WESTERN NEW YORK
BloodCare
SPECIALISTS • LAB • PHARMACY

FORWARD MOTION

2024 ANNUAL REPORT

FORWARD MOTION

Worldwide, more than 380,000 people have been diagnosed with some type of bleeding disorder. If you were one of them, life used to be quite precarious. You sat inside at recess. You avoided crowds. Physical sports were off-limits. Certain careers were unthinkable.

Not Anymore. Today, Western New Yorkers with these disorders usually lead normal lives – because WNY BloodCare helps them live theirs to the fullest.

On the Cover: WNY BloodCare patient, mentor and advocate Jessica Graham serves as a certified Emergency Medical Technician (EMT) in Wyoming County.

MISSION

WNY BloodCare is a separate, not-for-profit, New York State-licensed diagnostic and treatment center offering a variety of specialized diagnostic and health maintenance services for those with blood disorders that require lifelong medical management. Through its clinical services, advocacy, education, and research initiatives, WNY BloodCare strives to improve the quality of life for people affected by these conditions.

HISTORY

WNY BloodCare was founded as the Hemophilia Center of WNY in 1969 within the E.J. Meyer Memorial Hospital — now ECMC. In 1984, a pediatric satellite was established at Children's Hospital of Buffalo. In 2009, both the adult and pediatric sites merged, enabling all patients to be treated at one site. **Our comprehensive care model for treatment and disease management has been used since our inception, as we've served patients and their families across WNY's eight counties for nearly 55 years.**

Dear Patients, Partners and Supporters,

This is an exciting time for WNY Bloodcare. As I enter my third year leading this talented team of physicians, staff and supportive caregivers, I'm pleased at the progress we have made – and energized at the prospects which lay before us.

Chief among these is the five-year strategic plan which we are close to completing. Led by a broadly represented committee of key staff and board members, we have objectively evaluated all segments of our operations, garnering honest feedback from patients, community partners and team members as we assess our strengths, weaknesses and opportunities. As a result, we have identified four main organizations goals: Clinical Growth, Fiscal Viability, Human Capital and, 340B Fund Stewardship

GROWTH: Our main goal has always been to help as many patients as possible lead more complete lives. We continuously look to expand our services to those in need across Western New York. From infusion services to new and novel treatments, we explore ideas to expand geographically while also serving populations in Buffalo's underserved regions. For example, we eagerly anticipate the launch of a new mobile unit by our partners at the University at Buffalo's School of Public Health and Health Professions. We hope to collaborate with them to educate and serve low-income urban residents facing socio-economic challenges, in addition to bringing bleeding disorder care to regions and counties along the Southern Tier.

FISCAL VIABILITY: Of course, our daily financial operations are critical to supporting our infrastructure and providing comprehensive patient care. We are focused on maintaining our fiscal health while saving and planning for our future. Investments in high-demand equipment and technologies along with new grant opportunities and strategic partnerships all help to ensure that we can provide a broad spectrum of services in a convenient, efficient, one-stop care model.

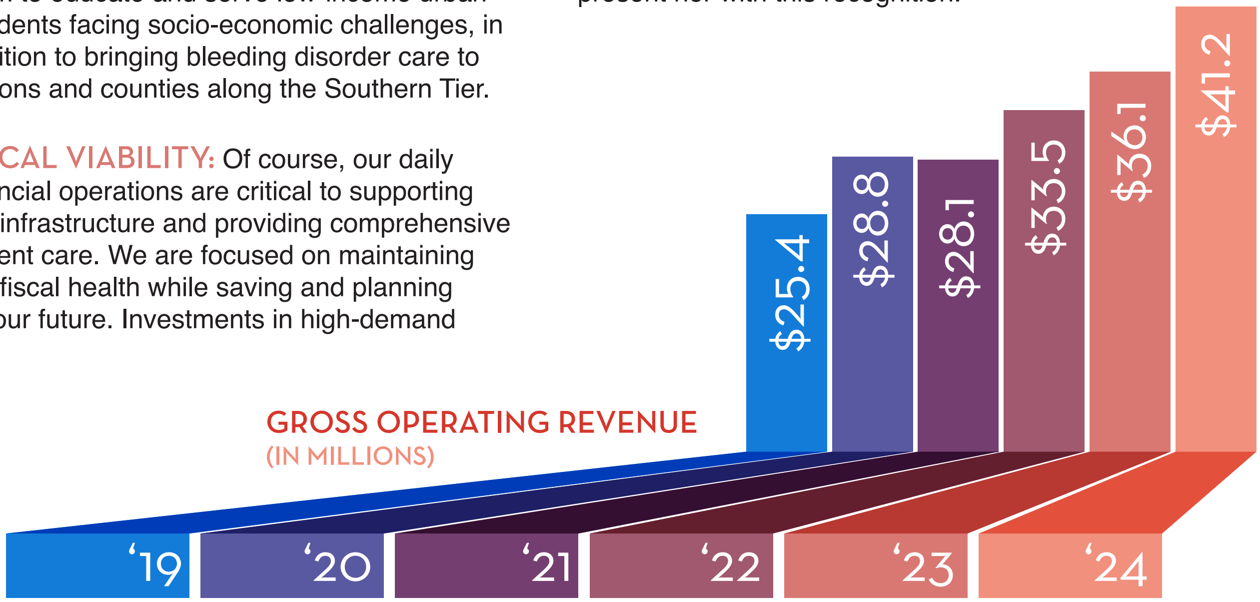
HUMAN CAPITAL: If you'll pardon the pun, our people are our lifeblood. Their knowledge and compassion help patients and families lead their lives with minimal interruptions. We are proud of our history of having a well-rounded team. We work hard to assemble, develop and maintain this incredibly talented and diverse group of employees and board members with various backgrounds and skills.

Recent additions include Dr. Katie Carlberg, a pediatric hematologist who also serves as a pediatric oncologist with Roswell Park Cancer Institute. Her work in cancer care adds a highly valuable skill set to our physician lenses, including her expertise in thalassemia, sickle cell anemia, pediatric benign hematology, noninvasive prenatal teasing and international medicine.

We also look for opportunities to promote from within, as Renee Czarniak's recent rise to Laboratory Manager illustrates. Her performance with us for more than eight years has been exemplary and we were thrilled to present her with this recognition.

Dr. Katie Carlberg

Renee Czarniak



GROSS OPERATING REVENUE
(IN MILLIONS)


Alice Del Toro


Stephanie Norris


Martina Salanis


Sharon Snell

Other newcomers include Alice Del Toro, our senior clinical laboratory scientist; Stephanie Norris, our specialty pharmacy technician; Martina Salinas, our intake coordinator; and Sharon Snell, our revenue cycle manager. They all have added their own special talents to enhance our team. We consistently try to provide as many perspectives and as much expertise as possible, allowing us to care for an entire patient – not just treat symptoms – as we align staff capabilities with our organization's needs and opportunities.

340B FUND STEWARDSHIP: Part of a federal drug pricing program requiring pharmaceutical manufacturers to provide drugs to eligible health care organizations at reduced costs, it allows qualifying pharmacies like ours to purchase medications and other pharmaceuticals at a discounted cost. We have always been highly appreciative of and responsible with those proceeds, reinvesting them into our program so that patients get the most long-term benefits. Named for the section of the Public Health Service Act which authorized it, the program allows covered entities to stretch scarce resources as far as possible, reaching more eligible patients and providing more comprehensive services in the process. In our case, those funds allow us to provide more patient care and a superior environment. We re-invest those dollars in staff development, equipment and supplies, thereby increasing our clinic's spectrum of comprehensive care.

Another recent highlight is the decision to rebrand our former S.H.E. (Specialized Hematology Experts) Clinic to the Heavy Period Clinic, a name that's much more relatable to describe the specialized care which these teen girls and women receive. With its focus on heavy menstruation and related ailments, we've created a more organic and complete approach to bleeding disorder care, not just in our clinic but supported with education and outreach to females of all ages in schools and other youth organizations.

As we look ahead, we are excited to roll out a new patient portal later in 2025. Its new technologies will enhance our electronic medical record system to make our providers' and patients' lives even easier, including improved communications and the ability to access certain records and results online.

We're also increasing our communication and collaboration with external physicians and health care providers. We're developing an outreach and education curriculum designed to help our medical partners better understand what we treat and what to look for in their own patients. From primary care physicians to orthopedic surgeons to OB/GYNs, we can become a trusted resource – one they know does not represent a competitive risk.

For instance, our specialized musculoskeletal ultrasounds can help determine if those with excessive bleeding may actually be suffering from Von Willebrand Disease, which affects an estimated 3% of people in the U.S. Similarly, joint issues are an inherent symptom and outcome of patients with hemophilia, allowing us to complement orthopedic care (including joint replacement surgeries) with physical therapy and recovery programs at our clinic. And OB/GYNs represent a tremendous opportunity for our education and prevention services, such as our "Period Pack" program which is distributed through physicians, schools and other community organizations.

We are also pleased to continue the leadership position we have within our field through our advocacy, research and foundation efforts.

We have maintained a strong presence in Albany and Washington, with regular trips to visit our representatives in each. Our advocacy has resulted in several positive developments, including the New York State Senate's recent vote to create a Permanent Rare Disease Advisory Council, which will assist patients like ours in numerous ways. In addition, we steadfastly underscore how important continued federal support is for our patients – many of whom rely on Medicaid – and our 340B-designated specialty pharmacy, which allows them to access their life-saving medications at affordable prices.

We have expanded our translational research efforts as well, awarding grantees at Mercy Children's Hospital of Kansas City, Mo., and Nationwide Children's Hospital in Columbus, Ohio, in addition to our two local grantees at the University of Buffalo.

Then in May, we held our fourth annual research symposium, which brings dozens of blood disorder professionals together to discuss a host of topics that positively or adversely affect our patients. These initiatives not only increase the amount and variety of work being done within our field; they also serve to establish us as a leader on a national landscape and beyond.

Lastly, our foundation continues to host many events designed to bring patients and families together, in addition to raising funds and awareness surrounding bleeding disorders. Examples include trips to the Buffalo Zoo, Buffalo Bisons and holiday parties, in addition to our annual 5K run/walk, which drew roughly 150 participants in 2024. It will be held at a new location this year – Delaware Park – on Aug. 10.

As you can see, we're making an important difference in the lives of many neighbors across the region. In the coming pages, you'll meet several of them as they share their stories. Each is unique – and we're honored to have played a role in their journeys. We're touched that they've taken time out of their lives to speak on our behalf. It's also humbling and gratifying to know that we've aided in their Forward Motion. So, whether you're a patient, team member, community partner or funding provider, rest assured that we, too, are focused ahead – like our patients – with no intention of slowing down.

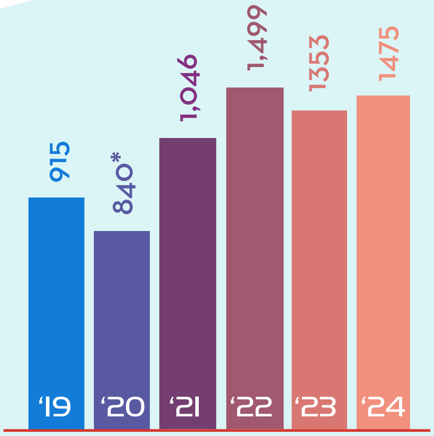
Thomas V. Greico, CEO

Thank you for your continued support of our team,

Thomas Greico

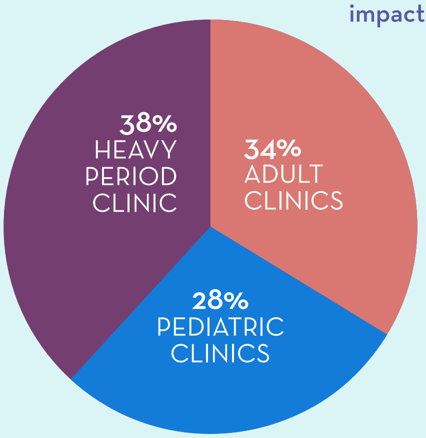
Thomas V. Greico
Chief Executive Officer

From left, Dr. Shaveta Malik (OB/GYN), Nurse Practitioner Emily Skinner, Director of Clinical Operations Angela Ciraolo and Dr. Katie Carlberg (Hematologist).



PATIENT THRESHOLD VISITS

* COVID impacted



PATIENTS SERVED BY CLINIC 2024

TURNING A CHALLENGE INTO A CALLING

Growing up in Wyoming County, Jessica Graham was an excellent student – so strong, she became her high school salutatorian in 1996. Her collegiate plans were altered, however, when she learned she was pregnant during her senior year.

“I was overly trusting of my high school boyfriend,” she says. “It was a hard lesson to learn.”

Her son, Jeremy, was born weeks before her graduation. However, following his circumcision, the hospital staff were surprised to find an inordinate amount of blood in his diaper. He was quickly transferred to Children’s Hospital in Buffalo in hopes of getting it under control.

They could not.

Jeremy lost almost half of his blood. Doctors conducted a series of tests over several days, eventually making a diagnosis: severe von Willebrand Disease (VWD).

Jessica had never heard of it. In fact, the hospital’s staff had limited knowledge of it and referred her to the Hemophilia Center of WNY (today’s WNY BloodCare). It turned out Jeremy’s father had it, too – and they discovered Jessica had a mild form of it as well.

“Looking back, I always had prolonged bleeding after vaccines and allergy shots, and heavy periods, but I thought it was normal,” she says.

The Hemophilia Center diagnosed Jessica with Type 1 VWD. Jeremy had Type 3 – the first patient they had ever seen with that severity.

“They told me to pad everything in our house, and (he could play) no sports,” she recalls. “We treated him as if he had hemophilia. Any injury at risk of internal bleeding meant an immediate trip to the hospital.”

She will never forget the emergency room (ER) encounter she had when Jeremy was a toddler. The doctor on call was not aware of the disease – a common occurrence during those days. Instead, he prescribed something that would not have helped. Jessica disagreed with him but, due to her young age, he didn’t take her seriously.

She pushed back and insisted that they contact the Hemophilia Center.

“Back in those days, Dr. Petruzzi was the pediatric hematologist,” Jessica shares. “She set him straight. She was a huge advocate for us. She always listened and answered our questions.”

As a single mom, Jessica was fortunate to have the support of her parents, Nancy and Carl. She lived at home so they could help raise Jeremy as she earned a biotechnology degree from the Rochester Institute of Technology and began a career as a laboratory technician.

As Jeremy grew, he had different kinds of bleeds – almost like fashion styles, says Jessica.

“First, he had nose bleeds – one so bad he was hospitalized,” she recalls. “Then came joint bleeds, then muscle bleeds. Then they installed a port to help administer his medications.”

Still, Jeremy worked to be as self-sufficient as possible. He began doing his own infusions at age 13 while at summer camp. He also developed a love of cycling – despite its potential risks.

Jeremy earned a bachelor’s degree in mechanical engineering – and the resourcefulness he developed to survive as a child has fostered an entrepreneurial spirit in him. Now 28, he hopes to open a bicycle rental/repair shop, the perfect blend of his passions, which he balances seamlessly with his twice weekly infusions.

“He’s really good with people. He’s able to explain things,” Jessica notes. “And, he loves outdoor adventure.”

Does he ever! Jeremy has traveled the Erie Canal from end-to-end three different ways: by bike, hike and kayak. Jessica even joined him for part of the kayak journey, calling those nine days some of the hardest but most enjoyable of her life.

Today, though Jeremy is no longer her primary responsibility, she’s not done caring for others. She began to volunteer at the Varysburg Fire Department, which inspired a career change in 2022 when she became a certified Emergency Medical Technician (EMT). Now a squad captain, she recently began working on a bachelor’s in nursing.

She’s also become one of our strongest advocates. After years of working with – and briefly for – WNY BloodCare, she’s now president of the Bleeding Disorders Advocacy Network and a coordinator for the NYS Bleeding Disorders Coalition. She routinely travels to Albany to train patients and families on how to advocate to legislators and their staff.

Happily, she’s not doing this work alone anymore. She has Bob, her husband and former bleeding disorders camp director. He has been the coalition’s volunteer public policy director for 16 years. Together they lead conferences and other events, including a Columbus Day Weekend camp for patients.

Their inspiration traces back to Jessica’s early ER experiences, and the clear lack of education and awareness which existed – and still does – among many healthcare professionals.

Part of that education is her collaboration with our mentor program, which pairs actual patients with current medical students. It allows Jessica and others to share their first-hand experiences, advising future physicians on what to look for – and the needs bleeding disorder patients have, physiologically and emotionally. She’s even developed a board game to help them learn in a fun way while laying the groundwork for what they will learn.

For Jessica, it’s a major initiative that she is very thankful to see finally occurring.

“For years, we’ve been saying, we need to educate the doctors,” she says. “For most, it’s (essentially) a paragraph in their training. And it’s not just doctors…it’s dentists, it’s physical therapists. We’re so appreciative that (WNYBC) is finally doing it. Someone has stepped up.”

For our part, it wasn’t that hard. We just followed Jessica’s lead.

Jessica Graham and her son, Jeremy.

HEMOPHILIA DOESN'T KEEP BATES FAMILY ON SIDELINES

Felicia Bates has never known life without hemophilia. Her father suffered from it severely. She remembers traveling from her Riverside Buffalo home to the old Hemophilia Center. In those days, experts believed hemophilia only affected males, but as the years went by, she too, began experiencing symptoms.

It seems appropriate, then, that she would meet a man living with the same condition in 2002 and make him her husband.

"I met Dan through his sister, who worked with me at the time," she recalls. "I heard her say he'd been in a car accident and there were complications. I knew instantly what it was."

Today, Felicia, a nurse, and Dan, a chef, have built quite a family in Williamsville. They have four boys: Austin (16), Alex (13), Richard (8) and Jackson (6). Hemophilia, which is carried on the mother's side with a 50% chance of being passed on, exists in all but Alex.

"God knows what he's doing, because Alex is my accident-prone one!" Felicia jokes.

Over the years, the family has come to know our WNY BloodCare team quite well. Our pediatricians diagnose issues and prescribe medications. Our physical therapists help them maintain a full range of motion, as hemophilia causes joint deterioration. Our nutritionist guards against obesity, which can further damage joints. Our pediatric dentists limit oral trauma. Our social worker helps with bills which can pile up due to missed worktime.

In short, the Bates have come to rely on us to improve their quality of life. With four boys, that typically revolves around school and sports.

"The #1 thing is getting them to self-advocate," Felicia says, "explaining why they can't fully do something – and what they can do, if done safely."

That takes sports like football and hockey off the list, but they're willing to try most others. Austin, who you'll meet later, is quite a baseball player. The boys have also played flag football, soccer, basketball – even taekwondo.

"If there's a safe way to do it, we usually give it a try," she adds. "We don't want that 'what if' lingering in their heads as they grow up."

Their advocacy includes making sure those in their sons' lives know what to do in case of an accident. Simple playgrounds can be dangerous, so our team educates teachers, school nurses, coaches and others.

"There's a step-by-step plan that they go through with (caregivers)," Felicia says. "WNY BloodCare educates them, from providing onsite Factor injections to recognizing when they need to get to a hospital."

Medication advances have also improved their quality of life, as has our specialty pharmacy team, which stays on top of the latest developments.

"We used to have daily infusions. It's tough to work that into your schedule," Felicia recounts. "Now, it's just a tiny needle in their belly every other week."

Best of all, no one in the family has had serious complications or setbacks.

"The meds are doing what they're supposed to do," she attests. "We live a pretty normal life."

The Bates consider themselves lucky, especially compared to patients across the U.S.

"Having WNY BloodCare here is a real asset," Felicia affirms. "They make a big difference."

Felicia Bates at a clinic visit with her sons, Richard and Jackson.

PHARMACEUTICAL ACCESS HELPS BASEBALL PLAYER STAY “SAFE!”

Felicia Bates says her son, Austin, has loved baseball since he took his first breath.

“It feels like he started the moment he came out of the womb,” she jokes. “He’d watch baseball on TV but didn’t care about cartoons.”

He began playing as soon as he could – even before kindergarten – but to do so, he had to prepare much more than most kids.

Austin has hemophilia, which meant he had risks that the other kids did not. A minor scrape or bruise could cause serious bleeding, and if gone unchecked and untreated, become life threatening. While baseball is not as intense as other contact sports, it has the potential for plenty of mishaps. From errant pitches to nasty one-hoppers to collisions at home plate, baseball is fully capable of sending a hemophiliac to the emergency room. Yet, thanks to his lifelong relationship with WNY BloodCare, those trips are rare.

That’s because Austin is able to give himself clotting Factor injections before he plays, courtesy of our specialty pharmacy, part of the federal 340B program. It ensures his family’s insurance will cover his critical medication and allows him to take it where and when he needs it – often at tournaments far from home.

Another important part of Austin’s playing conditions is communication – both with our team of pharmacists and physicians, and with his coaches and teammates, so they understand what to do if an injury occurs.

Fortunately, Austin has never been shy.

“I remember being five years old and running up to my coaches to tell them I had hemophilia,” he laughs. “And almost every time, none of them knew anything about it.”

He would also tell teachers, teammates, friends – anyone with whom he spent significant time. That made Austin one of the region’s youngest bleeding disorder educators. And with every conversation, a new person learned what to do if he – or someone down the road with a similar condition – got injured.

Austin’s love of baseball has only grown. Now a junior at Williamsville South High School, he is a pitcher and third baseman on his varsity team. He hopes to play collegiately and is looking forward to many campus visits in the coming months.

Williamsville South’s Austin Bates hopes to continue his baseball career collegiately.

That makes his self-advocacy as important as ever, his mother reminds him.

“Especially as a pitcher, he needs his rest as much as he needs his practice time,” she counsels. “He understands, if he wants to go where he hopes to with this, he’s got to take care of his body.”

He’s able to play more freely, however, knowing WNY BloodCare is right there with him for every pitch and catch.

“It means the world,” he says. “They’ve been tremendous to me and my family over the years. It’s really helpful to know that they’re available if I need them.”

In other words, they allow him to just focus on the game – without playing games with his health.

HEAVY PERIOD CLINIC BLENDS COMFORT WITH SPECIALIZED CARE

At age 19, Shaveta Malik moved from India to Buffalo with her family. She pursued her dream of becoming a physician and considered hematology-oncology as a specialty. However, she also liked the hands-on aspects the obstetrics and gynecology (OB/GYN) field offered. She decided to pursue OB/GYN, but hematology-oncology still held a special place for her.

Then one day, she came across an opportunity to combine both passions – and she didn't have to go far to find it. "Our neighbor, Dr. Shilpa Jain, told me about a specialized clinic in another city run by hematologists and gynecologists for women with bleeding disorders," Dr. Malik recalls. "She wanted to create something similar in Buffalo and asked if I knew an OB/GYN who might be interested in helping."

Dr. Malik was that someone – and the pair did exactly that, opening the S.H.E. (Specialized Hematology Experts) Clinic at WNY BloodCare. It's now known as the Heavy Period Clinic, to more clearly define its services. Dr. Jain and Dr. Malik began operating it just a half-day per month. It has since expanded to a full day and is far exceeding that capacity, with extra hours now offered and added options being evaluated.

Dr. Jain has since relocated, so today, Dr. Malik – now also an assistant clinical professor with the University at Buffalo – works alongside Drs. Beverly Schaefer and Katie Carlberg. Their patients range from eight to 40+ in age, with most in their teens and 20s. They often present symptoms soon after their periods start. These include feeling fatigue or light-headed and missing school during menstrual cycles.

"Many come to us because they haven't gotten good answers for why their periods are so heavy," Dr. Malik explains. "Here, we're able to perform a more in-depth work-up."

The clinic is unique because it offers hematologists and OB/GYNs in one place, working in tandem on every patient they see. General OB/GYNs often can't provide the time and lack the in-depth knowledge to care for complex patients with bleeding disorders. Here, we can provide the patient with a comprehensive treatment plan – made by two specialists – that best fits their needs.

"Most OB/GYN medical texts dedicate only a few pages on issues such as bleeding disorders," Dr. Malik says. "Thus, many of us aren't well-versed in rare disorders requiring specialized care."

Some of the patients at the HPC have such diagnoses as von Willebrand's Disease (VWD), hemophilia, factor deficiencies, Tar Syndrome, platelet disorders and other causes, all of which are causes of heavy periods.

"Here, I not only get to provide care, but we also learn from one another," Dr. Malik adds. "It makes patients and families feel more comfortable, because gynecology and hematology experts are in agreement with prescribed treatments."

The HPC is especially comforting to young girls who may fear a typical OB/GYN office. Our clinic does not perform invasive procedures, so it is a less intimidating first step for sensitive conversations.

In one case, a patient with Type II VWD experienced excessive hemorrhaging and almost died during childbirth. It turns out, she had heavy periods throughout her life – as well as fibroids, which enhanced her risk. Our team provided her with OB/GYN options (hormonal methods) as well as hematological options (factor infusions). Eventually, the patient's heavy menses stopped responding to medical treatments alone.

"A hysterectomy would have been risky, due to the bleeding which occurs in surgery," Dr. Malik explains. "Instead, we recommended a minimally invasive procedure which decreased the blood flow to her uterus and shrank her fibroids, thus making her periods lighter. Now, she's a forever fan!"

More recently, a young patient from Southeast Asia visited the clinic. She had two bleeding disorders – plus a cultural barrier to overcome.

"Some people hear 'birth control,' and it triggers concerns that aren't accurate or relevant," Dr. Malik attests. "But her parents came in, listened, learned and eventually let us treat their daughter in the way she needed with hormonal methods."

Looking ahead, the HPC team is considering ways to serve women with sickle cell disease, which is prevalent in the African American community. They would also like to expand their services to pregnant patients with bleeding disorders.

"The key for me is that our patients need to feel heard," Dr. Malik summarizes. "They often feel dismissed – and that can have a terrible impact on their quality of life. Our ability to provide collaborative care can improve that substantially."

RESEARCH GRANT HELPS KANSAS CITY RESEARCHER MAKE THE EXTRA EFFORT

After earning his bachelor's degree, Thomas Cochran began his career as a research associate before moving on to medical school. His lab worked on ways to prevent cardiotoxicity in children undergoing chemotherapy.

He pursued pediatrics, furthering his commitment to caring for children and young adults. Today, Dr. Cochran is a hematologist and oncologist at Children's Mercy Kansas City, where he treats hundreds of patients each year. Still, his thirst for research never left.

"I'd been discussing an idea with my mentor, Dr. Shannon Carpenter, regarding iron deficiencies in children with bleeding disorders," Cochran says. "Their occurrence rates are remarkably higher than the general population's, which puts them at higher risk for other health problems."

Iron deficiency is one of the most common nutritional issues among children in the U.S. It has been linked to negative neurocognitive development as well as cardiovascular and immunological health. Its prevalence is higher in children with hemophilia, with some evidence suggesting they might be in a low-grade inflammatory state due to their blood factor deficit.

"The question then is, why?" says Cochran. "If these kids are becoming more iron-deficient than the general population, what is causing that, aside from increased blood loss?"

Persistent inflammation can elevate levels of hepcidin, a liver hormone which diminishes intestinal absorption of iron. If hepcidin levels are unknowingly elevated, doctors might prescribe courses of oral treatment which may not be adequately absorbed. In such cases, intravenous treatments would be needed.

"If we can better understand the role hepcidin plays, we might prevent complications in these kids," Cochran added. "It could improve their quality of life."

He wanted to take on this research project, but doing so required roughly 150 study participants – and the funding to make it all happen. Then he learned of a grant for which he might qualify – based in Western New York, of all places.

Several years ago, we began our Hematology Translational Research Group. Designed to foster knowledge-sharing and collaboration among physicians and scientists, its reach often extends beyond our region. Together with the WNY BloodCare Foundation, the group selects two grant recipients each year to support bleeding disorder research.

"We do an excellent job in patient care. We need to do the same in research," says Dr. Beverly Schaefer, our medical director. "It might not benefit this patient in front of you, but it may down the road. Let's be part of that discovery."

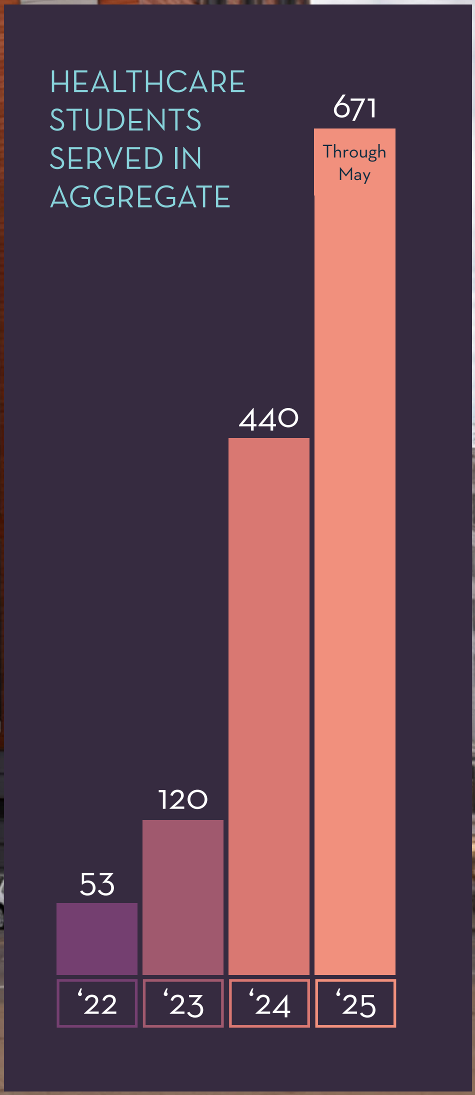
Dr. Cochran hesitated briefly to apply, due to his distance from the region. However, to his delight, he was chosen to receive a three-year, $185,704 Discovery and Innovation Award for his project.

> *"I was blown away when I got that approval letter," he admits. "I was thrilled to hear the news, and we've wasted no time in getting the project rolling."*

Over one-third of his 150-participant goal has been recruited. If all goes well, he hopes to have all his data collected in about two years, publish a research paper in a scientific journal and present his findings at various conferences.

"Ultimately, I hope this study becomes the foundation of a multi-site collaboration with other treatment centers," he adds. "That would truly expand the impact of this work and those funds – and make a real difference to patients around the world."

That's why we do it. It underscores the amazing team WNY BloodCare has been fortunate enough to assemble – and why our work is so important.



HEALTHCARE STUDENTS SERVED IN AGGREGATE

Brandon Hundley and Pia Corujo Avila, two students at the University at Buffalo's Jacobs School of Medicine and Biological Sciences, recently completed WNY BloodCare's WISTER program. The partnership is designed to provide future healthcare professionals with a more thorough understanding of the many issues which patients with bleeding disorders must contend.

TEACHING THE NEXT GENERATION OF CAREGIVERS

Some of the greatest hurdles our patients must overcome is the lack of understanding – even within the medical community. We're trying to change that by educating future physicians like Pia Corujo Avila and Brandon Hundley.

Although the pair of University at Buffalo (UB) medical students aren't specializing in hematology, they recognize the importance of understanding it. That's because each has completed the WISTER program. An acronym for WNYBC's Interprofessional Student Team Experiential Rotations, it is one of three WNY BloodCare-affiliated programs in which students from UB as well as Canisius University's Physician Assistant Program can participate. The others include our Health Mentors program, which pairs patients with students, so they can see what it's like to live with a chronic illness; and our Innovation Sprint program, which challenges student researchers to develop solutions to medical problems identified and funded by our team.

Combined, these programs serve roughly 280 students annually – and have guided more than 1,000 to date.

"Students in these programs learn about bleeding and clotting disorders, something most don't receive much training on," says Dr. Jessica Kruger, director of Teaching Innovation and Excellence for UB's School of Public Health and Health Professions.

> *"It also exposes them to the importance of hematology treatment centers like WNY BloodCare, which is valuable information for when they are in practice."*

Both Pia and Brandon were pleased to have the opportunity to learn more about these disorders, beyond what they have been taught to date.

"This field doesn't get a lot of exposure in medical school. We get only one lecture on it," says Pia, a Puerto Rico native completing her research (third) year at Oishei Children's Hospital as she prepares to become a pediatric surgeon.

"WISTER was recommended by some classmates, as well as my girlfriend, a dental student, who had completed it a few months earlier," adds Brandon, whose mother – a UB alumna – is a primary care physician in his rural Missouri hometown.

Both were also curious to see how our clinic functions with multiple providers and services available during a single visit. They followed patients through their entire visit, watching them be treated by and interact with physicians, nurses, physical therapists, dentists, lab techs and pharmacists, as well as our dietician, geneticist, and social worker.

"I was blown away," attests Pia, who hopes to remain in Buffalo and build her career here. "I watched them interact with every specialist. Then, after they left, the team huddled and reviewed each case, sharing information and observations. It leaves little space for error because everyone's on the same page."

Brandon, who will graduate in May and begin a community psychiatry residency at the University of Wisconsin, agrees.

"The team meeting is a very streamlined, efficient process," he adds. "It also removes the need to chase down colleagues who jotted down notes without enough context."

He was especially moved by how well our team knows those in our care.

"Dr. Schaefer knew their mother, cousins and grandmother. She knew their whole history because it's so genetically linked. Another patient spoke a foreign language, so they connected him to social services to help him get settled in the region. I was quite touched. Very rarely do you see that in a clinical, outpatient setting."

In all, the students found the experience to be worthwhile and educational, especially our interprofessional focus, which Brandon describes as the pinnacle of quality healthcare.

"This has been very meaningful," Pia adds. "It reminds you of the value of a holistic approach to care. People living with rare and chronic disorders have unique challenges, as do those who treat them – no matter their specialty. It's clear that WNY BloodCare is doing everything they can to make their lives easier."

Dan Sheron, his wife, Mary, and daughter, Lilly, prepare to meet with U.S. lawmakers on a recent advocacy trip to Washington, D.C.

SHARING HIS STORY. MAKING A DIFFERENCE.

Dan Sheron has lived with hemophilia all his life. Now age 43, he's experienced the full gamut of care. It started with blood infusions and emergency room visits as a child. Then there were plasma infusions. Then came recombinant factor products in the late 80s and 90s. Then synthetic products were invented, which lowered the risk for infectious disease.

He's witnessed the industry's evolution from reactive treatment methods to today's more proactive approach. He's seen the required frequency of infusions drop from three times per week to once weekly.

Thus, when he was asked to join WNY BloodCare's advocacy efforts a few years ago, he realized he had a valuable voice to lend.

"I feel like I've got a really good perspective on the disorder and the industry," he says. "As my kids grew older and began asking me questions (about it), it got me thinking… maybe I can do more?"

Dan and his family collaborate with our Chapter Services team. They help us advocate to our state and federal lawmakers about the importance of funding various initiatives that lead to healthy, normal lives for those with bleeding disorders. This includes sufficiently funding Medicaid – which many of our patients rely on – as well as the federal 340B program, which keeps their costly specialized pharmaceuticals affordable.

"It's critically important that legislators hear from patients," explains Community Outreach Coordinator John Alduino.

UPCOMING EVENTS

3rd Annual
"It's In My Blood"
Walk & 5K

Sunday, August 10
9AM

Delaware Park, Buffalo

Family Day at The Zoo

Saturday, July 12
10AM-1:30PM

The Buffalo Zoo
300 Parkside Ave, Buffalo

> *“They learn how their decisions impact real people...how this disease affects them daily. Patients tell a story the way no one else can.”*

Dan, his wife, Mary, and daughter, Lilly, shared their story this past March in Washington, D.C., part of an effort led by the National Bleeding Disorders Foundation which this year included over 400 participants from 49 states.

The Sherons met with members of New York Representative Claudia Tenney and Tim Kennedy’s teams, as well as Senator Kirsten Gillibrand’s office – and even 10-year-old Lilly contributed to the conversation.

“They (lawmakers) listened and seemed empathetic,” Sheron confirms. “And, Lilly loved it! She had never been to D.C. before, so to see all the sights and learn about the legislative process like this was really special.”

On the state level, our advocacy team enjoyed a recent win, as a bill that would establish a permanent Rare Disease Advisory Council passed the Senate in early 2025. Co-sponsored by State Senator Angelo Marinello, our hope is that it will also pass the Assembly soon.

“It’s impactful,” Sheron attests. “It’s interesting to share your story and help people see how potential cuts and policy changes would negatively impact patients in ways they might not have considered.

“These programs are efficient – and critical for patients to maintain their quality of life,” he added. “I’ve found this work to be fun, and I’d encourage others to do it as well. You learn a lot, and it’s great to see all the people you meet and help along the way.”

To learn more or register for
any of these events, please visit
wnybloodcare.org/events.

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Medical Director/ Hematologist – Pediatrics and Young Adults

Dr. Adam Kotowski, MD
Hematologist – Adult / Director of the Hemostasis Laboratory

Dr. Katie Carlberg, MD
Hematologist – Pediatrics and Young Adults

Emily Skinner, FNP-BC
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OUR CORE VALUES

- Universal Accountability
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