50 years

Cyprus Thalassaemia Association

WHO IS CYPRUS THALASSAEMIA ASSOCIATION

Cyprus Thalassaemia Association is a non-governmental organization which enrolled in 1977 in the Register of the Registrar of Foundations and Unions (No. 0072), after 8 years of efforts, by parents and friends of people with Thalassaemia (PwT) to protect their children's rights against critical medical, social, and economic problems. For 5 decades, it has been continuously active, always with the aim of providing all assistance to sufferers with thalassemia.

CTA is a founding member of the Thalassaemia International Federation (TIF), which has developed rich research and writing work, is one of the collaborators of the World Health Organization and has recently been awarded for this work by the WHO.

The need to secure blood supplies for the transfusions of PwT, urged the CTA to establish the Coordinating Committee on Blood Donation and Enlightenment which in collaboration with the services of the Ministry of Health have established Cyprus as a pioneer in the field of voluntary blood donation.

CTA is also actively involved in other organizations since it has a seat at the Board of the Cyprus Institute of Neurology and Genetics (CING), the Pancyprian Patient Associations Federation (OSAK) and the Pancyprian Alliance of Rare Diseases (PASSP).

Today, CTA numbers around 850 members in all the provinces of Cyprus. Approximately 650 of these are people with β-homozygous thalassemia, with the vast majority of these being between 35-55 years. In the association is also registered a very small number of people out of the 500 people with a-thalassemia in Cyprus.

Most of them excel in their field and are an example to be emulated as parents, as academics in universities, as builders, as carpenters, as teachers, as doctors, as business executives, as artists, architects, pioneers, productive and useful members of Cypriot society.

OBJECTIVES OF THE ASSOCIATION

The main aims of the association are:

1. General care and safeguarding of the rights of PwT.

2. To inform and raise awareness of the community for thalassemia and blood donation.

3. The application of appropriate means for effective treatment of thalassemia in accordance with the international protocols of disease treatment.

4. Education, social adaptation, training, psychological support, professional rehabilitation and general care of PwT.

5. The support and reinforcement of the medical centres and any installation of any kind serves the chronic therapeutic needs of the PwT.

ACTIVITIES

CTA, in its effort to protect the rights of PwT and strengthen their voice, has a strong participation in a wide range of activities:

- Participates with 2 members in the Board of the Thalassaemia International Federation, one of which is the current president of TIF, honorary president, former president and founding member of PAS, Mr. Panos Englezos.
- Participates, with a representative, in the National Committee of Thalassaemia.
- Participates, with a representative, in the Board of directors of the Cyprus Institute of Neurology and Genetics (CING) with which he has recently concluded a cooperation agreement in research projects and is a key partner in the development of a clinical programme on gene treatment of thalassemia in Cyprus.
- Participates in the Ad Hoc Committee for Blood Donation
- Is an active member of the Board of the Pancyprian Patient Associations Federation (OSAK).
- Is an active member of the Board of the Pancyprian Alliance of Rare Diseases (PASSP).
- Is the founder and constant supporter of the Coordinating Committee for Blood Donation and enlightenment.
- Has stable cooperation with the Ministry of Health at the highest level, with the Blood Centre and the Blood Banks, the medical and nursing staff of clinics and hospital management in Cyprus.

During its 5 decades of action, CTA has focused on almost every aspect of the treatment PwT, their integration into society and the working environment, their psychological support and training both the PwT and the medical and nursing staff.

The challenges CTA is facing are the medical needs, the adequacy and the safety of the blood, the access to medicines and consumables and high level holistic medical care. Additionally, social acceptance and inclusion, right to work, psychological support and the whole management of a serious chronic disease.

CTA, perceiving the role it is called to perform by defending the interests of the PwT in the constant struggle of them and their families, has developed and continues to develop rich and multi-level action:

- Founded the Thalassaemia Centre in Nicosia, in collaboration with the state and the Church. Continuing this cooperation, in collaboration with the state, the New Thalassaemia Center is now being created.
- Monitors, in cooperation with the clinics, every development in relation to the treatment and intervenes accordingly to ensure as much as possible access to high quality preparations, consumables and services.
- Participates in meetings with officials of the Ministry of Health and the HIO, giving feedback and demanding specifications for the consumables used.
- Organizes workshops and conferences with distinguished doctors and personalities from Cyprus and abroad to educate patients, doctors and nursing staff on issues that concern the thalassaemia community and supports the attendance of seminars.
- Supports psychological support programs and extensive and preventive physiotherapy, which the state is unable to provide to patients and their families through meetings and workshops.
- Studies and informs patients about their rights by the state and claims their application and the safeguarding of rights that patients are required to have in a modern, European state.
- Supports and enhances blood donation with various interventions at all levels.
- Supports thalassaemia clinics with medical and other equipment and offering services to patients during their treatment.
- Supports the families of children who go abroad for genetic therapy through a collaboration with the “One Dream One Wish” foundation.

HISTORY FACTS FOR THE ASSOCIATION

The idea for the establishment of an organized association of people suffering from Thalassemia was developed since 1969, by parents of children with Thalassemia, facing family and social problems along with economic exploitation. The support from the scientific world was rare. The first meeting was on May 14, 1973, at the 1st Elementary School of Pallouriotissa with about 30 parents. The organization was founded at the time "Association of Parents of Mediterranean Anemia Children", based in Nicosia with the aim of mass mobilizations to find a solution to current problems.

Later, in March 1974, because it was found that the problem of Mediterranean Anemia concerned all of Cyprus, it was decided in by a general meeting the renaming of the Organization to "Pancyprian Antianemic Association" (PAS in Greek – Cyprus Thalassaemia Association is used for English) in order to address the problem on a pancyprian scale and in 2020 the General Assembly approved the renaming (in English) in Cyprus Thalassaemia Association (CTA)

The approval of its statutes was taken by the Board of Directors at 29/4/77 and submitted to the Minister of the Interior for approval in 31/5/1977. The official approval was given on 3/9/1977.

CTA with decisions of the Board of Directors, decided as to promote to the General Assembly of 2016 as well as General Assembly of 2019, which approved it on both cases, changes, modifications and updating of the Statute, to address functional and structural problems in the operation of the association.Στην Γενική Συνέλευση του 2022, λαμβάνεται η απόφαση όπως ο Σύνδεσμος, ενόψει και της συμπλήρωσης της πρώτης πεντηκονταετίας δράσης και προσφοράς, προχωρήσει σε αλλαγή ονόματος και εταιρικής εικόνας.

During the General Assembly of 2023, it is decided that the new name of the Association will be "Cyprus Thalassaemia Association" and the logo a red "Θ" (from the Greek word "Θαλασσαιμία" for "Thalassaemia") that will include 2 white drops, inverted, symbolizing the blood offered during blood donation and taken during transfusion. This change was approved by the Registrar of Associations and Foundations in June 2023.

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For more information, visit our website.

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