

Agnes Nsofwa RN, MsN, BBA

Co-Founder & Executive Director – Australian Sickle Cell Advocacy Inc (ASCA)
Co- Founder Sickle Cell Educational Resources Initiative (SERI)

Agnes Nsofwa is a mother of four children with the youngest child being born with sickle cell anaemia in 2009. She is a Data Analyst by profession who became a Registered Nurse, a career that she found herself in due to the illness of her daughter. In 2012, she changed careers from Banking to Nursing so that she could understand Sickle Cell Disease (SCD) and what her daughter was going through. Agnes also hold a bachelor's degree in business and a Diploma in accounting with experience in taxation and banking.



In 2014, Agnes and her husband Preston started a SCD Awareness Facebook page to support other people affected by the disease. After the following grew to over 5000 people and receiving so many queries regarding SCD, the initiative was formally registered as a not for profit organisation in October 2018 under the name Australian Sickle Cell Advocacy Inc.

Since founding ASCA, Agnes has been spearheading awareness about SCD in Australia where the disease is considered as rare. Her association focuses on awareness and education programs, community outreach, Peer to peer support, advocating for scientific research. Agnes and ASCA team have expanded the association to 5 states of Australia. Within the 12 months of being registered, they advocated for the formation of SCD clinical guidelines in Australia. They designed an E-learning course for primary nurses. They have also taken the cause to the Australian Parliament asking for better services for people affected by SCD. Their work was reported in the Federal Parliament of Australia. Agnes supports other SCD programs and initiatives that enhance the lives of people from disadvantaged backgrounds.

Just recently her idea of providing SCD Educational Resources to all parts of the world especially the most remote areas around the world has become a reality. An idea that started because of her experience of not knowing what SCD was when she was growing up in Zambia Southern Africa. And even after having the first three children, no one told her about it. But all this changed in 2008 when their daughter was born. Since 2008, Agnes has been trying to find ways to be of help to other people who have no idea what this condition is. She would like to see that every person at risk of having the SCT gets tested and be informed. Just as those living with SCD should have information at their fingertips to help them live a healthy lifestyle despite the challenges that come with living with SCD. Agnes is originally from Zambia and has lived in Australia for the past 16 years.