**Saturday, March 7, 2020 | Adult Track**

9:00 am - 9:45 am **Registration Opens | Visit Exhibits**

9:45 am - 10:00 am **Welcome | Acknowledgement of Bleeding Disorders Awareness Month**

**Presenter:** Kelly Waters, VHF Executive Director

10:00 am - 11:00 am **Keynote Presentation | Emerging Therapies**

 **Presenter:** Christopher E Walsh, MD, PhD

11:00 am - 11:45 am **Break-out Session 1 | Presenter Sponsors**

 **Company:** BioMarin

 **Presenter:** Rhonda Fritz, MSN, CPNP, Sr. Medical Science Liaison

**Topic: Gene Therapy Research: Understanding the Science**

*Presentation with Q&A focused on what causes a genetic disorder, how investigational gene therapies are being developed and researched, and what the clinical trials are aiming to understand. Many gene therapies are being studied in people living with a range of conditions, including hemophilia A and B, to determine if they are safe and effective. No gene therapies for hemophilia have been approved for use. Join us as we look into the science of gene therapy research and the biology behind it.*

**Company:** Sanofi Genzyme

 **Presenter:** TBD

**Topic: TBD**

11:45 am - 11:55 pm**Break | Visit Exhibits**

11:55 am - 12:40 pm **Break-out Session 2 | Presenter Sponsors**

 **Company:** Genentech

**Presenters:** Dr Tamuella Singleton, MD, Director of the Mississippi Center for Advanced Medicine's Hemophilia Treatment Center and Division Chief of Pediatric Hematology and Louis C., Patient Ambassador

**Topic: Give it a Shot: A Different Type of Hemophilia A Therapy**

*This program will provide detailed information about HEMLIBRA and Genentech support programs.*

**Company:** Takeda

**Presenter:** Betsy Koval, Sr Clinical Specialist

 **Topic: Understanding Von Willebrand Disease**

*Please join us to learn about the what, why, and how behind VONVENDI - the first and only recombinant therapy for adult patients with von Willebrand disease. The following topics will be covered during the program: The underlying cause of von Willebrand disease (VWD), what VONVENDI is, who it is for, and how it works, and how to properly store, prepare, and administer VONVENDI.*

12:40 pm - 1:15 pm **Lunch | On-Site**

1:15 pm - 2:00 pm **Break-out Session 3 | Presenter Sponsors**

 **Company:** Bayer

**Presenter:** Evan Kerstetter

**Topic: My Journey to Jivi**

*The talk features a member of the community, Evan Kerstetter, who will share his stories about his life experiences and transition to Jivi- a treatment option from Bayer. Evan Kestetter is a student from Pennsylvania.*

**Company:** Spark

**Presenter:** Laureen Temple, Senior Patient Education Liaison at Spark Therapeutics

**Topic: Understanding Gene Therapy Research and Its Potential Application to Hemophilia**

*This presentation is intended to walk you through the journey that started over 50 years ago with the beginnings of gene therapy research. We will walk through the basics of genetics and how that plays a role in hemophilia. With that knowledge, we will look at how gene therapy is meant to work and discuss both the potential for and the challenges of investigational gene therapy research today.*

2:00 pm - 2:10 pm **Break | Visit Exhibits**

2:10 pm - 2:25 pm **Roundtable Session** **|** **Premier Sponsors**

**Company:** CSL Behring

*“To Clot or Not to Clot!” Become a part of the clotting process in this fun, interactive approach to understanding how different bleeding disorders affect your body’s ability to form a clot, whether it’s hemophilia A, B, C, or VWD!*

**Company:** Pfizer

*Pfizer has been in the hemophilia field for over 20 years and remains committed to this rare disease. Come hear about what offerings Pfizer has available.*

2:25 pm - 2:35 pm **Break | Visit Exhibits**

2:35 pm - 3:30 pm **Presentation | Avoiding the Magic Eight Ball: Strategies in Medical Decision Making**

**Presenter:** Tahnee Causey, MS, LCGC, Assistant Director, VCU Genetic Counseling Program, VCU Health

*Patients and families are faced with an ever-increasing list of healthcare choices that can be overwhelming to assess. The aim of this talk is to discuss possible decision-making strategies families can use when making decision about management and treatment.*

3:30 pm - 3:45 pm **Break | Visit Exhibits**

3:45 pm - 4:45 pm **Presentation | Product Safety – An Update from Hemophilia Federation of America (HFA) and National Hemophilia Foundation (NHF)**

**Presenter:** Miriam Goldstein, Director of Policy, HFA

*Product recalls in 2019 raised a lot of concerns among the bleeding disorders community. Recognizing and seeking to address those concerns, NHF and HFA worked jointly to convene a Safety Summit in January 2020, bringing diverse stakeholders together to address product safety and safety communications. In this session, HFA and NHF staff will discuss Summit findings and next steps.*

6:30 pm - 8:00 pm **Community Reception | Off-Site**

 *\*Space is limited pre-registration required*

**Location:** CSL Plasma, 5500 Lakeside Ave., Richmond, VA 23228

**Sunday, March 8, 2020 | All Ages**

8:00 am - 9:00 am **Education Breakfast | On-Site**

**Presentation:** Advocacy

**Presenters:** Miriam Goldstein, Director of Policy, Hemophilia Federation of America (HFA)

10:00 am - 12:00 pm **Community Event | Off-Site**

*\*Space is limited pre-registration required*

 **Location:** Top Golf, 2308 Westwood Ave., Richmond, VA 23230