

PPTA Attends World Federation of Hemophilia Congress

BY **MAT GULICK**, DIRECTOR, GLOBAL COMMUNICATIONS, PPTA
SONIA BALBONI, DIRECTOR, SOURCE & STANDARDS, PPTA

PPTA attended and was pleased to exhibit for the first time at the World Federation of Hemophilia (WFH) World Congress, held May 20–24, in Glasgow, Scotland. The conference was attended by nearly 5,000 people with hemophilia, as well as family members and medical professionals who treat various aspects of patient health. The purpose of the exhibition was to highlight the recently launched “How Is Your Day?” global education campaign and to draw attention to PPTA’s voluntary industry standards programs.





In addition to sharing information about the campaign and the standards program during the event, PPTA representatives were able to personally meet with individuals affected by hemophilia and hear their emotional stories and testimonies.

After spending several months gaining the support of national and international stakeholder groups, the WFH conference was PPTA's first opportunity to share the "How Is Your Day?" initiative directly with patients, caregivers, and advocates. The response was overwhelming, as people from all over the world eagerly shared their stories and the impact of access to clotting factor on their lives. For example, Ekawat lives in Thailand and described his father carrying him to the hospital for infusions until he was 10 years old. Today, thanks to clotting factor, he runs his own graphic design company and is able to keep up with his two young and active children. Additionally, Mayda, who is an oral surgeon, understands how incredibly important access to clotting factor is for people living with bleeding disorders.

PPTA will continue discussing and promoting the "How Is Your Day?" campaign at patient meetings in the coming months and looks forward to learning from individuals whose lives are improved by having access to plasma protein therapies. Ultimately, the campaign's goal is to showcase these stories to improve awareness of the diseases treated by these therapies, with the goal of working with legislators and payer sources to increase access globally for these unique medicines.

As Alain Weill, President of the World Federation of Hemophilia, stated, "Treatment for all: This is our global vision. I would love to have the situation, where, if we were to ask anyone, anywhere in the world, 'How is your day?' they would be able to answer 'Fine!' That would be a key achievement."

PPTA's standards exhibit educated attendees about its two voluntary standards programs, the International Quality Plasma Program (IQPP) and Quality Standards of Excellence, Assurance and Leadership (QSEAL) voluntary standards programs. Staff explained to attendees the level of commitment that companies invest in the programs, including high-level participation on the committees that develop and oversee the programs, meeting monthly to ensure that the requirements represent state-of-the-art safety

HOW IS YOUR DAY?

MAKING THE DIFFERENCE WITH PLASMA PROTEINS.

protocols, efficiency, and reliability for plasma collection and manufacturing. Staff members, who welcomed visitor questions, also explained how the IQPP and the QSEAL programs work jointly to promote the quality and safety of source plasma and of the final therapies.

Visitors also learned about the roles of the National Donor Deferral Registry (NDDR), the Qualified Donor Standard, the Inventory Hold Standard, and other requirements of the programs that help to ensure plasma safety and product safety. Staff described how the audit programs work and the requirements for a center or facility to receive IQPP or QSEAL certification, respectively. Furthermore, staff gave conference attendees an overview of the standards designed to protect donor health, including the newer IQPP Fluid Administration Standard and the Donor Adverse Events Recording Standard. PPTA staff also answered questions about the debate in some countries surrounding compensated donation.

Staff had the opportunity to meet patients from all over the world, as far away as Africa and the Middle East and as near as the conference's hometown of Glasgow. Each patient had a unique story to share. Many detailed their long journey toward achieving a diagnosis, which in some cases did not come until they were almost adults. Others conveyed the difficulty they had in obtaining therapy within their countries and, when therapies were available, the hours-long journeys they had to undertake to reach a facility where the therapy could be administered.

For some individuals, treatment meant simply the administration of cryoprecipitate, and even for that, only when a bleed occurred. Others in some regions had access

to plasma protein therapies, but only thanks to grants and donations by generous individuals or companies. Parents discussed the anguish they felt in trying to get the right treatment to their children. One mother recounted how her son had to relocate to another country to be treated because therapy was not available in their homeland.

These patients' stories, coupled with the promotion of the "How Is Your Day?" initiative and the sharing of information about the IQPP and QSEAL standards programs, helped reinforce for all those in attendance PPTA's mission "to promote the availability of and access to safe and effective plasma protein therapeutics for all patients in the world." •



"MY FATHER CARRIED ME TO THE HOSPITAL IN BANGKOK, 90 MINUTES EACH WAY, FOR INFUSIONS UNTIL I WAS 10 YEARS OLD. TODAY, ACCESS TO CLOTTING FACTOR ALLOWS ME TO OWN MY OWN GRAPHIC DESIGN COMPANY AND PLAY WITH MY KIDS."

Ekawat, living with Hemophilia

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"I HOPE THAT ALL PATIENTS IN MY COUNTRY CAN HAVE ACCESS TO PLASMA PROTEIN THERAPIES SO THEY CAN HAVE A BETTER QUALITY OF LIFE; AND WHEN OTHERS ASK THEM, 'HOW IS YOUR DAY', THEY CAN SAY, 'ALL IS WELL. BETTER THAN WELL, IN FACT!'"

Mayda, odontologist treating individuals with bleeding disorders

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