

Very brief snippets of the 2010 WFH World Congress

File 2 - Disclaimer: Following includes some excerpts that have been extracted from the official newspaper of the 2010 WFH World Congress. Opinions expressed are those of the individuals and organizations cited. I felt that sharing some thoughts and quotes from this newspaper would be a good way to communicate the spirit of information that was shared at the Congress, to those who would not have had the opportunity. Individual's photos taken by Cheryl D'Ambrosio with verbal permission from most individuals.

Established strategies, networks support children and parents

After the first shock of receiving a diagnosis, children with bleeding disorders need reassurance and supportive care. WFH national member organizations (NMO) can all do their part to help. Parents can rely on an established set of strategies and support networks to protect their children and improve their quality of life. The most immediate coping strategies are to understand the disease, learn about the available treatments, and teach children to participate in their own care.

Rare bleeding disorders lead to lifelong commitment

A diagnosis of combined factor V and factor VIII deficiency was the catalyst for Latifa Lemhene to translate a lifetime of severe bleeding episodes and abdominal pain into a mission for action.



Latifa Lemhene
President of the Algerian Hemophilia Association
And woman with Factor V and VIII deficiencies

“My hemorrhagic disorder affected my life and changed my vision of things, and I think my experience has made me enjoy life more,” she told participants in the Sunday

afternoon concurrent session on living with rare bleeding disorders (RBDs). “Now my objectives are to fight the ignorance and loneliness caused by bleeding disorders, and spread my experience beyond political or geographic borders.”

Two years after receiving her diagnosis in 2001, Lemhene formed a hemophilia association in her community. By 2006 she had become president of the Algerian Hemophilia Association.

But she described her first 19 years as a “period of ignorance for me, my family, and the doctors,” characterized by multiple external bleeds from falls, dental extractions, epistaxis, and hematomas due to intramuscular injections and trauma.

Gabriel Lottaz of Switzerland described his experience with afibrinogenemia, or factor I deficiency. The first evidence that he had an RBD came when he began bleeding from the umbilical cord at the age of 10 days. At three months he suffered a gastric perforation and was lucky to survive a laparotomy. On his second birthday, his dad left a razor unattended, and Gabriel required treatment after trying to shave and cutting his lips.

“My hemorrhagic disorder affected my life and changed my vision of things, and I think my experience has made me enjoy life more.” He said. Lottaz became president of the Swiss Hemophilia Association in 2009.



Evelyn Grimberg of the Netherlands traced her experience with Glanzmann’s thrombasthenia

Acceptance, education and outreach key in supporting women with bleeding disorders

Despite significant differences in access to care and cultural environments, the keys to providing psychosocial and therapeutic support for women with bleeding disorders are the same: education and outreach. Patients need help to integrate their bleeding disorder

diagnoses into their identities, and in helping their families, medical practitioners, and communities understand their conditions.

“Our aim is always to facilitate our patients’ psychological well-being so that, as they and their families go through life with a bleeding disorder, they are able to cope with what is difficult and enjoy what is good,” said family therapist Nicola Dunn of the U.K.



Shirin Ravanbod a woman from Iran and symptomatic carrier

However, promoting acceptance, support, and understanding does pose additional challenges in some parts of the world, particularly in conservative cultures. Shirin Ravanbod, of Iran and a woman who is also a symptomatic carrier, said the most significant challenges stem from prevailing moral, religious, and cultural values that prevent women from talking about their bleeding, particularly menstruation. These cultural factors are compounded by lack of diagnostic facilities and limited knowledge of women’s bleeding disorders by medical personnel, along with relatively high numbers of women with bleeding disorders, largely due to high rates of consanguineous marriage.

Ravanbod described some of the strategies used to promote improved medical and psychosocial care for women with bleeding disorders. These include better classification and accurate diagnosis of vWD; educational seminars for gynecologists, hematologists, and nurses; outreach targeting teenage girls at school and the broader population; and creation of a fund to help pay for hospitalization and treatment of women with bleeding disorders.

A participant from Pakistan underscored the need to be sensitive and creative in helping women with bleeding disorders in conservative countries. She described programs in Islamabad that train young girls with vWD to become peer counselors. This not only increases awareness of the bleeding disorders facing women, it also empowers the counselors and gives them a greater sense of control.

Dr. Susan Halemi of Germany knows first-hand about the bleeding disorders she treats. Diagnosed with severe vWD at two years of age, she is acutely aware of the psychological distress the disorders cause and the importance of taking practical steps to lessen their impact on patients' personal lives. For example, understanding that gum bleeding can cause severe bad breath can lead to social stigma and alienation. Dr. Halemi encourages the women she treats to have regular professional dental care. She also stresses the importance of encouraging women with bleeding disorders to find a sport in which they can safely participate, to bolster their sense of belonging and community.

Save One Life

Laurie Kelley, Founder of Save One Life, held a Thank You luncheon for many who have been involved with the important work of Save One Life, a registered nonprofit international organization that offers individuals, families, companies and/or organizations the opportunity to sponsor a child or adult with a bleeding disorder in a developing country.



Laurie Kelley, (standing) Founder of Save One Life greets her guests

Laurie's attendees included individuals representing nearly a dozen countries each introducing themselves and sharing a bit about their work. In this photo, Laurie is visiting with individuals responsible to manage the Tanzania (far left and middle) and the Ghana Hemophilia programs. These two new hemophilia associations were going to be inducted as members of the World Federation of Hemophilia the following day. Laurie has been advising them the past 5 years in order to help them establish their hemophilia societies. At long last, their hard work will be paid off by becoming members. Being an official member means that they will be eligible for many more resources from the community, such as training, factor donations and potentially twinning. I was fortunate to have been invited by Laurie to this inspiring luncheon.

Parovirus elimination continues to be elusive

Parovirus B-19 continues to confound manufacturers' efforts to eliminate it from both recombinant and plasma-derived products, although several promising developments have been reported. Dr. Jeanne Ann Jordan explained that parovirus B-19 is an extremely small, non-enveloped molecule, barely half the size of HCV. As a result, it is highly resistant to solvent and detergent treatments, heat inactivation and fractionation.

More than half of those infected with parovirus B-19 are asymptomatic, and it leads to a mild, self-limited illness in most others. In high-risk populations who are immunocompromised, however, the symptoms can be much more severe. They include aplastic crisis, pancytopenia, and pure red cell aplasia. In pregnant women, infection can be passed to the developing fetus and result in spontaneous abortion.

Jordan explained that one of the major challenges in trying to ensure the safety of the blood supply is that there is a long asymptomatic period and an early period of rapid viremia. Transmission most often occurs when a person donates blood during this window.

There is reassuring news on the horizon, however. Nanofiltration has been used to eliminate small, non-enveloped viruses like B-19, and NAT testing is allowing the removal of material with the highest viral load to reduce risk. In addition, Jordan said manufacturers are developing nano-exchange and chromatographic techniques to eliminate the virus.

HIV and HCV both continue to be viral pathogens of significant concern to people living with bleeding disorders. Dr. Marget Ragni noted that HCV infection is the leading cause of end-stage liver disease in people with hemophilia.