

# THALASSAEMIA INTERNATIONAL FEDERATION

In official relations with the World Health Organization



## PRESS RELEASE

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### **Cyprus-Based Thalassaemia International Federation Gains Representation on the Board of European Patients' Forum**

**TIF President Mr Panos Englezos was elected on 8 April 2008 for a two-year term on the Board of the EPF, a highly influential umbrella group of pan-European patient groups active in the field of public health and health advocacy at the European level.**

The EPF has since its establishment in 2003 become the main point of reference for the European Commission and the European Parliament in public health policy. Mr Englezos will be representing Thalassaemia International Federation (TIF) and Cyprus as a Board Member for the next two years, during which he will be involved in crucial European-level policy-making activities in areas such as patients' rights, patient safety and rare diseases.

The appointment of Mr Englezos to the EPF Board is a recognition of TIF's efforts for the past two years to extend its activities in Europe and engage in working relationships with a number of important European-level organisations. It is also a reflection of the achievements of TIF worldwide for the last two decades, for example through its longstanding collaboration with WHO which recently resulted in a joint five-year plan of action for the global implementation of WHO resolutions on thalassaemia and sickle cell disease. Last but not least, it is a fitting recognition of Mr Englezos's personal commitment throughout his life to the promotion of thalassaemia control worldwide. TIF Executive Director, Dr Androulla Eleftheriou said: "TIF is very proud of the selection of its President to be involved in such a prominent European-level organisation together with several other distinguished personalities, and Cyprus should be proud, too. Panos Englezos's sensitivity, dedication and tireless work on behalf of patients and parents fighting for survival and a better life are an example to every one of us."

### **Decades of pioneering work for thalassaemia patients in Cyprus and worldwide**

Panos Englezos is well known to most Cypriots in his high-profile role as the Chairman of the Board of the Cyprus Tourism Organisation. Less known is the fact that he has devoted most of his life to voluntary work promoting the control of thalassaemia (also known as Mediterranean anaemia) at the national and international level. A parent of a son with thalassaemia major, he was among the founding members of the Pancyprian Antianaemia Society (PAS) in the 1970s, and of the International Thalassaemia Federation in 1986. He served as President of the Board of Directors of PAS for over 30 years and was elected as the first President of

TIF – a position he still holds. His personal contribution towards the patients and parents fighting for survival and a better life has been enormous, and the international medical and patients/parents' communities recognised this by adopting the 8<sup>th</sup> of May – the day of his son George's death – as International Thalassaemia Day, during which awareness campaigns are organised around the world. Panos Englezos has raised the visibility of TIF to a level that many other patient organisations can only wish they could reach. Despite losing his son in 1993 he continues his tireless work at TIF to establish and promote national patient support associations and to fight for the right of every patient across the world to optimal healthcare.

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### **Information for editors**

#### **Thalassaemia International Federation**

Thalassaemia International Federation (TIF) was established in 1986 by patients and parents mainly from the Mediterranean countries, the UK and USA to coordinate the struggle against thalassaemia on a worldwide basis and to support and strengthen the efforts of local thalassaemia associations. Since 1996, TIF has been in official relations with WHO and is considered the international reference organisation for thalassaemia.

TIF's mission is to obtain equal access to quality health care for every patient with thalassaemia, and to support the establishment of effective control programmes across the world. To achieve these goals, TIF focuses on:

- (i) supporting the activities of national patients' and parents' organisations;
- (ii) establishing new associations where they do not yet exist; and
- (ii) supporting national health authorities in their efforts to develop effective national control strategies.

One of the main challenges for TIF is to "bridge the gap" that today exists between industrialised and developing countries – to extend the knowledge, experience and expertise gained in those countries that first recognised thalassaemia and developed effective control programmes, to other affected countries across the world. TIF's longstanding collaboration with WHO has recently resulted in the adoption of resolutions on sickle cell disease and thalassaemia, and work is now underway to implement a joint five-year plan of action to put these resolutions into practice across the world.

A major focus of TIF's activities is its educational programme, aimed at spreading information and awareness about thalassaemia prevention, management and cure. To this end the Federation organises regular conferences, workshops and seminars, and publishes an extensive range of educational materials. Between 1989 and 2006, TIF organised 44 educational events at international, regional and local levels, with some 18,000 participants from over 60 countries. To date it has published 11 books and numerous leaflets, distributed globally and translated into more than 11 different languages.

Whilst TIF will continue its work on a global basis, for the past two years the Federation has also been strengthening its activities within Europe and developing a network of collaboration with European patients' associations, medical community and healthcare providers. It actively participates in the work of organisations such as the European Public Health Alliance (EPHA), the European Organisation for Rare Diseases (Eurordis), the

European Platform for Patients' Organisations, Science and Industry (EPPOSI) and the European Medicines Agency (EMA). TIF has also been invited to participate in several European Union -funded research and other projects.

### **About thalassaemia and other haemoglobinopathies**

Thalassaemia and other haemoglobinopathies affect a large percentage of the global population, being among the most common of hereditary disorders worldwide. According to WHO data, around 7% of the global population are carriers of an abnormal Hb gene (of which some 3% thalassaemia) and over 300,000 children affected by thalassaemia are born annually, a great majority of them in developing countries. Many of these children die undiagnosed, without appropriate treatment, or without any treatment at all.

TIF's impact on the establishment and promotion of control programmes for thalassaemia and other hereditary haemoglobinopathies across the world has been tremendous since its establishment in 1987. With the gradual reduction of infant mortality, and the slow but significant improvements implemented in addressing other health priorities in low-resource countries, chronic diseases including thalassaemias and other haemoglobinopathies are now recognised – albeit at varying levels of priority – as major public health concerns that require attention by national governments.

In the industrialised countries of Europe, thalassaemia and other haemoglobinopathies were for many years considered to be well controlled. In recent years, however, it has become evident that they pose a significant public health problem in many countries, mainly as a result of increasing numbers of immigrants from affected areas of the world. Accurate epidemiological data and national prevention programmes are still largely lacking, and despite the generally high quality of health services there is a lack of understanding about these disorders – not only by patients and their families, but also by health professionals, authorities and the general public. For this reason there is now an urgent need to raise awareness of haemoglobin disorders and to implement national prevention and clinical management strategies in European countries.

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