

CHAPTER

Factors

WINTER 2020

MHA Goes

VIRTUAL!



**Midwest
Hemophilia
Association**



HemDifferently

Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

What questions do you have? Get them answered. Explore gene therapy at **HemDifferently.com**.

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

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THE 5 STEPS OF INVESTIGATIONAL GENE TRANSFER

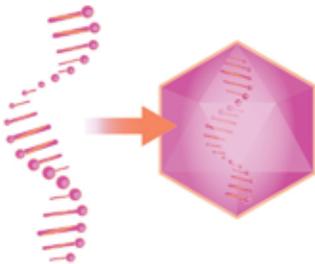
One method of gene therapy currently being explored in clinical trials is called gene transfer. This approach aims to introduce a working gene into the body to determine if it can produce a needed protein.



STEP 1

CREATING A WORKING GENE

A working copy of a mutated gene is created in a laboratory.



STEP 2

BUILDING A THERAPEUTIC VECTOR

A therapeutic vector is used to protect the working gene and serves as a transport vehicle for the gene to enter the body. The therapeutic vector is created from a neutralized virus, meaning no viral genes remain inside.



STEP 3

DELIVERING THE WORKING GENE

A single, one-time infusion delivers large numbers of therapeutic vectors into the body.

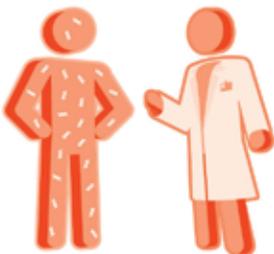


STEP 4

MAKING PROTEINS

Once in the body, the new working gene is designed to provide instructions for the body to make the protein it needs on its own.

 =Proteins.



STEP 5

MONITORING AND MANAGING HEALTH

Clinical trial participants are regularly monitored to better understand the safety of the gene transfer and to evaluate its effect on the body.

To me, it's personal.

As a Community Relations and Education Manager for Sanofi Genzyme, I'm here to help provide support and resources for you and the Missouri hemophilia community.

Vicki Oberkrom
CoRe Manager for Missouri

Let's connect.

Call, text, video chat: 660-281-9518

Email: vicki.oberkrom@sanofi.com

Facebook: [@HemophiliaCoRes](https://www.facebook.com/HemophiliaCoRes)



SANOFI GENZYME 

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Brand names of treatment products are provided for information only. They are not an endorsement of a particular product or company by MHA. Acceptance of advertising for products and services in Chapter Factors in no way constitutes endorsement by the Midwest Hemophilia Association.

FROM THE EXECUTIVE DIRECTOR



I recently read a Facebook post that said, “I’m going to stay up on New Year’s Eve this year. Not to see the New Year in, but to make sure this one leaves.” I chuckled, but then seriously considered the reality--I am ready to say good-bye to 2020.

But before I kick 2020 to the curb, there are a few things about the past year I am grateful for that most likely would not have happened otherwise: the opportunity to spend time with my children (they grow up so fast), finishing a project I never could find the time for (my honey-do list has only grown), learning new technology skills (I still have much to learn), and getting to interact with the MHA family virtually. Obviously, it is not the preferred way to provide education or do fundraising, but spending time together, even online, has been uplifting. I hope those who have had the chance to attend also find it encouraging.

No doubt some of the unpleasantness of 2020 will run into 2021 and bring its own difficulties. But let me invite you to join me in choosing to make the best of it together! Take a moment to be grateful for what you have...maybe it is a beautiful sunrise, a fresh breath of air, a playful pet, or a loved one. Then, take the opportunity to share what you have...a good deed, a genuine smile, a joke, a gift, or a talent. Indeed, if you find yourself in need, be brave enough to seek support from those you trust or admire.

Finally, consider the fact that we can choose how to respond to life’s challenges. I encourage everyone to decide to do the right thing no matter what may come and make the world a better place by touching others with kindness, understanding, forgiveness and love.

Sincerely,
Angela Brown
angela.brown@midwesthemophilia.org



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AIDS Memorial Quilt Displayed Virtually

The National AIDS Memorial (stewards of the AIDS Memorial Quilt and the National AIDS Memorial Grove) launched a virtual exhibition of the AIDS Memorial Quilt featuring more than 10,000 panels representing all 50 states and U.S. territories on World Aids Day, December 1, 2020. Thanks to a long partnership between NHF and the National AIDS Memorial, the Midwest Hemophilia Association and other bleeding disorder chapters around the country, were offered the opportunity to participate in this event.

During the 1980's, approximately half of the people with hemophilia in the US became infected with HIV/AIDS and/or Hepatitis C through contaminated blood products used to treat their bleeding episodes. In those with severe hemophilia, the infection rate was over 90%. Thousands of lives were lost—including loved ones from our own MHA family. MHA is participating with the Aids Memorial Quilt Virtual Exhibition to honor those lost to AIDS and remember

our family members who are gone, but not forgotten.

The exhibition is free to the public. Displays are categorized by state under the organization host name. The exhibition will run through March 31, 2021. To view the virtual quilt, please visit www.aidsmemorial.org/2020virtual.

7 Safety & Privacy Tips for Social Media

1. Manage your privacy settings.

Learn about and use the privacy and security settings on your social networking sites. They help you control who sees not only what you post but your personal information from your profile. For example, on Facebook, you can manage if Friends, certain Friends, or the public can see not only your posts but your photos, your likes, your birthday, etc.

2. Once posted, always posted.

Don't post anything you wouldn't



want your grandmother to see because even if you delete that post, social media platforms keep it, and someone might have taken a screenshot of that post. You can't control it or how it's used by others once it's "out there".

3. Keep personal info personal.

Be careful how much personal info you provide on social networking sites, not only on your page but in groups as well.

4. Know the groups you're in.

Groups are a great place to talk with other like-minded people and create a community. But some groups are closed groups, private, or public—meaning there are degrees in how people can join the groups. If it is a large group, be careful of sharing too much personal information as you don't know who all is in the group.

5. Know what action to take.

If someone is harassing or threatening you, remove them from your friends' list, block them, and report them to the site administrator.

6. Be cautious on social networking sites.

Just like getting a suspicious email from someone with a link or attachment, this can happen on social media, even if it is from a friend. If you get something like this, contact the friend and the site.

7. Know and manage your friends/ followers.

Know who your friends are on social sites, especially if you are sharing





personal information. If you're trying to create a public persona as a blogger or expert, create an open profile or a "fan" page that encourages broad participation and limits your personal information.

KC HTC Welcomes New Staff Member

Please welcome Mindy Eldridge, Nurse Practitioner, to Children's Mercy Kansas City Regional Hemophilia Treatment Center.



Variety of Assistance Resources Available to MHA Members

MHA Financial Assistance Program

In April of 2020, MHA's Board of Directors approved the Financial Assistance Program. The guidelines and application can be found on our website. To date, we have given out over \$3,450 in financial assistance to our community members. We have also helped secure over \$2,000 in assistance from other sources through referrals. We are extremely grateful to the individual donors, grants, and other fundraisers for supporting this cause. All funds raised during our Giving Tuesday campaign this year will help us continue to build

this fund. Additional contributions can be made at midwesthemophilia.org by clicking the donate button or by mailing a check to 1471. W. South St., Suite F, Ozark, MO 65721.

If you or someone you know who is affected by a bleeding disorder experience a financial hardship, please feel free to utilize this resource. You may contact Angela Brown at the office for additional information and/or referrals.

Kansas Consumer Assistance

If you or someone you know has an issue with their insurance, Kansas Consumer Assistance Division (KCAD) is happy to help! Please use the contact information below to reach out if you need help.

- **Main Line:** (785) 296-3071
- **KCAD Hotline:** 1-800-432-2484
- **Email:** KID.Commissioner@ks.gov
- **Website:** Insurance.kansas.gov
- **Consumer Complaint:** kid.webcomplaints@ks.gov
- **Producer Licensing:** kid.licensing@ks.gov

Missouri Consumer Assistance

Don't understand your insurance policy? Do you think you have been treated unfairly by your insurance company, agent, broker or agency? The Missouri Consumer Assistance Department welcomes any questions or complaints you may have. You can also email us or call the Insurance Consumer Hotline at 800-726-7390.

Project CALLS

If you have been experiencing issues with your insurance company, HFA wants to hear your story!

Project CALLS is an opportunity for you to share your story and help the entire bleeding disorders community. HFA collects stories from across the country, collates the data, identifies trends, and uses the information to help policymakers and providers better understand and meet the needs of our community. Visit the Project Calls website at: www.hemophiliafed.org/for-patient-families/navigate-insurance/project-calls/

2021 CALENDAR

To stay up-to-date on MHA events, please watch for email invites, check our chapter website, and follow us on social media. (Facebook, Twitter & Instagram)

March 3-5

NHF's Washington Days (Virtual)

July 26-30, 2021

Camp Wilderness

Lake Doniphan Conference & Event Center
Excelsior Springs, MO

August 26-29

NHF Bleeding Disorders Conference
Denver, CO

September 24

23rd Annual MHA Golf Tournament

September 25-26

29th Annual Family Education Weekend
@ Marriott KC, Overland Park, KS

October 8-10

Females And Bleeding (FAB) Conference
@ Margaritaville Lake Resort
Osage Beach, MO 65065

October 16

UNITE for Bleeding Disorders Walk

October 21-24:

HFA Symposium
San Antonio, TX

2021 EVENTS DATES TO BE DETERMINED:

- Trivia Night
- Dodge City Education Day
- Springfield Education Day
- Wichita Education Day



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Takeda

Not an actual patient.

Let's get together to talk about IXINITY[®]

Many families affected by a rare disease have compelling and uplifting stories of support to tell. I am honored to be part of the bleeding disorders community and to hear these stories firsthand.

—Craig Watkins, your resource for all things IXINITY



▶ Contact Craig at 816-550-7214 or craig.watkins@medexus.com



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Optimizing On-Demand Treatment of Hemophilia B

Featured Speaker:
Amanda Zuse, APRN

Tuesday, September 15, 2020
8:00 PM – 9:00 PM ET

Tuesday, January 19, 2021
8:00 PM – 9:00 PM ET

Common Connections 2-Part Webinar
Part 1: Learn About IDELVION for the Treatment of Hemophilia B
Part 2: Explore the Mind-Body Connection to Pain Management

Featured Speakers:
Dezarae Tate, RN
Diane Dimon, DrRS

Tuesday, October 20, 2020
8:00 PM – 9:00 PM ET

Tuesday, February 16, 2021
8:00 PM – 9:00 PM ET

Common Connections 2-Part Webinar
Part 1: Learn About IDELVION for the Treatment of Hemophilia B
Part 2: Explore Music Therapy

Featured Speakers:
Dezarae Tate, RN
Tim Ringgold, MT-BC

Thursday, November 19, 2020
8:00 PM – 9:00 PM ET

Thursday, March 18, 2021
8:00 PM – 9:00 PM ET

REGISTER NOW



REGISTER ONLINE or **BY PHONE**

Online: www.CommonConnectionsCSL.com

Phone: 1-866-992-9940

Important Safety Information

IDELVION®, Coagulation Factor IX (Recombinant), Albumin Fusion Protein (rFIX-FP), is used to control and prevent bleeding episodes in people with hemophilia B. Your doctor might also give you IDELVION before surgical procedures. Used regularly as prophylaxis, IDELVION can reduce number of bleeding episodes.

IDELVION is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Do not inject IDELVION without training and approval from your healthcare provider or hemophilia treatment center.

Tell your healthcare provider of any medical condition you might have, including allergies and pregnancy, as well as all medications you are taking. Do not use IDELVION if you know you are allergic to any of its ingredients, including hamster proteins. Tell your doctor if you previously had an allergic reaction to any FIX product.

Stop treatment and immediately contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against Factor IX, which could stop IDELVION from working properly. You might need to be tested for inhibitors from time to time. IDELVION might also increase the risk of abnormal blood clots in your body, especially if you have risk factors. Call your healthcare provider if you have chest pain, difficulty breathing, or leg tenderness or swelling.

In clinical trials for IDELVION, headache was the only side effect occurring in more than 1% of patients (1.8%), but is not the only side effect possible. Tell your healthcare provider about any side effect that bothers you or does not go away, or if bleeding is not controlled with IDELVION.

Please see accompanying full prescribing information for IDELVION, including the patient product information.

You are also encouraged to report negative side effects of prescription drugs to the FDA. Visit <http://www.fda.gov/medwatch>, or call 1-800-FDA-1088.

You can also report side effects to CSL Behring's Pharmacovigilance Department at 1-866-915-6958.

IDELVION is manufactured by CSL Behring GmbH and distributed by CSL Behring LLC.

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MHA Goes VIRTUAL

Despite the health crisis that began early this year and continues on, the Midwest Hemophilia Association has been able to pivot successfully to continue its mission: to improve the quality of life of those affected by bleeding disorders through advocacy, education, and support--greatly due to the availability of virtual reality.

All of our events and programs with the exception of the annual golf tournament have been moved to the virtual space. MHA has invested funds into the Zoom platform where meetings and webinars can be held online with our community members. While it is not our favorite or preferred way of meeting, we are choosing to make the best of it and acknowledge the positives: going virtual has given those in outlying areas the chance to attend many more programs, we are not limited by location as to who can attend, we have access to a wider variety of speakers from across the country who can more readily present, the cost savings to put on programs has been helpful with the budget, and seeing your handsome and lovely faces on the screen is better than not seeing them at all!!!

Our first virtual event was Garden City Education Night. Nearly 20 households logged on to learn and play several rounds of the "Bleeding Disorders Quiz Bowl." Much was learned about VWD and hemophilia! Prizes were awarded to the top 3 individual scorers. Raffle prizes were also part of the fun in between rounds. All registrants received a post-event package with sponsor materials and a few 'swag' items.

Camp Wilderness was also affected by the pandemic. In June, the extremely difficult decision was made not to hold camp in person, however, the camp committee went to work to create different opportunities for campers to keep the camp spirit alive! To kick off the virtual celebration, campers signed up to receive a special Camp Wilderness Care package, followed by the opportunity to connect online during Family Education Weekend for the first ever Camp Wilderness Virtual Bonfire led by camp director, Luke Saulsberry. Campers and their immediate family members then signed up in the fall to receive a one-of-a-kind camp tie-dye t-shirt just in time for Christmas. Not to be forgotten, our camp volunteers and staff met virtually for a Camp Wilderness Holiday Razzle-Dazzle Volunteer & Counselor Appreciation Happy Hour to stay connected and create excitement for next year's camp. (Camp Wilderness 2021 is scheduled for July 26-30!!!)

Family Education Weekend was also held virtually with over 45 community members and sponsors in attendance. Kid Distraction Kits were mailed out prior to the event so parents could enjoy the sessions with minimal interruptions. Six education breakout sessions on a variety of bleeding disorder topics were offered during the day-long event. An update about

the Kansas City Hemophilia Treatment Center and future treatments was presented by Dr. Lauren Amos. Also included were two Camp Wilderness Virtual Bonfires, one for the teens and one for the youth, as well as our annual awards and recognition ceremony. Fifteen hundred dollars in gift cards, prizes, and raffles were given out in a special event box to registered attendees!

During the virtual Springfield Education Night attendees participated in an education session, "Put a Stop to Bullying". This discussion-based presentation took a look at bullying as a complex social situation that requires education and prevention. We learned about specific actions to combat bullying and its effects. Parents, youth, and children benefited from solutions and focused on developing a strong self-identity to overcome obstacles. Attendees also had the chance to visit with one another and with sponsor representatives through the virtual exhibit breakout rooms. Raffle prizes and food gift cards were also part of the event.

The virtual Wichita Education Day included 24 registered households and 13 sponsors. Ellen Kachalsky, MSW, presented on, "Cannabis, Chronic Pain, & Caveats for Bleeding Disorder Patients" and was followed by a question and answer session. Sponsors also presented information about their company's services and visited with attendees in the exhibit booth breakout rooms. Attendees received \$25 food gift cards in their event boxes along with information from sponsors.

Virtual UNITE Walk

On behalf of MHA's Board and myself, I want to sincerely thank everyone who participated, donated, and volunteered on the planning committee for your tireless efforts to support this year's UNITE Walk. While this year brought unprecedented change and challenges, our community has continued to be

a source of hope and constant support. We truly stood UNITED through our sense of community, common connection, and

resilience to overcome adversity!

Team Captains who registered by October 1st and raised money with their team, received their own at-home Walk Kit prior to the

We are extremely grateful to this year's team captains, team members, industry sponsors, and donors!

— Angela Brown, MHA Executive Director

event on October 10th! The box was designed to encapsulate the excitement of the Walk from their homes and included items such

L!

What is a C.O.P.?

You may have received several email invitations to attend one of MHA's C.O.P.s in the past several months. So, what exactly is a C.O.P? C.O.P stands for Community Outreach Program and they are educational programs designed to reach outlying MHA members who would typically be required to drive a long distance to attend most of our events. They are usually sponsored by an industry partner—manufacturer or specialty pharmacy—who provide either a branded (product specific) or non-branded (topical education) education piece. We've offered a variety of topics in 2020: physical therapy, insurance navigation, food and fitness, gene therapy science, emotional wellness, and more. Some also include a fun activity with their presentation such as trivia, painting, and cooking class.

If we were meeting in-person, these would typically take place in Wichita, KS, Springfield, MO, and some surrounding areas of Kansas City (both Missouri & Kansas sides). However, because our industry partners are following health guidelines and have travel restrictions, these too have been held virtually. This has opened the opportunity not just for locals to attend but also anyone in our entire coverage area of Kansas and western Missouri—including some from surrounding states like Arkansas, Iowa and Nebraska



Why do we offer vCOPs? MHA is paid a fee for these programs by sponsors which help us financially continue providing education and resources for future events. By attending you help support your fellow bleeders and future bleeders and their families! It also provides an opportunity for attendees to connect with each other for support through these difficult and somewhat isolating times.

Because we hope to eventually transition from virtual to in-person when the time is appropriate and it is beneficial to know which type of event it will be, we will most likely add a "v" for virtual to the COP—vCOP—virtual Community Outreach Program—and use the COP for in-person events in the invitations.

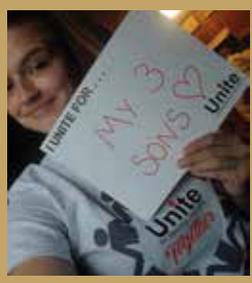


TOP: Volunteers pack boxes to be sent to Family Education Weekend virtual attendees.
BOTTOM: Camp Pictures from past years with the Big Stick awards bundle.

a Huge Success

as the official UNITE t-shirts, pinwheels, signs, balloons, sidewalk chalk, bubbles, tattoos and more! Team Captains were encouraged to utilize the items in their box to celebrate with their family, team members, and/or friends (following their local health safety guidelines) by walking in their neighborhoods, parks, or even their backyards.

Together, six national sponsors, seven local sponsors, fifteen Team Captains, forty-five participants, and 100 donors participated and raised over \$15,000 for this year's Unite for Bleeding Disorders Walk!



TOP 3 FUNDRAISING COMMUNITY TEAMS:

- 1st Place:** Brown Bruiser's
- 2nd Place:** Bleeding Black & Gold,
- 3rd Place:** Conner & Nikolaus's Minions

TOP 3 FUNDRAISING INDUSTRY TEAMS:

- 1st Place:** Team Genentech
- 2nd Place:** Team Sanofi Genzyme
- 3rd Place:** Team Brother's Healthcare

FACTOR CLUB INDUCTEES:

- Angela Brown
- Bobbi Sellers
- Mareena Snarey
- Kristin Marema
- Nora Ancel

REMINDER:

Scholarship Applications Open January 1

If you are sending a child to college or attending college yourself, please make note that applications for the Midwest Hemophilia Association scholarships open on January 1, 2021. In 2020-2021, a total of \$26,000 in scholarship funds were awarded.

MHA offers two separate \$1,000 scholarships for post-secondary education to students with a bleeding disorder living in the organization's service area. The Midwest Hemophilia Association Scholarship has been offered for the past 25+ years. The Mark Dudley Scholarship was established in 2016 in honor of our past treasurer. These scholarships may be used for college or trade school during the 2021-22 school year. Funds may be used at the discretion of the recipient (i.e. books, tuition, room and board, etc.). These two scholarships together have awarded over \$30,000 in educational funding.

MHA also offers the Georgia Northway Scholarship, managed by the Truman Heartland Foundation. This scholarship is available to high school seniors and college students diagnosed with a bleeding disorder who are pursuing an undergraduate degree. Each year, approximately 5% of the principal balance is available for scholarships, resulting in awards of \$293,188.44 in 113 scholarships to over 43 students. The great part of the Georgia Northway Scholarship is that it is renewable. Recipients can re-apply each year, potentially receiving funding beyond freshman year.

To qualify for these scholarships, applicants or their family (if under 21) must be members in good standing with MHA. Applications are available online at www.midwesthemophilia.org. Visit the Scholarship section located under the Resources tab drop-down menu.

GEORGIA NORTHWAY SCHOLARSHIP

DEADLINE: MAY 1, 2021

MIDWEST HEMOPHILIA ASSOCIATION SCHOLARSHIP

DEADLINE: JUNE 1, 2021

MARK DUDLEY SCHOLARSHIP

DEADLINE: JUNE 1, 2021

Additional scholarship opportunities are available for persons with bleeding disorders. A partial listing is also available on the website.



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Amos



Carpenter



Jennings



Moormeier



Shrestha



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arjinfusion.com/LevelUpMHA

ARJ Infusion SERVICES

Brittany Slossberg

Relationship builder

About Brittany

Brittany is a Hemophilia Community Liaison who has a passion for creating long-lasting relationships with others. She has built a strong comradery with many patients in the Colorado community.

Hobbies

- Athletics
- Traveling abroad

"Being able to hear people's stories of overcoming struggle is really what made me interested in working with the hemophilia community."

Connect with Brittany

BTSO@novonordisk.com
(561) 289-3275

Hemophilia Community Liaison

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MHA GOLF TOURNAMENT

Recap



To say holding any event live in 2020 was a challenge is perhaps the understatement of the century. However, with the assistance of many and the cooperation of all, MHA held the 22nd Annual Golf Tournament in person at Winterstone Golf Club in Independence, Missouri. On September 18, 2020, 24 teams braved the day (75 degrees and sunny as promised by the golf committee!) to make the day a huge success. While things were a little different this year, everyone seemed to have an enjoyable time and more importantly, we raised right at \$12,500 for the chapter.

The day started with the teams checking in and enjoying a grab and go breakfast. The weather was absolutely perfect for a round of golf as well as our various special events on the course (Putting Contest, Long Drive, Floating Green, Hole in One etc.). As we were not going to be able to meet as a large group after the event, the normal crazy lunch raffle ticket sale was moved up to selling before the golfers all took off in the shotgun start. This allowed our volunteers to draw and post the winning tickets after the round maintaining the required social distancing as golfers could check their ticket numbers on their own. This worked so well it may become the new norm.

There is an old saying that the worst day on the golf course is better than the best day at work. A nice ride in a golf cart (sponsored by Soleo Health) and a complimentary beverage cart (sponsored by Superior Biologics) made the day even better.

As the golfers finished their round, lunch was served (again using a grab and go format) and everyone awaited the results of the event. We were outdoors and able to observe county health rules

related to social distancing. The event was “flighted” and the winner of the “A” flight with a score of 56 was Team Moss. Second place went to BioEthics and third place went to Superior Biologics #4. The “B” flight winner was ARJ #4. Team Newman took second place and Superior Biologics #1 finished in third place. Lee Ridenhour was our Long Drive Champion, Louis Tuten won the Closest to the Pin, David Hayes won the Floating Green Contest, and Bill Scheid won the putting contest. Unfortunately, no one won the car at the Hole in One hole.

MHA would like to thank all of our sponsors for their generous support in this trying year. We know it has been hard on all companies and your participation in this event is what makes it so special. We also want to thank the Golf Committee and our great group of volunteers. Without them this would not be possible.

Please mark September 24, 2021 on your calendar for the 23rd Annual MHA Golf Tournament to be held again at Winterstone Golf Club. We look forward to our 2020 golfers, those that could not make it this crazy year, and more of you participating next year! Come on out and enjoy the fun while helping MHA!



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THE FIRST NATIONAL PATIENT SATISFACTION

The federally funded hemophilia treatment center (HTC) network, with its model of a multidisciplinary care team (MDT) and regional infrastructure, has proven itself, over several decades, to be well suited to deliver quality, integrated healthcare to bleeding disorders patients across the U.S. While this system has allowed for various surveillance and data collection projects focused on patient demographics, clinical status, and mortality, it has not, until recently, been leveraged to gauge patient satisfaction on a national level.

The authors of a new paper published in the journal *Haemophilia* posit that patient satisfaction with the delivery of care is an important metric that is associated with treatment adherence and better overall health outcomes. Therefore, a first-of-its kind nationally uniform and comprehensive patient satisfaction survey (PSS) was conducted and made possible via the coordination of the HTC network's robust regional infrastructure. A steering committee made up of three of the network's regional coordinators initiated and managed the PSS. They were guided by performance standards of the hemophilia program of the U.S. Health Resources and Services Administration (HRSA); the agency provides limited funding to support the eight designated regions that make up the HTC network.

The survey was designed to assess patient demographics, their satisfaction with the HTC's core MDT, plus affiliated clinicians, services, and care processes. The MDT core includes the hematologist, nurse, nurse practitioner, social worker, and the physical therapist. In addition, three fundamental HTC services were

rated, including shared decision making and care coordination with both the primary doctor and with other specialists/providers. Lastly, five key HTC processes were evaluated for patient satisfaction: timeliness of care, ease of getting needed information, ease of understanding how the HTC clinic staff explained things, time spent with clinic staff, and being treated with respect.

All 138 HTCs that were operating in 2014 were invited to participate in the PSS. The eight regional coordinators of the Network helped facilitate the promotion and dissemination of the survey to HTCs and provided technical

(96.4%) opted into the survey. In sum, 5006 individuals who received care from a center in 2014 completed the PSS, representing a 17.7% national response rate. At 29.2%, females represented almost a third of the participants, the majority of which were White, non-Hispanic. A look at participants grouped by age shows a fairly even breakdown amongst the groups, while there were significant differences in participation levels amongst the four geographic regions with 42.1% (2109) from the Midwest, 27.9% (1398) from the Northeast, 19.0% (952) from the West and 10.9% (547) from the Southeast.

Overall, 94.2%-97.9% reporting responded that [respondents] were 'always' or 'usually' (A/U) satisfied with the overall care they received at their center.

assistance to ensure a nationally consistent administration. In February-March 2014 the survey was disseminated to an estimated 28,289 households of patients with which the HTC had a "significant clinical interaction" that same year. The subsequent data collection period through June of 2015, with the University of Colorado serving as coordinating institution for all data collection and aggregation. To make possible comparisons to other populations, regions were collapsed from eight to four standard regions including West, Midwest, South, and Northeast.

The overall participation rate for HTCs was high as 133 or 138 centers

The majority of the respondents, 3,106 (62%) had hemophilia, 1299 (25.9%) had von Willebrand disease (VWD), and 601 (12.0%) reported diagnosis as "other," "unknown" or did not specify. Overall, those with a severe hemophilia and type 3 severe von Willebrand disease represented 29.4%, of respondents, while those with a moderate bleeding disorder, including VWD type 2 or moderate hemophilia accounted for 17.8% of participants. Those with a mild bleeding disorder (VWD type 1 or mild hemophilia) comprised the largest group at 32.8%.

By virtually all measures, results of the PSS suggest consistently high levels

SURVEY

OF U.S. HTCS

of satisfaction with HTCs amongst the more than 5,000 respondents. Overall, 94.2%-97.9% reporting responded that they were 'always' or 'usually' (A/U) satisfied with the overall care they received at their center. Participants also rated highly their satisfaction with members of their HTC's core MDT, including the hematologist, nurses, nurse practitioners, social workers, and physical therapists (PTs). A national breakdown by member showed that 97.3% of respondents were A/U satisfied with the hematologist, 97.0% with the HTC nurse and nurse practitioner (combined), 95.1% with the social worker and 95.6% with the PT.

HTC care processes considered integral to PSS also scored very well nationally, with more than 95% of respondent's A/U satisfied with each of the five processes. These included timeliness of care (94.9%); ease of getting needed information (95.0%); ease of understanding how the HTC clinic staff explained things (97.3%); time spent with clinic staff (97.0%); and being treated with respect (98.0%). On a regional level, A/U satisfaction for each of the five care processes was at least 91.2%.

The survey also reflected well on transition issues nationally. Of respondents aged 12-17 years, 90.2% reported being A/U satisfied with how their HTC talked about how to care for their bleeding disorder as they became adults. Similarly, 92.8% of adolescents were A/U satisfied with how their HTC encouraged them to become more independent in managing their bleeding disorder.

The authors point to this initiative's

success as a "proof of concept" in the far-reaching utility of a regional infrastructure to deliver meaning and impactful national assessments now and in the future.

"This HTC PSS initiative provides new national data, reducing evidence gaps in quantifying the extent to which patients value the different healthcare professionals on the integrated HTC team, HTC services, processes and overall care. These high levels of patient satisfaction were articulated regardless of patient diagnoses, severity of disease, gender, race or ethnicity, or geographic location, and pose several implications," explained the authors. "First, these data indicate that patients highly value the HTC multidisciplinary team approach."

While the authors do acknowledge limitations, including an imbalance in regional representation, the take home message remains the same; there exists a strong correlation between patient satisfaction and quality of care. Further, such PSS data may be employed in various advocacy efforts, to engage payers, and ensure the viability of the HTC Network.

"The high level of patient satisfaction documented in this inaugural national survey of the US HTC Network's ambulatory services has several important policy implications. Specifically, in the United States, access to HTC care must be guaranteed," conclude the authors. "All payers must include HTCs in their networks to maintain high-quality patient care."

– Riske B, Shearer R, Baker J. *Patient Satisfaction with US Hemophilia Treatment Center Care, Teams and Services: The First National Survey. Haemophilia. 23 October 2020.*

A BIG Thank You TO OUR SPONSORS & VOLUNTEERS

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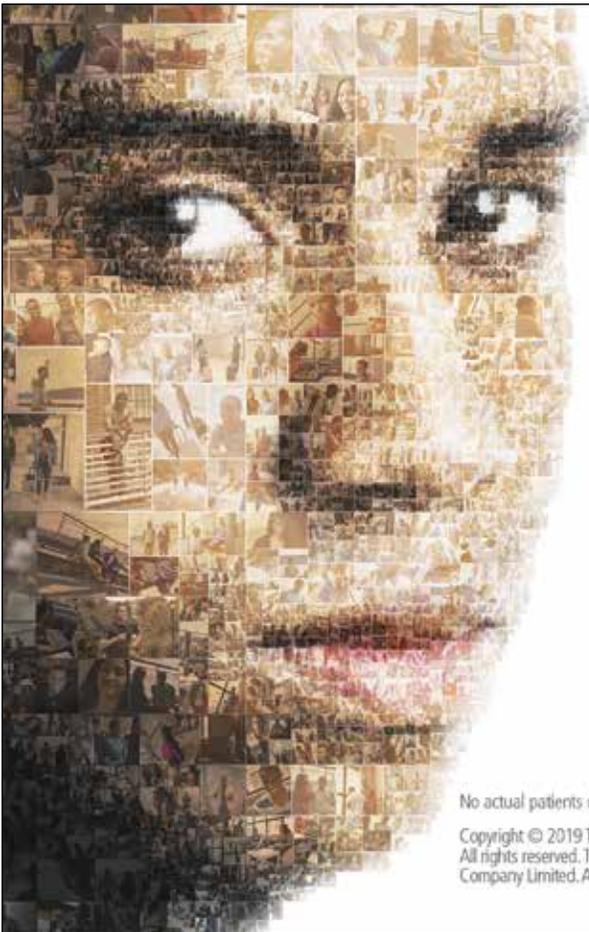
For offering to create an amazing quilt made from camp tie-dye t-shirts to use as a fundraising item for Camp Wilderness



Raymond Burnett

For volunteering his time, knowledge, and skills in helping make our virtual Family EducationWeekend possible!

And THANK YOU to 2020 Volunteers: Elizabeth Tandy - Nora Ancel - Kimberly Rosenfelt - Vicki Oberkrom




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