



MARY M. GOOLEY
Hemophilia Center

Caring is in our blood

Mary M. Gooley Hemophilia Center



2022 Annual Report

CEO/Chairperson Report



2022 was a year that finally felt back to normal. Patients were mostly back in-person, our annual walk was a resounding success with many patients, their families and our staff attending, our annual meeting was in-person again and the staff was able to attend our normal schedule of conferences. While we say that the feeling is a "return to normal" there is also a sense of renewal. There have been many new patients who the Center is now serving, there are two new wonderful employees at the Center, there is a new five year mission per our federal HRSA grant to seek out new patients who may benefit from the Center's expert care, we are updating the job descriptions of our physician team including adding a Nurse Practitioner position for the first time and our long time Medical Director, Dr. Ron Sham is transitioning in his practice to a part-time roll and has graciously agreed to serve the Center in a whole new way as a board member and medical consultant. Dr. Sham will be joining a highly engaged and expert board of directors. There was great collaboration and synergy between the board and staff working to ensure smooth operations at the Center.

As we move into 2023 (which is the 70th anniversary of the Center as an NHF chapter) we look forward to embracing all of the "new" while never losing focus on what has been at the heart of the Center's care since our founding - treating our patients and their families with dedicated, personal and compassionate comprehensive care.

Thank You,



Tom Wilmarth
President & CEO



Samantha Vitagliano
Board Chairperson

Welcome Kaitlin & Carey!



The Center is excited to announce the addition of two new staff members, Kaitlin Skelly and Carey Born!

Kaitlin has joined our team as a Billing Coordinator working directly with our Senior Billing Coordinator, Amy Wood. We were very fortunate that Kaitlin came to us via a referral from our Board Chair, Dr. Vitagliano. Kaitlin had been working at Perinton Dental in both billing and general office management. After a long interview process with some very good candidates, Kaitlin stood out as a great fit for what the Center was looking for. She has hit the ground running and ramped up quickly, already contributing at a level beyond what we expected at this point. Welcome Kaitlin!

Carey has joined our team as a Nurse Coordinator. After a yearlong search, we were thrilled to have Carey start her new role here at the Center in February. Carey previously served as a Clinical Technician at Strong Memorial Hospital before earning her Bachelors of Nursing at the University of Rochester. She worked as a Registered Nurse at both the Respiratory Step-Down Unit and at Ambulatory Gastroenterology and Hepatology for Strong Hospital before joining our team. In no time at all, Carey has embraced the Nurse Coordinator role and has accepted every challenge that has come her way. We are already impressed by Carey's commitment to superb patient care, exceptional IV skills and warm rapport with patients. Welcome to the Center, Carey!

Remembering Bob Fox



It is with a heavy heart that we pass along the news that Bob Fox passed away on April 3rd. Bob served as the CEO of the Mary M. Gooley Hemophilia Center from 2000-2017. During that time, Bob had a major impact both on the lives of our patients and their families and also the broader bleeding disorders community.

Bob's kind soul, gentle demeanor and passionate leadership made our patients feel welcomed and cared for when they came to the Center. Not only did his expertise in Hemophilia Treatment Center operations allow the Center to thrive, but Bob was also instrumental in providing guidance and leadership in national endeavors for the bleeding disorders community. Specifically, Bob was part of the teams that helped establish and grow the Hemophilia Alliance, ATHN and the New York State Bleeding Disorders Coalition. Bob had a particular passion for advocacy, being amongst the leaders for many years in helping to grow advocacy efforts both on the federal and state levels.

While Bob's legacy is filled with accolades of organizational leadership it is his compassion for patients and their families that he will most be remembered for. He never lost sight of the personal aspect of care and the emotional well-being of those whom he served.



2023 Bleeding Disorders Walk

We are very excited to have our annual Bleeding Disorders Walk back in 2023! 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.



Annual Bleeding Disorders Walk Sunday, September 10th 2023 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 2023 walk sponsors, but we wanted to recognize our 2022 sponsors in the annual report. 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 Group
- Mutual of America
- MVP Healthcare
- Kouides Family
- Zweigle's

Medical Report

Recently, two renowned colleagues of mine, one from Belgium, and the other from the United States, wrote an editorial in one of our Hemophilia journals, proclaiming the beginning of an era of a “Haemophilia-Free Mind”. For someone caring for patients with hemophilia now into my fourth decade, this is a stunning proclamation and gives me great joy. The author’s premise is that with all the recent advances both FDA approved treatments available for patients as well as the promise of gene therapy and other new therapeutics in the pipeline, we now can start to think of patients living a carefree life without thinking of having Hemophilia. Obviously, for older patients who’ve sustained irreversible arthritis it’s easier said than done, but even those patients can be helped in preventing recurrent bleeding. In the case of Hemophilia A, there is the option of the injectable under the skin, Hemlibra. Also, for those who are still infusing intravenously a Factor VIII product, we’re all very excited to offer at our Center the newly FDA approved product Altuviii, which achieves a Factor VIII level most of the week in the 40% range and by the end of the week in the 10 to 15% range. That latter range is what we call the “sweet spot” which prevents most bleeds!! And now for hemophilia B, the FDA since last year’s annual report has approved a gene therapy product.

Given all of this, “the sky is really the limit” and we are pleased on our 70th anniversary of our chapter to have my dear colleague Dr. Len Valentino president of National Hemophilia Foundation, give the keynote speech at our annual meeting and review these wonderful advances and how going forward our patients can live a “Hemophilia-free” lifestyle!! I look forward to seeing as many of you as possible on this special occasion. I also look forward in the next decade, bringing all of you to the point of achieving a Hemophilia free mind!



Peter Kouides, MD
Medical/Research
Director



Support Federal Bleeding Disorders Programs - Further Research, Enhance Prevention and Access to Care



On March 9th, the Center participated in NHF's annual Washington Days. We brought three patient families with us to Washington to meet with legislators and discuss issues that are very important to the Center and the national bleeding disorders community

National Institutes of Health (NIH)/National Heart Lung and Blood Institute (NHLBI)

Recognizing the devastating consequences of a person with hemophilia developing an inhibitor (when a patient's treatments stop working increasing the risk of bleeding, joint disease, and hospitalization), NHLBI held a State of the Science Workshop on Factor VIII Inhibitors in May 2018. The product of the workshop is a national blueprint for future basic, translational, and clinical research on the prevention and eradication of these inhibitors. NHF strongly supports furthering this area of critical research.

Request:

- Support funding for NHLBI to initiate high-priority research, as outlined in The National Blueprint for Factor VIII Inhibitor Research.
- Support overall NIH funding

Centers for Disease Control and Prevention (CDC)

The CDC Division of Blood Disorders provides funding for HTC surveillance and prevention activities, and supports outreach and education programs provided by national bleeding disorders patient organizations. Recently, the CDC's work has focused on inhibitors, today's most challenging and harmful complication of hemophilia. Funding for the CDC hemophilia programs should be maintained to improve treatment and prevention strategies, especially those related to inhibitors, and to monitor blood and blood product safety for our community.

Request:

- Maintain current funding levels for hemophilia-related programs and budget lines in the CDC's Division of Blood Disorders - \$5 million for hemophilia treatment centers and \$3.5 million for hemophilia activities.

Health Resources and Services Administration (HRSA)

HRSA's Maternal and Child Health Bureau provides funding to HTCs to provide multi-disciplinary services not typically reimbursed by insurance, such as physical therapy assessments, social work and case management services. As HRSA grantees, HTCs are also eligible to participate in the 340B Drug Discount Program, which allows for drugs to be purchased at a discount, and savings to be used to fund integrated care provided to all patients at the center.

Request:

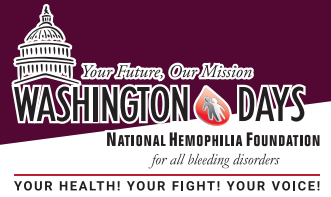
- Maintain current funding levels for HRSA's hemophilia program at \$4.9 million and ensure that HTC participation in the 340B program is maintained.



Maintain support for federal bleeding disorders programs at NIH, CDC, and HRSA



Support Policies That Increase Affordability and Access to Care



Bleeding Disorders Concerns About Affordability

People with bleeding disorders must have access to comprehensive health insurance that covers their life-saving treatments and expert care provided at hemophilia treatment centers (HTCs).

Annual treatment costs exceed \$350,000 per year for a person with severe hemophilia. Therefore, people with bleeding disorders hit their annual out-of-pocket (OOP) maximum each year. For 2022, the OOP limit is **\$9,100** for an individual and **\$18,200** for a family.

Thus, many community members worry about:

- Having access to and affording comprehensive insurance coverage
- Paying their OOP costs for treatment
- Hitting their OOP limit, often in the first month
- Needing financial assistance to afford their OOP costs

What are Copay Accumulator Adjustor Programs and How do they Impact Patient Access?

- Many people with bleeding disorders and other chronic conditions need copay assistance programs to help them afford their high OOP costs.
- An increasing number of private health insurance plans are implementing copay accumulator adjustor programs that disallow copay assistance from counting towards a patient's deductible and OOP maximum.
- When copay assistance is not allowed, many patients cannot afford their treatments and stop taking them or reduce the prescribed dosage. This often leads to complications and has unintended consequences (i.e., increased ER visits, joint bleeds/damage, and missed days from work/school) that harm patients and increase overall costs.
- This also affects people with other expensive conditions. NHF helps lead the All Copays Count Coalition, which has 120+ members representing people with cancer, MS, HIV/AIDS, arthritis, lupus, and other rare and chronic conditions.

The HELP Copays Act

Plans should be required to count all copays (regardless of who pays) towards a person's OOP maximum. The Help Lower Patient Copays Act (HELP Copays Act) is a bipartisan, two-part solution that:

- Clarifies the ACA definition of cost sharing to ensure payments made "by or on behalf of" patients count towards their deductible and OOP max.
- Closes the EHB loophole to ensure that any item or service covered by a health plan is part of the EHB package so that all related cost sharing counts towards a patient's cost sharing limits.

In the House, HR 830 was introduced by Reps. Carter (R-GA) and Barragan (R-CA). We are asking Representatives to co-sponsor the bill.

In the Senate, we are asking Senators to introduce a companion bill.

FAQ on the Issue

Has there been activity on the state level?

Yes, 16 states (AR, AZ, CT, DE, GA, IL, KY, LA, ME, NY, OK, NC, TN, VA, WA WV) and Puerto Rico have enacted laws, and there have been active campaigns in more than 20 additional states. We need Congress to enact a federal law so that all types of private plans are included.

How does this relate to broader debates on drug pricing?

Our costs are so high that some people couldn't afford their medicines even if prices were cut in half. NHF supports efforts to lower drug costs, but in the meantime, copay accumulator adjustor programs should be banned so patients are taken out of the middle.



Co-sponsor the HELP Copays Act (HR 830) / introduce a companion bill to ensure that all copays count for patients.

June 2023 NYS ISSUE UPDATE

Jessica Graham, NYSBDC Coordinator

Bob Graham, NYSBDC Public Policy Director

Tom Wilmarth, NYSBDC External Liaison



Though the budget ran late, it contained a flurry of policy making. Many issues are competing for attention in the few remaining weeks before the summer break. More work will be needed this summer/fall on our bills.

<p>Protect Patient Access to 3rd Party Assistance 2022 SUCCESS</p>	<p>A.3693 (Gottfried) / S.1350 (Rivera) Requires plans to count 3rd party assistance payments toward a patient’s out-of-pocket cost obligations</p> <ul style="list-style-type: none"> ▪ Passed & signed into law by Gov. Hochul Dec. 2022 ▪ Includes NYSBDC sought-after amendment to include protection for high-cost generics ▪ Takes effect July 1, 2023
<p>NY Rare Disease Work Group 2023-24 SUCCESS</p>	<p>Work group run by Dept. of Health, includes providers, patients, pharma, health plans, DOH officials and officials from NYS Dept. of Financial Services. Council will work for 2 years and issue a report of recommendations on how NYS can help people with rare diseases. Includes Bob Graham from NYSBDC.</p>
<p>2023-24 NYS Budget RELEVANT INFO</p>	<ul style="list-style-type: none"> ▪ Increased Medicaid reimbursement to hospitals for inpatient & outpatient services ▪ Increased coverage of certain mental & behavioral health services ▪ Establishes definition of health plan/PBM “clinical peer reviewer” as a medical expert with experience in the relevant area of practice (this is a compromise offering to offset the veto of the clinical peer review bill last year)
<p>Medicaid Pharmacy Transition to NYRx COVERAGE CHANGE</p>	<p>Medicaid pharmacy benefits were transitioned to NYRx, the NYS fee for service Medicaid pharmacy program. Factor/clotting products provided by HTCs are not currently impacted as they are billed under major medical.</p>
<p>Pre-authorization Reform 2023 ALBANY ASK</p>	<p>S.3400 (Breslin) / A.7268 (Weprin) Creates reasonable limits for prior authorization use by health plans/PBMs on already covered treatments/services</p> <ul style="list-style-type: none"> ▪ Passed Senate Health and in Senate Finance Committee; in Assembly Insurance Committee
<p>Step Therapy Reform 2023 ALBANY ASK</p>	<p>S.1267 (Breslin) / A.901 (McDonald) Creates guardrails around step therapy utilization</p> <ul style="list-style-type: none"> ▪ Passed Senate; in Assembly Insurance Committee <p>S.2677A (Breslin) / A.463A (McDonald) Patient notification of denials due to step therapy</p> <ul style="list-style-type: none"> ▪ Amended to include electronic notification (with patient consent); on 3rd reading in Senate; in Assembly Rules Committee <p>S.2800 (Breslin) / A.1384 (McDonald) Step therapy reporting requirements</p> <ul style="list-style-type: none"> ▪ In Senate & Assembly Insurance Committees
<p>Medicaid Unwinding COVERAGE CHANGE</p>	<p>Annual eligibility checks for Medicaid, Child Health Plus, and Essential Plan were put on hold during the COVID-19 pandemic to protect patient access to healthcare coverage. The hold ended earlier this year and renewals are being processed on a rolling basis over the next year. HHS estimates 45% of the disenrollments will be for procedural reasons, i.e., enrollee failure to provide required eligibility information.</p>
<p>Gold Card Prior Authorization Program RELEVANT BILL</p>	<p>A.859 (McDonald) / S.2680 (Breslin) Exempts prescribers with a 90% prior authorization approval rating from new prior authorization review for 6 months; renewable on a regular basis</p> <ul style="list-style-type: none"> ▪ On 3rd reading in Senate; in Assembly Insurance Committee

2022 Financial Results

Revenue and Support

Net patient services revenue	\$ 22,979,608
Special events	20,621
Grants and contributions	120,152

Total revenue and support \$ 23,120,381

Operating expenses

Blood products	\$ 16,802,084
Salaries, wages, and benefits	1,199,269
Medical and professional fees	368,764
Supplies, conferences, and other	219,268
Occupancy	145,343
Provision for doubtful accounts	141,363

Total operating expenses \$ 18,876,091

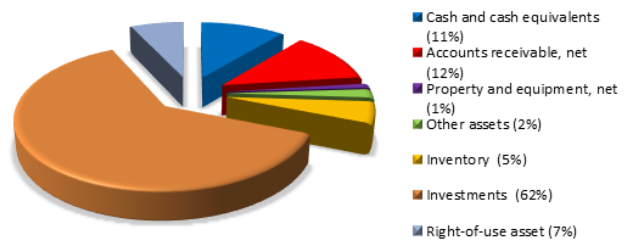
Change in net assets from operations \$ 4,244,290

Total assets 22,291,698

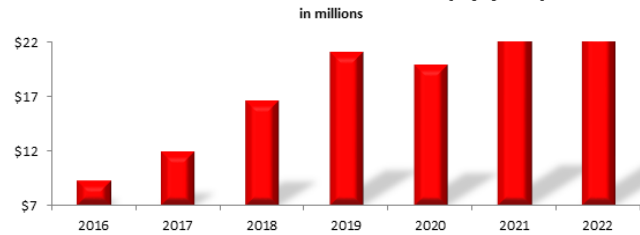
Total liabilities 3,721,511

Total net assets 18,570,187

Total Assets at December 31, 2022



Net Patient Service Revenue (by year)



Our Team: 2023-2024

Officers

Samantha Vitagliano, DMD

Board Chair

Andrew Park

Secretary

Dan Gurell

Treasurer

Directors

Akua Asante, MD

Larry Denk, MD

Christine Hay, MD

Khari Saab

Ron Sham, MD

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

Medical Director

Ronald Sham, MD

Associate Physician

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

Carey Born, 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

Kaitlin Skelly

Billing Coordinator

Tara Veith, MSN, FNP

Nurse Coordinator

Tom Wilmarth

President & CEO

Amy Wood

Senior Billing Coordinator