

DATELINE

F E D E R A T I O N

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Understanding Grief and Depression: Finding Ways to Move On at Your Own Pace

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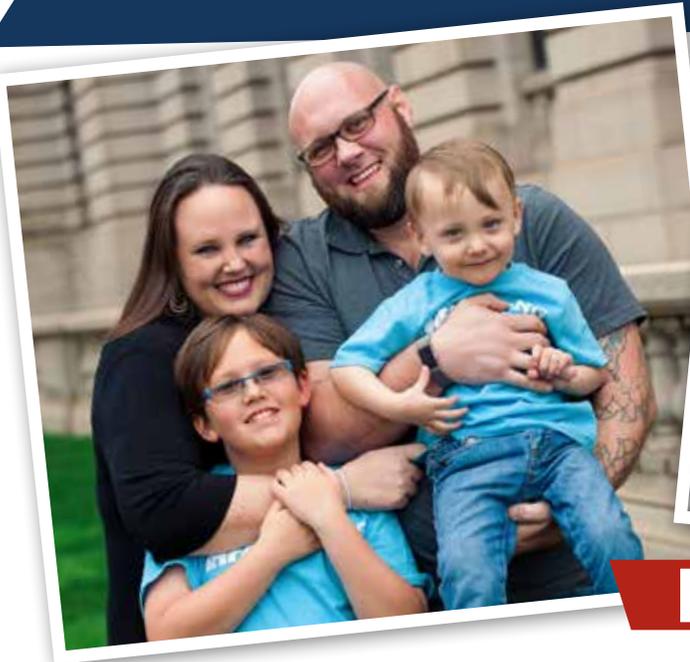
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**Coming Out of the Dark:
One Woman's Personal
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Symposium is an annual community-centered educational event that draws hundreds of members from the bleeding disorders community together to share information, learn new advancements, and build a network of support!



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- 🔥 Sesiones de Español

SAN DIEGO 🔥 **APRIL 4-7**



Register now at www.hemophiliafed.org!

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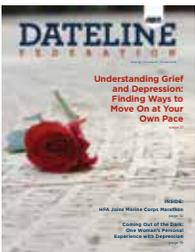
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ON THE COVER. The AIDS Grove in San Francisco, California, recognizes those who died of AIDS, represented in a permanent memorial in this picture, as well as a new circle which recognizes hemophilia community members. It's just a small nod to the 10,000 people who have died. But the loss is still touching the lives of those left behind, whether it's from grief, survivors' guilt, suicide or mental health issues. This issue takes a look at dealing with depression and grief. Photograph by Michael DeGrandpre.

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We recognize young ones need to learn about bleeding disorders, so we've created Kids Corner. This section contains information for parents and children to read together, followed by learning activities for the young ones!

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Dear Friends,

It is hard to believe 2018 is coming to an end. Each year seems to go by quicker than the previous. As I reflect on this past year and approaching a full year as HFA's board chairman, many things come to mind.

I think of Symposium in Cleveland. And even now that seems so long ago, but fresh in the mind. Each year our staff and countless volunteers seem to make Symposium the best it has ever been!



I think of the Marine Corps marathon in October, when I participated as a runner. Starting a new fundraising event is never easy, but to start it out raising more than \$30,000 to go toward Helping Hands is astounding.

This was not only my first time running in a marathon but doing a fundraising effort with HFA!

This first year has been a great start as the board chair, working with staff, meeting so many in the community and serving others. I am excited to see where HFA will go in 2019.

Josh Hemann

Josh Hemann
Board Chair



Above: Josh and his wife, Heather, in Washington, D.C., for the Marine Corps Marathon in October.



Assisting, educating, and advocating for the bleeding disorders community since 1994.

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Connect with us on social media for daily posts and updates about what's happening at HFA.



HAPPENING HIGHLIGHTS

HFA Research Featured on Social Media

Hemophilia Federation of America has completed a number of research surveys and is proud to share the results. HFA recently launched the Survey Says... social media campaign to share informative research results.

Search for Hemophilia Federation of America on Facebook or follow @hemophiliafed on Twitter to see the Survey Says... messages and other informative posts.

Stay Informed

Do you have vWD or an inhibitor? Would you like information specific to you? HFA is proud to offer monthly emails with information especially designed to address the needs of patients with vWD and inhibitors.

Join our vWD and inhibitor-specific email lists by visiting www.hemophiliafed.org and clicking on Sign-Up for Updates. 



Characteristics & Treatment Patterns of vWD in the U.S.*

- Among females with vWD, 87% report having heavy periods, with 22% of female respondents reporting a hysterectomy.
- Rates of both depression and anxiety among vWD participants is well above the national average.
- 34% of participants reported depression, 35% reported anxiety.

Burden of Illness of People with Hemophilia A**

- 11% had a current inhibitor.
- Respondents with an inhibitor had significantly more ER visits than people without an inhibitor.
- Average number of days missed from work/school/usual activities because of the bleeding disorder were *12 days for people without an inhibitor, and 23 days for people with an inhibitor.*

*Source: Characteristics & Treatment Patterns of vWD in the U.S. (2016 Poster with SHIRE on characteristics and treatment patterns of vWD in the U.S.)

**Source: Burden of Illness of People with Hemophilia A (2017 poster with Genentech on Burden of Illness of People with Hemophilia A With or Without a Current Inhibitor)



Recognizing 100 Years of von Willebrand

Uncharacteristic bleeds in young Finnish girl leads to first diagnosis of vWD

By **Andy Anderson, staff writer**

The Sundblom family lived in the town of Föglö in the Åland Islands, a small island group in the Baltic Sea halfway between Sweden and Finland. In 1924, the family asked the Finnish doctor Erik Adolf von Willebrand to see their 5-year-old daughter, Hjördis, who had come close to death several times because of recurrent bleeding.

After losing baby teeth, during nosebleeds, and when her lips had chapped from the cold sea air, she had bled to such an extent that her family was afraid for her life. Her parents, Oskar and Augusta, had every right to be worried. They had already lost five children, at least three of them to bleeding episodes.

The town boasted one telephone, a school and a library, but this was a fishing village so specialized medical care was not an option. The Sundbloms made the decision to travel with Hjördis to Helsinki, where she was seen at the Deaconess Hospital.

The visit might sound familiar to others in the modern-day bleeding disorders community - Dr. von Willebrand took a history of Hjördis' bleeding episodes, a family history and drew samples of blood. In the coming months, he worked to develop a genealogy of the Sundblom family through communication with the family and the local schoolteacher.

Two years later, Dr. von Willebrand published his findings: the Sundblom family had a condition different from hemophilia, but with somewhat similar characteristics when compared to the recessive inheritance pattern found in hemophilia. Most notably, it was an autosomal dominant condition, a pattern of inheritance in which an affected individual has one copy of a mutant gene and one normal gene on a pair of autosomal chromosomes.

Unfortunately, a diagnosis did not guarantee treatment, and there was little that could be done for Hjördis or her siblings beyond rest and home remedies. For the rest of her life, Hjördis had continued episodes of bleeding from the nose and mouth, and on at least one occasion bled into the joint of her ankle. On Dec. 30, 1932, at the age of 14, Hjördis bled to death during her fourth menstrual period.



Hjördis and her family were the first identified individuals with what we now know as von Willebrand Disease. Many people in the bleeding disorders community, who have faced their own barriers to treatment, will empathize with Hjördis's experience of uncontrolled bleeding.

Until advances in transfusion medicine were made in the 1940s, there was very little that could be done for people with von Willebrand Disease, especially in remote areas like the Åland Islands. Managing bleeding episodes at home might have been accomplished through various folk

remedies, like massaging animal fat on swollen joints and muscles, pressing silver to a wound to staunch bleeding and quell pain, reciting incantations against bleeding, and drinking herbal mixtures as remedies for post-partum hemorrhage or to strengthen the general constitution. To prevent chapping and splitting skin, animal fat was rubbed on the afflicted skin, similar to lip balm or hand cream.

Before the invention of modern feminine hygiene products, managing menstrual bleeding usually took a little bit of creativity. In the early 20th century, someone living in an industrialized society had the option of wearing a sanitary belt. This garment, similar to a modern garter belt, was worn around

the hips and held a reusable or disposable sanitary napkin in place.

For women in more rural areas, or of lower socioeconomic status, cloth was stuffed into the undergarments or carefully wound around the hips and legs to catch the flow of blood. These were typically washed and reused for several months before being discarded.

Many women today still use cloth pads as an environmentally-sustainable way of managing bleeding, but the designs have come a long way compared to the belts and rags of yesteryear! In various parts of the world, some have also used sea sponge, wool, cotton or linen inserted into the vagina or secured against the body as protection.

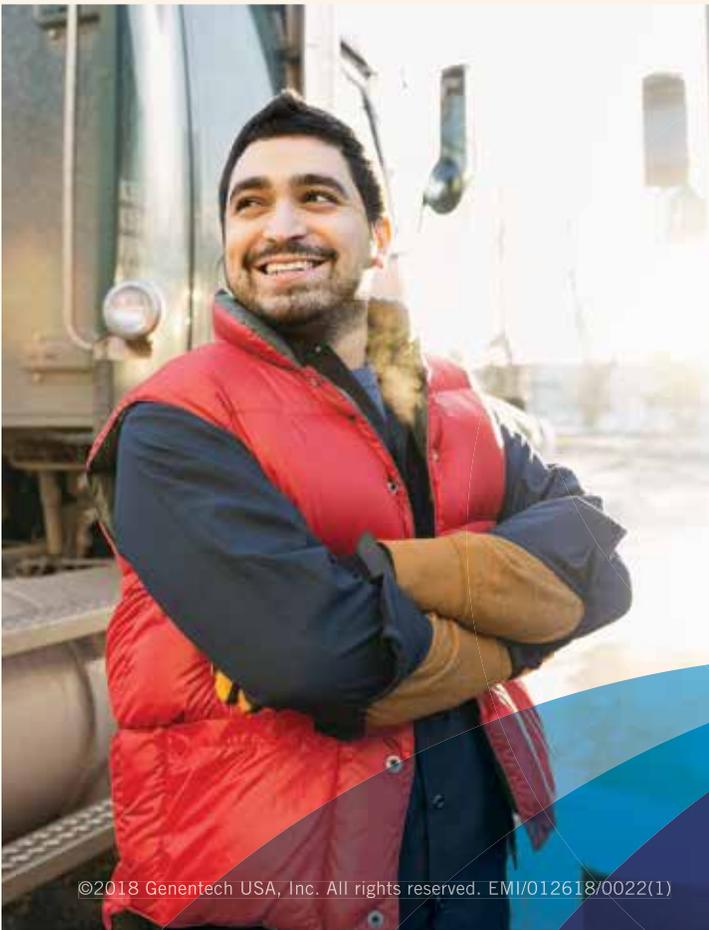
Women with heavy periods (whether due to a bleeding disorder or not) may have needed to “double up” protection or remained in bed for the duration of their period. Because menstruation ceases during pregnancy and is suppressed during breastfeeding, “marriage and motherhood” were sometimes proposed as cures for heavy menses. Malnutrition and the age and pace of childbearing also contributed to infrequent periods in the past.

Heavy menstruation was attributed to everything from a lack of exercise to too much exercise, poor diet, sexual activity, wearing ill-fitting clothes, mental or emotional stress, constipation, and even eating spicy or rich foods. Women and girls with heavy menses were generally encouraged to rest, and though this was beneficial for their health, they would have suffered in other areas. The struggles of missing school and falling behind in responsibilities with work and family are still common in women with bleeding disorders today.

We have come a long way in understanding what happens in the body of a person with a bleeding disorder, and innovations in treatment are constantly evolving. Though Hjördis’s story is not often told when we talk about von Willebrand Disease, many of us already know her experiences very well because they mirror what we have gone through in our own lives.

In the century since her birth, modern medicine has found not only a name for what killed her, but a number of effective treatments to prevent such an early, tragic death. Not only that - we have come to recognize that von Willebrand Disease is the most common bleeding disorder in the world. 

 We honor the memory of Hjördis Sundblom and our sisters who have died with little or no treatment or without even a name for the condition affecting their bodies.



The hemophilia treatments of today were once the dreams of yesterday. Proof that when

SCIENCE AND THE COMMUNITY

come together, great things happen.

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Let's put science to work

GenentechHemophilia.com

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A look at the emotions of motherhood expressed in Infusing Love in 2018

There's something about a hemophilia mom's words and raw emotions that appeals to others. It's real!

This year marked the fifth year of Hemophilia Federation of America's weekly Infusing Love blog, written entirely by women in the bleeding disorders community. The blog has become a favorite among posts on social media, likely because it's so honest and true.

It was started by HFA's Associate Director of Advocacy Sonji Wilkes (who, at the time, was in HFA's Families), who also shares her struggles and triumphs over the years, just as the other mom bloggers.

In 2018, HFA took a look back by sharing blogs from the past. The blogs have remained timeless - they cover topics that are as relevant today as they were when the blog began.

One mom, who learned she could be a carrier of the gene after her son was diagnosed, said "How did I get this far in life without knowing?" There are unknowns. There are also moms who share precious memories, worries, fear, love and pride. 💎

Find the blog on our website:

<http://www.hemophiliafed.org/news-stories/category/moms-blog/>

Love *and* FEAR

**Thank you to the moms
from our community
who have blogged
with us over the
last 5 years!**

**IT'S THE PEOPLE.
IT'S THE PASSION.
IT'S THE PURE JOY
OF BEING TOGETHER.**

~Wendy, hemophilia mom





HEMOPHILIA MOMS HANDLE THINGS, ADJUST AND MOVE ON ... JUST LIKE 'NORMAL' MOMS. -Carrie, hemophilia mom

SHE'S ACTIVE, COMPETITIVE AND GAINING CONFIDENCE.

-Kari, PSPD patient and mom



I AM GRATEFUL THAT HE IS HAPPY, HEALTHY AND THRIVING IN SPITE OF BLEEDS.

-Emily, hemophilia mom



HOW COULD I PERSONALLY BE FACED WITH SOMETHING ELSE SO CHALLENGING FOR MY FAMILY?

-Heather, hemophilia mom

I HAVE TRIED MY BEST TO AVOID FAVORING ONE CHILD OVER THE OTHER.

-Lindsay, hemophilia mom

AS MOMS WE WILL NEVER STOP WORRYING.

-Karen, hemophilia mom



HFA JOINS MARINE CORPS MARATHON

By Kyle McKendall, staff writer | Photography by Michael DeGrandpre

“Why am I doing this?”

This phrase that entered my mind countless times throughout the marathon process. I uttered it as I hit “register” on the online portal, through each of my training runs and I said it, possibly out loud to myself, as I exited the metro’s Pentagon station on the morning of the race, feeling like a cow in a herd of cattle.

Running hasn’t been a lifelong pastime of mine. In full disclosure, it was something I loathed in high school gym class. Yet, here I was, standing shoulder-to-shoulder with more than 20,000 runners waiting for the cannon’s fire to signify the start.

When friends ask about the marathon, I am quick to quip something snarky followed by a comment along the lines of “I’ll never do that again.” And, while I stand by my comment with my marathon running career starting and ending with the Marine Corps Marathon, I’d be lying by omission if I failed to highlight everything I gained from this experience.

Over the course of four months of training before the marathon, I received an unquantifiable amount of support. Runners provided their advice and training suggestions, many supported my fundraising campaign for Helping Hands with a donation, and my grandmother frequently asked me how many miles were in a marathon (it’s 26.2).

It seems to be the cliché thing to highlight out of this experience but having the opportunity to raise money for Hemophilia Federation of America’s Helping Hands program was a rewarding aspect of this journey. I’ve worked at HFA for more than three years, so I’ve known first-hand the good work that the program does. It was heartwarming to see my friends and family get behind a cause I am passionate about and make donations to my campaign. While I was busy training for the race, some of





Sometimes life presents us with challenges that are unavoidable and other times we sign ourselves up for the madness by entering to run a marathon.

Either way, it takes determination and willpower to overcome them. When people ask me now, “Why did you run it?” I simply answer, because I could.



the people I love most made a public affirmation of support by contributing.

The course itself was beautiful - Starting out between the Pentagon and Arlington National Cemetery, winding through many of the D.C. neighborhoods, making its way onto the National Mall, passing almost all of the must-see monuments and buildings in our nation's capital. If you're going to run a marathon, this is the course to do it.

Hosted by the Marines, the event highlighted the best of our nation's servicemen and servicewomen. Almost every stretch of the course was lined with spectators and residents who came out to support the runners, many offering snacks and drinks to me as I passed by. I'm forever indebted to the woman who handed me with candy

around mile 23. Without her, I might not have finished the race.

When you sign up to run this race next fall, you too will probably ask yourself and everyone around you "why am I doing this?"



Thomas Corry of Maryland, a personal trainer with hemophilia A, joined HFA in the marathon.

My short answer is, because you can! Despite the obstacles that you see in front of you, running a marathon requires few things: the will to do so, and the time and energy to invest in training.

Sure, my ankles haven't fully recovered, but crossing the finish line sits proudly toward the top of my list of personal accomplishments. I've worked hard at a lot of things in life, but the physical challenge of my body begging me to stop running, coupled with the mental toughness needed to stay focused for more than four hours, might be the most difficult thing I've put myself through. 🩸

When Hemophilia Federation of America was offered the opportunity to be a charity partner in the Marine Corps Marathon, we instantly thought about the connection we had with those serving our country... resilience. The men and women in uniform are resilient, just as those in the bleeding disorders community. We may not face the same challenges, but we do have to overcome obstacles and push through.

We had 59 runners supporting Team Resilience with seven of the runners either active duty military, spouses or veterans. HFA runners ran a combined total of 1,099.6 miles on Oct. 28 to spread awareness and raise funds for our community. Team Resilience raised \$34,737, which will assist 76 households through our Helping Hands Program.

THANK YOU TO OUR MARINE CORPS MARATHON SPONSORS:

Platinum: CSL Behring | Gold: Aptevo Therapeutics | Silver: Grifols

Bronze: Diplomat Specialty Infusion Group, Spark Therapeutics and CVS Specialty



Fairytale

BEGINS WHERE THE MARATHON ENDS

Memorable moment for runners captured by HFA

By Emily Roush-Bobolz, staff writer

Running in the Marine Corps Marathon could be considered a memorable experience on its own. For two runners in the 2018 marathon, what happened at the end of the marathon will be the most memorable moment of their lives.

At the finish line, surrounded by hundreds of marines, spectators and runners, Joe DeRose got down on one knee and proposed to his girlfriend, Tara Nolan. Nolan, the sister of Hemophilia Federation of America's Development Coordinator, Ashley Smith, was shocked. And she said yes!



Joe DeRose and Tara Nolan of New York state share a special moment at the finish line. Photo by Michael DeGrandpre

"I felt so many emotions all at once when he proposed," said Nolan. "It was surreal at first, then I felt so in love that it brought me to tears. It felt like we were the only people in the world. The people we were with and the strangers around us just fell far into the background."

"When (HFA) was chosen to be a charity partner for the Marine Corps Marathon, I instantly started recruiting," said Smith, who helps coordinate HFA's events, such as the charity partnership with Marine Corps Marathon. "Tara was one of the first calls I made."

Smith knew the big moment was coming when DeRose told her two months earlier, and she struggled to keep it quiet from her sister. The two talk on the phone nearly every day.

Nolan and DeRose, both of New York state, met through a mutual friend at a beer and wine festival. They were immediately drawn to each other and have been together since.

They're the type of couple who likes to have fun and laugh, whether they're at home doing nothing or whether they're being social and adventurous. They like to travel together. They're not, however, really the type to typically exercise together. Yet they joined the Marine Corps



Marathon to support Nolan's nephew and Smith's son, Jackson.

"We're not runners!" said Nolan. "This was new to us both, but it couldn't have gone any better."

The couple and a family member raised \$900 for the charity, which goes toward HFA's Helping Hands program, providing emergency assistance to families experiencing a financial hardship.

"I was so excited my sister was going to do something she's never done before, since she's not the running type," said Smith. "And after crossing the finish line, her life would be changing for the better."

The couple has struggled a bit with the first stages of wedding planning because of the number of options available. So perhaps the demands it took to complete the Marine Corps Marathon is a fitting beginning to a life together as husband and wife. If they can endure the marathon, they can endure anything together. 💧

Only Time Will Tell: 116th Congressional Outlook

Healthcare was a driving issue for many voters in 2018

By Kim Isenberg, staff writer

The results of the mid-term election are in and we now know that the 116th Congress will be a divided one—a Republican Senate and a Democratic House.

Will the new Congress do anything to impact access to meaningful healthcare? Because of the political division, it is unlikely that any big bills, such as a repeal of the Affordable Care Act, will advance. However, there is some indication that Congress may take up pre-existing protection, surprise billing, opioid and drug pricing legislation.

In addition, the House is responsible for government oversight, investigations and initiating the federal appropriations process. Pundits are saying the House is likely to use its oversight authority to investigate federal healthcare programs.

At the state level, Medicaid was also an issue in the midterm elections. Four states had ballot initiatives to expand Medicaid and there were three governor's races that included plans for expansion. With the exception of one state, the election results point to positive effects for access to healthcare for tens of thousands of uninsured people across the U.S.

Here is What Happened

Idaho, Nebraska and Utah passed ballot initiatives to expand Medicaid. That means a total of 36 states have now chosen to expand access to care for people up to the 138 percent of the federal poverty level. In addition, three governors who support expanding Medicaid were elected in Kansas, Maine and Wisconsin, providing a pathway for three more states to join the ranks of states expanding Medicaid.

The one outlier of the election was the state of Montana. A ballot initiative to raise taxes on tobacco and dedicate a portion of that increased revenue to Medicaid expansion failed. Without legislative action in 2019, Medicaid expansion currently underway in Montana will sunset and the total of number states choosing to expand Medicaid will decline to 35.

What does this mean for the bleeding disorders community?

Hemophilia Federation of America has long been a supporter of expanding Medicaid to help ensure access to care for people living with bleeding disorders, particularly for young adult males who had very limited access to Medicaid prior to the passage of the ACA in 2010. A substantial amount of research indicates that Medicaid expansion under the ACA positively impacts access to care, affordability and utilization, health outcomes, and various economic measures.¹ 💧

What HFA Will Be Monitoring in 2019:

- ✓ Accumulator Adjuster Programs
- ✓ Defending Pre-existing Conditions
- ✓ Step Therapy
- ✓ ACA Reinsurance
- ✓ Preferred Drug Lists
- ✓ Medicaid Expansion

¹ "The Effects of Medicaid Expansion Under the ACA: Updated Findings from a Literature Review," March 2018 Issue Brief, Kaiser Family Foundation. Accessed Nov. 19.





We Need YOU!

Having a strong army of advocates is important in the continued fight for access to care. That means we need your help monitoring, advocating and supporting federal and state policies which impact the lives of people living with bleeding disorders.

How Can You Help?

- ✔ Learn More About the Latest Legislation in HFA's Word from Washington
- ✔ Share Our Policy and Advocacy News on Social Media
- ✔ Talk to Local Legislators
- ✔ Write to Legislators
- ✔ Attend Hill Days in Your State

Check out our **Legislative Day Toolkit for Patients and Caregivers** at www.hemophiliafed.org/toolkits for webinars, videos and downloads with tips on talking to legislators, and links to valuable resources to help you be an advocate!

VISIT WWW.HEMOPHILIAFED.ORG/ADVOCACY

Healthy Body, Healthy Mind

Simple steps to improve physical health can improve mental well-being

By Angela Burton, MSW, staff writer

Everyone knows healthy living is beneficial for the physical body, but not often do we discuss the impact it can have on our mental health. Proper wellness, combined with safe and effective exercise, are particularly important for individuals living with bleeding disorders.

The National Alliance on Mental Illness confirms this and reminds us that mental health is a vital part of our overall health. Focusing on our physical health and wellness is an opportunity for bleeding disorders patients to take control of managing life's ups and downs.

It is also a way to become involved in your overall healthcare journey. Diet and exercise are complementary to many medical treatments and have been proven to enhance quality of life for individuals facing mental health challenges. Living a healthy lifestyle can have a positive impact on how we are able to deal with life's challenges without solely relying on medication or therapy.

Here are a few steps, suggested by NAMI, to begin your journey toward wellness:



Get Active: at least 20 minutes of safe physical activity daily has been proven to reduce anxiety, depression, improve mood, self-esteem and cognitive function. Exercise can also prevent or improve obesity, cardiovascular disease and Type 2 diabetes, and improve overall resistance to illness.



Eat Healthy: a healthy diet, with low amounts of refined sugar and appropriate portions of fruits, vegetables, whole grains and proteins can also improve mental health.



Become Mindful: Mindfulness or self-awareness is the process of focusing on mind, body and soul. Practicing mindfulness can help relieve stress, reduce chronic pain, moderate blood pressure and even address symptoms of heart disease. Activities such as yoga, have been proven to provide better control over processing emotions.



Avoid Substance Use and Smoking: Drugs and alcohol are often used as ways to cope with or ease the pain of mental and physical illness, but they actually make things worse. Also, certain prescription medications lose their effectiveness due to the use of drugs, alcohol and cigarettes.



Think Positive: Although it seems simple, how we view ourselves influences how we behave and what we feel. Low self-esteem is associated with many mental health conditions.



Get a Good Night's Sleep: Turn your bedroom into a sanctuary! Set a regular bed time and bedtime routine, and stick to it. Regular exercise and getting outside every day can help regulate circadian rhythms and help improve sleep. Turn off electronic devices! The blue light emitted from screens overstimulates the mind and suppresses melatonin, a hormone which promotes sleep.



Have a Support System: Being affected by chronic disease can be challenging if you are without support. It can often make you feel overwhelmed. Having someone to talk to, a family member, a community member or a friend can help you bear the load.



FIT FACTOR

Take advantage of local and national hemophilia communities. Hemophilia Federation of America also offers support through various programs, the website, webinars and educational and social support through groups such as Blood Brotherhood, Blood Sisterhood, Moms in Action and Dads in Action.

HFA's health and wellness initiative, FitFactor, is designed especially for people with bleeding disorders to improve health, fitness and quality of life through regular physical activity and proper nutrition. 🩸

Visit www.hemophiliafed.org/FitFactor to find inspiration, nutritional information and recipes, videos for safe exercise for those with bleeding disorders and more!



Dear Reader,

These days, change within our community seems to be a constant: companies are merging, new products are being released, clinical trial results are published and the scientific community is rethinking how we treat bleeding disorders. Though, despite the fast-paced world we live in, one thing remains steady: **vulnerable families in our community suffer financial hardship and rely on HFA to thrive.**

This year alone, we've distributed more than \$175,000 in direct aid to families in the community who experienced a financial hardship. Like me, you understand the challenges having a bleeding disorder can put on the household: missing work for a child's extended hospital stay, unforeseen medical expenses, an insurance issue resulting in a high co-payment, overdue rent or mortgage payments and utility bills piling up.

Our Helping Hands fund is there for you and every member of the community when you need it most. But, we can provide financial relief only if we have dollars to distribute. We all go through ups and downs, and when you find yourself in a good financial position, it's a great time to give back to the community and support others. **Will you make a contribution today to Helping Hands to ensure we can continue to help those in need?**

Your donation of any amount will make an impact. A gift of:

- ◆ \$25 provides a medical ID bracelet, elbow brace, or knee brace.
- ◆ \$50 fills a gas tank to get to and from the HTC.
- ◆ \$100 repairs a broken wheelchair.
- ◆ \$250 pays a month's utility bill.
- ◆ \$500 or more assists with a rent or mortgage payment.

Donating to Helping Hands means HFA can continue to aid our community's most vulnerable families in the year ahead.

I hope you'll join me in supporting the Helping Hands fund by donating today.

We've included an envelope to make donating even easier. Should you prefer to make a contribution online, visit www.hemophiliafed.org/donate.

With many thanks,

A handwritten signature in black ink that reads 'Josh Hemann'.

Josh Hemann, Board Chair

P.S. Many companies offer gift matching programs. If yours does, you can double your donation with an employer match. Contact us for more information.

HFA is a 501(c)(3) not-for-profit organization. All donations are tax deductible to the fullest extent of the law.





OUT OF THE DARK

One woman's personal story of overcoming depression and anxiety

By Cazandra Campos-MacDonald, guest writer

I have suffered from clinical depression most of my life. Five weeks after my eldest son was born over 22 years ago and diagnosed with hemophilia, my mom passed away. It was devastating. I had planned on taking maternity leave until after Labor Day, but after Mom's death, I knew I had to go back to teaching as soon as possible. It was those events that launched my depression into a new realm. Fortunately, once I saw a psychiatrist and a therapist, things were much better.

When my son was 5 years old, I was going through a very difficult time with the ending of a close, family relationship. It was extremely painful, and I lived in constant, debilitating anxiety. I was teaching full-time, taking care of my home and husband and son when I felt like I could not do it any longer.

I wanted the pain to stop. I got home early one afternoon and as I sat watching television, waiting for my husband and son to come home, I started taking pills, one by one very slowly. I was waiting for the pain to stop...but it only got worse.



I was admitted to the hospital for a drug overdose and ended up in rehab. It was a dark time, but somehow, I managed to crawl out of the deep, isolating hole I had been in for so long. It is a time I will never forget but am grateful that I overcame.

After my second son was born 10 years later, I experienced a terrifying condition: postpartum depression. If you ever hear of someone suffering from postpartum depression, please do not ignore it. It is hard to understand if you have not experienced it, but it is real and frightening. Fortunately, I had the help I needed, and after several months the depression lifted. But it was time stolen away from me and my precious son.

Many people in our bleeding disorder community suffer from mental health issues. Depression and chronic illness go hand in hand for many of us. The pain and suffering caused by a bleeding disorder (or any chronic illness) can sometimes be too much to bear.

There have been people in the bleeding disorders community who have attempted and committed

suicide. And even their closest friends may have had no idea how deep the depression went into their souls. Those who end their lives leave many left behind wondering why. “What could I have done? How did I not know?”

Sometimes it is hard to know if someone is suffering. Many of us function beautifully - we have a smile on our faces when we're with others, and the minute we are alone, or in the comfort of our homes, the weight of the depression takes over. It looks different in everyone, and when you are especially close to someone it can be difficult to see.

I am one of those people and fortunately I did not succumb to my choices while under the influence of pills. I can say that I am past those dark times and am living my best life, however those dark times can sneak up on me when I least expect them. I must always be on alert.

If you have a problem, find someone close to you and have a conversation. It is amazing how confiding in a good friend can help your spirit. Maybe *you* are the person who is being present and listening. Open your ears and your heart to truly “hear” a friend in need.

If you need help from a medical professional and aren't sure where to begin, talk to your hemophilia treatment center. They will help refer you to a mental health professional.

It's not anything to be ashamed about. Reach out. It could be a life-changing moment. 💧

If you or anyone you know is experiencing suicidal thoughts or needs someone to talk to, please call the National Suicide Prevention Line at (800) 273-8255 or visit suicidepreventionlifeline.org.

“It was a dark time, but somehow, I managed to crawl out of the deep, isolating hole I had been in for so long.”



Turning Grief Into Action

By Emily Roush-Bobolz, staff writer

It has been said that where there is grief, there is great love, and grief is the last act of love we have to give to those we loved.

Some in the bleeding disorders community are too young to remember the loss of 10,000+ people due to HIV/AIDS. For others, it's still a part of their life and they're still here and they don't want to be forgotten. They don't want their grief, sentiments and experiences to be forgotten either.

Whether it is decades-old grief or whether the loss is more recent, some are just dealing with grief. Or survivors' guilt. Or maybe an emotion they just can't pinpoint.

The Last Act of Love

Anna Bell, a clinical social worker who practices in Maryland, Virginia and D.C., says there are two things clinicians see in those "left behind" – survivors' guilt and bereavement.

Survivors' guilt is a mental condition that occurs when a person believes they have done something wrong by surviving when others did not. It is not rational for someone to feel responsible for another person's life path, but guilt is not something a person can control, and it can be a normal response to loss.

"It's displaced guilt," said Bell. "And although you must validate people's emotional responses to loss, it is hard to have guilt for something that you can't control."

Bereavement is feelings of overwhelming sadness, especially when there has been a battle, such as in someone with AIDS or depression. Bereavement often leads to anxiety and depression, especially in the bleeding disorders community, because of the constant care and management of a chronic condition.

"You're continually fighting this battle," said Bell. "Staying on top of the infusion regimen, the doctor's appointments, the HTC visits, the time and energy into making sure nothing gets overlooked and nothing slips, and, in some cases, we still lose our loved ones."

Dealing with Depression

Some people in the bleeding disorders community may not be dealing with the grief of a loved one or friend, but they might be dealing with the loss of a "normal life," therefore experiencing feelings of depression and anxiety.

Those with a chronic illness sometimes feel as if they're fighting a battle. There may be an underlying genetic predisposition to depression and when something happens, a person can find themselves depressed. Depression can be caused by any number of factors, including chemical imbalances, severe childhood or adult traumas, or a health crisis or event that results in short-term depressive symptoms.

Symptoms could include lethargy, loss of appetite, constant melancholy, inability to control emotions, bouts of crying, shutting down or feeling completely emotionless or numb, sleeping too much or not at all, isolation from family, and difficulty with normal daily functions.

"Many of these symptoms are a result of your brain trying to protect you," said Bell. "Often the brain does not possess the necessary coping mechanisms to deal with traumatic life events and therefore it tries a "whatever works" position and does anything to get from one point to another."

Whether depression, bereavement or survivor's guilt, what is unique is how an individual manages the situation. Symptoms vary based on whether someone is male or female, their socioeconomic status, support network, or chronological or developmental age.

"Men respond differently than women," says Bell. "Men tend to keep it to themselves, withdrawal from activity, and divert their grief into extra work or external outlets. Women show more emotion, tend to look to others for support, and generally rely on self to process the emotion and grief."

The time it takes to deal with grief or a mental health situation is as unique as the individual.

“There is no time frame to grief and feelings of loss,” says Bell. “It is very common for people to move through the stages of grief and then for a song, smell, or thought to bring back the emotions that came from the initial loss. Remember grieving is a process and it takes time to heal.”

To manage the feelings that come with loss, Bell says a clinician is going to look at a patient over a period of time to determine how long the feelings have lasted and discuss an event that may have triggered the symptoms. Although there is no set time frame on grief and depression, if someone finds they’re not going back their normal daily activities, it should be addressed. If symptoms last for an extended amount of time, there may be a need for therapeutic intervention.

“There will be moments of sadness and this is very common, but it is important to seek help if you just can’t seem to function, are unable to laugh again or smile, or even lift your head up off your pillow.” said Bell. “Find a support group, find a specialist or a counselor. It may not be possible to work through this process alone.”

.....
**It has been said that where there is grief,
there is great love, and grief is the last act
of love we have to give to those we loved.**
.....

Bell says the most serious symptom is thoughts of harming oneself. If at that crisis stage, go to a hospital or call a suicide prevention hotline such as (800) SUICIDE (784-2433).

There are other things that can be done to curb the depression. Speak to others with the same experience and build a rapport with an individual in the community or turn grief into action by volunteering and dedicating time and energy into helping others.

“There is consolation and solace in helping the community,” said Bell. 💧

Grief, Survivor’s Guilt or Depression Coping Tips:

- ♥ Give yourself time to grieve and be patient
- ♥ Take care of yourself physically and psychologically
- ♥ Turn grief into action. Volunteer, give back, dedicate time and energy to others
- ♥ Reach out to those you trust to share your feelings
- ♥ Seek professional help when you need it

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Handling the Winter Months

By Sommer Mallow-Harford, staff writer

The end of the year can bring mental health challenges. For much of the U.S., the winter months can be some of the darkest and longest. Many people cope by celebrating traditions with friends and family. For others, the holidays can trigger depression, anxiety and physical symptoms. It is important to remember to care for yourself during this time. A short walk, eating a nutritious meal, laughing with a friend, and remembering to rest can be enough to get through a tough day. It is not a sign of weakness, but one of strength, to ask for help if you are feeling overwhelmed.

Mayo Clinic Offers This Advice:

Try to prevent stress and depression in the first place, especially if the holidays have taken an emotional toll on you in the past:

- 1 Acknowledge your feelings
- 2 Be realistic – holidays are not perfect, and traditions can change
- 3 Set aside differences with family
- 4 Stick to a budget and don't overspend on gifts and entertainment
- 5 Learn to say no
- 6 Don't abandon healthy habits



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PARENTS!

Here is a great opportunity to sit down with your children to talk about bullying. Then encourage them to draw!

STAND UP, SPEAK UP

By Carrie Koenig, staff writer

Have you ever been **teased, called names, left out** on purpose?

You aren't alone. At some point in life kids will feel **down** or **sad** from being treated like that. When you are teased **over and over again**, this can be a **red flag** of **bullying**.

Bullied kids can feel **powerless, alone, different** or **unpopular**. They may have a **hard time standing up** for themselves. Sometimes bullying can cause **problems at school**.

When kids see bullying or are being bullied, they **may not know what to do**, may be **afraid** to go to school or scared to tell an adult. Someone who sees bullying may not tell an adult because they are **worried** they will **get bullied too**.

Been bullied? Noticed someone else being bullied? It's **absolutely important you tell an adult** you trust, such as a parent, family member, teacher or school counselor. When you are **assertive and confident, fear and helplessness** can go away! 📌

LOOKING BULLIES IN THE EYE:

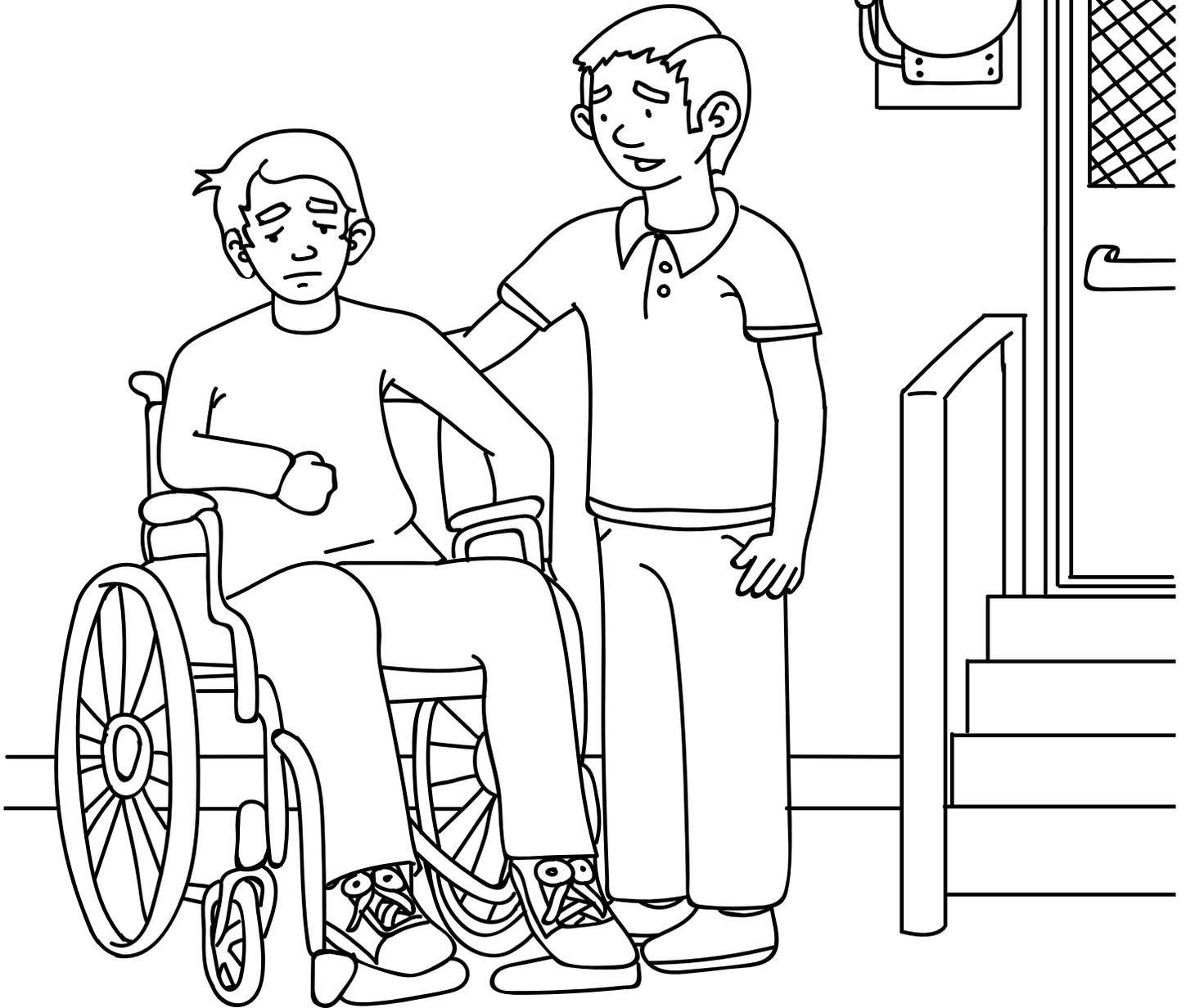
Tips for Standing Up to Bullies

- ⊗ Take a deep breath and let the air out slowly.
- ⊗ Keep your hands at your sides rather than on your hips or folded across your chest.
- ⊗ Have a relaxed facial expression, not angry or laughing.
- ⊗ Maintain eye contact.
- ⊗ Speak with a calm, confident voice, loud enough to be heard clearly with words that are not threatening.
- ⊗ Avoid name-calling, making threats or finger pointing.
- ⊗ Avoid bringing up past grudges.

Please use the space below to write a story or draw a picture of kids telling an adult, being confident and standing up to a bully!

COLOR ME!

One friend helps his friend with hemophilia deal with the bullying he experienced at school because he had to use a wheelchair during a knee bleed. Color the picture to show your feelings!



If you're feeling scared and don't know who to talk to first, know that help is out there. Talk to your school counselor or text HOME to 741741 to reach Crisis Text Line which is a free service available 24/7 anywhere in the USA where you can text with a trained crisis counselor for help.

RESOURCES: Eyesonbullying.org ✕ Stopbullying.gov



Young Adults Take on Washington

HFA's Young Adult Advocacy Summit builds future policy and advocacy leaders

By Sarah Shinkman, staff writer

Photography by Michael DeGrandpre



This fall, Hemophilia Federation of America hosted its second Young Adult Advocacy Summit. Seventeen young adults with bleeding disorders from across the country participated in the four-day event at HFA's office in Washington, D.C.

The bright and hopeful future leaders received training on state and federal policy, advocacy, project management, communications and health insurance. They also had the opportunity to meet with 30 Congressional offices, tour the Capitol and monuments, and discuss issues facing young adults with bleeding disorders.

Participants gained a deeper understanding of personal and legislative advocacy, developed ideas for engagement after the summit, and formed lifelong friendships! 💧

Want to attend the 2019 Young Adult Advocacy Summit? Watch www.hemophiliafed.org, HFA's social media in the future or email advocacy@hemophiliafed.org.

From left: Victoria, MaRee and Chelsee on a Capitol tour.



BriAnna listens to a presentation during the Young Adult Advocacy Summit.

“This was one of the **most well-organized events** I’ve been to with a **very well-planned agenda**. It was informative for all ages and I know **everyone got something out of it.**” ~Natalie of Pennsylvania, 2018 Participant



Above: Michelle, left, and Dylan at National Statuary Hall on a Capitol tour, looking at statues donated by individual states to honor notable historical figures from the state.

Left: Michelle, left, and Victoria engage in an ice-breaker activity.

Thank you to the sponsors of the Young Adult Advocacy Summit: Genentech, Bioverativ, Pfizer, Shire, CSL Behring, Spark Therapeutics and NCHS

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Are You Ready to Face Your Mental Health Challenges?

You have decided to take the first step toward mental health care, but how do you get started? Most times, the initial step of reaching out are with the individuals and groups that you most trust, such as family, friends, physician, human resources or a school counselor.

To relay your readiness for help, the following may help:

- 1. Understand the different types of mental health professionals.**
- 2. Do a self-assessment. Understanding your current struggles may help in identifying a mental health professional best suited to your needs.**
- 3. Understand your health insurance policy for in- or out-of-network providers as well as amounts, types and length of services covered.**
- 4. Know there may be a potential need for medication and therapy, which may influence your choice for the right mental health professional.**

Although the process of finding the right mental health professional may take some time, you will find that the investment is worth the care you will receive. Do not hesitate to ask questions, get referrals and ask for different opinions. This commitment you're taking is a courageous step forward to improving your life.

Types of Mental Health Professionals

There are many types of mental health professionals. Health care professional names can vary by state, but these basic descriptions from the National Alliance on Mental Illness provide an overview of what to look for and what to expect from a mental health professional.

Assessment

Counselors, Therapists and Clinicians help someone better understand and cope with thoughts, feelings and behaviors. They can also offer guidance and help improve a person's ability to achieve life goals. These mental health professionals may evaluate, assess and diagnose a person's mental health and use therapeutic techniques based on specific training programs. Working with one of these mental health professionals can lead not only to symptom reduction but to better ways of thinking, feeling and living.

Psychologists hold a doctoral degree in clinical psychology or another specialty such as counseling or education. They are trained to evaluate a person's mental health using clinical interviews, psychological evaluations and testing. They can make diagnoses and provide individual and group therapy.

Clinical Social Workers

Clinical social workers are trained to evaluate a person's mental health and use therapeutic techniques based on specific training programs. They are also trained in case management and advocacy services.

Prescribing and Monitoring Medication

The following health care professionals can prescribe medication. They may also offer assessments, diagnoses and therapy.

Psychiatrists are licensed medical doctors who have completed psychiatric training. They can diagnose mental health conditions, prescribe and monitor medications and provide therapy.

Psychiatric or Mental Health Nurse Practitioners can provide assessment, diagnosis and therapy for mental health conditions or substance use disorders. In some states, they are also qualified to prescribe and monitor medications. Requirements also vary by state as to the degree of supervision necessary by a licensed psychiatrist.

Primary Care Physicians can prescribe medication, but you might consider visiting someone who specializes in mental health care. Primary care and mental health professionals should work together to determine an individual's best treatment plan.

Family Nurse Practitioners can provide general medical services like those of a primary care physician, based on each state's laws. Like primary care physicians, they can prescribe medication, but you might consider visiting someone who specializes in mental health care.

Other Professionals You May Encounter

Certified Peer Specialists have experience with a mental health condition or substance use disorder. They are often trained, certified and prepared to assist with recovery by helping a person set goals and develop strengths. They provide support, mentoring and guidance.

Social Workers (B.A., B.S.W. or M.S.W.) can provide case management, inpatient discharge planning services, placement services and other services to support healthy living.

Pastoral Counselors are clergy members trained in clinical pastoral education. They are trained to diagnose and provide counseling. Pastoral counselors are members of the Association of Pastoral Counselors and can have equivalents to a doctorate in counseling.

It's important to remember that choosing a helping professional may take time. Their specializations may not align with your needs or it just may not be a good fit. It's perfectly acceptable to tell your helping professional that you're not getting value from the sessions and to ask for a referral or find someone else that can better serve you. 📌

For more information, visit www.nami.org. HFA does not make recommendations on care or types of health care professionals.

Understanding Your Insurance Policy

Addressing mental health issues is equally as important as addressing physical health issues. But because of the undesired stigma and cost often associated with counseling, many people hesitate to make behavioral health a priority. Whether you are living with a bleeding disorder or caring for a loved one with a bleeding disorder, you need to take care of your whole self.

The first step is to review your health insurance policy, which outlines your benefits, including what is covered, how it's covered, cost for treatment, and if a prior authorization is required.

Start with the summary of benefits and coverage. The summary should include a section on behavioral health services, as well as an overview of your deductible, cost of prescriptions, copays, what's included and not included in out-of-pocket expenses, and a glossary of terms. Ask your insurer or employer's HR department if you don't understand something in your policy.

If you receive care at a hemophilia treatment center, the HTC social worker might be able to provide guidance as well. The Affordable Care Act requires all health insurance plans to provide certain mental and behavioral services. For more information on what is required, visit MentalHealth.gov.

Spanish TEACH ofrece habilidades de liderazgo en la autogestión

By Martha Boria Negrón, staff writer

“¡Este programa fue increíble! Espero seguir participando de los programas de HFA en el futuro. Esta es una organización tan increíble. Ojalá lo hubiera encontrado antes. Asistir a los eventos me pone en perspectiva cuanto significa esta comunidad para mí. Fue una de las frases que escuchamos en HFA después de concluido el TEACH Immersion en español que se llevó a cabo del 3 - 5 de noviembre en nuestras oficinas en DC.”

TEACH español les dio la oportunidad a 16 adultos de la comunidad hispana de trastornos de sangrados a capacitarse con programas diseñados para educar acerca de la historia de los trastornos de sangrados y los esfuerzos de abogacía en proceso legislativo y las políticas actuales que afectan a la comunidad de trastornos de sangrados. Nuestro objetivo fue crear personas con liderazgo para que auto-aboguen por la comunidad de trastornos de sangrados y que pudieran tomar lo aprendido y aplicarlo en su comunidad local.

Los programas comenzaron viernes en la noche con una bienvenida e introducción y presentación de cada participante y la discusión de los objetivos del TEACH español. Luego sábado comenzaron las sesiones planificadas. Entre los temas discutidos estuvieron la Historia de los trastornos de Sangrados. Para los participantes este tema fue muy sensible, arrojó sentimientos de frustración, enojo, mucha tristeza, pero también mucha esperanza para las futuras generaciones.

Comprendieron que el tratamiento de la hemofilia ha evolucionado considerablemente en las últimas décadas y la calidad de vida ha mejorado dramáticamente en la mayoría de los casos con hemofilia y la esperanza de vida es casi la misma que la de la mayoría de las personas sanas.

Asimismo, durante sábado y domingo se facilitaron temas como: Como participar de Investigaciones y porque debemos participar de estas investigaciones, Salud Mental en la comunidad con trastornos de sangrados, Como construir una relación con tu legislador y Tu voz tiene peso. Luego el lunes le dimos una visita a Alma Acosta, Directora Ejecutiva del Caucus hispano en el congreso de los Estados Unidos. Allí pudimos poner en práctica lo aprendido, por qué abogamos, cómo abogamos para defender nuestra causa y preguntamos por mejores servicios de salud para nuestra comunidad. También, disfrutamos de una muy divertida clase de Zumba.

¡Un grupo de asistentes fantástico! Los presentes intercambiaron experiencias, recibieron y ofrecieron apoyo social, recibieron e intercambiaron experiencias con otras familias que lidian a diario con situaciones similares. Según el relato de algunos participantes en TEACH español, ellos se sintieron incluidos e incluidas, libres y en confianza de exteriorizar sentimientos, a gusto para discutir problemas comunes de la comunidad de trastornos de sangrados, por lo que salieron fortalecidos y empoderados. 📌

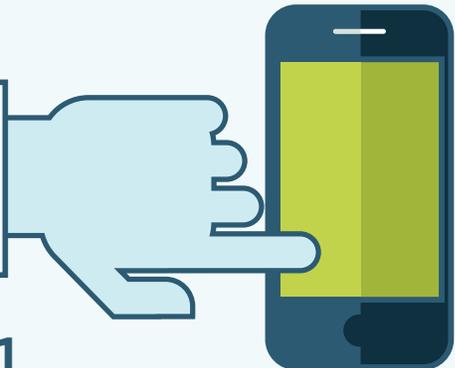




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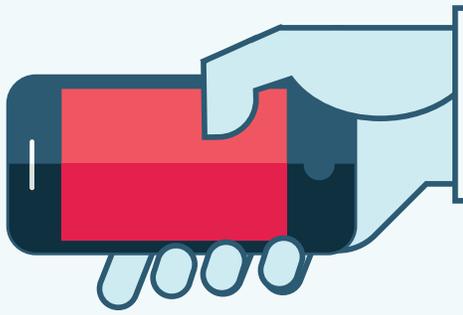


Text CONNECT to 741741

Crisis Text Line is a free 24/7 texting only support service. You are connected to a live, trained crisis counselor to help move you from a hot moment to a cool calm while helping you create a plan to stay safe and healthy.

www.crisistextline.org

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SUICIDE PREVENTION LIFELINE

Call (800) 273-8255

The lifeline provides 24/7, free and confidential support for people in distress, as well as prevention and crisis resources for you or your loved ones. www.suicidepreventionlifeline.org



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www.suicidepreventionlifeline.org**

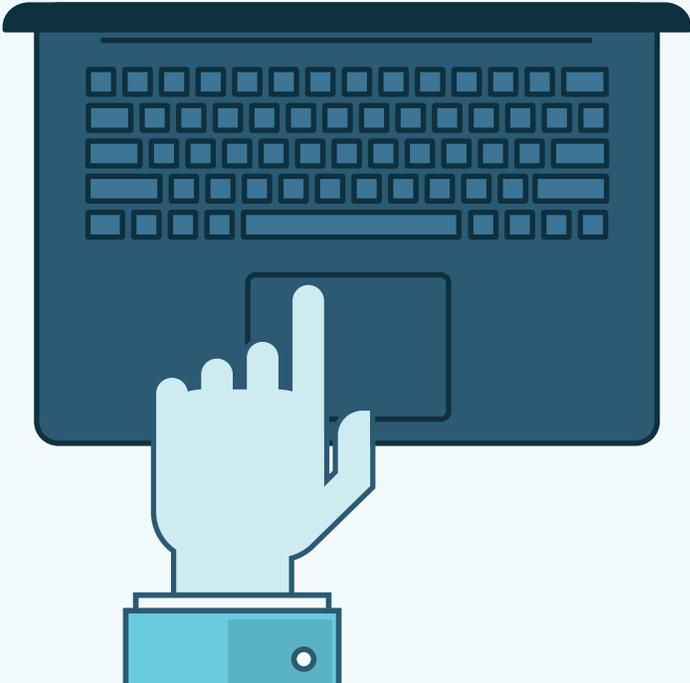
The National Suicide Prevention Lifeline website also has information on providing support on social media, such as how to report a suicidal post on Facebook, self-harm on Twitter or a safety concern on SnapChat. They have information on engaging and supporting someone online.

Other Reputable Resources: 

www.mentalhealthfirstaid.org

www.twloha.com

www.bethe1to.com



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April 4-7, 2019 • San Diego

Join us for the largest family-friendly conference
for the bleeding disorders community!

Symposium is a place to learn
and grow through powerful
sessions and tracks. **The
weekend includes:**



- vWD & Hemophilia Tracks and Sessions
- Rare Bleeding Disorders Track
- Blood Sisterhood, Blood Brotherhood & Families Tracks and Sessions
- Spouses and Partners Track
- Individual, Private Rap Sessions
- Sesión de HFA Sangre Latina
- Advocacy Sessions
- On the Horizon & the Future of Treatments Sessions
- Research Sessions & Research Poster Presentation
- Pain Management & Other Topics Important to the Community
- Yoga, Zumba & Wellness Activities
- Delicious Meals & an Exhibit Hall
- Childrens & Teens Programs



History Room

We'll recognize 25 years of serving the bleeding disorders community with a memorable and touching display remembering the last 80+ years of bleeding disorders.



NEW for 2019

Welcome to Symposium Session

We'll kick off the event with a fun welcome session with a keynote speaker and valuable information about the entire weekend.

Teen Overnight on the U.S.S. Midway

High school age children can attend an educational, STEM-based overnight program on the retired U.S.S. Midway, chaperoned by adults and the staff of the Midway.

Final Night Event on the U.S.S. Midway

The 2019 final night event is shaping up to be the biggest and best yet. Wrap up the weekend on the flight deck of the U.S.S. Midway, a four-acre, outdoor deck floating in San Diego Bay. Rising 50 feet over the water, it features unparalleled 360-degree views of San Diego, spanning the downtown skyline, San Diego-Coronado Bridge and Point Loma. More than 30 remarkably-restored naval aircraft are on display for guests to explore. After dinner, we'll dance the night away followed by a spectacular firework show.

Register NOW at
www.hemophiliafed.org!



“The experience was phenomenal from start to finish! At Symposium there was a rare bleeding disorders conference track. I felt like it was designed almost exclusively for me and it allowed for me to meet incredibly special people. Making these connections was worth the trip itself. I not only learned scientific data, but also about advocacy, healthcare, and being a mom to a child with hemophilia.”

-Sylvia, blind mother of child with mild cerebral palsy and severe parahemophilia

MEMBER ORGANIZATION SPOTLIGHT

Hemophilia Foundation of Southern California

Hemophilia Foundation of Southern California was founded in 1954. Like many foundations, HFSC began out of the vision of a few individuals who saw the need and importance of uniting in an effort to provide information, education and improved treatments. Over the years, it has continued this mission and has grown to meet the changing needs of the bleeding disorders community.

“We continue where medical treatment leaves off in our efforts to reach all people affected by hemophilia, and other serious forms of bleeding disorders,” says Executive Director, Michelle Kim.

The mission of HFSC is to improve the quality of life and build a community for families and individuals living with hemophilia or other bleeding disorders through a variety of quality programs and services in held in southern California.

HFSC created new strategic goals for programming and outreach several years ago and is proud to have attained those goals. Those goals include outreach to their Spanish-speaking community with the creation of Mujeres Enlazadas por Sangre, a bi-monthly support group of about 50 women and teen girls, and the launch of Familia de Sangre, the largest Spanish-speaking bleeding disorders conference in the nation which they co-host with other California bleeding disorder organizations. They hosted a Teen Leadership Summit, a week-long life skills, advocacy and leadership training and a Back-to-School event to train parents on school issues which drew 350 people. Last September, they held the second annual “gnarly” surf event led by a community member who surfs, emphasizing the importance of prophylaxis treatment.

Michelle Kim, Executive Director



Facts about HFSC



Number of counties HFSC serves

Los Angeles, Orange, Riverside, San Bernardino, Ventura, Santa Barbara, Kern, Inyo and San Luis Obispo counties



2,000
Approximate number of members of HFSC



12
Number of Board Members



Unique Populations
HFSC has a diverse population, including Spanish-speaking and Korean



The Future

Expand Men's Programming Expand programming to ultra-rare conditions

“We are very grateful for the enormous support HFA gives to its member organizations with its relevant and thoughtful programming. Our members greatly benefit from this impactful education and we appreciate HFA’s extreme commitment to the bleeding disorders community. We are so thankful to partner with you! You are the BEST! THANK YOU!”

To learn about becoming a Member Organization, email VP of Member Advancement, Michelle Burg at m.burg@hemophiliafed.org or Ann LeWalk at a.lewalk@hemophiliafed.org.

HFSC is the Host Organization for Symposium 2019



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Apply for the HFA Summer 2019 Policy & Government Relations Internship!

HFA will select two college students to work in Washington, D.C., for 10 weeks from May to August at HFA's headquarters and focus on projects related to federal and state health care policy and advocacy.

- ★ Receive leadership and guidance in policy, government relations and advocacy work.
- ★ Opportunities to visit Capitol Hill.
- ★ Housing, travel to and from D.C., and modest stipend is included.

Learn About Application Requirements & Apply at bit.ly/HFA2019Intern



Must be at least 21, enrolled in college or recent graduate, and either have a bleeding disorder or related to someone with a bleeding disorder.

NEXT ISSUE:

Women, Girls & Moms

The **strength of women** with bleeding disorders is **unmistakable**. The **relationship between moms and their children with bleeding disorders is inspirational**. We'll **pay tribute to women and moms**, with stories about moms **encouraging their children to soar**, unique stories of adoption and much more.

