

# New England Region Hemophilia Network • Annual Meeting 2024

October 28-29 • New York Academy of Medicine

## Day 1: October 28, 2024 8:00 am – 5:00 pm

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| 8:00 – 9:00 am   | <b>Breakfast / Welcome</b><br>***please sign in on Floor 3 upon arriving***  |
| 9:00 – 9:30 am   | <b>Welcome Address - Regional Updates (Reading Room)</b><br><i>Christopher Walsh, MD, PhD (Regional Director, New England Region)</i><br><i>Kaitlin Barnett, LCSW (Regional Administrator, New England Region)</i>   |
| 9:30 – 9:45 am   | <b>Case Study Program (Reading Room)</b><br><i>Joseph Stanco, NP (Nurse Practitioner, Northwell Health Hemostasis and Thrombosis Center)</i><br><i>Dr. Alice Cohen (Medical Director, Newark Beth Israel Hemophilia and Thrombosis Treatment Center)</i><br><i>Dr. Peter Kouides (Medical Director, Mary M. Gooley Hemophilia Center)</i>  |
| 9:45 – 10:45 am  | <b>Gene Therapy Collaboration (Reading Room)</b><br><i>Dr. Michael Recht, PhD, MBA (Yale Center for Bleeding and Clotting Disorders)</i><br><i>Dr. Catherine McGuinn (Director, NYPH-Weill Cornell Center for Hemophilia and Coagulation Disorders)</i>  |
| 10:45 – 11:00 am | <b>Break / Snack (Periodicals Room)</b>  |
| 11:00 – 12:00 pm | <b>340B Program Income (Reading Room)</b><br><i>Elizabeth Karan, JD, MPH (Legal Counsel, Hemophilia Alliance)</i>  |
| 12:00 – 1:00 pm  | <b>Lunch (Periodicals Room)</b>  |
| 1:00 – 1:30 pm   | <b>Grant Overview &amp; NHPCC Resources (Reading Room)</b><br><i>Abby Lowe-Wilson (Director, National Hemophilia Program Coordinating Center)</i><br><i>Kaitlin Barnett, LCSW (Regional Administrator, New England Region)</i>   |
| 1:30 – 1:45 pm   | <b>Transition to breakout room</b>   |
| 1:45 – 3:15 pm   | <b>Breakout by Discipline (see room below)</b><br><i>Providers/Nurses – Floor 3, Reading Room (Dr. Eric Grabowski / Joseph Stanco) CLOSED SESSION</i><br><i>Social Workers – Floor 4, Room 440 (Jackie Bottacari / Jessica Wulf) CLOSED SESSION</i><br><i>Data Managers – Floor 2, Room 21 (Dana Grass / Dayna Kennedy)</i><br><i>Physical Therapists – Floor 2, Room 20A (Sara McLean)</i><br><i>Lab/Pharmacy – Floor 2, Room 20A (Kenneth Wagg)</i><br><i>Finance/Administrators – Floor 3, Hartwell Room (Louise Baca / Tom Wilmarth)</i><br><i>Organizations/Patients – Floor 2, Room 20B (Elizabeth Cedeno)</i> |
| 3:15 – 3:30 pm   | <b>Transition to main room / Snack (Periodicals Room)</b>  |
| 3:30 – 4:00 pm   | <b>Breakout Debrief (Reading Room)</b>   |
| 4:00 – 5:00 pm   | <b>Reception (Periodicals and Reference Room)</b>  |

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# New England Region Hemophilia Network • Annual Meeting 2024

October 28-29 • New York Academy of Medicine

## Day 2: October 29, 2024 8:00 am – 2:30 pm

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| 8:00 – 9:00 am   | <b>Breakfast / Welcome back (Periodicals Room)</b><br>***please sign in on Floor 3 upon arriving***  |
| 9:00 – 10:00 am  | <b><u>Increasing Access for Underserved Populations (Reading Room)</u></b><br><i>Dr. Salley Pels (Medical Director, Rhode Island Hemostasis &amp; Thrombosis Center)</i><br><i>Abby Lowe-Wilson (Director, National Hemophilia Program Coordinating Center)</i><br><i>Kaitlin Barnett, LCSW (Regional Administrator, New England Region)</i> |
| 10:00 – 11:00 am | <b><u>Research Slam (Reading Room)</u></b><br><i>Dr. Jennifer Davila (Medical Director, Montefiore Hemophilia Treatment Center)</i><br><i>Dr. Chris Homes (Medical Director, Vermont Regional Hemophilia Center)</i>   |
| 11:00 – 11:15 am | <b>Break / Snack (Periodicals Room)</b>  |
| 11:15 – 11:30 pm | <b><u>BDSUMHAC Update (Reading Room)</u></b><br><i>Jaqueline Bottacari, LCSW (Social Worker, Yale Center for Bleeding and Clotting Disorders)</i><br><i>Jennifer Feldman, MSN RN (Clinical Nurse Coordinator, UMASS Hemophilia Treatment Center)</i>   |
| 11:30 – 12:30 pm | <b><u>New Treatments for Depression and Anxiety (Reading Room)</u></b><br><i>Dr. Rachel Fremont, PhD (Depression and Anxiety Center for Discovery and Treatment, MSH)</i>  |
| 12:30 – 1:30 pm  | <b>Lunch (Periodicals Room)</b>  |
| 1:00 – 2:30 pm   | <b><u>ATHN Office Hours (Reading Room)</u></b><br><i>Angela Riedel (Community Support Leader, American Thrombosis and Hemostasis Network)</i>  |

## How was the New England Region Annual Meeting?

Please take the evaluation survey by scanning the QR code  
or using the link here:

<https://www.surveymonkey.com/r/NEReval2024>



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 **New York Blood Center**  
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# New England Region Hemophilia Network • Annual Meeting 2024

October 28-29 • New York Academy of Medicine

## Speaker Bios

### **Louise Baca, MSN RN – Louise.Baca@mainehealth.org**

Louise has been in healthcare for over 40 years. Her career began as a phlebotomist and during that time began pursuing her passion for nursing. As an oncology nurse, she practiced as a clinical nurse in hospital and private practice settings, clinical lab instructor in an Associate's Degree Nursing program, oncology clinical trials nurse, adjunct professor in an RN to BSN program at Drexel University and is currently as an administrator in the oncology service line at MaineHealth. During the past 7 years, Louise has provided leadership to the Maine Bleeding Disorders Center at Maine Medical Center in Scarborough, Maine and is passionate about offering a quality and comprehensive program to people living with bleeding disorders in the state of Maine. Louise graduated from Atlantic Cape Community College, Mays Landing, New Jersey with an Associates Degree in Nursing, Thomas Jefferson University, Philadelphia, Pennsylvania with a Bachelors of Science in Nursing and Drexel University, Philadelphia, Pennsylvania with a Masters in Nursing Leadership and Administration.

### **Kaitlin Barnett, MSSW, LCSW – Kaitlin.Barnett@mountsinai.org**

Kaitlin Barnett, LCSW took on the role of New England Regional Administrator as of September 2022. Prior to assuming this role, Kaitlin was the Clinical Social Worker at the Mount Sinai Hospital Hemophilia Treatment Center. During her 6 years as the social worker, Kaitlin gained extensive experience and knowledge of the hemophilia population. She was also involved with the regional hemophilia treatment centers as well as quality improvement initiatives. Kaitlin uses her clinical skills as well as her program development background to help develop and enhance the region and support the HTC's within the New England Region Network. Kaitlin was awarded a Master of Science in Social Work degree from Columbia University and a Bachelor of Science in the School of Human Ecology at the University of Wisconsin.

### **Jackie Bottacari, LCSW – Jacqueline.Bottacari@YNHH.ORG**

Jackie Bottacari is a clinical social worker with over 10 years of experience in health care and behavioral health settings. Jackie received her master's in social work from Columbia University. Jackie has spent the last few years of her career working at the Yale Center for Bleeding and Clotting Disorders. In addition to direct clinical work, Jackie participates in local and national work groups. She is currently serving on the National Bleeding Disorders Social Work Working Group representing region 1 and 2. Jackie is also an active member within The Bleeding Disorders Substance Use and Mental Health Access Coalition and the Foundation for Women and Girls with Blood Disorders Learning Action Network. Jackie has served as facilitator and guest speaker for multiple national patient and provider educational events. Jackie's passion is advocating for health equity on behalf of patients with chronic health conditions and providing clinical therapeutic care.

### **Elizabeth Cedeno – Liz\_Ang@msn.com**

A born and raised New Yorker, native Brooklynite Elizabeth obtained her B.A. in economics from New York University, and later pursued a career in accounting. An affected member of the community herself, and with two affected children, Elizabeth brings over 16 years of experience serving as an advocate, parent, volunteer, panelist and executive board member of several local and national committees and organizations. Elizabeth's diverse perspectives, a combination of her academic background, and her years of experience, make her an invaluable addition to the HANY team. As Associate Director, Elizabeth passionately promotes the association's mission of fostering community, advocacy and education in efforts to advance the health outcomes of all its members. In her spare time, Elizabeth enjoys traveling, long distance cycling, building puzzles, and playing board games with her children.

### **Alice Cohen, MD – Alice.Cohen@rwjbh.org**



# New England Region Hemophilia Network • Annual Meeting 2023

September 26-27 • New York Academy of Medicine

Dr. Alice J. Cohen is Section Chief of Benign Hematology at Newark Beth Israel Medical Center, Newark N.J. She is the director of the State of NJ and federally funded Adult Sickle Cell Program and the Comprehensive Hemophilia and Thrombosis Center. She currently serves as Co-Chair of the Women and Thrombosis Subcommittee of VENUS group, part of the Hemophilia and Thrombosis Research Society. Dr. Cohen has participated in numerous clinical research trials seeking to find treatments for individuals with sickle cell anemia, bleeding and clotting disorders and cancer. Dr. Cohen is Associate Clinical Professor of Medicine at Rutgers-NJ Medical School. She previously was the hematology/oncology fellowship training program director and Director of Hematology/Oncology at Newark Beth Israel for 24 years.

## **Jennifer Davila, MD – [JEDAVILA@montefiore.org](mailto:JEDAVILA@montefiore.org)**

Jennifer Davila, is pediatric hematologist at the Children's Hospital of Montefiore (CHAM) in the Bronx, NY. She is co-director of the Hemophilia Treatment Center at Montefiore and is an Associate Professor of pediatrics at the Albert Einstein College of Medicine. Dr Davila specializes in the diagnosis and management of children with bleeding and clotting disorders. She a board member of the American Thrombosis and Hemostasis Network (ATHN), she is a physician advisor for the Medical and Scientific Advisory Committee(MASAC) of the national bleeding disorder foundation(NBDF) and she has participated in the development of national guidelines and advisory documents for the treatment and management of patients with hemostatic disorders. Her research focus lies in the prevention of thrombosis in special populations such as pediatric patients with sickle cell disease.

## **Jennifer Feldman, MSN RN – [Jennifer.Feldman@umassmemorial.org](mailto:Jennifer.Feldman@umassmemorial.org)**

Jen has been a nurse for 20 years, most of that time spent as a pediatric nurse at Baystate Childrens Hospital in Springfield. After finishing her masters degree in nursing education in 2014, Jen joined the New England Hemophilia Center in Worcester as the new clinical nurse coordinator for both the pediatric and adult bleeding disorder clinics. Jen became more involved with the bleeding disorder community by volunteering with the New England Hemophilia Association, including as a camp nurse for their annual Family Camp in New Hampshire. Jen is also the co-founder of the Bleeding Disorder Substance Use and Mental Health Access Coalition (BD SUMHAC), which advocates for equal access to mental health/substance use disorder treatment for patients with bleeding disorders.

## **Rachel Fremont, MD – [rachel.fremont@mssm.edu](mailto:rachel.fremont@mssm.edu)**

Dr. Fremont is an Assistant Professor of Psychiatry at the Icahn School of Medicine at Mount Sinai working in the Depression and Anxiety Center. She is board certified in Adult and Geriatric Psychiatry. She is licensed to practice in New York State. She completed residency, a clinical fellowship in Geriatric Psychiatry, and a T32 fellowship in Late Life Neuropsychiatry at Columbia University. Her research aims to investigate the phenotype and biological changes associated with psychiatric symptoms in neurodegenerative disorders and to develop novel therapies based on these findings. To this end, she has treated and assessed patients with degenerative brain disorders, including: mild cognitive impairment (MCI), Frontotemporal dementia (FTD) and related disorders, Huntington's Disease (HD), Lewy Body Dementia (LBD), and Alzheimer's disease (AD). She has been clinically active since medical school and continue to evaluate and treat older patients with and without neurodegenerative illness.

## **Katerina Funk – [Ekaterina.Funk@mainehealth.org](mailto:Ekaterina.Funk@mainehealth.org)**

Katerina Funk is a Family trained Nurse Practitioner at a MaineHealth Bleeding Disorders center with experience managing bleeding disorders across the lifespan. Prior to joining Maine HTC, she worked in primary care and adult gastroenterology. Katerina is involved in clinical, research/quality improvement and outreach projects within the HTC. Since joining the HTC, she worked on establishing a formal Healthcare transition plan for pediatric patients, outreach, and collaboration with



## New England Region Hemophilia Network • Annual Meeting 2023

September 26-27 • New York Academy of Medicine

ancillary services like case management, in-patient rehab program. She is a member of Nursing Hemostasis Certification Committee, NER Nursing Work Group, NHPCC APP CoP. Katerina has clinical interest in Women with bleeding disorders and Aging/chronic disease in patients with bleeding disorders.

### **Eric F. Grabowski, MD, DSci – EGRABOWSKI@mgh.harvard.edu**

As a hematologist/oncologist and biomedical engineer (in biofluid mechanics and physiologic blood flow), I have long-standing interests in clinical hemostasis and thrombosis, cardiovascular physiology, rheology and thrombosis, and the interactions of platelets with injured vessel wall as well as various substrates under controlled conditions of flowing blood. I am the Founder and Medical Director of the MGH Comprehensive Hemophilia and Thrombosis Treatment Center, Co-Founder and Co-Director of the Pediatric Stroke Services, and Director of the Cardiovascular Thrombosis (Grabowski) Laboratory. My medical degree is from Mayo Medical School, while my doctorate in biomedical engineering and biofluid mechanics is from Columbia University. I completed fellowships in Cardiovascular Physiology and Biophysics at the Mayo Graduate School of Medicine, and in Pediatric Hematology/Oncology at New York Presbyterian-Weil Cornell Medical Center and Memorial-Sloan Kettering Cancer Center, New York, NY. In my laboratory, I am excited to lead our effort to develop a first effective treatment for the enterohemorrhagic hemolytic syndrome (eHUS), with an interdisciplinary team with expertise in kidney diseases, complement biology, immunology, mouse models, and renal pathology. In addition, I have a strong background in coagulation and thrombotic pathways, digital image processing of immunofluorescent images, the culture of human endothelial cells, and in vitro modelling of the arterial vasculature. My most recent NIH R01, on eHUS, has led to compelling data in a mouse model that supports the use of a monoclonal antibody combination that targets both the lectin pathway of complement and the contact pathway of coagulation. A grant from a pharmaceutical sponsor has led to the demonstration, in a translational study with patient bloods, of an important hemostatic role for the von Willebrand Factor pro-peptide.

### **Dana Grass, MS – Dana.Grass@mainehealth.org**

Dana Grass is currently the Clinical Research Coordinator at Maine Health Bleeding Disorders (MHBD) in Scarborough, Maine. Dana joined the team in Scarborough in March of 2023. Dana joined the ATHN Community of Practice for Data Management as a co-chair for the New England Region in the summer of 2023. Dana has been involved in quality improvement initiatives and new research projects at MHBD since joining. She continues to utilize data from MHBD to find new ways to improve care for patients with bleeding disorders in the state of Maine. Dana was awarded a Master of Science in Biotechnology from Northeastern University and a Bachelor of Science in Biochemistry from the University of Vermont.

### **Chris Holmes, MD – chris.holmes@med.uvm.edu**

Dr. Chris Holmes MD PhD is a Professor of Medicine in the Division of Hematology and Oncology at the University of Vermont Larner College of Medicine. She currently serves as the Deputy Division Chief of Hematology & Oncology as well as Medical Director, Cancer and Hematology Programs, for the UVM Health Network. She also serves as the Medical Director of the Vermont Regional Hemophilia Treatment Center. In addition to her leadership roles, Dr. Holmes leads an active research program focused on the prevention of cancer associated thrombosis and bleeding and has recently created the WHAT clinic (Women Hemostasis and Thrombosis Clinic) at the University of Vermont Medical Center.

### **Elizabeth Karan, JD, MPH – elizabeth@karanlegalgroup.com**

Elizabeth (Issie) Karan focuses her career on health care legal work and advocacy. She serves as General Counsel for the Hemophilia Alliance. She founded the Karan Legal Group PLLC in 2020 to serve nonprofit health care providers, specializing



## New England Region Hemophilia Network • Annual Meeting 2023

September 26-27 • New York Academy of Medicine

in vulnerable and underserved patient populations. She is proud to have founded Artemis Policy Group with Johanna Gray and Ellen Riker shortly thereafter to provide lobbying and other consulting services. Elizabeth's expertise is compliance, transactional arrangements, and legislative and administrative advocacy with a focus on the 340B program, federal grants, the Anti-Kickback Statute, and reimbursement issues. Elizabeth moved to Washington, D.C. in 2012 as a Winston Health Policy Fellow where she worked with the Senate Finance Committee, learning firsthand the process of drafting and developing federal legislation. She then spent six years working as a Senior Associate at the law firm of Feldesman Tucker Leifer and Fidell LLP in Washington D.C. Elizabeth earned her J.D. and M.P.H. degrees from the University of Minnesota and her B.S. in Biology and Political Science from the University of Wisconsin-Madison. She currently splits her time between Minneapolis and Washington, D.C. and is admitted to practice law in D.C. and Minnesota.

### **Dayna Kennedy, MPH, CCRC – [DKennedy@connecticutchildrens.org](mailto:DKennedy@connecticutchildrens.org)**

Dayna has been involved with ATHN Dataset and CDC Community Counts for the past 9 years. As a Clinical Research Coordinator at Connecticut Children's Medical Center, she took over data and research coordination for the HTC 5 years ago. Dayna has a Master of Public Health degree with a concentration in research methods and worked for a number of years as a systems manager in a General Clinical Research Center. She has enjoyed working with the ATHN team and being a part of the Community of Practice Data Management team.

### **Jodi Kobeck, MPA – [jodi.kobeck@mountsinai.org](mailto:jodi.kobeck@mountsinai.org)**

Jodi Kobeck, MPA is the Administrative Manager of the Mount Sinai Benign Hematology division, which includes the Hemophilia Treatment Center, Sick Cell Program and Benign Hematology clinics, as of November 2022. Prior to joining Mount Sinai, Jodi was the Fiscal Administrator for the Montefiore Substance Abuse Programs for 20 years. During her time at the Hemophilia Treatment Center she has developed a transition program between the Pediatric and Adult Centers, as well as assist with the implementation of Gene Therapy for Hemophilia at Mount Sinai. Jodi was awarded a Masters of Public Administration with a concentration in Healthcare Economics from Long Island University and a Bachelor of Science in Laboratory Technology from Stony Brook University.

### **Peter Kouides, MD – [Peter.Kouides@rochesterregional.org](mailto:Peter.Kouides@rochesterregional.org)**

Dr. Kouides is Medical and Research director of the Mary M. Gooley Hemophilia Center. He is Clinical Professor of Medicine of the University of Rochester School of Medicine. He is an associate member of the Roswell Park Memorial Cancer Institute and associate director of the Rochester General Hospital (RGH) Anticoagulation Service, member of the RGH Institutional review board since 1995, member of the RGH transfusion committee since 1997 and member of the RGH Hematology-Oncology fellowship committee. In his nearly 30 years of affiliation with the Mary M. Gooley HTC, Dr. Kouides has served as principal investigator (PI) on a number of retrospective and prospective studies focused on the gynecological and obstetrical complications of von Willebrand disease (VWD) and a local PI on numerous hemophilia surveillance and treatment studies. Dr. Kouides has been co-chair of the Centers of Disease Control (CDC) Universal Data Collection study of women with bleeding disorders and is a steering committee member of the American Thrombosis and Hemostasis (ATHN) "ATHENA" project of women with inherited bleeding disorders. He is a mentor for a 2021-2022 ATHN DREAM award on hemophilia carriers. He is a member of the CDC/HRSA Comprehensive Hemophilia Treatment Centers Region I/II executive committee and mentor of the emicizumab study group. He is a member of the International Society of Thrombosis and Hemostasis (ISTH) Women's Health Issues Scientific Subcommittee and presently an appointed member of the VWF subcommittee. He is past section co-author of the American Society of Hematology (ASH) Self-Assessment Program chapter on Women with Hemostasis and Thrombosis issues. He is an appointed member of the ASH Committee on Clinical Practice (COP), COP liaison to the ASH Foundation committee, appointed member of ASH Palliative Care in



## New England Region Hemophilia Network • Annual Meeting 2023

September 26-27 • New York Academy of Medicine

Hematology working group, ASH Well-Being and Resilience working group and “Highlights of ASH” planning committee 2020- 2023. He is a member of the 2021 VWD guideline working group of ASH/ISTH/NHF/WFH and an appointed member of the NHF Medical and Scientific Advisory Committee, NHF VWD task force and the NHF State of the Science working group for VWD and other disorders of hemostasis. He is also an appointed member of the medical advisory committee of the National Blood Clot Alliance and the American Association on Health and Disability Venous thromboembolism Knowledge Translation project. He is a member of the Hemostasis Thrombosis Research Society (HTRS) VENUS women’s thrombosis research group. He is an appointed member of the Foundation for Women and Girls with Blood Disorders (FWGBD) medical advisory board and mentor of their Learning Action Network. He is an appointed member of the Women’s Health Collaborative in Anemia and menstrual bleeding. Dr. Kouides is immediate pastpresident of the Thrombosis and Hemostasis Societies of North America and present executive board member. He is an appointed member of the American Board of Internal Medicine Hematology certification question-writing task force. He serves on two drug monitoring safety boards including chairing one in hemophilia. He is a member of the Haemophilia journal editorial board and a regular invited peer reviewer for Haemophilia (≈10-15/year), Blood (≈6/year), Thrombosis Research (≈5-6/year), Journal of Thrombosis and Haemostasis (≈2-5/year), British Journal of Haematology, European Journal of Haematology, Blood Coagulation and Fibrinolysis and the journal Clinical and Applied Thrombosis/Hemostasis. He serves on the World Federation of Hemophilia Twinning (WFH) steering committee and has directed the WFH twinning program between the Mary M. Gooley Hemophilia Center initially with Bishkek, Kyrgyzstan 2009-2013 then Kathmandu, Nepal 2014-2019 with plans in progress with Rawalpindi, Pakistan.

### **Abby Lowe-Wilson, MPH – [alowewilson@athn.org](mailto:alowewilson@athn.org)**

As Director of the National Hemophilia Program Coordinating Center, Abby Lowe-Wilson is responsible for the strategic development and leadership of the NHPCC, including ongoing collaboration with HRSA and the Regional Hemophilia Networks to identify gaps in services, standardize and improve access to care and share best practices through the creation and implementation of national initiatives. Abby has more than 15 years’ experience in public health working across a range of topic areas, including physical activity promotion, obesity prevention, healthy communities, overdose prevention, and state-level chronic disease prevention, in research, non-profit, and government settings. Her work has focused on building collaborative relationships across organizations and partners, translating emerging and evidence-based interventions, creating opportunities to share best practices and successes, and designing both virtual and in-person peer learning opportunities – all with a focus on equity and systems thinking. She received her MPH from the UNC-Chapel Hill Gillings School of Global Public Health. She has been with the NHPCC for nearly 2 years and loves working with such dedicated professionals across the country to advance the collective work of improving patient care in bleeding disorders.

### **Catherine McGuinn, MD – [cam9061@med.cornell.edu](mailto:cam9061@med.cornell.edu)**

Dr. Catherine McGuinn is an Assistant Professor of Pediatrics in the Division of Pediatric Hematology/Oncology at Weill Cornell Medical College and an Assistant Attending Pediatrician at NewYork -Presbyterian Hospital/Weill Cornell Medical Center. Dr. McGuinn is board certified in Pediatrics. She completed her undergraduate work at Yale University receiving a Bachelor of Arts with a focus in History. A native of New York City, she returned to New York where she received her medical degree from New York University's School of Medicine and completed her internship and residency in Pediatrics at NewYork-Presbyterian Morgan Stanley Children's Hospital at the Columbia University Medical Center. Dr. McGuinn remained at Columbia for her fellowship training in Pediatric Hematology-Oncology, where she selected as Chief Fellow and recognized as Fellow of the Year in 2010. Dr. McGuinn's clinical interests include the diagnosis and management of children with hematologic and oncologic disorders, with a special interest in disorders of thrombosis and hemostasis, bone marrow failure syndromes, hemoglobinopathies, vascular tumors and benign hematology.



# New England Region Hemophilia Network • Annual Meeting 2023

September 26-27 • New York Academy of Medicine

## **Sarah McLean, PT DPT – Sarah.McLean@mainehealth.org**

Sarah McLean PT DPT has been on the PT team at the Maine Bleeding Disorders Clinic for almost 3 years. This is a lifespan clinic, and the team is also involved in several of the community activities, camps etc. Early in 2024 she became the North East Representative on the PT Working Group. Sarah's primary role within MaineHealth is in a hospital-based outpatient clinic with a focus on neurological and prosthetic rehab. Other roles include per diem acute care PT and teaching adjunct at the University of New England. Sarah began her career as a PT in London, England followed by a fascinating year working in South Africa. After working on the UK's first mobile PT clinic serving rural areas decided to travel again ending up in Maine!

## **Salley Pels, MD – spels@lifespan.org**

Dr. Salley Pels is a board certified Pediatric Hematologist Oncologist at Hasbro Children's Hospital and Associate Professor of Pediatrics at the Warren Alpert Medical School of Brown University. She received her undergraduate degree from Johns Hopkins University in Baltimore, MD and her medical degree from the University of Vermont in Burlington, VT. She completed both her residency in Pediatrics and a fellowship in Pediatric Hematology Oncology at Yale University School of Medicine in New Haven, CT, including additional training as an NHF-Baxter Clinic Fellow Awardee. After completing fellowship, she stayed on in the section of Hematology Oncology at Yale from 2010-2019 as the Associate Director of the Yale Hemophilia Treatment Center. In 2019, she transitioned to become the Medical Director of the Rhode Island Hemostasis and Thrombosis Center and an Associate Professor of Pediatrics at Brown University, in Providence, RI. Her area of expertise is in the care of children and young adults with bleeding disorders and thrombosis, and her work has focused on ensuring safe and high quality care for patients with blood disorders.

## **Michael Recht, MD, PhD, MBA – michael.recht@yale.edu**

Michael Recht, MD, PhD, MBA cares for children, adolescents, and young adults affected by bleeding and clotting disorders as a Professor of Clinical Pediatrics and member of the Hemophilia Treatment Center and Section of Pediatric Hematology-Oncology at Yale University School of Medicine. As Chief Medical and Scientific Officer for the National Bleeding Disorders Foundation (NBDF), Dr. Recht, works at the strategic and policy level to inform the scientific direction of NHF. He works across the organization to define, develop, and implement NHF's science and research strategy. Dr. Recht received his medical degree as well as his PhD from the University of Wisconsin-Madison. He completed his residency in pediatrics and fellowship in pediatric hematology-oncology at Yale New Haven Hospital/Yale University School of Medicine. He was the founding director of the Hemophilia Center at Phoenix Children's Hospital. From 2007 until 2020, Dr. Recht was the director of the Hemophilia Center at Oregon Health & Science University as well as the Mountain States Hemophilia Network. Dr. Recht has actively participated in over 110 clinical trials testing new treatments for people with inherited blood disorders, including leading research involving gene therapy for hemophilia.

## **Angela Reidel – ariedel@athn.org**

As the ATHN Community Support Lead for over five years, Angie is committed to leading her team in providing high-quality support and training on all aspects of ATHN Systems. As part of the Support team, she enjoys working with data management at both the treatment center and the regional level by providing one-on-one training, instructional webinars, development reports, and support tools to enhance the use of ATHN Systems. Before joining ATHN, Angie had over 10 years of treatment center experience, including being a member of the ATHN beta testing group for ATHN Systems during the initial implementation and more than 10 years of experience as a technology educator.



## New England Region Hemophilia Network • Annual Meeting 2023

September 26-27 • New York Academy of Medicine

### **Glen Roy, BSN, RN – [glen.roy@mainehealth.org](mailto:glen.roy@mainehealth.org)**

Glen Roy, BSN, RN, Nurse Coordinator at MaineHealth Bleeding Disorders. Glen has been involved in Bleeding Disorders Community since 1993 when he joined Maine HTC and co-founded Hemophilia Family Camp with Dr. Marjorie Boyd. Over the years Glen has been involved in numerous clinical, research and outreach projects within the Maine HTC, and initiation of the 340B Factor Program for the center is one of them. Glen has been a speaker at local, regional, and national meetings, and been awarded the NBDF Nurse of the Year award in 2018 and NEHA's Champion of Healthcare Award in 2023. Glen is currently serving on the NBDF Nurses Guide Committee, Hemostasis Certification Committee, and a former Regional Representative to NBDF 2011-2015 and NBDF executive committee 2016-2018. Glen is passionate about patient advocacy and has provided many self-infusion classes at many NEHA out-reach events, one the most rewarding aspects of the job to see the achievements of so many over a couple of generations.

### **Joseph Stanco – [jstanco@northwell.edu](mailto:jstanco@northwell.edu)**

Joseph Stanco, DNP is a doctoral prepared Family Nurse Practitioner at the Northwell Health Hemostasis and Thrombosis Center (HTC) since 2016, a lifespan clinic specialized in treating patients with inherited bleeding disorders. At the HTC, he has both clinical and research responsibilities. He is passionate about projects like Health Care Transition, which empower patients to take ownership of their health as they move from pediatric to adult care. In 2023, he received the National Bleeding Disorder Foundation (NBDF) Nursing Excellence Award for implementing Primary Care Screenings at the HTC. He represents the New England Region on the NBDF Nursing Working Group, serves on the Research Nurse Board of Directors at Northwell Health, and is leading a team to develop a national nursing certification in bleeding disorders.

### **Kenneth Wagg, RPH – [KWagg2@Lifespan.org](mailto:KWagg2@Lifespan.org)**

Kenneth Wagg is a Clinical Pharmacist Specialist at the Rhode Island Hemostasis and Thrombosis Center and the Comprehensive Sickle Cell Center at Rhode Island Hospital in Providence, Rhode Island. While having experience in many aspects of pharmacy practice, he is wrapping up his career on a high note as a staff member of the HTC. Ken started working with the bleeding disorder community in 2000 in New Mexico as a specialty pharmacist. During his professional career he has worn many hats: teacher, camp counselor, camp director, music leader, insurance advocate, legislative advocate, board member, salesman, and team leader. He is honored that some of his patients from New Mexico still contact him for advice and guidance. In his upcoming retirement, he hopes to spend time hanging out with his lovely wife, Barbara (Ken and Barbie), busking as a musician and working with his local church.

### **Thomas Wilmarth – [Thomas.Wilmarth@rochesterregional.org](mailto:Thomas.Wilmarth@rochesterregional.org)**

Tom is the President & CEO, Mary M. Gooley Hemophilia Center. He has been with the Center since 2010 having previously served in the capacity of Vice President of Public Policy. A passionate advocate for the bleeding disorders community, Tom enjoys working with other advocates and organizations at both the state and federal level. Tom also works directly with regional and national insurance companies on coverage issues, access to care, reimbursement structures and policies that affect the bleeding disorders community.

### **Jessica Wulf, LMSW – [jwulf@wnybloodcare.org](mailto:jwulf@wnybloodcare.org)**

Jessica Wulf is the chief operating officer and social worker at Western New York BloodCare, the Buffalo area's premier Hemophilia Treatment Center (HTC) and specialize in diagnostic and clinical services. Jessica started working at WNYBC in 2017 as a part time social worker. Throughout the years she has expanded her position within the center. Jessica has played a pivotal role in quality improvement, clinical operations, and expanding the local chapter. Jessica has had a variety of experiences, in the social work field; from mental health, case management, and to end of life care. She has a passion



## New England Region Hemophilia Network • Annual Meeting 2023

September 26-27 • New York Academy of Medicine

for helping vulnerable populations and advocating for social justice. Jessica hopes that her research efforts will continue to shed light on the mental health struggles of mothers and bring attention to maternal health. She also feels very passionate about bringing women into the forefront in the bleeding disorders community.

### **Adrienne Zhan, NP – [adrienne.zhan@mountsinai.org](mailto:adrienne.zhan@mountsinai.org)**

Adrienne Zhan, AGPCNP-BC joined the Mount Sinai Hemophilia Treatment Center in 2021. She spearheaded the creation of the Hemophilia gene therapy program by working with leadership at Mount Sinai to develop policy, procedures, and the overall framework for the administration of gene therapy. She earned her Bachelor of Science in Nursing as a Hillman Scholar from the University of Pennsylvania and her Master of Science from the Rory Meyers College of Nursing at New York University.

# New England Region Hemophilia Network • Annual Meeting 2024

October 28-29 • New York Academy of Medicine

## Information

NER Website:

[nernet.org](http://nernet.org)

Annual Meeting Website:

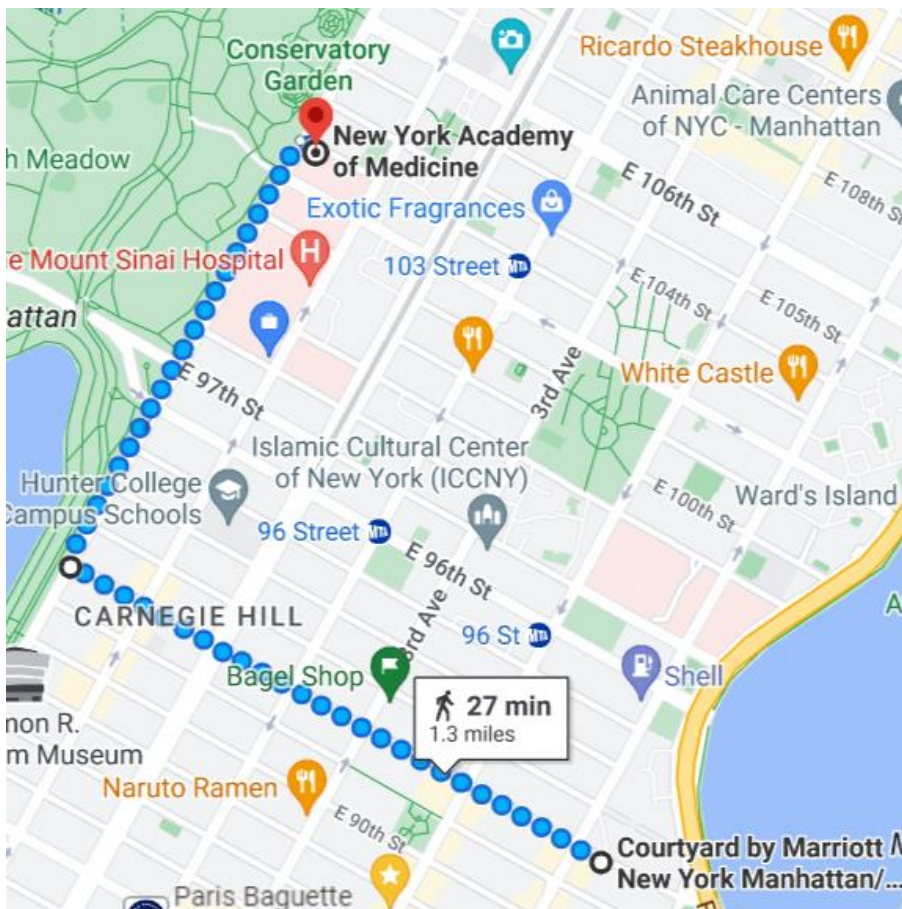
<https://newenglandregion.regfox.com/new-england-region-annual-meeting>

Courtyard Marriott UES:

<https://www.marriott.com/en-us/hotels/nycmh-courtyard-new-york-manhattan-upper-east-side/overview/>

New York Academy of Medicine:

<https://www.nyam.org/>



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## **To do:**

Carl Schurz park/mayor's mansion  
E 88th St &, East End Ave, New York, NY 10028

Central park reservoir  
2 E 90th St, New York, NY 10128

Museum's  
Along 5th Ave between 80th and 105th streets

## **Breakfast:**

Bagel shop  
1659 3rd Ave, New York, NY 10128

Michaelis bakery  
401 E 90th St, New York, NY 10128

Sarabeth's  
1295 Madison Ave, New York, NY 10128

## **Restaurants/drinks:**

Cafe d 'Alsace  
1703 2nd Ave, New York, NY 10128

Chez Nick  
1737 York Ave, New York, NY 10128

Nick's Pizza  
1814 2nd Ave, New York, NY 10128

Mole  
1735 2nd Ave, New York, NY 10128

Drunken Monkey  
338 E 92nd St, New York, NY 10128

Sojourn Social  
1708 2nd Ave, New York, NY 10128

Avoca  
1678 1st Ave, New York, NY 10128

