BIG RED FACTOR

2018—Issue I

Nebraska Chapter News

It's hard to believe we are already rounding into Spring and that we are a quarter of the way through the year. I want thank NHF and this community for being so incredibly loving and supportive during the last several months as I've navigated having a baby and losing my son, Jude. I have always been blown away by the love and support that this community resonates, and to see it come back to me in my time of need was truly beautiful. I'm happy to call NHF my home and I'm so blessed to be able to work for you all every day. Thank you from the bottom of my heart.

We are gearing into our busy season in the next couple weeks as we get ready for networking events, fundraisers and our Family Education Weekend. We are so excited for everything we are bringing in 2018, including a new VWD Day and a renewed Women's retreat. Our board is growing with new members ready and willing to direct our organization in a great way. We are set up for success so we can continue to offer you more programs and services.

I'm so glad to be back and ready to fully jump into 2018. As the world around bleeding disorders changes and evolves, we will work hard to stay relevant, up to date and continue to serve our community as best as we can. Please know you can always reach out to me if you have any questions, concerns or just need to talk.

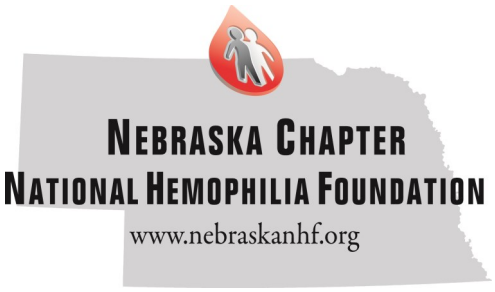
I look forward to seeing you soon.

-Maureen Grace, Executive Director

Inside this issue:

Calendar of Events	2
Surviving with Hemophilia	4
Advocacy Days 2018	8
Speaking up with Grace	10
Strength training 101	8
Washington Days	12
Finding your Future	16
Why Walk	18

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org



Our Mission:

The National Hemophilia Foundation—Nebraska Chapter is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy & research.

Staff

Executive Director
Maureen Grace

Development Manager
Kelsey Cunningham

Advisory Board of Directors
President - Dale Gibbs
Vice President - Geri Murphy
Secretary - Zach Blackman
Scott Gass
Dan Henson
Rebecca Runge
Peter Senior
Rick Starks– NEW!

The material in this newsletter is provided for your general information only. The Nebraska Chapter does not give medical advice or engage in the practice of medicine. NHF-NE does not recommend particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

2018
Second Quarter Events

April 25
Kearney Educational Dinner
Kearney, NE

April 21
Red/White Game Tailgate
Lincoln, NE

May 18
Mini Golf Tournament
Papillion, NE

May 19-20
Education Weekend
LaVista, NE

Save the Date
2018

March
Bleeding Disorders Awareness Month

April 17
World Hemophilia Day

June 30th
PING
Omaha– Location TBD

July 29
Infusion: A Bloody Mary Mix off

More Activities Coming Soon!
Watch our website for updates and register Online!

A Proud Member of

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

PAPIO GREENS
GOLF CENTER

Mini Golf Fore Good

Nebraska Chapter
National Hemophilia Foundation
www.nebraskanhf.org

Friday, May 18, 2018

6:00pm – Registration 6:30pm – Golfing Begins – Dinner & Awards to Follow

Papio Greens Golf Center
11050 S. 66th St, Papillion, NE

Sponsorship Opportunities!

Register a Team (2-5 players on a team) and Mini Golf FORE Good!

Go to www.nebraskanhf.org or contact Development Manager Kelsey Cunningham at 402-889-0572 or email at kcunningham@hemophilia.org to register or to receive more information.

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

JOIN US FOR THE ANNUAL EDUCATION WEEKEND!

When: May 19-20th, 2018
Where: Embassy Suites- La Vista
12520 Westport Pkwy
La Vista, NE 68128

This Years Includes:

- **Chris Bombardier, 7 Summit Climber, as our Keynote Speaker!**
- **Infusion Clinic -** Would you or your child like to learn to self-infuse or do you need a refresher?
- **Vendor Education Booths—**Gather information on consumer products, educational materials, and programs and services.
- **Networking—**Time to talk, share and learn from each other
- **Saturday Night Family Event—**Fun for the whole family with Spielbound Board Game Café
- **Sunday –** Discussion Round Tables and Year in Review

For Children & Youth

For Children 0– 12 —Professional Childcare provided with age appropriate activities and Kidz Korner Activities and Education with Accredo.
For Teens Age 13-17 –Education, team building and a fun filled recreational field trip.

You can register online at www.nebraskanhf.org or
Please fill out & return the Registration Form with payment no later than

April 18, 2018.

Registrations received after that date will not guarantee you a Hotel Room!

NENHF will pay for hotels for all Nebraska Chapter member attendees for Saturday, May 19th.
If you live more than 120 miles away from Omaha, we will cover a hotel for Friday night as well.
Please register as soon as possible as hotel rooms for Friday night are limited.

Meet Chris Bombadier

2018 Keynote Speaker

Chris Bombardier is a mountaineer and outdoorsman that is living with severe hemophilia B in Denver, Colorado. Chris just completed climbing the Seven Summits, the highest peak on each of the seven continents, including Mt. Everest. Less than 500 people have completed this feat to date and Chris is the first with hemophilia to successful complete it. Chris uses these climbs to raise awareness for Save One Life, a international hemophilia nonprofit in which he serves on the board of directors. Save One Life provides individuals the opportunity to sponsor children with hemophilia in developing countries as well as funds educational scholarships, micro-enterprise grants, and funding for summer camps. Chris currently works for GutMonkey, an experience-based education company that utilizes adventure to impact those living with chronic medical conditions. Through GutMonkey, Chris leads backcountry canoe and sea kayaking trips, facilitates teen retreats, and week long residential programs for those in the hemophilia community. Chris is also very active in his local hemophilia chapter, the Colorado Chapter of the National Hemophilia Foundation, where he cofounded the program Backpacks and Bleeders that introduces the hemophilia community to outdoor adventures.

Saturday Night Family Game Night!

We are excited to welcome the staff of Spielbound Board Game Café to our Family Fun Night on Saturday, May 19th!

They will have games for every age and skill level. We will have an interactive strategy game session where you can learn how to play a new game or feel free to stick to a family favorite. Let us know if you have any special game requests.

SPIEL BOUND

Red/White Game

11th ANNUAL

RED WHITE GAME TAILGATE

April 21, 2018

Tailgating and Lunch with the Game on TV at the park!

10 am until the game is over
11:00 am Kick Off

Join us as we welcome Scott Frost back to Nebraska for the Husker Spring Game!

We couldn't get tickets this year due to overwhelming demand but we have a tailgating trailer sponsored by Silverstone Group set up to stream the game on TV while we grill and the kids can play in the park.

Can't wait to see you there for a Spring day full of family and fun!

RSVP at www.nebraskanhf.org today!

Oak Park Pavillion
133 Cornhusker Hwy
Lincoln, NE 68521

Inhibitor Summits

Inhibitor EDUCATION SUMMITS

NATIONAL HEMOPHILIA FOUNDATION

The Inhibitor Summits have been held for more than a decade, providing families affected by inhibitors with the education and support they often need as they face this serious complication.

To learn more and register, visit:
www.hemophilia.org/Inhibitors

NHF will continue this tradition in 2018, by hosting three Inhibitor Summits:

- **Thursday, June 14-Sunday, June 17 in Miami, Florida**
- **Thursday, July 26-Sunday, July 29 in New Orleans, Louisiana** (note registration for the New Orleans meeting will open in March 2018)
- **Thursday, August 16-Sunday, August 19, 2018 in San Diego, California**

Travel Grants: NHF Bleeding Disorders Conference

Every year the Nebraska Chapter sends members of our community to NHF's Annual Meeting. This year the meeting will be held in Orlando, FL from October 11-13th. If you are interested in attending, the deadline to fill out the application is May 31st, 2018! Please keep in mind that the grant may not cover all the expenses that go along with this trip. A committee will determine who we will send and how much of the budget will go to each family or individual chosen. Preference will be given to families who have not attended the meeting before.

Each year the Nebraska Chapter will fund the following Attendees completely

· Two Staff | One Board Member (and family if affected by a bleeding disorder)

The remaining number of travel grants will be awarded based up the amount the Nebraska Chapter has allotted in their yearly budget, and this amount is discussed and approved by the Advisory Board of Directors.

Travel Grants will be awarded in the following amounts:
Families of 1-4 - $1500 | Families of 5-8 - $2500

Preference will be given to applicants who are 1st Time Attendees (those who have never attended a National Conference), to applicants who did not attend the National Conference the previous year, and who are actively involved in Nebraska Chapter activities.

Download the application at www.nebraskanhf.org due May 31, 2018

SUPERIOR BIOLOGICS
Making a difference in Peoples' lives

EXPERTISE IN:
- Hemophilia A
- Hemophilia B
- Von Willebrand's Disease
- Other Bleeding Disorders

SERVICES INCLUDE:
- Nursing & Pharmacy 24/7
- Infusion Education & Training
- Reimbursement Specialists
- Direct Communication with the People You Know
- Same Day Delivery

Craig MacDonald
Regional Territory Manager
760-485-8281

Vanessa Sidwell
Regional Accounts Manager
816-739-9841

Office: 844.237.3561
Fax: 844.237.3562

WE ARE FAMILY

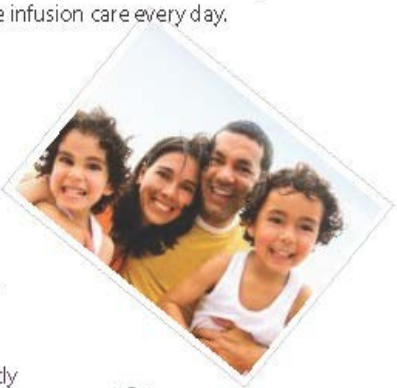
You and your family are unique.

So is your hemophilia.

Helping you get back to family time.

Experienced ARJ pharmacists and nurses are delivering Nebraskans personalized quality home infusion care every day.

- Last year, we secured over $625,000 in patient resource assistance.
- Most ARJ patients are recommended by friends or family.
- Patients love our Ready Pack® infusion kits for easy self-infusion.



Our pharmacy is conveniently located near you.
(866) 451-8804
arjinfusion.com/nebraska

ARJ Infusion SERVICES
Where Caring is the Ultimate Factor.

Advocacy Days 2018

Advocacy has always been important to the bleeding disorders community and as a chapter, we are working hard to grow our advocacy program each year. Nebraska NHF was proud to get a proclamation passed officially naming March as Bleeding Disorder Awareness Month. This Proclamation was presented by the Lieutenant Governor on March 5, 2018 at the State Capitol. We were excited that this year we expanded our advocacy programming to take place over two days, March 11th and 12th. March 11th, we hosted an educational dinner at Lazlo's in Omaha, to teach you how to be the best advocate you can be. Over 25 individuals attended this dinner, some who had never been to an advocacy event before, with training led by Roy Pura from CSL Behring's Governmental Relations Team.

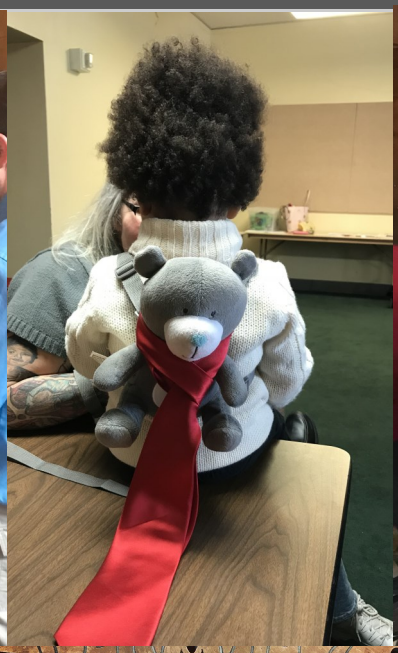
March 12, started off with a bang, a group of 20 advocates, and a lot of donuts with our senators. Kaylean Gentry was able to have an in depth discussion with her representative, Roy Baker, at breakfast. During our breakfast, Elizabeth Stoltz with NHF's Advocacy team provided information on how to talk to your senator. We were given a first hand look when Senator Dan Watermeier, representing District 1, came in for breakfast and we were able to give him a quick overview of bleeding disorders in Nebraska before he headed off to an Appropriations Meeting.

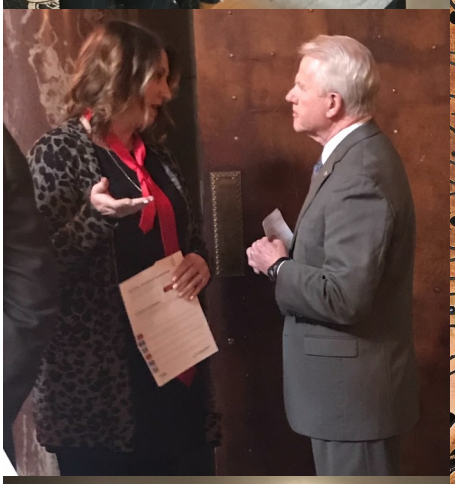
Following breakfast, we went into the morning senate session to have the opportunity to talk to our senators. We were a welcomed bunch and we could not be more proud with our awareness raising for bleeding disorders.

While March is Bleeding Disorders Awareness Month, it is imperative that we raise awareness every day. You can be your best advocate by writing letters to your representative, asking for meetings year round, and using social media to guide a discussion about bleeding disorders.

Be sure to don your red tie this month and send us a photo! We would love to see it!

Advocacy Days 2018





STATE OF NEBRASKA

Proclamation

WHEREAS, Hemophilia and Von Willebrand Disease are genetic disorders that impair the body's ability to control bleeding; and

WHEREAS, Hemophilia is defined as an inherited, uncontrollable bleeding because of a missing or low level clotting factor in the blood, and Von Willebrand Disease is defined as a bleeding disorder where the blood does not clot well; and

WHEREAS, Bleeding may occur even when there is no injury and most often occurs in the joints and in the brain; and

WHEREAS, There are approximately 18,000 United States citizens with Hemophilia; and

WHEREAS, There are over 270 citizens living in Nebraska with Hemophilia; and

WHEREAS, Von Willebrand Disease can affect both males and females and approximately 1% of the world's population is living with Von Willebrand Disease; and

WHEREAS, There is no cure for Hemophilia and Von Willebrand Disease – both lifelong conditions that may be controlled with intravenous infusion of factor replacement therapies.

NOW, THEREFORE, I, Pete Ricketts, Governor of the State of Nebraska, DO HEREBY PROCLAIM the month of March, 2018 as

BLEEDING DISORDER AWARENESS MONTH

in Nebraska, and I do hereby urge all citizens to take due note of the observance.

IN WITNESS WHEREOF, I have hereunto set my hand, and cause the Great Seal of the State of Nebraska to be affixed this First day of March, in the year of our Lord Two Thousand Eighteen.

Speaking Up with Grace and Simplicity

Author: Jennifer Baumert

In the past two weeks, my children have made me proud of how naturally they are able to advocate for themselves, at all levels. Speaking up with simplicity and grace seems to come more easily for children.

My younger son was visiting new high schools last week, and had a chance to speak with principals and counselors about his bleeding disorder, what his life was like, and what his teachers could expect. His entire "elevator speech" took less than 5 minutes, explained the basics in words they understood, and reassured them that his bleeding disorder was something they could handle. He answered their questions directly and calmly, and refocused the conversation on the things he could do, rather than the things he couldn't.

Two weeks ago, my older son advocated for himself at his own high school in his Senior Studies class. Each senior was supposed to choose a topic from an approved list to do a project and presentation for the class. All of the topics involved current ethical choices in America. My son noticed that nowhere on the list was the high price of pharmaceuticals and its' effect on patients-bleeding disorder drugs, cancer drugs, etc. He went to his teachers and advocated for adding this topic to next years list, using his own medical condition and problems with drug access as an example. He did this on his own, proving to me that he is truly ready to become an adult out in the world.

Three days ago, my children accompanied me to the state capital for Nebraska Advocacy Day. My older son knew his state representative, and showed me where his office was located from his previous tour during Boys State last summer. While I was nervous speaking to my representative, my sons felt free to see him as a person like themselves who was in a position to do something about the problems we have encountered. They smiled and joked with him, making the conversation flow smoothly. After this visit, I now have the courage to make plans to visit with my U.S. senators, knowing that speaking up is something we all can do everyday.

We all have a lot we can learn from our kids. Mine taught me that keeping things simple, speaking directly and calmly, and making others comfortable with bleeding disorders while educating them is something we can all do on an everyday basis. The more we speak up and join our voices with others, the more chance we have to have others listen and change the things that need changing. Have no fear!

Washington Days

Author: Joe Mickeliunas

On March 7, 2018, I departed from Omaha's Eppley Airfield and after a brief layover in Chicago, I landed at Reagan International Airport in Washington D.C. to take part in Washington Days, NHF's annual trip to Capitol Hill. Upon arriving to the hotel, I immediately ran into a familiar face in Maureen Grace, our wonderful Executive Director. I got my bearings and immediately looked around and saw many people wearing their red lanyard and nametag signifying they were here for NHF. Soon I found out that our numbers were near 500 from 47 states. It was exciting to be around so many people that were a part of this still new part of my life. My son Elliott was born in June 2016 and shortly after was diagnosed with Severe Hemophilia A, and I was here to advocate for him. As I checked in to the conference, I got my red skinny tie and an adorable clip-on tie for Elliott and was ready to go.

Our evening session helped to give us the big NHF talking points for the year, like access to affordable comprehensive health care without lifetime limits on benefits and the proposed 2019 budget that includes significant cuts to the CDC and HRSA. The cuts to those areas are problematic for our community due to the fact that they are instrumental in funding HTCs. Another issue we should discuss with our representatives is getting their assurance that they would support federal standards for essential health benefits so there will not be any difference in coverage from state-to-state. The opening session did a wonderful job of preparing us to be open minded, gracious, yet still firm with our representatives in discussing what is important for the bleeding disorders community. We needed preparation because 2017 was a year in which we saw five attempts to repeal the Affordable Care Act (ACA), which many of our families rely on to ensure that their needs are met. With midterm elections approaching quickly, another attempt at ACA repeal may not be on the agenda, but we needed to be aware what it means to be without it. The current administration has been fairly unpredictable, which the foundation recognized at the meeting, and living in a red state, us Nebraskans had to voice our concerns with bravado.

Washington Days: A Recap

We heard from NHF CEO, Val Bias, whose Washington experience is admirable to say the least. Mr. Bias is leading NHF into the future by truly creating an inclusive community that represents all bleeding disorders. The 2018 Red Tie Campaign is a big part of making bleeding disorders visible to those who are not familiar with what it means to live with a bleeding disorder. March has been designated as Bleeding Disorders Awareness Month, and with our red ties and our stories, we can help NHF move forward to help educate and ensure the best healthcare options for those living with bleeding disorders.

On Thursday morning we heard some words of wisdom from ABC News Political Director Rick Klein. Klein has a personal connection to the bleeding disorders community in that his nephew has Hemophilia. The talk focused on current politics, the need for conversation with our representatives, and health care and reform in the age of a Donald Trump presidency. While taking a slightly partisan tone, Klein was personable and encouraging by telling us that our stories matter. Advocacy is important regardless of what side of the political spectrum one finds themselves. The community that we share is what matters most. As he finished his speech, Mr. Klein graciously took questions from the audience about to embark on their journey to the Capitol. We received our final briefing on the issues at hand and were let go to plan our route with our advocacy teams.

It was finally time to take the fight to Capitol Hill. A brisk ten-minute walk led us to our first stops to visit members of Congress. The Nebraska team consisted of myself and Maureen Grace from Omaha, Dale Gibbs and Michael Gibbs from Kearney, and Rick Starks from Haigler. Dale, Michael, and Rick met with Adrian Smith, who represents Nebraska's Third District, while Maureen and I met with Dustin Ervin, a legislative aide to Don Bacon of Nebraska's Second District. Dustin listened to me tell my son Elliott's story with genuine concern as I showed pictures, discussed cost of healthcare, and how their position on healthcare could affect the bleeding disorders community.

After a detour through the awe-inspiring US Capitol building, the entire team went to the Senate side of the Hill to meet with Senator Ben Sasse. We met with one of the senator's legislative aides, who again listened to all of our stories. For me it was great to see various perspectives on Hemophilia. I'm a rookie to the scene and have only experienced Hemophilia as a caregiver.

Washington Days: A Recap

Dale has a wealth of knowledge from the healthcare side and Rick has an amazing story of being one of the oldest males living with Hemophilia B. The personal stories made me realize how important what we were doing truly was. Unfortunately, Senator Sasse missed our meeting and the powerful stories we shared, however he had impeccable timing to show up for a photo op as we were leaving his office.

Our final meeting was with a legislative aide to Senator Deb Fischer. We had a very nice conversation with the aide, who remembered Dale from a previous meeting. We again related our unique stories of living with a bleeding disorder and raised the issues that are important to the NHF as we head into the next election cycle. In all, I felt that our meetings were productive and that we did the most important thing that we can do as citizens, make our voices heard to our elected officials.

As our day on Capitol Hill ended, I couldn't help but smile as I saw red ties in the halls of every building. There were high fives and smiles exchanged from newfound friends and strangers who were now family. We encouraged each other and afterward talked about our experiences in talking about the issues with our legislators. I interacted with members of the bleeding disorders community from Hawaii, Minnesota, and Alabama who all had wonderful experiences meeting with their representatives. We came from near and far to advocate for the bleeding disorders community and left a lasting impression on our elected officials.

Rick Starks, Michael Gibbs, Maureen Grace, Dale Gibbs, Joe Mickeliunas

While 500 of us went to Washington, our work is not done. If you were unable to go to the Capitol, I urge you to contact your representatives and tell your story. Our members of Congress work for us and need to hear about what is important to us. Whether you call their office on the telephone or tag them on Twitter, it is imperative that we use our voices to let them know that we want them to support federal standards for public and private insurance. Take a drive to their office and let them know that we support programs at the CDC and HRSA that ensure access to care at HTCs. Go on Facebook and comment on your representative's page that you support a ban on lifetime and annual limits. The future of our community is in our hands. If we remain proactive and become advocates for the bleeding disorders community, we can ensure that we have access to the care that we need. I am already looking forward to next year's event and am ready to tell Elliott's story on the Hill again.

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

Indications

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).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADYNOVATE if you:
- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

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

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.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

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.

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.

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 the following page for ADYNOVATE Important Facts.

For full Prescribing Information, visit www.ADYNOVATE.com.

References: 1. ADYNOVATE Prescribing Information. **2.** Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2016 Nov 27. doi: 10.1111/hae.13119 [Epub ahead of print]. **3.** Data on file.

©2017 Shire US Inc., Lexington, MA 02421. All rights reserved. 1-800-828-2088.
SHIRE and the Shire Logo are registered trademarks of Shire Pharmaceutical Holdings Ireland Limited or its affiliates.
ADVATE and ADYNOVATE are trademarks or registered trademarks of Baxalta Incorporated, a wholly owned, indirect subsidiary of Shire plc.
S31486 05/17

Shire

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).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

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

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

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.shirecontent.com/PI/PDFs/ADYNOVATE_USA_ENG.pdf or 855-4-ADYNOVATE.

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.

Baxalta, Advate, and Adynovate are trademarks of Baxalta Incorporated, a wholly owned, indirect subsidiary of Shire plc.

Baxalta US Inc.
Westlake Village, CA 91362 USA
U.S. License No. 2020
Issued 12/2016

16I045-ADY-US S24587 01/17

Finding Your Future: Preparing for Your Educational Dream Now

Author: Jennifer Baumert

I have a dream….and so do you. Whatever it is, it inspires you and others close to you. Preparing to make that dream a reality means learning a lot about colleges/schools, work, finances, laws, insurance, medical systems, and your own bleeding disorder. Sound daunting? Learning some basics can get you off to a great start, and put you in touch with people who can help you along the way

Start as early as you can with:

1) **Learning to self-infuse.** It takes time to build the organizational skills you need to stay on schedule with medications, and the phlebotomy skills you need to be independent. Starting no later than the beginning of senior year in high school is recommended.

2**) Checking out educational paths that match your intended career path**. There are often several college majors that match up to the career you want. Information can be found online, in your local library, with a school counselor, or with a social worker at your HTC, if available. Try shadowing people in a job you think you might be interested in for a day, and ask questions. Many people are happy to share their stories of how they got where they are, and can give practical advice. Choose your study path to the goal, realizing that you can adjust it if need be.

3) **Wearing a medical alert bracelet or necklace.** Find one that fits you-sporty or stylish- and preferably is waterproof so you don't have to take it off while swimming or showering. This is important when you are living away from home, among people who are not aware of your bleeding disorder and what to do if you need help.

4) **Visiting colleges and trade schools.** It is important to see what is available to you, and at what cost. Even if you don't think you want to go to a big or small school, visit 1-2 just to be sure. Talk to students while you are there! You could be surprised to find you like something outside of your normal realm, and the opportunities available to you. Realize that many schools offer some type of financial assistance, and many full-time jobs provide money for classes. Schools may even negotiate financial assistance/pricing if you have competing offers from different schools.

5) **Keeping your grades in good shape, even with your bleeding disorder.** Schools reward good academic records, extracurricular activities, and people who are actively involved in their communities. Do your best to follow your treatment plan and stay in good health so you can reach your dream.

When it's time to transition:

1) Consider the size and type of campus you want, and the opportunities available. Do they have classes in the areas you want? Will local community classes transfer? Are the facilities adequate for you to maintain your exercise regimen or physical therapy exercises so you can stay in good health?

Finding Your Future: Preparing for Your Educational Dream Now

2) Investigate housing options-living on campus, at home, or in an apartment. Learn specific regulations about having a refrigerator for your medications, ability to keep medicines and iv needles in your dorm room, ability to do infusions in your dorm room vs. campus medical facility, how to handle used sharp disposal. Check your options for keeping your medication locked and safe. Where will ordered medications be received, and how will you be notified? Is refrigeration available until you can pick them up?

3) Look at transportation availability both on-campus and to needed off-campus areas. Are there transportation vans or buses you can use to reach classes/local work easily if your walking ability is limited or you get injured? Can you reach a part-time job you need to stay in school? Is there convenient parking if you have a car?

4) Check out the availability of on-campus medical care, access to local emergency care, and the location of the nearest HTC. Make sure to arrange at least one introductory visit with the HTC prior to starting classes, if possible. Many times they can help you with your transition questions. Also make sure your insurance covers treatment at all of the above facilities or make arrangements to have additional policy coverage. You don't want to have a large medical bill derail your educational dreams

5) Make sure you carry copies of all of your medical, pharmacy, and dental insurance with you in your wallet or purse. Also a list of your current medications and any emergency phone numbers staff would need to help you. Complete a medical power of attorney with parents if needed so they can access your medical records now that you are considered an adult.

6) Consider what you want to tell people close to you about your medical condition. Dorm reps, campus medical staff, and lab directors should have basic information so they can assist you if needed. What you tell roommates and dating partners (and when) is up to your discretion.

7) Investigate your financial options. Check out hemophilia-related scholarships, as well as any related to your college and particular interests. Many scholarship competitions are only open for a few weeks a year, so check frequently or set up scholarship website notifications to your email. Remember that small amounts add up to large amounts, so try everything you can to reduce your educational costs. If you are working full-time, check with your employer about reimbursement for college classes and any requirements. Your employer and any special groups you belong to may also have scholarship availability.

Remember to do your homework and make those daydreams a reality!

Why Walk, Why Now?

Unite for Bleeding Disorders

Social Media seems to have got a jumpstart on walk this year. Has .anyone else notice this? It is not only imperative you notice the change, but be willing to be the change with your Nebraska Chapter of the National Hemophilia Foundation.

We speak about advocacy and raising awareness year round, and this is EXACTLY what your walk does for you. Walk is not just one day. We UNITE our bleeding disorder community every single day. NHF and your Nebraska Chapter work tirelessly to ensure that the needs of the community are being met everyday. It is crucial that you join in with us, on Monday, on Tuesday...everyday to be bringing the walk to the forefront of our state. We want the UNITE walk to be recognized wherever we go. This is the key to having bleeding disorders talked about in everyone's homes, not just your home.

Ann Foster, our Gothenburg Walk Chair writes "The walk is important to me to bring continued and ongoing awareness of bleeding disorders. I don't want the walk or Hemophilia Awareness to be a one time event, but ongoing education!"

Our Nebraska Chapter is grateful for the work you do for our community, and there are steps you can take to help bring the UNITE walk into the ENTIRE state.

STEP ONE: Register your self and team for walk www.uniteforbleedingdisorders.org

STEP TWO: Customize your team page and personal page for the walk site

STEP THREE: Share your story

STEP FOUR: Meet with Kelsey to plan your walk strategy.

STEP FIVE: Have fun getting out in the community

START
Register Now!
www.uniteforbleedingdisorders.org
September 22, 2018

Now Approved

A ONCE-WEEKLY SUBCUTANEOUS (GIVEN UNDER THE SKIN) INJECTION FOR PEOPLE WITH HEMOPHILIA A WITH FACTOR VIII INHIBITORS

We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®. We thank you and celebrate with the community who made it a reality.

Discover **HEMLIBRA.com**

WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

HOW SHOULD I USE HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

WHAT ARE THE OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

The most common side effects of HEMLIBRA include: redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.

Medication Guide Brief Summary
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

- Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.
- HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

BEFORE USING HEMLIBRA, TELL YOUR HEALTHCARE PROVIDER ABOUT ALL OF YOUR MEDICAL CONDITIONS, INCLUDING IF YOU:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

HOW SHOULD I USE HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

WHAT ARE THE POSSIBLE SIDE EFFECTS OF HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

The most common side effects of HEMLIBRA include:
- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

HOW SHOULD I STORE HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than 7 days at 86°F (30°C) or below.
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

GENERAL INFORMATION ABOUT THE SAFE AND EFFECTIVE USE OF HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

WHAT ARE THE INGREDIENTS IN HEMLIBRA?

Active ingredient: emicizumab

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048
©2017 Genentech, Inc. All rights reserved.
For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Issued: 11/2017

HEMLIBRA™
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

©2017 Genentech USA, Inc. All rights reserved. EMI/062117/0004
HEMLIBRA is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The HEMLIBRA logo is a trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan.
The Genentech logo is a registered trademark of Genentech, Inc.
All other trademarks are the property of their respective owners.

Genentech
A Member of the Roche Group

Kid's Corner

When Your Brother or Sister Has a Bleeding Disorder

Author: Amy Lynn Smith

If you have a brother or sister with a bleeding disorder, you probably have a lot of questions. You may wonder if you will get a bleeding disorder, too. If you have a small bruise or bleed and worry it might mean you have a bleeding disorder, ask your parents about it.

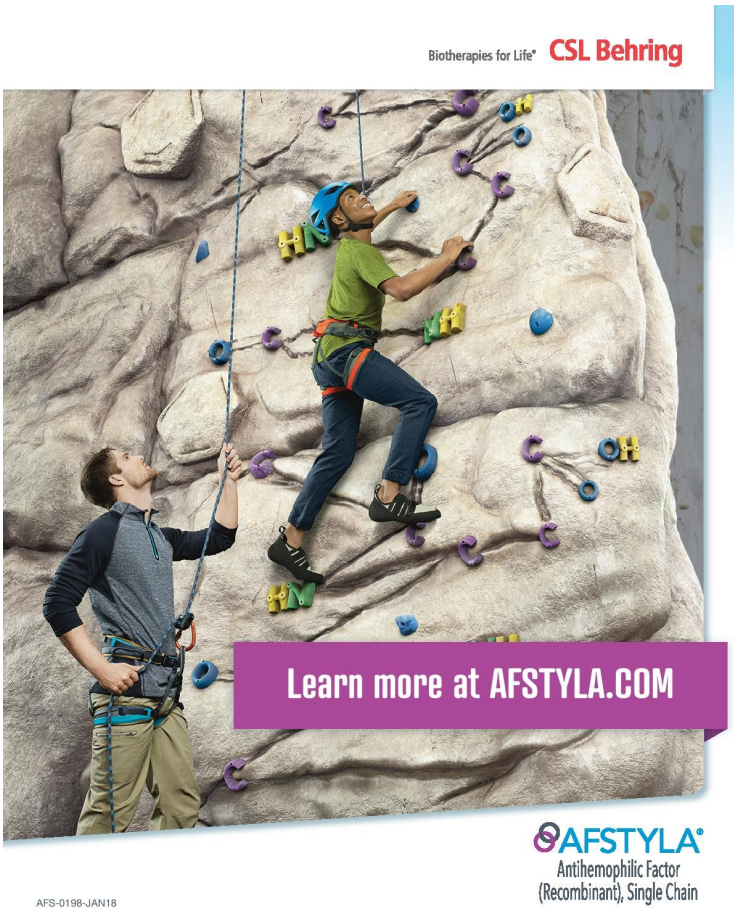
You may also wonder what it's like to have a bleeding disorder. Does your sister have a special doctor? Do those needles hurt? Maybe you worry about what games are safe to play with your brother or sister.

The more you know about your sibling's bleeding disorder, the less you will feel afraid or anxious.

Here are some other ideas that may help you and your family:

- **Learn more.** Find out about your sibling's treatment. Or just be there when your brother or sister wants to talk about it.
- **Share your feelings.** Talk to your parents if you're scared or if you feel like you don't get much attention. Those feelings are normal. Usually it feels better to share your feelings with others than to bottle them up inside.
- **Do things you enjoy.** Your parents may encourage you to do things with your brother or sister, as long as they're safe. But it's also OK to want to do things your sibling can't, like play basketball or ice skate. Talk to your mom or dad about trying a new hobby or sport—just for you.

At times, your brother or sister will need extra attention. Sometimes it may even seem as if your sibling gets all the attention. But remember that your parents are doing their best to love and support everyone in your family, including you.



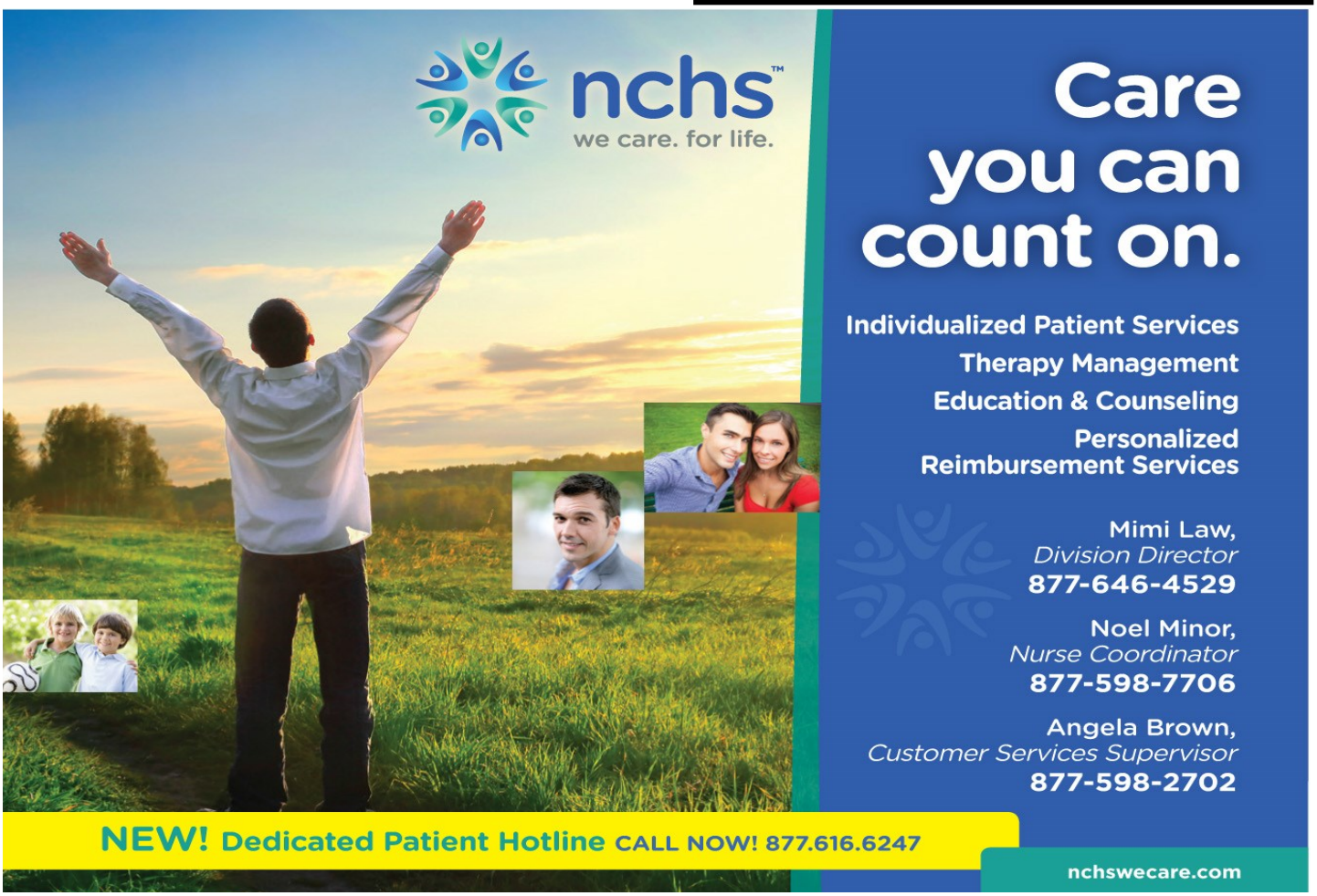
The June newsletter will be a printed and mailed newsletter.

Please help us make sure we have your correct address!

Email Maureen at mgrace@hemophilia.org

or

Kelsey at

kcunningham@hemophilia.org

to ensure we have your correct mailing addresses and email. We will be sending out an email form for this as well. Thank you!