



Thalassaemia Society of NSW



Theodora raising awareness at Liverpool Hospital for International Thalassaemia Day. During May and June we greeted over 320 people at 6 events. For more details visit our website page - [Out & About](#)

**This is a *modified printed version* of our new online newsletter via mailchimp.
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Issue 1 July 2017

Inside Snapshot:

- Welcome from the President
- Out & About for World Thalassaemia and Sickle Cell Days
- Remembering Fred Matsas – *a True Gentleman*.

A welcome from the President

Welcome to our new electronic newsletter for the Thalassaemia Society of NSW. This e-newsletter will be a great way for us to keep you updated on all the events and issues within the Thalassaemia Society and broader thalassaemia, sickle-cell and hemoglobinopathy community.

Our e-newsletter builds on our popular facebook page which is improving the way we communicate with our members and supporters. I encourage you to like our page and become active and engage with us because we can only grow and improve with the help of volunteers and supporters.

Since the start of the year, the Thalassaemia Society has undergone some changes which we hope will see us grow and build on the work from the previous years.

One of these changes has been the appointment of a new Coordinator for our Centre, Mr Cyril O'Connor. Cyril brings with him a vast amount of experience across the corporate and community sectors. Cyril has already proven to be a valuable asset to us and I encourage you to welcome him into our community and get in touch with him should you require any assistance.

Yours sincerely,

George Houssos

President, Thalassaemia Society of NSW



Support the Thalassaemia Society *when you give Blood*

National Blood Donor Week finished on June 18, however, continuing donations are needed. The week represents the Australian Red Cross Blood Service's special thank you to all the bloody legends whose generous donations support the 1 in 3 Australians who will need donated blood in their lifetime.

"National Blood Donor Week is the time to take that first step of making an appointment to give blood. We'd love to see some friends and family of the Thalassaemia Society donate to help ensure that we maintain blood stocks over the winter period." **David Rosseto**, Australian Red Cross

To become a blood legend, call 13 14 95 or visit : www.donateblood.com.au

Please donate in the name of the **Thalassaemia and Sickle Cell Society of Australia's Red 25 Group**.

Dia Dhuit from the new Coordinator

Dia Dhuit is Gaelic for “hello”. Irish or Gaelige is one of the national languages of Ireland, my place of origin, but for the last 8 years Australia is home.

I have been enjoying the role of Coordinator for the past four months and want to thank everyone who is helping me to settle in. I have been learning a huge amount and I appreciate the support.



A key focus for my role will be building community partnerships to increase awareness about being a genetic carrier and encouraging early testing. I worked originally in the corporate sector as a Human Resources manager and for the past

11 years, I have worked in the Community sector, within the housing & homeless sector, and later supporting migrant and refugee families.

As person, who has a life-long health condition, I appreciate the Society's work for patients and families, and the importance of having somewhere to contact for support. Please feel free to contact me anytime, to say hello, seek some support or share stories of achievement. - Cyril

PS: I would like to introduce you to the Irish sport of Hurling, my passion. Hurling is one of the oldest and fastest field games in the world. Check it out on youtube.



World Sickle-Cell Awareness Day - June 19th

Image: Karl Jobburn (CNC at Liverpool Hospital) and Ghada Toma (who provided Arabic language support) promoting awareness.

Recognised by the U.N as the day to celebrate the strength of the sickle community and raise awareness of Sickle-Cell disease as a public health priority.

For more information and videos about Sickle-Cell Disorders visit our website: [What is Sickle-Cell Anaemia?](#)

The Society held 2 awareness events at RPA and Liverpool Hospitals and spoke with almost 100 people including 3 nurses, a mid-wife and 6 medical students as well as 5 sickle-cell trait carriers.

Remembering Fred Frixos Matsas

With a sad heart, we shared the loss of a very valuable and loved member of the Thalassaemia Family.

Fred Frixos Matsas was one of the founding members of the Thalassaemia Society of NSW. He put his heart and soul in establishing and always supporting the Thalassaemia Society of N.S.W. His knowledge and passion to help make a difference for the patients with Thalassaemia has not gone unnoticed.

We pay deep respects to a wonderful man. His touching tribute from his beloved daughter Aleni sums up as a man, father, husband and friend.

“Fred fought the heroes battle until the very end. He will be remembered for his big warming smile, his heartfelt service to family, friends and the community, being a source of wisdom and knowledge about life, his road trips across Australia and travels exploring the world.”

Fred's Family wished, in lieu of flowers, to have donations made to the Thalassaemia Society of N.S.W. in his memory and over \$3,000.00 was donated in memory of a wonderful selfless gentleman.

Fred was laid to rest on Friday 30th December 2016. We wish his family, who have all played a major role at one point or another for Thalassaemia, all the strength for the time ahead.

**To a true gentlemen
Fred Frixos Matsas - may your memory be eternal.**

Thal NSW e-Newsletter July 2017

For information or support please mail call the coordinator on 0400 116 393 or email on coordinator@thalnsw.org.au

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