

**JOINT STATEMENT OF
THALASSAEMIA INTERNATIONAL FEDERATION
WORLD FEDERATION OF HEMOPHILIA
INTERNATIONAL ALLIANCE OF PATIENTS' ORGANIZATIONS
MARCH OF DIMES**

Agenda item 11.7 “Preparation for the third High-level Meeting of the General Assembly on the Prevention and Control of Non-Communicable Diseases, to be held in 2018”

Delivered by **Mrs. Paloma TEJADA, TIF Associate – Rare Diseases International**

Dear Chairperson, Distinguished Delegates, Ladies and Gentlemen,

[This is a joint statement of Thalassaemia International Federation, World Federation of Hemophilia, International Alliance of Patients' Organizations and March of Dimes.]

We welcome WHO's efforts in the prevention and control of NCDs and would like to ensure that in addressing this high priority, Member States do not leave behind significant but often neglected rare diseases, each of which affect relatively small numbers of patients but collectively affect at least 300 million people globally, a number underestimated due to the lack of epidemiological data and national registries.

Rare diseases are mostly chronic, highly complex and severely disabling diseases that present multiple comorbidities and affect life expectancy. There are between 6,000 to 7,000 rare diseases, characterized by their low prevalence and heterogeneity.

The rarity of these diseases often results in delayed diagnosis and intervention that increase morbidity and mortality. The lack of appropriate care engenders inequalities and difficulties in access to treatment, often resulting in significant social and financial burden on patients. We thus believe that research needs to be international to ensure that experts are networked and clinical trials are multinational with pooling of resources across borders.

We therefore solemnly request Member States to:

ACKNOWLEDGE the severity of the problem and take action by including rare diseases in the Agenda of the upcoming third High-level Meeting on the Prevention and Control of NCDs;

PROMOTE national strategies and plans for the management of the multiple needs of patients with rare diseases;

ADVOCATE for the adoption of the WHO fair pricing approach by pharmaceuticals in order to guarantee access to safe and affordable orphan drugs;

DEVELOP synergies to increase:

- a) their own negotiating power for procuring new medicines and health technologies and;
- b) the access of patients to timely, appropriate and effective diagnosis and treatment.

Thank you for your attention.