CHAPTER *Factors*

SUMMER 2020

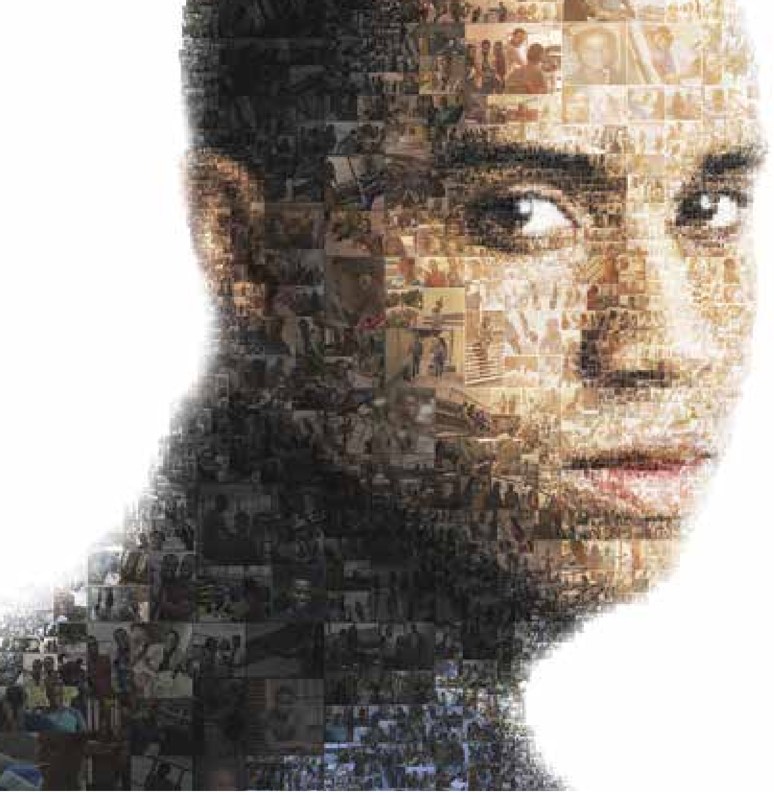
22nd Annual

MHA GOLF TOURNAMENT

September 18, 2020

@ WinterStone Golf Course

Midwest Hemophilia Association



No actual patients depicted.

ADYNOVATE
[Antihemophilic Factor
(Recombinant), PEGylated]

REAL LIFE. REAL BLEED PROTECTION.*

AdynovateRealLife.com

HEMOPHILIA A IS A PIECE OF YOU.

NOT ALL OF YOU.

ADYNOVATE® is a treatment that can be personalized to fit your lifestyle so you have more time to spend doing the other things that also make you, you. It has a simple, twice-weekly dosing schedule on the same 2 days every week.[1,2]

*In clinical trials, ADYNOVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.

ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds[2]

ADYNOVATE was proven in 2 pivotal clinical trials to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)[2]

- **Children Under 12 Years**: This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment[2]
  - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median[†] overall ABR[‡] of 2.0
  - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis
- **Adolescents and Adults 12 Years and Older**: This study evaluated the efficacy of ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic regimen with on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes in 137 patients. These adolescents and adults were given either ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal was to compare ABR between the prophylaxis and on-demand treatment groups[2]
  - 95% reduction in median overall ABR (41.5 median ABR with on-demand [17 patients] vs 1.9 median ABR with prophylaxis [120 patients])
  - 0 bleeds in 40% (40 out of 101 per-protocol[§] patients) during 6 months on twice-weekly prophylaxis

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[†] Median is defined as the middle number in a list of numbers arranged in numerical order.
[‡] ABR=annualized bleed rate, the number of bleeds that occur over a year.
[§] Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

ADYNOVATE Important Information

What is ADYNOVATE?

- ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNOVATE when you have surgery.
- ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

- Are allergic to mouse or hamster protein.
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)].

Tell your HCP if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

What should I tell my HCP before using ADYNOVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What important information do I need to know about ADYNOVATE?

- You can have an allergic reaction to ADYNOVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADYNOVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADYNOVATE?

- The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do not go away.

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

Please see Important Facts about ADYNOVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.adynovate.com.

References: 1. Valentino LA. Considerations in individualizing prophylaxis in patients with haemophilia A. *Haemophilia*. 2014;20(5):607-615. **2**. ADYNOVATE Prescribing Information.

S49399 08/19

ADYNOVATE
[Antihemophilic Factor
(Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

What is the most important information I need to know about ADYNOVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

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How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

How should I use ADYNOVATE? (cont'd)

Call your healthcare provider right away if your bleeding does not stop after taking ADYNOVATE.

What should I tell my healthcare provider before I use ADYNOVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE and Hemophilia A?

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADYNOVATE for a condition for which it is not prescribed. Do not share ADYNOVATE with other people, even if they have the same symptoms that you have.

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.ADYNOVATE.com or 1-877-825-3327.

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

Patented: see https://www.shire.com/legal-notice/product-patents

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Issued 05/2018

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NEW DATE!

Unite
for Bleeding Disorders

Saturday, October 10, 2020
@ Heritage Park – 16050 S Pflumm Road, Olathe, Kansas

REGISTRATION IS OPEN!

Visit ***www.uniteforbleedingdisorders.org*** and click “Find a Walk”. Search for walks in Kansas. Once on the local page, click Register Now to form your team!

Unite
for Bleeding Disorders

2020 Unite Walk
(Olathe, KS)
June 13, 2020

0%

My Progress
Raised
$0.00
Goal
$100.00

DOWNLOAD OUR MOBILE APP

Simply search by Unite For Bleeding Disorders

*(you must first register for our walk at **UniteForBleedingDisorders.org** and then you can activate your mobile app.*

GET IT ON Google Play

Download on the App Store

Summer 2020 • Volume 30 Number 2

Chapter Factors is published by:
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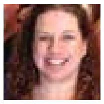

ANGELA BROWN
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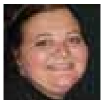
BOARD OF DIRECTORS

2020 OFFICERS



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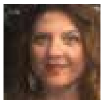

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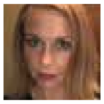

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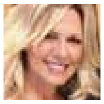

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FROM THE EXECUTIVE DIRECTOR

Dear MHA Community,

I certainly have missed getting together with everyone and look forward to when we can meet again in person! The Board of Directors and I continue to carefully monitor the changing situation related to COVID-19, keeping the community's health and safety in the forefront of our minds.

The difficult news is we have had to postpone and cancel events. Knowing how to proceed with our in-person programs is a challenge due to all of the unknowns and the wide variety of different restrictions in our coverage area. Several factors affect our decisions including, but not limited to, health safety, size of group gatherings allowed, travel restrictions for HTC staff and industry partners, availability of venues, dates, educational speakers, and cost.

The ***GOOD*** news is Midwest Hemophilia Association is still able to work on your behalf. We are doing what we can to support individuals and families by making personal check-in calls, continuing advocacy efforts by monitoring Kansas and Missouri legislation, and providing a much-needed resource to the community by writing and approving a new MHA Financial Assistance Program. The active focus is now seeking monetary contributions, donations, and grants to support the program so funds can begin to be dispensed for those who qualify.

For quicker and more frequent updates, please call the MHA office at 816-479-5900 to update or submit your email address.

In short, we are here for you and will continue to be here for you! Stay healthy. And I hope to see all of you soon!

Sincerely,
Angela Brown
angela.brown@midwesthemophilia.org

P.S. If you have questions or concerns related to your personal health and/or COVID-19, please contact the Kansas City Hemophilia Treatment Center, 816-302-6869, or your primary care doctor.

QUICK NOTES

Camp Wilderness Cancelled for 2020

It is with great sadness that we announce, Camp Wilderness at Lake Doniphan Conference and Retreat Center on July 26-31, 2020 has been cancelled.

After many hours of deliberation, it has become increasingly more difficult to continue with Camp Wilderness in its current format. Unfortunately, there are too many logistical and practical challenges to ensure everyone is safe and healthy while having the best week ever. We are hopeful that we can incorporate aspects of Camp Wilderness into Family Education Weekend in September!

Thank you for your patience and support for Camp Wilderness during this unusual time. We look forward to seeing you next year at Camp Wilderness!

– Luke Saulsberry,
Camp Wilderness Director

WFH Recognition

Midwest Hemophilia Association was recognized as a generous supporter of the World Federation of Hemophilia USA once again for their financial contribution. WFH USA advances the global mission of the World Federation of Hemophilia in the United States. They provide American citizens, foundations, and corporations with the opportunity to ensure Treatment for All for people with bleeding disorders worldwide.

MHA Introduces New Board Member

MHA is glad to announce the addition of Heather Ince to the Board of Directors. Heather and her husband, Randy, and son, Alexander, reside in Fair Grove, Missouri. They have been involved with both Gateway Hemophilia Association and Midwest Hemophilia Association for more than twenty years. Heather served on the GHA Board of directors and has been on chapter committees.

Currently, Heather works for Merrill Lynch as a financial advisor and certified retirement plan consultant. She brings a variety of skills to the board including, but not limited to, finance, accounting, public relations, communication, fundraising, management, and networking. Please join us in welcoming Heather Ince!

Bombardier Blood Movie Review

As a person who is not affected by a bleeding disorder, I was unsure how a movie related to people with bleeding disorders would impact me. However, as each second became minutes during the movie, I quickly realized why I was there. I was there to learn what living with a bleeding disorder truly incorporated and how mental health is a huge part of a healthy bleeder. I think the viewing of this movie came at just the right time as we soon would all face a huge challenge within the bleeding community. Chris Bombardier could not have been a more perfect example of how mental health can impact a person living with a bleeding disorder and the importance of facing huge challenges. He could have sat back and let life control him and his health. But instead, he decided he was going to control his life and his health. Every day that you wake up and let your life control you, the longer it takes to regain control. As those living with bleeding disorders know, life is full of being told “no” and “you can’t do that”. It’s a daily struggle to find where you fit and what you can do without getting hurt. Chris didn’t let this stop him from doing something he loved – mountain climbing. Yes, it is always important to be safe and know your limits, but there is such a freeing power and feeling when you are able to do something you love. So, don’t let your disorder define you but instead let your bleeding disorder define your success. Get out there and do what you love, be an example, and encourage those around you. Help those around you climb their mountains for we all have different challenges. Now is the time more than ever to come together as a community for the greater good of our health. I encourage each and every one of you to watch this movie and be inspired to get out and live your life, help others reach the top of their mountains, and enjoy the blessings around you.

— Cody York, MHA Board Member

2020 NHF Conference to be Held Virtually

Every year NHF's Bleeding Disorders Conference brings together thousands of families and passionate professionals for in-person education and networking. This year, in order to keep the community safe and help prevent the spread of COVID-19, NHF has made the decision to host the 2020 Bleeding Disorders Conference virtually from August 1 to August 8, 2020. Details will be provided as the new format of the conference develops.

Attendees who have already completed a paid registration and have reserved sleeping rooms in Atlanta via NHF's Housing Bureau will receive a 100% refund. Please do not contact the hotels directly.

The virtual educational conference will be full of interesting sessions and fun networking activities for all members of the bleeding disorders community. Everyone will be able to find something to pique their interest or strengthen their professional skills. Affected individuals and families will find sessions on nearly every aspect of living with a bleeding disorder, from the basics of hemophilia and VWD to the latest in gene therapy treatment. Providers will find information on the latest treatments and techniques, and chapter staff will be able to learn more about best practices and ways to strengthen their local organizations.

The NHF team is working tirelessly to bring the 2020 Bleeding Disorders Conference to the community, in the safety of their own homes.

HFA Symposium is Going Virtual

HFA has announced that its Annual Symposium will be converted to a virtual format. The community-centered educational event to be held August 24-29, 2020 draws hundreds of members from the bleeding disorders community to share information, learn new advancements and build a network of support.

Registration for attendees and exhibitors will be closed until details for the virtual conference are finalized. All current registrations are valid. If you are unable to join due to scheduling conflicts, please contact *symposium@hemophiliafed.org*. If you aren't registered, HFA plans to post information soon on its website *www.hemophilia.org* so that you can learn more about the virtual event and register.

COVID-19 UPDATES

Please visit HFA and NHF websites for updated information on COVID-19, related issues and other helpful information.

Both groups are providing valuable information to the community, some of which are interactive or online formats.

2020 EVENTS CALENDAR

Please check our website for the most up-to-date on events! Your health & safety are important to us so we will consider health recommendations/guidelines of local and state levels to determine whether additional events will be postponed/cancelled or rescheduled.

August 1 -8	**National Hemophilia Foundation Bleeding Disorders Virtual Conference**
August 24-29	**Hemophilia Federation of America Virtual Symposium**
September 18	**22nd Annual Golf Tournament** *WinterStone Golf Course, Independence, MO*
September 19-20	**28th Annual Family Education Weekend & Awards Ceremony** *Marriott Kansas City, Overland Park, KS*
October 10	**UNITE for Bleeding Disorders Walk** *Heritage Park, Olathe KS*
October 16-18	**Females And Bleeding (F.A.B.) Conference** *Margaritaville Lake Resort, Osage Beach MO*
November 7	**Wichta Education Day** *Wichita, KS*
TBD	**Trivia Night Fundraiser**

ADVOCACY DAYS Review

Missouri Advocacy

by Mareena Snarey

I finally got a chance to attend Advocacy Days with my family this year. It was a pretty awesome experience!

What is "Advocacy Days," you may ask? Well lemme tell ya. Once a year, usually in early March, members of the bleeding disorder community living in Missouri gather at the capitol in Jefferson City to meet their local representatives and share their experiences living with bleeding disorders.

Most often, this is simply an opportunity to educate and inform local politicians and raise awareness about the needs and concerns of those living with bleeding disorders. That's it! No begging for money, or asking them to sign a particular bill, just putting faces to the community and sharing our concerns.

We bravely brought the whole family this year: all 4 kids including our kindergartner, who was not impressed with meeting politicians. He was not impressed with a lot of things, to be honest, other than the hotel atrium.

After checking in to the hotel Wednesday evening, we had a dinner/training meeting with Representative Greg Razer. This gave us a chance to ask questions, role play what we would be discussing the next day, and get acquainted with a very down-to-earth politician. And then the kids went swimming.

Thursday morning after breakfast we headed over to the capital, set-up our display table, and then went to our appointments with representatives. The appointments were all arranged for us, so all we had to do was show up! It was so awesome.

Everyone we met with was so kind to our family! We visited with Representative Scott Cupps and talked about wrestling and bleeding disorders. (It's our non-hemophilic son that has started wrestling this year.) Senator David Sater stepped out of session to meet with us briefly, and our former representative Scott Fitzpatrick welcomed us in for a bit despite feeling pretty ill. It impressed me how each of these men took time from their busy schedules to meet with us and listen to our story.

I'm glad we had a chance to visit the capitol before Covid-19 reared its ugly head. I enjoyed meeting new people and speaking up for the community, and look forward to attending Advocacy Days again next year.

Washington Days

by Kim Rosenfelt

As I made my way home from Washington D.C., I reflected on the exhilarating and impactful day on "The Hill" amongst 460 blood brothers and sisters representing 45 States, with "One" mission!

On February 27th, our small team from Missouri, (representing Midwest Hemophilia Association and Gateway Hemophilia Association) made quite an impression as we clearly stated the importance to maintain the current budget for the federally funded programs that support our Hemophilia Treatment Centers, (HTCs.)

These programs are:

- National Institutes of Health (NIH)
- National Heart Lung and Blood Institute (NHLBI)
- Centers for Disease Control (CDC)
- Health Resources and Services (HRSA)

I am optimistic our team from Missouri will see each of our Legislator's names appear as co-sponsors for both the Senate and House Bill allowing access to Skilled Nursing Facilities, (SNF) for patients affected by bleeding disorders on Medicare, (S3233 HR5952.) Reported by the National Hemophilia Foundation, a survey of HTCs found over 90% of Medicare patients with a bleeding disorder were faced with complications trying to access this program or worse case scenario, they were completely denied access due to the cost of their treatment. Unfortunately, this often leads to a longer stay in a hospital or being sent home without the much needed extended care.

We were pleasantly surprised by an unscheduled visit with

Senator Roy Blunt. Our story inspired Senator Blunt to request a second meeting to further educate himself in regards to our community's needs. That just goes to show, "Yes", our stories are powerful!

Lastly, but absolutely the most important, "Thank You" to both the National Hemophilia Foundation and the Hemophilia Federation of America for All they do for our community and to the team members for their tireless efforts in organizing this incredible opportunity for allowing us to be the voices for those that can't speak!

Our community is powerful as our voices continue to make a positive impact on the future of those of us affected by bleeding disorders!

Asking and Advocacy Helped My Family

by Nora Ancel

Our family of five was blessed this past year with a huge move to a new town. We had lived in another town for the past 11 years and our boys attended a school district that was not accepting of all their health and education needs.

Our experience in the new school district has been very positive! We met with school officials and had our boys' IEPs and 504 plans put in place before they started at their new schools. Minus a bus hiccup that was quickly fixed, the schools have been incredible to work with and truly want the best for our kids. The communication has been greatly appreciated and our kids are HAPPY. They are thriving and growing.

Prior to March, which is Bleeding Disorders Awareness Month, we decided to ask the school if we could educate the other students in the district about our boys' bleeding disorder and health, just so that we didn't have misunderstandings when or if an issue occurred. We were met with positive responses from school personnel such as, "Yes, please come" and "Where can we get more information?". After several emails and planning, the school agreed to hold an assembly and I was able to speak to the student body and staff about our family's bleeding disorder.

At the same time, we also decided to reach out to the Mayor to ask if he would make a proclamation declaring March as "Bleeding Disorders Awareness Month" for our town. Much to my surprise the Mayor's office was very open to the information and did just that: made a proclamation declaring March "Bleeding Disorder Awareness Month" in Pleasant Hill, Missouri!

After the assembly, the school decided to participate in the Red Tie Challenge and wanted to do a group photo. Because the Mayor had made the proclamation, we decided to invite him to join in the photo opportunity. Not only did the Mayor call me personally to respond to our request, but he also met us at the school and brought the Sheriff—red tie and all!

Community, belonging, understanding--this is what we craved. Advocacy is what we did to get it! Sometime advocacy is just being willing to ask if you can share your story. Being part of the bleeding disorder community has helped me grow in my advocacy efforts and create a better life for our children! And we have found a place where we belong and feel accepted in Pleasant Hill.

CONGRATULATIONS

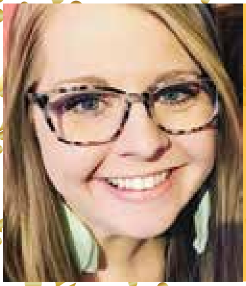
to our 2020 graduates

SPENCER BROWN

PARENTS: Matthew & Angela Brown

FUTURE PLANS: Attend OTC and transfer to Missouri S&T to pursue a degree in Computer Science

MESSAGE FROM FAMILY: Spencer, It's hard to believe you have reached the milestone of graduating high school. We are so proud of you. You've demonstrated integrity, discipline, and hard work not only in your academics, but in your everyday life. Continue with these character traits while loving God first and most, and He will bless your life. Love, Dad & Mom

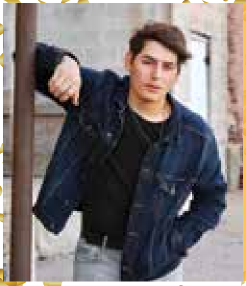


KATHRYN BURGESS

SPOUSE: Ben Burgess

FUTURE PLANS: Pursuing work in the Psychology field

MESSAGE FROM FAMILY: I'm proud of my wife Kathryn for her commitment to all things-wife, mother, employee, and scholar! You did it baby! The big leagues won't know what hit 'em.



KINDRIC CASTRO

PARENTS: Roberto & Bridget Castro

FUTURE PLANS: Information Technology Computer Science and Engineering at Barton Community College

MESSAGE FROM FAMILY: Kindric, You are a humble individual with ambition that will change the world around you. We're proud of you because of who you are and what you stand for. We're blessed because you're our son! – Mom & Dad

ALEX INCE

PARENTS: Ken & Dori Smith

FUTURE PLANS: Kansas University Lawrence, KS; Officially accepted a pharmacist position with Walgreens

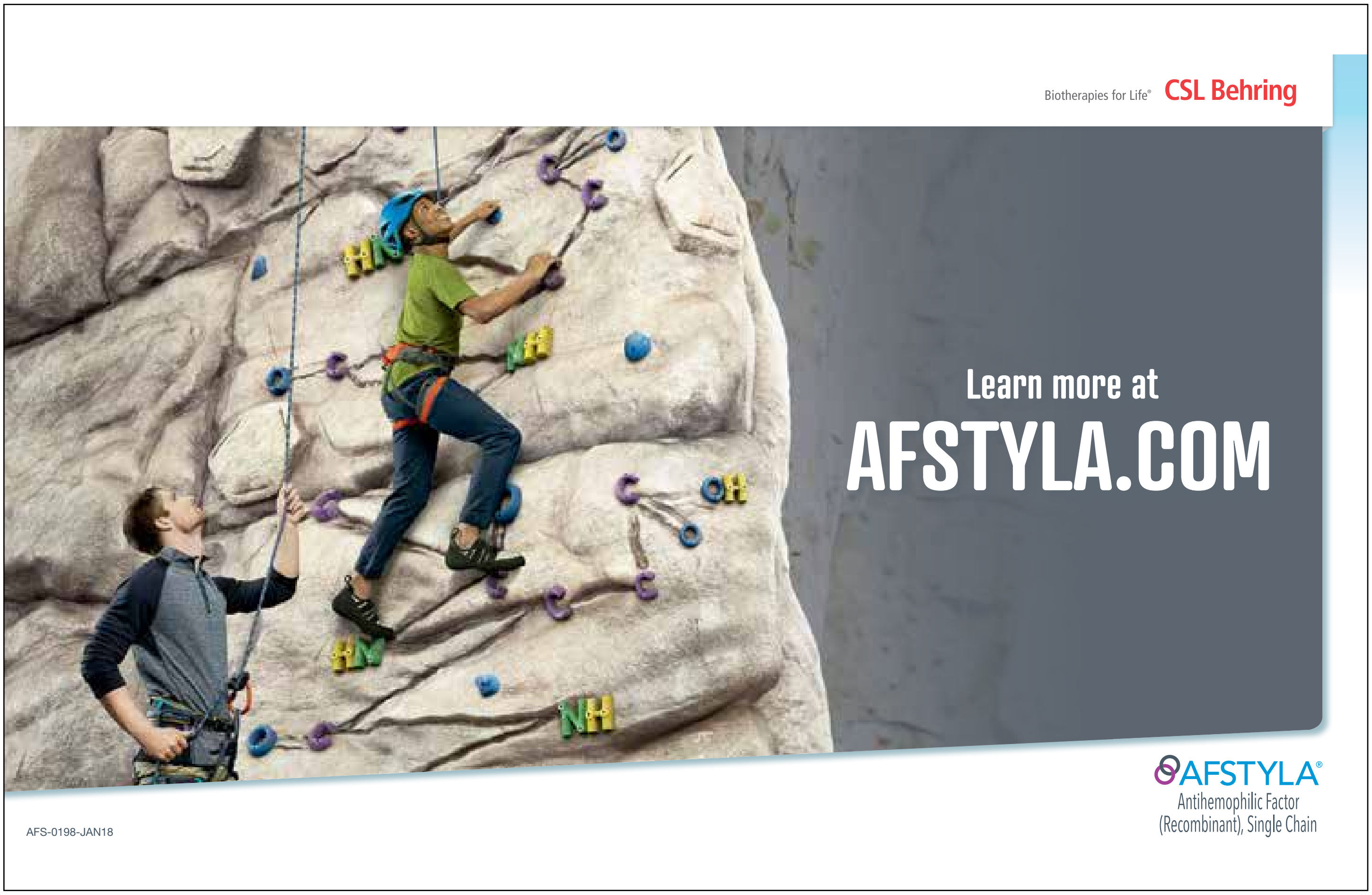
MESSAGE FROM FAMILY: Kyrie, We are all so proud of your accomplishments! Especially graduating from Kansas University with your PharmD. I know that Grandma is so very proud of you too! Congrats! Love, Mom & Dad, Isaac, Andy & Tiffany, Gpa & Julia, Brian & Carla, Avery & Quinn!

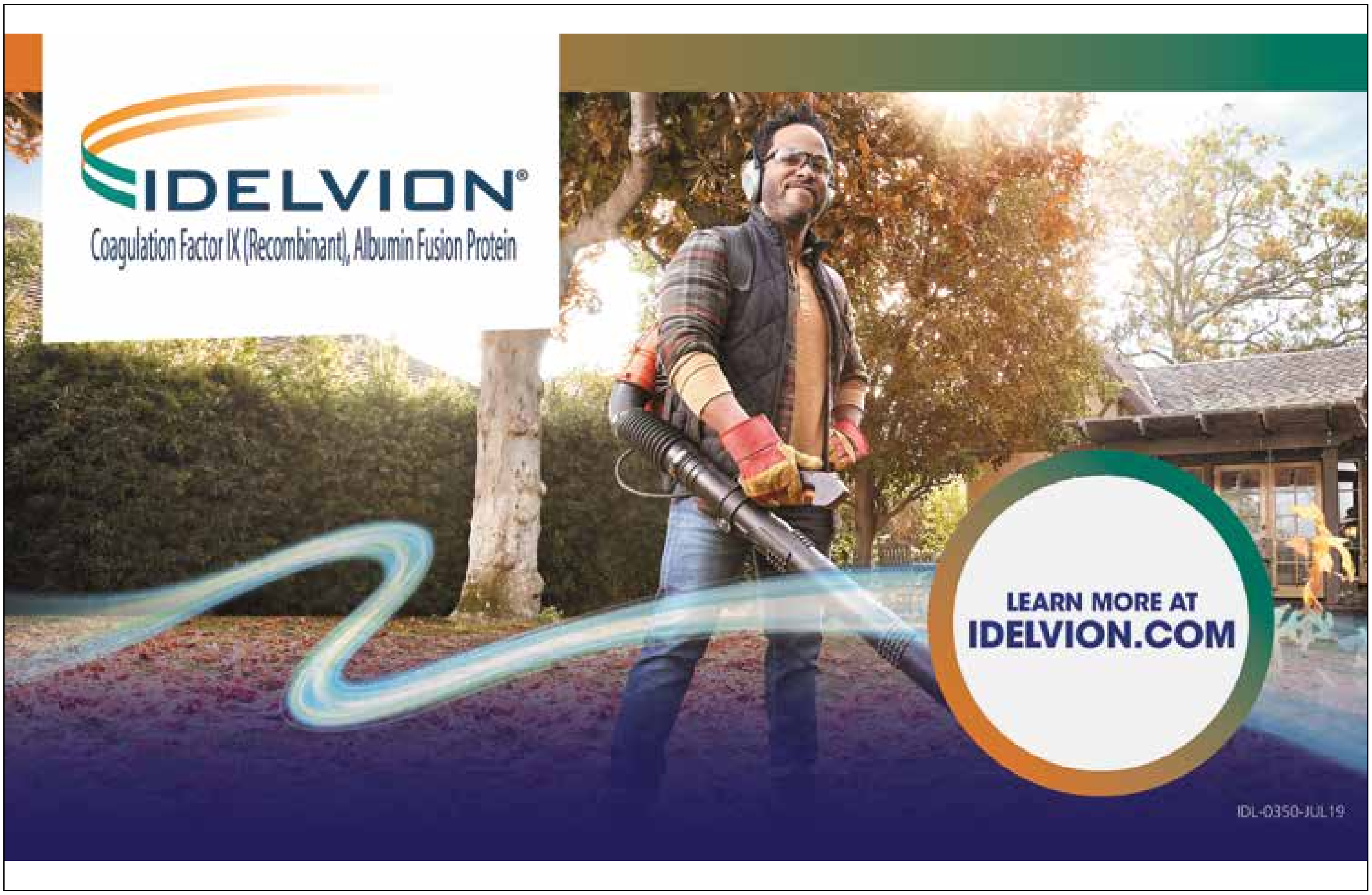
KYRIE SMITH

PARENTS: Randall & Heather Ince

FUTURE PLANS: Attend Washington University in St. Louis in the Pre-Health Program with the goal of becoming a surgeon

MESSAGE FROM FAMILY: Alex, We absolutely love being your parents. It's such a blessing to watch you work hard to achieve your goals. We are excited for your future. Enjoy the journey! – Mom & Dad





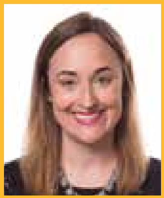
HELPFUL NUMBERS

KANSAS CITY REGIONAL HEMOPHILIA CENTER

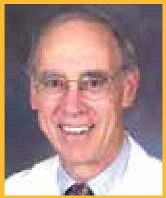
1-816-302-6869 • 1-800-236-1713

PEDIATRIC PHYSICIANS:
Dr. Shannon Carpenter • Dr. Michael Silvey
Dr. Lauren Amos

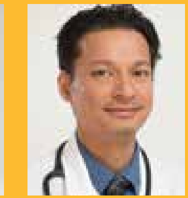
ADULT PHYSICIANS:
Dr. William Jennings • Dr. Jill Moormeier • Dr. Anuj Shrestha

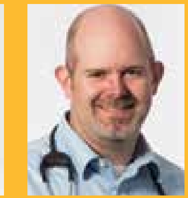

Amos


Carpenter


Jennings


Moormeier


Shrestha


Silvey

UNIVERSITY OF MISSOURI HOSPITAL AND CLINICS HEMOPHILIA TREATMENT CENTER

1-573-882-9355

NATIONAL HEMOPHILIA FOUNDATION (NHF)

1-800-42-HANDI • www.hemophilia.org

HEMOPHILIA FEDERATION OF AMERICA (HFA)

202-675-6984 • www.hemophiliafed.org

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Vanessa Sidwell
Regional Accounts
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Ed Chomyak RN/BSN
Hemophilia Infusion Specialist
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NEW DATE & LOCATION!

"Females And Bleeding" Conference

October 16-18, 2020

@ Margaritaville Lake Resort
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Open to all women ages 18+ within the MHA, GHA, HOI, & Nebraska chapters. Deadline for registration and payment is September 1, 2020.

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HEMOPHILIA OF IOWA, INC

Midwest Hemophilia Association

Raising the Meadow Boys

Living life to the fullest despite living with chronic disorders

By Charity Meadows

With everything that has happened lately I am sure everyone is stir crazy by now. My kids have been working hard at school, and have been getting on each others nerves. I am very thankful we have gotten to have more family time but there is such a thing as too much. But! Summer is around the corner! The time to kick them out the door and let them figure some things out on their own, or create something, or imagine something or just sit and soak up the sun (with spf 50 of course).

The Great Pause has also allowed me to sit and think about what I am thankful for.

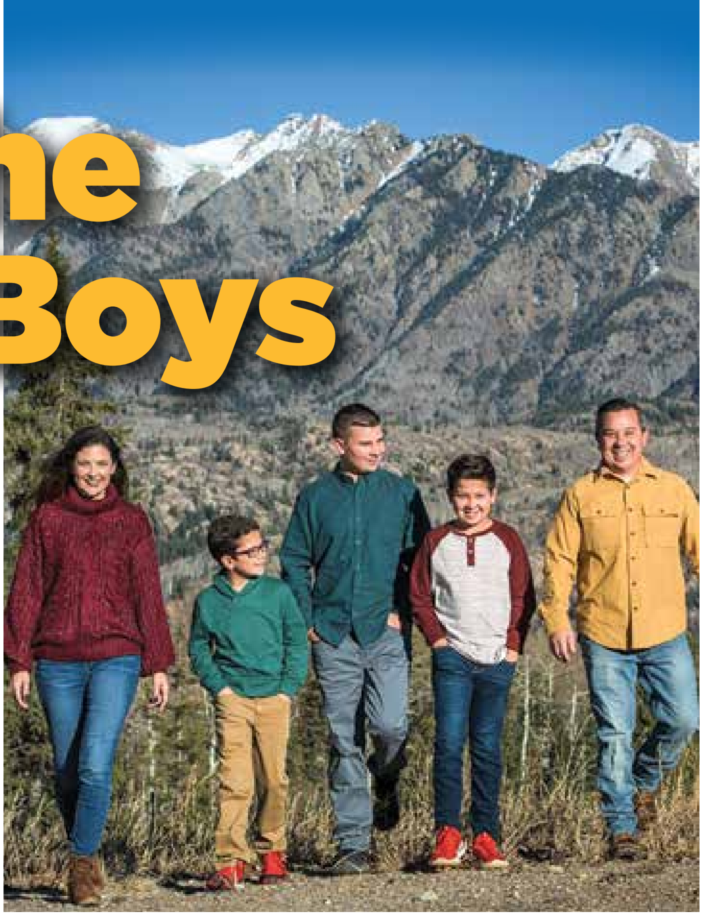
Family time, getting extra time with my kids because they won't live at home all their life. They will eventually leave the nest, so having more time with them, one on one and all together has really been a blessing.

Taking extra time with my husband and driving the backroads. Discovering hidden out-of-the-way places we would never have discovered before.

Handwriting and snail mailing sweet family and friends that I have missed during this time.

Enjoying sunrises more since I have the time to sit and watch. The nature that comes alive when we are quiet and take the time to enjoy. The extra morning quiet time is very nice too. To be able to hear myself think and take more time to pray has been very relaxing.

For warmer weather!! We can now go berry picking! Strawberries, blueberries, blackberries, raspberries, elderberries! I love to find my local berry farms and pick my own. I love supporting local and the fact I know my food source and more then likely, they don't use gmo seeds or harmful chemicals on their crops.



And the recipes! I thought I would share one. This is my healthy version of strawberry shortcake. Not only does my 11 year old son have severe hemophilia b, but he also was diagnosed with Type 1 diabetes in 2016 at the age of 7. So we have learned to take some of our summer favorites and make them healthier. We try to eat lower carb and this low carb strawberry shortcake is one of his favorites. This pound cake makes about 16 slices. This is one of my favorite summer desserts! Hope you all give this a try and enjoy!!

I hope you all stay healthy, safe and enjoy your summer!

ABOUT THE AUTHOR: My name is Charity. I have been married 18 years to my wonderful hardworking husband Aaron and a mom to three handsome boys. My oldest son has a rare bleeding disorder, hemophilia B. My youngest has hemophilia B and type 1 diabetes. My middle child is just that, the classic middle child. Life is full of surprises, some good and some not so good. I hope this blog will encourage you that no matter what life throws at you, you can still live life to the fullest. This is our journey while living with chronic disorders. I hope to encourage you while raising awareness for Hemophilia B and Type 1 Diabetes. Hope you will stay awhile so we can encourage each other!!

LOW CARB STRAWBERRY SHORTCAKE

INGREDIENTS:

1/2 cup butter softened
4 oz cream cheese softened
1/2 cup monkfruit or I use Swerve
5 eggs room temperature
1 tsp lemon ectract
1 tsp vanilla extract
1 1/2 cups plus 2 TBSP almond flour
1 tsp baking powder
16 strawberries
sugar free whipped cream or regular

DIRECTIONS:

1. Preheat oven at 325*F. Cream the butter, cream cheese, monkfruit or swerve with mixer. Add in the eggs one at a time then add the extracts.
2. Mix in the almond flour and baking powder.
3. Pour into a well greased 9×5 loaf pan.
4. Bake for 50-55 minutes OR until well browned.
5. Let cool 10 minutes and remove from pan.
6. Slice cake, take one piece and put whip and cut up berries on top and if you want add another slice and more berries and whip for a layered cake.

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 in a way you can understand.

Let's explore gene therapy together at **HemDifferently.com**

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

BIOMARIN®

What Health Coverage Is Available To Individuals & Families Without Job-Based Coverage?

As a community, we know how important it is for people with bleeding disorders to maintain comprehensive health insurance. There are insurance options available to you if you are experiencing job or other economic impacts of the ongoing coronavirus pandemic.

Your options will depend on: 1) the state where you live, 2) your household's monthly income right now, including unemployment insurance or other benefits, and 3) your household's projected annual income for the entire calendar year, including earnings before losing your job, from unemployment insurance and other temporary benefits, and income you expect to earn later in the year.

Medicaid expansion coverage

In 37 states, Medicaid is available to anyone with an income that qualifies. Medicaid is usually available for $0 or very low premiums, and you can sign up at any time.

Medicaid expansion states: Eligibility is based on your household's current monthly income, including any severance pay or unemployment insurance. It doesn't matter how much you earned before you lost your job - Medicaid considers only your new income level. A single person with currently monthly income below $1467 or a family of four with current monthly income below $3013 will qualify. (This includes people with no income.) If you live in one of the 37 Medicaid expansion states, you should go to the website for your state's Medicaid program and enter your information; the website will let you know if you qualify for Medicaid coverage.

Other Medicaid coverage: Some people with incomes too high to qualify, or who live in one of the fourteen states that have chosen not to expand Medicaid, might still qualify for public health insurance based on current monthly income. This is especially true for children, pregnant women, and, to a lesser degree, parents. To explore coverage options for children, visit *www.InsureKidsNow.gov*.

HOW CAN PEOPLE SIGN UP FOR MARKETPLACE COVERAGE?

Visit www.HealthCare.gov to start the process of signing up for coverage. Most people who lost coverage due to a job loss will qualify for a "Special Enrollment Period" (SEP) and can follow the appropriate prompts at www.HealthCare.gov.

Subsidized coverage in the individual market

Most people who do not qualify for Medicaid will qualify for subsidized coverage in the individual market ("ACA marketplace"). Subsidies are available in all 50 states and can cover all or almost all of the cost of premiums.

Subsidies are calculated based on how much money a household expects to earn for the entire calendar year. The lower a household's projected income, the more generous the subsidy.[1]

Most households have just 60 days after losing their job-based coverage to sign up for insurance coverage in the ACA marketplace.

COBRA coverage from a job

Under a law known as "COBRA," most employers are required to offer families the option to "continue" in their job-based coverage, even if the employed family member is laid off. Because under COBRA, the family is responsible for paying the full premium (including any amount previously paid by the employer), COBRA will usually be much more expensive than other options – so you should look carefully at all your options before signing up for COBRA. People have 60 days after they lose their job-based coverage to sign up for COBRA, and can enroll by contacting their employer's HR department directly.

Protect Yourself: Avoid Key Mistakes!

Beware of imposter websites. Unfortunately, some misleading, look-alike websites sell skimpy forms of coverage (e.g., short-term health plans) that do not meet ACA consumer protection standards and will not provide adequate coverage for your bleeding disorder. Families who want to get comprehensive coverage should always go to a ".gov" website.

Don't wait too long to apply. Many people have just 60 days following a loss of employer-sponsored insurance to sign up for an insurance plan in the ACA marketplace or via COBRA.

Don't forget to provide required documents. When you sign up for coverage you may be asked for documentation of your address, your income, and when you lost coverage. People who don't provide that information quickly may not get coverage, so make sure you gather as much information as possible ahead of time and respond promptly to any follow-up requests for documentation.

- Check your spam and junk folder to make sure that nothing falls through the cracks!

Your national organizations are here to help. Please contact **NHF** or **HFA** if you have questions about how to navigate coverage issues.

This article draws heavily upon a March 17, 2020, article by Christen Linke Young of the USC- Brookings Schaeffer Initiative for Health Policy. You can find the full article at www.brookings.edu.

[1] *There is one exception: due to an unfortunate glitch in the law, your household must expect to earn at least 100% of the Federal Poverty Level ($12,760 per year for an individual, or $26,200 per year for a family of four people) for all of calendar year 2020 in order to qualify for subsidies.*

SAVE THE DATE

Midwest Hemophilia Association

FAMILY EDUCATION Weekend

Connecting the Bleeding Disorder Community

SEPTEMBER 19-20, 2020

Join us for a weekend of fun and education!

Saturday, September 19, 2020
& Sunday, September 20, 2020

@ Marriott KC/Overland Park
10800 Metcalf Avenue
Overland Park, Kansas 66210

www.midwesthemophilia.org/events/

MHA will cover the cost of a hotel room on Friday night for anyone driving in 150+ miles. Contact mhaevents@midwesthemophilia.org for details.

WEEKEND ACTIVITIES

ADULT EDUCATION

YOUTH & TEEN PROGRAMS

CHILD CARE

MEN’S & WOMEN’S BREAKOUT SESSIONS

RAFFLE

RECOGNITION & AWARDS

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- Camp “Big Stick” Celebration
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- Volunteer of the Year
- Top Golf Teams

AND MUCH MORE!

22nd Annual

MHA GOLF TOURNAMENT

September 18, 2020

WinterStone Golf Course
17101 E. Kentucky Road
Independence, MO 64058

Check-In Time 7am • Tee Time 8am

RAFFLE • HOLE CONTESTS

Includes Breakfast plus Lunch After Rounds.
Awards Banquet at Conclusion of Play.

Accumulated Sponsorship Recognized with Plaque/Trophy:
GOLD: $3,500+
SILVER: $2,500-$3,499
BRONZE: $1,500-$2,499

For sponsorship opportunities, questions or to save your place on the green, contact Mark Dudley at:
mdudley@blueridgebank.net

Proceeds benefit:

Midwest Hemophilia Association

Make checks payable to ***Midwest Hemophilia Association.*** *Please mail payment and registration form by August 31, 2020 to:*

Midwest Hemophilia Association
1471 W. South St, Suite F
Ozark, MO 65721

SPONSORSHIP OPPORTUNITIES:

Title Sponsor - $5,000
Top Billing of Company Name & Logo on Event Banner; 2 Teams of 4; Recognition with up to 5 minute, Non-Branded Presentation; Tee & Green Signage; Recognition in the MHA Newsletter, Social Media and Family Education Weekend Awards Ceremony

Lunch Sponsor - $2,500
1 team of 4; Company Name on Event Banner; Recognition During Lunch with up to 3 minute, Non-Branded Presentation; Recognition in the MHA Newsletter, Social Media and Family Education Weekend Awards Ceremony

Golf Cart Sponsor - $2,000
1 team of 4; Company Name on Event Banner; Name on All Team Golf Carts; Recognition in the MHA Newsletter, Social Media and Family Education Weekend Awards Ceremony

Hole Sponsorship - $1,500
1 team of 4; Company Name on Event Banner; Tee & Green Signage; Recognition in the MHA Newsletter, Social Media and Family Education Weekend Awards Ceremony

Beverage Cart Sponsorship - $1,500
1 team of 4; Company Name on Event Banner; Name & Logo on Cart; Recognition in the MHA Newsletter, Social Media and Family Education Weekend Awards Ceremony

Breakfast Sponsorship - $1,500
1 team of 4; Company Name on Event Banner; Recognition During Breakfast with up to 3 minute, Non-Branded Presentation; Recognition in the MHA Newsletter, Social Media and Family Education Weekend Awards Ceremony

Corporate Exhibit Only - $1,000
Recognition on Event Banner; 1 Exhibit Booth Space for Duration of Event; Recognition in the MHA Newsletter, Social Media and Family Education Weekend Awards Ceremony

Team Sponsorship - $600
1 team of 4; Recognition in the MHA Newsletter and Social Media

Cut along dashed line and mail to Midwest Hemophilia Association by August 31, 2020

REGISTRATION FORM

MHA GOLF TOURNAMENT

September 18, 2020 @ WinterStone Golf Course in Independence, Missouri

Now more than ever the Midwest Hemophilia Association will need to continue our work to ensure that the bleeding disorder community is supported through this unknown time.

The annual golf tournament is a way we continue to raise imperative funds necessary to obtain our mission: to improve the lives of those living with a bleeding disorder through education, advocacy, resources, and support!

Thank you for being part of that mission by participating in our golf tournament!

SPONSORSHIP OPPORTUNITIES

Title Sponsor	**$5,000**	**[ ]**
Lunch Sponsor	**$2,500**	**[ ]**
Golf Cart Sponsor	**$2,000**	**[ ]**
Hole Sponsorship	**$1,500**	**[ ]**
Beverage Cart Sponsorship	**$1,500**	**[ ]**
Breakfast Sponsorship	**$1,500**	**[ ]**
Corporate Exhibit Only	**$1,000**	**[ ]**
Team Sponsorship	**$600**	**[ ]**

SPONSOR/TEAM NAME

Contact Person

Phone

Address

E-mail

PLAYER NAMES & EMAIL ADDRESSES

Name E-mail

Name E-mail

Name E-mail

Name E-mail

To download the registration form or for more information, visit

https://midwesthemophilia.org/events

Proceeds go to the Midwest Hemophilia Association, a non-profit 501(c)(3) organization registered in Missouri.

MOVING?
NEW ADDRESS?

Update your contact information by visiting *MidwestHemophilia.org* and clicking on the “Become a Member” tab. Once complete, click JOIN and you’re done!

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