

Education for Empowerment

2024 Workshop List - English

Adults			
Workshop Title	Workshop Description	Length	Facilitated by
Advocating in the ER	Having to advocate for yourself or a loved one's care 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 you navigate difficult situations that you may encounter when you are in the emergency room.	60min	NBDF Staff
Aging as a Person with a Bleeding Disorder	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 discussion-based workshop will explore what we have learned about aging with a bleeding disorder, while providing a space for sharing lived experiences. You will provide with resources and skills to navigate the unknown.	60min	Speaker Bureau
Candid Conversations	The bleeding disorders community is witnessing tremendous growth in the number and types of therapies to treat hemophilia. This is a moderated panel discussion that includes lived experience experts (LEEs) who are on different types of treatments – (factor replacement, bispecific antibody therapy, and gene therapy), and physicians. This workshop will provide you with a “bird’s eye view” into the real-world experience of both consumers and providers, the path to shared decision-making, and how innovative therapies are changing the landscape of the bleeding disorders community.	60-90 min	Speaker Bureau

Workshop Title	Workshop Description	Length	Facilitated by
Don't Fear the Poke	There are gloves and tourniquets and medication; skin to sterilize and steps to follow: no wonder infusions and injections feel scary to you and your child. Managing these stressors will be important for your family's quality of life. This workshop will explore needle fear and phobia and will provide you with essential skills to navigate the daunting task.	60min	Speaker Bureau
Finding the Strength through the Struggle	As a person 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 you; your hopes and your empowerment. You will learn how to harness frustration and turn it into positive action. You will walk away feeling energized and ready to face a new day!	60min	NBDF Staff
Gene Therapy Basics for Hemophilia: What You Need to Know	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 you to have robust conversations with your providers and to ultimately make the best decision on treatment.	60min	Speaker Bureau

Workshop Title	Workshop Description	Length	Facilitated by
How to be a Savvy Community Member	Having a blood or 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. You will learn the critical questions to ask when choosing a medication provider. You will also gain an understanding of the responsibility that parents, patients, pharmaceutical and homecare representatives have in following the rules and laws that affect us all.	60min	NBDF Staff
Journey Through the Clotting Cascade	"Journey Through the Clotting Cascade" is an engaging and interactive workshop that brings the complex clotting process to life through a hands-on activity. You will gain a deeper understanding of the clotting cascade and the vital role it plays in the body's response to bleeding. During the session, we will also explore how various treatments for bleeding disorders fit into the clotting cascade, providing a clearer picture of how these therapies work to manage and prevent bleeding episodes.	60min	NBDF Staff
Medical Marijuana: A Way to Manage Your Pain?	Medical marijuana is increasingly legal and used as a remedy for pain. This workshop will explain what people with bleeding disorders need to know should you be considering medical marijuana as part of a pain treatment plan.	60min	Speaker Bureau
Mental Health: A Deeper Dive	Millions of people in the U.S. are affected by mental health issues. While we have started to have more open conversations about our mental health, it is time to dig deeper and move beyond the basics. This workshop will investigate mental health issues seen in the blood and bleeding disorders community and provide innovative skills and resources to you.	60min	Speaker Bureau

Workshop Title	Workshop Description	Length	Facilitated by
Moving forward from the WGPPM Summit	The Women, Girls, and People who have or had the Potential to Menstruate (WGPPM) Summit took place in May 2023 bringing together people with bleeding disorders, health care professionals, chapter representatives, and national organizations to map out a coordinated plan for progress. This interactive workshop will highlight the outcomes of the summit and invite everyone to become part of the movement. You will walk away feeling empowered with the advocacy tools and knowledge to create change for this community.	60min	NBDF Staff
Navigating Clinical Trials	Clinical trials are key to advancing safe and effective treatments for blood and 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, it is important to understand the Clinical Trials process - including informed consent - and what your role is should you choose to participate.	60min	Speaker Bureau
Pain Explained	Many people with blood and bleeding disorders find that bleeding-related pain and joint damage impact their quality of life. This workshop will improve your understanding of how pain affects people with and approaches for managing pain. It will also provide you with innovative tips, tools, and skills to decrease your experience of pain without taking a pill.	60min	NBDF Staff Speaker Bureau

Workshop Title	Workshop Description	Length	Facilitated by
Reproductive Health, Menstruation, and Menopause	Reproductive health, menstruation, and menopause are vital topics in the lives of girls, women, and those who have or had the potential to menstruate. Yet, our conversations about these within the blood and bleeding disorders community have been sparse. It's time to change. This workshop will provide a deeper dive into physiological components of these topics, highlight implications for bleeding disorders, and provide essential skills and resources to you.	60min	Speaker Bureau
Shared Decision Making and the Shift to Person Centered Care	You are the lived experience expert of your and/or your child's blood or bleeding disorder. And, as the lived experienced 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, you will gain advocacy and communications skills as well as important resources.	60min	NBDF Staff Speaker Bureau
Super Seven: Family Fireside Chat	Living with or taking care of someone with an ultra-rare bleeding disorder can feel confusing and isolating. This discussion-based workshop will explore NBDFs children's book Super Seven. You will participate in a variety of activities to explore some of the book's themes. By the end of the workshop, you will be able to identify steps to foster independence and include the entire family in the experience.	60min	NBDF Staff

Workshop Title	Workshop Description	Length	Facilitated by
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 innovations – what they are, how they work in the body and how safe they are. Understanding all the options including currently approved treatments and the promise and limitations of each type of therapy will enable you to have informative conversations with your providers to make the best treatment decision for you. This workshop will provide a basic overview of current and future treatment options for hemophilia and make these complex concepts more understandable.	60min	Speaker Bureau
Who is Taking Care of the Caregiver?	Parents and caregivers, who are responsible for day-to-day care of someone with a blood or bleeding disorder may face burnout at some point in their lives. This workshop will introduce the concepts of prioritizing and practicing self-care, so that you are ready and able to take care of others. We will explore various self-care options and motivate you with practical ideas to make self-care a priority.	60min	NBDF Staff
Ultra-Rares and Personal Advocacy	This interactive workshop will explore the lived experiences of the ultra- rare bleeding disorders community through a personal advocacy lens. This is a discussion- based workshop that will allow you to learn from fellow community members' experiences in addition to sharing your challenges, experiences, and perspectives.	60min	NBDF Staff

Teens

Workshop Title	Workshop Description	Length	Facilitated by
Being Different, Belonging Together!	Bullying has become a major public health issue. In this interactive workshop we will be tackling the topic of bullying amongst teenagers. Through a creative process you will be able to address questions, feelings, and concerns you might have. You will receive helpful tips on how to navigate difficult situations and come up with creative solutions for creating a safe environment.	60min	NBDF Staff
Do You Bleed Like Me?	The blood and bleeding disorders community is a very educated and empowered group of people, but how much do you know about bleeding disorders other than your own? "Do You Bleed Like Me?" gives you an opportunity to test your knowledge with your peers! By the end of the workshop, you will be able to assess your knowledge, discuss things you wished others knew, and break down barriers within your community.	60min	NBDF Staff
Don't Fear the Poke	Infusions and injections are scary. There are gloves and tourniquets and medication; skin to sterilize and steps to follow. And then, there is the poke. This workshop will explore needle fear and phobia in teenagers and will provide you with essential skills to take charge of your fears and navigate the daunting task.	60min	Speaker Bureau
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, you will learn how to celebrate your failures in a safe environment and walk away feeling more empowered and confident.	60min	NBDF Staff

Workshop Title	Workshop Description	Length	Facilitated by
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 you discuss the benefits of independence and identify the necessary steps to help you achieve your family's goals.	60min	NBDF Staff
Journey Through the Clotting Cascade	"Journey Through the Clotting Cascade" is an engaging and interactive workshop that brings the complex clotting process to life through a hands-on activity. You will gain a deeper understanding of the clotting cascade and the vital role it plays in the body's response to bleeding. During the session, we will also explore how various treatments for bleeding disorders fit into the clotting cascade, providing a clearer picture of how these therapies work to manage and prevent bleeding episodes.	60min	NBDF Staff
Mental Health for Teens	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 blood and bleeding disorders community. This workshop will equip you with greater knowledge, innovative strategies, skills, and resources to tackle these challenges.	60min	Speaker Bureau
Super Seven: Fireside Chat	Living with an ultra-rare bleeding disorder can sometimes feel like no one understands. This interactive workshop will explore NBDF's children's book Super Seven. You will get to participate in a fun workshop with lots of discussions, including disclosing your bleeding disorder, talking to school staff, sleepovers, sports, and encouraging independence in decision making.	60min	NBDF Staff

Kids

Workshop Title	Workshop Description	Length	Facilitated by
Being Different, Belonging Together!	Bullying has become a major public health issue, and it often starts at a very young age. Through a creative process we will discuss this topic and you will be able to address questions, feelings, and concerns you might have. You will receive helpful tips on how to navigate difficult situations and come up with creative solutions for creating a safe environment.	60min	NBDF Staff
Clotting for Kids	Understanding the clotting process is important when learning about your blood or bleeding disorder. This fun and interactive workshop assigns a job to each player in the clotting process and will bring the science to life by acting out what is happening in the body to stop the bleeding.	60min	NBDF Staff
Don't Fear the Poke	Infusions and injections are scary. There are gloves and tourniquets and medication; skin to sterilize and steps to follow. And then, there is the poke. This workshop will explore needle fear and phobia in kids and will provide you with essential skills to take charge of your fears and navigate the daunting task.	60min	Speaker Bureau
Super Seven: Fireside Chat	Living with an ultra-rare bleeding disorder can sometimes feel like no one understands. This interactive workshop will explore NBDFs children's book Super Seven. You will get to participate in a fun discussion, including talking about your blood or bleeding disorder, conversations with school staff, sleepovers, sports, and much more.	60min	NBDF Staff