The Hemophilia Center of Western New York (HCWNY) aims to be your first and best choice for health management of your bleeding or clotting disorder. We proudly specialize in diagnostic and clinical services, advocacy, education, community outreach and research initiatives for nearly 50 years.
Dear Friends and Families of the Hemophilia Center,

If you are anything like me, you are asking “Where did 2017 go?” Wow; we’ve experienced tremendous growth here at the Center both in patient engagement and with staff.

Dr. Beverly Schaefer is a Pediatric Hematologist who joined our team in March. Jessica Niethe joined our team as our Medical Social Worker. Angela Ciraolo joined the nursing staff and Michele Burgwin came on board as our Community Outreach Coordinator in the Spring. Our lab added Renee Czarniak, Medical Technologist to help with the growing volume our lab receives. Erin Burch, a registered dietitian joined our Comprehensive Care team, treating both children and adults. These additional team members have all been added to better serve our patients in a team-oriented, quality driven, efficient environment. I hope you enjoy the changes.

Speaking of quality, our performance improvement committee has created ‘Transition Guidelines’ to help direct our patients on the journey from pediatric to adult care. These guidelines provide each discipline with specific criteria to help educate and manage each patient’s disease, as well as, empower them to achieve independence with quality of life management.

We opened our clinic for Girls and Women with Bleeding Disorders, known as the S.H.E. clinic in March. Dr. Shilpa Jain (Hematologist) and Dr. Shaveta Malik (OBGYN) run this clinic monthly and has been targeted to girls and women with heavy menstrual bleeding and easy bruising.

Visit us at www.hemophiliawny.com and check out our new website. It is now mobile friendly and has valuable educational resources to learn more about managing bleeding disorders.

Our HTC is now a participant in HEALTHeLink. This allows our providers to get up to date health information on our patients through other healthcare providers.

We have grown our patient and community outreach efforts by leaps and bounds. Please check out the Chapter Services page within the report for a summary of chapter programs we held in 2017.

We thank you for allowing us to be of service to you and be part of your medical care. Visit our website and LIKE us on Facebook to stay in touch.

Best regards,

Laurie Reger,
Executive Director
The hemophilia treatments of today were once the dreams of yesterday. Proof that when

SCIENCE AND THE COMMUNITY

come together, great things happen.

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WHO WE ARE

Laurel Reger
Executive Director

Lauren Lewis, Executive Assistant and Compliance Officer

Michelle Dunn
Finance Manager

Stacie Lesinski
Senior Biller

Jessica Niethe
Social Work

Karen Kovach
Laboratory Manager

Rose Ritchie
Product Coordinator

Renee Czarniak
Medical Technologist

Michelle Acosta
Research Coordinator

Andrea Rimbeck
Medical Secretary/Reception

Michele Burgwin, Community Outreach Coordinator

Joan Wagner
Phlebotomist and Clerk

Linda Belling
Nurse, Clinical Program Coordinator

Dawn Harrison
Family Nurse Practitioner

Angela Ciraulo, RN, BSN
Nurse

Julia Thiel, RN, BSN
Nurse

Dr. Adam Kotowski
Adult Medical Director

Dr. Shilpa Jain
Pediatric Medical Director

Dr. Beverly Schaef er
Pediatric and Young Adults

Dr. Steven Ambrusko
Pediatrics

Dominique Safar-Riessen
Pediatrics Physical Therapist

Gene Wojcinski
Adult Physical Therapist

Geoffrey Zielinski
Pharmacist

Erin Burch
Dietitian

Mary Beth Dunn
Dentist

Daniel Ford
Physician Assistants

James Miller
Physician Assistants

Timothy Mahoney
Dentist

Robert Long
Chairman

Dr. Marcia Gellin, Ed.D
Vice President

Michael Cimato
Secretary

George Anderson
Martin Brecher, MD
Katherine Burdette
Clare Hunter
Ashley Long
Elizabeth McNamara

Jonathan Moyer
Jeffrey Otterstein
Michael Zevon

Thomas Long
President

Mary Haggerty
Assistant Vice President

Karin Kubicki
Treasurer

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Research Update

In 2017, we successfully met our research objective of expanding our services to particularly help women with bleeding disorders in the community. The goal is to appropriately diagnose and treat young women with heavy menstrual bleeding. Various projects were conducted in collaboration with investigators across the nation to incorporate a comprehensive tool to evaluate bleeding symptoms in women and ultimately improve their quality of life at home, school, and/or work.

This year, we also completed enrollment for the My Life Our Future: A Hemophilia Genotyping Initiative Data and Sample Research Repository. This was a nationwide initiative to provide free genotyping to HTC patients with hemophilia A or B, as well as family members. In addition, patients who opted to participate in the repository allow researchers to study and understand hemophilia better and the variables that affect bleeding patterns. This initiative was founded by leaders in the hemophilia community, including the American Thrombosis and Hemostasis Network (ATHN), the National Hemophilia Foundation (NHF), Bloodworks Northwest, and Bioverativ.

Enrollment for the Community Counts study continues for the third year and is a continuation of the Universal Data Collection that ended in 2011. It is a public health monitoring program funded by the Centers for Disease Control and Prevention (CDC) with the aim to collect information on health issues and complications associated with bleeding disorders. The project is conducted in partnership with ATHN and various hemophilia treatment centers all across the nation.

Conferences and Continuing Education

As an effort to bring our patients the best comprehensive clinical care, our Physicians and Staff are continuously attending educational conferences and seminars. The treatment for bleeding and clotting disorders is ever-changing and evolving at a quick pace. We at HCWNY strive to provide our patients with the newest information in order to receive the highest level of care.

Conferences we attended in 2017 include:

- National Hemophilia Program Coordinating Center (NHPCC) for Quality Improvement
- Steps for Living- Hemophilia education for every life stage
- Washington Days and Albany Days (Advocacy)
- Hemostasis Thrombosis Research Society (HTRS) Scientific Symposium
- National Hemophilia Foundation (NHF) Region Leadership Training
- Thrombosis & Hemostasis Summit of North America (THSNA)
- International Society on Thrombosis and Haemostasis (ISTH) Congress presented by Octapharma
- American Society of Hematology Annual Meeting and Exposition (ASH)
- Hemophilia Alliance Meeting
- New England Regional Meeting (Hemophilia Treatment Centers)
- 340B Summit
- National Hemophilia Foundation Annual Meeting
- Mayo Clinic Laboratories Conference
In 2017 the Hemophilia Center of WNY’s multi-disciplinary Quality Improvement (QI) team worked on a number of projects to improve the process for patients to transition from pediatric to adult care. The implementation of ‘Transition Guidelines’ were put into use to establish a standard of teaching for our various providers at the Center. A ‘transition readiness tool’ was created and modified to assess the patient’s knowledge of their disease.

Through the use of this tool and Provider feedback, improvements were made to better capture the information necessary to make a patients transition from a pediatric patient to an adult patient successful. Quality Improvement processes have been incorporated into all aspects of our Center in order to more effectively serve our patients and to improve overall operations of the Hemophilia Center of WNY.

A subgroup of the HCWNY QI team attended the ATHN Data Summit in Chicago, IL to present our process and findings.
At CSL Behring, we are committed to providing treatments and supportive services that make a meaningful difference in the lives of people with bleeding disorders and those who care for them.

We set out on this journey with you more than a century ago, starting with the development of treatments for those with rare and serious diseases.

As we look to the future, we see the promise of new innovations and opportunities—just as we always have.

Over the years, we have never lost sight of what matters most: you and the countless others who inspire our efforts every day.
Dr. Beverly Schaefer joined the Hemophilia Center of WNY in the Spring of 2017 as a member of our Medical Staff. Dr. Schaefer attended SUNY Upstate Medical University in Syracuse, NY and continued on to complete her pediatric residency at the A.I. duPont Hospital for Children in Wilmington, DE and Thomas Jefferson University in Philadelphia, PA. She did her fellowship in Pediatric Hematology and Oncology at Cincinnati Children’s Hospital Medical Center, where she nurtured her interests in non-malignant hematology, including bleeding disorders, thrombosis and sickle cell disease. She is board certified by the American Board of Pediatrics in both Pediatrics and Pediatric Hematology and Oncology.

In addition to caring for children and young adults at the Hemophilia Center of WNY, Dr. Schaefer treats patients at Roswell Park Comprehensive Cancer Center and John R. Oishei Children’s Hospital.

Dr. Schaefer is enjoying life with her family back in her hometown. When not working on household projects and renovations, she enjoys cooking, exploring Buffalo’s food scene and yoga.
In 2017, the S.H.E. Clinic, which stands for Specialized Hematology Experts, was created as a division of the Hemophilia Center or WNY. This specialty clinic run by Dr. Shilpa Jain, Pediatric Hematologist and Dr. Shaveta Malik, OBGYN, is dedicated to the awareness, diagnosis and treatment of girls and women with bleeding disorders.

Bleeding issues in females are often overlooked or misdiagnosed. It is estimated that there is up to a 30% prevalence of underlying bleeding disorders in women who present with heavy menstrual bleeding and bruising. Correct diagnosis and effective treatment could improve one’s quality of life. S.H.E. Clinic services include a Hematology evaluation, specialty lab services, Gynecology and Social Work. The S.H.E. Clinic prides itself on being a medical home for girls and women at every stage of their lives.

The article below was part of our promotional campaign published in Business First.
Elizabeth McNamara, RN, MSN, HCWNY Board Member

“The Hemophilia Center of WNY found me on the first hole of their annual golf event in July 2017. A fellow board member and golf partner introduced me to Laurie, the Center’s Executive Director and the net was cast. I was asked to consider joining the board, in which the board agreed and the rest is history!

My love of healthcare started many years ago when so many of my friends were checking out nursing schools. As a new nurse myself, I found my way into critical care nursing and then teaching. Cardiology became my area of expertise and it opened up my participation as an active volunteer with the American Heart Association. I was a board member and Chair of the Western NY Chapter as well as holding Board positions at the State and National levels. In doing so I realized the importance of giving back to the community and this was one way I felt I could help.

My time on the HCWNY board has expanded my knowledge as to the significance of bleeding disorders in the WNY community and their impact on individual lives and families. The association as a source for care and a resource for information and services are significant especially as they are aligned with the unique style of insurance coverage and reimbursement. Complicated to say the least; the HCWNY team makes it work for each client based on their individual needs. The care and comfort offered to each patient and family is readily apparent.

In my free time, I am active with golf - The driver which pitched me to the organization! I golf in a league and play as often as possible. In addition, I am a volunteer coach for children age 5-8. Some may be PGA worthy in the decades to come! I live in Orchard Park near the New Era Field. I love home football games – the excitement, the commotion and the hope of a win! Go Bills!”

~Betty McNamara
In an effort to reach a wider audience HCWNY stepped up it’s game in the marketing and promotional department this year. With the creation of the S.H.E. Clinic, a clinic specifically for women and girls, the Center wanted to ensure greater visibility to better reach those members of our community who may be undiagnosed.

We invested in radio and television commercials, as well as, print advertising in Buffalo Spree magazine and Business First for the S.H.E. Clinic. Drs. Shilpa Jain and Shaveta Malik appeared on WNY Living with Janet Snyder to better explain the services the S.H.E. Clinic offers as well.

During our Facebook Live interview with Courtney Corbetta from WKBW, a patient shared their perspective, along with Dr. Jain, taking live questions from the audience watching. In addition, we launched a direct mail campaign targeting area pediatricians, OB/GYNs, school nurses and physical education teachers promoting not only the Center’s services but also offering additional education resources to all.

Our “In My Blood” Hemophilia Awareness Walk was also featured in an on-air interview with Linda Pellegrino on AM Buffalo.
In 2014, the HCWNY Foundation was established to provide financial assistance and support to families in the Western New York community. The Board of Directors of our Hemophilia Treatment Center (HTC) felt a strong desire to work more vigorously toward it’s mission and the population they serve.

Mission
The HCWNY Foundation works to provide support through financial and educational assistance in collaboration amongst individual families and organizations throughout the bleeding and clotting disorder community.

“Friends Making a Difference” Golf Tournament
Our “Friends Making a Difference” Golf Tournament, held each July, was a tremendous success for the 19th year in a row! The tournament, held at Chestnut Hills Country Club in Darien, NY raised nearly $23,000.00 for the Hemophilia Foundation of WNY, Inc. All proceeds will go directly back into the bleeding disorders community through our scholarship, camperships, and compassionate care programs. We are looking forward to another successful event, in it’s twentieth year in July 2018! For more information on our golf tournament contact us today.

Scholarships
The mission of the HCWNY Scholarship Program is to provide a better quality of life for individuals affected by bleeding and clotting disorders by awarding financial assistance for advanced education and training, leading to employment and access to health insurance. Jessica Niethe, our Social Worker coordinates the Scholarship Program and is available to answer any questions. Additional information can also be found on our website: www.hemophiliawny.com.

2017 Scholarship Recipients:
- Julianna Klinko
- Jeremy Kocsis
- Jacob Schultz
- Wade Tomaszewski
- Gary Broadhead
- Abigail Cimato
- Reuben Sass
- Samuel Cimato

Camperships
The HTC can help sponsor pediatric patients, who are compliant, to attend a bleeding disorder camp. Patients will learn to infuse, as well as, bond with other kids in a safe and fun environment. These camps include: Camp High Hopes, Camp Little Oak and Camp Hot-to-Clot located in New York State and Pennsylvania.
Hello! I’m Danielle Mueller Durham and I’m a CoRe Manager for Bioverativ. It is my job to connect you with others in the community, introduce our educational programs, and to support you on your journey. I am here so we can take action together! I also previously served as the Development & Programs Manager for the Bleeding Disorder Foundation of Washington.

Contact me!
danielle.durham@bioverativ.com  |  781.663.9299
The Hemophilia Center of WNY is committed to compassionately caring for patients, their families and our unique community. In addition to providing state-of-the-art medical care, the Center is proud to offer a vast range of supportive programs and services. The Hemophilia Center of WNY is a chapter of the National Hemophilia Foundation and the following is a summary of our events we’ve successfully accomplished this year.

- “How Not To Marry Your Mother” Dinner Program- An interactive presentation that provided patients with resources and self-management tools to help with self-sufficiency and increased confidence.

- Women’s Workshop 2017- Overnight program for women who are affected by bleeding and clotting disorders. Women are able to connect with others for education, support and a nurturing getaway.

- Naval Park Overnight- Community building/social networking event to help our patients get together and have a fun educational evening. Participants were given the opportunity to tour and stay overnight on actual Navy ships.

- Healthy Aging Dinner Program- Presentation that provided patients with various information on aging and how having a bleeding disorder plays a part.

- 19th Annual ‘Friends Making a Difference’ Golf Tournament- All proceeds are donated to the HCWNY Foundation.

- ‘In My Blood’ Awareness Walk- Annual Hemophilia awareness walk. The walk raises awareness about hemophilia and bleeding disorders in addition to providing a healthy community activity for our patients. Save the date for 2018!

- Transition to Independence- Interactive program at Holiday Valley’s Sky High. Transition patients have been invited to participate in an aerial course as well as listen to presentations about the responsibility of transferring from a pediatric to adult patients.

- HCWNY Holiday Party- Patients, family and staff celebrated the holidays with Santa, crafts and karaoke at Pearl Street Grill and Brewery.
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For more information, contact Pfizer Hemophilia Connect, one number with access to all of Pfizer Hemophilia’s resources and support programs.

Call **1.844.989.HEMO (4366)** Monday through Friday from 8:00 AM to 8:00 PM Eastern Time.

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**Washington, DC: March 8-10, 2017**

The National Hemophilia Foundation (NHF) hosted its annual Washington Days advocacy event on Capitol Hill in Washington, DC. More than 480 volunteer advocates from 46 states met with legislators and staff to discuss maintaining key patient protections in the Affordable Care Act (ACA). Washington Days is an opportunity for people affected by bleeding disorders to advocate for issues that are important to them. NHF’s advocacy this year focused on the debate surrounding the repeal and replacement of the ACA, and how that has affected the bleeding disorders community.

This year we asked our volunteer advocates to ask Congress to keep several key patient protections in any healthcare legislation that might be introduced to replace the Affordable Care Act (ACA).

- Maintain the elimination of lifetime and annual limits on essential health benefits.
- Maintain federal requirements for essential health benefits to ensure patient protections are meaningful.
- Maintain the Medicaid expansion, including the categorical eligibility for childless men and women and the enhanced federal funding for the expansion population.

**Albany, NY: March 19-20, 2017**

Together HCWNY families and staff visited Albany, NY to meet with senators and assembly members for our annual NYS Advocacy Days. We rallied with other chapters from across New York State to discuss policies that affect our patient families. On Saturday, March 18th there was a first time Teen Advocacy Training in which teens from our Center took part.

State advocacy days give elected officials the opportunity to learn firsthand from affected individuals and families how expensive treating bleeding disorders can be, and how important it is to have access to comprehensive care and continuity of care. Legislators learn how not having access to the proper treatment can be detrimental to the health of someone with a bleeding disorder, and potentially cost the state a lot of money in the long run. We look forward to 2018!
A Year in Review

HCWNY is a Hemophilia Treatment Center which provides multidisciplinary care to our patients for a broad array of bleeding and clotting disorders. This care includes assessment by Hematologists, Nursing, Social Work, Physical Therapists, Nutritionists, Specialty Pharmacy, Dentists, Researchers and our Hemostasis and Thrombosis laboratory. The Hemophilia Center of WNY has specialists that treat bleeding disorders all in one place, at one time. We are extremely proud to be able to offer these services to our patients under one roof. As we continue to grow, we always strive to provide the best comprehensive care for our patients.

New in 2017

Nutrition Discipline added to Comprehensive Clinic
We’ve added a new discipline to our Comprehensive Care Clinics. Erin Burch, a registered Dietitian Nutritionist joined our Comprehensive Care Provider team treating both our adult and pediatric patients. Erin received a B.S. from Fredonia State University, a B.S. from Buffalo State and a Masters in Exercise Science and Health Promotion from the California University of Pennsylvania. Erin has over eight years' experience in community nutrition, group education and counseling and heart healthy and diabetic cooking.

Medicaid Managed Care
As of July 1st the Department of Health has transitioned Clotting Factor Products under Managed Medicaid. What this means for our patients that have Managed Medicaid is that clotting factor is now being managed by your Insurance Plan versus New York State Fee for Service Program. Those patients receiving factor from our Pharmacy saw a seamless transition.

340B “Center of Excellence”
This year, HCWNY continued to develop ways which help to provide the highest level of care for those living with bleeding and clotting disorders. This extends to our in-house specialty pharmacy. We developed a committee to ensure the accuracy and compliance of our 340B program through a series of measures, tools and audits. Continuously collecting and keeping accurate data allows the Center to put the 340B savings to good use.
IN HEMOPHILIA B, THERE’S ONE THING YOU CAN COUNT ON

INNOVATION FROM NOVO NORDISK

We strive to help improve the lives of people with hemophilia

For 30 years, Novo Nordisk has been a driving force for people living with rare bleeding disorders. We take pride in striving for innovative solutions to help improve patients' lives. This motivates us to uphold the highest standards in our product research and development. This vital research is just the beginning of our commitment in hemophilia.

Through the B-HERO-S study in hemophilia B, we uncovered unmet needs around the impact of hemophilia on education, employment, activities, and other aspects of the lives of patients and their families.

We will continue our research and connect with patients and health care professionals to ensure we understand and respond to the specific needs of the hemophilia B community.

With a rich history, Novo Nordisk remains at the forefront of discovery. We are poised to continue to develop innovative solutions that can help improve the lives of patients with hemophilia in the future.

*B-HERO-S = Bridging Hemophilia Experiences, Results and Opportunities into Solutions. A U.S. survey of 449 people.
Your dreams. Our dedication.

At Shire we are driven to help improve the lives of members of the bleeding disorders community. You inspire us. Each pioneering new product and program represents another step toward our ultimate goal: a life full of dreams and free of bleeds.