



Supporting the Hemophilia Community

Thursday, January 28, 2021



Hemophilia is a rare and life-long bleeding disorder in which the blood does not clot normally. While people with hemophilia can lead fairly normal lives with certain precautions to prevent and control bleeds, managing the condition can be challenging. Those living with hemophilia or caring for someone with hemophilia can face a wide range of difficulties—including medical, psychological, social and financial - which is why a strong network of support is a vital part of comprehensive care.

Each year on April 17, the World Federation of Hemophilia (WFH) and the global hemophilia community celebrate **World Hemophilia Day** to raise awareness and increase support for people with hemophilia and other inherited bleeding disorders. Members of the community are encouraged to get involved, speak out and share their

experiences. This year's theme is focused on **building a family of support** for those impacted by hemophilia.

For instance, at a Town Hall meeting hosted by Pfizer Hemophilia, Patrick James Lynch, an actor, writer, producer, and advocate living with severe hemophilia A, spoke about what providing support means to him. "It means focusing on ways to reduce any negative psychosocial effects of the disease," said Patrick. "One of the ways I support the hemophilia community is through a program called Breaking Barriers. This program provides our teens with an opportunity to take control over their care, and their lives. With location-specific workshops on wellness, creative expression, and healthy eating, we aim to teach teens how to identify challenges and develop strategies to overcome them."

Caregiver Justin Neustadt spoke of his commitment to improving care and driving positive change in the hemophilia space. "My wife and I have three boys with hemophilia. As caregivers, we participate in local advocacy activities to meet and talk about issues," Justin stated. "Connecting with others in the community has been very helpful in learning about challenges and successes. We have applied those learnings in our own parenting to provide optimal support to our children."

In celebration of World Hemophilia Day, consider joining the hemophilia community. Here are some tips on how you can support and advocate for people with hemophilia all year long:

Educate yourself about hemophilia. Visit www.stepsforliving.hemophilia.org/. Here you can find tips for communicating about the condition, ways to become a resilient family, and resources on many other topics. **Learn how you can get involved.** Check out the WFH's website to see how you can support the community. **Take advantage of available programs.** Make sure you are aware of the resources and support programs available to you or a loved one, such as the many scholarships for people with hemophilia including Pfizer's Soozie Courter scholarship program.

Dr. Bart Tortella is a Medical Director on the Hemophilia team at Pfizer.

Originally published, Thursday, January 28, 2021