Partners Basic
Partners in Bleeding Disorders Education

Topics and Learning Objectives

Comprehensive Clinic Observation: *Attendees will observe in real-time an adult comprehensive clinic visit.*

- Identify discipline-specific comprehensive clinic responsibilities in the multidisciplinary, patient-centered care model utilized at federally recognized hemophilia treatment centers to treat persons with congenital bleeding disorders
- Modify a nursing assessment to include a review of bleeding issues or concerns, identification of emerging concerns, and education regarding bleeding disorder management and bleed prevention
- Describe resources available to assist in comprehensive care and clinical management of bleeding disorders in affected patients and families

Hemophilia Treatment Centers: The Big Picture

- Describe the organization of the U.S. Hemophilia Treatment Center (HTC) network
- Identify significant funding sources for the US HTC network
- Evaluate important partnerships within the US HTC network

Understanding Hemostasis & Hemophilia

- Define the three components of the coagulation system and the three major processes that contribute to hemostasis
- Specify the deficits in the coagulation cascade that interfere with stable fibrin clot formation, causing hemophilia A, B, and C
- Explain the X-linked recessive inheritance pattern of FVIII and FIX deficiencies as derived from a pedigree analysis
- Identify the appropriate laboratory tests used to assist in the diagnosis of FVIII and FIX deficiencies
- Distinguish predicted bleeding patterns and clinical presentation of hemophilia based upon a classification of FVIII or FIX deficiency as severe, moderate, or mild
- Evaluate clinical considerations regarding women with hemophilia and carriers
- Discuss introductory information regarding factor XI deficiency

Bleeding Episodes & Treatment

- Examine bleeding risks in a neonate born to a carrier of hemophilia and in women and girls with hemophilia
- Differentiate bleeding episodes of hemophilia based on anatomical location and type and severity of bleed
- Explain principles of treatment for bleeding episodes in hemophilia with standard and extended half-life factor products
- Evaluate clotting factor concentrates available in the U.S. based on safety, product class, manufacturer, and patient support resources
- Avoid common errors in administration of clotting factor concentrates
- Identify treatments in addition to clotting factor concentrates that are available to treat hemophilia
- Discuss surgical management of hemophilia

Prophylaxis in Hemophilia

- Review the historical foundations and current status of prophylactic management of hemophilia
- Define the different types of prophylaxis and the value/benefits and long-term goals of these treatment regimens
- Discuss practical considerations in management of persons with hemophilia utilizing prophylactic regimens
- Determine a patient's optimal prophylactic clotting factor concentrate dosage using population-based pharmacokinetics
- Summarize the mechanism of action, dosing options, and study findings for the novel agent emicizumab
- Describe the mechanism of action and goal of gene therapy for hemophilia

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Topics and Learning Objectives – continued

Inhibitors I: Introduction to Inhibitors

- Differentiate high-responding, low responding, and transient inhibitors as defined by Bethesda unit (BU) measure
- Discuss the epidemiology of inhibitor development, including prevalence, risk factors, and clinical presentation of persons with hemophilia A and B
- Describe the potential effects of an inhibitor on the family
- Summarize the epidemiology and treatment options for acquired hemophilia
- Report SIPPET study results and the implications for the management of previously untreated patients (PUPs) in the U.S.

Inhibitors II: Inhibitor Treatment Strategies

- Analyze the various treatment modalities, including their advantages and disadvantages, for persons with hemophilia with inhibitors
- Examine the challenges, considerations, costs, and positive health outcomes of immune tolerance induction (ITI) therapy management
- Discuss emicizumab prophylaxis as an emerging treatment option for persons with FVIII deficiency with inhibitors

Coordination of Bleeding Disorder Care Across the Lifespan

- Discuss essential concepts in bleeding disorder management of obligate carriers and affected newborns
- Summarize the need for individualized treatment of bleeding disorders throughout the lifespan
- Identify educational resources and supportive services to the patient's community of providers and caregivers

Musculoskeletal Complications & Physical Therapy Management in Hemophilia

- Describe the role of the physical therapist on the hemophilia comprehensive care team
- Discuss musculoskeletal bleeding and associated complications in persons with hemophilia
- Analyze three imaging techniques including when they are used and how they are scored
- Assess physical therapy interventions for acute bleeding episodes and chronic hemarthropathy
- Recommend healthy activity guidelines for prevention of joint disease in persons with hemophilia

Helping Patients Flourish: The Role of the IHTC Career Counselor

- Identify the roles and responsibilities of the Psychosocial Team including the School and Career Counselor at an HTC
- Discuss the impact of School and Career Counselor services when addressing specific patient needs related to bleeding disorders
- Recall basic information and resources that can be effectively utilized to improve patient care involving bleeding disorders

Psychosocial Issues in Hemophilia: Impact Across the Lifespan

- Examine the effects of hemophilia on patients and families coping with the stressors and changes of everyday life
- Identify common transition stages and areas in which persons with hemophilia often need social work assistance
- Discuss social work interventions in priority areas
- Locate resources for hemophilia education, mental health and addiction referrals, transition guidance, and aging information

von Willebrand Disease

- Examine the prevalence, common bleeding symptoms, and genetics of von Willebrand disease (VWD)
- Identify the laboratory tests used to diagnose VWD
- Evaluate the categorization criteria for different types of VWD
- Review potential treatment modalities for VWD types 1, 2 and 3
- Recommend appropriate treatments in routine clinical encounters with persons with VWD

For additional questions regarding the Basic Partners Program, please email
partners@ihtc.org

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