

## **TIF Side Events at World Health Assembly**

### **- Invitation to attend**

Dear friends and collaborators,

The Thalassaemia International Federation (TIF) cordially invites you to attend the Side Events organized by the Federation and its partners during the 72<sup>nd</sup> World Health Assembly in Geneva, Switzerland on 20 – 28 May 2019. The events will focus on the topic of Universal Health Coverage addressing the issues of (1) Gene and Cell Therapies, (2) Digital Technologies, and (3) Rare Diseases.

### **Side Event 1: “Health for all: Gene and Cell Therapies in Universal Health Coverage (UHC)”**

This Side Event seeks to highlight and discuss the possibilities offered by such therapies for healthcare systems across the world, hosting a faculty of speakers that will include medical experts in genomic science, representatives of the World Health Organization and the IFPMA, and testimonials of

thalassaemia patients, where breaking new ground and providing a showcase of a genetic disorder with huge medical and socio-economic repercussions experienced by the patients, their families and the national healthcare systems in more than 62 countries across the world, which genomic science may radically impact.

**Date:** Wednesday 22 May 2019

**Time:** 13:00 – 14:00

**Location:** International Red Cross Museum (Henry Dunant Room), Geneva, Switzerland

**Co-organisers:** TIF, the International Alliance of Patients' Organizations (IAPO), and the International Federation of Pharmaceutical Manufacturers & Associations (IFPMA)

**Side Event 2: “How transformational digital technologies can contribute to leave no one behind in UHC: the case of rare diseases”**

New digital tools are already being used to address the

challenges of the 300 million people living with a rare disease to connect highly isolated patients, enable access and speed up diagnosis, refer to specialised medical expertise, to gather and share expertise on highly complex care, and accelerate clinical research over 6000 different diseases, each affecting a small population. Thus the event will demonstrate the global added value of using digital technologies to improve access to diagnosis and care while reducing the cost of health services. Moreover, particular emphasis will be placed on the efforts of the EU to strengthen the European Reference Networks (ERNs) and lay the foundations for the development of Global Reference Networks, encouraging the use of new technologies for tele-medicine / tele-collaboration between healthcare professionals and Centres of Expertise.

**Date:** Thursday 23 May 2019

**Time:** 12:30 – 14:00

**Location:** Palais des Nations in Geneva, Switzerland

**Co-organisers:** Permanent Missions of the European Union,

Romania and Kuwait in collaboration with TIF, Rare Diseases International (RDI), and the European Organisation for Rare Diseases (EURORDIS)

**Side Event 3: “Universal Health Coverage: Including Rare Diseases to leave no one behind”**

Through this high-level event awareness and knowledge on the topic of rare diseases will be promoted, as well as the strengthening of the unity of the international community, the patient community and all relevant stakeholders to address the unmet needs of this largely ignored and vulnerable population within Universal Health Coverage. The event will start with a drinks reception followed by keynote addresses and a panel discussion. Delegates attending the WHA will have the opportunity to meet with patient advocates and other stakeholders from the rare disease community.

**Date:** Thursday 23 May 2019

**Time:** 18:00 – 20:00

**Location:** International Red Cross Museum (Henry Dunant Room)

**Co-organisers:** RDI in collaboration with TIF, EURORDIS and Orphanet

Admittance to all events is free, so please spread the word and extend this invitation to your friends and colleagues. Please note however that the organizers are unable to offer financial aid to participants to attend these events.

FOR MORE INFORMATION

Thalassaemia International Federation

Tel: +357 22 319 129

Fax: +357 22 314 552

Email: [thalassaemia@cytanet.com.cy](mailto:thalassaemia@cytanet.com.cy)