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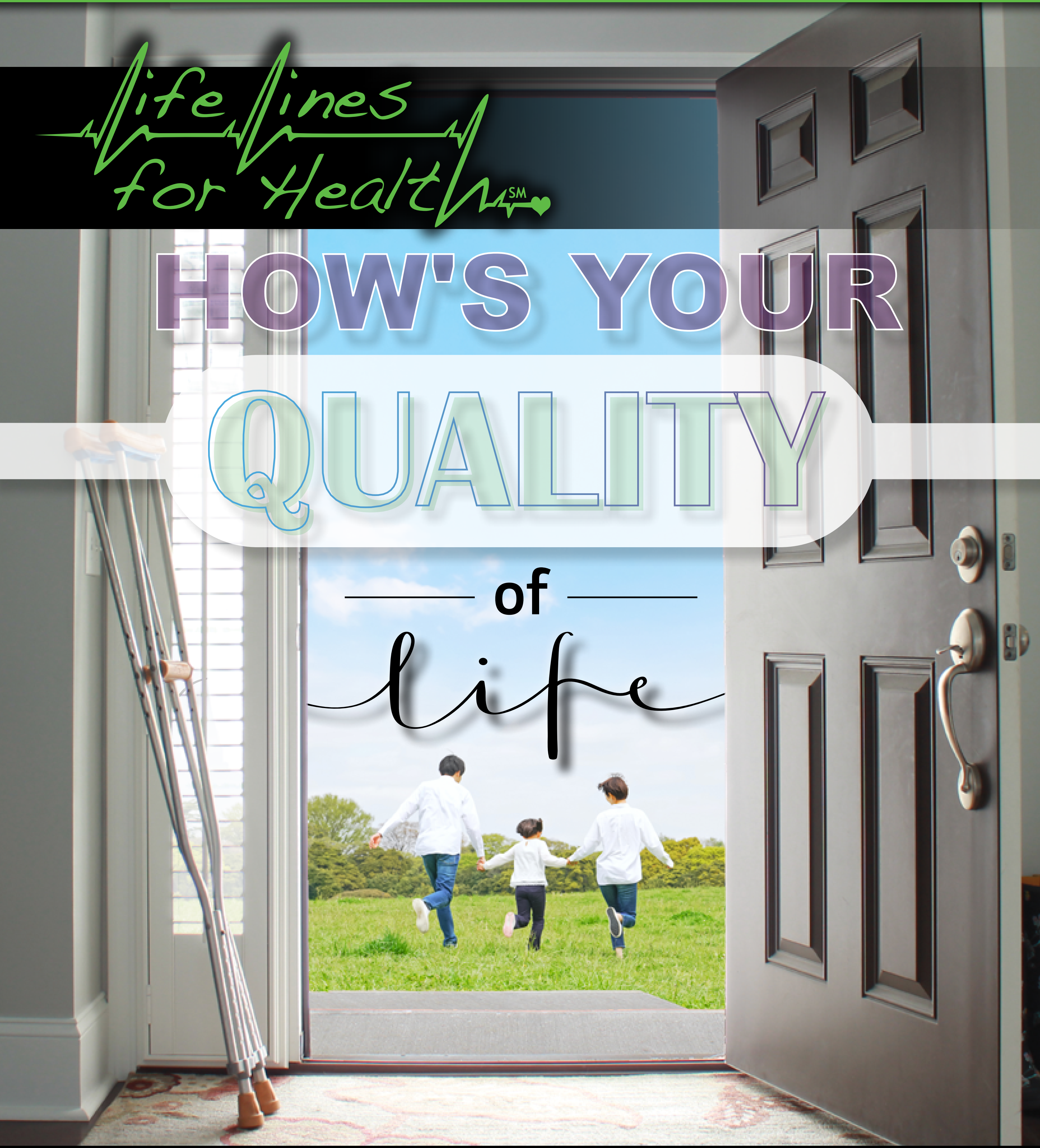
lifelines for Health℠



HOW'S YOUR QUALITY of life

Innovative Approaches: For Hemophilia A & B with/without Inhibitors

Impact of COVID-19 on Education ● **Accumulator Adjustors:** Court Ruling

Employer-Sponsored Health Insurance: What You Need to Know

New **CHES Initiatives** ● And more!

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This newsletter is designed to provide a forum for community members to express their views from an open and honest platform. It is meant to provide a sharing of knowledge and experience to help one another. Nothing in this newsletter is meant to replace the advice of your HTC, medical professional team or insurance provider. You are always urged to seek the opinion of a healthcare professional for treatment and your specific insurance provider for information.

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Letter From the Editors

Welcome!

What a gift it has been to see sooo many of you this summer and fall! It really felt like things are returning to "normal"-whatever that is. But your presence renews our determination and mission to continue to serve and support YOU-our community. Be sure to read our participant stories in Community Chatter and what it means to be together again.

Hopefully many of you now receive our bi-weekly e-newsletter from Paul Wheatley, Director of Communications and Development. It is FULL of great stories, and new developments in the rapidly evolving world of bleeding disorders. If you don't receive it, you can sign up here https://ches.education/communications-profile-form Our print LifeLines for Health publication will be published annually from now on. Archives of editions since 2013 can be accessed via ches.education/newsletter. There are 10 amazing years of articles and resources on topics such as pain, cannabis, inhibitors, ultra-rare bleeding disorders and the challenge for diagnosis for women to name a few. We are so grateful to our sponsor Takeda, for their steadfast support.

Donate now!

By the time you read this, we will be completing our first year as CHES Foundation, Inc. You may ask, "What Changed?" Merging nSpiration and CHES Foundation provided the best of both worlds. A 501c3 nonprofit that enables us to compete for additional grant funding and fundraising to provide the resources YOU have come to rely upon. What DIDN'T Change? The expertise and people you have come to rely upon at CHES for the last 14 years. We could never have done it without you-as a matter of fact-you suggested it! Want to help? Please consider making a tax-deductible contribution https://www.paypal.com/us/fundraiser/charity/3831253 or become a CHES Champion! Paul Wheatley has lots of ideas! pwheatley@ches.foundation

Our website, www.ches.foundation continues its transformation as we add resources and links to studies. In the ever-changing and challenging medical community, it is more important than ever to be a well- educated advocate. Like us on Facebook, follow us on Instagram to stay apprised of how to keep up to date and connected to programs, resources, webinars, and services. Don't forget to share with friends.

We have a lot to share in this issue and hope that you find an article that resonates with you. If you have an idea, comment, or suggestion, don't hesitate to let us know at info@ches.foundation. We love to hear from you!

It is so hard to believe the holiday season is upon us. Hoping your fall was glorious and you can use the winter months to rest and rejuvenate. We recognize the holidays are also a time of stress; so, if you are struggling, please reach out. We are here. Be safe, be well and we look forward to seeing you again in 2024!

- Janet Brewer & Eric Lowe

jbrewer@CHES.foundation elowe@CHES.foundation

"If you're someone people count on, particularly in difficult moments, that's a sign of a life lived honorably."

-Rachel Maddow

FEATURE

25 | How's Your Quality of Life?

Reflect on your own definition of a fulfilling life and explore the multifaceted concept of *quality of life* with seasoned therapist, Dr. Gary McClain. Find guidance to advocate for yours and your family's well-being through ideas to embrace life's possibilities and acquire a future with improved quality of life despite the challenges posed by chronic conditions.

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9 | 2023 CHES Programs: in Review

CHES hosted four live, national support experiences in 2023 that provided clinical/treatment education from healthcare professionals, positive mental health, and connectivity with others alike. In-person support focused on Hemophilia with Inhibitors and Ultra Rare bleeding disorders, including factor and platelet deficiencies.

WHAT's the PLAN?

35 | Impact of COVID-19 on Education

The pandemic had a profound impact on education, causing widespread disruptions and challenges. Children who rely on specialized services were especially hit hard, and trauma, in various forms, affected individuals differently - impacting attention, reactivity, and anxiety. Recovery is in motion through schools and resources, but these parent-pointers could be just what our students need to catch up at a more practical pace.

WHAT'S NEW

27 | Employer-Sponsored Health Insurance: What You Need to Know

Choosing the right health insurance, especially when managing chronic health conditions, is a complex task that requires careful consideration. More than half of the bleeding disorder community relies on employer-sponsored health insurance. Understanding the distinctions between these plans is crucial, as self-funded plans may not adhere to all Affordable Care Act provisions, potentially affecting prescription drug coverage and out-of-pocket costs.

31 | Accumulator Adjustors: a Small Victory in the Right Direction

Accumulator Adjustors are potentially problematic for anyone insured by a policy that contains this so-called "feature" by insurance carriers. And they are especially troublesome for anyone relying on cost-savings tools, such as co-pay cards to cover expensive treatment. But one court ruling has turned the tables. See if your household is affected.

32 | Hermanas de Sangre

CHES Foundation has been awarded the Sanofi Health Equity Accelerator Award. CHES' initiative, entitled *Hermanas de Sangre* [translated as *Blood Sisters*], is dedicated to providing culturally relevant support for Hispanic women, girls, and individuals with the potential to menstruate through a variety of these approaches.

33 | The SHEmophilia Initiative

Discover the impactful journey of CHES Foundation's SHEmophilia™ initiative, a year-long and well-received endeavor. SHEmophilia featured recorded interviews with courageous women, as well as, Dr. Robert Sidonio's valuable insights and suggestions for women seeking better understanding, diagnosis, care, and treatment.

2024 Education Programs

CHES™
FOUNDATION

nSpiration through Education

Comprehensive Health Education Services has been serving the needs of those with rare bleeding conditions since 2009.

As long time members of the bleeding disorder community, our mission is to inspire awareness and self-reliance for patients with chronic health conditions, their families, and their communities.

More details on our programs can be found on our website:
www.ches.foundation

Virtual Programming

We will host virtual sessions periodically throughout 2024. To receive up-to-date info on our virtual programs, live experiences, and other resources, use the QR code or link below.

To receive info on additional upcoming programs and webinars visit: https://ches.education/communications-profile-form

Webinar Recordings

Watch them on YouTube: https://www.youtube.com/@ches1

LIVE programs

After the Shock℠ inhibitor camp

June 21-24, 2024
Camp Zeke - Lakewood, PA

One Drop™
Ultra Rare Bleeding Disorders Consortium

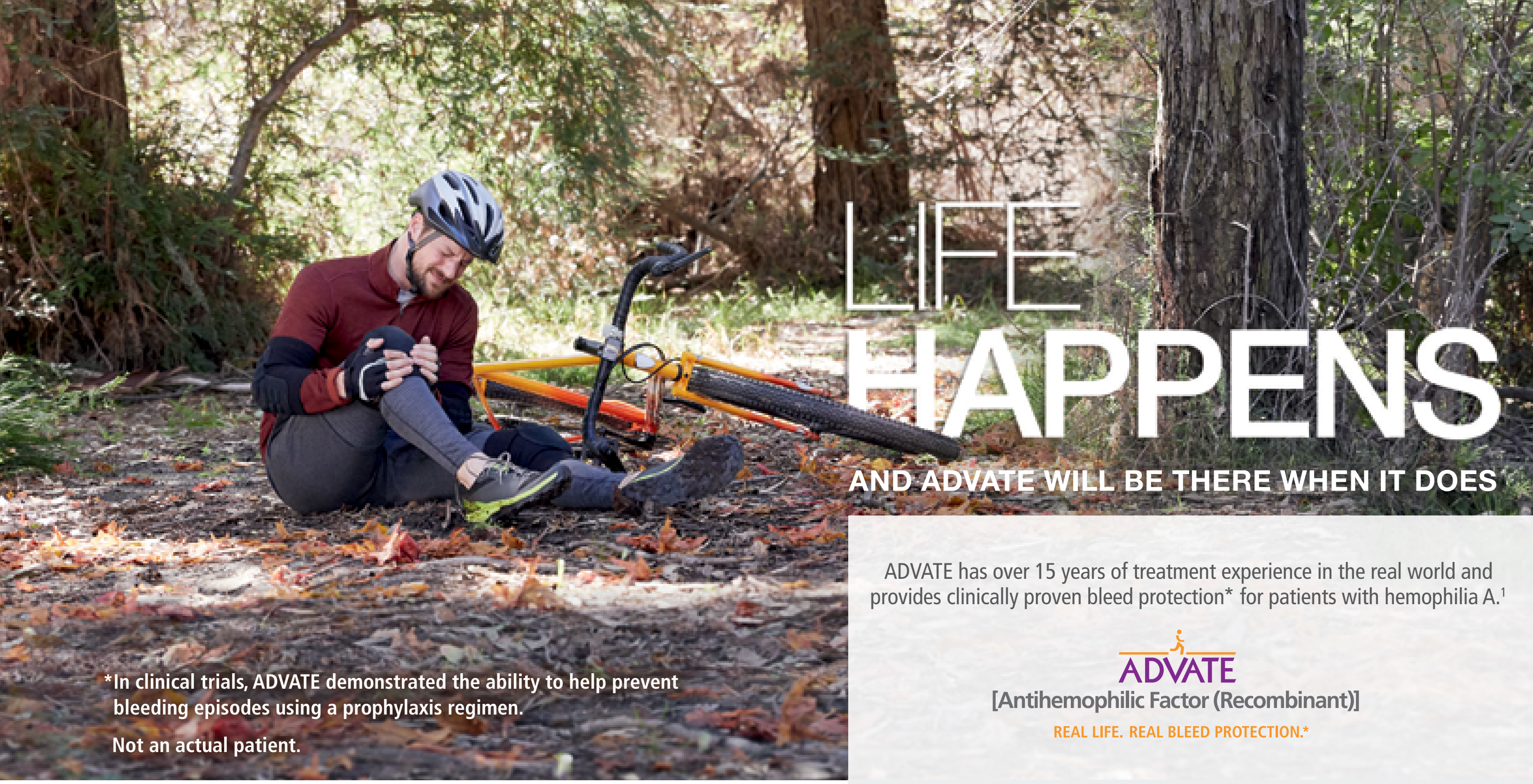
November 1-3, 2024
Tampa Marriott Airport - Florida

InhibitCon
Inhibitor Conference - ages 12 and up

&

MOMENTUM℠
CHES FOUNDATION

August 2-4, 2024
Houston Airport Marriott - Houston, TX



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

Not an actual patient.

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.[1]

ADVATE
[Antihemophilic Factor (Recombinant)]
REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

Prophylaxis with ADVATE prevented bleeds[1]

The ability of ADVATE to treat or prevent bleeds was evaluated in a clinical study using a standard prophylaxis, pharmacokinetic driven prophylaxis, and on-demand treatment.

53 previously treated patients (PTPs) with severe to moderately severe hemophilia A were analyzed. For the first 6 months of the study, patients received on-demand treatment. For the following 12 months of the study, patients received either standard prophylaxis every 48 hours or a pharmacokinetic-driven prophylaxis every 72 hours. The primary goal of the study was to compare annual bleeding rates between those receiving prophylaxis treatment and those receiving treatment on-demand. The number of bleeds per year for the 2 prophylaxis regimens were comparable.

- Those patients experienced a median of 1 overall bleed per year on either prophylaxis treatment vs 44 overall bleeds per year with on-demand treatment.[†] This represented a 98% reduction in overall bleeds per year.
- Zero bleeds were reported in 42% of patients (22 out of 53 patients) during 12 months on prophylaxis

[†] Median is the middle number in a group of numbers arranged from lowest to highest.

ADVATE Important Information

What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

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

What should I tell my HCP before using ADVATE?

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 ADVATE passes into your milk and if it can harm your baby.

What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP 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 ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE 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 ADVATE 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 ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

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 ADVATE on the following page and discuss with your HCP.

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

Reference: 1. ADVATE Prescribing Information.

ADVATE

[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. 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 ADVATE. If you have any questions after reading this, ask your healthcare provider.

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

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 ADVATE so that your treatment will work best for you.

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

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

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE 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 ADVATE by themselves or with the help of a family member.

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

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

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

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

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 ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

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.

Side effects that have been reported with ADVATE include:

cough
sore throat
unusual taste
abdominal pain
diarrhea
nausea/vomiting
headache
fever
dizziness
hot flashes
chills
sweating
joint swelling/aching
itching
hematoma
swelling of legs
runny nose/congestion
rash

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 ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE 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 ADVATE 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 ADVATE for a condition for which it is not prescribed. Do not share ADVATE 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 ADVATE. The FDA-approved product labeling can be found at www.ADVATE.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.takeda.com/en-us/patents/

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Innovative Approaches

FOR HEMOPHILIA A AND B WITH OR WITHOUT INHIBITORS

*by **Janet Brewer, M.Ed***

Ever wonder just how many studies there are in hemophilia? A quick visit to clinicaltrials.gov with search criteria of "hemophilia and USA" yields 310 studies with status' ranging from:

- Looking for participants (not yet recruiting to recruiting)
- No longer looking for participants (active, not recruiting, completed, and terminated)

If you have time, it is a fascinating review. Especially as you start looking at which ones are open to women; not many but it is improving! We looked at a few with novel mechanisms of action.

Safety, Tolerability, and Efficacy Study of Valoctocogene Roxaparvovec In Hemophilia A with Active or Prior Inhibitors

Sponsor: BioMarin Pharmaceutical

First Submitted: 12/10/2020

Last Posted Update: 01/04/2023

BioMarin is announcing the opening of their clinical study-BMN270-205 or GENEr8-inh in adult male hemophilia A patients with active inhibitors and/or a history of hemophilia A with inhibitors to study the safety and efficacy of Roctavian (Valoctocogene roxaparvovec). Roctavian was FDA approved on June 29, 2023. It is an adeno-associated virus vector-based gene therapy for the treatment of adults with severe hemophilia A without pre-existing antibodies to adeno-associated virus serotype 5 detected by an FDA-approved test. There are 5 United States study sites.

Severe, only

GENE THERAPY

8 DEFICIENCY

INHIBITORS

18 &⇧ AGE GROUP

https://clinicaltrials.gov/study/NCT04684940?locStr=United States&country=United States&cond=Hemophilia A With Inhibitors&term=gene therapy&intr=gene therapy&aggFilters=ages:adult,sex:m&rank=1

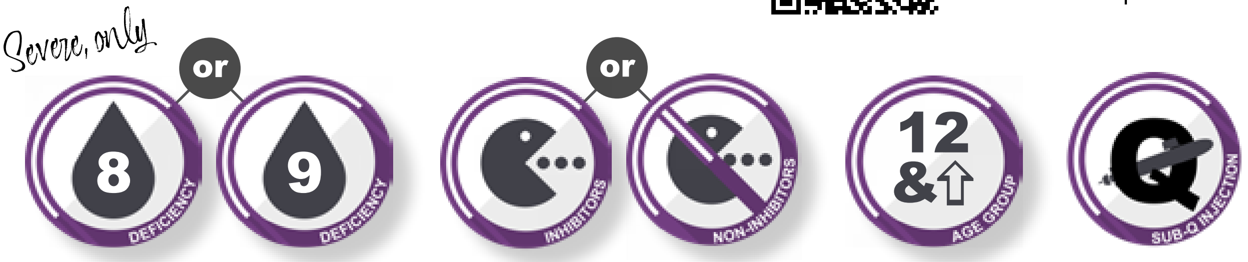
A Study of Fitusiran in Severe Hemophilia A and B Patients Previously Receiving Factor or Bypassing Agent Prophylaxis

Fitusiran is a subcutaneous, investigational small interfering RNA therapy, that reduces antithrombin to rebalance hemostasis in people with hemophilia A or hemophilia B, regardless of inhibitor status.

Sponsor: Genzyme, a Sanofi Company

First Submitted: 05/25/2018

Last Posted Update: 02/06/2023



https://clinicaltrials.gov/study/NCT03549871?cond=hemophilia&term=with%20without%20inhibitor&intr=fitusiran&rank=1

Open-Label Extension Study of Marstacimab in Hemophilia Participants With or Without Inhibitors

Marstacimab is a novel, investigational anti-tissue factor pathway inhibitor (anti-TFPI) that could become the first once-weekly non-factor treatment for people with hemophilia B and the first treatment administered as a flat dose (not weight based) for people living with hemophilia A or B.

Sponsor: Pfizer

First Submitted: 11/11/2021

Last Posted Update: 01/05/2024

https://clinicaltrials.gov/study/NCT05145127?cond=Hemophilia&intr=marstacimab&rank=2

Want to read more about current trends and updates on genotyping and more?

Subscribe to our bi-weekly e-newsletter at: mailto:newsletter@CHES.foundation or use the QR code

Research Study to Look at How Well the Drug Concizumab Works in Your Body if You Have Haemophilia With Inhibitors (explorer7)

Concizumab is a subcutaneous monoclonal antibody that targets the tissue factor pathway inhibitor (TFPI) to improve hemostasis in people with hemophilia A or B with inhibitors.

Sponsor: Novo Nordisk
First Submitted: 09/06/2019
Last Posted Update: 12/05/2023

8 DEFICIENCY or 9 DEFICIENCY
INHIBITORS
12 & ⇧ AGE GROUP
SUB-Q INJECTION

https://clinicaltrials.gov/study/NCT04083781?cond=hemophilia&intr=Concizumab&rank=1

The following is a research project conducted by Haemnet, a European specialist research and communications consultancy working in the bleeding disorders community who has partnered with manufactures such as Biomarin, CSL Behring, Novo Nordisk, and Roche.

Help us make sure your voice is heard

Ask any clinician and they'll tell you that treatment of bleeding disorders is so good that patients' lives should be relatively easy. Maybe that's the case if you just look at the results of clinical trials. But we know – and you know – that is far from the case in everyday life.

The fact is living with – or caring for someone who lives with - a bleeding disorder can be tough.

We at Haemnet firmly believe that we should do all we can to reflect the everyday lives of people who live with bleeding disorders and to do all we can to make them easier.

Haemnet is a UK-based research/communications consultancy working in the bleeding disorders community. The team includes nurses who have worked in haemophilia clinical and research worlds; other team members have bleeding disorders themselves or in the family.

All of our research is designed to make the patient (or parent/carer) voice heard. We do that by talking to patients and collecting the everyday information that doesn't get reported in clinical trials, and reflecting that back to clinicians and industry. We also work with patient organisations so that our findings have real impact and can be used for advocacy at local, regional and global levels.

At the end of each study, we feedback our results to participants through publications, animations and blogs.

FVIID◎360

Haemnet is undertaking a research project to better understand the challenges those living with Factor VII Deficiency face in every day life.

Take part in the survey at https://haemnet.typeform.com/FVIID360

There are 6x £50 Amazon Gift Cards to be won!

We have recently completed a study into Glanzmann's Thrombasthenia – thank you to everyone who completed that survey, the results of which will be published and shared next year.

We have just opened a study looking at Factor VII deficiency that is recruiting into a survey and opt-in interview, all of which will be done on-line.

We'd love to hear from you. If you are interested you can scan the QR code below, type the link into your internet server or download our new SEEK by Haemnet app from Google Play or the Apple app store.

-Sincerely, Haemnet

CHES 2023 Programs… in Review

by ***Janet Brewer, M.Ed***

CHES Foundation was honored and thrilled to provide 4 live, in-person patient community educational events in 2023 with a huge thanks to our sponsors.

After the Shock: an Inhibitor Family Camp

June 23-26, 2023 at Camp Zeke - Lakewood, PA

Camp Zeke has been the home of CHES' After the Shock - annual camp program for families with a child ages infant to 18, affected by an active inhibitor since 2018. CHES as an organization has been offering an Inhibitor Family Camp since 2010, when we partnered with Paul Newman's Serious Fun Network at Victory Junction in Randleman, NC. Over the years, we offered 2 camps per year, one at Victory Junction and one at The Painted Turtle in Lake Hughes, CA.

It is an immensely valuable program to our attendees, with past campers now in the role as Camp Counselors and Mentors. They allow parents free time to attend education sessions, an extra helping hand, and a role model for affected campers and siblings who share similar experiences.

This year we welcomed families to Camp Zeke for a wet, but wonderful camp weekend! Educational sessions included information about current inhibitor treatment trends, mental health maintenance, a physical therapy session where we body painted our muscles, infusion tips and tricks, and rap sessions. And of course, all the usual camp activities from boating activities, outdoor games, ziplining, swimming pool, arts and crafts, and archery!

We are eternally grateful to Novo Nordisk for their legacy sponsorship of Inhibitor Family Camp and now After the Shock. We look forward to After the Shock 2024 at Camp Zeke June 21-24, 2024.

100% **of our participants say this program supports their mental health!**

...but that's not all they said. Here's just a few of many comments.

"It's personal, balanced, and informative on a level that I needed. CHES cares and is compassionate to everyone here, new, or returning we always feel loved, supported, and heard before we leave."

"ATS [After the Shock] gave our family the opportunity to connect and collaborate with other families who live daily in a small subset of the hemophilia community. We found support that is often missed when discussing hemophilia."

More info on After the Shock
https://ches.education/after-the-shock

Made possible through the support of:

novo nordisk®

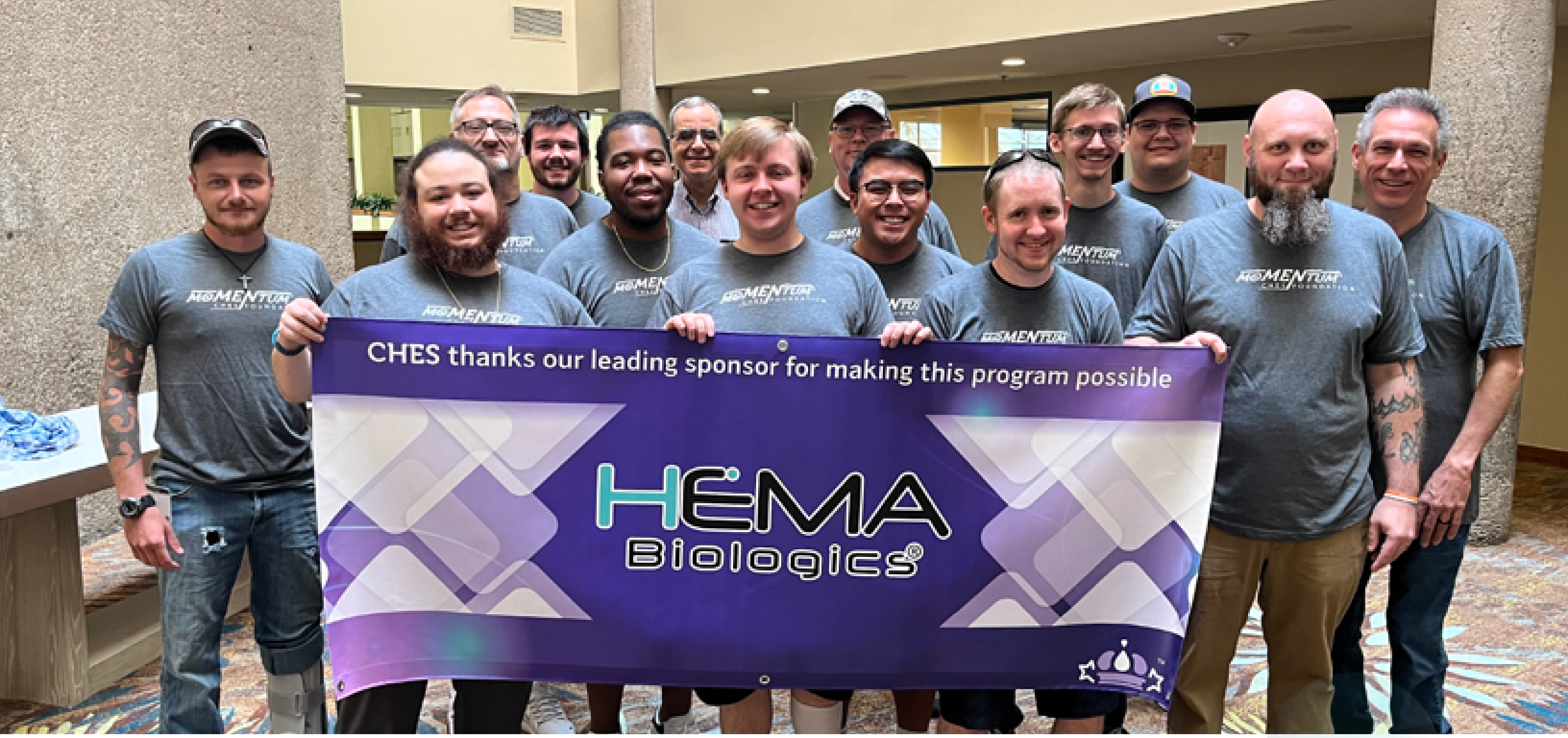
MOMENTUM℠
CHES FOUNDATION

Momentum: Men's Inhibitor Retreat

July 28-30, 2023 at Westin Atlanta Airport - Atlanta, GA

The Momentum program began in 2015 as a place where adult men with inhibitors could gather in an environment that supports their unique needs. An environment that embraces aging, joint damage, coinfection, pain, and the unique mental health challenges that come with living with a lifelong inhibitor. Sessions this year focused on the evolving landscape of inhibitor treatment with Dr. Guy Young, Orthopedics and Joint Health with Dr. James Luck, Kinesiotaping with Kim Baumann, MPT and Updates in Hemophilia Inheritance with Dr. Megan Brown.

We are especially grateful to HEMA Biologics for their legacy sponsorship of this valuable, one-of-a-kind program. Stay tuned for exciting information regarding expansion of this program scheduled for August 2-4 of 2024.



100% of our participants say this program supports their mental health!

...but that's not all they said. Here's just a few of many comments.

"The sessions were relevant and informative, the group of guys were incredible, and the atmosphere and culture of the weekend was such a great difference from typical inhibitor summits or hemophilia events."

"I like that this is one of the few events where we can connect with our fellow inhibitor blood brothers. The sessions are always great and helpful in keeping us informed."

More info on Momentum
https://ches.education/momentum

Made possible through the support of:

HEMA Biologics®

One Drop™

Ultra Rare Bleeding Disorders Consortium

One Drop: the Ultra Rare Bleeding Disorder Consortium

November 3-5, 2023 at Tampa Marriott Airport - Tampa, FL

Since 2012, CHES has been supporting the FVII community, and in 2016, the Glanzmann's Thrombasthenia community. In 2020, both individual programs combined to include those with ultra-rare factor and platelet disorders for one conference to serve the needs of all with ultra-rare bleeding disorders. We were honored to have Dr. Meera Chitlur and Dr. Rajiv Pruthi as our physician experts to lead sessions on all aspects of rare bleeding disorders for adults and teens. Sessions were provided that addressed the mental health challenges of rare bleeding disorders with Dr. Anna Bell. An ABC's of Anatomy physical therapy session was provided by Dr. Angela Forsyth and Kim Baumann. Self-infusion classes are a must session for participants with our treasured and experienced nurses. Separate teen and childcare sessions are offered throughout the weekend.

We are grateful to Novo Nordisk for their legacy sponsorship of the One Drop program. We look forward to next year's program on November 1-3, 2024, at the Tampa Marriott Airport, Tampa FL.

"We love the generosity, adaptability, experts, and staff passionate about ultra-rare disorders. The opportunity to be with other families and share strength, experience, and hope is crucial."

"The quality of the speakers is excellent. I love the level of science that is provided. Many other programs shy away from providing the science. Meeting and interacting with others that get it."

'23
TAMPA, FL
One Drop™
CHES FOUNDATION

More info on One Drop
https://ches.education/one-drop

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LEVERAGE℠

LEVERAGE: Experiental camp for adults with inhibitors

September 10-14, 2023 at Camp Collins - Gresham, OR

Leverage began in 2015 as a partnership between Comprehensive Health Education Services and GutMonkey to provide a program for 10-15 young adults from ages 18-40+ affected by hemophilia with an inhibitor. It is designed to provide truly life changing experiences for participants to visit awe inspiring outdoor spaces and challenge themselves in ways they never have before through a series of outdoor adventure activities. The unique aspect of the program is to allow individuals to participate in specially designed experiential educational experiences to challenge real and perceived physical and emotional boundaries.

It was a thrill to bring this live program back after COVID to participate in white water rafting, ropes courses, art therapy, and experiential games.

We are especially grateful to HEMA Biologics for their sponsorship of this valuable program experience!

In collaboration with:

GUTMONKEY
BE BRAVE.

Made possible through the support of:

HEMA Biologics®

"This was one of the best programs I have been to in my life. Everyone was so good and open, and the program was very insightful."

"I will benefit immensely from this. This made me realize that I need to take care of me and my happiness first instead of the needs and wants of someone else. It also showed me that we have such a great support system within our community."

More info on Leverage
https://ches.education/leverage

How's Your QUALITY of Life

As a therapist, I frequently talk with my clients about their quality of life. In fact, assisting them in increasing their quality of life is often one of our goals. As you might agree, quality of life is an especially important concern and, yes, challenge, for individuals and families who are living with a chronic condition like a bleeding disorder. Agreed?

Now, you may already be asking, that's a pretty general term so how do you make that an actionable goal. That's a good question. So, let's take a step back and consider what having quality of life actually means.

Just What Is Quality of Life?

Google provides what I think is a nice overall definition of quality of life:

"The standard of health, comfort, and happiness experienced by an individual or group."

Three important words here: standard, individual, and group. What that says to me is that quality of life is defined by the individual or the group. Group can include the family the individual belongs to. And standards can vary from one individual or group to the next. Your definition of quality of life may be very different from mine.

By: **Gary McClain, PhD**

QUALI

FEATURE

To help further define quality of life, let's take a look at the elements that make up quality of life. These include:

Your ***health****, of course. I would place that at the top of the list. And keep in mind that health includes both your physical and your emotional health.*

Access to adequate ***healthcare****, another important topic for members of this community.*

Access to ***education****, something else that we talk about often in the bleeding disorder community.*

Feeling ***safe*** *and* ***secure****, in our homes and in our communities. Just read the news if you have any doubts about how safety and security contribute to quality of life. Your physical surroundings have an impact on your quality of life, like clean water and air.*

Meaningful work*, as you define it, is an important aspect of quality of life. Holding a job, or choosing not to work outside of the home. It's all work. I would include work-life balance here as well. Again, as you define it. Some of us live to work, others work to live.*

Adequate ***financial resources****. Again, this might be defined by the individual and family. A livable home and regular meals might be considered necessary for quality of life, it sure is for me. Someone else may consider Disney World and a cruise to the Bahamas as necessary for a quality life.*

To me, ***social interaction*** *is a really important factor in having a quality of life, and I often talk to my clients about how to increase their interactions with other people. We need other people in our lives: friends, family, community involvement.*

Being able to ***make your own decisions****, or at least to be considered in decisions that are made about you, contribute to quality of life. We talk about this so often with other members of the bleeding disorder community, right?*

Social status *might be on your quality of life list, whether that means being considered a leader in your community or being considered wealthy.*

As you may have guessed by now, I break down the components of quality of life with each of my clients. We define quality of life based on their vision of their own quality of life. We break down the overall goal of quality of life into realistic and reachable goals and then work on them together.

So, some questions for you to consider: What does quality of life mean to you? Right now, what does your individual quality of life look like? What does quality of life for your family look like?

Chronic Conditions and Quality of Life

Please pardon me while I take a brief moment to preach to the choir.

Let's be honest with each other. Living with a chronic condition like a bleeding disorder has a big impact on your quality of life, for the family member living with the bleeding disorder, as well as other family members. Preventing bleeds and responding when they occur. That's a starting point. But also dealing with healthcare providers and insurance companies or Medicaid. Copayments. Vacations versus staycations. Household chores. Making sure everyone in the family feels cared for and valued. And on and on. I am sure you have additional challenges unique to you and your family.

My quality of life flew out the window

Quality of life? For me?

But let's also not assume quality of life is out of reach. Almost every week, I talk to a client living with a chronic condition who says to me, **"My quality of life flew out the window."**

For a mental health professional, hearing those words is like dangling red meat in front of a lion. I know I have my work cut out for me. I accept the challenge! Because I truly believe that regardless of the limitations and frequent curveballs a chronic condition, like a bleeding disorder, can throw in your path, having quality of life is not out of reach.

So… ready to see how you can have more quality of life for you and your family?

Building More Quality *INTO* Your Life

Quality of life is actionable! It's possible to increase the quality of life at your house by paying more attention to the areas of your life that, for you, are important to achieving quality of life. Here are some ideas to consider to help you achieve more quality.

1 Building More Quality into your Life

Pay Attention to Where You are Paying Attention!

As a mental health professional, of course I can't help but to place your emotional wellness at the top of the list of ideas to enhance your quality of life. But I think you might agree with me that your mental health is a big factor in how you experience the day. So here are some ideas for helping your day go better:

Take a look at your perspective. Are you all about where you aren't in your life or where you are? You can choose to get down on yourself for not living up to an ideal image of where you think you should be in life, or you can choose to focus on where you are now. It's up to you. How about looking not at where your life is lacking in quality – by your definition – and focusing on where you are achieving quality!

Start out the day with gratefulness. Take a moment every morning to think of something you are grateful for. Encourage friends and family members to do the same. Psychological research has shown that being grateful keeps you more open to what's possible. Gratefulness picks up your mood. Mood, in turn, affects your quality of life.

Accept life on life's terms. When you accept where you are now in your life – and tell that critical voice to be quiet – you're on your way to being more compassionate toward yourself. Along with freeing yourself up to start looking at what's possible! How do you come to this place of acceptance? It starts with the messages you play inside of your head. Acceptance is a big one!

The worst thing that can happen is not always the worst thing that can happen. It's easy to get caught in the trap of "catastrophizing," making every situation that comes up feel like an emergency. Take a step back and ask yourself: Am I looking at life through the lens of fear? And is this causing me to create the worst possible scenario that may not even be realistic? Catastrophizing and quality of life don't go together.

Remember: Having a chronic condition doesn't mean you are "damaged goods." When I talk to clients about the impact of their chronic condition on their life, the word that often comes up is the word "normal." They worry that they aren't like other people. And their biggest fear about not being normal is being socially disconnected, not included in social events, not fun, not datable. All because their chronic condition feels like a stamp on their forehead. Your bleeding disorder is a part of your life, sure. And yes, it presents responsibilities and challenges. But this is a slice out of a very multi-faceted pie. It is not all of who you are, it's not all of who your child is. Shift your perspective by embracing the kind, caring, engaging person that you are inside, and then commit to showing that to the outside world! Teach your child to do the same.

Building More Quality into your Life

2

Manage Your Stress

I never stop talking about the importance of stress management. Why? Because my clients never stop talking about their stress. You've probably heard all the stress lectures. They never go out of style. Let me just say: Better stress management equals better quality of life.

Monitor yourself and your family members for signs of stress. And then address it. What are your stress buttons? And when you are feeling stressed, where do you feel it? How does your stress affect your behavior? Your stress affects your emotional wellness. In turn, when you are stressed, you also affect the mood and the quality of life in your home. So, pay attention to yourself. While you are at it, also watch for stress signs in your partner and your children. What helps you to bring the stress down in your home? Keep your stress management techniques handy!

Look for ways to relax. Doing things to promote your own calmness and peace of mind can go a long way toward healing yourself emotionally. Taking a walk, sitting in a quiet place, listening to soft music ... choose an activity that helps you to relax and build it into your schedule. Especially when your emotions are threatening to boil over.

Treat the part of your brain that doesn't talk. You've probably been hearing a lot about the benefits of yoga and meditation. Regularly practiced, they can help you maintain your inner balance so that when a stressful event does occur, you are that much better prepared to handle it emotionally. Yoga and meditation, even martial arts, can have a positive impact on areas of the brain that you are less aware of yet are also involved in your emotions. Let's work on tackling the stress that impacts our quality of life from all angles!

Building More Quality into your Life

3

Pay Attention to Wellness in the Other Parts of Your Life

Body and mind work in tandem. Don't forget to pay attention to your physical health.

Be aware of your basic self-care needs. Take an inventory of what you need to function at your best every day. What do your meals need to look like? How many hours of sleep? Exercise? Breaks? Following your healthcare provider's advice for managing your bleeding disorder? Sure, on some days, you may have to settle for meeting the baseline requirements – diet, medication, and as much rest as reasonably possible. But don't allow yourself to let the self-care regimen slide day after day.

Watch out for unhealthy coping. During the pandemic, I often spoke with clients who said, "I used to have a glass of wine in the evening. Now I drink the whole bottle." It's all too easy to use alcohol as a way of coping with difficult situations and the feelings that come up. So is misuse of prescription medications as well as marijuana and illegal substances. When you are using substances, legal or otherwise, to cope, you are essentially kicking the can down the road, and setting your self up for a fall. And short-circuiting your quality of life.

Encourage Better Quality of Life in Your Home and Community

4

Building More Quality into your Life

Decide to be kinder. Take time to give other people compliments. Make it a point to say thanks for acts of courtesy and kindness in your daily life, no matter how small. Look for reasons to give compliments. And say thank you when someone compliments you. Own it, don't brush it off. Make giving compliments a part of your daily interactions with people around you, starting at home. Smile more, even if that means smiling first. Kindness is a boomerang, pass it around and sooner or later it comes back in your direction.

Encourage other people for their strengths, starting with your family members. When someone does well, your partner, your child, for example, focus on their strengths and how you or others benefited. Identify strengths in others. Identifying strengths builds confidence, and relationships, criticism does just the opposite. Get specific, e.g. "You're really good at..." This encourages others to be grateful for their own gifts. Let's help each other to feel good about ourselves.

When hit with a challenge, look for the opportunity to connect with your support team. Ask yourself: Is this a chance to learn to work together better? To share our collective expertise? To learn from each other? To strengthen our bond as family members, friends, co-workers? Think back to situations that felt hopeless at first but left you feeling stronger, supported, better prepared for the next challenge... And yes, grateful for the people who have your back. Support from other people is a key ingredient in quality of life!

Some Advice for Parents

Parents can do a lot to bring more quality of life into their home, starting with creating an environment where emotional wellness is valued. Here's how:

Make your home a safe place for sharing thoughts and feelings. Kids have all kinds of emotions. Ask your children what kinds of feelings they are having. Listen without judgment. Encourage your children to open up, to express and talk about their emotions. Talk about your own feelings. Keep in mind that children have a sixth sense about what their parents want to hear about and don't want to hear about, so make it clear to your kids that they can speak about whatever's on their mind.

Share the decision-making. While you're at it, give your children some control in their lives. Listen to their opinions. Negotiate. Encourage good decision-making and accountability.

Talk to your kids about unhealthy coping. And that may mean talking to them about alcohol and drug use. So back to my previous point. If your home is a safe place for your kids to share what's on their mind, they will also feel more comfortable talking with you about what they are being offered by other kids at school, including alcohol and drugs. Open the conversation. Ask questions. Don't hesitate to make your concerns known. Keep an eye on your kids, who they are hanging out with and what they are doing. Give them lots of love and support. Speak up when you have a concern and talk it out together. And connect them with a mental health professional if they need it.

Advocate for yourself and your family. Do your research on you or your child's bleeding disorder and its treatment. Stay up on the latest research. Ask your healthcare providers questions. Give yourself permission to question their recommendations, too. And advocate at school and in your communities. Sometimes you have to make some demands to help assure quality of life for yourself and your children. And in the process, you also are acting as a role model for your children in how to advocate for their own quality of life.

Going Forward...

Here are a few additional ideas to create more quality of life at home:

Stay focused on the possibilities that each day holds. It's all too easy to get caught up with what's hard in life. If you need some help, just take a look at the daily news. Sure, we all have some bad days, but here's something to consider: A disappointment or a setback is a blip on the radar screen of your life. It's not all of your life. In other words, a bad day doesn't mean a bad life. And a bad day makes us all that much grateful on the good days.

Stay optimistic. Back to the big picture. The way things look right now isn't necessarily the way they will look in the future. Life never stays the same for long. And you're a resilient person. Remind yourself every day that life is good. Remind your kids, too.

Love yourself. The road hasn't been easy. Start by going easier on yourself and not piling on the self-criticism. Give yourself a few words of encouragement. Do things you enjoy, that promote your wellness, that connect you with people you care about. Watch your self-care. Have more balance in your life.

Let go of resentment. Sure, you've had some big disappointments along the way. And that's left a lot of hurt behind. But the past is past. Sitting with all that resentment is keeping you stuck there. Make a conscious effort to give up on changing what's already happened or getting back at someone who caused you pain. Let's move on.

Have a vision. What's possible in your life? I mean, what's possible when you stop placing all those limitations on yourself? Be realistic but also have a vision for your future: The kind of person you want to be, how you want to be living, who you want to be to the people you value the most. Have a vision for the quality of life you want to work toward.

Quality. On Life's Terms. On Your Terms.

I can't write an article on a mental health topic without reminding you that we are not in control of most of life. If you or a family member are living with a chronic condition like a bleeding disorder, I'm probably preaching to the choir again. Quality of life begins and ends with acceptance of life on life's terms, including the terms set forth by your bleeding disorder, or your child's bleeding disorder, and your healthcare providers. But there's room in the middle for finding quality, in your life and in your home, on your terms.

What does QUALITY of LIFE mean at your house?

Take time to define it, and then take action.

Dr. McClain's book, "The Power of Closure: Why We Need It, How to Get It, and When to Walk Away," will be published by Tarcher Perigee in the spring of 2024.

Scan with your smart device to access Dr. McClain's support site.

Just Got Diagnosed

Gary McClain, PhD Gary McClain, PhD, is a therapist, patient advocate, and educator, specializing in helping clients deal with the emotional impact of chronic and life-threatening health conditions, as well as their families and professional caregivers. He works with them to understand and cope with their emotions, to learn about their lifestyle and treatment options, to maintain compliance with medical regimens, to communicate effectively with each other and healthcare professionals, and to listen to their own inner voice as they make decisions about the future. His website is JustGotDiagnosed.com. He is a frequent presenter at bleeding disorder conferences.

Employer Sponsored HEALTH INSURANCE

What You Need to Know

by *Michelle Rice*

Living with a chronic health condition and trying to find the right health insurance can be a challenge. Then add on your family's health care needs, and it can be quite a process. Your health plan choice can impact both your physical and financial health. Do your homework!

As the cost of healthcare has increased over the years, health insurers and employers who provide health insurance to their employees continue to search for ways to cut costs.

About 65% of bleeding disorder community members receive their coverage through an employer. Employer plans are classified as fully insured or self-funded plans. It is important that you understand the difference between the two types and what it may mean to you. While it is possible that a small employer may be self-insured, it is rare. Typically, most self-insured employers have 400 or more employees. One of the biggest differences is that self-funded plans do **NOT** have to comply with all provisions of the Affordable Care Act (ACA): these plans aren't even **required** to cover prescription drugs, and this could result in a big difference in your out-of-pocket costs!

FULLY INSURED VS SELF-FUNDED

FULLY INSURED	SELF-FUNDED
PAYMENTS The employer pays monthly premiums to an insurance carrier.	**PAYMENTS** The employer pays fixed cost administrative fees, stop-loss premiums, and variable costs.
ASSUMPTION OF RISKS The insurance company assumes the risk.	**ASSUMPTION OF RISKS** The employer assumes the risk.
PLAN DESIGN The employers are more limited by insurer's plan design options.	**PLAN DESIGN** Employers have more control and freedom over plan designs.

Being able to access health coverage through an employer is often a more affordable way to obtain a comprehensive health policy. However, as healthcare costs continue to rise, employers have had to find ways to lower their costs. Some strategies they may use to accomplish this are listed below.

Cost-Lowering Employer Strategies:

- Increase the employee's share of the monthly premium cost
- Offer only one health plan option (typically most employers have offered multiple options for employees to choose from, such as a PPO, HMO and High Deductible plans)
- Offer employee only plans

A few other cost saving strategies that are not as "easy" to identify but that can have a significant impact on your wallet and on access to the medications you need are listed below. It is imperative that you review your plan closely to see if it is subject to any of these programs/policies.

Sneaky Cost-Lowering Insurer Strategies:

- Accumulator Adjustor or Maximizer programs
- Stricter prior authorization (PA) and utilization management requirements (i.e. quarterly PA approvals vs annual, requirement to try and fail a particular drug before another, etc.)
- Exclusion of certain specialty pharmacy medications which **MAY** include hemophilia therapies

Accumulator Adjustors

Accumulator adjustment programs prevent any co-payment assistance that may be available for high-cost specialty drugs from counting toward a patient's deductible or maximum out-of-pocket expenses.

Read the latest update on accumulator adjustors on page 21.

https://www.arthritis.org/advocate/issue-briefs/accumulator-adjustment-programs

BEWARE:

- If you find that your plan has an accumulator adjuster or maximizer OR is excluding your specialty medication AND has referred you to a third-party program to "assist you in gaining access to your medication" please reach out to one of the many resources available to you as a member of the community. The National Bleeding Disorders Foundation *(formerly NHF)* payer and HFA policy teams, your local chapter or HTC social worker can provide you with more information about these programs and how they may impact you. These are tricky situations, and we recommend getting some help.

Here are some additional tips for successfully choosing a health insurance plan:

Begin by making a list of which providers and/or other benefits, including prescription medications are critical for you & your family. Examples include:

- Your hematologist
- Other specialists that are critical to you and/or your family
- Primary care provider (PCP)
- Your HTC
- Your bleeding disorders therapy
- Prescriptions (don't forget to include your family's needs)
- Out of network coverage (not all plans offer out of network coverage)

What are the costs associated with each plan option including premium, copays, and coinsurance?

Then identify which plan best suits you and your family's health care needs.

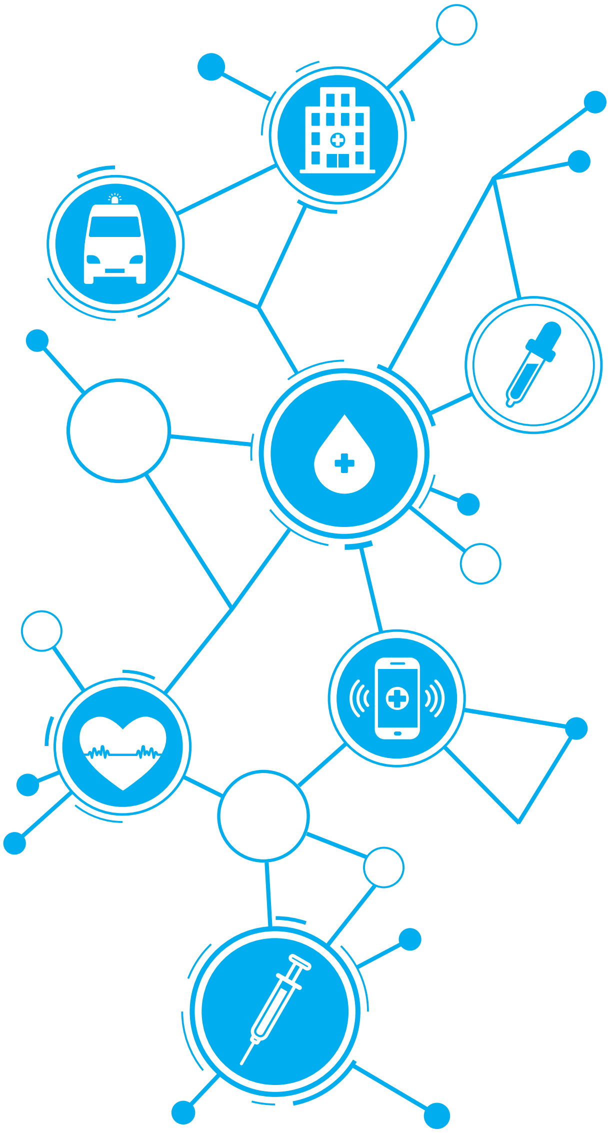
When making your final decision, think about trade-offs. You may not find one plan that has <u>everything</u> you **WANT**. What are the few things that you can't give up – things that are "non-negotiable?"

For example:

You find a plan that has your hematologist in network, and that may be "non-negotiable" for you. BUT that plan doesn't have your primary care provider (PCP) in network. Would you be willing to change PCPs? Does your plan offer out of network coverage? If so, you could keep your PCP and pay the out of network rate which is typically higher than in network rates.

Hint: if the plan documents are available electronically, do a SEARCH within the document using keywords, i.e. name of medication or physician, accumulator, maximizer, prescription savings program, etc.

REMEMBER, you are not alone, don't be afraid to ask for help from one of the many resources available to the bleeding disorder community!



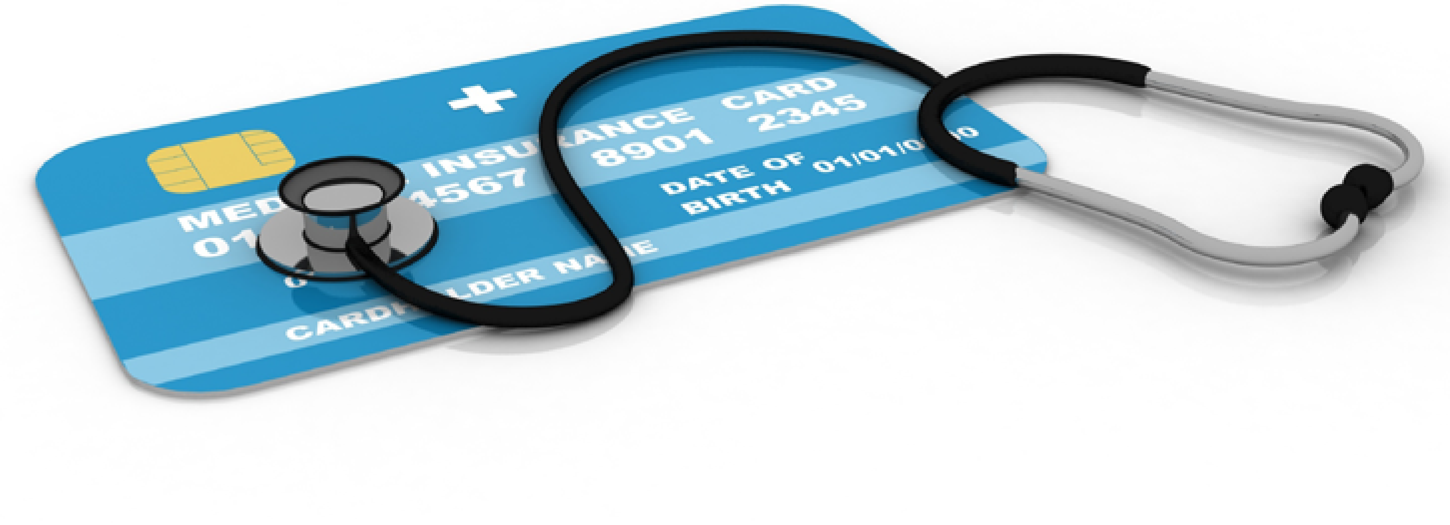
Michelle is an experienced executive in healthcare policy and advocacy, including payer relations, federal and state policy, and pharmacy concerns. As a mother of two sons with hemophilia, Michelle has spent over 33 years advocating and leading change in various roles, including several board positions throughout her career.

Michelle served as the Chief External Affairs Officer with the National Bleeding Disorders Foundation (formerly NHF), responsible for NBDF's public policy strategy and agenda, and building key external partnerships. While at NBDF, she created the Comprehensive Care Sustainability Collaboration, which is now being replicated by other national patient organizations.

Accumulator Adjusters:

a Small Victory in the Right Direction

by ***Janet Brewer, M.Ed***

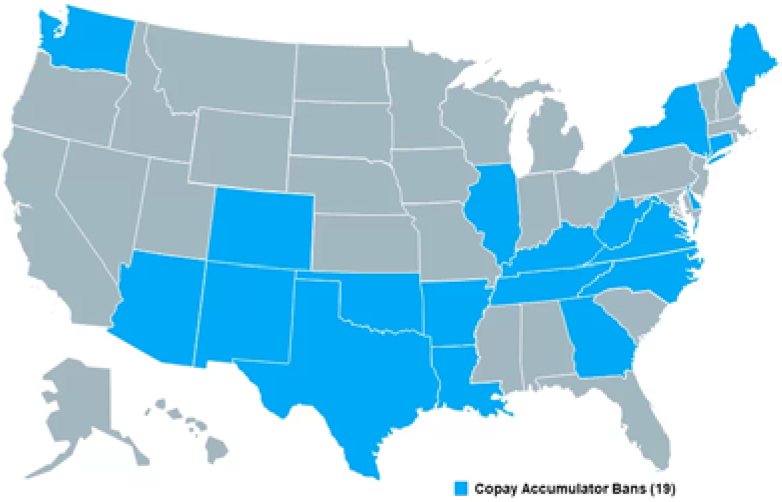


We have been hearing about the deleterious effects of Accumulator Adjusters for years in our community (See LifeLines for Health Volume 17 Spring/Summer 2021). Many of us have relied on co-pay assistance, manufacturers coupons, or co-pay cards to access expensive factor products. These programs have increasingly been used to prevent this assistance from counting towards patient's deductible or annual out-of-pocket premiums.

On September 29, 2023, the United States District Court for the District of Columbia ruled that insurers can't implement copay accumulator adjustor programs for drugs that lack generic equivalents.

https://www.hemophilia.org/news/court-rules-in-favor-of-patients-regarding-copay-accumulator-adjustor-programs

Currently, 19 states have banned co-pay accumulators.



https://avalere.com/insights/state-copay-accumulator-bans-impact-11-of-us-commercial-lives

This is indeed a step forward for our community given that the majority of current products used to treat bleeding disorders do not have generic equivalents. Enforcement however will remain a challenge as it will fall to individual state insurance commissions. These laws apply to state-regulated plans, to include individual, fully insured small and large group markets; not to self-insured plans (also referred to as "self-funded" plans in this issue's article entitled, "Employer Sponsored Health Insurance: What You Need to Know".

https://www.formularywatch.com/view/court-ruling-takes-aim-at-copay-accumulators

HERMANAS DE SANGRE

by Janet Brewer, M.Ed

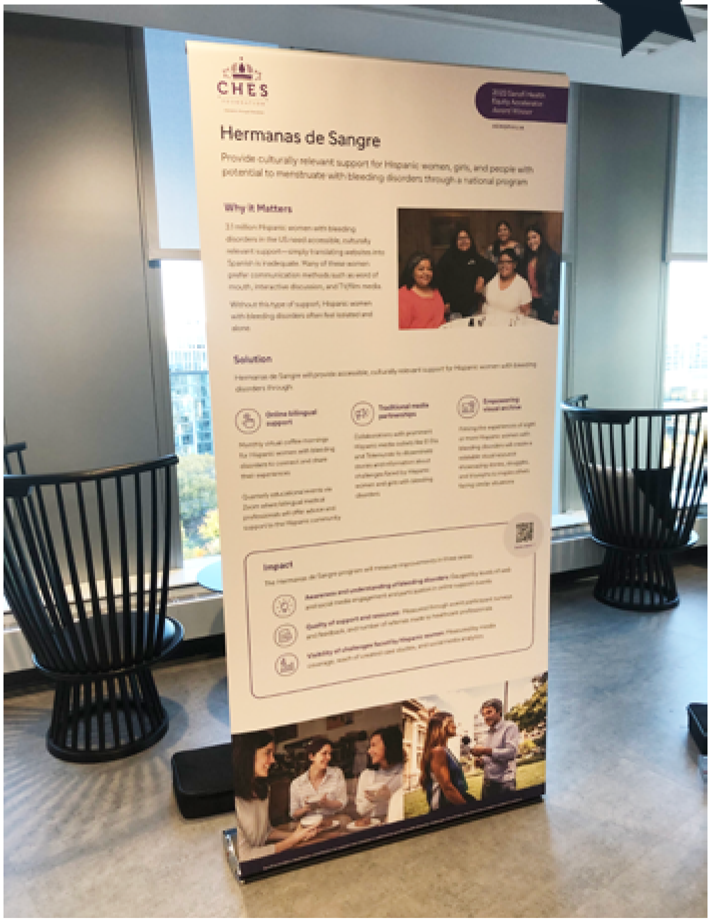
CHES Foundation is honored to officially announce they are a winner of a Sanofi Health Equity Accelerator Award in 2023. The Hermanas de Sangre [Blood Sisters] CHES initiative was created to provide culturally relevant support for Hispanic women, girls, and people with potential to menstruate through a national program to provide accessible, culturally relevant support for Hispanic women with hemophilia A or B via online coffee mornings, quarterly educational events via Zoom where bilingual medical Professionals will offer advice and support to the Hispanic community, and an empowering visual archive in Spanish.

The Sanofi Health Equity Accelerator Awards are designed to help not-for-profit, advocacy organizations in the United States and their community. The awards aim to expand solutions for health equity gaps, including those that present the largest racial inequity gaps in health care.

Paul Wheatley

Our Director of Public Relations and Marketing, Paul Wheatley accepted the award as the grant writer and lead-coordinator of this initiative.

More info about Hermanas de Sangre
https://ches.education/hermanas-de-sangre



CHES

Hermanas de Sangre

Provide culturally relevant support for Hispanic women, girls, and people with potential to menstruate with bleeding disorders through a national program

Why it Matters

Solution

Impact

Hermanas de Sangre banner presented at Sanofi's Health Equity Awards ceremony, November 2023 in Boston, MA.

https://www.sanofi.us/en/about-us/our-stories/About-the-2023-Health-Equity-Accelerator-Award-Winners *by **Janet Brewer, M.Ed***

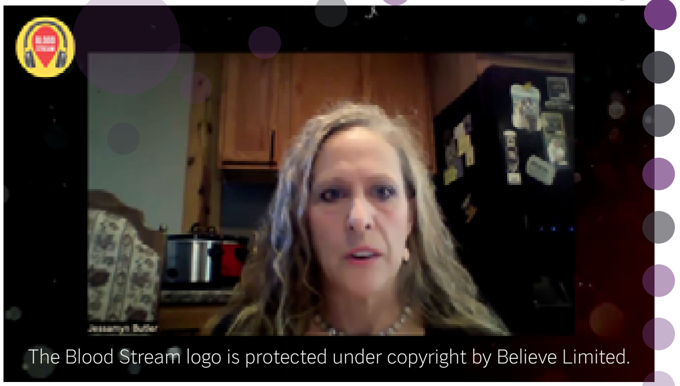
The SHEmophilia™ CHES FOUNDATION INITIATIVE

CHES Foundation’s year-long SHEmophilia™ initiative was a great success! Launched in 2022, with generous support from the Hemophilia Alliance Foundation Innovation Award, we videorecorded interviews of six women in the bleeding disorders community with a variety of diagnoses. Their stories were brave, poignant, heartbreaking, and heartwarming.

Dr. Robert Sidonio also provided insights regarding the gaps associated with normal vs abnormal bleeding and length of time to diagnosis for women. His suggestions for what women can do to advocate for better understanding, diagnosis, care, and treatment are:

- Provide objective documentation of bleeding symptoms to include bruises (especially in strange places), nosebleeds, HMB (heavy menstrual bleeding), and iron deficiency anemia.
- Photos are the most accurate; and yes, pictures of menstrual blood loss are acceptable.
- Document dates, duration of symptoms, your physical activity levels, or lack thereof, and days missed from school or work.

Missed the premiere?



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Visit

www.shemophilia.com

for these resources and more!

Want to share your story?

Looking for resources to share?

We have compiled a library.

IMPACT of COVID-19 on Education

Pandemic? Coronavirus? For many of us, including myself, I can confidently say that I had no idea what a pandemic was. Seven days before the world “shut down”, I was in New York City enjoying a Broadway show, oblivious to what was about to happen. DoorDash® and Instacart became part of our vocabulary, and grocery store aisles became a complicated traffic pattern. At the time, I was working as a Special Education Team Chairperson/IEP Coordinator in Lowell, Massachusetts, a large, urban district with 68 languages spoken and 15,000 students. We were called for an emergency staff meeting that week and were told we were going to shut down the schools for 2 weeks. Little did we know that 2 weeks would turn into the rest of the school year and the majority of the following year. The impact this had on our community, our families, staff, and children were like nothing ever seen before.

The Acedemic Implications

Elementary aged children missed vital learning year/s. They missed the basics in letter recognition, reading, writing, and math. Older students needed to take responsibility for their own education, and many lacked the maturity to do so. The difficulty in engaging in remote learning was felt across entire families. Parents suddenly became teachers; Older siblings became teachers while they were trying to engage in their own learning. Trying to get a 5-year-old, or any age student, to sit at a computer for several hours a day was difficult to say the least. Students were required to have WIFI/Hotspots or access to computers to engage in learning. Many did not have that access which further impacted the educational and academic loss during remote learning. In urban and rural districts, generational families often share living arrangements and since everyone was home, this further became a challenge as students were trying to learn remotely in homes with multiple people. In addition to all these challenges, students with disabilities or chronic conditions were further impacted whether it was access to their special education needs, specialized services, providers etc. The access available during the pandemic was extremely limited. As with general academics, if services were delivered, they were delivered remotely.

by: ***Lisa Cosseboom, M.Ed, C.A.G.S.***

WHATS the PLAN?

> *The Education Recovery Scorecard, a collaboration between researchers at Stanford and Harvard, analyzed states' scores on the 2022 National Assessment of Educational Progress. They compared these scores to the average amount of time that a district in the state spent in remote learning. For the most part, this analysis confirmed the findings of previous research: In states where districts were remote longer, student achievement was worse.*

More recent research and test scores are showing signs of rebounding, but not at a pre-pandemic rate.

Social Emotional Impact

This may not fully be understood anytime soon. One parent noted in US news, *"They've (Our kids) lost time with friends; they have lost freedom; they have lost security; they have lost the carefree tone of childhood; they have lost time in the classroom; they have lost time with family; and some have even lost loved ones."*

The definition of trauma takes on many meanings and differs for each person. Feelings and experiences belong to each individual. Although our children, and ourselves, experienced this pandemic, we all have different feelings regarding it. Trauma takes on different meanings for all. There is, however, no doubt that our children all experienced trauma on some level. Trauma also impacts learning. It can impact attention, reactivity to situations, and anxiety. Schools became a very different place then they were used to. Desks were 6 feet apart. Students were constantly being pulled for Covid testing and tracing. Masks were being worn, gloves in some cases. Teachers were constantly disinfecting. Schools became a very sterile, uninviting place to be. A survey of 800 schools conducted by the Institute for Educational Sciences notes Covid 19 was *"affecting staffing, students' behavior, attendance, nutrition, and mental health."* They noted significant increases in the need for mental health services in the schools.

Regaining Lost Ground

The Elementary and Secondary School Emergency Relief Fund is a federal program administered by the Department of Education in response to the COVID-19 pandemic. The program provided emergency financial assistance to public school districts across the country. K-12 institutions could use ESSER funding to address pandemic learning loss and invest in infrastructure and programs to open and operate safely. When schools reopened, many created enrichment programs after school during vacations and summer break to help try and close the gaps that the pandemic created due to closures. Many of these programs still exist and parents should take advantage and enroll their students in any opportunities that their districts are providing.

What else can parents do to help their children in the aftermath of the pandemic? The biggest thing that can be done - communication with your child's school/teacher. Staying in close contact gives you the ability to gauge what your child's needs may be. Is tutoring possible? Investigate what the school offers that may be able to help your child both academically and socially. Get your children involved in extracurricular activities to help boost their social emotional learning. Take advantage of the online programs your school offers and encourage your children to utilize at home. And if they tell you that they don't know their log-in information, they are fooling you! Check in with your local community happenings, libraries etc. So many programs are being offered through towns! Lego clubs, STEAM groups, book clubs etc. Most importantly, don't push your children too hard; the academic gaps will slowly close. Bring them out into your community, take them to a museum, and/or encourage learning through their environment.

https://www.edweek.org/leadership/covid-hurt-student-learning-key-findings-from-a-year-of-research/2022/11#:~:text=Researchers%20at%20NWEA%2C%20the%20American,that%20offered%20in%2Dperson%20learning.

https://www.usnews.com/education/k12/articles/helping-students-catch-up-on-unfinished-learning

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