

Workshop Title	Description	Target Audience	Length (min)	Facilitated by
Aging as a Person with a Bleeding Disorder	<p>While getting older is part of our lives, it often comes with new and unknown hurdles. This holds particularly true for the inherited blood disorder community. This workshop will explore what we have learned about aging with a bleeding disorder and will provide resources and useful skills to navigate the unknown.</p>	Adults; 18+ all genders	60 min	Speaker Bureau NHF staff
Gene Therapy Basics for Hemophilia: What You Need to Know	<p>Recently there has been an explosion of innovative research in the treatment of Hemophilia utilizing gene therapy technology. This workshop will help you develop a basic understanding of the complexities of gene therapy including terminology, how gene therapy works, and identifying the potential, limitations, risks, and unknowns associated with gene therapy. We also provide a brief introduction to other novel therapies and an overview of what treatments are currently approved. Gaining a high-level understanding of gene therapy will enable community members to have robust conversations with their providers and to ultimately make the best decision on treatment.</p>	Adults; 18+ all genders	60 min	Speaker Bureau
How to Navigate Health Insurance with a Chronic Disease	<p>Choosing the right insurance plan is important for everyone, but critical for those living with a serious chronic health condition. The complexity of health plan rules and policy changes are cumbersome even for the most educated in this area, however the rate these changes occur, and the vernacular used to identify these new policies make it hard to keep up with. This workshop will provide an overview of the current health insurance landscape, including those plans which must comply with the ACA, and which don't, and what health plan types should be avoided. We will also give an update on copay accumulators and provide a review of the ACA EHB loophole that enables copay maximizers and alternative funding programs to continue to gain in popularity, what NHF has/is doing to put an end to these schemes and how you can help.</p>	Adults; 18+ all genders	60 min	NHF staff
Looking from the Outside in: Musculoskeletal Ultrasound	<p>Ultrasound of the joints and muscles is slowly becoming a staple in many Hemophilia Treatment Centers to detect bleeding episodes and to follow joint health over a long time. But how does this work and what are the benefits? Participants will walk away feeling informed about this innovative technique and being able to engage with their healthcare provider about joint health.</p>	Adults; 18+ all genders	60 min	Speaker Bureau NHF staff

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Medical Marijuana: A Way to Manage Your Pain?	Marijuana is increasingly legal and used as a remedy for pain. This workshop will explain what people with bleeding disorders need to know should they be considering medical marijuana as part of a pain treatment plan.	Adults; 18+ all genders	60 min	Speaker Bureau NHF staff
Mental Health: A Deeper Dive	Millions of people in the U.S. are affected by mental health issues. The COVID19 pandemic has brought many of these much more to the forefront and allowed us to begin honest conversations. But it is time to dig deeper and move beyond the basics. This workshop will investigate mental health issues seen in the inheritable blood disorder community and provide innovative skills and resources to the participants.	Adults; 18+all genders	60 min	Speaker Bureau
Navigating Clinical Trials	Clinical trials are key to advancing safe and effective treatments for bleeding disorders. They are an important step in the FDA drug-approval process and provide researchers with invaluable data about a drug’s effectiveness and side effects. With the pace of innovation in the bleeding disorders community, it is important for consumers to understand the Clinical Trials process and what their role is should they choose to participate. Some of the topics covered include an overview of the phases of the clinical trials process, informed consent, and consumer responsibilities of participation in trials.	Adults; 18+ all genders	60 min	Speaker Bureau NHF staff
Pain Explained	Many people with bleeding disorders find that bleeding-related pain and joint damage impact their quality of life. This session will improve understanding of how pain affects people with bleeding disorders and approaches for managing pain. It will also provide resources for communicating with your provider to ensure that pain associated with bleeding and joint damage is addressed appropriately.	Adults; 18+ all genders	60 min	Speaker Bureau NHF staff
Reproductive Health, Menstruation, and Menopause	Reproductive health, menstruation, and menopause are vital topics in the lives of girls, women, and those who have the potential to menstruate. Yet, our conversations about these within the inherited blood disorder community have been sparse. It's time to change. This workshop will provide a deeper dive into physiological components of these, highlight implications for bleeding disorders, and provide essential skills and resources to the participants.	Adults; 18+ all genders	60 min	Speaker Bureau

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Shared Decision Making and the Shift to Person Centered Care	You are the subject matter expert of you and/or your child's bleeding disorder. And, as the subject matter expert you are the center of your care network and a vital member of the shared decision-making process. This workshop will explore the shift towards person-centered care and outline the concepts of shared decision-making. In addition, participants will gain advocacy and communications skills as well as important resources.	Adults; 18+ all genders	60 min	NHF staff
Storytelling	This workshop provides a review of the power of oral history and lived experiences to illustrate the victories and challenges of living with a bleeding disorder. Attendees will learn of various modalities for storytelling and how to make the most of shared lived experiences for community members.	Adults; 18+ all genders	60 min	NHF staff
The Basics of Innovative Therapies: What You Need to Know	We continue to see significant research and innovation in the treatment of Hemophilia. It is becoming more important than ever to stay informed on all the advancements and innovation – what they are, how they work in the body and how safe they are. Understanding all the options including currently approved treatments, the pros and cons and the promise and limitations of each type of therapy will enable community members to have informative conversations with their providers and to ultimately make the best decision on treatment. This presentation is designed to provide a basic overview of current and future treatment options for hemophilia, making these complex concepts more understandable.	Adults; 18+ all genders	60 min	Speaker Bureau
Unconscious Bias	This workshop provides a look into how our cultural upbringing, environment, and values influence how we see the world, how we interact with one another and may lose great partnership or collaborative opportunities because we are unaware of the subconscious biases that we hold.	Adults; 18+ all genders	61 min	NHF staff
VWD Guidelines: What They Mean for You	In 2021 the new VWD guidelines on diagnosis and treatment were published. In this workshop, participants will learn more about the innovative international development and the most important changes. But even more so, participants will learn what these guidelines mean for them and how to use these as a foundation for shared decision making to advocate for their own best care.	Adults; 18+ VWD all genders	60 min	Speaker Bureau NHF staff

Teens and Young Adults

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Failure is an Option	We often hear that “failure is not an option.” However, by acknowledging and understanding our greatest failures, we can experience some of our deepest moments of personal growth. In this interactive workshop, participants will learn how to celebrate their failures in a safe environment and walk away feeling more empowered and confident.	Young Adults all genders	60 min	NHF staff co-facilitated by NYLI <i>(as able)</i>
Financial Planning	Financial independence often comes with substantial challenges as people are moving into adulthood. Outcomes of poor financial planning can potentially impact a person's health, especially when dealing with a chronic condition, such as a bleeding disorder. Efficient planning abilities and tools provide the foundation for success. This workshop will provide skills and resources to young adults to help increase their comfort and competence in financial planning.	Young Adults all genders	60 min	Speaker Bureau NHF staff co-facilitated by NYLI <i>(as able)</i>
Independence & Management	Parents of children with bleeding disorders are often very involved in their child’s medical treatment. The transition of care from the parent to the child can be difficult for a family, but it’s important. This workshop will help families discuss the benefits of independence and identify the necessary steps to help them achieve their family goals.	Families or Teenagers <i>only</i> ; 13+ all genders	60 min	NHF staff co-facilitated by NYLI <i>(as able)</i>
Let's Talk Period	While periods and puberty are a healthy and normal part of a girl’s life, it can feel like a true hardship for a girl with a bleeding disorder. Many may feel alone in what they are dealing with and not know where to turn for answers to questions they may have. In this interactive workshop, girls will have the opportunity to discuss scenarios and solutions relating to puberty and periods in a safe environment. They will leave with tips on how to transition into this new chapter of their lives, feeling connected and empowered.	Teenagers; 13+ girls and those with the potential to menstruate	60 min	NHF staff co-facilitated by NYLI <i>(as able)</i>

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<p>Mental Health for Teens</p>	<p>Mental Health issues are not just for adults, but also affect younger generations. It is important to recognize and understand the mental health challenges impacting teenagers in the inherited blood disorder community. This workshop will equip teenagers with a greater knowledge, innovative strategies, skills, and resources about these challenges.</p>	<p>Teenagers; 13+ all genders</p>	<p>60 min</p>	<p>Speaker Bureau</p>
<p>Workplace & Disclosure</p>	<p>Disclosure can be a crucial issue in the workplace when you have a bleeding disorder and require accommodations in the workplace. The Americans with Disabilities Acts of 1990 (ADA) protects individuals with disabilities from discrimination in the workplace. It can be hard to know when, to whom and what to disclose. This workshop will help to make your disclosure experience easier, strategic and a thoughtful process.</p>	<p>Young Adults all genders</p>	<p>60 min</p>	<p>NHF staff co-facilitated by NYLI (as able)</p>