A DOUBLE-EDGED SWORD: HEMOPHILIA AND MENTAL HEALTH
page 22

THE THREAT TO FINANCIAL SECURITY
page 10

A FOCUS ON MENTAL HEALTH
page 20
**HI FRIENDS,**

With spring upon us and everything in full bloom, I hope you’ve had a good start to the year and found time to recharge and energize. My husband and I were able to spend some quality time with a few family members. I’ve been loving spending time in my new backyard garden — so much lettuce to harvest!

The Board of Directors has been busy this year and is looking forward to continue to partner with the HFA staff and community in creating an HFA strategic plan, as well as continuing to look for ways to become a stronger, more focused governing board.

Mental health continues to be a priority for HFA and our community. In addition to adding more education and social media content, we plan to partner with other bleeding disorder organizations to collaborate on this important topic. Your mental health is extremely important. We hope you are finding ways to cope with the daily stressors and that you understand and can identify the warning signs that may indicate you or someone you love is in need of more professional support.

I am proud to share that HFA has been awarded the 2021 Gold Bell Seal for Workplace Mental Health by Mental Health America (MHA). This Bell Seal is a first-of-its-kind workplace mental health certification that recognizes employers who strive to create mentally healthy workplaces for their employees. Our status at Gold demonstrates our dedication to employee well-being for outstanding scores in workplace culture, employee perks and programs, legal and ethical compliance and leadership and community engagement.

Sharing experiences about heavy and personal topics can be intimidating and difficult to do. However, an individual’s story about facing and overcoming adversity can be the catalyst for the healing of others. I hope this issue’s cover story profiling Ryan Seeley (pg. 22) serves as that catalyst as you read about his struggles with anxiety, depression and suicidal thoughts. I’m also proud to see Michael Bishop, one of HFA’s own staff members, share his experience managing depression (pg. 26) within these pages. Michael’s story is one that many can resonate with and I hope his message of continuing to work towards a better tomorrow is something you take away.

Whether it’s through daily light exercise, finding small joys, having gratitude or talking with a mental health provider, we encourage you to support your mental health. We are here to help educate, advocate and support you in that process. (Turn to page 20 for HFA’s mental health resources.)

We also hope that your family is staying healthy during this time. As COVID-19 vaccines begin to roll out more widely, HFA is here to offer education on the vaccine and support your decision-making. As a health care worker, I was fortunate to receive my vaccine and am thankful that I had the opportunity to better protect myself and my loved ones.

Despite the challenging times, the bleeding disorders community remains strong and is here to support one another. HFA is excited for what is in store as 2021 unfolds, and we hope you are too.

Allie Ritchey
Chair, HFA Board of Directors
Hemophilia Association of New Jersey (HANJ) has been serving the bleeding disorders community in the state since 1950. HANJ currently provides resources and programs for around 800 people, including programs for men, women, children, families and clinicians.

“Our organization is unique in it has strong advocacy roots that go back decades upon decades,” said Stephanie Lapidow, HANJ executive director. “We really set the stage for other local bleeding disorders organizations to understand the impact of advocacy and how to do it.”

The association’s most popular program is its annual Winter Membership Gathering. It usually takes place in February at iPlay America in Freehold, New Jersey, and brings out most of the community. But in 2021, it was held over Zoom, as a two-day event filled with activities, education and opportunities for the community to connect.

“The HANJ is proud to offer many longstanding resources to our New Jersey community,” Lapidow said. “As we move though this new digital space, we have learned new ways to reach our members. We have many new initiatives in store, so stay tuned.”

Hemophilia Organizations Release COVID-19 Vaccination Guidelines

The World Federation of Hemophilia, European Association for Haemophilia and Allied Disorders, European Haemophilia Consortium and the National Hemophilia Foundation collaborated to develop guidelines on the COVID-19 vaccination for patients with bleeding disorders. Their hope is hemophilia treatment centers, in close collaboration with patient organizations, take action to inform people with bleeding disorders about the COVID-19 vaccines and contribute to an effective vaccination program. The guidelines include how to work the vaccination into an infusion schedule, whether there are contradictions with other diseases or treatments and how it should be administered.


HFA to Offer Regular Chat for Blood Sisters

Hemophilia Federation of America recently hosted its first SisterSpace, a new virtual safe space for women with a diagnosed bleeding disorder or those seeking diagnosis. This online get-together will be a space for adult women to engage in conversation with other blood sisters across the country. Future SisterSpace dates and times will be shared on HFA’s social media and website at www.hemophiliafed.org.

HFA Partners with RareDiseaseLive to Share On-Demand Video on Hemophilia A

Hemophilia Federation of America, the National Hemophilia Foundation and the National Organization for Rare Disorders partnered to provide “A Closer Look at Hemophilia Management: Improving Outcomes with Personalized Care,” an on-demand session presented by RareDiseaseLive. The interactive, expert-led education activity addresses questions from patients and families regarding their treatment and overall care, tips for working with a health care team, and helpful strategies other families have employed to address day-to-day challenges. It features a pediatric specialist with expertise in hemophilia, an advanced practice provider, an HFA patient advocate, and parent of a child with hemophilia. The session is presented by RareDiseaseLive supported by an educational grant from Genentech.

Watch the session at www.rarediseaselive.com/hemophilia-a.

Our organization is unique in it has strong advocacy roots that go back decades upon decades.

—Stephanie Lapidow

Hemophilia Organizations Release COVID-19 Vaccination Guidelines

PROGRAMS FOR

- Men
- Women
- Children
- Families
- Clinicians
GETTING TO KNOW HFA’S STAFF

This past year Hemophilia Federation of America welcomed the following new staff members to help better serve the bleeding disorders community.

Tatiana works on HFA’s Helping Hands team, working to provide direct financial assistance to families in need, as well as connects community members with vital resources and services. She also collaborates with other HFA staff members to create accessible and culturally competent resources for Spanish-speaking community members.

Keirsten’s main focus is enhancing HFA’s online content and website to provide the bleeding disorder’s community with the information and resources they need in a positive user experience, including improving use on mobile devices, as the world has shifted into using phones to look for information and conduct daily business. “We want our community to have a great experience when looking for information or seeking assistance on our digital platforms,” she said.

Keirsten has been in the world of communications since college. Over the years, she has done community work with her communications background, such as founding a farmers market that is still thriving and directing a pilot program to assist small businesses with startup or growth.

She has launched two businesses — a Pilates studio and a public relations agency.

She is the proud mom to a very cool 20-year-old, who is a personal trainer in D.C.

She loves to travel, so she doesn’t own pets or plants, but she loves cooking and calls it her therapy. She is a Pilates instructor and licensed massage therapist and loves working with clients to make them feel better. She also loves to hike.

Keirsten Shaffer
Digital Communications Manager

Mark serves on our Policy, Advocacy and Government Education team, assisting member organizations in 26 states with advocacy initiatives, such as legislative days, stakeholder meetings and advocacy-related events. He’s also responsible for HFA’s quarterly State of the States report, which summarizes relevant state legislative and regulatory developments. He also plays a key role in preparing HFA’s written federal and state comment letters and educational materials related to policy and advocacy.

He has worked with the bleeding disorders community for more than 15 years, first through the ACCESS Program in Tampa, Florida, which helped people with bleeding disorders and other rare or chronic conditions obtain federal disability benefits, then as part of the government relations team for Patient Services Inc., a premium and copay assistance foundation. Previously, he managed the institutional reimbursement programs for Wyoming Medicaid, supervised the reimbursement staff for the manufacturer of cochlear implant devices, and directed advocacy efforts for national associations representing speech, hearing and durable medical equipment providers.

He and his wife, Sandra, have a 9-year-old son, Felipe, who they adopted from Colombia. While living in Florida, Felipe (and mom and dad too) loves swimming and fishing and playing sports year-round. Mark has been to every state, except Alaska, but is looking forward to someday going hiking in Alaska.

Mark Hobracz
Senior Policy Manager

Heather Case
Associate Director, Programs

Heather manages HFA’s Blood Sisterhood program, supports member organizations in reaching their educational goals, and works diligently to help the bleeding disorders community feel more connected.

Prior to joining HFA, Heather was the program director/family camp director at New England Hemophilia Association. Prior to that, she worked for Big Brothers Big Sisters and was a high school Spanish teacher. (Her Spanish skills are valuable with HFA’s Sangre Latina program as well.)

Heather lives in a nearly 300-year-old home north of Boston with her husband, two kids and a potcake dog.

She loves the outdoors, cooking and yoga. She’s also always reading and loves to hear recommendations for good books!

Heather Case
Associate Director, Programs

ON THE MOVE

Michael Bishop, who had served as HFA’s website specialist, has moved to HFA’s Institute, which consists of Learning Central and staff and board online training, as content design specialist.

Michael Bishop
Associate Director, Learning Central

SPRING 2021
Proven protection against bleeds in adults and adolescents

| 1.2 overall bleeds per year* |

*Effect halved half-life.

For up to 3 months

• 175 previously treated patients with severe hemophilia A received Esperoct® 50 IU/kg every 4 days for 76 weeks based on median annualized bleed rates shown.

• Through level goal is 1% for prophylaxis.

**Data shown are from a study where 175 previously treated adolescents and adults received routine prophylaxis with Esperoct® 50 IU/kg every 4 days for 76 weeks. Pre-dose factor activity (trough) levels were evaluated at follow-up visits. Mean trough levels for adolescents (12-<18 years) were 2.7 IU/dL.

**Don't delay. IVI activity levels were estimated in 143 adults and adolescents using pharmacokinetic modeling.

What is Esperoct®?

Esperoct® [antihemophilic factor (recombinant), glycopegylated-exel] is an injectable medicine to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A. Your healthcare provider may give you Esperoct® when you have surgery. Esperoct® is not used to treat von Willebrand Disease

IMPORTANT SAFETY INFORMATION

Who should not use Esperoct®?

If you are allergic to factor VIII or any of the other ingredients of Esperoct® or if you are allergic to hamster proteins

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

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

• Call your healthcare provider right away if your bleeding does not stop after taking Esperoct®

What are the possible side effects of Esperoct®

Common side effects of Esperoct® include rash or itching, and swelling, pain, rash or redness at the location of an infusion. Please see Brief Summary of Prescribing Information on the following page.

High factor levels from one dose to the next in adults and adolescents

• At or above 3% trough level for 100% of the time

• At or above 5% trough level for 90% of the time

You may infuse Esperoct® at a hemophilia treatment center, at your healthcare provider’s office or in your home. You should be trained on how to infuse your hemophilia treatment center or healthcare provider. Many patients with hemophilia A learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much Esperoct® to use based on your weight, the severity of your hemophilia A, and where you are bleeding. Your dose will be calculated in international units (IU).

How to start taking Esperoct®

If your bleeding is not adequately controlled, it could be due to the development of Factor VIII inhibitors. This should be checked by your healthcare provider. You might need a higher dose of Esperoct® or even a different product to control bleeding. Do not increase the total dose of Esperoct® to control your bleeding without consulting your healthcare provider.

Use in children

Esperoct® can be used in children. Your healthcare provider will decide the dose of Esperoct® you will receive.

If you forget to use Esperoct®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using Esperoct®

Do not stop using Espereoct® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much Esperoct®?

Always take Esperoct® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure if you infuse more Esperoct® than recommended, by your healthcare provider as soon as possible.

What are the possible side effects of Esperoct®

Common Side Effects Include:

• Rash or itching

• Swelling, pain, rash or redness at the location of infusion

Other Possible Side Effects:

You could have an allergic reaction to coagulation Factor VIII products. Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as: hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.

What should I tell my healthcare provider before using Esperoct®?

• Before taking Esperoct®, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to Factor VIII.

• Your body can make antibodies called “inhibitors” against Esperoct®, which may stop Esperoct® from working properly. Call your healthcare provider right away if your bleeding does not stop after taking Esperoct®

• Do not return the product to the refrigerator.

• Do not use after 12 months if stored up to 86°F (30°C) for up to 2 months or 104°F (40°C) for no longer than 3 months.

• Do not use the medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

How to Reconstitute:

The reconstituted (final product once the powder is mixed with the diluent) Esperoct® should appear clear and colorless without visible particles.

The reconstituted Esperoct® should be used immediately.

If you cannot use the reconstituted Esperoct® immediately, it should be refrigerated at 36°F to 46°F (2°C to 8°C) for up to 4 hours. The reconstituted product in the vial should be stored at or below 86°F (30°C) or in a refrigerator at 36°F to 46°F (2°C to 8°C).

Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about Esperoct® and hemophilia A?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use Esperoct® for a condition for which it has not been prescribed.

Revised: 10/2019

For Information, please refer to: http://www.novonordisk-us.com/patients/product/patient-info.html

For Patien information, refer to: http://novonordisk-us.com/patients/product/patient-info.html

More detailed information is available upon request by prescription only.

Manufactured by Novo Nordisk A/S.

Novo Albina

DK-2880 Bagsvaerd, Denmark

For information about that do not go on page.

What are the possible side effects of Esperoct®

Esperoct® comes in five different dosage strengths. The actual number of international units (IU) of Factor VIII in the vial will be imprinted on the label and on the box. The five different strengths are as follows:

- 50 IU/kg per vial
- 100 IU/kg per vial
- 150 IU/kg per vial
- 200 IU/kg per vial
- 300 IU/kg per vial

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

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

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Limits on Copay Assistance Can Threaten Families’ Financial Security

By HFA Policy and Advocacy Team, with assistance from an actuarial professional

For many in the bleeding disorders community, drug manufacturer copay assistance programs are a source of financial relief and the sole protection against perpetually high out-of-pocket health care costs. Unfortunately, health insurers, citing the need to curb medical inflation, are increasingly refusing to credit copay assistance toward patients’ deductibles and out-of-pocket maximums, via the implementation of “accumulator adjuster programs.”

This strategy shifts thousands of dollars of cost-sharing back to the patient. Because the implications of this shift are far-reaching, addressing this issue has become a top advocacy priority for HFA and many other patient advocates.

Accumulators create significant confusion, financial risk and barriers to care. Those confronting high-cost sharing may find themselves hard-pressed to afford their prescription refills, forcing them to weigh discontinuing treatment or turning to emergency rooms for care. Both options lead to bad health outcomes and higher overall health spending in the near term. But people exposed to high year-after-year out-of-pocket costs also face long-term, grossly disproportionate threats to their financial security as well as their physical well-being.

When copay assistance is working as intended, it greatly reduces the cost-share for those who must rely on ultra-high-cost drugs. It effectively levels the playing field, bringing out-of-pocket expenditures for this population down to a level that is comparable to a person of more typical risk. Should accumulator adjusters be allowed to spread across the insurance landscape, copay assistance would no longer be an effective tool to combat high patient cost-sharing. Suddenly, many with a bleeding disorder could face the maximum out-of-pocket costs allowed under their health plan, year after year after year. The level playing field would be gone and those who rely on high-cost drugs to preserve their health would face a financial burden starkly different from those of more typical risk.

There is evidence proving this is already happening: A 2019 article from RealClearHealth.com reported, “On average, individuals with two or more chronic diseases spend five times more out-of-pocket than patients without any chronic conditions. People with three or more conditions pay 10 times more.”

To illustrate, examine the out-of-pocket claims spend of two individuals: Maximum Mike and Average Joe. Both have an Affordable Care Act Marketplace plan with an out-of-pocket maximum of $8,550, the upper limit allowed for 2021. Maximum Mike has a chronic condition

**For more information and resources, please visit www.hemophiliafed.org**
requiring expensive medication, so he will reliably reach his plan’s OOP limit each and every year. Average Joe spends the U.S. average on out-of-pocket costs, which is $800 per year, according to the Kaiser Family Foundation. The table below shows their cumulative spending over time. (For this exercise, both the ACA out-of-pocket limit and U.S. average out-of-pocket spend are assumed to increase 4.4 percent each year. This matches the average annual increase in the ACA out-of-pocket limit from 2014 to 2021.)

In year one, Maximum Mike tops out his out-of-pocket spending at $8,550 — compared to Joe’s out-of-pocket cost of $800, for a difference of $7,750. With no protection from copay assistance, this dynamic plays out year after year and Mike quickly faces an overwhelming cost burden.

Within 10 years, his costs exceed $100,000, while Joe’s remain under $10,000. The following graph highlights this huge cost disparity.

In summary, it is clear that accumulators cause serious short- and long-term harm to individuals who rely on high-cost drugs to maintain their health. Maximum Mike and Average Joe are imagined, but the comparison of their projected spending over time is not merely a theoretical exercise. These charts show hard-earned money not being put in a 401k, not being saved for college, not being spent in pursuit of the American dream. They show lost opportunities that will become reality for our families and friends if accumulator adjusters continue to proliferate.

As a community, we must understand the threat that accumulator adjusters pose, educate our lawmakers and advocate for change.

<table>
<thead>
<tr>
<th>Year</th>
<th>Maximum Mike</th>
<th>Average Joe</th>
<th>Cost Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 1</td>
<td>$8,550</td>
<td>$800</td>
<td>$7,750</td>
</tr>
<tr>
<td>Year 5</td>
<td>$46,681</td>
<td>$4,368</td>
<td>$42,313</td>
</tr>
<tr>
<td>Year 10</td>
<td>$104,577</td>
<td>$9,785</td>
<td>$94,792</td>
</tr>
<tr>
<td>Year 15</td>
<td>$176,380</td>
<td>$16,503</td>
<td>$159,877</td>
</tr>
<tr>
<td>Year 20</td>
<td>$265,434</td>
<td>$24,836</td>
<td>$240,598</td>
</tr>
</tbody>
</table>

WHAT IS HAPPENING IN YOUR STATE?

WHAT LEGISLATIVE PROTECTIONS ARE IN PLACE?

As of May 13, 2021, nine states and one territory (Arizona, Arkansas, Georgia, Illinois, Kentucky, Oklahoma, Tennessee, Virginia, West Virginia and Puerto Rico) have passed laws prohibiting or limiting the use of accumulator adjusters for all individual and small group plans. More than 20 states considered (or are still considering) accumulator bills during their 2021 legislative sessions.

HOW CAN I REACH OUT TO MY STATE AND FEDERAL ELECTED OFFICIALS TO ASK FOR ALL COPAYS TO COUNT?

Use HFA’s easy-to-use Legislative Action Center to send a letter to your representatives: http://bit.ly/AllCopaysCount.
TIME FOR A LIVING ROOM dance party!

Ways to help you from being sad sometimes

Everyone gets sad sometimes! It’s OK. And sometimes when we get sad, it almost seems like it’s really hard to handle. Here’s what you can do if you’re sad:

SPEND TIME WITH FAMILY! If you have a phone, computer or games, put them away for a little while and spend time with your family. Playing board games and making crafts is a great way to connect with your family.

BE ACTIVE! Go for a walk or play outside with the adults in your family or ask them to join you for dancing and singing in the living room.

GET SLEEP! Getting enough sleep will make you feel better — both in your body and in your mind. If you have trouble falling asleep, try reading or listening to calming music.

EAT HEALTHY! We know, broccoli might not be as good as pizza, but be sure to eat fruits and vegetables and healthy foods often. That makes your body and your brain healthier, which could help you feel better.

REMEMBER: Tell your mom, dad, caregiver or an adult you trust about your feelings because they would love to help you feel better.

WHAT DO YOU DO WHEN YOU’RE SAD?
DRAW A PICTURE BELOW:
**How is Gene Transfer Therapy Research Designed to Work?**

Provided by and printed with permission by Biogen.

It's not magic—it's science in progress. Many gene therapies are under investigation and some have been approved for use for conditions other than hemophilia A or B. The risks and benefits of each gene therapy are evaluated independently, and if a clinical trial for a particular gene therapy is successful, it has the potential to offer a remarkably different approach to the way we've historically managed genetic diseases. No gene therapies for hemophilia A or B have been approved for use or determined to be safe or effective.

*Gene Transfer*

Currently undergoing clinical trials in many different conditions, including hemophilia A and B, this method of gene therapy aims to introduce a working, or functional, gene into the body intended to produce a needed protein.

*Creating a Working Gene*

The gene therapy begins when a working gene is created in a laboratory. The working gene is developed to contain the instructions for making a needed protein.

Scientists design working genes to meet a disease’s specific needs. For example, in patients with hemophilia A, an F8 gene is needed to code for factor VIII protein, which is essential for clotting, and in hemophilia B, an F9 gene is needed to code for factor IX protein.

*Building a Therapeutic Vector*

The working gene now has to be delivered into the body. To do so, a therapeutic vector is created. This therapeutic vector is created by modifying a naturally-occurring virus; the shell of the virus is created without the viral DNA, and the working gene is put inside the empty shell. No longer a virus, the therapeutic vector is designed to deliver the working gene to the cells in the body where it is needed.

*Determining Eligibility*

As part of gene therapy research, a healthcare provider must determine whether a patient is eligible.

Factors such as age, gender and liver health may be considered. Therapeutic vectors being used in research are commonly made from adeno-associated viruses (AAVs). These viruses are not known to make people sick. They are found naturally around the world, so some people will have already developed immunity to them via exposure at some point in the past. Having preexisting immunity to the AAV used by a gene therapy could reduce or eliminate its effectiveness. Because of this, candidates may have to be screened with a blood test to ensure that they do not have immunity.

*Delivering the Working Gene*

Once the patient is determined to be eligible, the gene therapy is ready for administration to evaluate its safety and effectiveness. A single, one-time infusion in an appropriate clinical infusion setting delivers large numbers of therapeutic vectors into the body. The therapeutic vector is designed to both protect and guide the working gene toward preferred cells where it can be used to make the needed proteins.

Research is ongoing to determine the possible impact of the therapeutic vector delivering the working gene to the other cells in the body. Once in the body, the new gene is designed to do the work of the gene that is missing or isn’t functioning properly. The goal is to provide instructions for the body to make the protein it needs on its own, and ongoing research is evaluating the risks and impact of introducing the new gene.

Because the new, working gene is not intended to become part of your DNA, the original missing or mutated gene is left unchanged. Gene transfer is not designed to replace or edit the existing gene, which means that the mutated gene could still be passed to future generations.

*Monitoring Safety and Efficacy*

Regular monitoring after gene therapy is important because it allows researchers to understand any risks and what impact the gene transfer is having. Patients in clinical trials meet with their care team for blood tests, and to discuss their medication regimen and lifestyle to collect data as part of the study. As with all medications, response to gene therapy may vary. How long gene therapy might keep working is being evaluated in ongoing clinical trials with researchers aiming to create a long-lasting therapy.

As of publication, no gene therapies for hemophilia A or B have been approved for use or determined to be safe or effective.
We’re counting down the days for HFA hugs to resume

Until then, we’re here for you and your family at www.hemophiliafed.org

Discover more about IXINITY®
Visit IXINITY.com
HFA FOCUSES ON MENTAL HEALTH & WELLNESS IN 2021

BY ANN LEWALK, MA, HFA VICE PRESIDENT OF EDUCATION

In the best of times, people with bleeding disorders are at a greater risk of depression. However, during the COVID-19 pandemic, the isolating effects of a chronic disorder, coupled with the forced social distancing, has only magnified mental health issues in the bleeding disorders community.

Recognizing the importance of mental health and wellness, Hemophilia Federation of America has committed 2021 to a focus on mental initiatives by raising awareness, providing resources and advocating for mental health services for the bleeding disorders community across all programs and services throughout this year and beyond.

HFA began the initiative by creating an internal Mental Health and Wellness Task Force. To ensure communication of the initiative across the organization, each HFA department is represented. Staff members act as the liaison between their team and the task force. All HFA staff members have incorporated mental health initiatives into their annual goals, demonstrating our organizational commitment to mental health and wellness.

LISTEN FIRST

As with all initiatives HFA commits to, the Mental Health and Wellness initiative is in response to the voice of the bleeding disorders community. HFA and its staff make it a priority to listen to the community, to reach out to all segments and be responsive to the community’s needs by meeting members where they are.

Over the past year, the world has learned to pivot, change and adapt to new ways of conducting business, educating and socializing. For some people, adapting to these changes without social interaction and support is too much to handle. Recognizing the bleeding disorders community was especially vulnerable, HFA conducted educational webinars and surveys of the community in 2020 to determine the impact of COVID-19 on their lives.

Through HFA’s communications, community members voiced frequent concerns about depression, anxiety, isolation, trauma, addiction, suicide and grief. The Mental Health and Wellness Task Force is using the community’s voice to develop ways to address these mental health issues across all HFA programs and services.

RAISE AWARENESS

From the beginning of the mental health initiative, HFA has acknowledged that it is not a mental health service provider and does not have the expertise to solve the growing mental health crisis. But, as a national bleeding disorders organization, HFA does have the capacity and the obligation to address issues that affect the bleeding disorders community in disproportionate numbers.

HFA will leverage its national reach to raise awareness about mental health and wellness through social media, publications and educational webinars and build a repository of easily accessible mental health resources on its website.

GATHER RESOURCES

As a national organization, HFA is fortunate to have access to many highly qualified, nationally recognized mental health professionals interested in providing information and acting as trusting resources for members of the bleeding disorders community. Leveraging these relationships, HFA is able to provide the community with educational webinars, toolkits of materials, links to support groups and crisis lines, and trainings to identify, understand and respond to signs of mental health crises.

ADVOCATE FOR MENTAL HEALTH SERVICES

As an advocacy organization, access to quality, affordable health care is a priority for HFA. That includes access to appropriate, affordable mental health services. With the increase of mental health concerns since the pandemic started, reports have surfaced about community members who have been denied access to in-patient mental health services because they have a bleeding disorder.

HFA’s policy and advocacy team will complete an environmental scan to identify barriers to in-patient mental health care and determine how widespread the issue is in the bleeding disorders community. The organization will consult with other infusion/injectable patient advocacy organizations to determine the depth of the issue. Depending on what is found, HFA hopes to identify stakeholders at mental health in-patient facilities to establish mitigation solutions.

WORKING TOGETHER

HFA and the National Hemophilia Foundation have agreed to work collaboratively to prioritize mental health and wellness in the bleeding disorders community through the formation of a coalition of organizations with similar interests. The two organizations aim to partner with mental health organizations, bleeding disorders organizations, HFA member organizations, NHF chapters and hemophilia treatment centers to address mental health and wellness in the bleeding disorders community.

Throughout 2021, HFA and NHF will launch coordinated messaging and resources on their respective websites and begin to cross-promote educational events and training opportunities. Through the spirit of collaboration, the two national organizations will address the mental health crisis in the bleeding disorders community more efficiently and effectively.

HFA’S MENTAL HEALTH INITIATIVES INCLUDE:

Webinar and forum recordings at www.youtube.com/HemophiliaFederationofAmerica:
• “Gratitude Works! How Gratitude Heals, Energizes and Transforms Lives” webinar
• COVID-19 vaccine forums (in both English and Spanish)
• Mental Health Professionals Panel

Visit www.hemophiliafed.org for information about upcoming mental health programs or to access recordings of previously held webinars.

HFA STAFF COMMUNITY OUTREACH PROGRAM:

- Outreach to HFA patient chapters and regional HFA office outreach
- Trainings for member organizations and the community:
  - HFA Learning Central Mental Health Courses at www.lifelearning.org
  - Quarterly Mental Health First Aid Trainings
  - Stress and Anxiety Cohort Workshops

HFA STAFF COMMUNITY OUTREACH PROGRAM, which includes opportunities for staff to play a role in staying connected with the community through writing letters and other outreach.

SPRING 2021 21
Ryan Seeley, of Orchard Park, New York, has dealt with mental health issues for most of his life. About 10 years ago Seeley, now 52, was forced to retire from the nursing career he loved and go on disability. He has severe hemophilia A and multiple chronic illnesses, including psoriatic arthritis. In an in-depth interview in late February with Dateline Federation, Seeley shared how mental health issues have affected him, what has helped him over the years and what happened when the pandemic struck last year. (This interview has been edited and condensed.)

**What was your mental health like before the pandemic?**

A: I’ve been diagnosed with generalized anxiety disorder and social anxiety disorder, and I was officially diagnosed with depression at the age of 25. However, my symptoms started well before that, probably in my junior high years. There was a lot of bullying going on that made the depression worse. Of course, back then, I didn’t know that it was depression. I just knew that I didn’t feel good. I was and have been for many years, since age 25, on an antidepressant medication. I had to go through probably eight different medications to find the one that helped me best.

Prior to the pandemic, I would say overall all of my issues were well-managed, but there was definitely— in depression at least— ebbs and flows, meaning that you can be good one day and then all of a sudden it feels like a heavy wool wet blanket was plopped on top of you and you can’t get it off.

**How does hemophilia fit into this?**

A: I don’t know that I would say hemophilia was a cause of it, but I think with anyone living with any type of severe or chronic illness, it can affect their mental well-being. But, people with depression, anxiety and other mental health disorders are more at risk for those symptoms to become exacerbated because of the chronic illness. In my case, I have multiple chronic illnesses that ultimately forced me to retire 10 years ago and go on disability. You deal with a lot of loss when you live with a chronic illness because there’s a lot of things that you either can’t do physically, aren’t up to doing mentally or you just feel isolated because you feel like you’re the only person that feels this way.

You go through feelings of feeling different because nobody else has this, especially hemophilia because it’s so rare. I come from a generation of death, to be honest. My brother was infected with HIV and died in the ‘80s. I am also gay, and I watched the LGBT community, as well as the hemophilia community, decimated by HIV and AIDS and lost many people on both sides. Out of it all, it came out and here I am at 52 still alive. I’ve lived with a lot of survivor’s guilt because of that, and that’s definitely affected my mental health issues as far as depression and anxiety.

In the hemophilia community, men in general have a really hard time talking about emotional things. I think society dictates that a man is not supposed to show emotion, not supposed to talk about taboo subjects like depression and mental health disorders because they fear they’ll appear as weak. I think that our community has done a wonderful job providing resources to younger people to cut this off at the pass. I see younger people in our community more open to talking about these things versus someone in my age group.

When the pandemic hit, how did that affect your mental health?

A: When everything started, I could see the writing on the wall. I’m a retired nurse. I’m a trained medical person, even though I’m no longer in practice, and that training never goes away. When I started seeing these reports on the news and started seeing issues with food shelves emptying out, I would say that I had a mini-breakdown. I told my husband, “We need to prepare for the worst because it’s happening. We’re not there yet, but we’re going to be in a week or two.” I remember that minute going to the grocery store and completely terrified that anybody that brushed against me was going to give me this. I’m at high risk because the psoriatic arthritis is an autoimmune disorder. That means my immune system is not as strong as someone without it, and the biologic I take is an immunosuppressing drug. I’m at very high risk and very susceptible to not only contract COVID but also die from it.

I spent $400 loading up on things that would sustain us. We created a shelving system like our own grocery store in the basement. I even have an app that I use to track it, so I know when to use stuff. I created all of that in a matter of 48 hours because I saw how bad things were going to get, and I also knew that I was going to have to be isolated in the house and not be able to leave because if I did, I could risk dying.

My husband works as a manager with Home Depot, so he was exposed to the public. Probably about a week or so into this after it really ramped up, he actually went to his boss and said, “My husband is high risk. I cannot risk bringing this home to him and killing him.” Home Depot was generous enough to give him six weeks off with pay, so that he could stay home and protect me.

We stayed locked down and didn’t leave the house other than to walk the dogs for those six weeks that we were home together. Then we learned that it wasn’t as contractible as maybe we thought, meaning there has to be a perfect storm for somebody to actually get it out in public, but we were masking and bleaching things and washing hands. We developed our own coping scenario. I did use a grocery delivery service for most of the summer. It costs more money, but I didn’t have to put myself at risk.

It was different in the summer. Spring, summer and fall here in the Buffalo area is actually quite pleasant. We lived at the time in downtown Buffalo and had a humongous outdoor patio. I was able to be outside over the summer with the dogs. We actually adopted a rescue puppy in July. We bought a house in the middle of the pandemic. We did some major life things throughout the late spring and into early fall. We bought the house and moved to a suburb of Buffalo in the middle of September. It was a little bit easier to manage those mental health issues because I was able to be outside. Even though we were in our little walled fortress, I was still able to be out and feel like I was able to leave the house safely.
The hardest part has been the isolation of not being able to just go out and have dinner, just my husband and I, which we used to do a lot. We live in an area of Western New York that has amazing restaurants, and we’re foodies. We have friends that we did stuff with that we’ve not been able to see—some in a year—because they know that I’m at high risk and they’re not willing to risk it and I’m not willing to risk anything.

As far as coping with all that, I definitely have developed coping skills. I’m a Buddhist, and I meditate every day anyway, so I’ve amped that up, and that’s helped ease some of the anxiety. I’m a planner too, so I think that having a plan gives me security. I have a routine.

When I’m home by myself, having the dogs and having to take care of them gives me purpose. Plus, they’re enjoyable. They show love, and they play, and they’re funny. I think that’s helped me.

I’m very much into music therapy. I listen to all sorts of music, and I’ll make playlists of songs that make me feel good. I’ve categorized them as “this list of songs helps me if I’m feeling this way.” I read a lot, so that’s been a nice diversion. Those are a couple coping skills, but also I have an online presence with a group of people that I’m able to reach out to, so I don’t feel completely cut off. I know that at any time I can send one of those friends in that circle a private message and that support system will be there.

I’ve used therapy as an option intermittently over the past 25+ years. I’m at a point now where so much has happened and it’s been a long time since I had a professional therapist that I’m actually in the process of setting it up now. I think that it’s important to note that I am not ashamed that I need to see a therapist. I’m not ashamed that I have to take medication, no different than I take medication for hemophilia. It’s the same thing: it’s a disease. The mental health issues are no different than my physical health issues. They both need medication.

Q: THE PANDEMIC HAS BEEN WITH US FOR MORE THAN A YEAR. BUT NOW WE HAVE VACCINES AVAILABLE, AND MANY PEOPLE SEE HOPE ON THE HORIZON. HOW DO YOU FEEL NOW?

A: Going back to my training as a medical professional, I believe in science. I always knew that a vaccine would help us pull out of this eventually. I’m definitely very hopeful. At the same time though, I’m extremely angry and frustrated. I see how it’s still not where it needs to be. In fact, I’ve been waiting for months for a vaccine. Two weeks ago, they opened up the appointments to people in my group, and they were booked across the state within minutes. Now, it could be April or May before I get my vaccine. I’m very frustrated. Again, I’m a planner.

I’m very frustrated with our state as well because, as much as I think our governor has done a wonderful job with most things, I could have had an appointment today or tomorrow at a Walgreens here, 10 minutes from my house. However, they’ve mandated that pharmacies that are vaccinating can only do age 65 and over. You’re going to let somebody who could die from this by going to the grocery store wait months?

When someone’s feeling desperate, that’s when they make rush decisions that they may regret or that are irreversible. I’m talking about suicide. I don’t know if there have been any studies or numbers on that during the pandemic, but I would bet that there’s been an increase. I’ve been there before, and I know how in the snap of a moment you can feel one way and then you just feel like, “That’s it, I’m done.” Most people think that these people who commit suicide are making these big plans and all that. Ninety percent of the time, it’s not that at all. You can feel fine, and then you can be so despondent that you don’t.

While it’s hopeful, and I see people, lots and lots of friends who are teachers and first responders, getting their vaccines, and I’m ecstatic for them—over the moon happy—at the same time, I’m angry because here I sit and I live in one of the most economically stable or rich states in the entire country.

It’s been frustrating, and I would say that it has caused the depression to dip a bit because you feel like there’s no end in sight. I definitely think that that’s had a bearing, and I feel for people who may not have the coping skills that I do because I know how easily it can change and how quickly that mood can change.
I've been wanting to write this article for a few months now. It seems like the conversation surrounding mental health is one constantly being had in the hemophilia community, and even so, is the one we don't have enough. I've written different versions of this article. Stepped away from it. Come back to it. Deleted it. Missed my deadline. Given up on it. Rewritten it. Missed my deadline again. Deleted it again. But I do want to write it, because I think it needs written.

I've struggled with depression for most of my life. I think the first time it really appeared was when I was 15. I had just had my fourth or fifth surgery. Surgeries were nothing new. Pain was nothing new. But, it was the first time I could consciously feel my life drifting away from the rhythm of the people and things around me. And it is incredibly difficult, if not impossible, to completely cope with something so dynamically ever-changing.

I've struggled with suicidal ideations when I was 25. I was dating someone who, throughout our relationship, had made me feel better about how uncertain my future had begun to seem. My plans for my future continued to change, but suddenly I had someone in my life who made that OK. Instead of going to therapy, or addressing my depression head-on, I thought, “As long as I have her, it doesn’t matter how bad things get.”

Then she left. And with her, the mental safety net I had been building. This threw me into an overwhelming depression. All the mental health issues that had come as a result of my hemophilia, which I had been repressing, came flooding back all at once. I had to call a crisis line, get my friends to come over, change my surroundings and really start taking care of myself and addressing these issues. Thankfully, I was able to do all of those things, and eventually. I'm in a much better place now. The depression is still there, though. My plans are still changing all the time, and I’m still struggling with that. My hemophilia and depression are a challenge every day. They sometimes make me feel like a bad boyfriend, a bad friend, a bad son, a bad employee. But the important word in that last sentence is ‘sometimes.’ I’m still fighting. We talk a lot about how strong this community is, not only how strong we are as a whole, but also how strong we all are individually. But being strong doesn’t mean being strong all the time. It’s OK to be sad. It’s OK if you’re depressed and if you think hemophilia is hard and overwhelming sometimes. It is hard, and it is overwhelming sometimes.

Truthfully, the reason it took me so long to write this article is because I didn’t know how to end it. As a writer, it’s frustrating not knowing how to end something. I don’t have a perfect resolution to give you, one that would solve all these issues, one that led me to a place where I could say, “This is how I learned to completely cope with my hemophilia!” or “This is why our futures are going to be perfect!” Having that would let me wrap up this piece of writing with a nice little bow. But I don’t have that. I wanted to write this anyway, though. Because the point is you just need to keep writing. It’s OK to not have a satisfying answer right now. That’s why you keep looking for it. Don’t ever stop looking.
HFA Launches Mental Health Courses

BY EMILY ROUSH-BOBOLZ, STAFF WRITER

The Hemophilia Federation of America’s Learning Center now offers a Mental Health and Wellbeing courses, which provides a library of information and resources that you can explore at your own pace and revisit at any time. Specific topic areas include anxiety, suicide, trauma, pain, depression, grief and more.

HFA staff had its first conversation about doing courses on mental health in 2017 after noticing issues with depression and anxiety coming up more frequently among Blood Brothers, Blood Sisters and parents. Some who had survived the HIV crisis of the 1980s — where it’s estimated that 90% of people with severe hemophilia contracted HIV through contaminated clotting factor — were now asking “why me?” as challenges arose.

“There were also people fighting insurance companies and trying to do infusions — they were failing apart,” said Lori Long, director of Institute/HFA’s Learning Central. “There were stories of people having meltdowns at their HTC and stories of women trying to get diagnosed and not getting treatment.”

HFA and the community as a whole rarely used the term “mental health” before — using phrases such as “stress management” instead — but it was time to address mental health head on.

“Our community has been through collective trauma together,” said Lauren Black, HFA associate director. “Whether it was the HIV crisis or just being diagnosed, they felt no one was really listening to them.”

For Long, a critical turning point in the discussion on mental health in the bleeding disorders community came at a Symposium. There had been some suicides of well-known community members who were passionate and seemed to have a strong perspective on life. If it could happen to them, what about everyone else?

“Blood Brothers were talking and crying and saying, ‘we need help with mental health and there needs to be a conversation,’” she said.

Demystify and Destigmatize

The new mental health courses can't fix depression and anxiety, but they are meant to help people understand and recognize whether they have mental health issues and how to seek help.

HFA staff examined what people with chronic pain and chronic illness experience, basing the courses on the personal experiences and messages from the community. Long and other Learning Central staff engaged in personal phone calls, monitored social media chatter and spoke to community members at Symposium. Unlike some other learning resources, the topics and resources didn’t come from focus groups or surveys but are instead based on years of listening and observing.

The online courses include members of the bleeding disorders community who act as “guides,” walking you through the materials through their videos, photos and quotes. “I found it very cathartic to speak up,” said Michael Bishop, Institute content design specialist, who served as a guide in the courses. “I was eager to talk about it.” (See Bishop’s article about mental health on page 26.)

It could also be reassuring for the guides to hear other community members share their experiences. “In some ways, it was good to hear those things coming from other people because you know you’re not the only one, but it was emotionally exhausting,” Bishop said. “I forget how much those things affect me. Ultimately, the feelings of universality was enough to get me through. I’m in this with the whole community.”

Course material was developed by tapping into the intracacies of managing pain during an opioid crisis and tips for coping with pain, including palliative care.

“Palliative care is not just for people who are dying,” Long said. “It helps many people with comfort and endocrinology for ways to make opioids more effective.”

HFA staff plans for the courses to be a leaping off point for other possibilities. Community members could take the courses before attending a Zoom meeting on mental health, for example, so they have background knowledge. Possible additions to the courses might include a similar course focused on Latino culture using Spanish-speaking guides and stories; more in-depth coverage of other mental health issues such as bipolar disorder, eating disorders and Alzheimer’s disease and dementia; and a deeper section on grief and bereavement.

Topics Linked to Mental Health

In addition to discussing specific mental health topics, the courses also touch on topics connected to mental health, such as pain management and forced lifestyle changes. Some people come to a realization that they can no longer do a certain type of job because it doesn’t give reliable insurance or because of physical issues, so that may lead to a conversation around mental health.

“Michael’s (Bishop) sound bite on pain management is powerful,” Long said. The section also discusses the intricacies of managing pain during an opioid crisis and tips for coping with pain, including palliative care.

“It’s OK to go through the courses slowly and to come back,” Black said. “You don’t have to finish all at once.”

Two community members mentioned in the course have since passed away. In the course, “we were able to memorialize and honor some of those in the community who have passed,” Long said.

“Blood Brothers were talking and crying and saying, ‘we need help with mental health and there needs to be a conversation,’” she said.

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—MICHAEL BISHOP

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Our admiration for the hemophilia community knows no bounds. It pushes us to discover, advocate, and support you in ways big and small. So more moments like this are possible.

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