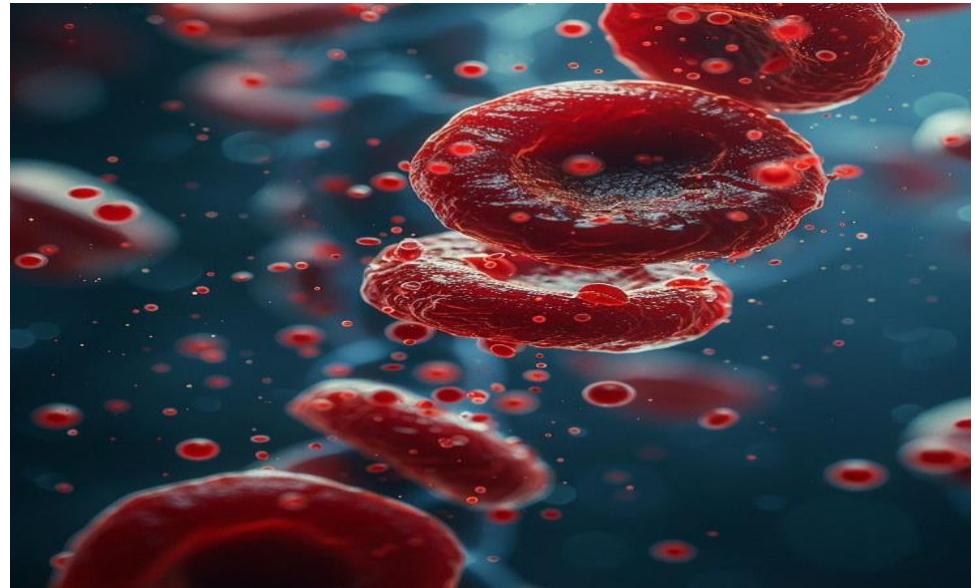


# SICKLE CELL MAPPING PROGRAM



An Initiative of David Mone Foundation

## HISTORICAL

The history of sickle cell anemia spans millennia, with the underlying mutation likely originating in Africa over 7,000 years ago as a protective trait against malaria, which is why it is most prevalent in regions historically affected by this malaria, such as sub-Saharan Africa and India. It was first officially described in Western medicine in 1910 by Dr. James Herrick, who noted the unique sickle-shaped red blood cells in a patient named Walter Clement Noel aged 20 from Grenada. Noel experienced recurrent episodes of "muscular rheumatism" and "bilious attacks" over a period of 3 years. A blood work on Noel, showed an unusual sickle-shaped red blood cells in the sample under the microscope. This mark the beginning of research in Sickle Cell Disease, in 1927 Researchers identify that lack of blood oxygen is a factor in the sickling of red blood cells. In 1950s-1960s Geneticists identify the gene responsible for the disease and begin using blood transfusions as a treatment. In 1990 The American Red Cross begins local blood donation programs specifically for sickle cell patients. The 63rd session of the UN General Assembly in December 2008 adopted a resolution on "recognition of sickle-cell anemia as a public health problem," and urged Member States and UN organisations to raise awareness of SCD on June 19 of each year. Despite the fact that the UN has called for global efforts "to bring the disease out of the shadows," relatively little attention has been given to assessing the burden of SCD and how to reduce it in sub-saharan Africa, where about 85% of children with SCD are born.

## WHAT IS SICKLE CELL DISEASE?

Sickle cell disease (SCD) is an inherited blood disorder. That means it is passed down from a parent's genes. It causes the body to make abnormal hemoglobin. Hemoglobin is the protein in red blood cells that carries oxygen to all parts of your body. When you have SCD, your body's tissues and organs don't get enough oxygen. It's a disease that affects the hemoglobin that carries oxygen through the body. It is the most common inherited blood disorder in the world. Sickel cell disease is caused by genetic changes which lead to abnormal red blood cells and anemia. There are various subtypes and variations of Sickel cell disease depending on the exact mutation on the hemoglobin gene. Healthy red blood cells are round and move easily all over the body. With SCD, the red blood cells are hard and sticky. They are shaped like the letter C (and like a farm tool called a sickle). These damaged red blood cells (sickle cells) clump together. They can't move easily through the blood vessels. They get stuck in small blood vessels and block blood flow. This blockage stops the movement of healthy oxygen-rich blood. This blockage can cause pain. It can also damage major organs. A number of health problems may develop, such as attacks of pain (known as a sickle cell crisis) in joints, anemia, swelling in the hands and feet, bacterial infections, dizziness and stroke. Without treatment, people with SCD rarely reach adulthood.

## RECENT HIGHLIGHTS

Sickle Cell disorder (SCD) affects nearly 100 million people in the world. Of the 300,000 children born annually worldwide with SCD, more than 70% are in Sub-Saharan Africa – the vast majority in Nigeria. By virtue of its population, Nigeria stands out as the most sickle cell-endemic country in the world; an estimated 150,000 babies are born every year in Nigeria with SCD and sadly, 50 – 90% do not live to 5 years old. Approximately 10% of children born in Nigeria die before reaching the age of five – a statistic that we can deal a blow with interventions targeted at SCD). This will take strong political will and intentionally prioritising SCD as a public health problem in Nigeria.



Life Expectancy: The average life expectancy of persons with sickle cell in Nigeria remains very low – less than 20 years; whereas in the US for instance, it is now over 60 years. High mortality due to SCD in children under 5 years has been virtually eliminated from North America through policies and legislation that ensure ready access to a number of simple interventions, including newborn screening and prevention of infection through the provision of penicillin prophylaxis and polyvalent pneumococcal vaccination. We can achieve this in Nigeria

## OUR PLAN

To address this gap in our health sector, the government, private sector, hospitals and communities must work together and explore several strategy to end this problem once and for all.

- With Partnering with local businesses, major companies and organizations to secure sponsorships and donations we want to build a Sickle Cell hospital where sickle cell disease patients can be treated for free.
- With Partnership with state and federal government, local businesses, major companies and organizations we also want to build a research center where the cure for Sickle Cell Disease can be achieved.
- Through community engagement, local and state government, private and public hospitals we want to have a global database of every Sickle Cell Disease patient in Nigeria so we can identify, keep track and provide care for them with precision,
- Collaboration with federal and state governments to provide a Sickle Cell Disease department in every public health facility in Nigeria.
- Creating more awareness for Sickle Cell Disease across Nigeria and the world and the need for everyone to come together to end this global crisis.
- **Advocacy for Increased Funding:** Lobbying for more state and federal funding for public

By taking the time and truly understanding and addressing these challenges, Sickle Cell Disease can be eradicated from our society.. .

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