

SESSION DESCRIPTIONS

9:00AM - 10:15PM

All Welcome

Keynote: The Power of Joy

Steve MaGuire, GoTurnstone

Professional speaker and author Steve Maguire will take you through this fun and interactive session as we focus on the power of joy and positivity in our lives. Despite challenges, life can be determined by our choice for joy over all else!

10:45AM - 11:45AM

Patients & Families

Community Roundtables

A place to share your experiences and learn from your peers as you face living with a bleeding disorder. Please select a topic of interest to participate in from the following:

Mild Hemophilia (Parents)

Severe Hemophilia (Parents)

VonWillebrand Disease

Transitioning into Adulthood

Men's Group

Women's Group

Allies (Caregivers, Spouses, Siblings etc.)

Spanish Speaking

1:00PM - 2:00PM

All Welcome

General Session: Ex Fabula Story Telling

We can learn a lot from listening to the life experiences of others. Each tale of struggle, triumph, and discovery reveals who we are now, and who we hope to become. Everyone has a story to tell, let us help you share yours! The professional storytelling team, Ex Fabula, will help you identify, craft and share your story.

Celebrate the power of true and personal stories that connect communities like our own at the Story Slam Saturday evening during dinner.

8:00AM - 9:30AM

All Welcome

Sunday Breakfast Symposiums

Resilience: Growing Through Life's Changes

Managing stress is an important aspect of our everyday lives. This presentation will discuss some of the common causes of stress and provide examples of how to better adapt and manage adversity. Through interactive and fun activities, you will explore what it means to be resilient and learn skills, and tips and tools for living a healthy lifestyle.

Spotlight on Unaffected Siblings

Ever wonder how a bleeding disorder may impact unaffected brothers and sisters? Raising multiple kids can have plenty of ups and downs, especially if one child has a chronic condition. Sometimes balancing the needs of the child without a bleeding disorder can be a challenge. This workshop will help empower parents and caregivers with new tools to ensure that each child's needs are met.



BREAKOUT SESSIONS

2:10PM - 3:00PM

Panel of Experts: Hemophilia

A Hematologist, Nurse, Genetic Counselor, Dental Hygienist and Specialty Pharmacy Coordinator walk into a...breakout session! Join our panel of experts in an open Q & A discussion about living with Hemophilia.

Laughter Yoga

Betsy Kennedy, MS, OTR, CLT, CLYL
Remember, "Laughter is the best medicine?" Scientific research in multiple fields of study have proven the health benefits of laughter, including that you get all the goodness even from 'fake' laughter! If you can breathe, you can do Laughter Yoga! HA HA HA HA!

A World Wide Mission

Jay Charles, RN
The Hemophilia Outreach Center recently took their mission to a whole new level with a Twinning Program in Ethiopia in partnership with Minnesota's Children's Hospital. Learn about the new adventures in self-infusion training, starting a new lab and outreach clinics as well as staff training. We'll discuss barriers and challenges as well as differences between our two countries.

Communication with Healthcare Providers (Spanish)

Fel Echandi, NHF
Mayra Cantu, NHF
Navigating the healthcare system in the US can be difficult without the information, language or cultural knowledge needed to effectively communicate with medical providers. This workshop will answer questions people may have about managing their interactions in a complex health system.

3:10PM - 4:00PM

Panel of Experts: vWD & Platelet Disorders

A Hematologist, Nurse, Genetic Counselor, Dental Hygienist and Specialty Pharmacy Coordinator walk into a...breakout session! Join our panel of experts in an open Q & A discussion about living with vonWillebrand Disease and Platelet Disorders.

Pokes & Procedures: How to Help Your Child/Teen Cope **Katie Glass, Ed.D & Certified Child Life Specialist**

This session will explore how to help your child and teen cope with the variety of stressors that come with coping with a chronic illness. The developmental use of child friendly language, the power of diversion and tools to achieve pain control will be discussed.

The Power of Camp

Steve MaGuire, GoTurnstone
This camp readiness session will help caregivers continue to support the skills and behaviors learned at camp in their home environment. This interactive session will give you some tangible takeaways to continue the magic of camp!

Managing Stress & Wellness (Spanish)

Fel Echandi, NHF
Mayra Cantu, NHF
The areas that cause the most stress may change in different phases of your life. During this interactive workshop, you will get the chance to identify and talk about these areas that cause stress. You will be given tools on how to manage this stress so that you not only survive but thrive!

4:10PM - 5:00PM

Emerging Therapies

Sumedha Ghate, MS, CGC
Kenneth Friedman, MD
During this session we'll discuss genetic counseling and therapies new to the market, what they mean, and how they can assist treatment in the future.

Exercises to Prevent Joint Bleeds

Becky Kohl, PT
A gradual, well-designed program of regular exercise is an important part of maintaining muscle strength and preventing joint or muscle bleeds. We'll go over exercises to strengthen your core and muscles around common target joints, and modifications to match your fitness capabilities. Athletic attire is recommended.

Social Media in the Bleeding Disorders Community

Marlee Whetten, NHF
Have you ever discussed your or your child's bleeding disorder on a website, or joined an online discussion group to give or receive advice? Talking about your own bleeding disorder or your child's online can create history that may last longer than you intended. Join the discussion on the best ways to use social media as a member of the community, what to look for and what to avoid, and what the future might hold.

Going to School with a Bleeding Disorder (Spanish)

Mary Jane Frey, RN-BC, BSN, CPN
What are IEPs and 504 Plans, and how can they help your child with a bleeding disorder? We'll talk more in depth about what these school services and accommodations are, and what you can do to start putting a plan into action!