 2020 Foresight Study, EURORDIS

Sickle cell disease – a global issue

MP Olivier Serva highlighted the disproportionate impact of SCD in the French overseas territories, which have double the number of SCD patients than mainland France. In these more remote regions, healthcare structures are fragile, accessing care is difficult and the current outbreak of Chagas disease has reduced the availability of blood transfusions in French Guiana. Cooperation across the health care system is needed on a global scale to ensure that all patients, regardless of their location, have equitable access to SCD treatments.

HEALTH INEQUALITIES

We asked what health inequalities meant to the attendees...

Word cloud containing terms: discrimination, stigma, struggle, racism, loneliness, inconsiderate, access, lack of diagnosis, forgotten, unbalanced care, despair, ignorance, less funding, fear, lack of help, mistrust, wrong medication, lack of humanity, failure of society, exclusion, ignorance, stigmatisation, challenges.

OUR PANELISTS



MP Olivier Serva
Assemblée Nationale

“Society is not prepared to support and integrate SCD patients who feel side-lined and forgotten”



Dianaba Ba
SOS Globi

“Being born with a rare disease is challenging and unfair. But what is even more unfair is the stigma and discrimination we have to face as patients”



John James OBE
Sickle Cell Society

“It beholds all of us, clinicians and advocacy organisations, to do everything to dispel myths about SCD”



Simone Boselli
EURORDIS

“People living with rare diseases are often marginalised and invisible and there are few treatment options”



Professor Baba Inusa
Evelina Children’s Hospital

“We need patients to dictate the agenda”

The challenges facing SCD patients...

- 1 Stigma and discrimination
- 2 Physical and psychological burden
- 3 Few treatment options and unequal access
- 4 Slow diagnosis
- 5 Limited medical research
- 6 Ignorance amongst healthcare practitioners
- 7 Lack of data
- 8 Little policy attention



and how we might address them

- ➔ Improved disease awareness and advocacy
- ➔ Comprehensive and coordinated healthcare programmes
- ➔ Greater and equitable access to transformative treatments
- ➔ Coordinated approach to standardised newborn screening
- ➔ Establish and fund a research agenda
- ➔ Training for all healthcare practitioners
- ➔ National data coordination and patient registries
- ➔ Incentives for policy and healthcare programmes

For further information, please contact:

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