THALASSAEMIA INTERNATIONAL FEDERATION

"In official relations with the World Health Organization"

HEADQUARTERS:
P.O. Box 28807, 2083 Strovolos; 31 Ifigenias Street, 3rd Floor, 2007 Strovolos, Cyprus
Tel: 357-22-319129, Fax: 357-22-314552, E-mail: thalassaemia@cytanet.com.cy
Web-site address: http://www.thalassaemia.org.cy

8TH OF MAY MESSAGE 2012
INTERNATIONAL THLASSAEMIA DAY

THEME: "PATIENTS RIGHTS-REVISITED"

Position paper 5.4 **PP11/2012**

30 March 2012

Dear Friends,

Continuous provision of updated, quality information to patients and their families particularly in the case of genetic (chronic) diseases such as thalassaemia constitutes a major objective for the existence of any patients' orientated organisation in any part of the world.

"Knowledge is our power" was the theme of one of TIF's largest Regional Conferences in 2008 and a concept, on which the Federation has since its establishment in the 1986, focused considerable attention and work. Promoting information and ensuring that knowledge on the disease itself, new advances, results of clinical trials, expressed concerns by experts and upcoming developments in treatment reaches every patient, undoubtedly forms an essential component of our mission, as an international patients' organisation.

In addition, it is equally important for NGOs to focus on the education of patients on existing, new and developing upcoming regulations, directives, recommendations, resolutions, declarations, on policies within and outside the field of health that may affect directly or indirectly the patients' health and quality of life. Particularly essential knowledge in the case of a rare genetic disease such as thalassaemia with immense social and economic repercussions in addition to its medical and public health ones.

Patients' rights were being considered since the very old times in the context of laws/recommendation, binding the medical profession: ***"First, Do No Harm"*** the father of western medicine, Hippocrates (470-360BC) advised his fellow medical professionals.

Today, the rights of patients to information and access to quality health care, two of the basic important rights, are no longer protected only through Hippocrates Oath, or by the rules of medical bio-ethics.

Patients' rights stem from the UN's universal declaration in the 1940s on human rights, in the context of which a special article (Art.25) focused specifically on ***"The right of everyone for a standard of living adequate for the health and well being of himself and of his family, including food, clothing housing and medical care…"***

This constituted a critical first step in establishing the concept of patients' rights reflected also through the words marking the founding on Word Health Organisation (WHO) in 1948:

"The enjoyment of the highest attainable standard of health is one of the fundamental rights, of every human being, without distinction of…"

Despite ongoing efforts and work in securing these rights, it was not until the 1960's and 1970's that Patients' Rights began to receive more serious attention.

In today's world, official health bodies, globally, are striving more than ever before to reduce health inequalities to provide better health for ALL.
Today's world is focusing on the reorientation of health care systems towards more patient centred ones, into which patients would have a role and a voice, and into which their opinion and contribution would be respected and recognised.

"Nothing for the patients without the patients"; "Trust us – We are Patients"; "The wisdom of patients is not effectively harnessed". Therefore phrases that marked the organisation of congresses and the founding of the patients alliances in 2004, specifically focused on the rights of patients, for active involvement, recognition of participation and for equal access to quality health care and safety.

The establishment of the "World Alliance for Patients Safety" by WHO in 2004 was a global initiative and is indeed a key approach addressing issues such as the mobilization and empowerment of patients – "Patients for Patients Safety" and included the **SPEAK UP** campaign, most appropriately describing the responsibilities of patients towards securing and promoting their rights:

- √ **Speak- Up** if you have questions or concerns: It's your rights to know.
- √ **Pay attention** to the care you are receiving.
- √ **Educate** yourself about your diagnosis and treatment
- √ **Ask** a trusted family member or a friend to be your advocate
- √ **Know** what medication you take and why
- √ **Use** a health care provider that rigorously evaluates him/herself against safety standards
- √ **Participate** in all decisions about your care and contribute to the development or reforming of policies that affect your health the quality of your treatment.

It is obvious that Knowledge is a prerequisite to exercising your rights.

The WHO, the EU and other health bodies across the world have focused considerable attention on safeguarding the basic rights of patients and it was not until 2002 that these took in Europe at least the form of a Charter (EU Charter) on the basis of which European Countries were encouraged and prompt to build their legislation.

This Charter described 14 basic rights in total. The right to:

- Preventative medicines
- Access to health services needed according to the disease without discrimination
- Information
- Consent
- Free choice
- Privacy and Confidentiality
- Respect of patients time
- Observance of quality standards
- Safety
- Innovation
- Avoid unnecessary suffering and pain
- Personalised treatment
- Complains
- Compensation

Many countries in Europe have already transformed this Charter into national laws, tailored to each one's needs and existing regulations on prevailing cultural and societal norms. Of course many countries outside Europe (mainly industrialised) have developed their own Charters or regulation based on and encouraged by and following mainly the work of WHO and its regional offices in the different parts of the world.

However, a common devastating realization is the vast gap existing in many of these countries between the transposition into law and the implementation and evaluation of the

impact of these on patients' quality of life and active involvement in discussions on health care services. Still more worrying and painful is the realisation that patients in many more countries across the world including in many industrialised ones, have no defined rights, recognition and respect as patients and certainly no room for active involvement or participation in policy making.

On behalf of the patients, the great concern is that patients themselves are Not Aware, Do Not Know, are incompletely informed or misinformed in what exists or does not exist in their country.

In Europe for example further to the 14 basic rights described above, a plethora of other policies, directives, regulations, recommendations are also in place and many others are on the way or planned for the near or more distant future, all aiming to safeguard the rights of patients in many areas of health, including: those in rare Diseases, participation in clinical trials, protection against counterfeit medicines, establishment of rights of patients for Cross Boarder Health Care, for safe and adequate blood and blood products, protection of personal data and many others, which complement the rights of patients. Patients in Europe, thus, need to become more knowledgeable in order to be in a position, to utilise more effectively what has been already granted to them and in order to become actively and truly involved in the reforming processes in their countries that affect their healthy ageing, quality of life and free mobility across Europe.

In other regions of the world, with the exception of North America, where rights have also received considerable attention for some time now, patients need to fight to learn what exists in their countries in term of patients rights, charters or legislation and fight to put those to the forefront to support their efforts for better health and quality of life.

In other countries, unfortunately, patients have to fight from scratch for their rights, having the UN and WHO declaration s as their solid basis and TIF as their closest ally.

Dear friends, let us join hands – Unity Is Our Strength – and let is focus this year for the 8th of May activities on **"Patients Rights".**

On behalf of TIF, I urge every patient to look and learn about his/her rights, how these are protected and respected in their country, to ensure that they are continuously and accurately informed through their authorities, national patient associations, TIF and accredited sides on the internet.

On behalf of TIF I urge you to join hands in a unified effort to overcome the barrier of ignorance, misinformation and misguidance on what your Rights are.

Join TIF on this 8th of May theme: "Patients Rights _ Revisited" and organise events, workshops, discussions, print educational material, investigate and write to TIF how patients' rights are protected in your country or region. A special webpage will soon be uploaded on TIF's website especially for this theme.

Let us collect this year what the current state of affair is in each country, aiming to put forward for 2013 campaigns specific tailored to the needs of each country.

I encourage everyone to visit the following WHO web-site which includes a list of documents on human rights listed below: http://www.who.int/genomics/public/patientrights/en/

Best regards,

Panos Englezos
President
Thalassaemia International Federation

International / multinational patient rights documents

- Declaration of Alma-Ata, International Conference on Primary Health Care (1978)
- Declaration on the Promotion of Patients' Rights in Europe pdf, 159kb
- Ljubljana Charter on Reforming Health Care (1996)
- Universal Declaration on the Human Genome and Human Rights, UNESCO (1997)
- Convention for Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Biomedicine: Convention of Human Rights and Biomedicine, Council of Europe (1997)
- Patient's Rights and Citizen's Empowerment: Through Visions to Reality (1999)
- Council of Europe: Recommendations – Health and Quality of Life (2000)
- Office of the United Nations High Commissioner for Human Rights: Human Rights and Biotechnology (2002)

National documents on patients' rights

- International Digest of Health Legislation (Belgium)
- International Digest of Health Legislation, 50 (1) (Denmark, Turkey, Lithuania)
- International Digest of Health Legislation, 50 (1) (Denmark, Lithuania, and Turkey)
- Le Service Public de L'Accès au Droit (France)
- Patient's Charter (Hong Kong)
- Rights and Obligations of Healthcare Workers (Hungary)
- How to Enforce Patients' Rights (Hungary)
- Patient Advocacy According to Act CLIV of 1997 on Health (Hungary)
- Patient's Rights Act, 1996 (Israel)
- Patients' Rights Ombudsman (Japan)
- Law on the Rights of Patients and Compensation of the Damage to their Health (Lithuania)
- Patient's Rights (Malaysia)
- Patient's Responsibilities (Malaysia)
- The Patient's Charter (Malaysia)
- Patient's Responsibilities (Malaysia)
- The Patients' Rights Charter (South Africa)
- Patient Rights and Responsibilities: A Draft for Consultation (Scotland)
- The Royal Marsden Hospital Patients' Charter (United Kingdom)
- Your Guide to the National Health System (United Kingdom)
- The Hippocratic Oath (USA)
- American Nurses Association Code of Ethics (USA)
- American Hospital Association Patient's Bill of Rights (USA)
- Testimony on Access to Medical Treatment Act (USA)
- Mental Health Patient's Bill of Rights (USA)

Human rights organizations and documents

- Amnesty International
- Human Rights Organizations Database
- Human Rights Watch
- Physicians for Human Rights
- United Nations High Commissioner for Human Rights