



HEADQUARTERS

31 Ifigenias, 2007 Nicosia, Cyprus • P.O.Box 28807, 2083 Nicosia, Cyprus
Tel.: +357 22 319 129, Fax: +357 22 314 552, E-mail: thalassaemia@cytanet.com.cy

68th session of the WHO Regional Committee for Europe Rome, Italy, 17–20 September 2018

STATEMENT OF THALASSAEMIA INTERNATIONAL FEDERATION (TIF)

Agenda Item 5 (o): Action Plan for the Prevention and Control of Noncommunicable Diseases in the WHO European Region (resolution EUR/RC66/R11)

It is a gratifying sign of the progress achieved over the years in the health profile of many nations, that non-communicable diseases have come to be recognised as a health priority and subject of the Resolution WHA66.10, which gives emphasis to the fact these conditions are now taking prevalence over infectious diseases and malnutrition. This change also comes at a time when health systems in Europe and globally are being reviewed to attain the Sustainable Development Goals and the importance of these conditions as recognised by the UN General Assembly (see resolutions A/RES/70/1 and A/RES/66/2), in many nations and new ideas are being introduced to address the economic and other consequences of the changing disease pattern and the aging population.

According to UN and WHO resolutions, the issue of non-communicable diseases has become synonymous with the most prevalent categories of cardiovascular diseases, diabetes, cancer and chronic respiratory diseases, and obesity, primarily because they are linked to common risk factors and so preventable. Even though it is recognised that children 'can die from treatable conditions, other than the above, (see WHA66/2013/REC/1, annex 4), the whole policy revolves around the adult conditions mentioned above.

The Thalassaemia International Federation represents a group of chronic, hereditary disorders affecting the haemoglobin molecule, which are the commonest of a much wider group of chronic disorders, each one rare in itself but which as a whole affect a very large proportion of the population and have very serious social consequences. These rare and chronic disorders are under the general title of birth defects and are given a secondary role.

Our intervention aims to emphasise the need for a closer look at these disorders and to consider a separate approach in planning health services from the strategies and plans under discussion in this Consultation.

Concerning the haemoglobin disorders it must be noted that they are highly prevalent in countries of southern Europe, but their incidence is increasing almost daily in the non-prevalent regions Europe, through migrations and general population flows. From the epidemiological database of our organisation we estimate that at least 1250 new cases are added each year suffering from beta thalassaemia syndromes and 650 cases suffering from sickle cell syndromes, if no prevention measures are taken. These are added to over 27000 patients with beta thalassaemia syndromes and at least 45000 sickle cell patients, currently known in Europe. These numbers are likely to be underestimates, in the absence of registries in most countries, and will be changing year by year due to population flows and lack of prevention. These are patients who expect a long and good quality of life by the provision of adequate treatment, which must be lifelong and is beyond the reach of individual families. There are well documented strategies which can address both the prevention and the management of these disorders but which are not included in health planning of most countries of the region. This despite WHO resolutions WHA 59.20 and EB118.R1 on haemoglobin disorders as well as WHA63.17 on Birth Defects..



THALASSAEMIA INTERNATIONAL FEDERATION
is the 2015 WINNER of
DR LEE JONG-ILKON MEMORIAL PRIZE
for its OUTSTANDING CONTRIBUTION IN PUBLIC HEALTH

www.thalassaemia.org.cy



Birth defects are in general underestimated. If we consider that there are more than 5000 rare diseases listed most of which are congenital and chronic and which according to western sources affect 6-8% of the population, even if each disorder is rare. This is not a negligible health burden when considering the chronicity and complexity of care that they require.

It is the position of our organisation that the haemoglobin disorders as well as the many other chronic and hereditary disorders require special attention and separate policies from the major non-communicable diseases, which are so far promoted in the WHO agenda for non-communicable diseases. We propose that a major section is initiated for these diseases, in order to establish strategies and policies suitable for the countries of the European WHO region, which is targeted by a migration and refugee influx.