MARY M. GOOLEY
Hemophilia Center
Caring is in our blood

Mary M. Gooley Hemophilia Center

2021 Annual Report

CEO/Chairperson Report

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2021 was a year of two steps forward and one step backwards. As COVID rates went down and society and medicine found ways to adapt, it seemed like life was returning to normal or at least some version of a new normal. However, COVID had other plans for us and we found ourselves at times feeling like we were back at the beginning. Throughout the turmoil, the Center stayed steady and stable just as we did in 2020. Our January and February comprehensive care clinics were remote, March was a hybrid and the rest were all in-person. We were able to maintain our phlebotomy schedule uninterrupted throughout the year and our pharmacy was fully functional with no delays in orders, inventory, dispensations and shipping. Lastly, telemedicine slowly phased out as the year progressed and moved back into mostly in-person appointments as we transitioned into 2022.

Through these turbulent times, the Center has shown its strength and resiliency. No matter the challenge, patient care and services are always top notch and Center operations are rock solid thanks to our dedicated, expert and compassionate staff.

As we progress through 2022, we look forward to a much more normal year. Our annual meeting will be in-person for the first time in three years, board meetings will transition to in-person optional, patient events are being planned and our Bleeding Disorders Walk is full steam ahead for September 18th. The Mary M. Gooley Hemophilia Center is strong and thriving. Our team is ready to serve our community for many years to come.

Thank You,
Tom Wilmarth-President & CEO

This year's annual meeting marks the end of my sixth year on the Mary M. Gooley Hemophilia Center Board of Directors and my fourth year as Chairperson, and now it is my turn to step down. While I am privileged to remain as Immediate Past Chair, that role is an ex-officio position. The Center's bylaws, which the board revised and modernized in 2021, continue to limit board members to two three-year terms. Our term limits are designed to revitalize and reinvigorate the board with new ideas and fresh insight. Term limits also serve as a reminder that the board is a steward of the Center and its mission—to improve the lives of people affected by bleeding disorders and iron overload—and exists solely in service to that mission.

In full demonstration of the benefits of renewal and transition, the Center's small but elite all-volunteer 2022-2023 board roster is as strong as it has ever been. The board's continuing faith in the Center's President and CEO, Tom Wilmarth, and the rest of the Center staff and senior leadership team was well rewarded in 2021-2022 as the Center continued to experience a veritable renaissance, perhaps unequaled in its over 60-year history. Challenges and threats abound, from the omnipresent threats to health care funding to the exclusion of copay assistance from patient deductibles; however, the Center is well positioned to navigate these ever changing waters and to continue to provide the highest level of service to patients and their families.

I wish to extend my personal and heartfelt thanks to Tom Wilmarth, Eric Iglewski, Dr. Peter Kouides, Greg Lighthouse, all of the Center's employees and medical staff, as well as my fellow board members for a profound and collegial six years.

Michael Scott-Kristansen
Outgoing Board Chairperson

Thank You Jan & Michael!

This December, Jan Stolte will retire from the Center. Jan's superhero name should be, "The Quiet Legend." Hired by Mary Gooley in 1979, Jan is the longest serving employee in the Center's history - and that includes Mary Gooley. Starting out as a receptionist, Jan learned more about the Center's operations year after year and eventually progressed into one of the most frustrating jobs in healthcare - billing and reimbursement. Learning under the tutelage of another Center legend, Linda Magliocco, Jan quickly became our trusted Billing Coordinator. With Linda having broad leadership responsibilities across the Center's full operations, Jan essentially became our trusted "billing department." While help has come and gone, Jan has been the constant, the rock that the Center has relied upon to ensure that our patients' insurance covers them correctly so that they can receive care and that the Center gets proper reimbursement to stay open.

In 2020, the Center recognized that Jan was not going to work here for another 40+ years and we wanted another Billing Coordinator to have a lot of time to learn from Jan. So, we were very fortunate to hire Amy Wood, an experienced Billing Coordinator from Rochester Regional. After a few months on the job, Amy provided the best testament to how great Jan has been for the Center. She came to the management team and said, "I don't how Jan has been doing this alone for so many years - it doesn't seem possible." If there is a model for the perfect employee - Jan is it. She shows up every day, works hard, does exemplary work, is dedicated, never complains, cares deeply about our mission and is loved and respected by all of her colleagues. Thank you for everything that you have done for the Center and our patients Jan! You will be sorely missed.

Michael Scott-Kristansen will be stepping down as Board Chair at the Center's annual meeting on June 10th. Michael got to know the Center when he was an attorney with the Center's law firm, Pullano & Farrow and agreed to join our board in 2016. In 2018, Michael was elected as Board Chair. During his six years as a board member and four years as Board Chair, Michael has provided steady thoughtful leadership and expert advice for the Center. His guidance through some challenging transitions helped the Center stay stable and become an even stronger organization. We have also been fortunate to tap into Michael's expertise on healthcare law and compliance. Thankfully, Michael has agreed to stay affiliated with the board in the capacity of "Immediate Past Chair" which is noted in our bylaws as a non-voting position that exists to provide guidance to the new Board Chair and Executive Committee. Thank you so much Michael for your service and dedication to the Center!

Annual Medical Report

The impact of the COVID-19 pandemic on healthcare providers has been overwhelming with incredibly high rates of burn-out and psychological distress. Close to 1 in 5 healthcare workers nationwide have quit. Despite these turbulent times, it is comforting to know that the hemophilia center has remained a pillar of strength for our patients as we continue to offer unflinchingly state of the art care while maintaining staff satisfaction and retention.

From the start of the pandemic in March 2020, the center did not “miss a step.” There were no gaps in care, and we continue to adjust accordingly with the endemic stage of COVID-19. On behalf of the medical team, I cannot adequately express our gratitude to the staff in maintaining the quality of care at such a high level. Day in and day out they prove the adage that it takes a team to care for a patient. This begins with that first step into our waiting room when you are greeted by our incredibly pleasant and efficient front office staff of Alison Schoeffler and Kris Hurlbutt. In case you were nervous in coming to your visit, you are then quickly reassured and warmly greeted by our nurses Rose Ann Bovenzi and Tara Veith as they do your initial intake. But there is a lot more work they do particularly behind the scenes. They are often the first provider you’ll talk to when you call in with a bleed or other medical issue. Their initial triage of your issue makes my role so much easier because chances are that they have already answered your question and reassured you. The next time you see them, you can also thank them for other behind-the-scenes important work they do that you may not be aware of. For instance, Rose Ann, working with our pharmacist Jim Martin, is responsible for making sure that your clotting factor is arranged for you on-time and that there is adequate factor available at the time of a bleed or surgery. You can also thank Tara for keeping you on schedule with your comprehensive care clinic visits and subsequent follow ups. For our Hemochromatosis patients, it could be an unpleasant experience getting poked with a large needle but at our Center, it can be a very pleasant experience thanks to the great skill and bedside manner of Rose Ann and Tara.

Further behind the scenes but also playing a critical role in your care are our billing specialists, Jan Stolte and Amy Wood. Initially, sometimes reimbursement is denied and as a provider we worry about the possibility that the patient will not be able to receive a treatment blocked by their insurer. Time and again they come to the rescue. This report gives me a chance to acknowledge the great work Jan Stolte has done dealing with your insurance issues for amazingly four decades. We will sorely miss her as she retires at the end of this year, but we know she is passing on her institutional memory and methods that will continue to serve all of you well with our support team that also includes our CFO, Greg Lighthouse. He is also another important person behind the scenes as medical care of course is financially a very complex endeavor, let alone running a healthcare facility.

Finally, as someone entering his 30th year as a Hemophilia provider, my gray hairs remind me that leading a hemophilia center cannot be done by a physician alone. As above, there are so many aspects of care outside of examining a patient and prescribing treatments. When I travel to meetings around the country, I am frequently reminded about what a great center we have and leadership at the top beginning with our CEO Tom Wilmarth and Vice-President Eric Iglewski. They have been a very steady hand during this pandemic. Eric, in my book, is a world expert on occupational standards during the pandemic! Tom continues to be your greatest advocate, very involved at the state and national level.

I know on behalf of my fellow providers, Dr. Farhan Imran, Dr. Saad Jamshed, Dr. Prad Phatak, Dr. Robin Reid and Dr. Ron Sham, I can state that it is you the patients and the staff that make providing care at the Hemophilia Center one of the best parts of our day!

When I was first going to write this report, I was going to focus on all the great advances in treatment that we have, including the fact that our hemophilia A patients can prevent bleeding using an injectable medicine (Hemlibra) under the skin as opposed to poking their veins three times a week with a needle. We also anticipate FDA approval for both a Hemophilia A and Hemophilia B gene therapy product next year. So, this report could have been jam-packed with all these new products that make us feel like we are “kids in a candy store” but at the end of the day, high level technology will never supplant the healing touch that the Mary M. Gooley Hemophilia Center staff gives you directly and indirectly 365 days a year. Thank you again Tom, Eric, Rose Ann, Tara, Jim, Alison, Kris, Jan, Amy and Greg!

Peter Kouides, MD
Medical/Research
Director

2021 Bleeding Disorders Walk

We are very excited to have our annual Bleeding Disorders Walk back in 2022! 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
Sunday, September 18th 2022
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 2022 walk sponsors, but we wanted to recognize our sponsors that have already committed for this year. 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

2021-2022 Programs and Events

Unfortunately, the COVID pandemic continued to make delivering our usual robust schedule of educational programs and family events difficult. However, the Center has been able to adapt with remote technology and we are now starting to deliver some more in-person events.

2021 Programs and Conferences

- Hemophilia 101 Program - February 9th
- Virtual Washington Days - March 1-5
- Von Willebrand Disease A thru Z Program - March 9th
- Virtual Albany Days - March 21-22
- NHF Virtual BDC Conference - August 26-28
- HFA Virtual Symposium - October 18-28
- Virtual Bleeding Disorders Walk - September 11th

2022 Programs and Conferences

- Virtual Washington Days - March 1-2
- Hybrid Albany Days - March 27-28
- HFA Symposium - April 20-23
- Virtual WFH World Congress - May 8-11
- NHF BDC Conference (Houston) - August 24-27
- Mary Gooley Center Bleeding Disorders Walk - September 18th
- Family Fun Day - (October TBD)
- Center Holiday Party - (December TBD)

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

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

On March 2nd, the Center participated in NHF's annual Washington Days. While the meetings were remote, they were very productive and allowed us educate legislators on issues that impact the 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

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

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.

Support Policies That Increase Affordability and Access to Care

Your Future, Our Mission
WASHINGTON DAYS
National Hemophilia Foundation
for all bleeding disorders
YOUR HEALTH! YOUR FIGHT! YOUR VOICE!

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 **$8,700** for an individual and **$17,400** 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.

Co-sponsor the HELP Copays Act (HR 5801) / introduce a companion bill to ensure that all copays count for patients.

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 5801 was introduced by Reps. McEachin (D-VA) and Davis (R-IL). 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, 12 states (AR, AZ, CT, GA, IL, KY, LA, OK, NC, TN, VA, 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.

May 2022 NY Bill Watch

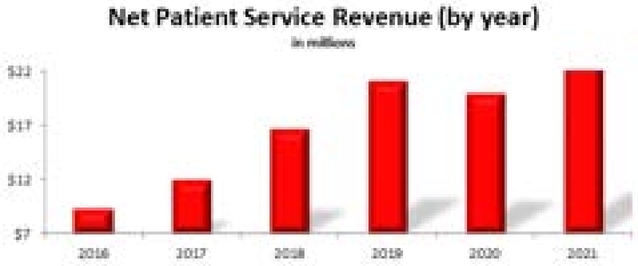
Jessica Graham, NYSBDC Coordinator
Bob Graham, NYSBDC Public Policy Director
Tom Wilmarth, NYSBDC External Liaison

On March 27-28, the Center once again participated in the annual Bleeding Disorders Albany Day. With a new Governor and an impending election there is a flurry of activity to pass many bills aimed at helping people in the final few days of the legislative session (expected to end June 2).

NY Rare Disease Council 2019 ASK	Council will work for 2 years and issue a report of recommendations on how NYS can help people with rare diseases (like bleeding disorders) in NYS. The Department of Health is finally selecting members for this council and plans to begin meeting this year.
RX Access Reform 2021 ASK	**A.5854a (Joyner) / S.3566 (Breslin)** limits use of additional terms and conditions on local pharmacies by health plans/PBMs to preclude local pharmacies from serving patients. SIGNED BY GOVERNOR HOCHUL IN 12/21.
PBM Regulation 2021 ASK	**A.1396 (Gottfried) / S.3762 (Breslin)** requires PBMs to register with NYS Dep. of Financial Services and follow reporting requirements. Previously blocked by Governor Cuomo. SIGNED BY GOVERNOR HOCHUL IN 12/21.
Permits Patient Assistance Programs 2022 ASK	**A.1741a (Gottfried) / S.5299a (Rivera)** requires plans to count 3rd party assistance payments toward a patient's out-of-pocket cost obligations ▪ A.1741a recently PASSED ASSEMBLY 5-18 by a vote of 129-9 ▪ S.5299a recently PASSED SENATE by a vote of 61-0 ▪ Gov. Hochul has until 12/31 to act on the bill Bill has 54 Assembly & 14 Senate co-sponsors. We're working with a coalition of 71 patient & provider groups to pass the bill and will begin outreach to Gov. Hochul soon.
Prior Authorization Reform 2022 ALBANY ASK	**A.7129a (Gottfried) / S.6435b (Breslin)** creates reasonable limits for prior authorization use by health plans/PBMs on already covered treatments/services. ▪ A.7129a in Assembly Insurance Committee ▪ S.6435b on 3rd reading in Senate
Gold Card Prior Auth Program 2022 OF INTEREST	**A.9908a (McDonald) / S.8299 (Breslin)** Exempts prescribers with a 90% prior authorization approval rating from new prior auth review for 6 months; renewable on a regular basis. ▪ A.9908a in Assembly Insurance Committee ▪ S.8299 on 3rd reading in Senate
2022-23 BUDGET RELEVANT INFO	▪ NYS Department of Health will begin a competitive bidding process to select new health plans to provide managed Medicaid coverage. The final number of plans selected will be limited with a goal of achieving savings to NYS through economy of scale. ▪ NYS Dept. of Health is requesting extension and modification of their current 1115 waiver from the US Centers for Medicaid/Medicare to implement new ideas for NYS Medicaid, especially in the areas of independent living care and health equity. ▪ Restored previous 1% cut in Medicaid reimbursements to providers & adds an additional 1.5% reimbursement increase to providers.

2021 Financial Results

Revenue and Support	
Net patient services revenue	$ 23,235,963
Special events	7,527
Grants and contributions	106,780
Total revenue and support	$ 23,350,270
Operating expenses	
Blood products	$ 17,324,940
Salaries, wages, and benefits	1,219,117
Medical and professional fees	357,460
Supplies, conferences, and other	165,258
Occupancy	127,693
Provision for doubtful accounts	77,395
Total operating expenses	$ 19,271,863
Change in net assets from operations	$ 4,078,407
Total assets	16,939,860
Total liabilities	1,400,357
Total net assets	15,539,503



Our Team: 2022-2023

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Board Chair
Andrew Park
Secretary
Dan Gurell
Treasurer

Directors

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

Immediate Past Chair

Michael Scott-Kristansen, Esq.

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

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