INTERNATIONAL THALASSAEMIA DAY

2023 ACTIVITIES REPORT

8th May
INTERNATIONAL THALASSAEMIA DAY
THALASSAEMIA INTERNATIONAL FEDERATION

BE AWARE • SHARE • CARE
2023

#ITD2023
BeAwareShareCare

www.thalassaemia.org.cy/itd2023

INTERNATIONAL THALASSAEMIA DAY 2022

Activities Report

Introduction:

International Thalassaemia Day goes far beyond being just another day on the calendar. It is a global movement, coordinated by the Thalassaemia International Federation (TIF) and designed to encourage positive change and drive meaningful progress and action long after the day has passed.

Marking the 29th International Thalassaemia Day on 8 May 2023, the Thalassaemia International Federation (TIF) brought the global haemoglobin disorders community together once again, by raising awareness, sharing knowledge, and bringing thalassaemia to the spotlight all across the world.

The ‘Be Aware. Share. Care’ campaign continued for the second year in a row, under the dedicated theme ***‘Strengthening Education to Bridge the Thalassaemia Care Gap’,*** showcasing the empowering force of disease-specific education and its correlation with the appropriate and quality care of thalassaemia.

We are grateful to all the members, partners, and supporters of the global thalassaemia community who have actively and collectively contributed to International Thalassaemia Day (ITD) 2023 and to TIF’s ongoing, worldwide efforts for improved prevention, control, management, and care for all the people affected by this disorder. Let us continue to work together to bridge the gap and achieve equity in the health, social and other care for thalassaemia.

Together, we can make a difference in the lives of millions of people around the world.

The ITD2023 Campaign:

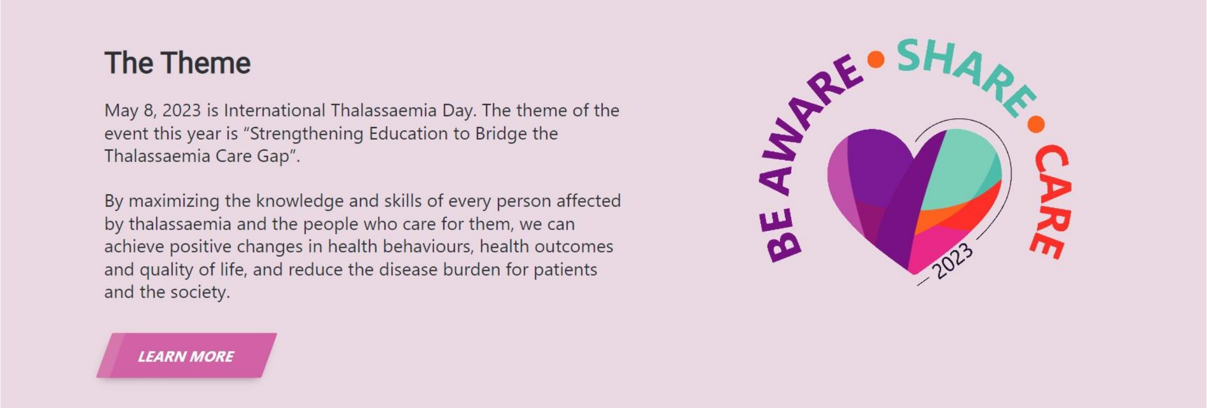
Seeking to reiterate that thalassaemia awareness and effective patient care must become a priority in public health at the national, regional, and global level, TIF has launched a massive online Global Campaign for ITD2023 containing a vast array of communication and informational resources, with the objective of:

a) disseminating the key messages and information of the #BeAwareShareCare theme, and

b) encouraging the active participation of all supporters/stakeholders.

An ITD2023 official page was created and launched within the Federation’s website in order to host the campaign’s resources and materials.

Detailed information on the value and contribution of disease-specific education in bridging the care gap and bringing forth development in health interventions, a brief overview of the challenges still afflicting the majority of patients with thalassaemia worldwide, according to TIF data, as well as the implications of poor health and disease literacy on life expectancy, morbidity, and health behaviours, were explored in **‘The Theme’** section of this year's campaign.

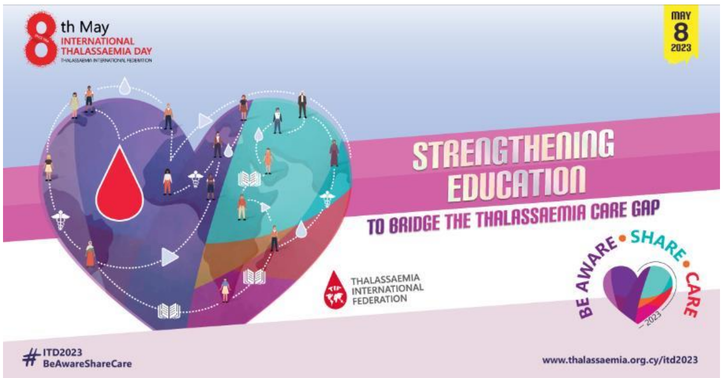


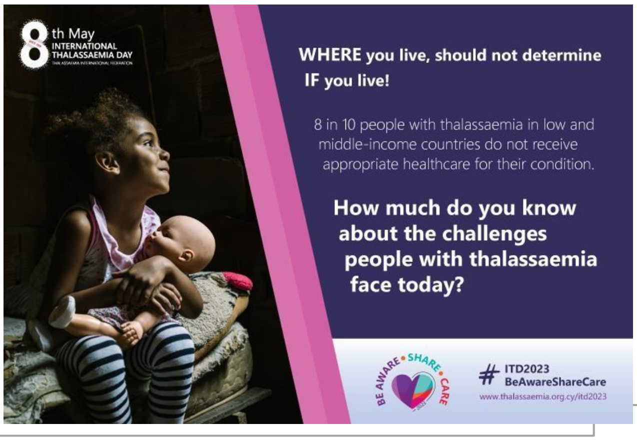
The Theme

May 8, 2023 is International Thalassaemia Day. The theme of the event this year is “Strengthening Education to Bridge the Thalassaemia Care Gap”.

By maximizing the knowledge and skills of every person affected by thalassaemia and the people who care for them, we can achieve positive changes in health behaviours, health outcomes and quality of life, and reduce the disease burden for patients and the society.

Multiple resources were created by TIF and featured in **‘The Material’** section to help communities and individuals in their awareness-raising efforts and the promotion of the campaign’s advocacy messages, facts and information, both in online and offline awareness activities.





WHERE you live, should not determine IF you live!

8 in 10 people with thalassaemia in low and middle-income countries do not receive appropriate healthcare for their condition.

How much do you know about the challenges people with thalassaemia face today?

Materials included campaign logos, posters, email banners, gifs, social media assets, such as profile frames, infocards, infographics, pledge cards, etc. The poster and several of the social media materials were translated and made available **in 18 different languages**, aside English, to facilitate their access to international audiences and further amplify the campaign's messages.

THALASSAEMIA FOR PARENTS:

How Do I Care for my Child?

WHAT IS THALASSAEMIA?

Thalassaemia is a term used to describe a set of diseases that belong to a larger group, the anaemias. When someone has anaemia, his body cannot produce enough normal red blood cells, which are cells that carry oxygen from the lungs throughout the whole body. They flow in the blood stream and give it its red color. Thalassaemias are hereditary diseases, meaning that they are caused by problems within our genetic make-up, and not because of nutrition or other environmental factors, and are passed on to children from their two parents – both mother and father. What is at fault in thalassaemia is a change in the haemoglobin molecule, a protein found within each red cell, responsible for carrying oxygen to tissues and organs.

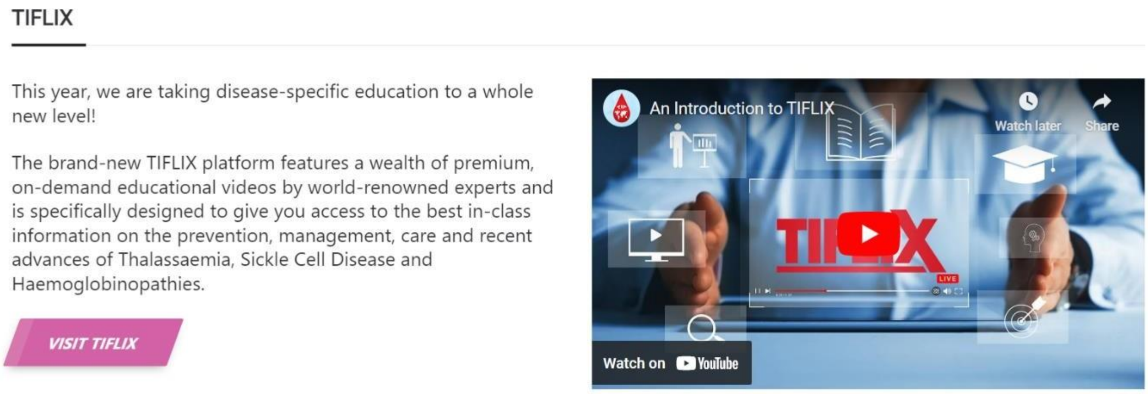
There are different types of thalassaemia, some of which require more demanding therapy than others. In any case, patients with thalassaemia must be followed by healthcare professional experts in specialized centers throughout their lifetime to have the best possible health outcomes.

TIF also continued its successful **'Thalassaemia Brochures'** series, started in 2022, aimed at providing the public and patients/parents with comprehensive, easy-to-read information on multiple aspects pertaining to thalassaemia, ranging from the thalassaemia trait and the care of a child with the condition, to the key aspects of α- and β-thalassaemia and the current and emerging novel therapies to advance care.

This year, the series was enriched with two (2) novel brochures, *entitled 'Thalassaemia for Parents: How Do I Care for My Child?'*, and *'Treating Thalassaemia: New Advances, New Hope'*, which were translated and made available in 18 languages, apart from English.

These materials can be found in the 'Understanding Thalassaemia' section of the ITD2023 page and the 'TIF Publications' webpage and have been **downloaded to date by people in 81 countries** across the world.

To highlight TIF-provided learning opportunities to all people concerned by thalassaemia, through multi-media educational resources and suitable for different learning styles and audiences, the **'Unlock Education'** section was featured in the ITD2023 page, including the newly-launched video library TIFLIX, the latest animated video by TIF, 'Jo's Story with β-Thalassaemia', and the renowned TIF e-Academy with 5 online course on thalassaemia and sickle cell disease for patients, healthcare professionals and laboratorians.

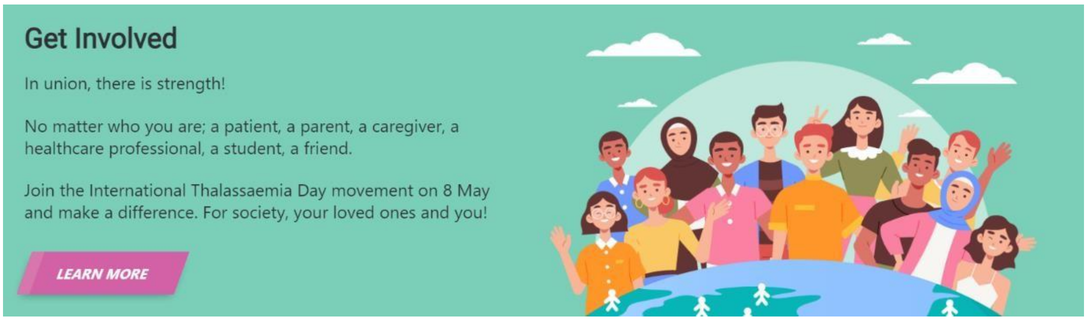


TIFLIX

This year, we are taking disease-specific education to a whole new level!

The brand-new TIFLIX platform features a wealth of premium, on-demand educational videos by world-renowned experts and is specifically designed to give you access to the best in-class information on the prevention, management, care and recent advances of Thalassaemia, Sickle Cell Disease and Haemoglobinopathies.

A wealth of ideas on how anyone could mark the occasion of International Thalassaemia Day and participate in the campaign to get thalassaemia noticed as far and as wide as possible, highlight progress in the field, and show solidarity to people living with the disorder, was included in the **'Get Involved'** section of the page.



Get Involved

In union, there is strength!

No matter who you are; a patient, a parent, a caregiver, a healthcare professional, a student, a friend.

Join the International Thalassaemia Day movement on 8 May and make a difference. For society, your loved ones and you!

Activities Outreach:

On the 8th of May, the #BeAwareShareCare campaign united the global thalassaemia community with hundreds of thousands of people around the globe showing an overwhelming amount of support to all those impacted by thalassaemia and embracing the call for improved disease-specific education for better thalassaemia care.

A Peek at the ITD2023 Global Reach

500+ activities and events in 127 countries

25,500+ social media posts

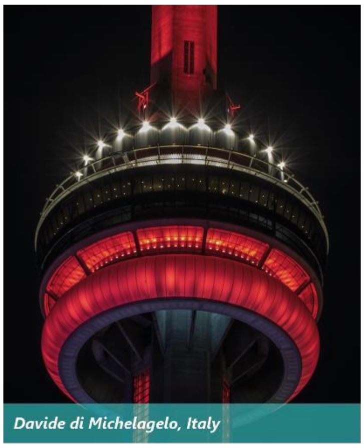
2,300,000 impressions only on TIF's social media pages

14,000+ campaign materials downloaded

50+ iconic landmarks and buildings illuminated

The **numbers reflect the impact** of International Thalassaemia Day 2023; More than 500 activities and events were organised to mark the occasion in 127 countries. Over 25,500 social media posts were shared, helping generate discussions around equity in thalassaemia care and control, with posts only on TIF's social media pages gaining over 2.300.000 impressions More than 14,000 materials were downloaded throughout the campaign from TIF's website, and over 2,000 people used the ITD2023 profile frame on social media to draw attention on the disease and its impact on patients.

As the night of 8 May fell, **more than 50 iconic landmarks and buildings** in various countries were lit red, as a beacon of hope and solidarity for people affected by thalassaemia and a testimony to the power of combined efforts towards achieving greater disease awareness.


Davide di Michelagelo, Italy

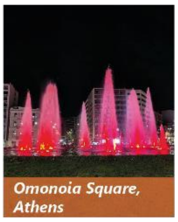

Teatro Massimo, Italy


Ayia Napa Marina, Cyprus


Ras Al Khaimah, UAE


Dubai Frame, UAE


Sharjah Monument, UAE

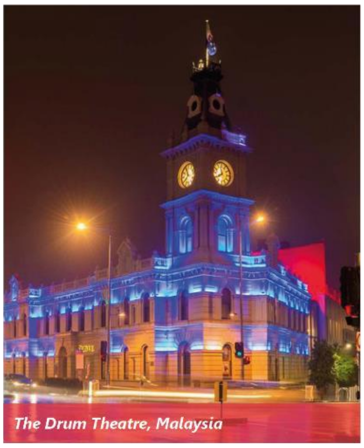

Omonoia Square, Athens


Archbishop Makarios III Hospital, Cyprus


Davide di Michelangelo, Italy


Electricity Authority Cyprus Building, Cyprus


Alor Seta Tower, Malaysia

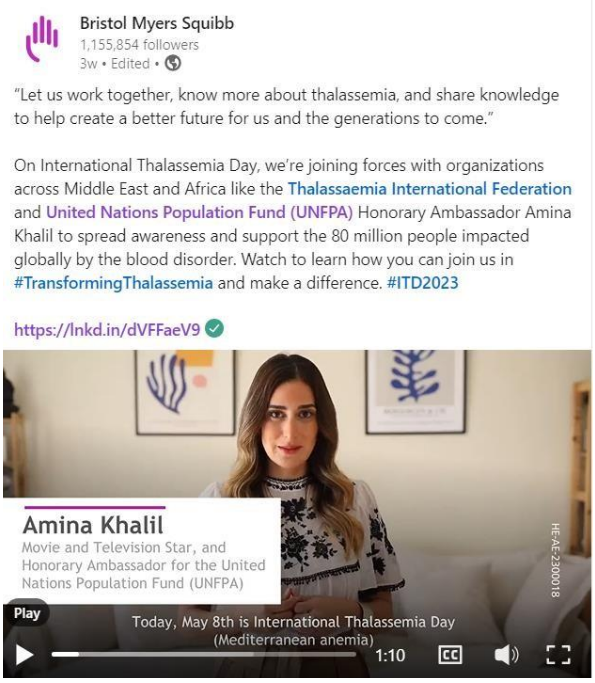

The Drum Theatre, Malaysia

Partnerships in Action:

Many industry representatives, international and regional medical associations, national health authorities, and other health-related stakeholders stood by the global thalassaemia community, sharing statements and messages of solidarity and support on and around 8 May.

International Thalassaemia Day 2023 official sponsors, Bristol Myers Squibb, Chiesi Group, and Silence Therapeutics provided invaluable support, while reiterating their unwavering commitment to making a difference and positive impact in the fight against thalassaemia worldwide.

Bristol Myers Squibb (BMS) joined forces with TIF, the Emirates Thalassaemia Society, organisations across the Middle East and Africa regions, as well as with TV and social media celebrities Amina Khalil, Zahra Lari, and Mona Abu Suleiman to spread awareness on thalassaemia and encourage support for patients.

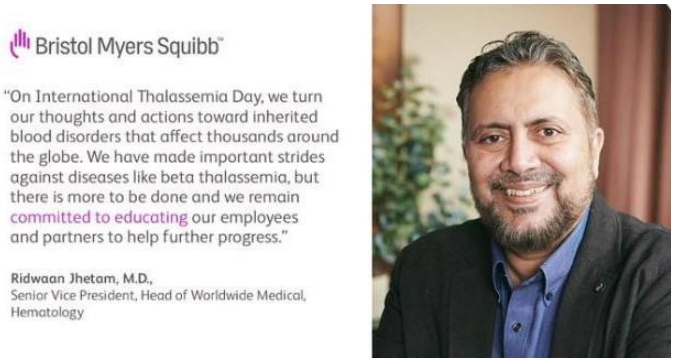


Bristol Myers Squibb
1,155,854 followers
3w • Edited •

"Let us work together, know more about thalassemia, and share knowledge to help create a better future for us and the generations to come."

On International Thalassemia Day, we're joining forces with organizations across Middle East and Africa like the Thalassaemia International Federation and United Nations Population Fund (UNFPA) Honorary Ambassador Amina Khalil to spread awareness and support the 80 million people impacted globally by the blood disorder. Watch to learn how you can join us in #TransformingThalassemia and make a difference. #ITD2023

https://lnkd.in/dVFFaeV9



Bristol Myers Squibb

"On International Thalassemia Day, we turn our thoughts and actions toward inherited blood disorders that affect thousands around the globe. We have made important strides against diseases like beta thalassemia, but there is more to be done and we remain committed to educating our employees and partners to help further progress."

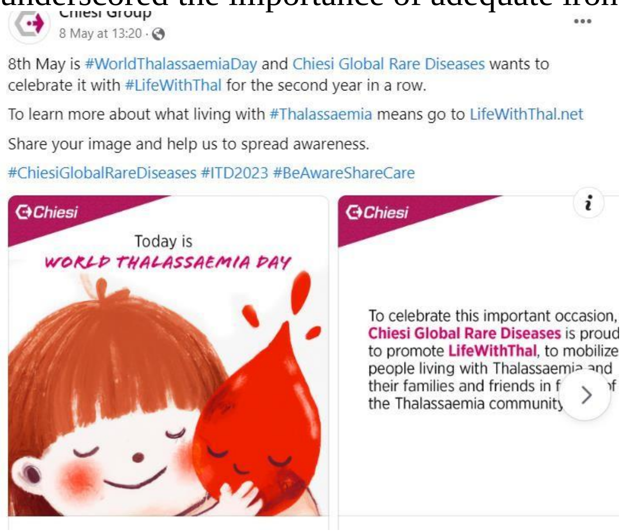
Ridwaan Jhetam, M.D.,
Senior Vice President, Head of Worldwide Medical, Hematology

In addition, BMS's Senior Vice President and Head of Worldwide Medical Hematology, Dr Ridwaan Jhetam, M.D., emphasized the need to focus more efforts on thalassaemia education to help achieve further progress on thalassaemia, while stressing the company's ongoing research efforts to tackle the disease-burden of people affected by inherited blood disorders.

Chiesi Group and **Chiesi Global Rare Diseases** continued the #LifeWithThal initiative for the second consecutive year to raise awareness about thalassaemia major across different cultures.

Chiesi invited everyone to express what living with thalassaemia means to them by using Artificial Intelligence by creating unique, artistic images in celebration of International Thalassaemia Day and sharing them online to bring more attention to the disease and its burden. With this campaign, Chiesi aimed at amplifying the voice of the thalassemia community and raising broader awareness on this disease in the general population of the most affected countries, giving the word directly to the community.

Moreover, the company encouraged learning about iron overload in thalassaemia and underscored the importance of adequate iron chelation for its effective treatment.



Chiesi Group
8 May at 13:20 ·

8th May is #WorldThalassaemiaDay and Chiesi Global Rare Diseases wants to celebrate it with #LifeWithThal for the second year in a row.

To learn more about what living with #Thalassaemia means go to LifeWithThal.net

Share your image and help us to spread awareness.

#ChiesiGlobalRareDiseases #ITD2023 #BeAwareShareCare

To celebrate this important occasion, Chiesi Global Rare Diseases is proud to promote LifeWithThal, to mobilize people living with Thalassaemia and their families and friends in f of the Thalassaemia community

'A man carrying a drop of blood in a field full of flowers' interpreted by DALL·E 2 artificial intelligence

Silence Therapeutics @SilenceTheraPlc · May 8
Today is #InternationalThalassemiaDay. We're celebrating the work done by @thalassaemiaTIF, @teamukts and all involved in awareness and education that supports those affected by #thalassemia to receive better care. We can all play a role in spreading the word. #BeAwareShareCare

Silence Therapeutics, in collaboration with TIF, invited its employees to a Listen & Learn (L&L) virtual event, where the importance of the awareness day and the contribution of disease-specific education to improve thalassaemia-related care were showcased.

Dr Michael Angastiniotis, TIF's Medical Advisor, and Mr George Constantinou, TIF's Board Member and Patient Advocate, participated in the discussion that revolved around the different perceptions from someone living with thalassemia in terms of challenges and unmet needs, and the heterogeneity of these needs across the world.

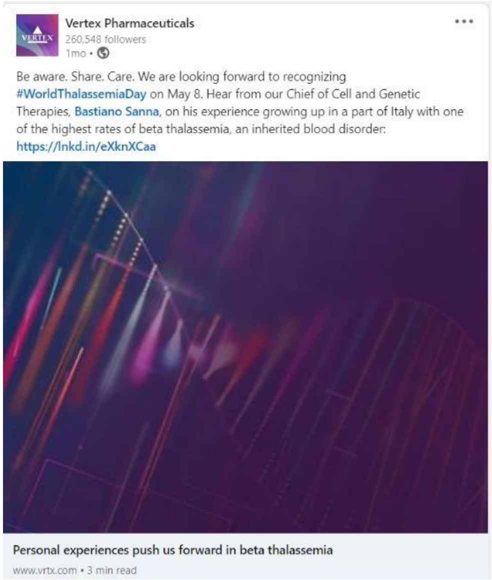
Additionally, the company also posted various messages in support of ITD2023 across its social media channels.

Vertex Pharmaceuticals @VertexPharma · May 8

Getting blood transfusions every 3 weeks is just part of life for these brave sisters. They are living with transfusion-dependent beta thalassemia (TDT), an inherited blood disorder, but they don't let the disease define who they are. Hear from the girls themselves.

Vertex Pharmaceuticals marked ITD2023 by sharing the poignant stories of Franny and Rosie, 2 young girls with transfusion-dependent β-thalassaemia, who shared their life stories with the disorder in an inspiring video.

The company also showcased the experience of its Chief of Cell and Gene Therapies, Bastiano Sanna, who grew up in Sardinia, a part of Italy with one of the highest rates with β-thalassaemia in the world, that motivated him to work in the field of transformative therapies for people with the disease. In recognition of ITD and the people living with thalassaemia, Vertex also lit up its Boston offices in blue on the night of 8 May.



Vertex Pharmaceuticals
260,548 followers
1mo •

Be aware. Share. Care. We are looking forward to recognizing #WorldThalassemiaDay on May 8. Hear from our Chief of Cell and Genetic Therapies, Bastiano Sanna, on his experience growing up in a part of Italy with one of the highest rates of beta thalassemia, an inherited blood disorder: https://lnkd.in/eXknXCaa

Personal experiences push us forward in beta thalassemia
www.vrtx.com • 3 min read

Vertex Pharmaceuticals @VertexPharma · May 8

Today, on #WorldThalassemiaDay, our Boston office will be lit up blue to represent the people around the world living with #betathalassemia. vrtx.com/patients/beta-...

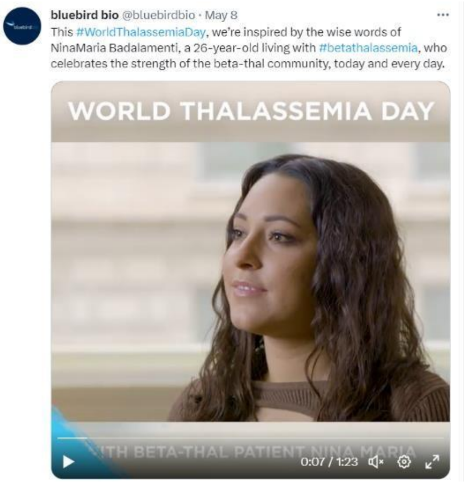
Editas Medicine and **bluebird bio** observed ITD2023 by releasing videos and stories of patients with β-thalassaemia, spreading awareness about the importance of bridging the care gap and inspiring others to take action.

Editas Medicine @editasmed · May 8

In honor of #InternationalThalassemiaDay, Ryan, who is living with beta thalassemia, shares his thoughts. Visit thalassaemia.org.cy/itd2023/ ✓ to learn more about #ITD2023. #BeAwareShareCare #StrongerTogether

"International Thalassemia Day is a day where we get to take pride in existing and knowing that others see us and what we're facing. It's our special day, a celebration of life. I hope that it motivates someone who is part of the Thalassemia community to go out and teach someone about the impact of this disease and the importance of advancing treatments that can improve our wellbeing."

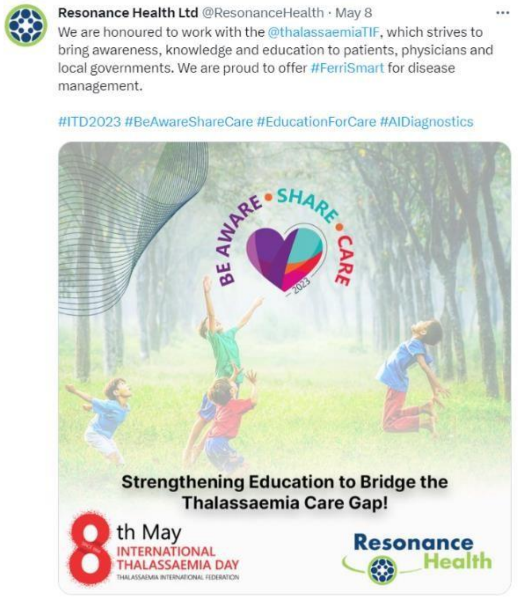
Ryan, living with beta thalassemia



bluebird bio @bluebirdbio · May 8

This #WorldThalassemiaDay, we're inspired by the wise words of NinaMaria Badalamenti, a 26-year-old living with #betathalassemia, who celebrates the strength of the beta-thal community, today and every day.

[Resonance Health](https://resonancehealth.com) and [Hemanext](https://hemanext.com) aligned with the International Thalassaemia Day campaign and showcased their collaboration with TIF, highlighting the crucial components of awareness and education in the global fight against thalassaemia.



Resonance Health Ltd @ResonanceHealth · May 8

We are honoured to work with the @thalassaemiaTIF, which strives to bring awareness, knowledge and education to patients, physicians and local governments. We are proud to offer #FerriSmart for disease management.

#ITD2023 #BeAwareShareCare #EducationForCare #AIDiagnostics

Hemanext
5 May at 21:00

Education and awareness are crucial in the fight against #thalassaemia. On this International Thalassaemia Day next week Monday May 8, let's come together to support the thalassaemia community and spread the word about this genetic blood disorder. Visit https://thalassaemia.org.cy/itd2023/learnmore/ to learn how you can make a difference.

#Hemanext #ITD2023 #BeAwareShareCare #CareForEducation #InternationalThalassaemiaDay

In line with the theme of this year's International Thalassemia Day – "Be Aware. Share. Care", BGI Genomics will co-host an event with the Shenzhen Municipal Health Commission for thalassemia patients and their family members on May 6, 2023, in Shenzhen, China, providing tips on thalassemia control and leading an HSCT donation drive.

This event will be followed by a seminar and another HSCT donation drive for children with thalassemia in Chenzhou, Hunan province, China, on May 8, 2023 – International Thalassemia Day – where BGI Genomics will participate.

[BGI Genomics](https://www.bgi.com) amplified messages on social media and the press about the importance of thalassaemia awareness and effective screening and control, as well as its commitment to further push forward research in the field of genomics for the benefit of people living with the disorder.

Several important international and regional organisations and scientific communities operating in the fields of Haematology and Transfusion Medicine, such as the

European Blood Alliance (EBA), the **European Hematology Association (EHA)**, the **International Society of Blood Transfusion (ISBT)**, the **European Society for Blood and Marrow Transplantation (EBST)**, the **Association for the Advancement of Blood & Biotherapies (AABB)** and others, joined TIF in recognition of International Thalassaemia Day and amplified thalassaemia awareness messages, along with resources from the ITD campaign, through their various channels.

For this special occasion, the AABB turned over its Instragram account for the whole day of May 8 to Maria Hadjidemetriou, TIF's Patient Advocate Group (TPAG) Member and Cooley's Anemia Foundation (CAF) Board Member, where she shared with audiences videos of what a transfusion day for a patient with thalassaemia is like, and explained why blood donations and iron chelation are of essence for people with TDT.

European Blood Alliance @EUBloodAlliance · May 8

Today is International Thalassaemia Day.

We join @thalassaemiaTIF, patients, their families and the medical and scientist community in their call for "Strengthening Education to Bridge the Thalassaemia Care Gap".

Learn more at thalassaemia.org.cy ✓

#ITD2023 #BeAwareShareCare

More than **half a million children** are expected to be **born with thalassaemia and other haemoglobin disorders** worldwide by 2030.

Only a handful of countries with medium- and high-disease prevalence have **nationally coordinated prevention programmes** in place.

In most **countries with medium- and high-disease prevalence,** patients with β-thalassaemia major **do not reach the age of 20 years.**

More than **80% of β-thalassaemia patients** worldwide **struggle to get appropriate and timely** blood transfusions and iron chelation therapy.

SOURCE: TIF Global Thalassaemia Review, 2021
https://thalassaemia.org.cy/what-we-do/global-thalassaemia-review/

ISBT Central Office @ISBTCO · May 8

🩸 Today is #WorldThalassemiaDay, a day to raise awareness of this genetic blood disorder that affects millions of people worldwide.

Let's work together towards a future where thalassemia no longer poses a threat to the health and wellbeing of those affected.

World Thalassemia Day 2023

Did you know that people living with thalassemia need lifelong blood transfusions and chelation therapy to manage their condition?

Let's show our support by spreading awareness and donating blood. Your donation can make a huge difference in someone's life!

The EBMT @TheEBMT · May 8

Today on #InternationalThalassaemiaDay, let's work together to raise awareness about thalassaemia and help the global community work towards equity in care & access to therapies for people living with the disorder 🩸❤️ @thalassaemiaTIF #ITD2023 #BeAwareShareCare

Thalassaemia is a manageable chronic disorder.

Healthcare Professionals must know how to accurately diagnose the condition early on and provide patients with timely & appropriate care.

When did you last update your thalassaemia knowledge?

TIF’s Participation in National Events

An overwhelming number of awareness-raising events, including blood drives, educational workshops, scientific meetings, awareness-walks, and other engaging initiatives took place for International Thalassaemia Day 2023 all over the world.

TIF co-organised with or contributed to several virtual and physical events of its member patient associations in countries, such as Greece, the UAE, Italy, China, Azerbaijan, Brazil, Egypt, Indonesia, and Saudi Arabia.

University Hospital of Sharjah - UAE

TIF joined forces with the University Hospital Sharjah (UHS), in the United Arab Emirates, where a compelling awareness event was held on May 8, 2023, with the objective to raise thalassaemia awareness, share disease-related information and resources, and highlight the significance of thalassaemia prevention through medical screenings.

The event included academic lectures, free screening sessions and haematology consultation. TIF’s Executive Director, Dr Androulla Eleftheriou, addressed participants through a recorded video speech, in which she complimented the exemplary, patient-centred care offered by UHS to patients with thalassaemia in the UAE and the wider MENA region, whilst reaffirming TIF’s commitment to strengthening and expanding its relations and work in the country.

The event received extensive press coverage, with several newspapers, radio broadcasts, and media channels reporting on its proceedings.

Greek Thalassaemia Federation - Greece

The ‘Panhellenic Thalassaemia and Sickle Cell Disease Awareness Conference 2023’ returned after two years of absence in 2023 and was held on the eve of International Thalassaemia Day, on May 5-7, 2023, at Lake Plastiras, Greece.

The Conference, jointly organized by the Greek Thalassaemia Federation (E.O.TH.A.) and the Thalassaemia Patients Association of Karditsa, and held under the auspices of TIF, presented to the public the latest developments in scientific research regarding both thalassaemia and sickle cell disease, and constituted a unique opportunity for patients and their families from all over Greece to acquire invaluable knowledge for the treatment of these disorders.

The challenges faced by people living with thalassaemia and their families in accessing quality care and the efforts required to ensure blood safety and sufficiency, were also accentuated.

Representing TIF, Dr Androulla Eleftheriou, Executive Director, participated in the event and delivered a welcome address on behalf of the Federation’s Board of Directors.

New Sunshine Charity Foundation - China

New Sunshine Charity Foundation organised on May 8, 2023, the ‘National Thalassaemia Forum’, in partnership with other stakeholders in the health sector, including patient leaders, healthcare professionals, medical doctors, policymakers and the media. The event raised awareness about the importance of early detection of thalassaemia and featured panel discussions on various thalassaemia-related topics, including the latest advances in treatment, the challenges of patient access to adequate care, and the importance of community involvement in the fight against the disorder.

People with thalassaemia shared their stories and experiences, thus inspiring hope and encouraging others to seek treatment. TIF's Executive Director, Dr Androulla Eleftheriou, addressed participants through a recorded welcome speech, calling for the strengthening of thalassaemia prevention programmes and other relevant policies, especially in areas of high disease prevalence, such as Guangxi and Guangdong provinces in southern China.

In addition, more than 300 volunteers participated in multiple other awareness activities, coordinated by the Foundation on and around ITD2023, such as blood drives, outreach sessions in musical concerts and regional hospitals.

Azerbaijan Thalassaemia Centre - Azerbaijan

On May 8, 2023, an International Thalassemia Day event dedicated to the 100th anniversary of the birth of Heydar Alirza oglu Aliyev, the third President of the Republic of Azerbaijan, was held at the National Hematology and Transfusion Center of the Ministry of Health of the Republic of Azerbaijan, in Baku.

The event saw the participation of Fazil Hüseynbəyov, Director of the Health Organization Department of the Ministry of Health of the Republic of Azerbaijan, Naila Quliyeva, President of the Azerbaijan Thalassaemia Federation and former TIF Board of Directors Member, and other health-related stakeholders.

Dr Michael Angastiniotis, TIF's Medical Advisor, and Professor Duran Canatan, Antalya Bilim University, joined the event online to share useful insights on the topics discussed, including thalassaemia diagnosis and treatment standards, the implementation of TIF's TDT Guidelines for the management of β-thalassaemia, and national blood supply and donation challenges.

A short video clip from the event can be viewed here.

Egyptian Thalassaemia Association (ETA) - Egypt

The 24th International Thalassaemia Conference, organized by the Egyptian Thalassemia Association (ETA) in collaboration with the Thalassaemia International Federation (TIF), took place on May 10-11, 2022, in Cairo.

The event brought together the elite of local haematologists, as well as renowned international experts in the haemoglobinopathies field, who explored and updated their knowledge in topics, such as recent advances in thalassaemia management, thalassaemia epidemiology, diagnosis, complications, and vulnerable groups, stem cell transplantation, gene therapy, and much more.

The Conference attracted more than 250 participants and was held in hybrid format, allowing both virtual and face-to-face participation. Dr Androulla Eleftheriou, TIF's Executive Director, represented the Federation in the event and delivered an engaging welcome message.

The full recording of the Conference is available here.

Brazilian Thalassaemia Association (ABRASTA)

The ‘3rd International Meeting for People with Thalassemia’ was organized on May 6, 2023, by the Brazilian Thalassaemia Association (ABRASTA) and in collaboration with TIF.

This meeting represented a unique opportunity for patients with thalassaemia from all over the world to exchange experiences with their peers and engage in meaningful discussions over issues, such as relationships, treatment, mental health, and much more.

Through an online platform, segmented by age group and topics of interest, with simultaneous translation in Portuguese, English, and Spanish, all participants were able to share experiences from their everyday life with the disorder and acquire new knowledge.

An important masterclass with Hematology Specialists Dr Anronio Piga and Dr Monica Verissimo concluded the successful event. More than 250 patients from 25+ countries registered for the meeting.

Franco and Piera Cutino Association – Italy

Marking International Thalassaemia Day 2023 and its 25th anniversary, the Franco and Piera Cutino Association organised a Conference entitled ‘Thalassaemia Today: Celebrating Successes and Addressing Persistent Unmet Needs in Thalassaemia’, which took place on May 8, 2023, in Palermo, Italy.

Disease-modifying and curative therapies were discussed in the context of unmet needs for patients with β-thalassemia, transfusion- and non-transfusion-dependent, and sickle cell disease.

These field updates were followed by two practical sessions relevant to the introduction of novel therapies for thalassaemia into clinical care and a round table discussion with representatives of regulatory agencies and patient associations to discuss current and anticipated challenges in access to novel treatment approaches in the EU and globally.

The event was held under the patronage of the Thalassaemia International Federation - TIF, the Italian Society for Thalassemia and Hemoglobinopathies (SITE), United Onlus, and other scientific and patient organizations.

In recognition of International Thalassaemia Day and to honour the Association’s anniversary, the President of Italy, Hn. Sergio Matarella, addressed the event through a written statement which was read during the opening ceremony by Giuseppe Cutino.

Mr Panos Englezos, TIF’s President, conveyed a message on behalf of the Federation, while Mr Loris Brunetta, TIF’s Board of Directors Member, and Mr Marco Bianchi, TIF’s Patient Advocacy Group Member and United Onlus representative, took active part in the event.

The full recording of the Conference is available here.

TIF’s Arab Thalassaemia Societies Forum (TATAF)

To mark International Thalassaemia Day, the Thalassaemia International Federation (TIF) and the TIF Arab Thalassemia Societies Forum (TATAF) organised the 2nd virtual meeting for young thalassaemia patients on May 3, 2023, under the topic “*Empowering Young Thalassaemia Patients Through Training and Developing their Abilities*”.

A group of young people from Saudi Arabia, Iraq, Algeria, Lebanon, Palestine, and Egypt organised the meeting that saw the participation of many patients, caregivers, and individuals with a vested interest in thalassaemia.

The meeting focused on the importance of self-development, community integration and health education of patients, with participants openly talking about their issues and needs, and sharing experiences with their peers.

Indonesian Society of Hematology & Transfusion Medicine - Indonesia

Marking International Thalassaemia Day 2023, the 2nd National Thalassemia Meeting was jointly organised by the Indonesian Pediatric Society, the Indonesian Society of Hematology & Transfusion Medicine, the Thalassemia Indonesian Foundation, the Indonesian Thalassemia Parents Association, and the Thalassemia Movement, on May 6-7, 2023, in Jakarta, Indonesia.

Seeking to strengthen the exchange of knowledge amongst thalassaemia-treating physicians, the Meeting comprised of two distinct scientific sessions including a vast array of topics, such as early disease detection and screening, management of thalassaemia-related complications, bone marrow transplantations and case study presentations.

Dr Androulla Eleftheriou, TIF's Executive Director, addressed the event through a recorded welcome speech.

Madinah Hereditary Blood Disorders Society – Saudi Arabia

The Madinah Hereditary Blood Disorders Society celebrated International Thalassemia Day, on 27 May 2023, with activities that included numerous activities, such as community-directed awareness, educational workshops for patients and parents, and psychosocial support and rehabilitation discussions.

A recorded introduction speech by Dr Androulla Eleftheriou, TIF's Executive Director, was displayed during celebration.

Snapshots from World Celebrations

FAITH, Pakistan

Thalassaemia Society of Mauritius, Mauritius

Cooley's Anemia Foundation, USA

Amina Bashir Memorial Trust Hospital, Pakistan

Thalassaemia Society of Mauritius, Mauritius

FAITH, Pakistan

Thalassaemia Society of Mauritius, Mauritius

Cooley's Anemia Foundation, USA

SHE, Maldives

Hoi Tan mau bam sinh, Viet Nam

Help International Welfare Trust (HIWT), Pakistan

Hoi Tan mau bam sinh, Viet Nam

Regional Blood Centre, Islamabad, Pakistan

Regional Blood Centre, Islamabad, Pakistan

Hoi Tan mau bam sinh, Viet Nam

Fuvahmullah Hospital, Maldives


Fuvahmullah Hospital, Maldives

Artistic Creations


KASH - Koi Apna Sa Ho Foundation, India

National Blood Bank, Afghanistan


Association JOIE DE VIVRE, Tunisia

ATA, Argentina

Birmingham Children's Hospital, UK


Chronic Care Centre, Lebanon

Chronic Care Centre, Lebanon


Cyprus Thalassaemia Association, Cyprus


Cyprus Thalassaemia Association, Cyprus


Foundation Against Thalassaemia Regd., India


LabOne Foundation, Bangladesh

LabOne Foundation, Bangladesh


Foundation Against Thalassaemia Regd., India

LabOne Foundation, Bangladesh

Northwest School of Medicine, Peshawar, Pakistan

Omair Sana Foundation, Pakistan

Northwest School of Medicine, Peshawar, Pakistan

Northwest School of Medicine, Peshawar, Pakistan

Help International Welfare Trust (HIWT), Pakista

Greek Thalassaemia Association, Greece

Greek Thalassaemia Association, Greece

Omair Sana Foundation, Pakistan

AMAMI Associazione Malati Anemia Mediterranea Italiana, Italy

AMAMI Associazione Malati Anemia Mediterranea Italiana, Italy

Amina Bashir Memorial Trust Hospital, Pakistan

Suriname Thalassemia Association

Amina Bashir Memorial Trust Hospital, Pakistan

Dubai Thalassaemia Centre, UAE

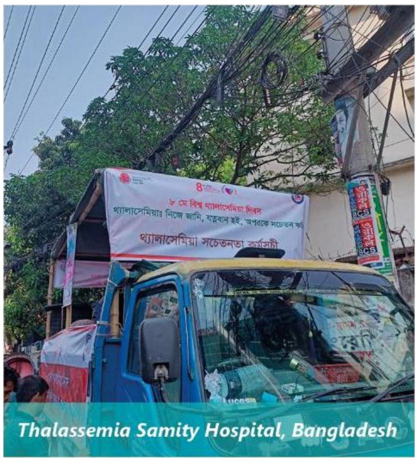
Dubai Thalassaemia Centre, UAE

ATA, Argentina

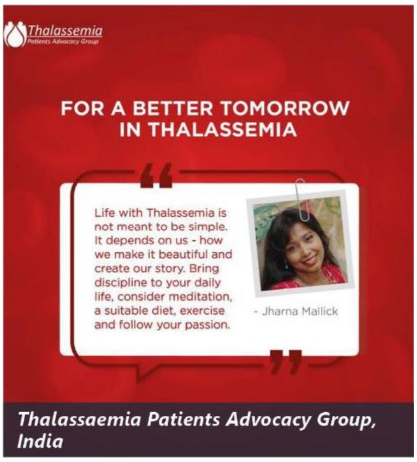

Azerbaijan Thalassaemia Federation, Azerbaijan


Azerbaijan Thalassaemia Federation, Azerbaijan

Thalassemia Samity Hospital, Bangladesh



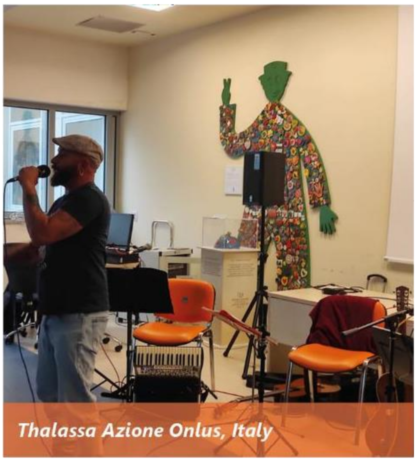
Thalassemia Samity Hospital, Bangladesh



Thalassaemia Patients Advocacy Group, India

Artistic Creations

TASCA, Australia


Thalassa Azione Onlus, Italy

Association JOIE DE VIVRE, Tunisia


TASCA, Australia


Dattaji Bhale Blood Bank, India

Department of Haematology, Ward-37, CMCH, Bangladesh

Fatimid Foundation Hyderabad, Pakistan


Dattaji Bhale Blood Bank, India

Department of Haematology, Ward-37, CMCH, Bangladesh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Department of Haematology, Ward-37, CMCH, Bangladesh

Another fantastic International Thalassaemia Day came to an end!

The Thalassaemia International Federation (TIF) gives a huge shoutout to all the amazing supporters who stepped up, spoke out, rallied their communities, and helped make a difference this ITD2023.

We couldn’t have done it without the hundreds of thousands of supporters around the world! We must not forget the incredible TIF member associations and the international thalassaemia community, whose tireless efforts every day bring the world closer, one step at a time, to bridging that care gap.

We are honoured to be a part of this extraordinary community. Let’s keep this momentum going!

Thank you.