ISSUE 3

The SUPPORT AND INNOVATION FOR THE HEMOPHILIA COMMUNITY

STAYING CONNECTED
ADAPTING TO THE VIRTUAL WORLD

FINDING YOUR PASSION
SUPPORTING PROFESSIONAL DEVELOPMENT IN THE COMMUNITY

MAKING IT POSSIBLE
DELIVERING TREATMENT DURING A PANDEMIC
Welcome to the third issue of The Edge, Genentech’s biannual newsletter for the hemophilia community. When crafting the stories for this issue, we noticed one underlying theme throughout—the strength and unity of this community.

Adapting to a “new normal” during COVID-19 was a challenge for us all, but this community stepped up to help one another stay informed, entertained, and above all, supported. This became evident in every story we dove into.

In our discussion with Clinical Education Managers serving different hemophilia chapters across the country, we learned about the various ways chapters brought the community together during this unprecedented time. We heard stories of transforming live events into virtual programs at the drop of a hat, and throwing virtual screenings and game nights week after week to keep the community connected and uplifted. Shifting to the virtual world has opened a new door for this community, as people welcomed new faces into their homes and their hearts.

In this issue, you’ll meet 5 inspiring individuals who share the challenges and triumphs they faced throughout their professional journeys in the hopes of helping others discover their passions and achieve their goals. These experiences helped shape HemeWork, a new career hub created by Genentech to help guide and support professional development in the hemophilia community. At Genentech, we are committed to helping people with hemophilia succeed in all areas of life and we are so excited to share this new program with you all!

In our last spotlight we spoke to Sophie and Jennifer, 2 key members of our team at Genentech, about solving an improbable task due to travel lockdowns. They share the details behind this incredible story and how everyone came together to support the community during a pandemic, no matter how far.

We hope you enjoy the third issue of The Edge and the camaraderie these stories have to share. We at Genentech believe that if there’s one thing to learn from all of this, it is that anything is possible when a community comes together.

– Suha Patel
Marketing Director – Hemophilia

“We hope to unite, inspire, and support professional development in the hemophilia community.”
– Adam Pryor, Senior Communications Manager

FOR MORE EDGE CONTENT AND RESOURCES FOR THE COMMUNITY, INCLUDING PHARMACOVIGILANCE, VISIT: WWW.GENENTECHHEMOPHILIA.COM
During this time of social distancing, it can be challenging to stay connected with one another. But hemophilia chapters across the country have stepped up to the task, finding ways to bring the hemophilia community together, virtually.

The Hawaii Chapter had its annual educational weekend for the bleeding disorders community already scheduled for March 21. When everything changed, Executive Director Ziggy Douglas had to quickly transform a 3-day live event into a 1-day virtual experience. “My initial reaction may have been panic, but embracing the challenge is what this community is all about,” explained Angelica Flores, a Genentech Clinical Education Manager. So, to no one’s surprise, the team pulled it off.

The day-long event included virtual presentations, group activities, and a screening of CHALLENGE ACCEPTED Episode 6, “Laugh.” “They enjoyed the energy and enthusiasm that came with the episode — especially at the end of a long virtual day!” said Angelica.

The “Laugh” episode has been a popular remedy during this time. The Illinois and Ohio Chapters hosted virtual viewing parties of the episode in April as a way to bring a little levity to the community. “As Clinical Education Managers, we draw our passion from the community and the experiences we have with them. Since we are unable to meet in person, this online forum worked well as a backup,” said Genentech Clinical Education Managers Ami Seligman and Diana Cauto.

The New Jersey Chapter also featured Episode 6 in a number of events. “I think it is a wonderful opportunity for our members to stay connected and share ideas and relate with some of the topics and conversations that are addressed,” said Theresa Coia, Clinical Education Manager.

Going virtual has allowed the community and its leaders to connect in ways they had never imagined. “Seeing people in their real environments helped us get to know them on a different level; we got to see their dogs, their families, into their living rooms, and it really humanized our interactions,” says Renee Derider, a Clinical Education Manager from the New York Chapter. Renee goes on to explain that these virtual events provide an opportunity for families that aren’t usually able to attend live events to meet, connect, and share with new members of the community. “There has been a real silver lining to all of this,” she says.

The community truly hasn’t skipped a beat. The New York City Chapter hosted a video game night featuring the popular Fortnite, as well as a virtual scavenger hunt. The New England Chapter hosted a virtual family “Ohana” camp, and the New Jersey Chapter hosted a trivia night where teens with hemophilia created the questions and ran the show. The discussions at these events have allowed members of the community to share advice and help one another during these unpredictable times. “Seeing people in their real environments helped us get to know them on a different level...embrace the challenge is what this community is all about.”

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CHALLENGE ACCEPTED brought together the entire cast of Season 1 for a virtual reunion, discussing their experiences since the show aired.

CHECK OUT THE REUNION EPISODE AT YOUTUBE.COM/CHALLENGEACCEPTEDSHOW AND BE ON THE LOOKOUT FOR SEASON 2! COMING SOON.
Living with a bleeding disorder shouldn’t stop you from reaching your full potential. That’s why Genentech is proud to launch HemeWork, a program designed by and for the community to support career development for people through inspirational community stories and tailored resources.

During a summit at Genentech with community and advocacy leaders, Genentech heard that there was a gap in professional development and career advancement resources within the community. Through a series of follow-up conversations, patients, caregivers, and advocacy leaders across the country echoed a need for meaningful resources that support career development for people on all educational and professional paths.

To ensure HemeWork would reflect the experiences and concerns of the community, Genentech collaborated with the Hemophilia Federation of America (HFA), Believe Limited, and bleeding disorders advocates to develop the program.

HemeWork.com launched in August 2020 featuring a 5-part mini-documentary series produced by Believe Limited, highlighting the challenges and triumphs of 5 people in the community as they pursue their professional goals. “You’re never too young to start thinking about what you want to do. Not what makes the most money or what will make your parents happy—but actually figuring out what you want to do,” says Myles, one of the people featured in the documentary videos.

The site also includes a curated collection of career resources for patients and caregivers to learn more about their rights in the workplace and help find assistance when transitioning to college or a new job.

“The ultimate goal of this program is to empower people with hemophilia to feel more confident in their ability to find and maintain a fulfilling career, and overcome the additional challenges facing members of the workforce who are also managing a chronic condition,” explains Adam Pryor, Senior Communications Manager at Genentech. “We look forward to updating HemeWork.com with additional resources to unite, inspire, and support professional development in the hemophilia community, including resources developed in partnership with the community and career counselors.”

“Five members of the hemophilia community share their career experiences in a mini-documentary series produced by Believe Limited, the team behind Bombardier Blood and the hemophilia web series Stop The Bleeding. Watch their stories at HemeWork.com.”

“I think mentoring is really important. I call people in the community ‘blood brothers’ and ‘blood sisters.’ We’re connected and can all learn a lot from each other—not just about living with hemophilia, but about love and dealing with the challenges of life.”

“Mike Hargett
Professional Chef, living with hemophilia

“Ivan Giron
Ophthalmic Technician, living with hemophilia

Christina Olivarria
Project Manager, hemophilia caregiver

Mike Hargett
Professional Chef, living with hemophilia

Myles Ganley
Bleeding Disorders Advocate, living with hemophilia

John Farra
Software Engineer, living with hemophilia

Ivan Giron
Ophthalmic Technician, living with hemophilia

Christina Olivarria
Project Manager, hemophilia caregiver
At Genentech, we take safety very seriously. Our top priority is making sure that when people take their medicine, they know what to expect from it. That’s why we have a robust program designed to monitor your safety while taking our medicine. This imperative program needed a name that fit the bill. No simple name was going to cut it.

Introducing pharmacovigilance. Pharmacovigilance is a complicated word that can be broken down into 2 parts: “pharma” meaning medicine and “vigilance” meaning watchfulness. This involves looking into any adverse event (better known as a side effect) that someone may experience while on a medicine.

There are 3 key components to pharmacovigilance:

1. Monitoring
2. Investigating
3. Communicating

At Genentech, over 2,000 employees monitor and analyze reports of adverse events (side effects) to a medication from healthcare providers and the people in the community. No obvious connection between the event and the medication is needed to be considered.

“Everybody at our company has a shared responsibility to report adverse events when they hear about them.”

-Claudia, PV Clinical Specialist, NP

Genentech collects data from all over the world to find patterns. This provides the clearest, most robust picture of how a drug is working in a real-world setting. Every adverse event (side effect) report is thoroughly reviewed, and follow-up is performed if more information is needed to fully analyze it.

“As we’re getting more and more information, the picture becomes much more clear. This means we are creating an ongoing and evolving understanding of the drug in the real-world setting.”

-Peter, Safety Strategy Leader

If we identify that the balance of benefit to risk of a medicine has changed, we proactively notify the FDA, healthcare professionals, and the public of the new information and we update the medication’s package insert or label.

Here at Genentech, your safety matters. If you have experienced any adverse event (side effect) while on treatment, please let Genentech know. This will help us continue our goal of keeping the community safe.

Visit OurCommitmentToSafety.com to learn how Genentech is making safety its top priority.

As always, tell your healthcare professional if you experience a new reaction to your medication. He/she can get in touch with Genentech right away. Adverse events should also be reported to the FDA at (800) FDA-1088 or www.fda.gov/medwatch
Making the Impossible Possible:

How a Group of Experts Came Together to Deliver Treatment During a Pandemic

At the start of their trips to India and Kenya, 2 US families in the hemophilia community would have never expected a global pandemic to keep them from coming back home. Bringing along with them only enough treatment for a short trip, when all flights were grounded, they were suddenly unsure of how they would resupply. That’s when the team at Genentech stepped in. This wasn’t an easy challenge to overcome, but they were determined to get these families the treatment they needed—banding together to solve this unprecedented task.

The first step was locating the families. The Genentech team was notified of the family in Kenya by their specialty pharmacy. News quickly spread to the Access Solutions team, a team that is committed to helping patients get the medicine they need. This is when Jennifer, a Case Manager at Genentech, was contacted for guidance. Little did they know that at the same time, Jennifer was also being notified of a family in India with the same challenge.

At this point, the teams at Genentech realized they had a very unique situation on their hands. Questions about logistics, coverage, and distribution all needed to be answered—and quickly. To make sure all options were being explored, members from Account Management, Strategy, and Operations were all brought together (virtually, of course) to problem-solve. “When I step back and look at everything holistically, it was really helpful to have a number of people with different backgrounds. Their experiences really made us look at this problem from all angles and make sure we planned everything out,” says Sophie, Group Strategy Manager at Genentech.

While the team worked out a plan, Jennifer kept direct communication with the family in India. Even if it meant arranging calls before dawn to account for the 10-hour time difference, she was willing to do whatever it took to make sure the family felt supported.

Soon enough, the team was able to forge a path to deliver treatment to the families on time, solving every logistical obstacle along the way. “Seeing how committed everyone was and how we all came together to problem-solve this unique situation was really amazing,” says Jennifer. Three months later, the family in India was notified that they could finally return home.

The team at Genentech worked quickly and decisively, always with one common goal in mind—to help fellow community members in need. No matter how far you may be or how insurmountable a task may seem, the team at Genentech will always work to find a solution, staying by your side every step of the way.

“Seeing how committed everyone was and how we all came together to problem-solve this unique situation was really amazing.”

Genentech Takes the Health and Safety of Our Patients, Customers, Employees, and Local Communities Very Seriously, and We Are Actively Responding to the Global COVID-19 Pandemic.

For more, please visit www.gene.com/covid19 or call 1-877-436-3683.
IN THE NEXT ISSUE

THE IMPACT OF GENENTECH’S SUPPORT FOR THE WORLD FEDERATION OF HEMOPHILIA IN ZAMBIA
(DELAYED DUE TO COVID-19)