

## Sickle Cell Disorder: Empowering Patients and Managing Pain Through Art and Creativity

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### Background

Sickle Cell Disorder (SCD) is a complex genetic disorder characterized by chronic pain and a range of physical and psychological challenges. SCD is the most common inherited disease, especially among the African and Afro-descendant population, with an estimated 8 million people living with SCD worldwide. Each year over half a million babies are born with SCD in sub-Saharan Africa, with most dying without treatment before the age of five<sup>1</sup>. However, it remains an invisible and neglected condition, both in a society where it is rarely mentioned and among many healthcare providers and policymakers. As exposed by The Black Panther Party in the 1970s, SCD is still a major symbol of the burden of structural racism and Eurocentrism in healthcare politics.<sup>2</sup>

Like the disorder itself, the severe pain and progressive dysfunction associated with it are equally invisible. When it shows up, they can turn into a source of stigma, associating these people with the xenomorph-like body that led Nigerian actor Bolaji Badejo to portray Alien, before dying of SCD 13 years later<sup>3</sup>.

The medicalized life and severe pain of SCD patients have been strongly represented in art, often outside the Western gaze. In his works, Haitian artist Hertz Nazaire painted a pain way above the referent 10-point scale<sup>4</sup>. BLK Art Group member Donald Rodney, also with SCD, worked on his own X-rays and sculpted his own skin while denouncing racial discrimination<sup>5</sup>. The Los Angeles-based artist Panteha Abareshi uses their own experience with SCD to “disembody pain” and create a unique discourse on the medical gaze and the illness experience<sup>5</sup>.

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**Neusa Negrão** is a Portuguese artist of Mozambican origin that through her paintings aims to transmit a sense of well-being while connecting to her own roots.



**Lwimba Kasongo** is a warrior and a global SCD Advocate and Artist, living in Zambia, and ex-CEO of the Global Alliance of SCD Organizations (GASCO)



**Free your pain /Free your smile** painted mural by sickle cell patients last September at DrepaFest, an awareness gathering in Parque Verde do Mondego, Coimbra.



**Joana Cardona** wrote a story of her childhood and, together with illustrator Madalena Sena, created “The Girl with yellow eyes”, a story about discrimination and bullying but also of resilience and sense of community.



**Maysha** is a 13 years old boy Portuguese/ São Tomé e Príncipe boy, that builds small statues to fight his own pain.

The conventional management of SCD primarily involves pain medication among a robust medical approach, but in most cases fails to comprehensively address the holistic well-being of patients. As exemplified above, art and creativity can turn out as innovative and complementary approaches to enhance the quality of life for individuals living with chronic conditions like SCD. Engaging in artistic activities offers a unique and holistic approach to managing physical and emotional challenges. Through art, individuals with SCD can find avenues for self-expression, pain distraction, and emotional release. By participating in creative endeavours, they may experience improved emotional well-being, increased resilience, and a sense of empowerment over their condition. Art has the potential to foster a sense of community and provide a platform for raising awareness about SCD, reducing stigma, and promoting understanding. While medical interventions remain vital, integrating art into the lives of those with SCD can contribute to a more comprehensive and patient-centred approach to care.

**References:** <sup>1</sup>Global, regional, and national prevalence and mortality burden of sickle cell disease, 2000–2021: a systematic analysis from the Global Burden of Disease Study 2021. (2023). GBD 2021 SCD Collaborators. The Lancet Haemat. 10 (8) E585-E599. <sup>2</sup>Body and Soul: The Black Panther Party and the Fight Against Medical Discrimination (2011) A Nelson; <sup>3</sup>Sickle Cell and the Social Sciences: Health, Racism and Disablement(2019) S Dyson; <sup>4</sup><https://everylifefoundation.org/portfolio-item/ten-redefined/>; <sup>5</sup><https://www.tate.org.uk/art/artworks/rodney-in-the-house-of-my-father-p78529>; <sup>6</sup><https://www.panteha.com/>



**DrepaComunidade** is a project of the Portuguese Association of Hemoglobinopathies (APPDH) and pretends to be a platform for a common sharing of knowledge and information between patients, relatives, carers and healthcare workers around the disease in Portuguese-speaking countries. We aim to promote clinical and research cooperation between countries and to create content to help patients to cope with the disease and to raise their visibility. Through the work and testimonies of four SCD patients, this work explores the potential of utilizing art and creativity as therapeutic interventions to empower SCD patients and effectively manage their pain.

Our goal as an SCD associatoin’s coalition is to give voice to all these patients and use art not only for their well-being but also as a powerful and impactful way to educate the public, reduce stigma, and promote support for affected individuals.

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