

Women: caregivers to patients to advocates

Lara Nicholson

This session discussed the work of women advocates to overcome the general and longstanding misunderstanding that women are only carriers and do not have bleeding disorders, a notion that was challenged by the personal anecdotes and clinical case presentations at WFH 2024 World Congress. It explored how the idea that bleeding disorders are only experienced by men denies the impact on women and on their health services. The complexity of women's needs and their clinical presentations in this area of medicine have historically been largely dismissed or deprioritised. Hence the absolute cruciality of a collaborative partnership between Haemophilia Treatment Centres (HTCs) and women in the community and the Foundations that represent them.

How to go from caregiver to patient, and from patient to advocate?

Chair ~ Pam Wilton, Canada

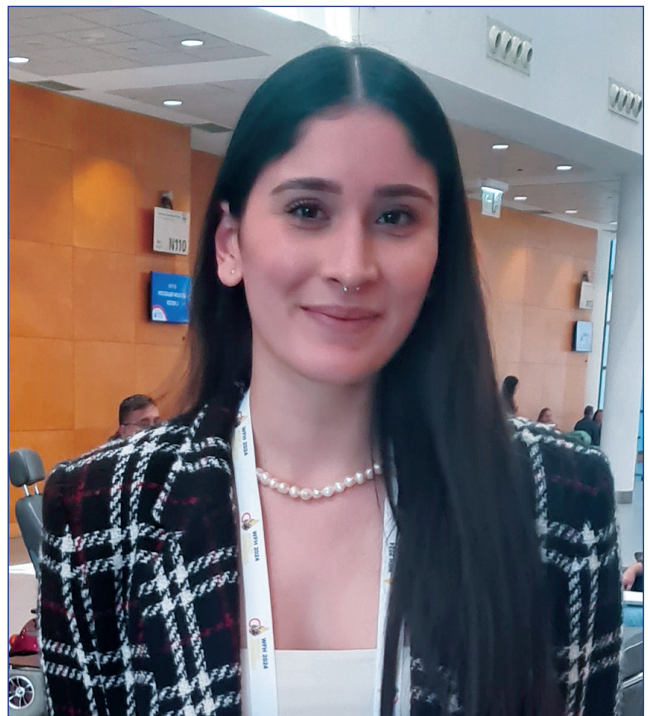
The journey to self-advocacy – community testimonial ~ Noemy Esther Diaz-Burgos, USA

Overcoming psychological barriers
~ Meila Roy, UK

Creating supportive networks and advocacy initiatives ~ Suzanne O'Callaghan, Australia

SELF-ADVOCACY

Noemy Diaz-Burgos delivered a community testimonial as a woman with a bleeding disorder in the United States, relaying her personal experience growing up with symptoms and indicators she refused to let be dismissed. She spoke about her own personal experience becoming a career pathway where she is now actively pursuing change for women and girls with bleeding disorders in the United States and internationally, but noted



Noemy Diaz-Burgos

that actually receiving a diagnosis was a long and challenging battle that required advocacy in itself.

Noemy described advocacy as varying from the act of speaking up, to representing the marginalised, to campaigning for change, to educating stakeholders to engaging your community and raising awareness.

Noemy was raised by a single mother from Puerto Rico and has a brother with severe haemophilia A. She initially advocated for her brother but eventually began advocating for herself to receive a diagnosis and a treatment plan that she said, even as a woman in her twenties, is still evolving as she works with her treating team to manage bleeding symptoms.

She spoke about her own challenges: worsening symptoms as she entered puberty, not being insured in the United States, experiencing a gender bias, gaps in education and being gaslit and >

misdiagnosed by health professionals – something that Noemy said fuelled her passion to campaign at a higher level.

She gave examples of the comments she heard from health professionals: *‘but girls don’t have haemophilia’*, *‘it’s just a heavy period’*, *‘must be all the stress you’re getting yourself into’*, *‘you’re too young to be worrying about this’*, *‘stop trying to take the attention away from your brother’* and *‘your symptoms can’t be that bad’*.

Subsequently Noemy chose to follow up with speakers and attendees from bleeding disorders events, scheduled appointments with community-vetted doctors, documented and questioned everything and used handouts/toolkits for bleeding disorders organisations in her communication with health professionals and haematologists.

Noemy was validated when she was diagnosed with mild haemophilia A in November 2022 and could reconsider her treatment options.

Noemy then decided to intern with the US government and Hemophilia Federation of America (HFA) and researched pharmacy benefit management reform, inclusive language and genetic testing and began sharing her story as a powerful tool of advocacy. Noemy’s advocacy efforts became her own career journey, and she has protested for reproductive rights in Washington DC, been on the Panel for the Department of Hispanic Health Services Secretary and Staff, trained advocates within the Florida bleeding disorders community and worked on Prison Health Reform.

Noemy emphasised her earlier point that advocacy can look different in different individual’s contexts. Just being heard by a haematologist and receiving a diagnosis can be the most powerful outcome for a woman or girl with a bleeding disorder. Sharing the story of that effort and journey is an extension of advocacy work she encourages in other women and girls with bleeding disorders worldwide in their respective cultural contexts.

PSYCHOLOGICAL BARRIERS

Meila Roy is a Clinical Psychologist in the UK who works within the National Health Service (NHS) and acknowledged that her presentation draws on models and thinking developed in the West.



Left to right: Suzanne O’Callaghan, Meila Roy, Pam Wilton

Meila explored what we mean by a psychological barrier for an individual in the context of their person, their family, their healthcare and their society and referred to the Haemnet research group Cinderella studies by Kate Khair and colleagues in 2022, which aimed to understand the lived experience of women and girls with bleeding disorders in the UK. The study’s main findings spoke to the difficulties experienced by women with bleeding disorders, even in a well-resourced country with a health care system that includes specialised bleeding disorder clinics. Difficulties obtaining a diagnosis, lack of awareness among health care professionals, and normalisation of symptoms by non-specialists were common.

Meila spoke of the pervasive notion that haemophilia is a condition that only affects males and the stigma around the discussion of women’s health issues as being two of the barriers women and girls with bleeding disorders face in the UK, despite the fact that bleeding disorders affect both men and women – and that women experience additional, unique issues due to their biology.

Other prominent psychological barriers for women include guilt and blame of females and a lack of space for women’s needs in this medical area. The study showed significant issues with access to care and consistent themes of feeling dismissed and minimized by health care providers as well as diagnostic delay, poor communication around

obstetric issues, misdiagnosis and gross health uncertainty. These outcomes all point to a lack of understanding of the health risks for women and girls with bleeding disorders.

Broader societal and cultural factors impacting on women and girls include caring responsibility/burden, feelings of isolation and stigmatization.

Meila suggested a larger story about women and girls is being told within our community, a story that is *'changing, but not changed'*. She noted advocacy does not always look the same and her practice aims to empower women and girls to identify sources of support in their own context and equip clinicians to encourage this for our patients.

Finally, Meila pointed to several animated patient stories produced by the Cinderella team and available on the Haemnet YouTube channel (<https://www.youtube.com/@Haemnet>) including:

Struggles & Support: A mother's haemophilia story; The Cinderella Study

It's not all about boys: A story of haemophilia

Bruises, bleeds and babies: A story of Type 3 VWD

PEER SUPPORT AND ADVOCACY INITIATIVES

Suzanne O'Callaghan, Policy Research and Education Manager at Haemophilia Foundation Australia (HFA), spoke about the Australian experience of women's peer support and advocacy initiatives. She drew on the strategies and experiences of Australian women leaders as well as HFA initiatives for the content of this session and thanked the women who contributed to her presentation, who are patient advocates and peer support leaders.

Suzanne explored the trajectory for a woman from the first step of recognising she has a bleeding disorder, to self-advocacy and supporting her peers, and then to education and advocacy at a national or international level.

She began by describing the importance of stepping back and acknowledging women's peer support and advocacy strategies that have worked, honouring their wisdom, no matter how simple or obvious the strategy may appear to be. Sensitivity to local and cultural issues is pivotal in this area of advocacy as is observing and sharing what works in women's individual environments.

What barriers can literally get in the way of diagnosis for women and girls with bleeding disorders? Apart from the issues discussed by the other presenters, Suzanne also mentioned that their symptoms can be put down to gynaecological problems therefore making them harder to define as a bleeding disorder. Relatively speaking, a woman's family might consider an amount of bleeding normal in their family, given this is their only experience of menstruation and this can lead to misconception of 'normal' bleeding.

Suzanne spoke about the awkward and culturally specific nature of discussions around menstruation, often making women and girls silent and also the additional comparisons women and girls may make to their male siblings regarding their severity of bleeding.

What we know about women socially and culturally are the priorities placed on family, partner, work and aspects of life other than their individual health and wellbeing. Suzanne noted this as a significant systemic barrier to diagnosis of bleeding disorders for women and girls. Finally, the simple difficulty in advocating for oneself when unwell and lacking energy is also a barrier for those living with chronic conditions.

Suzanne spoke of creating truly safe spaces where women and girls can have conversations that develop organically in an informal and relaxed environment, for example, with fun workshop-based activities, activities at community camps and women's brunches, as well as private online platforms. This supports child focussed conversations with women that can often evolve to discussion around women's bleeding problems.

One woman leader's experience was that *'women are more comfortable talking about their periods and bleeding with other women; I will openly talk about it to start the conversation; I'll talk about my experience with childbirth or with my period before I was diagnosed compared to now that I have treatment and that gets rid of the awkwardness'*. This conversation gave a clear message to women that *'you may be in a caring role but your health matters too'*.

Opportunities to raise the question about symptoms are important in identification and treatment and need to be done in a respectful and sensitive manner. HTC information sessions discussing mild haemophilia could be a good starting point, >

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as are regular collaborations between an HTC and a local haemophilia foundation to meet patients in clinic and develop peer support relationships with warm handover from HTC clinicians.

Cultural change is often challenging and Suzanne suggested drawing on the experience of change management in organisations. This approach speaks of *'bringing everyone with you'*, *'engaging hearts as well as minds'*. Change can be promoted by *'showing how'* with peer support, creation of safe spaces and managing the typical stages that are reactions to change - denial, resistance, anger and grief. And of course the importance of persistence and celebrating small gains. Suzanne emphasised the complexity and art of persuasion in this and how individual cultures will need to approach this differently.

In an evaluation of HFA's 'Female Factors' education resources, 50% of community members had given the resources to health professionals, family and friends and colleagues to educate them. Female Factors resources aim to augment the female voice. Suzanne noted that resources are evidence-based and high quality and include personal stories, tips and self-advocacy strategies shared by women in the community.

There are a number of tools that have worked for women and girls in Australia, including HFA Female Factors resources and the Canadian *'Let's Talk Period'* self-assessment tool. The Australian Bleeding Disorders Registry (ABDR) patient card is also standardised nationally to communicate with other health professionals - but we still need to advocate and ensure that women are registered in the ABDR.

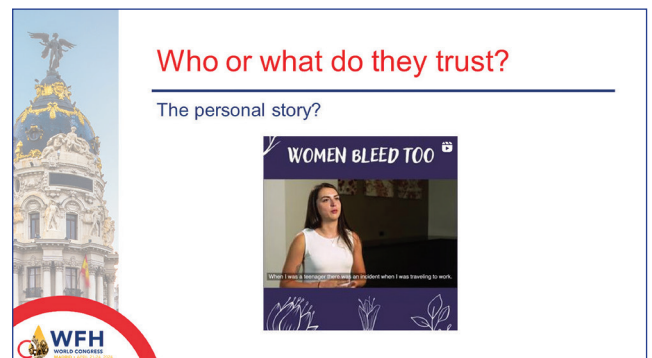
Similarly, the evidence about women's experience is crucial and researchers are currently investigating worldwide to understand how bleeding disorders affect females.

Contributing to the evidence through the ABDR, the PROBE Australia study and other research is vital to inform data going forward.

Suzanne encouraged women to seek support in advocating for themselves and know who their allies are, such as family, partner, friends, health professionals from relevant areas and also connecting with male peers who have become 'champions' in the community.

Then looking systemically, Suzanne spoke of changing the conversation at every level; for example, the HFA Council's commitment that

'women and girls are a priority issue'. Social media, newsletters, information sessions and awareness campaigns need to repeat the message to the broader community and of course national conferences are an excellent forum for health professionals and community to share information and stories that aim to inform research and ultimately include women and girls alongside their male relatives in what is already a small and rare population.



Collaborations with wider health professional and community networks are crucial for this community, including schools, midwives and general practitioners (GPs) and this can be done by the simple sharing of a personal story in their professional education – to spark discussion and thought about women and girls with bleeding disorders and an evolving area of research.

Women leaders also need safe spaces and structures to connect, network, share skills and create their advocacy community. Bleeding disorders can impact on energy and ability to contribute and many women are also juggling other stressful life issues. We as a community need to consider this risk of burnout and support them to engage with their advocacy journey sustainably. This may be through the support and network of professionals and other women who can empathise with the complexity of their experiences.

Lara Nicholson was assisted by funding from HFA to attend WFH World Congress.

Photo: HFA

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