THALASSAEMIA INTERNATIONAL FEDERATION

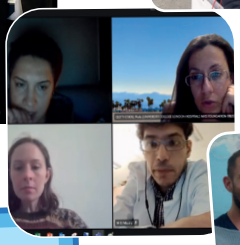
Thalassaemia In Action (THALIA): TIF's work programme in Europe

Serving a growing European community of more than 30,000 people living with thalassaemia

> "...I don't want my children to feel isolated or depressed or have limited access to appropriate care as they go on with their lives so I became a Board Member of the new thalassaemia association created as a result of encouragement of TIF. **Now my children have a voice!**"

> "THALIA activities have taught me **what to look for** in terms of quality care, **how to ask for it** and how to ensure that it is provided to patients. They have also taught me that the united voice of patients and their families is stronger that the voice of an individual."

a comprehensive advocacy campaign in support of policy improvements / EU Policy Recommendations, National Charters of Priorities, Global Thalassaemia Review 2021, TIF.ACCESS for accessible, affordable and available novel therapies



a comprehensive, multilingual, educational programme for patients / meetings, conferences, twinning programmes, publications, leaflets, infographics, online courses, mobile application

> "...**a blessing** for people with thalassaemia living in Austria and Sweden, many of whom had never met another patient. It enabled the establishment in 2019 of the Austrian Thalassaemia & Sickle Cell Forum (ThalSiFo) and Kronisk blodsjukdom KBS."

> "...my understanding of haemoglobinopathies enormously increased and I got a **much broader view** on the many aspects included in managing a patient. I am convinced that through this training the standard of care in our hospital will reach another level for patients with these diseases."

on-site visits to bring patients together and a thalassaemia-specific registry for better healthcare policy and service planning

Continuing Medical Education opportunities for healthcare professionals & an update and wide dissemination of TIF's flagship publications / fellowships, preceptorships, scientific conferences, online courses, Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia, medical publications

About the **Thalassaemia International Federation**

226
members

- **134** National Thalassaemia Associations
- **66** Countries
- **160+** Volunteers
- **225** International Patient Advocates
- **46** International Medical Advisors
- **9** Staff members

1986
Founded

2015
Awarded 'Dr Lee Jong-Wook Memorial Prize' of the WHO for outstanding contribution to public health

1996
Official Relations with WHO

2017
Consultative Status of UN ECOSOC

2018
European Commission partner in the field of Health

2019
Member of the Council of Europe Conference of International NGO's

Mission

The development and implementation of National Control Programmes, including both prevention and management, in every affected country

Vision

The establishment of equal access to quality health, social and other care for all patients with thalassaemia globally, in truly patient-centred healthcare systems

1	2	3	4	5
Policy Advocacy	**Education**	**Networking**	**Projects**	**Research**
Establishment of the new and promotion of existing National Thalassaemia patient/ parents Associations, across the world	Development and continuous upgrading of an educational programme including organisation of events, publications & promotion of academic courses	Collaborations with national health authorities and other relevant health related bodies or medical/ scientific associations	The undertaking of, or contribution to projects that aim to further improve existing policies or develop new innovative ones	Supporting and contributing to research & scientific programmes for the improvement of existing and the development of new treatment procedures

About THALIA

THALassaemia In Action (THALIA) is TIF's work programme for European Union countries, implemented since 2018, in strategic collaboration and with the support of the European Commission.

Learn more on TIF's website...
Available in EN, FR, DE, GR, IT and AR.

Want to get involved?
Let us know at thalassaemia@cytanet.com.cy

THALIA

Co-funded by the European Union

Disclaimer: Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not reflect those of the European Union or HaDEA. Neither the European Union nor the granting authority can be held responsible for them.

31 Ifigenias Street, 3rd Floor, 2007 Strovolos, Nicosia Cyprus
P. O. Box 28807, 2083 Strovolos, Nicosia Cyprus
+357 22 319 129 thalassaemia@cytanet.com.cy
www.thalassaemia.org.cy