

Program Agendas and Faculty

NHF's 72nd Virtual Bleeding Disorders Conference – **Medical Track**

Sunday, August 2, 2020

2:00 PM - 5:00 PM (Eastern Time)

FORGING A NEW PATH – GENE THERAPY READINESS AND HTC IMPLEMENTATION *CME/ACPE

Moderator/Speaker: **Steven W. Pipe, MD, Faculty Chair**

*Professor of Pediatrics and Pathology
Laurence A. Boxer Research Professor of Pediatrics and Communicable Diseases,
Pediatric Medical Director, Hemophilia and Coagulation Disorders Program,
Director, Special Coagulation Laboratory,
University of Michigan
Ann Arbor, Michigan*

Speakers:

Kollet Koulianos, MBA

Senior Director Payer Relations
National Hemophilia Foundation

Kayla Douglas, PharmD, CSP

Director of Pharmacy
Mississippi Center for Advanced Medicine
Madison, MS

Michael Wang, MD

Hemophilia Treatment Center Clinical Director
Hemophilia & Thrombosis Center
University of Colorado Denver

Rebecca Kruse-Jarres, MD, MPH

Director, Washington Center for Bleeding Disorders
BloodWorks NW
Associate Professor of Medicine
University of Washington
Seattle, WA

Radek Kaczmarek, PhD;

Postdoctoral Research Associate
Gene and Cell Therapy Group
Herman B. Wells Ctr for Pediatric Research
Indiana University School of Medicine
Indianapolis, IN

Discussant:

Christopher E. Walsh, MD, PhD

Associate Professor of Medicine, Division of Hematology and Medical Oncology
Icahn School of Medicine at Mount Sinai
Director, Hemophilia Treatment Center, Mount Sinai Hospital
New York, NY

By the end of this session, the participant should be better able to:

- *Describe the latest developments in hemophilia gene therapy and practical considerations needed to identify eligible patients and meet their ongoing therapeutic needs*
- *Review the logistics, precautions and staffing infrastructure needs for hemophilia treatment centers to adequately deliver and implement gene therapy infusions to patients with hemophilia*
- *Describe alternative and potential non-viral approaches for addressing more challenging patients who face eligibility challenges to hemophilia gene therapy*
- *Discuss the pharmacy considerations needed in receiving, storing or reconstituting a novel gene therapy product for hemophilia*
- *Recognize the clinical concerns raised by Covid-19 and its effects upon bleeding disorder patients with compromised health and/or in gene therapy trials with added immunomodulating therapies.*

Thursday, August 6, 2020

5:30 PM - 7:00 PM (Eastern Time)

THE NEXT WAVE: CLINICAL UPDATES ON NEW AND EMERGING TREATMENT OPTIONS IN HEMOPHILIA (PART 1) *CME/ACPE

Moderator: Stacy E. Croteau, MD, MMS

*Assistant Professor of Pediatrics, Harvard Medical School
Director, Hemophilia/VWD Program, Boston Children's Hospital
Medical Director, Boston Hemophilia Center
Dana-Farber/Boston Children's Cancer Center & Blood Disorders Center
Boston, MA*

Speakers: Robert F. Sidonio, Jr, MD, MSc

*Medical Director of Hemophilia Program
Director of Clinical Operations and Clinical Research
Aflac Cancer and Blood Disorders Center
Children's Healthcare of Atlanta/ Emory University
Atlanta, GA*

Mark T. Reding, MD

*Associate Professor of Medicine
Division of Hematology, Oncology & Transplantation
Director, Center for Bleeding and Clotting Disorders
University of Minnesota Medical Center*

By the end of this session, the participant should be better able to:

- *Describe the emerging therapies and novel non-factor approaches in development for treating patients with hemophilia A and B.*
- *Discuss the mechanisms of action for FVIIIa mimetic bispecific antibodies and the assays needed to monitor their safety and efficacy*
- *Recommend appropriate patients enroll in clinical trials for the evaluation of these therapies when and where available.*

Friday August 7, 2020

5:30 PM - 7:00 PM (Eastern Time)

**THE NEXT WAVE: CLINICAL UPDATES ON NEW AND EMERGING TREATMENT
OPTIONS IN HEMOPHILIA (PART 2) *CME/ACPE**

Moderator: Christopher E. Walsh, MD, PhD

*Associate Professor of Medicine, Division of Hematology and Medical Oncology
Icahn School of Medicine at Mount Sinai
Director, Hemophilia Treatment Center, Mount Sinai Hospital
New York, NY*

Speakers: Margaret V. Ragni, MD, MPH

*Professor of Medicine and Clinical Translational Science
Department of Medicine, Division of Hematology/Oncology
University of Pittsburgh Medical Center
Director, Hemophilia Center of Western PA
Pittsburgh, PA*

Guy A. Young, MD

*Professor of Pediatrics – Clinical Scholar
Keck School of Medicine
University of Southern California
Director, Hemostasis and Thrombosis Program
Children's Hospital of Los Angeles
Los Angeles, CA*

By the end of this session, the participant should be better able to:

- Describe the emerging therapies and novel non-factor approaches in development for treating patients with hemophilia A and B.*
- Summarize the latest clinical trial data available on new and emerging therapies.*

NHF's 72nd Virtual Bleeding Disorders Conference – **Nursing Track**

Saturday, August 1, 2020

2:00 PM – 5:00 PM (Eastern Time)

MANAGEMENT OF PATIENTS ON NOVEL THERAPIES *ANCC

Moderators: **Penny Kumpf, RN-BC, BSN**

Von Willebrand Outreach Nurse, Hemophilia of Georgia

Kelly Tickle, MSN, APN, PPCNP-BC

Pediatric Nurse Practitioner, Children's Healthcare of Atlanta

Speakers: **Lydia Johnson, RN, BSN**

Hemostasis Clinical Nurse Coordinator

SSM Cardinal Glennon Children's Medical Center

Saint Louis Univ. Dept of Pediatrics

Robert Sidonio, Jr., MD, MSc.

Medical Director of Hemophilia

Aflac Cancer & Blood Disorders Center/Children's Healthcare of Atlanta

Associate Professor of Pediatrics, Emory University School of Medicine

Emily Bisson, APRN, CPNP * (panel moderator)

Nurse Practitioner

Connecticut Children's Medical Center

Leigh Carpenter, R.Ph.

Pharmacist

Hemophilia of Georgia

Becky Garcia, RN, BSN, CPN

Pediatric Hemophilia & von Willebrand Clinical Coordinator

Hemophilia and Thrombosis Center, Phoenix Children's Hospital

Susan Knight, PT, PCS

Physical Therapist

Children's Hospital of Los Angeles

Kathaleen Schnur, LSW

Social Worker

Hemophilia Center of Western PA

By the end of this session, the participant should be better able to:

- *Summarize progress to date of Nursing Excellence Awardee - EMS Education/Awareness*
- *List 2 new developments in the clinical care of patients with bleeding disorders*
- *Review clinical indications for use of non-factor replacement products in conjunction with immune tolerance induction (ITI)*
- *Describe challenges & solutions for facilitating adherence*
- *Describe the multidisciplinary approach to care for the patient on novel therapy*

Sunday, August 2, 2020

3:00 PM - 4:00 PM (Eastern Time)

WALKING A NEW PATHWAY: COAGULATION & MEASURES OF HEMOSTASIS

*ANCC

Moderator: Kerry Hansen, RN
Nurse Clinician
University of Minnesota Health, Center for Bleeding and Clotting Disorders

Speaker: Jim Munn, MS, BS, BSN, RN-BC
Program Nurse Coordinator
Hemophilia and Coagulation Disorders Center, University of Michigan

By the end of this session, the participant should be better able to:

- List 4 laboratory measurements of hemostasis
- Review the role of novel therapies on the coagulation system
- Identify appropriate lab tests based on individualized therapy

Sunday, August 2, 2020

4:00 PM - 5:00 PM (Eastern Time)

DISORDERS OF FIBRINOGEN *ANCC

Moderator: Kimberly Hurdstrom, RN, BSN
Hemophilia & Thrombosis Center, University of Colorado School of Medicine
University of Colorado Denver

Speaker: Marilyn Manco-Johnson, MD
Director, Hemophilia & Thrombosis Center
Professor, Pediatrics Hematology-Oncology
University of Colorado School of Medicine
University of Colorado Denver

By the end of this session, the participant should be better able to:

- List 3 disorders of fibrinogen
- Describe medications used for the management of fibrinogen disorders
- Identify 3 clinical presentations of fibrinogen disorders

Monday, August 3, 2020

6:00 PM - 7:00 PM (Eastern Time)

TODAY'S TECHNOLOGY *ANCC

Moderator: **Tamara Bullock, RN-BC, BSN**
Hemophilia Community Nurse, University of Iowa Hospitals and Clinics

Speakers: **Penny Kumpf, RN-BC, BSN**
Von Willebrand Outreach Nurse
Hemophilia of Georgia

Michael DeGrandpre
Creative Director
Hemophilia Federation of America

By the end of this session, the participant should be better able to:

- Identify 3 potential concerns with social media use by nurses
- List 3 smartphone applications available for patients with bleeding disorders

Tuesday, August 4, 2020

6:00 PM - 7:00 PM (Eastern Time)

MILD PHENOTYPES: THE STRUGGLE IS REAL *ANCC

Moderator: **Jennifer Donkin, RN, DNP, CPNP, CFNP**
Nurse Practitioner, Children's Hospital of Los Angeles

Speakers: **Sharon L. Littig, RN**
Clinical Coordinator
Cardeza Foundation Hemophilia Center at Jefferson University

Penni J. Smith, MPA, BSN, RN-BC
Hemophilia/Hematology RN Coordinator
Utah Center for Bleeding and Clotting Disorders, Primary Children's Hospital

Brooke Towns, RN, BSN
Nurse Manager
Indiana Hemophilia and Thrombosis Center

By the end of this session, the participant should be better able to:

- Recognize barriers to care for patients with mild phenotypes of bleeding disorders
- Describe nursing care management strategies for patients with mild phenotypes of bleeding disorders

Wednesday, August 5, 2020

6:00 PM - 7:00 PM (Eastern Time)

CANNABIS APPLICATIONS & IMPLICATIONS *ANCC

Speakers: **Khalid Namoos**
Medical Fellow, UCLA David Geffen School of Medicine

By the end of this session, the participant should be better able to:

- Compare cannabis formulations and discuss the evidence for their potential use
- Discuss the evidence for clinical indications for cannabis use
- Describe the pharmacokinetics and physiological effects of cannabis

Thursday, August 6, 2020

6:00 PM - 7:00 PM (Eastern Time)

GYNECOLOGIC MANAGEMENT FOR FEMALES WITH BLEEDING DISORDERS *ANCC

Moderator: **Kelly Tickle, MSN, APN, PPCNP-BC**
Pediatric Nurse Practitioner, Children's Healthcare of Atlanta

Speaker: **Kalinda Woods, MD, FACOG**
Assistant Professor, Department of Gynecology and Obstetrics
Emory University School of Medicine

By the end of this session, the participant should be better able to:

- State therapeutic interventions for management of gynecologic conditions
- Discuss comorbidities contributing to dysfunctional uterine bleeding

Friday, August 7, 2020

6:00 PM - 7:00 PM (Eastern Time)

CARE COORDINATION FOR THE AGING BLEEDING DISORDERS POPULATION

*ANCC

Moderator: **Tamara Bullock, RN-BC, BSN**
Hemophilia Community Nurse, University of Iowa Hospitals and Clinics

Speakers: **Jeff Cornett, MSN, RN**
Vice President of Research and Public Policy
Hemophilia of Georgia

Shanna Mattis, MPH
Public Health Associate and Social Worker
Hemophilia of Georgia Center for Bleeding and Clotting at Emory University

By the end of this session, the participant should be better able to:

- Recognize challenges in obtaining services for the aging patient
- Identify 2 strategies to provide care to the aging adult

Saturday, August 8, 2020

3:00 PM - 5:00 PM (Eastern Time)

CHALLENGING CASES *ANCC

Moderators: **Sharon L. Littig, RN**

Clinical Coordinator

Cardeza Foundation Hemophilia Center at Jefferson University

Jessica Pindilli, BSN, RN

University of Wisconsin Hospital & Clinics

UWHC Comprehensive Program for Bleeding Disorders

Speakers: **Maria Tovar-Herrera, RN-BC, BSN**

RN Coordinator

Rush Hemophilia and Thrombophilia Center

Elisabeth Ambrose, BSN, RN

Nurse Coordinator

Mary M. Gooley Hemophilia Center

Courtney Carr, RN-BC, MSN, CPNP

Pediatric Nurse Practitioner

St. Jude Affiliate Clinic at Novant Health Hemby Children's Hospital

Shelia O'Donnell, FNP-C

Nurse Practitioner

Maine Hemophilia and Thrombosis Center

Charmaine Biega, RN

Nurse Coordinator

Nationwide Children's Hospital Hemostasis and Thrombosis Center

Pamela Widener, BSN, RN

Nurse Coordinator

Nationwide Children's Hospital Hemostasis and Thrombosis Center

By the end of this session, the participant should be better able to:

- Discuss challenging cases in bleeding disorders management*
- Explain the nursing interventions and skills needed to better assess and manage particularly challenging bleeding disorder cases.*

NHF's 72nd Virtual Bleeding Disorders Conference – Social Work
Sunday, August 2, 2020 **3:00 PM - 5:00 PM** (Eastern Time)

ETHICS: BLURRED BOUNDARIES *ASWB

Moderators: **Kathaleen Schnur, LSW**
Social Worker, Hemophilia Center of Western Pennsylvania

Lucy Ramirez, MSW, LCSW
Clinical Social Worker, Rush Hemophilia & Thrombophilia Center

Speaker: **Alana Brunner, LCPC, NCC, CCMHC**
Mental Health Therapist
St. Luke's Psychiatric Wellness

By the end of this session, the participant should be better able to:

- *Explain the importance of boundaries in social work practice*
- *Distinguish a boundary extension from a boundary violation*
- *Identify ethical codes related to boundary issues in therapeutic settings*
- *Evaluate ethical decision-making models to aid in working through ethical dilemmas*

Monday, August 3, 2020 **6:00 PM - 7:00 PM** (Eastern Time)

COVID-19 AND PROVIDER MENTAL HEALTH*ASWB

Moderators: **Amanda Stahl, MSW, LICSW**
Clinical Social Worker
Boston Hemophilia Center, Brigham and Women's Hospital

Lucy Ramirez, MSW, LCSW
Clinical Social Worker, Rush Hemophilia & Thrombophilia Center

Speaker: **Jeannie Aschkenasy, PhD**
Psychologist
Rush Hemophilia and Thrombophilia Center
Rush University Medical Center

By the end of this session, the participant should be better able to:

- *Demonstrate insight about causes and effects of compassion fatigue considering the ongoing Covid-19 pandemic*
- *Recognize the symptoms of compassion fatigue, secondary trauma and professional burnout in yourself and among your colleagues*
- *Identify 2 self-regulation practice skills to prevent compassion fatigue and promote professional resiliency in social work*

Tuesday August 4, 2020

6:00 PM - 7:00 PM (Eastern Time)

PREVALENCE OF DEPRESSION AND/OR ANXIETY IN CHILDREN SEEN AT THE ARIZONA HEMOPHILIA AND THROMBOSIS CENTER*ASWB

Moderators: **Amy Schadewald, MSW, LICSW, ACM**
Clinical Social Worker, M Health Fairview Center for Bleeding and Clotting Disorders

Connie Thibodeaux, MSW, LCSW, BAC
*Hemophilia Social Work Coordinator
Louisiana Center for Bleeding & Clotting Disorders
Tulane University School of Medicine / Deming Department of Medicine*

Speaker: **Maria Ianonne, MA, LPC**
*Arizona Hemophilia and Thrombosis Center
University of Arizona*

Discussant: **Laurel Pennick, LCSW**
*Arizona Hemophilia and Thrombosis Center
University of Arizona Health Sciences Center*

By the end of this session, the participant should be better able to:

- *Define the clinical diagnosis of depression and/or anxiety, including the use of validated instruments*
- *Discuss the ethical implications associated with screening for depression and anxiety*

Wednesday, August 5, 2020

6:00 PM - 7:00 PM (Eastern Time)

POVERTY AND BARRIERS IN HEALTHCARE *ASWB

Moderator: **Christi Humphrey, LCSW**
Social Worker, Hemophilia of Georgia, Inc.

Speakers: **Diane Bartlett, LCSW, OSW-C**
*Social Worker
St. Luke's Hemophilia Center*

Robert Loudon, MSW, LCSW
*Social Worker
Indiana Hemophilia & Thrombosis Center*

By the end of this session, the participant should be better able to:

- *Establish a framework for understanding poverty*
- *Recognize the impact poverty has on those living in a chronic disease state*
- *Manage the complexities of poverty in the bleeding disorder population*

Thursday, August 6, 2020

6:00 PM - 7:00 PM (Eastern Time)

MARIJUANA: BREAKING IT DOWN, THE GOOD, THE BAD, AND THE CONSUMPTION*ASWB

Moderators: **Kathaleen Schnur, LSW**
Social Worker, Hemophilia Center of Western Pennsylvania

Alfredo A. Narvaez, Jr., MSW, LMSW
*Social Worker, Louisiana Comprehensive Hemophilia Center
Tulane University Medical Center*

Speakers: **Khalid Namooos**
Medical Fellow, UCLA David Geffen School of Medicine

By the end of this session, the participant should be better able to:

- *Explain the biochemical components of marijuana*
- *Describe how marijuana affects the brain and the potential long-term effects on the brain*
- *Discuss the clinical evidence regarding potential medical benefits of marijuana use for patients*
- *Outline the current legal status of recreational or medicinal marijuana use across the US*

Saturday, August 8, 2020

3:30 PM - 5:00 PM (Eastern Time)

OUR RESILIENT MINDS, BODIES AND SOULS: EMPOWERMENT THROUGH STORYTELLING*ASWB

Moderators: **Damia Dillard, LCSW**
Social Worker, UC Davis Medical Center

Denise Lowery, LCSW
Social Worker, UC Davis Medical Center

Speaker: **Caroline Giroux, MD, FRCPC**
*Associate Clinical Professor, Psychiatry
UC Davis Medical Center, Behavioral Health Clinic
Director, UC Davis Trauma Recovery Center
Co-Director, RESTART Program: Resilience, Education and Supportive Tools for Adults
Recovering from Trauma*

By the end of this session, the participant should be better able to:

- *Describe key findings from the study of ACEs and the impact on the whole person, including the characteristics of the trauma experience for older adults*
- *Discuss the essential ingredients for harmonious development and the mechanisms within the stress response system*
- *Define TIC, practical strategies, and treatment modalities for trauma-related disorders*
- *List resilience factors in older populations and ways to enhance resilience*