

THE EDGE

SUPPORT AND INNOVATION
FOR THE HEMOPHILIA
COMMUNITY

Genentech
A Member of the Roche Group

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CONTINUING THE COMMITMENT

FACING FORWARD WITH THE
HEMOPHILIA A COMMUNITY

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ACCEPTING THE CHALLENGE

INSPIRATION FROM THE
HEMOPHILIA A COMMUNITY

FOREWORD



UNITE FOR BLEEDING DISORDERS WALK
IN OAKLAND, CA, WITH TEAM GENENTECH



GENENTECH REPRESENTATIVES
AND MARIA SANTAELLA, RESEARCH NURSE, AT CAMP BOGGY



2 THE FLORIDA GATOR CLOT TROT
ENGAGES FAMILIES ACROSS GENERATIONS

Welcome to the first issue of *The Edge*, Genentech's biannual newsletter for the hemophilia community. Over the course of my career, the values of transparency, trust, integrity, and inclusivity have been fundamental to my approach to life and work. I'm proud to be at Genentech, a company that shares and nurtures these values.

We believe that this community-minded approach will allow people with hemophilia and the rest of the community to thrive. Genentech is dedicated to supporting this mission through three pillars: Treatment for All, Connect the Community, and Support the Person. Each of the stories we tell in *The Edge* reflects these pillars.

Genentech has been working to expand treatment options and support hemophilia A care for some time now. On page 4 of *The Edge* you will find a timeline that highlights some of these important moments, including Genentech's partnership with global organizations to make sure hemophilia A treatments are within reach of people who need them.

The Edge spotlights people in the hemophilia community who have never given up. It is about documenting this exciting time while supporting the people who are part of it. In this issue you will find stories about *Challenge Accepted*, a series inspired by the hemophilia A community and created by Genentech. It is our exploration of the personal growth and resilience unique to people with hemophilia.

You'll also meet Judy Saltzberg, a facilitator from the Positive Psychology Center at the University of Pennsylvania. Genentech is collaborating with the Positive Psychology Center to help people from the hemophilia community build strategies that harness their inner strength as they confront bleeding disorders. Genentech has always pushed the edge with innovation. We hope you see that spirit in this and future editions of *The Edge*.

– **DAUD CHAUDRY**
HEAD OF HEMOPHILIA, GENENTECH US



DAUD CHAUDRY
HEAD OF HEMOPHILIA, GENENTECH US

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

GENENTECH CONTINUES ITS COMMITMENT TO THE HEMOPHILIA A COMMUNITY

THROUGHOUT ITS HISTORY, GENENTECH HAS WORKED TO SUPPORT TREATMENT FOR ALL BY EXPANDING TREATMENT OPTIONS AND SUPPORTING HEMOPHILIA A CARE

DID YOU KNOW?

IN 1984, GENENTECH CREATED THE FIRST CLONED, VIRUS-FREE, NONBLOOD-DERIVED FACTOR VIII PROTEIN USING RECOMBINANT DNA (RDNA) TECHNOLOGY*

*Genentech outlicensed worldwide production and marketing of factor VIII.



2012

Working with Chugai, research begins on innovative approaches to treatment of hemophilia A



2018

Genentech's parent company, Roche, joins the European Haemophilia Consortium PARTNERS program to provide better treatment access to people with hemophilia A around the world



2019

Genentech partners with the University of Pennsylvania Positive Psychology Center to explore how the science of positive psychology can help people with hemophilia thrive in times of change through interactive workshops

READ MORE ON PG. 6

2002

Genentech begins its partnership with Chugai Pharmaceutical



DID YOU KNOW?

PRIOR TO 2017, THE LAST FDA APPROVAL FOR A NEW MEDICINE TO TREAT HEMOPHILIA A WITH FVIII INHIBITORS WAS IN THE 1990s

2017

Genentech brings to market a new treatment



2019

Genentech launches its new series, *Challenge Accepted*, which dives into the real, everyday challenges of living with hemophilia A

READ MORE ON PG. 8

CHALLENGE ACCEPTED

2019

Roche joins the World Federation of Hemophilia Humanitarian Aid Program to provide treatment to people with hemophilia A in developing countries



AS A MEMBER OF THE ROCHE GROUP, CHUGAI PHARMACEUTICAL IS A KEY RESEARCH AND DEVELOPMENT PARTNER WITH GENENTECH

THE PSYCHOLOGY OF OPTIMISM, GROUNDED IN REALITY

SUPPORTING THE PERSON WITH AN INNOVATIVE PROGRAM THAT HELPS PEOPLE WITH HEMOPHILIA AND CAREGIVERS BUILD THE SKILLS TO THRIVE

People in the hemophilia community know that the impact of bleeding disorders goes beyond the blood's inability to clot. The disorder places psychological and social burdens on both people with hemophilia and their caregivers.

So what can we do about it?

While there are a number of programs aimed at improving disease management of hemophilia, Genentech recognizes the need for more resources to address related psychosocial issues.

This spurred Genentech to partner with the University of Pennsylvania's Positive Psychology Center—the pioneering research and training group on positive psychology—to develop two workshops. These 90-minute sessions (The Science of Optimism and The Science of Connection) are practical, science-based programs designed to help members of the hemophilia community develop their cognitive and emotional skills to thrive despite the challenges associated with bleeding disorders.

"The Science of Optimism focuses on the process of developing optimism because this can be strengthened and has value," says Judy Saltzberg, a clinical psychologist and facilitator from the Positive Psychology Center. "People who are optimistic are able to assess situations accurately and to problem-solve effectively. So we teach people to develop an optimistic mindset. This doesn't mean ignoring problems. It means seeing problems, then focusing on what you can control, and taking productive action."

Similarly, it is known that people with strong relationships are better able to steer through challenges. In The Science of Connection workshop, people learn skills that help them to have difficult conversations in a way that builds trust, as well as how to celebrate positive experiences to deepen their connection to each other. In these workshops, many people find new connections with others in attendance, in addition to learning techniques to apply to their existing relationships.

The focus on these two areas helps people build their psychological resilience. Sonya Bross, a Genentech representative who has organized workshops, says that they create situations where caregivers and people with hemophilia open up about difficult experiences. "People are more comfortable discussing emotional issues when everyone else is vulnerable, too. They know they're not alone."



INTERACTIVE EXERCISES HELP PARTICIPANTS APPLY LEARNING



JUDY SALTZBERG
CLINICAL PSYCHOLOGIST AND FACILITATOR FOR
GENENTECH UPENN WORKSHOPS

PEOPLE WHO ARE OPTIMISTIC ASSESS SITUATIONS ACCURATELY AND PROBLEM-SOLVE EFFECTIVELY

FIND A WORKSHOP NEAR YOU

The two programs have been rolled out across the country this spring. Groups range from 12 to more than 50 participants. Genentech Clinical Educators organize the workshops through local chapters and hemophilia treatment centers.

Talk to your local chapter or contact your local Genentech representative if you're interested in attending a workshop.

To contact someone from Genentech, please call **1-866-436-5427**.

THE SCIENCE OF OPTIMISM



THE SCIENCE OF CONNECTION



CHALLENGE ACCEPTED

A NEW WEB SERIES!

FIND THE FUNNY AND THE MAGIC IN THE EVERYDAY CHALLENGES OF LIFE WITH HEMOPHILIA A

Challenge Accepted is a new Web series that puts the real everyday challenges of living with hemophilia A to the test. It follows a magician-comedian host as he dares people to go outside their comfort zones and challenge the meaning of living with a bleeding disorder.

Challenge Accepted also brings the Genentech approach to Supporting the Person to life on the small screen.

Each of the six episodes in Season 1 builds on a theme that highlights specific challenges commonly faced, but not always talked about, by people with hemophilia and their families. Aided by celebrity coaches with a broad array of expertise, the host helps show members of the hemophilia community how to achieve their goals.

“Branch Out” pulls a young man from his suburban routine and into a wilderness adventure. “Indulge” tasks two parents to treat themselves and take some time away from the struggle of caring for their sons with hemophilia. “Buy Green Bananas” takes a look at the prospect of living into old age that is now faced by people with hemophilia. “Laugh” confronts the challenge of depression some families experience by arming them with humor.

COACHES LIKE FORMER WFH PRESIDENT MARK SKINNER AND DR. OZ HELP PEOPLE WITH HEMOPHILIA FOCUS ON GOALS

YOU CAN WATCH *CHALLENGE ACCEPTED* AT [YOUTUBE.COM/CHALLENGEACCEPTEDSHOW](https://www.youtube.com/challengeacceptedshow)

HEMOPHILIA COMMUNITY CAST

TAYLOR



Taylor, a young man with hemophilia A, is challenged to branch out by wilderness survival expert **Cody Lundin**.

DEVON



Devon, a young man with hemophilia A, gets some wisdom about growing older from **Mark Skinner**, former president of the World Federation of Hemophilia.

BRAXTON & KARLEE



Braxton and Karlee, a brother and sister, take on sibling rivalry with former NFL player **Nick Mangold** and his sister, Olympic powerlifter **Holley Mangold**.

MARK & JESSICA



Mark and Jessica, parents of boys with hemophilia A, strengthen their relationship with the help of award-winning chef **Graham Elliot**.

LELAND



Leland gets advice on developing a career while managing hemophilia A from **Dr. Oz**.

ASHLEY, BODE & BRYSTOL



Ashley and her sons Bode and Bristol are supported through the emotional impact of hemophilia by Emmy winner **Alex Borstein**.

GETTING INSPIRED TO FACE THE FUTURE WITH HEMOPHILIA

Sometimes the universe speaks to you, and you need to be ready to listen, according to Devon, the featured guest on the “Buy Green Bananas” episode of *Challenge Accepted*.

A 26-year-old man with hemophilia A, Devon had recently moved to Seattle, started a new job, and begun thinking about how he could become more engaged with the hemophilia community when he decided to appear on *Challenge Accepted*.

“I said to myself, ‘I see you, universe, and I hear you, and I think I know what you’re trying to tell me,’” Devon says.

The episode pairs Devon with Mark Skinner, former president of the World Federation of Hemophilia. Together they explore the unique features of aging gracefully with hemophilia.

Like everyone with hemophilia, Devon had been confronting the different facets of this bleeding disorder his whole life, but it wasn’t until he reached adulthood that its full scope became obvious.

“I wore a blue helmet when I was on the playground, but I never really knew how it affected me until I was an adult,” he says. “The reality of it hit me when I was 18, when I became responsible for my own healthcare.”

Along with Mark Skinner and a little levity from the host, Devon explores the importance of staying active in a way that both sustains his health and inspires him. An avid online gamer, he also has a background in theater and dance, but he took a break after getting injured in a production of *Grease*. After an emotional discussion with Mark while filming *Challenge Accepted*, he returned to that passion.

“I enrolled in dance classes again,” he says. “I’m planning on taking more and trying to get into teaching dance. That’s a way that I can stay fit and control what movements I do, so I don’t risk damaging anything.”



DEVON AND FORMER WFH PRESIDENT MARK SKINNER DISCUSS THE FUTURE

Beyond the inspiration to maintain his physical health, Devon reports that participating in the show stoked his larger interest in the hemophilia community. “My biggest thing is making sure that I’m an advocate, sharing education about the disease and treatments, especially since we’re getting closer to important breakthroughs. I want to get more involved and inspire others with hemophilia A.”

I ENROLLED IN DANCE CLASSES AGAIN...
I’M PLANNING ON TAKING MORE AND
TRYING TO GET INTO TEACHING DANCE.

**CHALLENGE
ACCEPTED**

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[YOUTUBE.COM/CHALLENGEACCEPTEDSHOW](https://www.youtube.com/challengeacceptedshow)



DEVON
FEATURED IN THE “BUY GREEN BANANAS”
EPISODE OF *CHALLENGE ACCEPTED*

IN THE NEXT ISSUE

HOW GENENTECH HELPS
SUPPORT UNDERSERVED
HEMOPHILIA COMMUNITIES
AROUND THE WORLD.