

Showing incredible determination the Thalassaemia Society of NSW was started as a self-help society in 1979 by the families of children suffering from thalassaemia. The aim was to form a support and advocacy network for those affected by thalassaemia, sickle-cell anaemia and other haemoglobin disorders.

Today, the Society is a registered not-for-profit charity. The Society continues to provide patient and family support services as well as awareness programs about being a carrier of the genetic trait for the blood disorders.

We also raise funds for medical research and equipment for hospitals.

Our Society is a state-wide service and we are evolving to reflect the diversity of languages and cultural backgrounds of the communities we support.

Contact us today! e: coordinator@thalnsw.org.au m: 0400 116 393 www.thalnsw.org.au www.facebook.com/thalnsw/

INFORM

SUPPORT

RESEARCH

PO BOX M120, Camperdown, NSW 2050





Thalassaemia Society of NSW

Thalassaemia, Sickle-cell anaemia and other haemoglogbin blood disorders







## OUR SERVICES

- Financial Support for patients with • medical costs
- **Counselling Services** for patients and family members
- Peer support and social events •
- **Community Awareness program** to encourage testing for the genetic trait
- Education events on health and wellbeing •
- Assist the Australian Red Cross blood • donation campaigns
- Raise our voice for greater Government support
- Fundraising to support Medical Research • , Equipment and services for patients



#### Did you know?

We also support patients in ACT

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## WHAT IS THALASSAEMIA AND SICKLE CELL ANAEMIA?

These are inherited conditions which affect the production of haemoglobin, the oxygen-carrying component in the red blood cells.

The *Major forms (disorders)* are life-long conditions requiring lifelong care and treatment. The disorder is recessively inherited meaning a child must inherit the gene from <u>both parents</u>.

If both parents carry the genetic trait then there is a 25% risk of the child developing the disorder.

The *Minor forms are carrier states.* Often people have no symptoms and are unaware. However, they can pass on the genetic trait to their children.

The trait can be passed on by one parent.



# WHO MAY GET IT?

Anyone, but the genetic traits and the disorders are most common in people with ancestral history from the following regions:

Mediterranean, Middle-East, South-East Asia and Southern China, India and South Asian countries, North and Sub-Saharan African countries and South America.

#### Did you know?

Between 5%-15% of these populations carry the genetic trait.

Due to migration we recommend everyone consider a simple blood test to know their trait. The trait can be present even if your parents or grand-parents were all born in Australia.

A family history of anaemia may be another risk indicator for you to get a test.



# Get Involved

There are many ways to get involved:

JOIN Become a Member of a network of people supporting awareness and prevention in their communities as well as those who are touched by thalassaemia and sickle-cell anaemia.

Memberships is \$20 per year. Register online at: <u>http://thalnsw.org.au/membership</u> or contact the coordinator.

ATTEND Come along to support our awareness days or fundraising events. Stay up to date on <u>www.</u> <u>thalnsw.org.au</u>

LEARN Visit: www.knowmytrait.org.au and www. thalnsw.org.au

**LIKE US** Join our online community at www. facebook.com/thalnsw/ and #thalsoc

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## HELP US

**DONATE** We need your financial support to continue to deliver patient services and reach new communities to increase awareness.

You can donate online via our website or our Go Fundraise page or simply by contacting the coordinator. All donations over \$2 are tax-deductible.

**INVITE** Invite us to make a presentation at your workplace, community or faith group to raise awareness of about being a genetic carrier.

**PROMOTE** Promote our awareness campaign: #knowmytrait and www.knowmytrait.org.au

**VOLUNTEER** Help us through the year with awareness events, office support or fundraising events.

**GIVE BLOOD** Between 20-25% of donated blood is used for the treatment of haemoglobin disorders.