A DOSE OF EQUALITY
GENENTECH’S PUSH FOR HEALTH EQUITY WITHIN THE WORLD OF BLOOD DISORDERS

DEAR HEMOPHILIA
A LOVE LETTER

TREATMENT WITHOUT BORDERS
HOW THE WFH CONTINUES TO PROVIDE HOPE AROUND THE WORLD

BOOTS ON THE GROUND
ADVOCATING WITH HEMOPHILIA PATIENTS LOCALLY AND NATIONWIDE

Matt
Living with hemophilia A
FOREWORD

Welcome to the fifth edition of The Edge, Genentech’s newsletter for the hemophilia community. We continue to find stories from members of the community who are thriving and taking their hemophilia head on.

Getting diagnosed with hemophilia isn’t something these community members ask for; however, it’s what they do in the face of their disease that reflects who they are. In this edition, Matt writes a love letter to his hemophilia, where he tells his emotional story about living with the disease. He talks about his journey from resenting hemophilia, to learning to be appreciative of all it has given him. We hear from Sonali Chopra and Gina Truslow, who work on the patient advocacy relations team at Genentech, about their advocacy work with hemophilia patients. Their group takes a personal approach to understanding the community’s needs that starts as early as possible—even before starting to develop a medicine.

You will also get an update on the WFH’s Humanitarian Aid Program and their continued efforts to provide “Treatment for All”.

Additionally, we get an inside look at what Genentech is doing to embrace Diversity and Inclusion to drive innovation by speaking with Daud Chaudry, our company’s Head of Hemophilia.

Please enjoy the fifth issue of The Edge. At Genentech, we will continue to support the community by truly understanding what they need. We hope to inspire you all, just as you inspire us to do better for the hemophilia community.

Suha Patel
Senior Marketing Director
The nation’s reckoning with social and racial justice as well as COVID-19 spotlights the healthcare inequities faced by various communities such as Black, Indigenous, people of color (BIPOC) and the organizations grappling with making health equity a reality. For Genentech, this means expanding efforts to diversify its workforce, fostering a culture of belonging, advancing health equity through research, education, and authentic engagement, as well as transformative cross-sector partnerships. This includes further understanding, identifying, and addressing specific unmet needs of people who are historically underserved in the bleeding disorders community. We spoke with Daud Chaudry, Genentech’s US Head of Hemophilia and Rare Blood Disorders to learn about efforts to address inequities.

“You can’t live in America, do this work, and be untroubled by the health inequities impacting racial/ethnic communities that are underserved by systemic racial and structural barriers,” Chaudry said. “In our recent health equity study, 54% of medically disenfranchised patients reported feeling the system is rigged against them and overwhelmingly agreed that healthcare inequities worsened over the pandemic. Our Rare Blood Disorders team is invested in helping solve and reimagine what optimal care is for all patients.”

Genentech formed the Allyship, Connection, and Transformation team (ACT) in 2020 to focus internal and external efforts and deepen the understanding of patient experiences, cultural diversity of communities of color, how the social determinants of health (SDOH) impact them in different ways, and learn how diverse stakeholders can work to improve hemophilia care and outcomes.

“Earning the trust of our diverse community is important, so is self-examination,” Chaudry said. “We looked at our own unconscious biases and how they impact our decisions, who we meet, and how we show up and engage the community. Also, we realize achieving health equity is a system-level, community-wide effort requiring collective action.”

ACT implemented programs to listen, learn, and identify supportive structures to accelerate health equity, including a February 2021 Virtual Advisory Panel hosted with the National Hemophilia Foundation (NHF) for BIOPC patients to share their experiences when navigating healthcare. Common themes included mistrust of providers, shame and stigma, need for self-advocacy, access, and linguistic competency. In May, multidisciplinary stakeholders gathered for a Blood & Clotting Disorders Health Equity Summit hosted by Genentech to discuss the multiple barriers racial/ethnic communities face in pursuit of care. They explored how to deploy their experience, perspectives, vision, and resources to achieve and sustain health equity by addressing the elevated risk from factors like access, geography, adequate structural and culturally competent care.

Participants—American Thrombosis and Hemostasis Network, the Hemophilia Federation of America, NHF, and community advocates—agreed that everyone has a role and responsibility in fighting for health equity and can take practical actions to help people who are marginalized receive respectful care, improve patient-provider encounters, and help build trust in healthcare to improve and save lives. They identified tangible opportunities to meet patients where they are, center and elevate patient voices, co-create solutions, improve trusted and culturally responsive care, increase sharing across the community/industry-advocacy to address educational and resource gaps, and generate evidence. The team is currently conducting an analysis of activities, where they are concentrated and need additional focus to identify opportunities to provide equitable care.

For 2022, ACT will collaborate with participants and other leaders to impact vital areas, including research, where there’s a lack of data to better understand diverse patient journeys and provide meaningful, scalable solutions. Chaudry is inspired by the community’s commitment to end inequities and the impact it will have on lives.

“We can move toward health equity by listening to and responding to patients’ voices. What motivates us is knowing that these efforts won’t just change a life but can change the trajectory of a family and their legacy, of a community. We see that as momentous. Just to be any part of it, working as a community, I think is amazing.”

“Earning the trust of our diverse community is important, so is self-examination.”
DAUD CHAUDRY
Head of Hemophilia

“Genentech’s push for health equity is for all patients.”
DAUD CHAUDRY
Head of Hemophilia
A LOVE LETTER TO MY HEMOPHILIA

Dear Hemophilia A,

I never asked for you. I never asked for all the pain and limitations you would introduce into my life. When I met you, at 4 days old, I couldn’t articulate it yet, but I hated you. As I got older and spent more time with you, I resented you even more.

But now, as I write you this letter, I find myself seeing you in a different light. Without you, what would my life have been? How would things be different? For all the pain you have brought me, I see you as a part of me now. In many ways, you have made me who I am. And for that, I’m grateful. But it hasn’t always been so easy...

Growing up, you were always with me, right by my side. When I would see other kids playing, I would stay back because of you. I knew you’d at least try to stop me. And honestly, I didn’t want them to meet you, for fear they might not understand our relationship. And maybe that confusion would lead to them not liking me.

So I saw another side of childhood. While other kids were meeting friends and going on dates, I was spending my time with you, and our dates would be at the hematologist or emergency room. Other kids looked forward to birthday parties or proms, while I looked forward to simpler things, like going home to my own bed after a day at the ER.

You taught me to appreciate the small things, even if you put me in situations that were scary, painful or both. Even still, I became grateful that you were the worst thing I had to deal with in my life, because there are far worse things I could have faced.

As time went on, you forced me to take life more slowly, to let it come to me in some ways. Moving at that slower pace brought many amazing people into my life, people who would stay with me and guide me forever. One of those amazing people is my wife.

I still remember falling for her—remember that day? We were out bowling with her and her friends and took a walk after. You were holding me back from keeping up with the group. My knee was causing me to not keep up. She looked back and noticed I was struggling to keep up (after all, I was carrying you too) and turned back to be with me. She gave me the biggest smile and never once judged me for bringing you along, and I knew I would be with her forever. I can’t thank you enough for introducing me to her. She makes everything worth it.

You’ve also introduced me to a community of people who support and inspire me on a constant basis, a community that feels like my own, with others who know you well. In a way you are my ticket into that community that makes me feel so much less alone. And it’s you that has brought us all together.

Even with all the good you may have brought into my life; I have tried consistently to limit your influence on me or at least my need to show you attention and I am hopeful that our interactions will be less as time goes on.

At first, I resented you and felt dragged down by you, but as I’ve grown up, I see you as part of me, part of my happiness. I appreciate all you have given me, and all that you will continue to give. Thank you, hemophilia, for making me who I am.

Matt

I FIND MYSELF SEEING YOU IN A DIFFERENT LIGHT

Matt
Living with hemophilia A, and his wife, Geniva
As of autumn 2021, 806 patients in 30 different countries have received prophylactic treatment through this program.

This commitment marked the first time patients in developing countries will get access to a subcutaneous prophylactic treatment. It will also make a significant impact, as children with severe hemophilia who do not have access to treatment often do not survive to adulthood and most patients had no or very limited access to inhibitor treatment therapies.

With this partnership, the WFH has been able to hold training sessions in developing countries as well, allowing healthcare professionals to learn about this novel prophylactic treatment and how to properly use it for people living with hemophilia A.

As their work continues, the WFH and Roche/Genentech plan to address more unmet needs in the hemophilia community and continue to positively improve the lives of people with hemophilia A, no matter where they live.

Living with hemophilia in resource-poor countries comes with a tremendous impact on livelihoods that is very distinct from experiences in the US. Approximately 75% of the 794,000 people living with hemophilia worldwide receive inadequate or no treatment. Furthermore, 90% of people living with hemophilia in developing countries aren’t diagnosed and many do not survive due to lack of appropriate treatment.

At the end of 2018, the WFH and Roche/Genentech formed the Humanitarian Aid partnership, and Roche/Genentech committed to providing prophylactic treatment for 1,000 people with hemophilia A over 5 years. In addition, this partnership also provides funding to support the program’s integrated care development training, the local infrastructure, logistics, and medical expertise.

Two patients in Zambia received the first Roche/Genentech donations in 2020, followed by patients in Nepal.

In 1996, The World Federation of Hemophilia’s (WFH) Humanitarian Aid Program was built on a commitment of “Treatment for All”—providing care to people with bleeding disorders in developing countries who had limited access to life-saving treatment. Twenty-five years later, the program is continuing to deliver on its promise. And in the beginning of 2019, Roche/Genentech began its support to help further this goal.

The vision of the WFH for “Treatment for All” aligned perfectly with Roche/Genentech’s values. Before Roche/Genentech launched their prophylactic treatment, it too had a vision to bring treatment to patients all over the world. By supporting the WFH program, more unmet needs can be addressed and the lives of people living with bleeding disorders can be improved, no matter where they live.
It’s not every day that advocacy leaders get to tour a treatment’s manufacturing facility. For the hemophilia community members touring Genentech’s South San Francisco manufacturing plant in December 2016, however, their visit marked an early step in learning more about—and building trust with—Genentech.

“The approach that we take is, from the earliest stage possible,” says Sonali Chopra, Executive Director of Patient Advocacy Relations at Genentech, “we really try to go out, meet the community, understand the advocacy landscape, and understand patient needs before we even start to develop a medicine.”

At Genentech, the patient perspective is paramount to driving advocacy. “You want to build real relationships,” Chopra says. “This is not transactional; this is not a check-the-box exercise. You want to build strong, real relationships so that people will tell you when you’ve done something that they don’t trust or believe in, so that you can fix it.”

Chopra isn’t alone in the mission to advocate on behalf of patients at Genentech. She and her team work with nearly 100 hemophilia and blood disease advocacy groups across the country, at the national and local levels. Together with the Genentech external affairs, ecosystems, marketing, medical, and other cross-functional teams, they work to address key issues for hemophilia patients. Some of these issues include clinical development, patient support services, insurance access, and state and local policy. This mission is starting to show signs of success, according to the patient advocates who rated Genentech #1 spot for Advocacy Relations in the PatientView survey for 2021.

Genentech’s approach is to incorporate the patient voice throughout the entirety of drug development: from clinical trial development through commercial launch, including development of patient services and marketing. In fact, these efforts began when Genentech started to look at working in the hemophilia space.

As an advocacy partner, “you’re leaning on these national and local organizations to really be the supporting service for their local community,” says Gina Truslow, Senior Manager of Patient Advocacy Relations at Genentech, who works directly with the bleeding disorders community. Many of the current initiatives that benefit people living with hemophilia have come from this grassroots approach. For example, when a local advocacy chapter sent a survey to people living with hemophilia, it underscored the need for more of a nuanced focus on older patients: because hemophilia patients are living longer, more patients are having to manage comorbidities now. “That was an unmet need that was found,” Truslow says, thanks to this perspective from the patient community.

In addition to aging and comorbidities, advocacy chapters are prioritizing mental health, women’s health, telehealth, rare and ultra-rare diseases, and future therapies as further needs to be addressed. As a company, Genentech shares many of these priorities including telehealth, rare disease patient needs, health equity, and more inclusive trials.

Any change, of course, starts with the patient. “We must treat patients like experts because they are experts in their lived experience,” Chopra says. “Working with the hemophilia advocates, bringing them to campus, sharing their stories [has caused us to think] differently about what it means to be patient-centric and what it means to listen to the community, especially one as educated and strong as the hemophilia community.” Adds Truslow, “everyone has to learn from the patient in order to understand the needs of the patient.”
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