

2020 NHF Education for Empowerment Workshop Offerings

Workshop Title	Target Audience	Description	Length (min)	Group Size	Facilitated By	Funding*
Advocating for Your 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	15-40	<ul style="list-style-type: none"> • Speakers Bureau • 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	15-40	<ul style="list-style-type: none"> • Speakers Bureau • NHF Staff 	CES*
All About Advocacy: Becoming an Impactful Advocate	<ul style="list-style-type: none"> •Teenagers; 13-19 yrs. old •M/F 	Learn the basics of our government; how to effect change in lawmaking, how to tell your impactful story to lawmakers & legislators, and how a bill becomes a law, focus on just one part or sample all three topics!	60	10-30	<ul style="list-style-type: none"> • NYLI • NHF Staff 	CES*
Artistically Speaking for Women	<ul style="list-style-type: none"> •Females ONLY 18+ 	Art can help encourage the self-expression of thoughts and feelings related to living with a bleeding disorder. This workshop uses a peer education model along with experiential art techniques to assist participants in recognizing the impact of their bleeding disorder on their health, and provide a process through which they can build skills and share with each other.	60	15-50	<ul style="list-style-type: none"> • Speakers Bureau • NHF Staff • NYLI (Kids & Teens) 	CES*
Becoming Independent on My Own***	<ul style="list-style-type: none"> •Teenagers; 14+ •Parents •M/F 	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	15-60	<ul style="list-style-type: none"> •NYLI •Guías Culturales •NHF Staff 	CES*

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Building Blocks of You	<ul style="list-style-type: none"> •Children; 5-12 yrs. old •M/F 	There are many different aspects that make up how an individual perceives themselves and their larger community. This interactive workshop is an exploration of the parts that make up <i>you</i> , the role we each play in our smaller communities <i>and</i> the bleeding disorders community, allowing participants to explore these questions and more through hands-on activities and guided open discussions. <i>Can be modified for an all male audience*</i>	60	15-30	<ul style="list-style-type: none"> •NYLI •NHF Staff 	CES*
Choose to Take Control	<ul style="list-style-type: none"> •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	15-200	<ul style="list-style-type: none"> • Speakers Bureau • NHF Staff 	CES*
Clotting for Kids	<ul style="list-style-type: none"> •Children; 9-12 yrs. old •M/F 	Understanding the clotting process is important to understanding a bleeding disorder. This workshop assigns a job to each player in the clotting process - bringing the science to life by participants acting out what is happening in their own bodies to stop the bleeding.	45-60	15-30	<ul style="list-style-type: none"> •NYLI •NHF Staff 	CES*
Communicating with Providers	<ul style="list-style-type: none"> •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, you can learn to speak more effectively and secure appropriate treatment.	60	15-40	<ul style="list-style-type: none"> • Speakers Bureau • NHF Staff 	CES*
Disclosing Your Child's Bleeding Disorder	<ul style="list-style-type: none"> •Adults; 18+ •Relatives, Caregivers, Parents •M/F 	One of the biggest challenges parents face is letting people know about your child's bleeding disorder. You may be unsure of "when" and "how" to disclose to friends and family. This workshop will help you make decisions around disclosure and gain comfort around discussing your child's bleeding disorder with others.	45-60	15-40	<ul style="list-style-type: none"> • Speakers Bureau • NHF Staff 	CES*
Do You Bleed Like Me?***	<ul style="list-style-type: none"> •Adults; 18-22 •Children/Teenagers ;10-17 yrs. old (<i>in groups of ≤ 5yr range ex. 13-17 year old's</i>) •Siblings •M/F 	The bleeding disorders community is a very educated and empowered group of people, but how much do they know about bleeding disorders other than their own? "Do You Bleed Like Me?" gives participants an opportunity to test their knowledge... on each other! By the end of the workshop, participants will be able to assess their knowledge, discuss things they wished others knew, and break down barriers within our community.	30-45	15-40	<ul style="list-style-type: none"> •NYLI •Guías Culturales •NHF Staff 	CES*

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Factor Feud***	•Children; 9-12 yrs. old •M/F	Participants will compete against each other in a “Family Feud” style game. Here’s the catch - instead of getting a bright red “X” for a missed term, teams will have to complete a physical activity. This active and educational competition will reinforce the participants’ knowledge of bleeding disorders, as well as empower them to share, rather than hide, their conditions to their friends and family.	30-45	30-45	•NYLI •Guías Culturales •NHF Staff	CES*
Factor Function: How Half-Life Affects You**	•Adults; 18+ •M/F	It’s time to clear up the confusion about half-life of clotting factor. You will leave this session with a deeper understanding of how long factor replacement lasts in a person’s body, how it prevents joint bleeds and allows for physical activity, and how it can affect prophylaxis schedules.	60-90	15-200	•Registered Nurse	CDC, CES*
Failure <i>Is</i> an Option***	•Adults; 18+ •M/F	We often hear that “failure is <u>not</u> 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.	45-90	15-30	•NHF Staff	CES*
Finding Strength through the Struggle***	•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. Learn how to harness frustration and turn it into positive action. Walk away feeling energized and ready to face a new day!	60	15-40	•Guías Culturales •NHF Staff	CES*
Free Rides & Better Jobs; Game of Life	•Teenagers; 13-17 yrs. old •Adults; 18-22 yrs. old •M/F	Chapters support people with bleeding disorders in several different ways throughout every stage of life! In this interactive workshop teens will learn how their chapter can help them along the way <i>and</i> in return how they can give back, and in the end there may be something in <i>it</i> for them.	90-120	15-40	•NYLI •NHF Staff	CES*
Free Rides & Better Jobs; Storytelling	•Teenagers; 13-17 yrs. old •Adults; 18-22 yrs. old •M/F	Scholarships for college are available exclusively to members of the bleeding disorders community. Storytelling is an important part of applying for these scholarships. Participants will learn how to create an outline of their story and fill in the rest in an engaging manner.	60	15-40	•NYLI •NHF Staff	CES*

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Gene Therapy Basics for Hemophilia; What You Need to Know	<ul style="list-style-type: none"> •Adults; 18+ •M/F 	Recently there has been an explosion of innovation in the treatment of Hemophilia. It is becoming more important than ever to stay informed on all the advancements - what they are and how they work in the body. Understanding all the options, the potential as well as the limitations, risks and unknowns of each type of therapy will enable community members to have robust conversations with their providers and to ultimately make the best decision on treatment. This presentation is designed to provide a basic overview making these complex concepts more understandable.	60	15-200	<ul style="list-style-type: none"> •NHF Staff •Speakers Bureau - Nurse Educator 	Gene and Innovative Therapies Sponsors**
Girl Identity; A Look in the Mirror	<ul style="list-style-type: none"> •Children; 9-12 yrs. old •Teenagers; 13-18 yrs. old •Females ONLY 	Trying to figure out who you are and how you fit in can be hard enough when you are a teen/pre-teen, but adding a bleeding disorder on top of it adds a whole different dimension to the concept of identity exploration. Who am I? What makes me, me? What makes me special? How does my bleeding disorder influence and fit into my identity and my future? This interactive workshop will allow girls to explore identity through hands-on activities and guided discussions. Participants will be able to connect and walk away with the knowledge that they are supported and not alone.	60	15-30	<ul style="list-style-type: none"> •NYLI •NHF Staff 	CES*
Go to Dinner, Go to Jail	<ul style="list-style-type: none"> •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	15-200	<ul style="list-style-type: none"> •NHF Staff 	CES*
Independence & Management**	<ul style="list-style-type: none"> •Families ONLY •M/F 	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, <i>but</i> 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.	60	15-40	<ul style="list-style-type: none"> •NYLI •Guías Culturales •NHF Staff 	CES*
It's Not Too Late to Save Your Joints***	<ul style="list-style-type: none"> •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	15-200	<ul style="list-style-type: none"> •Registered Nurse 	CDC, CES*

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Jeopardy***	<ul style="list-style-type: none"> •Teenagers;13+ •Adults;18+ •M/F 	<i>Bleeding disorders for 500 Please!</i> Who wouldn't want to test their knowledge in a fun, interactive way? This versatile game engages teens and families, and everyone will go home with new information on bleeding disorders... unless they're already experts!	60	15-60	<ul style="list-style-type: none"> •NYLI •NHF Staff 	CES*
Kahoot Bleeding Disorders Trivia	<ul style="list-style-type: none"> •Children; 9-12 yrs. old •Teenagers;13+ •Adults;18+ •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.	30-60	15- 60+	<ul style="list-style-type: none"> •NHF Staff 	CES*
Let's "Hear" It for the Girls!	<ul style="list-style-type: none"> •Teenagers; 13-18 yrs. old •Females ONLY 	Girls are affected by a bleeding disorder, or they are a sibling of someone who is, nonetheless they may have their own set of concerns when it comes to life with a bleeding disorder, and it's important to identify the people who can support them through that journey. This sibling-inclusive workshop covers how to identify and communicate feelings, how to constructively communicate with those who support you, and how to identify your community and build your support network - all to set these girls up for success. <i>Let's hear it for the girls!</i>	60	15-30	<ul style="list-style-type: none"> •NYLI •NHF Staff 	CES*
Let's Talk Bullying...***	<ul style="list-style-type: none"> •Children; 5-8 yrs. old •Children/Teens;11-15 yrs. old •Adults; 18+ •Parents & Caregivers •M/F 	<ul style="list-style-type: none"> •Art Project (ages 8-13): Art is a wonderful way for children to express their thoughts and feelings on difficult topics. Depending on a child's experience, the topic of bullying can cause them to be anxious and/or to feel uncomfortable. Through a creative process, participants will have the opportunity to discuss bullying and express themselves through art. •Miss Spider's Tea Party (ages 5-8):It is never too early to talk about bullying. Miss Spider's Tea Party is a storybook that will help lead a discussion about questions, feelings and concerns children might have about this complex topic. They will gain tips on how to deal with a difficult situation and understand the importance of talking to an adult when faced with bullying. •Scenarios (ages 11-15): Bullying is a loaded word and can be a difficult topic for young adolescents to discuss. Through discussion of different scenarios and role playing, participants will have the opportunity to come up with creative solutions in a safe environment. •For Parents: In 2012, the CDC declared bullying a major public health issue. Parents play a crucial role in supporting and educating their children about this important issue. Through discussion and realistic scenarios parents are given the opportunity to think about what they might do to support their child(ren) if they are being bullied. 	<ul style="list-style-type: none"> •30 •For Parents 60 	<ul style="list-style-type: none"> •15-30 •For Parents:15-60 	<ul style="list-style-type: none"> •NYLI (Kids & Teens) •Guías Culturales •NHF Staff 	CES*

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Let's Talk <i>Period</i>	<ul style="list-style-type: none"> •Children; 9-12 yrs. old •Teenagers; 13-18 yrs. old •<i>Females ONLY</i> 	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. <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	15-30	<ul style="list-style-type: none"> •NYLI •NHF Staff 	CES*
Managing Stress & Improving Wellness***	<ul style="list-style-type: none"> •Adults; 18+ •M/F 	The areas that cause the most stress may change in different phases of your life. During this interactive workshop, you will get the chance to identify and talk about these areas that cause stress. You will be given tools on how to manage this stress so that you not only survive but <i>thrive!</i>	60	15-60	<ul style="list-style-type: none"> •Guías Culturales •NHF Staff 	CES*
Medical Marijuana	<ul style="list-style-type: none"> •Adults; 18+ •M/F 	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.	60-75	15-60	<ul style="list-style-type: none"> •NHF Staff 	CES*
Meet the Joints: Ankles & Knees***	<ul style="list-style-type: none"> •Adults; 18+ •M/F 	Time to get to know your joints more in depth! Come meet your ankle and knee joints, both of which can be common spots for target joints. In this presentation you will gain an understanding of the anatomy and function of the ankle and knee, the impact of a joint bleed in those places and learn exercises that can be done to help in recovery of a joint bleed.	60	60	<ul style="list-style-type: none"> •Speakers Bureau - PTs or Nurses 	CES* & CDC
Meet the Muscle Bleed***	<ul style="list-style-type: none"> •Adults; 18+ •M/F 	This workshop will focus on learning the signs of a muscle bleed, common causes and locations, how to modify activities, and physical therapy tips.	60	60	<ul style="list-style-type: none"> •Speakers Bureau - PTs or Nurses 	CES* & CDC
Mental Health Basics	<ul style="list-style-type: none"> •Adults; 18+ •M/F 	This workshop is in development by NHF's Mental Health Working Group, in partnership with Mental Health Matters Too, and will be available starting in March 2020. The description and title are not final but this topic will define mental health and mental wellness, and give an overview of anxiety, depression, PTSD and other mental health disorders. It will also focus on working through the stigma related to mental health.	60	15-60	<ul style="list-style-type: none"> •Speakers Bureau - SW or Licensed Professional Counselor 	CES*
Personal Advocacy: Making a Positive Impression	<ul style="list-style-type: none"> •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	10-30	<ul style="list-style-type: none"> •NYLI •NHF Staff 	CES*

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Playing it Safe for Kids***	<ul style="list-style-type: none"> •Children; 9-13 yrs. old •M/F 	Kids will be kids, but the kids in our community have to take special precautions. This workshop will discuss what's safe... and what isn't. By the end of the workshop, participants will be able to identify safe from unsafe activities and sports, and engage in safe, fun activities. Participants will end with some physical activities to show them easy and fun ways to stay active!	60-90	15-30	<ul style="list-style-type: none"> •NYLI •Guías Culturales •Speakers Bureau •NHF Staff 	CES*
Playing it Safe***	<ul style="list-style-type: none"> •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	15-200	<ul style="list-style-type: none"> •Physical Therapist 	CES*
PTSD in Chronic Conditions	<ul style="list-style-type: none"> •Adults; 18+ •M/F 	This workshop is in development by NHF's Mental Health Working Group, in partnership with Mental Health Matters Too, and will be available starting in March 2020. The description and title are not final but this topic will explore the multilayers of PTSD (post-traumatic stress disorder), especially the newer research showing that having a chronic health condition can lead to PTSD, not just a trigger one time traumatic event. This workshop will help define PTSD, understanding it's effects on self, relationships, family, friends and work.	60	15-60	<ul style="list-style-type: none"> •Speakers Bureau - SW or Licensed Professional Counselor 	CES*
Relationships & Disclosures***	<ul style="list-style-type: none"> •Teenagers; 14-19 yrs. old •M/F 	Being in a new relationship is often an exciting time. For those with bleeding disorders disclosure to their partner can be nerve-wracking. This workshop will offer adolescents 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	15-40	<ul style="list-style-type: none"> •NYLI •Guías Culturales •Speakers Bureau •NHF Staff 	CES*
Relationships & Intimacy	<ul style="list-style-type: none"> •Adults; 18+ •M/F 	Intimacy and relationships can have special dynamics for people with bleeding disorders, and for caregivers of a child with a bleeding disorder. This workshop explores different types of intimacy, and offers communication tools and practical ideas to cultivate a rewarding, enjoyable connection with a partner.	60	15-60	<ul style="list-style-type: none"> •Social Worker 	CES*
Social Media & Advocacy: Being an Effective User	<ul style="list-style-type: none"> •Teenagers; 13-19 yrs. old •M/F 	Learn how to responsibly and effectively use social media platforms to spread a <i>positive</i> message as well as the necessary components to make your next post go viral!	60	10-30	<ul style="list-style-type: none"> •NYLI •NHF Staff 	CES*
Social Media in the Bleeding Disorders Community; Benefits & Risks	<ul style="list-style-type: none"> •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	15-30	<ul style="list-style-type: none"> •NHF Staff 	CES*

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Talking About What Isn't Talked About / Hablando de lo que no she habla**	•Adults; 18+ •M/F	This workshop is in development by NHF's Mental Health Working Group, in partnership with Mental Health Matters Too, and will be available starting in March 2020. The description and title are not final but this topic will explore stigma around mental health, and when in Spanish will dive in more deeply to cultral and other considerations for the Latinx community.	60	15-30	•Speakers Bureau - SW or Licensed Professional Counselor	CES*
The Identity Card	•Teenagers;12-18 yrs. old •M/F	Teenage years can be challenging and overwhelming, trying to figure out who you are and and what's your identity can be a lot to take on! What is an identity? What makes me, me? How does my bleeding disorder affect, influence, and fit into my identity? This interactive workshop will explore these questions and more through hands-on activities and guided discussions.	60	15-30	•NYLI •NHF Staff	CES*
TIPs to Improve Communication with Healthcare Providers (<i>Spanish ONLY</i>)	•Adults; 18+ •M/F	Navigating the healthcare system in the US can be difficult without the information, language or cultural knowledge needed to effectively communicate with medical providers. This workshop will answer questions people may have about managing their interactions in a complex health system. TIPs = Tomar las riendas, Informar, Planear (Take control, Inform, Plan).	60	15-30	•Guías Culturales •NHF Staff	CES*
VWD: Ask the Expert	•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	15-200	•Registered Nurse	CES*
VWD: <i>Your Voice Matters</i> ***	•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	15-40	•Guías Culturales •Speakers Bureau •NHF Staff	CES*
What Everyone Who Treats with Factor Needs To Know About Inhibitors	•Adults; 18+ •M/F	If you treat with clotting factor, you may be at risk for developing an inhibitor. If you know someone or have heard of someone living with an inhibitor, you know it can be scary. But it doesn't mean you should know whether you or your family member are at risk for developing one. If you don't have an inhibitor, it's still important to know whether you're at risk. If you have hemophilia or VWD type 3 and use a factor product, you are at risk for developing an inhibitor. <i>This workshop is for people that do not have an inhibitor</i> and will explain inhibitors, how they develop as well as how and why you should have a conversation with your healthcare provider about screening for an inhibitor.	60	15-30	• Nurse	CDC, CES*

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Women Bleed Too :Q&A	<ul style="list-style-type: none"> • Teenagers; 14+ • Adults; 18+ • <i>FEMALES ONLY</i> 	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	15-200	•Registered Nurse	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

***Workshop also available in Spanish