



# Welcome to the 2020 Virtual Annual Meeting

**August 15, 2020**

We are pleased to welcome you to the Hemophilia of Indiana Virtual Annual Meeting in Indianapolis. Hemophilia of Indiana (HoiI) is dedicated to empowering people with bleeding disorders through education and support, while advocating access to quality care and product safety. While we are sad to not be able to hold the live event this year due to the current pandemic, we are excited to still be able to provide a great day of education and community interaction!

We have set up several different informational and educational sessions throughout the weekend. We have several great speakers, experts in their fields, who are here to provide you with the latest and greatest information. We hope that you can use what you learn to positively influence the lives of you and your family.

We are so glad you are here and look forward to a great meeting!

Sincerely,

Scott Ehnes  
Executive Director

Kristy McConnell  
Development & Event Director

Angel Couch  
Program Director/Community  
Outreach Coordinator

**Our Mission:** Hemophilia of Indiana is dedicated to empowering the bleeding disorder community, through education and support, while advocating access to quality care and product safety.

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## Saturday, August 15, 2020

**9:00AM – 9:15AM**

**Opening Comments – Scott Ehnes**

**9:15AM – 10:15AM**

**General Session**

***Let's Talk***

**Presenter:** Patrick James Lynch and Debbie de la Riva

**Description:** Five Stories, One Theme: Mental Health Matters Too. Believe Limited set out to start a candid conversation about the physical and emotional challenges of life with a bleeding disorder. Five community members agreed to participate, fully, and the resulting narrative has come together in Believe Limited's latest Film, Let's Talk.

**10:20AM - 11:00PM**

**Happy Hour with Jen and Angel**

**Presenter:** Jennifer Maahs, Angel DiRuzza, Dr. Anne Greist, and Dr. Amy Shapiro

**Description:** Back by popular demand is "Happy Hour" Angel Diruzza, Hemophilia of Indiana, and Jen Maahs, Indiana Hemophilia & Thrombosis Center. This episode Will feature 2 of the fabulous IHTC physicians, Drs. Anne Greist and Amy Shapiro. Angel and Jen will focus the discussion on medical questions related to COVID-19 testing and treatment, impact on person with bleeding disorders, the new "normal" in our daily lives, and tips for staying healthy amid a pandemic.

**11:00AM - 12:30PM**

**Industry Round Table Breakout Sessions**

Attendees will have small group breakout sessions with each industry sponsor. Each attendee will automatically be moved to a Zoom breakout room to hear a short presentation from each event sponsor.

**12:30PM – 1:30PM**

**Lunch Break**

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## Afternoon Educational Sessions

**1:30PM – 2:15PM**

### [Navigating Through Rough Waters](#)

Sponsored by Indiana Hemophilia & Thrombosis Center

**Presenter:** Brenda McLean and Brittany Jones

**Description:** Smooth sailing on rough waters requires Planning. You need instruments and maps to find your way through any new or existing detours. This session will focus on job loss, career changes, insurance, roadblocks, work from home, virtual school, and other life challenges.

**1:30PM – 2:15PM**

### [von Willebrand A to Z](#)

Sponsored by Takeda

**Presenter:** Honey Blankenship

**Description:** Get to know inheritance patterns and types of VWD and its various symptoms, including those that are specific to women. Treatment approaches available to people living with VWD will be described, as well.

**1:30PM – 2:15PM**

### [Planning your Future: Aging with Hemophilia](#)

Sponsored by Pfizer

**Presenter:** Chris Liddell

**Description:** An overview of the potential ways' adults with hemophilia can plan for their financial futures. Emphasis is on defining retirement goals and identifying future needs, aspects of long-term care, and the benefits of a support network.

**2:30PM – 3:15PM**

**[Braving Change](#)**

Sponsored by Sanofi Genzyme

**Presenter: Shelley Gerson**

**Description:** Ever wonder how to stay positive when confronted with personal challenges? We all experience moments of change in our lives – some bumpier than others. We'll explore the concept of resilience in the face of change, for both children and adults, including ways to help adapt to difficult circumstances, factors that may help you, characteristics of resilient individuals, and ways of fostering these skills within your family, at school, and in the larger community.

**2:30PM – 3:15PM**

**[Gene Therapy Research: Understanding the Science](#)**

Sponsored by BioMarin

**Presenter: Julie Mook**

**Description:** An introduction to BioMarin and our company's latest gene therapy research. We will discuss: what is gene therapy, what kind of gene therapy is currently being conducted and what are we trying to figure out from gene therapy trials.

**2:30PM – 3:15PM**

**[Relationships: The Flavor of Life](#)**

Sponsored by the Indiana Hemophilia & Thrombosis Center

**Presenter: Don Molter, Cara Hannemann, Gail Jordan**

**Description:** What is the recipe for a good relationship? The presence of a health concern can make any relationship more challenging. Whether it is parent-child relationship or a partner, a bleeding disorder can add an extra "spice". This session is designed to give professional tips to make all your relationships more flavorful.

**3:30PM – 4:15PM**

**[Von Wille-What? Diagnosed with a bleeding disorder as an adult](#)**

Sponsored by CSL Behring

**Presenter: Kristin P.**

**Description:** From an early age, Kristin experienced bruising and was teased for being clumsy. And yet, she could never recall exactly how she got the purple and red splotches. When she started menstruating, her periods were long and heavy. Kristin thought it was normal since her mother and sister experienced the same thing. It was not until her son was diagnosed with hemophilia A and von Willebrand's disease that the true cause of her bleeding disorder was revealed. Today Kristin shares her story to help educate others about living with hemophilia and vWD.

**3:30PM - 4:15PM**

**[Joint Ventures](#)**

Sponsored by the Indiana Hemophilia & Thrombosis Center

**Presenter: Stacie Akins, Melissa Barnes, Fred Loeffler, And Dr. Nihal Bakeer**

**Description:** The physical therapists at IHTC and Dr. Nihal Bakeer will pool their expertise in a "joint venture" about joints. This interactive presentation will combine medical information and physical therapy techniques to help maintain and improve your joint functioning. Tips will focus on all ages from young children to adults.

**3:30PM – 4:15PM**

**[Challenge Accepted Episode: Laugh](#)**

Sponsored by Genentech

**Presenter: Diana Caito**

**Description:** Challenge Accepted is a series created by Genentech to demonstrate how we support the person, by educating the community beyond the medicine as well as providing tools and resources to help the community live a better life. This episode sheds light on the emotional aspects of being a family member in the bleeding disorder community.

**3:30PM – 4:15PM**

**[WWwBD: Wonder Women with Bleeding Disorders](#)**

Sponsored by the Indiana Hemophilia & Thrombosis Center

**Presenter: Dr. Lewandowska & Dr. Gupta**

**Dr. Gupta**

**Description:** This presentation will focus on tips to help all you superheroes conquer our bleeding symptoms. Knowledge is your special power. Please join our question and answer session with 2 physicians who specialize in the care of women and girls with bleeding disorders.

Thank to you our Title Sponsors:

