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Agenda item 7

STATEMENT BY THE THALASSAEMIA INTERNATIONAL FEDERATION (TIF)

by Dr Chi Kong Li

Mr Chairperson, Ladies and Gentlemen,

Epidemiology:

Thalassaemia and sickle cell disease are among the world's most common genetic diseases and contribute hugely to the public health burden of affected countries. An estimated 7% of the global population carries an abnormal haemoglobin gene, including thalassaemia. More than 500,000 affected children are born each year, a significant percentage of whom die in affected middle and low-income countries. Despite the medical and technological advances in the field of thalassaemia experienced in recent years, still many hundreds of thousands of patients die undiagnosed, misdiagnosed or sub-optimally, particularly in highly affected developing countries of the world, including this region, because of the lack of effective national prevention and treatment policies major economic and organizational difficulties.

In the WPRO region, the latest WHO figures illustrate that the overall carrier prevalence for haemoglobin defective gene is 2-4 % (β-thalassaemia ~1.5%; α-thalassaemia ~2.5%, and HbE ~5%1). As accurate frequency data are still scarce for many countries of the WPRO region, this may still be a gross misrepresentation of the real problem. However, taking also into account the annual birth rates and the population sizes of the countries of this region (more than 35,000 of affected births per year2), enough is known to confirm the magnitude of the burden on health services that these diseases are already posing.1

Thalassaemia International Federation:

TIF (Thalassaemia International Federation) is a non-profit organization dedicated to improving quality of life and life expectancy for patients with inherited congenital haemoglobinopathies such as thalassaemia. TIF is comprised now of 97 thalassaemia member associations and others from over 60 countries and has been working in official relations with WHO since 1996. 13% of its member associations come from this region, e.g. Cambodia, Malaysia, Philippines, China, Singapore and Taiwan, China.

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[1] Cooley's Anemia – seventh Symposium. Ed. Alan R. Cohen. (1998). Annals of the New York Academy of Sciences. Vol.850

[2] March of Dimes: Global Report on Births defects (2006)

Within its ever-expanding educational activities across the world to spread knowledge on the latest advances on haemoglobinpathies control, including prevention and clinical management, TIF focuses considerable attention to the Western Pacific region by:

a) Supporting the establishment of new and strengthening the already existing patients associations in its effort to promote patient education on their disease, its treatment, prevention and other aspects of thalassaemia control, including public health, psychosocial care and patients rights to name but a few.

b) Promoting patient participation and active involvement in policies and strategies forwarded by national authorities of each country of the region, is another major objective so that these, include the patients' perspective and experience.

c) Supporting the participation of patients/parents and health professionals from the WPRO region countries in national, regional and international conferences on haemoglobinopathies;

d) Supporting the translation of TIF publications mainly on aspects of prevention and clinical management and public awareness on haemoglobinopathies, focusing on the needs of the region, into Chinese, Khmer, Vietnamese, Malay-Bahasa and Filipino.

e) Promoting the activities of the Asia Network of experts on haemoglobinopathies, created in 2003 by a group of experts from the region, with Prof Sir David Weatherall, Weatherall Institute of Molecular Medicine, John Ratcliff Hospital, Cambridge, UK, as the overall coordinator and Prof Suthat Fucharoen Thalassaemia Research Centre, Institute of Science & Technology for Research, Mahidol University, Thailand and Head of the WHO collaborating Centre, as the regional coordinator.

RECOMMENDATIONS:

Through this brief statement, TIF takes the opportunity to request from the WPRO Regional committee meeting to:

- Strengthen patients' voice, so that they can become informed patients and encourage their involvement in shaping up national health policies that would improve the health care provided to them;

- Encourage national health authorities to employ effective control strategies, considering the cost-effectiveness of the implementation of effective prevention programmes in highly affected countries, and bearing in mind the positive impact that resources reallocation and savings, through prevention programmes on the improvement of health care services provided to living patients with haemoglobinopathies, will have;

- Support national efforts to promote public awareness about these diseases.

- Support twinning programmes between countries whose haemoglobinopathies' control policies have achieved a measureable level of success with countries that have minimal or no progress achieved.

All recommendations stated above fall within the WHO Executive Board Resolution on thalassaemia and other haemoglobin disorders (EB118.R1), adopted in May 2006, and within the 5-year plan of

action, prepared in the last WHO-TIF joint meeting in Cyprus (November 2007) and fully endorsed by WHO in May 2008[3].

Finally, we express our deepest appreciation for the ongoing productive collaboration between TIF and the WHO and all the regional offices, including WPRO and reiterate TIF's firm determination to support their efforts in placing haemoglobinopathies on the priority national health agenda of every country of this region.

Thank you

[3] 'Management of Haemoglobin disorders'. Report of joint WHO-TIF meeting (2008).