MARY M. GOOLEY
Hemophilia Center
Caring is in our blood

Mary M. Gooley Hemophilia Center

2020 Annual Report

Chairperson/CEO Report

MARY M. GOOLEY
Hemophilia Center
Caring is in our blood

2020 was a dramatic and challenging year, not just for the Center, but for the whole world. The heart-wrenching stories of loss, separation, financial worries and fear will resonate with us all for many years to come. Within this context, we have a great deal to be thankful for here at the Center. Throughout the turmoil of the pandemic, the Center has been able to fully serve our patients and their families, keep all of our staff fully employed, support staff who have been affected by COVID, fully keep up with all of our operational obligations and remain completely financially stable.

The challenges of COVID were also a testament to the Center's ability to adapt and respond. Early on it became clear that the medical world needed to switch to telemedicine to be able to fully serve the needs of patients. We formed a task force at the Center and our team did the research and pulled in resources that enabled us to fully implement telemedicine quickly while maintaining the integrity of our standards of care and operations. It also became clear that the ability to execute high quality remote meetings was not only necessitated by COVID, but required to operate after COVID as remote meetings become an enduring trend. To that end, the Center applied for and received multiple grants that enabled us to invest in a high end remote audio and video conference platform that was installed in our conference room. This technology is a wonderful asset to the Center and gives us great flexibility in delivering education, programs, meetings and trainings now and into the future.

Whether as a patient, family member, staff, consultant, board, fund raiser or volunteer, we thank you and value you for your role in keeping the Center thriving. There are many ways to become more involved in how the Center serves our community, so please do not ever hesitate to reach out.

We look forward to serving our community for many more years to come.

Thank You,

Michael Scott-Kristansen - Board Chair
Tom Wilmarth - President & CEO

Annual Medical Report

2020 was a challenging year for everyone. Understandably it was also challenging for the staff at the Mary M Gooley Hemophilia Center. During the COVID pandemic we rapidly converted the vast majority of our appointments and follow-up visits to telemedicine. All non-urgent appointments and treatments were cancelled, including most therapeutic phlebotomies for our long standing hemochromatosis patients. We immediately interrupted the routine in person monthly comprehensive care clinics for patients with moderate or severe hemophilia by converting all clinics to telemedicine. Patients were still referred to physical therapy for assessment by Zoom and occasionally seen in person by physical therapy or the orthopedic surgeon depending on their needs. Overall, however, we had to learn and adjust to making assessments and providing care without physical touch and physical support.

The Center also had to socially distance from each other with many staff intermittently working remotely. Our small office with a tight knit staff were protecting each other by limiting contact and potential exposure. But I cannot emphasize enough, nor will I forget, that it was very difficult. During a time of immense fear and stress for all of us, we at many times also felt alone. During this year, together as a center, we were able to still provide the care our patients needed. We provided urgent appointments and assessments, we continued to answer the phone every day to assist with questions or changes in health, and we continued to provide the medications our patients needed; We continued to support you during this time.

This is a medical report for our annual report for 2020, but the reality is I am writing this in 2021.

2021 is thankfully better in many ways. Gradually, we were able to return to seeing our patients in-person. Even if we are masked and wearing face shields or goggles, and not hugging (as I personally am a fan of doing), we are so happy to see you. We are all very grateful that we are able to take care of you. The Center was never in jeopardy in 2020, but the people in the center and the people that we care for were. The physical health and the mental health of everyone was at risk.

At the time of writing this report, all of our patients with severe or moderate hemophilia have been able to have their annual comprehensive clinics for 2020. Our patients with hemochromatosis have come back to the Center for their phlebotomies. No one was missed. No one sacrificed their routine care.

Things still look different at the center. We of course are still wearing our masks and eye protection, and patients are still being scheduled at specified times to limit interaction with other patients in the Center if possible. But there is a different feel today. There is more of a sense of comfort and routine and more joy. We are seeing you and caring for you in person. For that we are thankful.

Robin Reid, MD
Clinical Director

The Third National HTC Patient Satisfaction Survey is now open!

We need your voice and experience to tell us what we're doing right, and areas we need to improve!

Take the survey at www.htcsurvey.com or fill out and return the survey you received in the mail.

Surveys must be completed by June 30, 2021.

2021 Bleeding Disorders Walk

We are very excited to have our annual Bleeding Disorders Walk back in 2021! This has become a wonderful event for our community to come together and celebrate the Center along with being our primary fundraising event. Planning is already under way via our Walk Committee and we look forward to seeing you all there.

MARY M. GOOLEY
Hemophilia Center
BLEEDING DISORDERS WALK
EVERY STEP COUNTS

Annual Bleeding Disorders Walk
Saturday, September 11
Genesee Valley Park

Register at www.RocEveryStepCounts.com

Thanks to our Event Chairs: Monica Gurell and Lindsay Hooper!

Corporate Walk Sponsors

We are still finalizing our 2021 walk sponsors, so we wanted to recognize our sponsors from the last two years along with those already committed for 2021. Please contact us for sponsorship details.

-Excellus
-Law Offices of Pullano & Farrow
-Canandaigua National Bank
-Benefits Management Inc.
-Bond Benefits Consulting
-Brown & Brown of New York
-Wegmans Food Markets
-Perinton Dental
-Mutual of America
-MVP Healthcare
-Kouides Family
-Tracy Catlin Beauty

2020-2021 Programs and Events

Unfortunately, the COVID pandemic has made delivering our usual robust schedule of educational programs and family events difficult. However, the Center has been able to adapt with remote technology and still deliver remote educational programs and we are exploring the possibility of hosting some in-person family events later this year.

Remote Educational Programs So Far...

- "NHF Annual Bleeding Disorders Conference" (remote) - August 1-8, 2020
- "HFA Symposium" (remote) - August 24-29, 2020
- "Changing Insurance Landscape" - September 19, 2020
- "Cannabis, Chronic Pain and Caveats for Bleeding Disorder Patients" - October 15, 2020
- "Hemophilia 101" - February 9, 2021
- "VWD: A-Z" - March 9, 2021
- "Adversity, Strength and Resilience" - May 26, 2021

Future Programs and Events...

- "Hemochromatosis 101" (TBD)
- Fall Family Fun Day (TBD)
- Holiday Party (TBD)
- More educational events (remote or in-person) as they become available
- "NHF Virtual Annual Bleeding Disorders Conference" - August 25-28, 2021
- "HFA Virtual Symposium" - October 18-28, 2021

2021 NYS Advocacy Watch

On March 21-22, the Center once again took part in the annual Bleeding Disorders Albany Days. Even though it was remote, it was a great two days of advocating and educating legislators on issues that impact the bleeding disorders community. With the new state budget passed, the Legislature has moved on to many other issues including Covid related relief and how to safely re-open the state. Here are updates on the bills we're tracking this year!

Patient Assistance	▪ Goal – ensure patients can use private party aid, e.g. co-pay/deductible assistance, etc. ▪ ***S.5299 (Rivera) – Passed the Senate Insurance committee, awaiting Senate floor vote*** ▪ ***A.1741 (Gottfried) – Passed Assembly Insurance com., awaiting Assembly floor vote*** ▪ History – Previous bill passed Senate, stalled in Assembly Insurance committee
Prior Authorization Reform	▪ Goal – limit barriers to care by creating guardrails on prior authorization rules ▪ ***S.6435A (Breslin) – In the Senate Health committee*** ▪ ***A.7129 (Gottfried) – In the Assembly Insurance committee*** ▪ History – Previous bill stalled in Assembly
Pharmacy Access Reform	▪ Goal – ensure equal patient access to a local and mail order pharmacy option ▪ ***Sponsors are being lined up and bill language reviewed*** ▪ History – Previous bills have stalled in committee
Non-Medical Switching	▪ Goal – ensure access to medications by barring adverse mid-year formulary changes ▪ ***S.4111 (Breslin) – Passed the Senate on 4/27/21*** ▪ ***A.4668 (People-Stokes) – Referred to Ways and Means committee on 4/28/21*** ▪ History – Previous bill vetoed by Governor in 2020
Medicaid	▪ Goal – ensure a robust program which also covers many people with bleeding disorders ▪ ***The passage of the New York State Budget in April delayed the transition of the Medicaid pharmacy benefit from Managed Care to the Medicaid Fee-For-Service (FFS) Program by two years, until April 1, 2023.***

COMMUNITY ADVOCACY

- **Virtual Calls to Action** – Good news - ***your advocacy work has made a real impact!*** The Patient Assistance bills that we advocated for at NYSBDC's Virtual Albany Days 2021 have passed through their committees and are now on the State Senate and Assembly floor! ***Now we need your help to encourage legislators to vote in favor of the bill. Head to nysbd.org for more information and specifics on what you can do to help us pass the bills above!***

On March 3rd-5th, the Center participated in NHF's annual Washington Days. While the meetings were remote, they were very productive and allowed us to advocate and educate legislators on the issues that impact the bleeding disorders community. Below are the main issues that were discussed this year. The Center is very proud to have a long standing reputation as being leaders in bleeding disorders advocacy!

Your Future, Our Mission
WASHINGTON DAYS
NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders
YOUR HEALTH! YOUR FIGHT! YOUR VOICE!

Introductions/Bleeding Disorders 101/ Bleeding Disorders Awareness Month

- Introduce everyone and then the constituent (person who lives in district) should take the lead.
- Red ties are in honor of March as Bleeding Disorders Awareness Month.
- Tell YOUR story of how bleeding disorders affect you/ your family:
  - What is your condition and how do you treat it? What is your daily life like? What worries you about living with a bleeding disorder?
  - Share the name and location of your HTC and describe the multidisciplinary care you receive (who you see and what services they provide). Explain why your HTC is important to you.

Federal Bleeding Disorders Programs

Explain that there are federal programs that support our community. We ask Congress to support these programs:

- **National Institutes of Health (NIH):** Funds biomedical research on bleeding disorders. NIH is working to implement a national blueprint for research on inhibitor prevention and eradication.
- **Centers for Disease Control and Prevention (CDC):** Funds HTC surveillance and prevention activities, and supports outreach and education programs provided by national bleeding disorders patient organizations.
- **Health Resources and Services Administration (HRSA):** Provides funding for HTCs to provide multi-disciplinary services not typically covered by insurance, such as PT and social work services. Also, as HRSA grantees, most HTCs participate in the 340B Drug Discount Program, which supports comprehensive care offered to all of their patients.

Affordability and Access to Care

Bleeding Disorders Concerns About Affordability

Since we must have access to comprehensive health insurance that covers treatments and expert care provided at HTCs, many people with bleeding disorders worry about:

- Having access to and affording comprehensive insurance coverage
- Paying out-of-pocket (OOP) costs for treatment and hitting the OOP max in Jan./Feb. each year
- Needing assistance to afford OOP costs

What are Co-pay Accumulator Adjustor Programs and How do they Impact Patient Access?

- Co-pay accumulator programs say that co-pay assistance does not count towards a patient’s deductible or OOP max.
- These programs harm people with bleeding disorders and other conditions who need co-pay assistance to afford their treatments.
- Without assistance, patients who can’t afford treatments may stop taking them or reduce the prescribed dosage. This leads to complications (i.e., increased ER visits, joint bleeds/damage, and missed days from work/school) that harm patients and increase overall costs.
- Private plans should be required to count all co-pays (regardless of who pays) towards a person’s OOP max.
- **Please support patient access to treatments by cosigning the McEachin-Davis letter to President Biden urging him to prohibit accumulator adjustor programs and ensure patient access.**

Improving Access to Coverage during COVID-19 Public Health Emergency

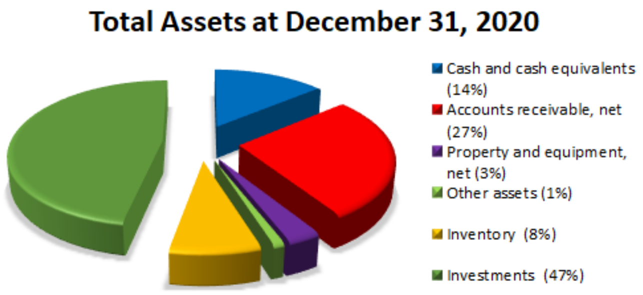
Our community strongly supports COVID relief provisions being considered that make it easier for people to get coverage, including:

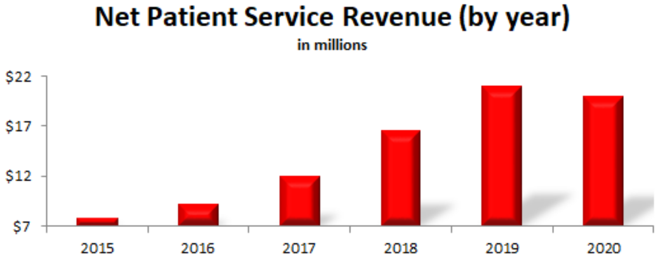
- Financial incentives for states to expand Medicaid
- Subsidies for people to maintain employer-sponsored coverage via COBRA
- Subsidies for marketplace plans for people eligible for unemployment insurance but not COBRA

NHF urges Congress to pass these provisions into law and to enact permanent policies to make coverage more accessible for people with bleeding disorders and others with chronic conditions.

2020 Financial Results

Revenue and Support	
Net Patient Services Revenue	$ 19,966,185
Special Events	2,854
Grants and Contributions	157,728
Total revenue and support	$ 20,126,767
Operating expenses	
Blood products	$ 15,215,001
Salaries, wages, and benefits	1,137,171
Medical and professional fees	351,518
Supplies, conferences, and other	174,584
Occupancy	120,655
Provision for doubtful accounts	180,389
Total operating expenses	$ 17,179,318
Change in net assets from operations	$ 2,947,449
Total assets	$ 12,364,457
Total liabilities	$ 2,011,191
Total net assets	$ 10,623,266


Total Assets at December 31, 2020


Net Patient Service Revenue (by year)
in millions

Our Team - 2021

Officers

Michael Scott-Kristansen, Esq.
Board Chair
Samantha Vitagliano, DMD
Secretary
Dan Gurell
Treasurer

Directors

Akua Asante, MD
Larry Denk, MD
Christine Hay, MD
Andy Park
Khari Saab

Medical Team

Farhan Imran, MD
Associate Physician
Saad Jamshed, MD
Associate Physician
Peter Kouides, MD
Medical/Research Director
Prad Phatak, MD
Associate Medical Director
Robin Reid, MD
Clinical Director
Ronald Sham, MD
Medical Director

Consultants

David Carrier, MD
Orthopedic
Larry Denk, MD
Pediatrician
Jim Martin, PharmD
Pharmacist
Allison Pulvino, MPST, CMP
Physical Therapist
Samantha Vitagliano, DMD
Dentist

Center Staff

Elisabeth Ambrose, BSN, RN
Nurse Coordinator
Rose Ann Bovenzi, BSN, RN
Nurse Coordinator
Kris Hurlbutt
Administrative Assistant
Eric Iglewski, LMSW
VP Clinical Services, Social Worker
Greg Lighthouse, CPA
CFO
Alison Schoeffler
Administrative Assistant
Jan Stolte
Billing Coordinator
Tara Veith, BSN, RN
Nurse Coordinator
Tom Wilmarth
President & CEO
Amy Wood
Billing Coordinator