

Workshop Title	Target Audience	Description	Length (min)	Facilitated By	Funding*
Series 1					
Piecing Together the VWD Puzzle					
VWD: Ask the Expert	<ul style="list-style-type: none"> •Teenagers; 14+ •Adults; 18+ •M/F 	As a person with or a caretaker of someone with VWD, you may have many questions, including, “What are the genetics of VWD? How do I manage my VWD? Can I get joint bleeds with VWD?” This nurse-led workshop will go over the basics of VWD and give participants a chance to ask questions so they can walk away feeling informed about their health!	60 min	<ul style="list-style-type: none"> • Nurse 	CES*
VWD Guidelines: What They Mean For You	<ul style="list-style-type: none"> •Adults; 18+ •VWD •M/F 	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.	60 min	<ul style="list-style-type: none"> • Speakers Bureau • NHF Staff 	CES*
Advocating for <i>Your</i> Care in the ER with VWD	<ul style="list-style-type: none"> •Adults; 18+ •M/F 	Having to advocate for yourself or a loved one’s care with VWD can be difficult, especially in an urgent situation! This workshop will cover how to prepare in advance for an emergency, and provide information to help navigate difficult situations that you may encounter when in the emergency room.	60 min	<ul style="list-style-type: none"> • Speakers Bureau • NHF Staff 	CES*
VWD: <i>Your</i> Voice Matters	<ul style="list-style-type: none"> •Adults; 18+ •VWD •M/F 	Knowing how to advocate for yourself, and feeling like your concerns are heard, can be an obstacle you face as you live with your bleeding disorder. During this workshop, participants will share their stories and gain tools on how to advocate for themselves in many facets of life including in their relationships, the healthcare system and in the workplace.	60 min	<ul style="list-style-type: none"> •Speakers Bureau •NHF Staff 	CES*
Series 2					
Women With Bleeding Disorders: Connections, Treatment, and Advocacy					
Women Bleed <i>Too</i> :Q&A	<ul style="list-style-type: none"> •Teenagers; 14+ •Adults; 18+ •FEMALES ONLY 	Women can have bleeding disorders, too! As a woman with a bleeding disorder, you may have questions about not only how your bleeding disorder may impact your life but how best to manage it. This workshop goes over the basics of bleeding disorders in women and allows participants to ask their questions to the nurse facilitator so they can walk away feeling empowered!	60 min	<ul style="list-style-type: none"> •Registered Nurse 	CES*
Finding Strength through the Struggle	<ul style="list-style-type: none"> •Adults; 18+ •Females ONLY 	As a woman with a bleeding disorder, you have individual struggles and triumphs. There are many people - even some you haven’t met - who care deeply about the challenges you face. Join us for this interactive workshop that will focus on <i>you</i> ; your hopes and your empowerment. Participants will learn how to harness frustration and turn it into positive action. They will walk away feeling energized and ready to face a new day!	60 min	<ul style="list-style-type: none"> •NHF Staff 	CES*
Let’s Talk <i>Period</i>	<ul style="list-style-type: none"> •Teenagers; 13-18 yrs. Old •Adults; 18+ •Females ONLY 	While periods and puberty are a healthy and normal part of a woman’s life, it can feel like a true hardship for a woman 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, women will have the opportunity to discuss scenarios and solutions relating to periods in a safe environment. They will leave with practical tips, feeling connected, and empowered. <i>This activity is best done with a nurse/social worker present* This workshop can also include: Mother/Daughter “It is not always easy to talk about puberty. Here, mothers and daughters will have the opportunity for discussion in a safe space. By the end, participants will be able to discuss concerns, share tips and support, and discuss solutions for difficult scenarios.</i>	60 min	<ul style="list-style-type: none"> •NYLI •NHF Staff 	CES*
Advocating for Yourself as a Woman	<ul style="list-style-type: none"> •Adults; 18+ •Females ONLY 	As a woman with a bleeding disorder, you will often face a lack of understanding about how your diagnosis affects <i>you</i> from an array of people; health care providers, co-workers, friends <i>and</i> policy-makers. This workshop teaches communication strategies and tools for you to advocate for your needs.	60 min	<ul style="list-style-type: none"> • Speakers Bureau • NHF Staff 	CES*
Series 3					
Hemophilia Treatment: Now and the Future					

Workshop Title	Target Audience	Description	Length (min)	Facilitated By	Funding*
Gene Therapy Basics for Hemophilia: What You Need to Know	•Adults; 18+ •M/F	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.	60 min	•NHF Staff •Speakers Bureau - Nurse Educator	Gene and Innovative Therapies Sponsors**
The Basics of Innovative Therapies: What You Need to Know	•Adults; 18+ •M/F	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.	60 min	•NHF Staff •Speakers Bureau - Nurse Educator	Gene and Innovative Therapies Sponsors**
Navigating Clinical Trials	•Adults; 18+ •M/F	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.	60 min	•NHF Staff •Speakers Bureau - Nurse Educator	Gene and Innovative Therapies Sponsors**
Communicating with Providers	•Adults; 18+ •Patients, Caregivers, Parents •M/F	YOU are your most important advocate in the health care system. If you have a child, you are also their most important advocate. In order to be a strong advocate for yourself and/or your child, it is important for you to learn how to make your concerns heard and understood. By improving communication and advocacy skills, participants will learn to speak more effectively and secure appropriate treatment.	60 min	• Speakers Bureau • NHF Staff	CES*
Series 4		Mental Health			
Mental Health Basics	•Adults; 18+ •M/F	Millions of people in the U.S. are affected by mental illness each year. According to the National Alliance on Mental Illness, approximately 20.6 % of U.S. adults experienced mental illness in 2019 (51.5 million people). This represents 1 in 5 adults. It is important to recognize and have a basic understanding of the spectrum of mental illness, in addition to understanding the layers of stigma related to mental health. This workshop will help define mental health and mental wellness giving participants an overview of anxiety, depression, and other mental health disorders.	60 min	•Speakers Bureau - SW or Licensed Professional Counselor	CES*
PTSD in Chronic Conditions	•Adults; 18+ •M/F	The Mayo Clinic defines Post-traumatic stress disorder (PTSD) as a mental health condition that's triggered by a terrifying event – either experiencing it or witnessing it. Most people who go through traumatic events may have temporary difficulty adjusting and coping, but with time and good self-care, they can get better. In this workshop we will explore the multilayers of PTSD, especially newer research showing how having a chronic health condition can lead to PTSD, not just a trigger one time traumatic event. This workshop will also help define PTSD, understanding it's effects on self, relationships, family, friends and work.	60 min	•Speakers Bureau - SW or Licensed Professional Counselor	CES*
Talking About What Isn't Talked About	•Adults; 18+ •M/F	Stigmas about mental illness is rooted within social media, culture, religion and personal perception. Having a negative belief about mental illness can be detrimental in a person's ability to seek help or even assist others. In this workshop we will learn and recognize the stigma around mental health as it relates to cultural norms and perception.	60 min	•Speakers Bureau - SW or Licensed Professional Counselor	CES*
Managing Stress & Improving Wellness	•Adults; 18+ •M/F	Everyone feels the elements of stress throughout their lifetime, from starting a new job to moving into a new home or dealing with the plethora of issues related to COVID 19 and social distress. As a result stress can affect your health in a variety of ways from the physical to the emotional. The areas that cause the most stress may change in different phases of a person's life. This workshop will explore the dynamics of stress and begin the discussion on how to work through stress. More importantly participants will also explore a variety of techniques and tools on how to manage stress in their daily lives.	60 min	•NHF Staff	CES*
Series 5		Navigating Your Bleeding Disorders Care and Community			

Workshop Title	Target Audience	Description	Length (min)	Facilitated By	Funding*
Choose to Take Control	•Teenagers; 14+ •Adults; 18+ •M/F	Being a good consumer is more than just access to products and care, it is also about knowing the do's and don'ts that impact your daily life with a bleeding disorder. It's about understanding your disease, choosing a care team, clearly communicating your needs and accepting responsibility for making the decisions that ensure your safety and wellbeing. During this interactive presentation, we will discuss tips, tricks and tools available to help you become a better self-advocate and an overall good consumer.	60 min	• Speakers Bureau • NHF Staff	CES*
Go to Dinner, Go to Jail	•Teenagers; 14-17 yrs. old •Adults; 18+ •M/F	Having a bleeding disorder comes with great responsibility to get the best care possible. This interactive session will give you information on the sometimes confusing acronyms - HTC, 340B, HRSA, etc. - which can be a roadblock to getting care. We will also cover the critical questions to ask when choosing a factor provider. Finally, we will address the responsibility that parents, patients, pharmaceutical and homecare representatives have in following the rules and laws that affect us all.	60 min	•NHF Staff	CES*
Social Media in the Bleeding Disorders Community; Benefits & Risks	•Adults; 18+ •M/F	Have you ever discussed your or your child's bleeding disorder on social media, or on a website for fundraising or advocacy purposes? Have you ever joined an online discussion group to give or receive advice? Talking about your own bleeding disorder or your child's online can create a digital 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.	60 min	•NHF Staff	CES*
How Do YOU Navigate?	•Adults; 18+ •M/F	Learning through the lived experiences of others is helpful in navigating the landscape of bleeding disorder care. In this workshop, participants will be given an opportunity to learn through investigating scenarios building on the previously delivered material but also through discussions of the issues they are facing in their own everyday life. By the end, participants will receive practical tips and will feel connected and empowered.	60 min	•NHF Staff	CES*
Series 6					
Hemophilia Basics: Learning & Fun					
Genetics	•Adults; 18+ •M/F	Whether you are new to explaining to others how hemophilia ended up in your family or have done it many times, come test your knowledge on the inheritance of hemophilia (aka how it can be passed on from biological parents to their children), get your questions answered, and walk away with tips for how you can discuss these concepts with family and friends.	60 min	•Speakers Bureau	CES*
Dental Care	•Adults; 18+ •M/F	Learn all about key concepts of dental and oral care for people with bleeding disorders. Good dental care not only keeps the teeth and gums healthy for a lifetime, but it also prevents unnecessary dental treatment and potential bleeding problems in the future.	60 min	•Speakers Bureau	CES*
Bleeds	•Adults; 18+ •M/F	Whether you have never had a joint or muscle bleed or have had more than you would like to count, it is important to understand some of the signs and symptoms as well as consequences of bleeding. This workshop will provide valuable information on what different bleeds might look like and provide practical tips for what to do when a bleed occurs.	60 min	•Speakers Bureau	CES*
Inhibitor Risk and Treatment	•Adults; 18+ •M/F	Everyone with hemophilia can benefit from knowing the basics of inhibitors, even if you don't have one, because if you treat with clotting factor, you may be at risk for developing an inhibitor. This workshop will explain inhibitor basics, how they develop, treatment options, as well as how and why you should have a conversation with your healthcare provider about screening for an inhibitor.	60 min	•Speakers Bureau	CES*
Series 7					
Teen Time					
Kahoot Bleeding Disorders Trivia	•Teenagers;13+ •M/F	Who says virtual can't be fun? This competitive game-based workshop will test community member's knowledge on various bleeding disorders, our community history, and fun trivia. Each participant will need access to two screens (smartphone, tablet, or laptop) in order to participate.	60 min	•NYLI •NHF Staff	CES*
Personal Advocacy: Making a Positive Impression	•Teenagers;13-19 yrs. old •M/F	Learn about the importance of personal advocacy through a variety of situational discussions. Consider how and when to set boundaries and say "no." Get tips on advocating for your health at school, at your HTC and throughout life in general.	60 min	•NYLI •NHF Staff	CES*
Relationships & Disclosures	•Teenagers; 13-19 yrs. old •M/F	For those with bleeding disorders, disclosure to their friends, partner, or even teachers and coaches can be nerve-racking. This workshop will offer teens the opportunity to discuss relationships and disclosure in a safe environment through scenarios and personal experiences. Participants will leave feeling more comfortable and ready to discuss their bleeding disorder.	60 min	•NYLI •Speakers Bureau •NHF Staff	CES*

Workshop Title	Target Audience	Description	Length (min)	Facilitated By	Funding*
Becoming Independent on My Own	•Teenagers; 13+ •M/F	It is never too soon to start thinking about the future. Leaving for college or entering the workplace after high school is both an exciting and challenging time. By the end of the workshop, participants will be able to consider financial planning, share tips and support on how to disclose their bleeding disorder, and create a plan for treatment adherence and emergencies.	60 min	•NYLI •NHF Staff	CES*
Series 8		Move and Improve			
It's Not Too Late to Save Your Joints	•Adults; 18+ •M/F	Whether you have never had a joint bleed or have had more than you would like to count, it isn't too late to learn more ways to prevent future joint damage. In this presentation you will learn small steps for incorporating safe physical activity into your routine and identifying and addressing a joint bleed when it takes place.	60 min	•Speakers Bureau - PTs or Nurses	CDC, CES*
Looking from the Outside in: Musculoskeletal Ultrasound	•Adults; 18+ •M/F	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.	60 min	•Speakers Bureau - PTs or Nurses	CES*
Navigating Pain	•Adults; 18+ •M/F	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.	60 min	•Speakers Bureau - PTs or Nurses	CES*
Playing it Safe	•Teenagers; 13+ •Adults; 18+ •M/F	Staying active is imperative for people with bleeding disorders, it helps you retain and regain joint health, prevent mobility issues and lead to a better quality of life. Join this presentation to find motivation, support, and easy-to-use resources that can help you find the sport or exercise that's the right fit for you.	60 min	•Speakers Bureau - PTs or Nurses	CES*

*Community Education Sponsors (CES): Accredo, Bayer, CSL Behring, Grifols, Hemophilia Alliance, Pfizer, Sanofi Genzyme, Takeda, and The Alliance Pharmacy

**Gene and Innovative Therapies Sponsors: BioMarin, Genentech, Optum Specialty Pharmacy, Pfizer, Inc., Sangamo, Sanofi Genzyme, Sigilon, Spark Therapeutics, Takeda and UniQure