

Sickle Cell Society Mid Term Strategy Update November 2021

In 2020 we issued a strategy describing how we would develop the Sickle Cell Society over the next three years, to 2023.

Since setting that strategy, we have weathered the storm of a global pandemic, and made some difficult decisions to ensure the resilience of our organisation, including staff pay cuts for roles that are not directly funded by project income. As a result of the actions we've taken, we ended the financial year in a healthy financial position, with a surplus of £184k. This will enable our organisation to continue to provide support to those who need it most.

We must however acknowledge that providing effective sickle cell care in the midst of current conditions will remain challenging. The ongoing nature of the global pandemic, together with economic instability, and major structural reorganisation of health services in the UK mean we will be navigating a difficult external environment for several years to come. We have established excellent relationships with our stakeholders and believe that continued investment in these relationships will determine the success of our influence in ensuring joined up care for sickle cell.

The current spending review period creates further instability; now is a critical time to raise political awareness that sickle cell disorder is the most commonly inherited blood condition in the UK. As such it must be addressed as a clinical priority. The wider social and economic factors that can mitigate sickle cell crises and avoidable hospital admissions must also receive continued investment and focus. Hospitals are now particularly dangerous places for patients with sickle cell disorder, which weakens patients' immune response and makes them more susceptible to viruses that attach the immune system, including COVID-19, subsequent strains of coronaviruses, and common viruses which have become more virulent post lockdown.

Our work remains vulnerable to changes in policy and priorities. In year funding for programmes can be a valuable source of innovation though we cannot rely on this alone. We must continue to diversify and strengthen our income streams. The course of the pandemic has been very challenging for the voluntary sector, and will continue to raise challenges.

In the last two years, operationally we achieved a fast shift to remote working. At the same time, we delivered a revamp of our offices to deliver facilities that are fit for purpose for our current organisation. This change includes renovation of the ground floor to create an environment that enables group meeting and working.

The tragic deaths of Evan Smith and Richard Okorogheye occurred in very different circumstances. However, both cases highlight that there are still significant deficiencies in sickle cell care and awareness. We share our very deepest condolences with the families of Evan and Richard, and extend our ongoing support to North Middlesex Hospital as well as healthcare, policing and community services across the UK. Further tragedies can and must be avoided if the right measures are put in place.

We continue to work closely with the All Party Parliamentary Group for Sickle Cell, and are leveraging the influence of MPs to ensure the importance of our work is highlighted. Practical measures include a templated letter to MPs, which can be obtained by emailing info@sicklecellsociety.org

John James OBE

**Chief Executive** 

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Chair

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