Reuters Events

HEMOPHILIA PATHMAKERS: ADVANCING GENDER EQUITY IN BLEEDING DISORDERS

WFH
WORLD FEDERATION OF HEMOPHILIA

sanofi

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INTRODUCTION

More than 1 million females worldwide are predicted to be affected by hemophilia.[1] Most of the women are likely not receiving timely or adequate care.

Stories of delayed diagnoses, condition-related anxiety and depression, reduced quality of life, and systemic barriers to innovative care and treatment remain far too common for women with bleeding disorders. Beyond empowering women to advocate for improved personal outcomes, the global hemophilia community must forge new pathways to policy reform, advancing gender-specific care to go Beyond the Bleed for all women and girls, now and in the future.

In response to these persistent challenges, Sanofi, the World Federation of Hemophilia (WFH), and Reuters Events convened advocacy leaders, healthcare professionals, and people living with hemophilias to discuss strategies to reduce the gender care gap. The roundtable explored how personal narratives can shape policy, leveraging insights from early screening programs, gender-specific health data, digital health innovations, and best practices to drive systemic change for the broader bleeding disorders community.
The need for change is clear. More than 1 million females worldwide are predicted to be affected by hemophilia.[1] Most of the women are likely not receiving timely or adequate care. Almost 60% of women with hemophilia were aged 25 years or older when they were diagnosed.[2] In the US, an average of 16 years pass between women having bleeding symptoms and being diagnosed with a bleeding disorder.[3]

There are human and economic costs to the delayed diagnosis and inadequate care that is common in women and girls. One study found women had a higher number of bleeds, concomitant diagnoses of soft tissue health issues and musculoskeletal pain, and emergency department visits than men.[4] Significant underrepresentation of women in clinical trials hides differences in how they respond to medicines.[5,6]

At the roundtable, patient activist Shellye Horowitz discussed the human side of the statistics. Asked what would make the biggest difference in how women and girls with bleeding disorders are diagnosed, treated, and cared for, Horowitz zeroed in on the fundamental need to tackle a persistent falsehood: the idea that women can't have hemophilia.

"I can't tell you how many times – even at major meetings with WFH – I've said, 'I'm a woman with hemophilia,' and people look at me with complete disbelief, even other women," Horowitz said.

Horowitz's story is not an isolated example. Daniel-Aníbal García Diego, a member of the WFH board of directors, discussed the experience of a woman with severe hemophilia A "who is repeatedly told by emergency room doctors, 'It's impossible, there are no women with severe hemophilia'."

That disbelief can ruin lives. In many ways that mirror their male counterparts, women with bleeding disorders report an inability to engage in recreational activities, school, or work.[7] Because bleeding disorders are underrecognized and undertreated, women have lost jobs and housing and experienced financial difficulties when their conditions have limited their ability to work.

Horowitz and the other roundtable panelists discussed best practices for addressing the problems faced by women and girls with bleeding disorders. In the pages ahead, we explore those insights to provide a roadmap for improving access to care, showing the power of humanizing challenges through personal storytelling, adopting data-driven strategies, and leveraging real-world insights.

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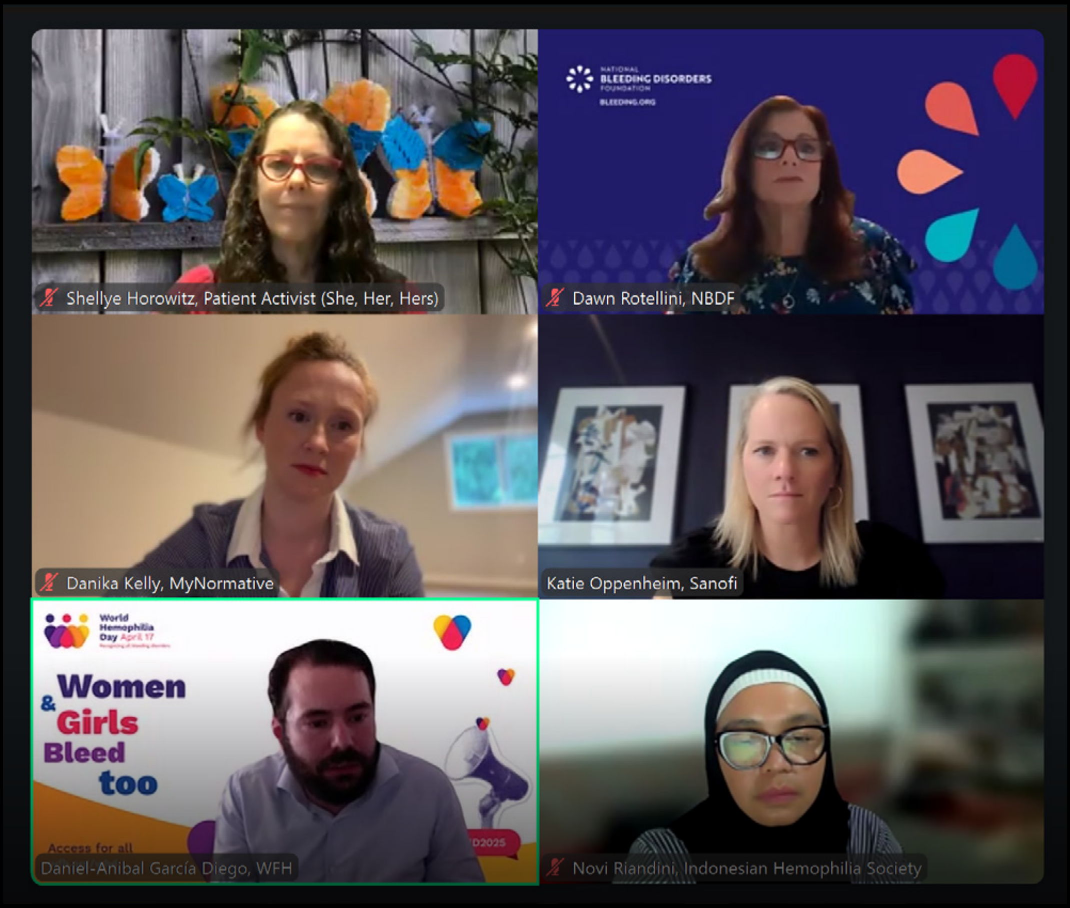

THE PATHMAKERS' MISSION

Horowitz was part of a panel of five Pathmakers on a roundtable moderated by Katie Oppenheim, VP, US Government Relations at Sanofi. The panelists shared their expertise and unique perspectives on gender inequity in hemophilia care with attendees from more than 70 countries. The audience included people from patient organizations, healthcare providers, treatment clinics, academia, and health systems.

Sanofi and WFH convened the roundtable as part of their work to change the status quo for how women and girls with hemophilia are treated. Diego explained how the organization has "really started opening the door more intentionally to women and girls with bleeding disorders" in recent years, working to help empower community-level stakeholders to drive gender equity in hemophilia care.

The WFH leadership team is driving the changes. After being re-elected for a four-year term as WFH president, Cesar Garrido said he hopes that by the end of his tenure it will no longer be necessary to say "hemophilia for men and women." It will simply be accepted that hemophilia can affect everyone.

Oppenheim discussed Sanofi's initiatives in the area, which include a global survey to better understand the unmet needs and opportunities to advance standards of care for people living with hemophilia. One-third of the patients who participated in the survey were female, giving Sanofi a clear picture of the unique challenges women with bleeding disorders face before and after diagnosis.

The insights have informed a documentary film that Sanofi has created with Believe Limited. Oppenheim said the film, which is called "Dismissed," is an intimate and unflinching look at the historical and current experiences of women living with hemophilia. The five women profiled in the film challenge what's "normal" and demand recognition, care, and justice.

HUMANIZING THE CHALLENGE

Humanizing the challenges faced by women and girls with hemophilia can build empathy and inspire action among policymakers and influencers while ensuring solutions that advance gender-equitable care are informed by lived experiences.

Personal storytelling is essential to humanizing the challenges. Several of the panelists shared lived experiences that both show the extent of the problems and provide the sort of powerful, first-hand testimonies that may be able to drive change when presented to policymakers and influencers.

Dawn Rotellini, chief operating officer at the National Bleeding Disorders Foundation (NBDF), discussed why it is so hard for women to get diagnosed. The normalization of symptoms is part of the problem. Rotellini said many women and girls say things such as 'Oh, my mom and sister bleed like this too, it's just normal for us'. However, the bleeding is abnormal. It has just been normalized.

Stigma is another barrier to diagnosis. In parts of the world where bleeding disorders are stigmatized, a hemophilia diagnosis can jeopardize marriage prospects or create fear, Diego said. The WFH director has seen women in rural Spain travel long distances to avoid their condition being known in their own village. Differences between the lives of women in different parts of the world need to inform strategies.

"We have to be realistic: we can't use the same playbook we use in the US, Latin America, or Europe," Diego said. "We need entirely different strategies in different regions, especially where stigma adds another layer of challenge."

Rotellini's story shows that normalization and stigma are only part of the problem. After decades of advocating for others, Rotellini, the parent of a son with hemophilia, was diagnosed herself aged 59.

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"Just this year, I finally accessed comprehensive care and got my first dose of factor. That's how long and hard the road can be for women," Rotellini said.

The challenges continue once women and girls receive a diagnosis. Horowitz said she has had bleeds, on prophylaxis, that are worse than some people classified as severe. Yet, Horowitz is limited in the care she can access because her condition is classed as mild, not severe. The current classification system does not work for many women and girls, Horowitz said, and reflects a fundamental misunderstanding.

"I've literally had to pull out my phone and show photos of my bleeds because people just don't believe it. I've heard, 'But you're mild, milds don't bleed like that,' more times than I can count. But they do. We do," Horowitz said. "People are imagining a completely different picture of what a bleeding disorder looks like, and it's leaving women and girls out of the conversation."

Horowitz's experience of the need to show people photos of bleeds to be believed informed her top piece of advice for women and girls navigating complex healthcare systems: document everything and use pictorial evidence.

"If your elbow swells up so badly it looks like you have two elbows, take a picture. If your bruises spread and deepen because you're not getting treatment, take a picture. If you're bleeding through your pads, staining your sheets, passing large clots in the toilet, yes, even that, document it," Horowitz said. "It might feel awkward, or even gross, but those images tell the truth in a way that words just don't."

ENGAGING DATA-DRIVEN STRATEGIES

Personal storytelling is most powerful when combined with data-driven strategies that highlight global disparities in diagnosing and treating hemophilia in women and girls. The WFH is leading efforts to collect data that can drive change.

"The WFH has made significant strides in the last three to four years by intentionally including women in our annual global surveys and the World Bleeding Disorders Registry," Diego said. "This data is vital. At the state level in Spain, we collect data on women specifically because the WFH asks for it. If they didn't, we wouldn't be storing it. This WFH-driven data collection directly supports local organizations in advocating for resources and tailored care."

Progress made by the WFH must be matched by the adoption of a more comprehensive and considered approach to data collection by all researchers. Danika Kelly, co-founder and CEO of MyNormative, identified one step researchers should take to start addressing the data challenges.

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"One of the most foundational things we can do, and it sounds simple, but it's often missed, is to disaggregate sex and gender data," Kelly said. "So many studies collect that information but then lump everyone together in analysis. When we do that, we lose the ability to see how women might be experiencing symptoms or responding to treatment differently than men."

The next step is to combine structured and unstructured data. The structured data collected in standard clinical forms and validated questionnaires is important but can only tell part of the story. To understand the lives of people with bleeding disorders, researchers also need to provide space for patients to share their experiences in their own words, even if the input does not fit neatly into a checkbox.

Artificial intelligence (AI) can accelerate the conversion of unstructured data into actionable insights by automating the analysis of free text. That AI use case is one of many potential applications, with digital health researchers also developing models that determine disease severity chatbots that support patient education and self-management.[8]

Kelly urged caution, though. AI models are only as good as the data they are given. The long history of underdiagnosis and misunderstanding of bleeding disorders in women and girls mean the comprehensive, high-quality data that is the bedrock of success in AI is missing.

"The reality is, the data we have for women with hemophilia is incredibly limited. So, if we just let AI run wild on what we do have, which is already biased, it can actually make the problem worse," Kelly said. "That's why I strongly advocate for using supervised machine learning first."

Across healthcare, some researchers are concerned that the "dominant datasets used to train predictive models overrepresent male, white, and affluent populations, resulting in algorithmic biases that often fail to reflect the physiological and socio-medical diversity of patients."[9] The problems are particularly acute in hemophilia, given the historical failure to recognize the bleeding disorder in women.

An unsupervised model might evaluate historical data, fail to recognize its limitations, and conclude only men have hemophilia. Supervised machine learning makes it possible to shape algorithms to recognize and include the experiences of women and girls.

Multiple efforts to improve the quality and quantity of data on women and girls with hemophilia are underway. Diego named the integration of gynecologists into comprehensive care teams as the single most impactful strategy for advancing gender equity in bleeding disorders.

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"In Spain, 20% of new diagnoses for women with bleeding disorders now come from OBGYNs. And we've seen incredible results, like in Paraguay, where simply adding a gynecologist to the care team led to a 300% increase in women seeking consultations," Diego said.

In the US, the Community Counts surveillance program has expanded the collection of data on people with bleeding disorders. The program tracked a 47.3% increase in females with bleeding disorders from 2012, the year the Centers for Disease Control and Prevention launched the initiative, to 2020.[10] Women went from 28.8% to 33.6% of the treated patient population over the same period.

There is much more work to do, though. Diego said "diagnosis rates for women, especially with hemophilia, are still incredibly low," citing figures for Colombia and Paraguay to support his argument.

"Our approach needs to shift," Diego said.

ENGAGING DATA-DRIVEN STRATEGIES

A 4-point plan for change

Diego and the other Pathmakers shared clear, actionable ideas for how to address the challenges. Here, we present Rotellini's four-step framework for change: Count women, educate, organize, and advocate.

Count women: Challenges around the use of AI and data-driven strategies in hemophilia speak to a clear need to build a better understanding of the patient population. Rotellini recommends starting projects to count women by focusing on carriers, daughters of men with hemophilia, and anyone showing symptoms. Work toward the goal is well underway, with the WFH putting identifying and diagnosing people with bleeding and collecting, interpreting, and disseminating data at the heart of its "Treatment for All" vision.[11]

Novi Riandini, a public relations expert and hemophilia advocate in Indonesia, explained why the next step in her work to improve the care of women and girls is to start gathering data on factors such as their symptom histories, ages, and carrier status.

"Without data, we can't push for access to better care or treatment," Riandini said. "We're already working on upgrading an existing Android app in Indonesia to help with this, something that can connect these women, track their experiences, and give us the information we need to advocate effectively."

Educate: Rotellini recommends sharing the signs of bleeding disorders in women, loudly and clearly. The recommendation goes beyond just communicating more with women. How people speak about bleeding needs to change too.

"We need to make conversations about periods normal. Not just in medical settings, but in everyday life," Rotellini said. "That means dropping the clinical language. Say heavy periods, not menorrhagia. Make it accessible."

NBDF's "Better You Know" symptom checker exemplifies the change in the language used to describe bleeding symptoms.[12] The first two questions ask women how many days their periods usually last and how often they experience a sensation of "flooding" or "gushing" during their periods.

Organize: Rotellini discussed the value of creating women's committees in patient advocacy groups, citing the annual women's conference in India as "an amazing model." Pathmakers such as Riandini are at the leading edge of efforts to put the recommendation to organize into practice, for example by acting as a bridge between women with medical questions and experts who can provide answers.

"I created a WhatsApp group for women with bleeding disorders in Indonesia," Riandini said. "Right now we have about 30 members from different parts of the country. It's become a really special space, a safe, supportive environment where these women can connect, ask questions, and not feel so alone."

Riandini's experience of advocating for her husband, a hemophilia B patient, shows what is possible. When Riandini met her husband, there were 98 diagnosed hemophilia patients in Indonesia. After three years of work to count, educate, and organize patients, there were 280 diagnosed patients. Today, 3,800 people in Indonesia are registered hemophilia patients.

Organizing means reaching across institutional boundaries to build broad coalitions of people who are working for change. Not every potential partner is ready to support the effort, though. At MyNormative, Kelly said she often jokes with her colleagues that they "look for partners who 'already know the cupboards are blue'," meaning they target organizations that are at least aware that there is a problem.

"If a group isn't even thinking about sex and gender in their research or innovation work, it's really hard to get them to shift gears," Kelly said. "So, our first priority has been to find those willing partners, people, and institutions who are truly ready to engage in honest conversations about the role sex and gender play in health outcomes."

Advocate: Once bleeding disorder communities are in place, patient advocates have a wealth of personal stories to take straight to health ministers and policymakers to push for change. NBDF puts that idea into practice every year with its Day on the Hill, when it brings hundreds of people to Washington, DC to meet with lawmakers, share their stories, and put a human face to the issues that NBDF is talking about. Women took center stage at the latest event.

"This year, with the World Hemophilia Day theme 'Women and Girls Bleed Too,' we dedicated a full day to this topic and brought about 30 women and girls to speak directly with Congress. And you know what? So many of the staffers we met had never even heard that women could have bleeding disorders," Rotellini said.

Rotellini's story speaks to a broader shift that the community needs to foster to empower women to advocate for themselves. Diego said that "women have been leading the charge for hemophilia care, but mostly for their sons." Rotellini first founded a bleeding disorder association as the parent of a son with hemophilia. Now Rotellini and women like her are diagnosed and starting to advocate for themselves.

"We're at a turning point. We need those same advocates to feel empowered to speak up for themselves, too," Diego said. "That's not always easy, especially when we've spent years telling people to focus on the community's needs instead of their own. But it's time to shift that mindset. Women are the community."

The results of a poll of the roundtable audience suggests there is appetite for advocacy by and on behalf of women and girls with bleeding disorders. Audience members were asked what they can commit to actioning now to advance gender equity and better the lives of women and girls with bleeding disorders. The most popular answer was to talk about the impact of bleeding disorders on women's lives.

CONCLUSION

The Reuters Events roundtable, in partnership with Sanofi and the WFH, shows the moral and economic imperative for gender-equitable care is undeniable. Women and girls can have hemophilia. The failure to recognize that fact and provide specialized care that reflects the unique needs of women and girls has been detrimental to patients' physical and mental health.

Recognizing the gender care gap is the first step. Once healthcare systems accept women and girls can have bleeding disorders, work to properly resource care, for example by funding integrated gyn-heme models and data systems, and to design more equitable pathways can begin. Re-designing pathways means embedding gender equity in every guideline, trial, and AI tool.

The insights Pathmakers shared at the roundtable showed how early diagnosis, policy reform, and the thoughtful use of data and technology are gradually making healthcare more equitable. The progress is built on grassroots advocacy and personal storytelling, which continues to play an invaluable role in making an inarguable case for systemic changes.

"At the end of the day, raising the voices of women and girls means exactly that: creating community, documenting their experiences, and using that evidence to push for change at every level, from doctors' offices all the way to national policymakers," Riandini said.

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