

hematology/oncology at Dayton Children's



the changing scene in hemophilia care

The expression “change is in the air” is particularly true in the world of hemophilia. Prevention of bleeding with intravenous prophylaxis and the opportunity to select extended half-life products remains a top choice for therapy. However, two new exciting treatment modalities have also emerged, including a new non-factor replacement product and gene therapy.

As with any new medications or treatment choices, risks versus benefits must be weighed. Both the Food and Drug Administration (FDA) in the United States and the European Medicines Agency (EMA), require completing stringent research before any new products can be sold commercially. Unfortunately, some risks and benefits are not apparent until many years after their use.

new medication

This emerging non-factor product being used in the treatment of Hemophilia A or Factor VIII deficiency is a bispecific monoclonal antibody that mimics the action of factor VIII by helping factor IX activate. In turn, this leads to normal clotting without having to replace missing clotting factor.

The FDA initially approved Emicizumab or Hemlibra in January 2018 for use in patients with Hemophilia A with an inhibitor. It was later approved for use in patients with or without inhibitors. This treatment does have a black box warning due to cases of thrombosis or thrombotic microangiopathies (TMA). These complications were noted when this product was used

concurrently with high doses of the bypassing agent FEIBA (>100 units/kg/day).

Patients with a high inhibitor titer who have taken Emicizumab for a period of time, report minimal breakthrough bleeding, improved joint health, less pain, increased independence and consequently, an improved quality of life. Patients also report the ease of administration has attributed to better adherence.

There are several other methods of treatment being developed, including tissue factor pathway inhibitor antagonists (TFPI) and anti-thrombin antagonists. All of these mentioned treatments can be administered subcutaneously and have the potential to alter current concepts of prophylaxis in hemophilia.

Both the tissue factor pathway inhibitor antagonists and the anti-thrombin antagonists remain in clinical trials. Both classes of drugs are being studied for treatment of patients with hemophilia A and hemophilia B, with or without inhibitors.

gene therapy

It is anticipated that gene therapy will be an option for treatment of both hemophilia A and B in the near future. Studies have shown promising results in patients with severe hemophilia (<1% activity) achieving sustained levels of factor VIII or IX of 5-20% activity. Trials are using an adeno-associated virus for transfection of the liver and have been limited to patients 18 years of age or older.

Many unanswered questions remain, such as length of response, how to manage patients



Melissa Tucker, RN, with Marcus Harrison, hemophilia patient

with inhibitors, if gene therapy can be used in children, how to treat patients who have antibodies to the viral vector and cost, just to name a few.

Currently, seven patients receiving care at Dayton Children’s Hemostasis and Thrombosis Center with the diagnosis of hemophilia A with and without inhibitors have transitioned to subcutaneous injections of Emicizumab. Patients receive a loading dose weekly for four weeks prior to transitioning to an individualized treatment plan allowing them to receive their injection every 7 days, every 14 days or every 28 days.

Melissa Tucker, RN, has developed a process to educate patients about the therapy and how to give subcutaneous injections. Melissa’s process

includes a teaching manual, directions for electronically logging doses, when to use factor 8 replacement therapy with a suspected bleed, as well as other educational and prevention topics. The hemophilia team feels optimistic that the new therapies will improve outcomes for many patients, especially those who were not successful with intravenous therapy.

“I believe the best treatment for hemophilia is an individualized plan that encompasses both the needs of the patient and the recommendations of the physician,” says Jordan Wright, MD, hemophilia director. “Although intravenous therapy is difficult, it may still be the optimal therapy for many. I look forward to discussing these new options with patients and their families.”

new partnership improves care for kids needing bone marrow transplants

Collaborative joins Nationwide Children's Hospital and Dayton Children's Hospital in cancer and blood disorders

Dayton Children's and Nationwide Children's have formed a cancer, blood disorder and bone marrow transplant collaborative that will enhance services, create more research opportunities for both institutions and allow more patients from the Dayton region to stay closer to home during treatment.

In addition to sharing physician services and offering more clinical trials to patient families than ever before, the collaboration will allow Dayton Children's to collect and harvest stem cells from the child's bone marrow in partnership with Hoxworth Blood Bank.

The harvested stem cells then are returned to the child after treatment is complete to help their body build normal blood cells.

"Our collaboration with Nationwide Children's Hospital will provide more advanced services than ever before at Dayton Children's, and make life

a little easier for our patients and families," says Ayman El-Sheikh, division chief of hematology/oncology at Dayton Children's. "The comfort and support system of home cannot be overstated for a family who is enduring a several-year treatment span for cancer."

Dayton Children's has a long tradition of quality cancer care. The overall survival rate for children treated at Dayton Children's is 87 percent, which is higher than the national average of 84 percent. Dayton Children's was one of the first hospitals in the country to offer a long-term follow-up program for children who have survived pediatric cancer. In the last eight years, the number of former cancer patients in the program has more than doubled, a reflection of those high cure rates.

In addition, Dayton Children's is a member of the Children's Oncology Group (COG), which means a child treated here receives the exact same advanced

treatment protocols that they would get at any of the 200 member children's hospitals and cancer centers anywhere in the world.

"The alliance with Dayton Children's is an example of Nationwide Children's vision to share learnings and discoveries that will provide best outcomes for children everywhere," said Timothy Cripe, MD, PhD, division chief of hematology, oncology and bone marrow transplant at Nationwide Children's Hospital.

This initiative is part of the Ohio Pediatric Care Alliance. Formed in October 2013, the Alliance formalized the long-standing partnership between Dayton Children's and Nationwide Children's and allowed the two independent children's hospitals to share resources, avoid duplication and better utilize limited pediatric specialists.

"The alliance provides a structure for working collaboratively on

initiatives that further the shared mission of both hospitals—to provide high quality, cost-effective, accessible care to all children," says Debbie Feldman, president and CEO, Dayton Children's.

Three other initiatives currently operate under this umbrella: a joint outpatient specialty care center and a pediatric practice in Springfield, a collaborative on heart services quality initiatives, as well as a clinic in Lima, Ohio, with shared services in urology.

"One of the most important ways pediatric hospitals achieve best outcomes for children is by learning from each other," says Steve Allen, CEO, MD, Nationwide Children's Hospital. "Our relationship with Dayton Children's has proven for years that families are best served when we work together, and this expansion of the alliance will allow even more of Ohio's youngest residents to benefit."



Henry went to Nationwide to have his stem cells harvested in 2018. This collaborative will allow kids like Henry to stay closer to home at Dayton Children's for this procedure in the future.

Photo: Emily and Matt Springer with their 2-year-old son Henry.

collaboration with the ED to improve care for kids with cancer



Caring for children in hematology/oncology requires a strong partnership with other areas of the hospital, including the emergency department. In 2018, the two teams collaborated on an initiative to decrease ED treatment time for these high-risk hematology/oncology patients and have seen significant improvement in decreasing treatment time.

Hematology/oncology patients who present to the emergency department require rapid blood testing and administration of antibiotics. The ED set a goal to give antibiotics within one hour of admission to the ED, but were not meeting this goal, despite education and process improvement efforts.

Jeremy Larson, MD, and Elaine Markland, BSN, RN, CPEN, spearheaded a committee to identify key drivers that were causing delays and possible interventions to reduce the delays.

There were two key changes:

1

Patients with fever.

Hematology/oncology patients with a fever would be immediately roomed in a special care room where they are met by a team of providers to expedite their initial assessment and care.

2

Patients with a port.

A port accessing team was formed in response to a concern that the delay in central venous line (port) access was contributing to the delay in door-to-drug time. The port accessing team launched in January 2019, and includes clinical team leaders, trauma nurse leaders and hematology/oncology team members who received port access training and will complete this specific competency every year.

Since implementing these two changes, the team has seen consistent improvement in their goal of antibiotic administration within one hour or less. In less than two years, the success rate went from 48 percent to 82 percent.

new “meds to beds” program improves care and service



In an effort to improve patient experience, streamline processes and assure patient medication adherence, the hematology/oncology department at Dayton Children’s is the first to test

the hospital’s new “meds to beds” program.

Families who enroll in the program have their child’s medication delivered to the bedside prior to discharge from

their inpatient hospital stay.

“Newly diagnosed families may not understand that you can’t get many medications for cancer at a local pharmacy,” explains Della Zona, clinical pharmacist for hematology/oncology. “We ask all newly-diagnosed patients to get their first medication fills through us due to the complexity of their treatment. As a pharmacist who specializes in working with these medications, I meet with the entire family to discuss their child’s medications to ensure understanding and adherence.”

According to Della, the program also helps keep immune-suppressed children out of a retail pharmacy, where there are likely to be around other sick children, putting them at risk. Additionally, when a family is ready for

discharge, they can simply leave versus waiting to receive their child’s medication.

“It’s been a huge satisfier for families because some of these complex medications can take time to fill,” says Chad Meyers, director of pharmacy at Dayton Children’s. “They no longer have to wait in a line for their medication; they have it before they ever walk out the door.”

In the past year, 64 percent of hematology/oncology patients filled their prescriptions at the hospital. After the “meds to beds” program implementation, that increased to 82 percent. Over the next year, the goal is to expand the program to the remaining units at Dayton Children’s.

supporting mental health and well-being of kids with cancer

Hematology and oncology disorders and treatment can be incredibly taxing on a child and family’s emotional well-being. The comprehensive cancer care committee needs assessment in 2018 confirmed that dedicated psychology and mental health support would greatly benefit patient families. The team undertook a few initiatives that would provide much needed support.

1 Increase collaboration with psychology to increase their presence inpatient and outpatient. Previously, any new diagnosis was referred to psychology, but patients would need to set up a separate appointment for any ongoing mental health care needs. Now, psychology is ingrained in the unit, available for patients both inpatient and outpatient when they are already on-site

receiving care. Patients are now seen by a psychologist as frequently as once or twice a week if they are inpatient. This helps relieve the burden on these families and ensures that we are addressing patients’ emotional well-being regularly.

2 Increase support for teens with cancer. Another important finding from the community needs assessment was a need for teenagers to connect and support each other. Heather Cantrell, RN, BSN, CPHON, assistant nurse manager, and Rita Falkenbach, child life specialist, responded by creating a monthly support group called “Teen Scene.” The support group is for oncology and hematology patients and gives teens a chance to relieve stress and anxiety by connecting with

peers with a similar diagnosis.

Activities include yoga, art therapy, journaling and games where the teens work together as a team. Teen Scene takes place on the unit so that inpatient teens have an opportunity to participate.

3 Increase support for parents. Parents whose children are in the hematology/oncology unit also need support for their mental health and well-being. To meet this need, the hospital’s family partnership coordinators set up a parent-led support group. The group meets monthly and provides a healing space where parents can connect with other parents who are going through similar experiences. Adrienne Duplechian, a mom whose son is in remission from leukemia, now leads the group. Adrienne shares, “I

wanted this so badly when my own son was in treatment. It’s huge knowing that you’re not alone, and that there are other parents who can be there and listen when you’re having a tough day. It provides hope.”

4 Increase support for learning and development of patients. Treatment for oncology disorders can also have an effect on patients’ learning and schoolwork. To help address these concerns, hematology/oncology patients can now be referred to a neuropsychologist. A neuropsychologist will meet with the patient to do a baseline evaluation, then will do a follow-up appointment after treatment to assess any changes. The neuropsychologist works with the patient, parents and their school to help address any concerns.

providing the right resources for families, including personal touch



Two of the priorities identified from the comprehensive cancer care committee needs assessment identified access to resources for cancer patients and their families. Families need to know what resources are available to them at Dayton Children's and in the community, including access to finding child care, taking time off and finding support during treatment.

A big step in the right direction was hiring a dedicated nurse navigator in fall 2017, Nancy Bangert, RN. As a nurse navigator, she provides education to patients, families, schools and the community as needed.

When a child is first diagnosed, parents are overwhelmed with information. Nancy compiles information on their child's specific diagnosis from credible sources, such as the Association of Pediatric Hematology/Oncology Nurses and Children's Oncology Group to make sure they have resource materials

at their fingertips. She is their clinical guide through the maze of steps that is cancer treatment.

Nancy thoroughly explains the diagnostic tests that confirm type and stage of a child's cancer diagnosis while they are inpatient. Before they leave, she sets up a monthly calendar with the family – what days to take which medicines and when they will be back next. She prepares them for steps they will need to take at home, such as dealing with the side effects of the medication or performing mouth care.

"It is all very personalized based on each individual child and family," says Nancy. "The type of cancer, the age of the child, where the family lives – all sorts of things factor into their plan of care. No plan is the same as another, because no child is like another."

Nancy also makes school visits to talk to principals, counselors,

teachers and students. A child with cancer often needs special considerations. She may need to be allowed to wear a hat or carry a water bottle. He may be tired by the afternoon and can only attend half days. "The best part is when we talk to the classmates, teaching them how to be a good friend to a child with cancer. We talk about the right way to cough, why it's so important to wash your hands, why the child may lose their hair or be absent a lot. This kind of support can make a big difference."

"By being here as a personal resource, I can guide families to the right places for information."

- Nancy Bangert

When it's time for a child to get services outside of Dayton Children's, Nancy is there to guide them along that journey, too. She connects them to

the right radiation therapy or a specialized surgeon for their unique needs. She makes sure that all the information transfers between the two hospitals and the family feels comfortable and confident in the transfer.

In the age of endless information on the internet, the personal touch of a nurse navigator is even more important. "Technology can be good and bad. There is an online support group through Children's Oncology Group called Momcology. Parents can connect with other moms and dads who are going through the same thing. No one can understand what you are going through – unless they have gone through it, too. It's a great comfort to parents. On the flip side, there are so many "sources" out there that can provide too much or the wrong information. By being here as a personal resource, I can guide families to the right places for information. It's much more comforting."

rescue and recovery

a case study in going above and beyond to provide resources for medical and social needs

Having a child with cancer would be enough to deal with in a lifetime for most families. For the Belcher family, the Memorial Day tornadoes hit them with a double whammy – destroying their home and demolishing the medicine 14-year-old Kelsey needs to survive.

When the tornadoes twisted overhead that night, dad Gary, mom Shana, Kelsey and two of her brothers huddled in the laundry room of their Beaver Creek home. “I told them to cover their ears because it was so loud,” she remembers. “I also had them close their eyes because there was so much debris flying around.” Crouched around the washer and dryer, they held each other, cried and prayed out loud as the storm raged around them.

“It ripped off the roof and the side of the house,” says Gary. “Our patio door was embedded in the front door at the other end of the house. Shana’s van was destroyed. Almost nothing was salvageable.”

That included Kelsey’s medication. She takes up to 10 medications a day to manage type 1 diabetes and to treat leukemia, but the twister turned them inside out. “We couldn’t even find all the parts,” says Shana. “Child-proof caps flew off the bottles, the droppers for the liquids were ripped out, there was dirt and debris mixed in with the medicine – it was all unusable.”

Stress raises blood sugar levels so Shana knew Kelsey would need some insulin right away to help her recover after the storm, not to mention all her cancer-fighting drugs. “I called Dayton Children’s, told them what happened and said I didn’t know what to do. They said ‘don’t even worry – we’ll take care of you.’”



The social work department as well as Christin Dewitt and Dawn Ronnebaum, pharmacy technicians, didn’t waste a second. They contacted CareSource to get fast approval for emergency supplies of the medications Kelsey needed and delivered them to her.

This wasn’t the first time Dayton Children’s staff helped the Belchers. “When Kelsey was first diagnosed, Christy helped us afford the move into a more suitable home for Kelsey – the same home the tornado destroyed. We had just moved in February,” says Gary.

Christy Blankenship, LSW, medical social worker assigned to hematology/oncology, focuses more on social needs of patients – and their families – going through cancer treatment. Christy meets with the family at diagnosis and during treatment, she provides resources related to finances,

insurance issues, transportation help or child care. She works closely with the Family Resource Connection, which screens families for social needs and then connects them to any and all agencies in the area that can help them.

“Going through cancer treatment is a heavy, heavy load for any family,” says Christy. “It drains your bank account, it drains your energy, it drains your spirit. We do whatever we can to take away as much stress on a family as possible. We want them to know they have a lot of people in their corner and they are not doing this alone.”

“I am so thankful to Dayton Children’s and the amazing staff here,” says Shana. “They take care of us, all of us, not just Kelsey.”

After the storm, the sun always shines again. Just when things looked bleakest for the

Belchers, more members of their community rallied. After seeing their story on the news, an anonymous good Samaritan gave them a home to stay in. Shawna’s Pantry in Dayton donated new furniture, clothing and other necessities. The Blanket Ministry from St. Ferdinand’s Church in Cranberry Township, Pennsylvania, made her a new blanket after hearing the one she had for surgery was lost in the storm.

“It’s special because it came from somebody and they took the time to do it just for me,” said Kelsey.

The road forward is still long. Kelsey and her family get nervous when the clouds grow dark or when a strong wind picks up, wondering if it could happen again. They are not alone in that fear, but they are overcoming it together with the help of a supportive community around them.

