ASCA
Australian Sickle Cell Advocacy
Together We Rise

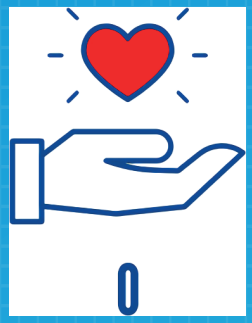
WHAT WE DO

- Raise awareness
- Provide valuable information to patients
- Provide support networks
- Engage Australian research scientists for the discovery of better curative options for all
- Start buddy programs between different age groups

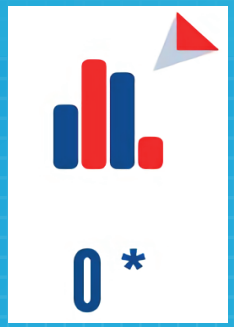
OUR MISSION

To be the leading advocacy organisation for people affected by Sickle Cell Disease within Australia and beyond.

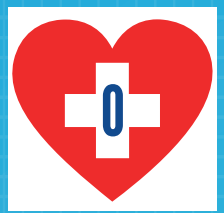
Sickle cell Disease Facts in Australia



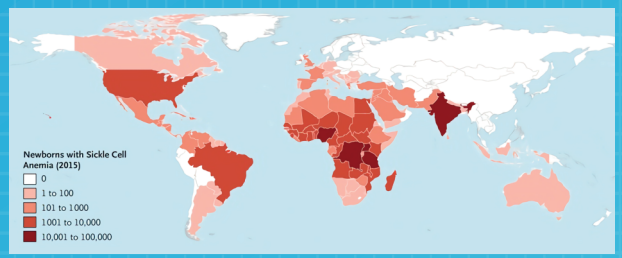
No sole Sickle advocacy support group



Limited Nationalwide surveillance data available (Incidents are uncertain) * Internal Medicine Journal(2016)



No National or Local standardized guidelines*Internal Medicine Journal (2016)



Sickle cell disease newborns statistics*New England Journal(2015)

ABOUT US

Australian Sickle Cell Advocacy Inc(ASCA) is a not-for-profit organisation dedicated to supporting people living with Sickle cell disease and their families. This advocacy group was formed to highlight the rising numbers of Sickle cell disease cases in Australia.

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WHAT IS SICKLE CELL DISEASE

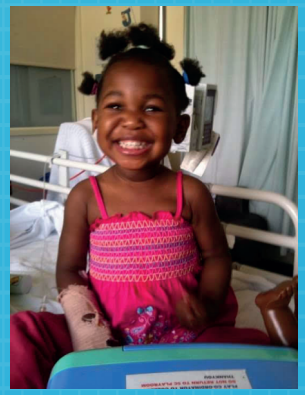
- Group of inherited red blood cell (RBC) disorders resulting instructurally abnormal haemoglobin (Hb S
- -SCD manifests when two abnormal Hb genes are inherited from both parents.
- Signs and symptoms of SCD are caused by the sickling of the red blood cells and results in inflexible sickle-shaped cells
- -Sickling of the RBC is the main cause of early symptoms, signs, and complications related to progressive organs damage.
- Abnormally adhesive sickled RBC, and activation of white blood cells and platelets also play a role
- Results in short lifespan of healthy red blood cells in the bone marrow
- People with SCD may experience many complications including acute pain crisis (vaso-occlusive crisis), chronic pain, chronic anaemia, severe anaemia

Images of sickle cells vs normal red blood cells and the probability of having sickle cell trait / SCD.

SICKLE CELL PREVALENCE IN AUSTRALIA

- Rare and uncommon in Australia
- No current and conclusive surveillance data
- No National guidelines

AGNES' STORY



ASCA was formed as a result of Agnes's frustration with challenges she endured during her pregnancy and months leading up to the diagnosis of Sickle cell disease in her daughter at 14 months.Things have not changed much since then. Her passion for advocating helped her cope with the difficulties of managing their daughter's condition while realising that many shared the same experience. The idea started in 2014 after Agnes created a facebook page and found comfort in researching sickle cell articles to share as a coping mechanism

PETER'S STORY

Peter was diagnosed as a little boy. For decades, the only treatments available to him were blood transfusions and preventative management of dehydration and infections which could result in crises. This changed in 2011 when he started red cell exchange treament.

TREATMENTS

- Preventative (prophylactic) antibiotics
- Regular Vaccines
- Pain medication if needed
- Treating symptoms when they occur
- Hydroxyurea if needed
- Blood transfusions routinely or as needed
- Red cell exchange with a combination of other treatments
- Monitoring for complications

CURATIVE TREATMENTS

- Bone marrow transplant subject to the availability of a suitably matched donor
- Gene therapy is currently being investigated as a potential option

Peter having the red cell exchange treatment.