

# The EDGE

SUPPORT AND INNOVATION FOR  
THE HEMOPHILIA COMMUNITY



**Chris Bombardier**  
Executive Director  
of Save One Life

**PG. 4** **TREATMENT  
FOR ALL**

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# FOREWORD

THE EDGE SPOTLIGHTS PEOPLE  
IN THE HEMOPHILIA COMMUNITY  
WHO HAVE NEVER GIVEN UP

Welcome to the second issue of *The Edge*, Genentech's biannual newsletter for the hemophilia community. As we were gathering stories for this issue, we started to see a few similarities that connected them, the most notable being compassion and a fight against complacency.

These are 2 traits that seem common to members of the hemophilia community. As a group, people with hemophilia recognize that everyone needs help sometimes and that there are many individuals who are willing to give it. This sense of compassion ignites the community with a drive for change and an unwillingness to accept the status quo.

You'll see all these traits on display in our discussion with Mark Skinner about how the World Federation of Hemophilia (WFH)—with the help of Genentech—is taking steps to making its goal of Treatment for All (people with hemophilia) a reality.

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In our profile of Save One Life, you'll meet that organization's executive director, Chris Bombardier, a mountaineer with hemophilia B who goes to great lengths to highlight the economic needs of people with bleeding disorders. One of Save One Life's most notable programs is the Micro-Enterprise Grant, which is supported by Genentech. Genentech support has helped increase the amount of grants awarded by 42% in just 1 year in developing countries.

Following up on the web TV series *Challenge Accepted*, we learn about the philosophy of David Quinn, head coach of the New York Rangers. Quinn learned in his early 20s that he had hemophilia B. This closed off the opportunity to turn pro as a hockey player but may have opened the door to his career as a coach. The experience gave him a unique window into handling adversity, and a path to sharing that wisdom with others.

We hope you'll enjoy these stories of radical compassion and rising to meet life's challenges. We at Genentech believe this spirit drives us all to better care for the people in the hemophilia community. **E**

—Suha Patel  
Marketing Director - Hemophilia

**Suha Patel**  
Marketing  
Director -  
Hemophilia



**Chris Bombardier**  
Executive Director  
of Save One Life



**Mark Skinner**  
Former President  
of WFH



# TREATMENT FOR ALL, MAKING IT REAL

TALKING ABOUT THE WFH HUMANITARIAN AID PROGRAM  
WITH FORMER WFH PRESIDENT MARK SKINNER

**M**ark Skinner's life bridges 2 eras of hemophilia treatment. The former president of the World Federation of Hemophilia (WFH), he grew up at a time when factor VIII replacement was nonexistent or often limited, used only after bleeding occurred. Now, he's a part of this emerging era when treatment options are multiplying, and prophylaxis has become the standard of care.

Meanwhile, availability of treatment in the developing world is lagging. The lack of access to care and treatment in developing countries is an urgent and important public health challenge, as the cost of products to treat is prohibitively expensive for the majority of those affected with a bleeding disorder. That's why Genentech/Roche is providing prophylactic treatment to as many as 1,000 people with hemophilia A in developing

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Photo courtesy  
of the World  
Federation of  
Hemophilia (WFH)

countries over the course of 5 years, with a focus on high-need patients, such as people of all ages with factor VIII inhibitors and children without factor VIII inhibitors. This donation, and others like it, have enabled the WFH Humanitarian Aid program to provide consistent and predictable access to prophylaxis.

Skinner's efforts in this area are summed up in the WFH commitment to Treatment for All. We spoke to Skinner about his time as president of the WFH and what Treatment for All means in practical terms.

“The goal is to bring prevention and early intervention to the developing world,” says Skinner. “It took 70 years to get to where we are today in the US. By working with partners, we can shorten that time in the developing world.”

“We coined ‘Treatment for All’ because we needed a vision statement everyone could rally behind,” says Skinner. “We knew it wouldn’t be achievable tomorrow, but it gave us a goal that we could move toward each year as we made strategic plans.”

Sustainability is crucial to the WFH strategy. “In the early 2000s, we began asking donor companies to commit to multiyear donations of product.”

Part of planning is understanding everything people with hemophilia need, beyond medicine. “As we go into a country, we assess the kind of healthcare support that’s present. We make sure that we can move medicine through the system well. We need to be sure that healthcare professionals and patients will receive the training they need for prophylaxis.”

Genentech/Roche has worked closely with the WFH to maximize the impact of donated prophylaxis. The WFH identifies those countries that have both a great need for access to care and also have healthcare systems in place to effectively use donated treatment. In this way, they ensure their contributions make the biggest possible difference.

The planning is grounded in a broad understanding of how hemophilia products must be stored and used in order to benefit patients. Genentech/Roche is funding training, lab facilities, and transportation infrastructure, which are all critical parts of patient care.

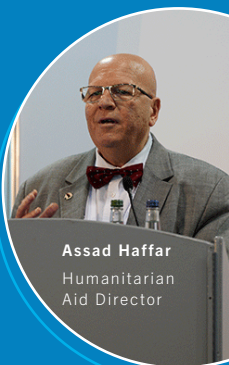
“Now we can plan, rather than just react to situations,” adds Skinner. [E](#)

## GENENTECH/ROCHE AND THE WFH, A PARTNERSHIP IN HUMANITARIAN AID

In 2019, Genentech/Roche joined the WFH Humanitarian Aid Program to provide therapies for countries in need. “Our program is always based on good distribution practices between our partners, the manufacturer, the WFH, and the receiving country,” says Assad Haffar, MD, Humanitarian Aid Director for the WFH. “We ensure quality management of the

product and training for healthcare providers. The contribution from Genentech/Roche takes all of these issues into consideration.”

The treating physicians in the program “are very excited because they will be able to offer a treatment for preventing bleeding episodes, particularly among patients with inhibitors,” according to Haffar.



Assad Haffar  
Humanitarian  
Aid Director



# FIGHTING CHALLENGES BEYOND HEMOPHILIA

HOW ONE ORGANIZATION IS IMPROVING THE LIVES OF PEOPLE WITH BLEEDING DISORDERS, ONE LIFE AT A TIME

Living with a bleeding disorder poses many difficulties. When added to the challenges that go with living in a developing country, finding ways to support oneself or one's family can become almost impossible. Chris Bombardier, who himself has hemophilia B, saw this firsthand in Nepal as he prepared to ascend Mount Everest. During his travels in Nepal, he met with other people with bleeding disorders and saw how they struggled.


Laurie Kelley, the founder of Save One Life, saw these challenges herself and decided something needed to be done. "It's important to us to find and provide support for these families," says Bombardier, now the Executive Director of Save One Life. "Our founder was inspired to start the Micro-Enterprise Grant program in 2014, after seeing these challenges on one of her trips."

SAVE ONE LIFE IS AN ORGANIZATION THAT WORKS TO IMPACT THE GLOBAL BLEEDING DISORDERS COMMUNITY, ONE LIFE AT A TIME.

The idea for Save One Life was sparked when Kelley spent time listening to one mother explain what would help support her child with a bleeding disorder to become more financially stable. "Something as small as selling cow's milk could impact one's life so tremendously in these developing countries," Bombardier says.

So began the Micro-Enterprise Grant program. Individuals or families with bleeding disorders in developing countries can apply for grants with business ideas that show promise. Grants can be used for anything from farming to technology services.

Throughout the years, the Save One Life team has seen a variety of ways for people to support themselves. "It's inspiring to see someone's pride in their own accomplishment," says Bombardier. "Just like anybody in any country, they have dreams and goals to provide for their families."

In the future, Bombardier plans to sponsor more grants and to find more partnerships with other nonprofits. "The commitment from Genentech and Roche has been one of the most exciting things to happen to the program in a while. This stability allows us to offer more." 

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Save One Life helps support people with bleeding disorders by supporting business and agriculture investments



Save One Life works with 50+ program partners in 14 developing countries. These program partners collect applications from individuals and families around their regions. The applications are evaluated by a committee of volunteers at Save One Life, which includes people from the hemophilia community.

Once this committee approves the application, the recipient is given the resources to create or expand their small business.

## HOW CAN YOU HELP?

Save One Life is always looking for people to be a part of their application review committee, specifically those with business experience and who are in the bleeding disorder community.

Visit [saveonelifenet.net](http://saveonelifenet.net) to learn more.

## COACH DAVID QUINN

OF THE NEW YORK RANGERS

## ART OF THE PIVOT

WE SAT DOWN WITH DAVID QUINN, HEAD COACH OF THE NEW YORK RANGERS AND GUEST COACH ON EPISODE 7 OF *CHALLENGE ACCEPTED*, FOR SOME ADVICE ON HOW TO DEAL WITH ADVERSITY—LIKE A PRO.

Q:

In the show, you help our guest, Damian, realize that no matter what obstacles come up—related to hemophilia or not—there's always a way to pivot and achieve your goals. How did your personal experience help you realize this?

A: You know, my experience in pivoting through a difficult time helped me for the rest of my life. The experience I had from the age of 20 to 22—when I was first diagnosed with hemophilia B and realized that playing hockey wasn't going to be a dream that I could achieve—allowed me to handle adversity throughout life.

That's all life is really about. Life is about handling adversity, because we all have it at different stages of our lives and adversity never stops. We're all thrown curveballs, whether it be professionally or personally—there's going to be adversity.

“I WAS DIAGNOSED WITH HEMOPHILIA B AND REALIZED THAT PLAYING HOCKEY WASN'T GOING TO BE A DREAM THAT I COULD ACHIEVE.”

How did you make up your mind to go from playing professional hockey to coaching it?

My goal getting into coaching was to try to offer the players I was fortunate enough to coach the same impact that my coaches had on me. Not only were they coaches to me, but they helped me through difficult times in my life. When you're a coach, you have a responsibility not only to the



David Quinn  
on the set of *Challenge Accepted*

player as an athlete, but to the player as a person. And that was something I really wanted to be able to do when I got into coaching.

Besides coaching Damian on the show, what was your favorite part about filming Episode 7?

Aside from meeting Damian, riding the Zamboni was definitely a great moment. Who would have thought that given all the time I've spent on the ice, I had never ridden on the Zamboni?

That does sound like a lot of fun. Any last words of wisdom?

You know, the sooner you realize that anything can happen—and anything can be conquered—the better chance you have of fighting through adversity. That's something that has stuck with me throughout my whole life. **E**

YOU CAN WATCH DAVID QUINN IN  
*CHALLENGE ACCEPTED: EPISODE 7* AT  
YOUTUBE.COM/CHALLENGEACCEPTEDSHOW

“LIFE IS ABOUT HANDLING ADVERSITY, BECAUSE WE ALL HAVE IT AT DIFFERENT STAGES OF OUR LIVES.”

# SUPPORT FOR PEOPLE WHO TAKE GENENTECH MEDICINES

Living with a serious illness can come with many challenges. Getting Genentech medicines shouldn't be one of them.

The Genentech Patient Foundation gives free Genentech medicine to people who don't have insurance coverage or who have financial concerns.

## THE IMPACT OF THE GENENTECH PATIENT FOUNDATION

**227,000**

NUMBER OF PATIENTS  
GENENTECH PATIENT SUPPORT  
SERVICES HELPED GET THE  
MEDICINE THEY NEED

**~44,000**

PATIENTS RECEIVED FREE  
MEDICINE THROUGH THE  
GENENTECH PATIENT  
FOUNDATION IN 2017

## GENENTECH PATIENT FOUNDATION

### APPLY FOR HELP

To see if you qualify, visit:

<https://www.gene.com/patients/patient-foundation/apply-for-help>



**Regina Lagman Cruz**  
Hemophilia Case Manager  
at Genentech

## IN THE NEXT ISSUE

### THE IMPACT OF GENENTECH SUPPORT FOR THE WFH