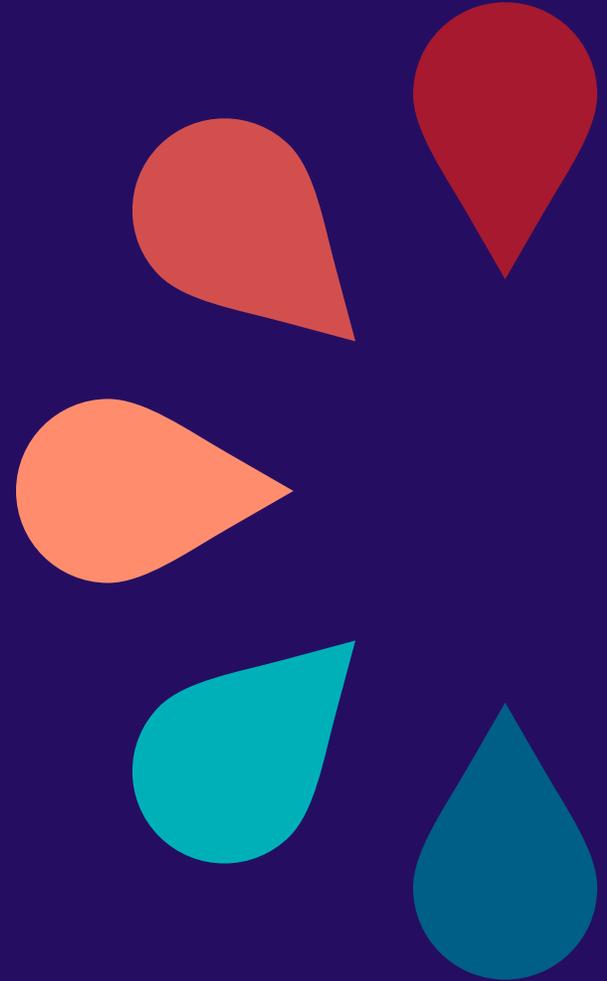




NATIONAL
BLEEDING DISORDERS
FOUNDATION
Formerly NHF

Improving Outcomes for Women, Girls, and People Who Have or Had the Potential to Menstruate (WGPPM): A Roadmap for Moving Forward



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November 2023



NATIONAL BLEEDING DISORDERS FOUNDATION

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EXECUTIVE SUMMARY

In May 2023, the National Bleeding Disorders Foundation (NBDF), formerly National Hemophilia Foundation, hosted a Women, Girls, & People who have or had the Potential to Menstruate (WGPPM) Summit to layout key barriers and facilitators of access to diagnosis, treatment, and care for WGPPM and began to prioritize and map out steps toward improving those areas. The meeting was held in Atlanta and was attended by over 50 people working together to move the needle towards creating better health outcomes for WGPPM.

NBDF worked intentionally to invite stakeholders who reflect the varied backgrounds, experiences, and professions within the bleeding disorders community. NBDF wanted to ensure that Lived Experience Experts (LEEs) ranged in age, bleeding disorder diagnosis and experiences, race and ethnicity, gender identity, and primary language spoken. Similarly, a range of health care providers and national organizations were invited, some with a focus on WGPPM in hematology and others from non-hematology settings. The aim was to identify barriers and opportunities for better collaboration. Through presentations, panels, and small group discussions, the key challenges, as described below, were identified.

WGPPM with bleeding disorders continue to be underrecognized and underdiagnosed. Those who are diagnosed often experience delays in diagnosis, feel their symptoms are dismissed or minimized, and face challenges in access to effective treatment. Bleeding disorders are serious chronic health conditions with immense individual, societal, health, and economic costs. There are unique problems for WGPPM because of their impact on reproductive health, including heavy menstrual bleeding, iron deficiency, and pregnancy issues. Spontaneous, traumatic, or uncontrollable bleeding episodes can potentially be life-threatening. Complications, such as joint damage and heavy menstrual bleeding, can limit an individual's functional capacity, quality of life, and economic viability.

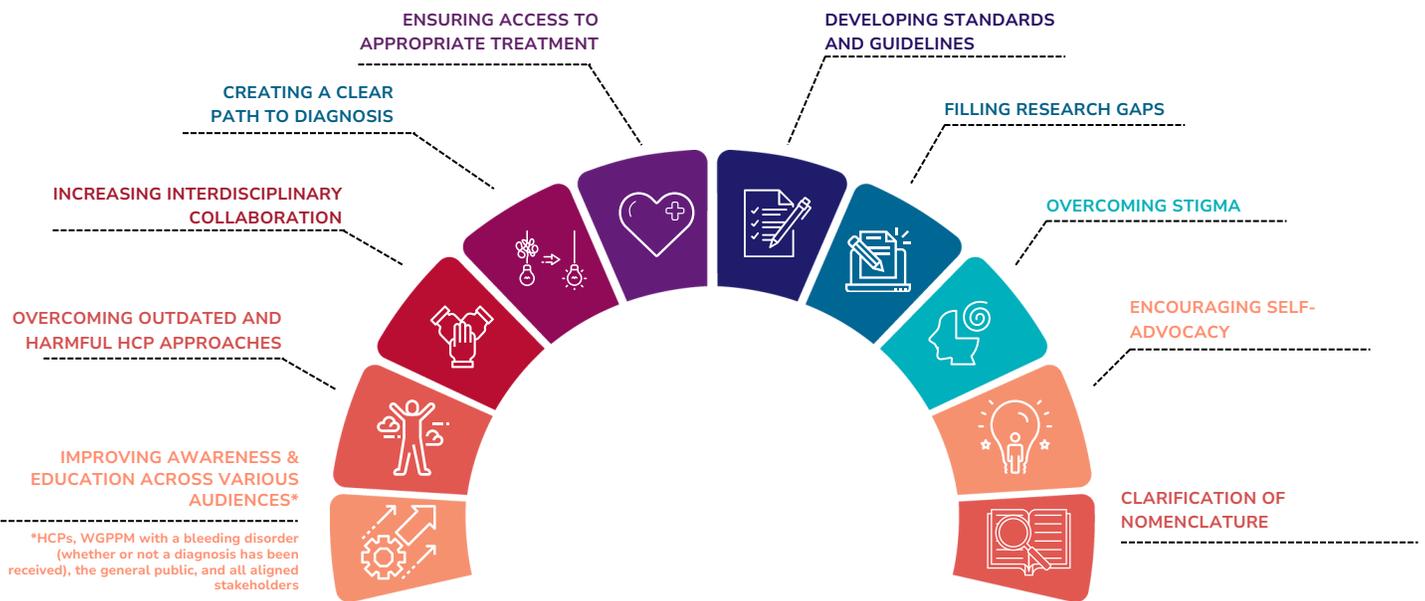
Sexism underlies all of this, from systems that haven't included WGPPM and outcomes important to them, to stigma in many cultures around discussing periods. Many WGPPM are impacted daily by health inequities and disparities. WGPPM with bleeding disorders are not monolithic in those experiences. Transgender people, people of color, and those of Hispanic or Latino/x origin are overlooked or receive sub-optimal care.

Some progress has been made, as shared by summit participants. Over the past decades, initiatives such as Project Red Flag, Victory for Women, Blood Sisterhood, Better You Know, Learning Action Networks (LANs), and others have helped to improve diagnosis and care. Other efforts have impacted WGPPM even if not explicitly just for them. In 2021, much-needed international guidelines on the diagnosis and management of von Willebrand disease (VWD) were published through a collaboration with the American Society of Hematology (ASH), the International Society on Thrombosis and Haemostasis (ISTH), NBDF and the World Federation of Hemophilia (WFH). The guidelines included diagnosis and management of issues such as heavy menstrual bleeding and pregnancy, delivery, and postpartum care. As VWD remains a disorder that is underdiagnosed in WGPPM, this was an important step.

Work continues at local, regional, national, and international levels. The WGPPM Summit is the continuation of this conversation that NBDF and partner organizations have already started. Summit participants were tasked with identifying strategic priorities and improvement areas for the diagnosis, treatment, and care of WGPPM. Despite the complexities and challenges within the bleeding disorders community, when participants were asked prior to the Summit “What do you believe to be the three most pressing issues currently facing WGPPM with bleeding disorders today?”, their answers were clear. They called for:

- 💧 A clear and structured pathway to diagnosis
- 💧 Access to appropriate treatment at HTC's
- 💧 Provision of more education about WGPPM with bleeding disorders, particularly for health care providers

After further exploration during the Summit, key action areas were identified. These are not in a priority order, which is a potential next step for the bleeding disorders community moving forward.



NBDF would also like to acknowledge that there are unique needs and challenges faced by trans and gender non-binary people with bleeding disorders and while some were brought up in this forum, further understanding is needed to collaborate to improve outcomes and care.

WGPPM have shared their voices and continue to do so. Now the challenge is for those voices to be heard, listened to, believed, and partnered with across various stakeholders to make for longer lasting impact.

As long as WGPPM with bleeding disorders remain under-recognized, under-diagnosed and under-treated, we have work to do. Most importantly, this Summit and paper calls for the entire bleeding disorders community to move forward together to address the inequities experienced by WGPPM, now and in the medium and long term. We acknowledge that our task is huge, but by tackling challenges together, one step at a time, we can all make a difference.

FOREWORD

Dr. Leonard Valentino



Dawn Rotellini



by Dr. Leonard Valentino (He, Him, His), President & Chief Executive Officer, National Bleeding Disorders Foundation and Dawn Rotellini (She, Her, Hers), Chief Operating Officer, National Bleeding Disorders Foundation

When you get turned away from a treatment center, when you aren't believed when you describe the challenges you face due to your bleeding disorder, when you're told that your symptoms are psychosomatic or attention-seeking, and when you receive less-effective treatments than your male counterparts, you know things need to change.

Living with an inheritable bleeding disorder can present daily challenges. The problems faced by women, girls and people who have or had the potential to menstruate (WGPPM) are magnified by gender inequity. The WGPPM community is a large one. For every male with severe hemophilia, there are 1.6 female carriers, many of whom have symptoms of the disorder.¹ Added to this number are WGPPM with von Willebrand disease (VWD) and other bleeding disorders totaling one percent of the U.S. female population, many of whom are unaware of their condition, despite having symptoms.² In fact, only one in 10,000 people with VWD have been diagnosed accurately, so many continue to suffer in silence.³

WGPPM uniquely live with the impact on their reproductive health including heavy menstrual bleeding, iron deficiency and pregnancy issues, as well as the commonly recognized symptoms of bleeding disorders including large bruises or bruising easily, frequent or long-lasting nosebleeds, bleeding gums, long-lasting bleeding from cuts, joint bleeds, and sustained bleeding after a tooth removal or other surgery.⁴

True to our mission that includes health equity and inclusion at National Bleeding Disorders Foundation (NBDF), the WGPPM Summit 2023 aimed to create better healthcare outcomes for WGPPM by shining a light on the diagnosis, access, and treatment barriers they face and prioritizing and mapping out steps towards improvement in treatment and care.

Some progress has been made. Over the past decades, initiatives such as Project Red Flag, [Victory for Women](#), [Blood Sisterhood](#), [Better You Know](#), [Learning Action Networks \(LANs\)](#), and more have worked to improve diagnosis and care.

In 2021, much-needed international [guidelines on the diagnosis and management of VWD](#) were published through a collaboration with the American Society of Hematology (ASH), the International Society on Thrombosis and Haemostasis (ISTH), NBDF and the World Federation of Hemophilia (WFH).

Work continues at local, regional, national and international levels. The WGPPM Summit is the continuation of this conversation that NBDF and partner organizations have already started.

But as long as WGPPM with bleeding disorders remain under-recognized, under-diagnosed and under-treated, we have work to do. We acknowledge that our task is huge, but by tackling challenges together, one step at a time, we can all make a difference.

WGPPM have shared their voices and continue to do so. Now the challenge is for those voices to be heard, listened to, believed, and partnered with to make for longer lasting impact.

~Dawn and Len

WGPPM SUMMIT OVERVIEW

This white paper is the outcome of the WGPPM Summit 2023, hosted by the National Bleeding Disorders Foundation (NBDF) and held in Atlanta, Georgia on May 23-24, 2023. At the time of the Summit, NBDF was still called the National Hemophilia Foundation (NHF) so some of the references or resources still uses that language. Over 50 people attended representing a wide range of stakeholders including:

- ◆ WGPPM living with a bleeding disorder, caregivers and family members (Lived Experience Experts, or LEEs)
- ◆ Health care providers (HCPs) including obstetrician-gynecologists (OB/GYN), hematologists, nurses, physical therapists, social workers
- ◆ Regional administrators
- ◆ NBDF chapter representatives
- ◆ NBDF partner organizations
- ◆ Pharmaceutical company partners
- ◆ Representatives from the Centers for Disease Control and Prevention (CDC) and health policy lobbying groups

NBDF worked intentionally to invite stakeholders who reflect the varied backgrounds, experiences, and professions. NBDF wanted to ensure LEEs ranged in age, bleeding disorder diagnosis and experiences, race and ethnicity, gender identity, and primary language spoken. Similarly, a range of health care providers and national organizations were invited, some with a focus on WGPPM in hematology and others from non-hematology settings. The aim was to identify barriers and opportunities for better collaboration.

Ideally, NBDF would have invited many more voices to the table if space was unlimited. For example, we were only able to invite three local chapters, even though NBDF knows many local organizations are doing a great deal of important work reaching and supporting their WGPPM communities. Unfortunately, due to last minute changes, the invited laboratorians were unable to attend the Summit. The NBDF acknowledges that this has left a gap, but we look to gain their valuable insights as part of the road map ahead.

NBDF also invited pharmaceutical partners to participate. The WGPPM Summit and this white paper were made possible through the support of Genentech, Novo Nordisk, Pfizer, Sanofi, and Takeda. These companies were invited to send a representative to participate.



Thank you for being in the room and listening to us. The only way we can make progress is with your resources.

Connie (She, Her, Hers)

Despite these limitation in numbers, the Summit brought new representatives into the fold. This will spearhead future conversations and collaborations, such as a representative from the Black Women’s Health Imperative.

Both participants and stakeholders unable to attend the Summit in person are already doing incredible work advancing outcomes for WPGGM with bleeding disorders. The Summit was an opportunity for people to impart their knowledge of what is already happening in this area, as well as helping to flesh out the continuing gaps and barriers to improved services and treatment.

Participants’ generous sharing of their work and experience has shaped this paper. It explores the causes and effects of gender inequities experienced by WGPPM within the bleeding disorder community, examines common challenges and identifies strategic priorities and improvement areas for the diagnosis, treatment, and care of WGPPM.

Most importantly, this paper calls for the entire bleeding disorders community to move forward together to address the inequities experienced by WGPPM, now and in the future.



We want everyone to be part of improving health outcomes for WGPPM living with bleeding disorders. I see the NBDF as a convener of community, a vehicle for bringing about action. For those not in the room, the opportunities will extend way beyond this Summit. We’ve got a lot of work to do but together we can climb mountains!

Dr Leonard Valentino (He, Him, His)

Language, terms, and explanations

NBDF strives to understand and meet the needs of all in the bleeding disorders community. To this end, NBDF must continually adapt the language used to reflect changes as they evolve.

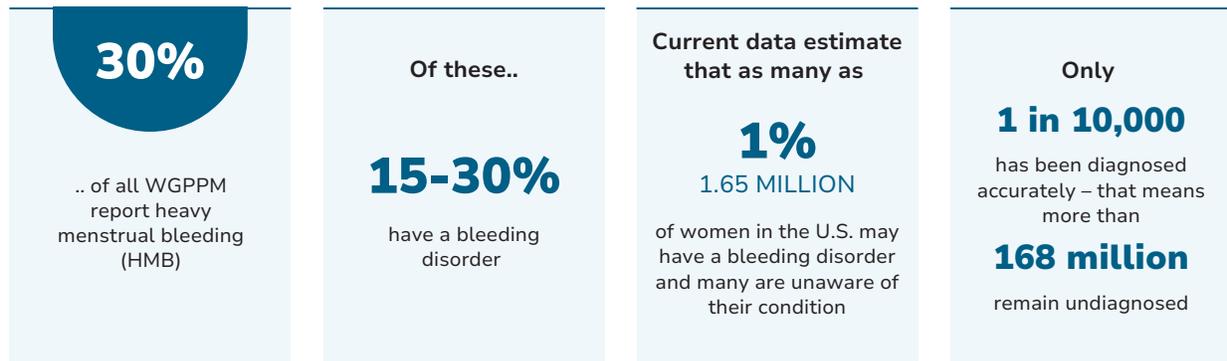
Over the course of this Summit, and beyond, various language terms and acronyms are used. NBDF acknowledges that these are not perfect and is mindful that some individuals feel more comfortable with one term while others prefer to use a different one when referring to their own experiences. NBDF wants to respect this while beginning to hone language which is inclusive of all those experiences.

For the purposes of this Summit, NBDF has used the term ‘women, girls and people who have or had the potential to menstruate’ or the acronym WGPPM.

In addition, we use the term ‘inherited bleeding disorder’ to describe those disorders that are generally passed down from parent to offspring genetically. We do not use the acronym IBD as this can be confused with other health conditions. For simplicity we have used ‘bleeding disorder’ throughout.

WGPPM IN NUMBERS

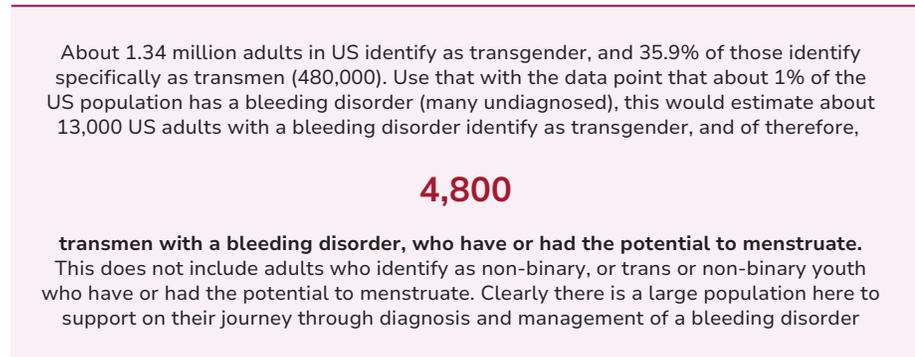
Many WGPPM remain undiagnosed.^{4,5,6,7,8,9}



Many WGPPM report delays to diagnosis.¹⁰



Transgender PPM are mainly hidden from view and suffer the consequences of health and gender inequities.¹¹



Complications arising from lack of diagnosis can be life-threatening.¹²



The economic cost of heavy menstrual bleeding is high.¹³



But the social, emotional, physical and psychological toll on WGPPM with bleeding disorders experiencing health and gender inequities and diminished lives is beyond reckoning.

IDENTIFYING AND QUANTIFYING THE IMPACT OF GENDER INEQUITIES ON WGPPM

Sadly, many women, girls, and people who have or had the potential to menstruate (WGPPM) are impacted daily by health inequities, inequalities, and disparities. Transgender people with a potential to menstruate fare particularly poorly, as they are overlooked and receive sub-optimal care. The challenge is to seek solutions that shine a light on these issues by understanding why so often they remain hidden and overcoming the barriers to quantifying their impact on these under-served groups.

Unfortunately, many WGPPM do not have their needs met due to lack of awareness of bleeding disorders overall and specifically in WGPPM.

Lack of awareness and education

A recurring theme from WGPPM with bleeding disorders is the need for more education to equip all stakeholders serving the bleeding disorders community to better meet the unique needs of this heterogeneous group. These stakeholders include:

- ◆ health care providers
- ◆ local and national organizations
- ◆ government agencies and elected officials
- ◆ insurance companies and payers
- ◆ general public

No one group is singled out as progress can only happen if everyone works together.



We are all in this together and we will work as a team to better our community and make sure that every individual with a bleeding disorder gets the help they need.

Participant in pre-Summit survey

The pathway to diagnosis can be very complex, particularly for von Willebrand disease (VWD) and ultra-rare blood disorders. Getting a diagnosis of hemophilia as a WGPPM faces other challenges from decades of medical focus only on males. When combined with misinformation about how female bleeding disorders manifest themselves, stigma, racial and geographic barriers, the road to diagnosis can be long.

Von Willebrand disease

Despite VWD being the most common bleeding disorder, the average time from first symptom (usually HMB) to clinician recognition is 16 years.¹⁰ Current best estimates obtained from the primary care setting suggest that VWD affects as many as one in 1,000 individuals. Despite this, many practitioners remain unaware of how to diagnose or treat the condition. The publication of the VWD clinical guidelines in 2021¹⁴ has created more standardization for testing and treating VWD but, still, many WGPPM remain undiagnosed or sub-optimally treated.



After surgery on my fibroids, I didn't stop bleeding. I was told I should have a hysterectomy. I refused as I know I have always had a bleeding problem, but when I told my doctor she wouldn't listen.

Addie (She, Her, Hers)

Hemophilia

Based on the Centers for Disease Control and Prevention (CDC), the median diagnosis is 36 months for people with mild hemophilia, eight months for those with moderate hemophilia, and one month for those with severe hemophilia.¹⁵ However, these averages don't tell the story of diagnosis for WGPPM.

Given its X-linked inheritance, historically it has been taught that hemophilia is a disorder that affects males, with females being "carriers" and then over time an acknowledgement of "symptomatic carriers". Therefore, it can be interpreted that the 'people' in the CDC's diagnostic timeline are predominantly men. Since 2012 it has been formally recognized that women can carry a diagnosis of hemophilia but the misinformation that hemophilia is solely a male disorder or more severe in males persists amongst many members of the medical profession and the public at large.

Even hematologists themselves are often focused on bleeding disorders in males and have a much lower index of suspicion when it comes to diagnosing bleeding disorders specific to WGPPM.



I was actually fairly lucky in that my bleeding disorder presented early and so severely with a life-threatening bleed into my knee when I was 9 months old. I had a typical 'male' presentation with joint bleeds and low factor levels which aided my diagnosis.

Rose (She, Her, Hers)

“

I was diagnosed with mild hemophilia A when I was in 4th grade. Unlike many WGPPM with bleeding disorders, getting diagnosed wasn't that hard as my dad has severe hemophilia so we always knew that there was a possibility and we wanted to check before I had a tooth surgery. My dad has always been my main support and advocate. My greatest hope is for people to be diagnosed more quickly and to have access to good care.”

Ryan, (She, Her, Hers)

Ultra rare bleeding disorders

Ultra-rare bleeding disorders are a heterogeneous group of clotting factor deficiencies and platelet disorders, making up only 3-5% of bleeding conditions.¹⁶ While research regarding hemophilia A and B has yielded clinical practice guidelines and safe and effective treatment options, and VWD now has its own published guidelines, there are no such guidelines available for this group of disorders. Ultra-rare blood disorders are underrecognized and underdiagnosed. Bleeding type, site, severity, age at onset, and duration vary enormously between disorders and individuals.

As mentioned, for WGPPM with bleeding disorders, the average time to diagnosis is 16 years. For some people, this is even longer.

“

I have rare FVII deficiency. It took three decades for me to get a proper diagnosis.

Connie (She, Her, Hers)

Stigma and dismissal of symptoms

Symptoms of bleeding disorders in women are often ignored. Due to societal stigma surrounding talking about periods, this is especially true for WGPPM who have heavy menstrual periods. Those who speak up are often classified as “over-reacting”, “catastrophizing”, “attention-seeking” and “over-dramatizing”. In other words, they are slotted into the age-old stereotype of the “hysterical female”. As a result, WGPPM often have to jump through hoops to receive minimum care and to be taken seriously.

“

It took me 5 years to get a diagnosis of VWD. I've often thought that my symptoms were all in my head.

Addie (She, Her, Hers)

We need to talk about periods

Up to 30% of all women report heavy menstrual bleeding at some point during their reproductive years and up to half seek medication attention. Of these, 15-30% have a bleeding disorder.⁴

As we know, heavy menstrual bleeding is often not recognized as abnormal, meaning many WGPPM remain without a diagnosis.

“Sexism has been an issue in bleeding disorders for centuries. Periods have been stigmatized across cultures from the ancient Romans and Greeks who viewed menstruating females as sources of evil, danger and madness, to major religions referring to menstruating females as ‘unclean’”.

Weyand, Angela C. Sexism in the management of bleeding disorders. *Research and Practice in Thrombosis and Haemostasis*. 2020 Dec, 13.

In some families, what WGPPM think is normal could be a sign of a bleeding disorder. They may say, “The women in our families have always had very heavy periods.” Or they may say nothing at all as, in many cultures, menstruation is a very private affair.

A suggestion for improvement was that female relatives of WGPPM under investigation should be screened in order to get the full picture and to pick up people who have been living with bleeding disorders unknowingly.



My daughter and I both had heavy periods. During that time, we would use a tampon and a pad together and go through two packs of pads each a day. We thought that was normal. Neither of us has been given a diagnosis but my son has severe hemophilia B and both my daughter and I have other symptoms including nose bleeds and bruising which lead me to think that we too share my son’s diagnosis.

Laura (She, Her, Hers)

Reluctance to talk about periods is not confined to WGPPM. Many health care providers feel uncomfortable or ill prepared to discuss the issue.¹⁷

Challenges in screening and testing

The current screening and laboratory testing of bleeding disorders in WGPPM also have created barriers for timely and accurate diagnosis.

Assessing Bleeding Symptoms

There are multiple menstrual tracking charts, also known as pictorial bleeding assessment charts (PBACs), and bleeding assessment tools (BATs) available for initial screening of bleeding symptoms. Use of the BAT is thought to reduce the amount of time to diagnosis from any sign of bleeding.^{18,19,20}

Some PBACs and BATs must be administered by a health care provider. Some charts and tools can be administered by WGPPM themselves.

This is good news, but there are a few challenges. The key issue is that not all HCPs are aware of these tools and, even if they are, not all use them. Added to this there are a lot of these tools around which can add to the confusion and lack of standardization by health care providers and WGPPM. The ASH ISTH NHF WFH 2021 guidelines on the diagnosis of von Willebrand disease do provide clear guidance on when to use a BAT.¹⁴

A metric unique to WGPPM is the measurement of heavy menstrual bleeding. Despite there being a definition of this (more than 80ml of menstrual blood per cycle,⁴ this leads to yet another challenge; some of the tools need updating to stay current with how WGPPM manage their periods (period underwear for example). Finally, there is an additional burden often put on WGPPM to demonstrate their symptoms at a much higher level than for males.



Even if we have the best tools, why is it that women have to track for 3-4 months to prove their bleeding and men are just believed with no proof?

Dawn (She, Her, Hers)

The unfortunate 'passing off' of heavy periods as being a trivial female problem belittles those WGPPM who do go to see their health care provider about their heavy bleeding issues making them reluctant to persist and ask for help.

Added to lack of health care provider education and clarity around the pathway to diagnosis, WGPPM themselves reported feeling uncomfortable tracking their bleeding in detail particularly using mobile device apps, often due to stigma and privacy concerns. And, again, the recurring theme of health care provider dismissal came out loud and clear at the Summit.

Overcoming period stigma is a work in progress. Positive efforts are being made though NBDF's [Victory for Women](#) and [Better You Know initiatives](#), [Let's Talk Period](#), [HFA's Blood Sisterhood](#), the World Federation of Hemophilia's [Women and Girls with Bleeding Disorders Initiative](#), and Black Women's Health Imperative (BWHI) [Positive Period](#), but attitudes don't change overnight, and much work remains.

Testing is complex

Testing WGPPM for bleeding disorders is complex even when heavy menstrual bleeding has been recognized.

Testing is an integral part of the process of diagnosis and, like other areas of medicine, is anchored to the perspective of those setting the standard. Because bleeding disorders have been and are currently viewed through a male lens, the laboratory references do not reflect the unique biology of WGPPM. ²¹

This is particularly the case with X-linked disorders. Frequently appropriate tests are not carried out due to health care providers' belief that females cannot carry a hemophilia diagnosis.

Even when the above misinformation is overcome, more challenges remain. There needs to be some new defining of what the factor levels mean for hemophilia A and B with regards to WGPPM.



I have been tested three times in my life, twice for a research study about carriers. My Factor IX levels have been mainly within the normal range. However, my symptoms don't reflect normal.

Dawn (She, Her, Hers)

Testing for VWD testing is more complex. The path to diagnosis is difficult due to the disorder being either quantitative or qualitative deficiencies in the individual's von Willebrand factor and the existence of three major subtypes all of which require a tailored approach. Tests are sensitive and may need to be done multiple times to achieve an accurate diagnosis. The VWD guidelines have created more standardization, but complexity remains.

The ultra-rare bleeding disorders suffer from an experience common among all rare diseases: they are rare and health care providers may not consider testing for them even in the unlikely scenario that the provider is familiar with the disorder.

Additional challenges to diagnosis include lack of access to laboratory testing, inter-state laboratory variability, and issues around disease classification and nomenclature (for example, work is underway to improve the nomenclature used for hemophilia carriers).¹

The lack of standards for testing WGPPM with a potential bleeding disorder was a strong discussion theme in the Summit workshops and it was suggested that serum ferritin was included in female screening and that anemia should be included as a symptom of a bleeding disorder.

Racism also has a part to play in the setting of testing standards. As testing standards have been calibrated to typically on the white male, these do not dovetail with the real-life laboratory reference intervals experienced by people of color. Black women with bleeding disorders, in particular, have to make do with a double dose of potential laboratory inaccuracy.²²

Reduced access to specialized care

There is no uniform route for WGPPM with a bleeding disorder to access the specialized care they need. Some will be tested by their primary care physician (PCP), OB/GYN, or hematologist. It is the recommendation for non-hematology providers to refer for diagnosis to a hematologist. Not all hematologists have a focus on bleeding disorders and then for those that do, and those that work within hemaophilia treatment Centers (HTCs), not all have been as welcoming or have specialized services for WGPPM. Despite the name, HTCs offer comprehensive care for all bleeding disorders. The Foundation for Women and Girls with Blood Disorders (FWGBD) has been working to address this with their provider education, [Clinics of Excellence](#), and [FWGBD Service Map Directory](#).

Due to lack of recognition of an individual's bleeding disorder by the medical profession, stigma, lack of specialists, geographical barriers, or a mixture of any or all of these, WGPPM have reduced access to the HTC services.

The labelling of X-linked bleeding disorders as “severe” or “mild” pose particular problems for WGPPM. The focus on “severe” symptoms is historical. For decades all the research and therefore clinical recommendations and guidelines have been based on the experiences of male patients so using these as the norm for the conditions overall then dismisses and misses how WGPPM show symptoms and how their bleeding disorders affect them uniquely.

Because bleeding disorders experienced by WGPPM do not usually present in a typical “male” way (bleeding into joints, low factor levels), their condition is generally classified as “mild”. This classification means that WGPPMs are often not offered the same diagnostics or treatment as males.

However, when WGPPM do report symptoms of joint bleeds, they are often ignored because of the assumption that females cannot have hemophilia, even though it has been known for over a decade that WGPPM can have hemophilia A or hemophilia B for a variety of genetic reasons. So even when reporting “traditional male” bleeding, many still are not treated.²³



I am an obligate carrier of hemophilia B. I have a factor IX gene mutation – meaning I produce normal levels of factor which has hampered my diagnosis. Over the years when visiting HTC's with my son, I have asked whether I should be tested for hemophilia due to my symptoms. I was told it really wasn't necessary. I was 59 when I had my first clinic visit even though I've had symptoms throughout my life from bruising, nose bleeds, heavy periods, heavy bleeding after dental work. I've also had undiagnosed joint bleeds and hematomas from injuries that sometimes took up to six months to heal.

Laura (She, Her, Hers)

The impact of late diagnosis and reduced access to specialized care on health outcomes

Not having access to the expertise and comprehensive care that HTC's are known for has serious health implications for WGPPM. Missing out on testing, diagnosis, and appropriate treatment has severe health implications, including quality of life and life expectancy.

According to the CDC, mortality and hospitalization rates for bleeding complications from hemophilia were 40% lower among people who received care in hemophilia treatment centers than among those who did not receive this care.¹²

Bleeding disorders in females cause higher rates of emergency department visits or hospitalization for vaginal bleeding, anemia, blood transfusions, hemorrhagic ovarian cysts, hysterectomies, and a younger age at time of hysterectomy, endometriosis, and fibroids.

Racial and ethnic barriers to diagnosis^{24, 25}

Racial and ethnic barriers in healthcare are nothing new. Black and Hispanic or Latino/x people in the United States have long struggled with many roadblocks including access to care and health insurance, unconscious bias of some health providers, as well as language, cultural barriers and immigration status.



There is an attitude towards immigrants, particularly those of color, that we should be grateful for whatever we get."

Addie (She, Her, Hers)

Within the bleeding disorders community, the above obstacles are compounded by health care providers, generally outside HTCs, tending to disbelieve the pain that a person with a bleeding disorder is experiencing or even thinking that they might be drug-seeking.

For women of color, there are particular cultural barriers which need to be understood in order for them to be overcome. There is a general mistrust of the medical profession due to systemic wrongs done to Black, indigenous, and people of color in healthcare. There are also strong feelings of privacy amongst some groups.

“

I come from South Carolina from a very proud family. We were brought up to guard our privacy – what happens in the family stays in the family. This is one of the reasons it took 30 years to get a diagnosis.

—Connie (She, Her, Hers)

Established white skin tone references may also hinder diagnosis. For example, bruising on the skin of people of color is not so noticeable as bruising on paler skin tones – and textbooks have historically focused on lighter skin tones.

Transgender issues

Lack of awareness of the unique needs of transgender WGPPM with a bleeding disorder amongst health care providers combined with symptom dismissal can be life-threatening when it comes to diagnosis.

“

I was diagnosed with hereditary FX deficiency aged nine after nearly bleeding to death in a children’s hospital. Being a person with the potential to menstruate has certainly had unique challenges that I wouldn’t have faced had I not been an assigned female at birth.

The biggest challenge for me personally is that doctors just don’t treat me seriously.

—Mason (He, Him, His)

Being treated seriously is an important part of transgender people experiencing healthcare equity as is listening to that patient, understanding all that is going on with them and making a plan that best suits their unique needs. Within the wider context, including WGPPM in trials, and researching how bleeding disorders treatments react to different hormone medications, is key in ensuring that a bank of knowledge is developed to draw on.

Geographic barriers²⁶

Geographic isolation impacts the entire spectrum of having a bleeding disorder from diagnosis to leading a healthy and productive life.

Screening and testing should ideally take place in specialized centers (HTCs) but for WGPPM with a bleeding disorder who live in rural locations, this option is not always available. Some of the larger HTCs have increased access to care by operating satellite clinics in rural areas but not everyone living in remote locations is so lucky.

Treating bleeding episodes promptly and effectively is key to healthy outcomes. Studies by the Centers for Disease Control and Prevention indicate that, for example, people with hemophilia who get care at HTCs are 40% less likely to be hospitalized and 40% less likely to die because of bleeding complications.¹² For WGPPM who live in remote areas, swift access and appropriate treatment is not always available.

It is not uncommon for people living with a bleeding disorder in a remote area to experience difficulties in obtaining the product that they need. Insurance companies may lack knowledge, experience, and a sense of urgency to approve vital therapies necessitating families to appeal and fight their corner. Pharmacies may be unwilling to coordinate with the insurance carrier and the bleeding disorders service. Health professionals in rural locations may themselves lack the specialist expertise and equipment that is needed to effectively manage WGPPM with bleeding disorders.

And of course, there is the barrier of geography itself. The distance to the nearest ER or HTC and the expense of travel incurred by families of those with a bleeding disorder can negatively affect outcomes for WPPGM living in rural areas.



Geographic isolation is perhaps the most difficult hurdle that I have had to overcome. In rural, frontier areas there is a persistent limited knowledge of bleeding disorders amongst health providers and systems. There is also the problem of having to travel long distances. The nearest hemophilia treatment center was a 14-hour drive away.

Sara (She, Her, Hers)

Gaps in knowledge on bleeding disorders in WGPPM

Research

Because the bleeding disorders research focus has been traditionally on males, there is a serious knowledge gap on how these conditions affect WGPPM physically, physiologically, mentally and economically.

These gaps are attributable to several factors. Disbelief that WGPPM can have hemophilia, which has already been touched upon, clearly plays a key role in lack of diagnosis in X-linked disorders. In addition, while there is acknowledgement of WGPPM with VWD, this overall is often seen as a less serious disorder so historically less research and attention were given. Ultra-rare bleeding disorders have even less research focused on them.

Transgender men and non-binary people who have or had the potential to menstruate do not fare well either. Even though researchers have been gathering more data on the health outcomes of transgender individuals, what we know about the hematologic considerations for transgender patients is eclipsed by what we do not know. One key to unlock greater understanding of the physiological needs of transgender WGPPM is representation of this population in clinical trials (see next section).

Discussions at the Summit highlighted the need for more WGPPM-specific research to be done in pathophysiology, prophylaxis, genetic ‘silencing’ of the second X chromosome which results in female hemophilia, and subsequent low factor levels and managing anti-coagulation. And on the socio-economic side, there is a need for more research to be focused on how bleeding disorders affect mental health as well as impact negatively on financial well-being.

Specific clinical trials for treatments

A recurring theme during the Summit was the call to pharmaceutical companies to include more WGPPM in clinical trials and ensure that more people of color and transgender people are included.

“Make sure you have WGPPM in your trials and do your best to recruit transgender and non-binary people as well. Medications react to different hormone profiles in different ways, so even if it may seem unrelated, do your best to include a diverse sample anyway.”

Participant in anonymous pre-Summit survey

Non-inclusion of WGPPM from clinical trials has meant a lack of data, real-world evidence, and poor understanding of how bleeding disorders affect WGPPM. Non-representation of Black and transgender people with the potential to menstruate increases these knowledge gaps. The reasons for exclusion of these populations can, to some extent, be attributed to male-centric clinical trials which have created the consensus of what the clinical endpoints should be (generally based on 'severe' disease).

These are not so applicable for WGPPM with bleeding disorders which are often labelled as 'mild'. In addition to the 'mild' label, the assumption persists that the inclusion of WGPPM from studies could impact the required outcome of the clinical trial negatively due to various differences from men i.e. hormones, organs, cultural influences, and differences in health.

The natural consequence of this is that pharmaceutical companies must use the agreed study frameworks for their randomized controlled trials (RCTs) to get new medicines approved, meaning that female-focused advancements are rare to non-existent. An obvious outcome is that securing pharmaceutical company research funding support for WGPPM is challenging.

Some pharmaceutical companies are trying to be more inclusive but ultimately, they are at the mercy of the regulatory authorities and their shareholders.

Lack of research is far-reaching. Lack of knowledge about how existing therapies work in WGPPM is missing. For example, little is understood about the pharmacokinetics of therapies used to treat bleeding disorders in WGPPM. There is no reproductive toxicity data available and it can be difficult to measure bleeding as WGPPM are often on multiple forms of contraception which affects true bleeding patterns.

This, along with male-focused laboratory parameters on, for example, 'normal' ferritin and hemoglobin levels, further impede WGPPM's chances of accessing a safe and effective treatment plan.



Lived Experience Experts (LEEs) as co- designers and co-creators partner with Care Teams from the beginning of the process, during and follow-up through the end for Clinical trials, Evaluation, Treatment and All services provided. We, as consumers have to our voices heard and be a part of “actionable” steps implemented to improve overall outcomes from the Board Rooms to product delivery. Gone are the days when we are willing to experience or inject a medication in our bodies or our loved ones’ bodies not being aware of the processes of development from start to end. We, LEEs are essentially the key missing piece to optimization healthcare standards, policies and services throughout the ecosystem.

Connie (she, her, hers)

Negative impact of bleeding disorders on WGPPM's quality of life and mental health

Research studies have described the morbidity associated with bleeding disorders such as hemophilia and VWD in women, but their effect on daily living has long been under-recognized.

According to a recent study,²⁷ women with a bleeding disorder experience obstacles to accessing care, difficulties living with their disorder, interference with schooling and work, and poor mental health. Diagnostic delay and lack of recognition of symptoms mean treatment and support may not be available. Where comparisons with controls were made, women's negative experiences were greater than those of men. These observations were eloquently echoed by the Lived Experience Experts (LEEs) who attended the Summit.

Lack of recognition of WGPPM's symptoms and their severity and, sadly on occasion, lack of compassion from medical professionals was testified by many of the attending LEEs.

Not being listened to by the medical profession was a recurring theme.

“

Because I get questioned, not believed, and ignored, I got to a stage where I didn't want to get help any more. I was bounced between doctors to be belittled, condescended to, and not given any help.

Nobody should have to feel like that – resigned to a life of suffering because a doctor won't listen.”

Mason (He, Him, His)

The socio-economic impact of bleeding disorders in WGPPM was clearly described during the Summit.

“

I was diagnosed with Type 1 severe VWD when I was 16, following a hemorrhage while I was out in public during my period. Since then, my menstrual cycle has played a huge part in my life. My schooling was cut short, my personal life has been severely affected and I was hospitalized every month for over a year to try to stop my bleeding.

Nikki (She, Her, Hers)

Period Poverty

WGPPM with bleeding disorders are not only impacted by having their schooling cut short and their professional lives subsequently affected, but they are also burdened with the cost of period products. The cost of 'normal' bleeding is over \$10,000 per lifetime²⁸. The math has never been done but the increased cost for WGPPM with heavy periods is exponentially higher. With 20.8 million females in poverty in the US²⁹ and with one study in St. Louis finding 46% of women could not afford to buy food and period products in the past year³⁰, period poverty potentially becomes more of a stark reality for WGPPM with bleeding disorders.

Lack of agency over health decisions

This document has already touched upon the fact that WGPPM with bleeding disorders are more likely to experience hysterectomies than people who bleed "normally". Often this option is not presented as a choice, but rather as the only solution to the bleeding. LEEs highlighted this at the Summit.



In my early 20s I was given a choice of either having a baby or a hysterectomy to deal with the bleeding. I decided to have a child. She has been diagnosed with VWD. Two years post-delivery I thought things would get better. I was wrong. I am still in pain. I am still hemorrhaging. Medication is not controlling my symptoms. So here I am faced with the same decision. Baby or hysterectomy. I am only 30 years old.

As a woman I have not yet been able to make my own decision about my own body because of my disease.

Nikki (She, Her, Hers)

Summary

It is clear that there are multiple inequities for WGPPM living with bleeding disorders that adversely affect their health outcomes. Much work needs to be done to meet their significant unmet needs and move the needle towards more equitable care regardless of gender, race or geography.

TACKLING GENDER INEQUITIES AND INEQUALITIES



To bring about change you must not be afraid to take the first step. We will fail when we fail to try.

Rosa Parks

For many stakeholders, the first step has already been taken and many are already doing incredible work advancing outcomes for WPGGM with bleeding disorders. For others, who are already thinking about what they can do to improve health outcomes for WPGGM with bleeding disorders, reviewing work-ongoing may be an inspiration to take the first step.

Wait, what shall we do?

One of resounding themes of the Summit, as we have already touched upon, is the need to work together. Collaboration is key to ensure that initiatives aren't duplicated, resources aren't re-invented, or research isn't started from scratch when projects may already be underway.

Sometimes it can take a different mindset to ask for expert help within the bleeding disorders community, to think outside the box and to share for the common benefit of the most important people, WGPPM with bleeding disorders.

But first, what work is going on now?

The NBDF is grateful to the expert panelists who attended the meeting and generously shared the projects that they are involved with.

A brief snapshot of the state of the movement is outlined below comprising global, national, regional and local initiatives, as well as what is going on in the science and research community.

Self-advocacy and empowerment

Having the confidence to speak up about the impact of bleeding disorders can be very difficult. Perhaps having had a history of HCPs dismissing symptoms or feeling ashamed or reluctant to discuss periods, many WGPPM feel alone and lacking in the tools they need to advocate for themselves.



I was 59 when I had my first clinic visit. I was about to have foot surgery and I advocated to be seen to avoid complications and to have a treatment plan in place. To my astonishment I was able to get an appointment and have my factor waiting in the fridge ready for the morning of surgery.

At that clinic visit I felt seen and heard for the first time in my life. I was surprised at the relief I felt, and I was also really proud of myself for not giving up and being my own advocate which I guess I haven't been very good at."

Dawn (She, Her, Hers)

Initiatives aiming to (and succeeding in) giving WGPPM a voice are going on at national, regional and local levels.

Women's empowerment retreats are taking place across the US, providing education, advocacy tools and, most importantly, building communities of WGPPM with bleeding disorders imparting the key message: "You are not alone". These are some of the efforts in this area from those who attended the Summit.



[The Coalition for Hemophilia B](#) hosts retreats for women with bleeding disorders, caregivers, mothers, and spouses in order to create a supportive environment where they will learn new methods of coping with the challenges of living with hemophilia B. The goal is to empower women in the hemophilia community to find their voices and bond with others in similar situations.



[The Hemophilia Foundation of Northern California](#) has formed **The Female Factor**, a large group of women and teens impacted by bleeding disorder. Each year they host a weekend retreat to address the group's needs related to diagnosis and treatment, social connections, education, and healthy living.



[Black Women's Health Imperative](#) is tackling the taboo about talking about periods in black communities with **Positive Period!**



National Conference for Women with Hemophilia, organized by [The Hemophilia Foundation of Michigan](#) is working to improving the quality of life for WGPPM affected by hemophilia, von Willebrand disease, other coagulation disorders with both LEE and health care provider participants.



[The NBDF's Victory for Women](#) celebrates the voices of women in the bleeding disorders community – a community forum where women can express themselves, ask their questions, share their challenges, and above all, celebrate the victory of standing up and being heard. NBDF extends Victory for Women into its national Bleeding Disorders Conference, with multiple sessions for WGPPM.



[Hemophilia Federation of America's Blood Sisterhood](#) serves females, non-binary, and trans women in the bleeding disorders community. We highlight current issues, talk about treatments and therapies, and advocate for representation in research.

Changing policy

With so many causes jostling for position, attention and funding at government level, shouting about WGPPM with bleeding disorders is never going to be easy. But work is going on!

- ◆ [Hemofilia Association of Puerto Rico](#) is advocating for a higher level of medical care for WGPPM with bleeding disorders in Puerto Rico with their Advocacy Days which take place at the Capitol to advocate for the rights and needs of patients. These days are part of our “Alza Tu Voz” [Raise Your Voice] advocacy program.
- ◆ The [NBDF is convening its Washington Days](#) - an opportunity for people affected by bleeding and blood disorders to advocate for issues that are important to them. In 2021, Washington Days had more than 400 volunteer advocates from 45 states that met with legislators and staff to discuss federal funding for bleeding disorder programs and support policies that increase affordability of coverage and access to care. 2024 days will be in person.

“A world without bleeding disorders starts with research.”

NBDF

Identifying and filling the research gaps

With so many unknowns when it comes to WGPPM and bleeding disorders, where do you start? Fortunately, some of the missing information is starting to be collected.

- ◆ The [CDC’s Community Counts](#) disease surveillance project is creating a solid basis for research by building a picture of the numbers of WGPPM with bleeding disorders, asking what do these bleeding patterns look like over time? Are we seeing more women being diagnosed? What and how are treatments changing?
- ◆ The WFH’s [Women and Girls with Bleeding Disorders Committee](#) is identifying research needs, providing education, and raising standards of care.
- ◆ The [American Thrombosis & Hemostasis Network \(ATHN\) ‘Transcends’ natural history study](#) is looking at how safe therapies are for people with bleeding disorders (including WGPPM) in the real world and what impact these therapies have on those who take them. There is a chapter within the study focusing specifically on WGPPM with VWD.
- ◆ The [NBDF’s National Research Blueprint](#) is a community-driven journey to shape the future of research for bleeding disorders. The goal is to establish a clear understanding of the most pressing issues challenging people and families with bleeding disorders with lived experience experts at the forefront of transformational research and examine where research can have the most community impact.
- ◆ The Hemophilia Federation of America (HFA) is encouraging WGPPM with bleeding disorders to get more involved in clinical studies and to keep research patient-centered with [‘Driving Stakeholder Support and Adoption of a Research Agenda to Improve Outcomes for Women with BD’](#)

Setting standards

Mindful of the need for a clear path for screening, diagnosis and appropriate treatment for WGPPM with bleeding disorders, preliminary work has started. Likewise, work is in progress to look at best practice for HTC's working towards standardization.

- ◆ Following on from the [International Von Willebrand Disease Guidelines](#), treating physicians who spearheaded these guidelines are cognizant of the need to work across other bleeding disorders. Work doesn't have to start from scratch as there is a trove of information available to mine in the auxillilary manuscripts, surveys and, of course, the physicians' themselves.
- ◆ Bringing contraception and treatment of menstrual bleeding research into the bleeding disorders setting and [research into hormonal treatments for WGPPM with bleeding disorders](#) is in progress.
- ◆ Setting the standards for HTC's is an initiative being taken forward by [The Foundation for Women & Girls with Blood Disorders](#).

Increasing interdisciplinary working

The need to break free from silos in order to maximize interdisciplinary networks was a topic which was returned to throughout the Summit. Progress is happening.

- ◆ [Hemophilia of Georgia](#) is working to maximize interdisciplinary networking to educate both health care providers and WGPPM with bleeding disorders.

Educating HCPs / changing attitudes

The LEEs attending the Summit have made it super clear that HCP education and attitudes must change if WGPPM health outcomes are to be improved.

- ◆ Dispelling the myth of mild is being addressed by the [HFA](#) with their Mild Matters campaign.
- ◆ The Foundation for Women and Girls with Blood Disorders (FWGBD) hosts [healthcare provider education](#) and facilitates collaboration and resource exchange for clinics devoted to caring for WGPPM through its [Learning Action Networks \(LANs\)](#).
- ◆ NBDF's recently hosted HCP training on the [Clinical Management for Women & Girls](#) and has HCP resources on diagnosis as part of the Better You Know campaign such as [Don't Miss the Signs: Steps for Screening, Testing & Coordinating Care](#)

Getting more people to recognize that they have symptoms

One of the most difficult challenges is to reach out to people who aren't aware that they may have a bleeding disorder.

- ◆ The [NBDF's Better You Know](#) initiative is tackling this issue.

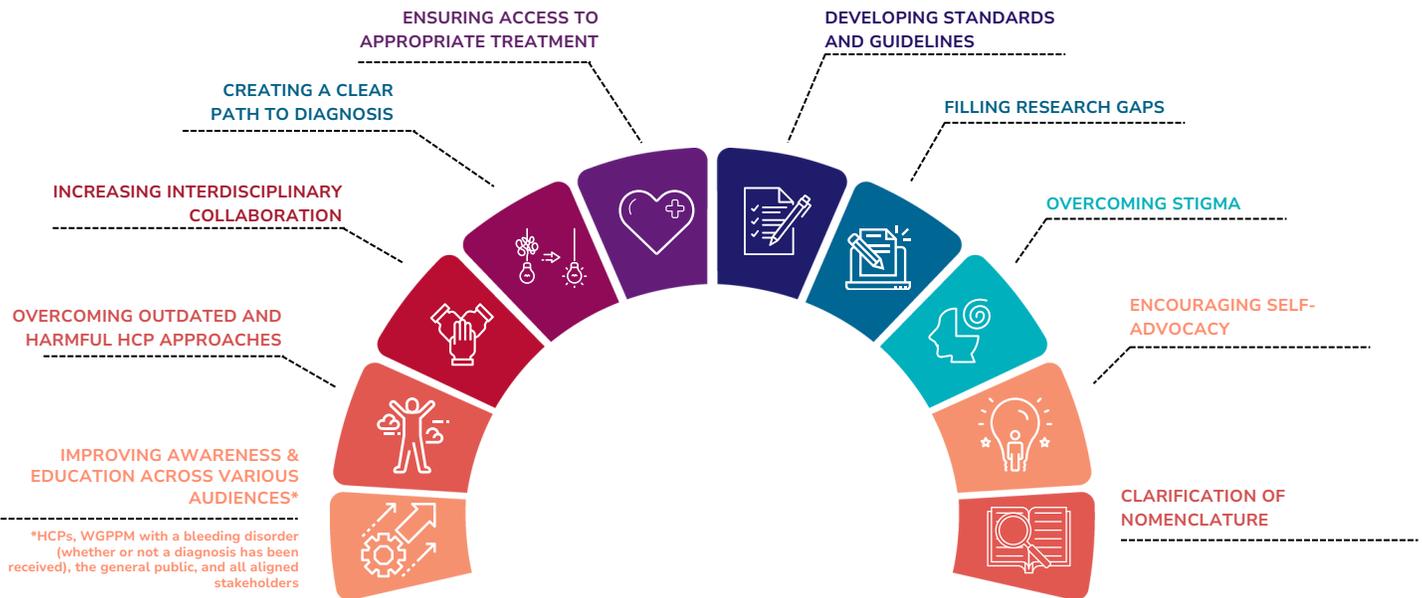
PRIORITIES AND RECOMMENDATIONS

The WGPPM Summit 2023 highlighted the key barriers to improving health outcomes for this group of people with bleeding disorders.

We were guided by the LEEs who generously participated in the pre-Summit survey. We asked “What do you perceive to be the three most pressing issues/challenges currently facing WGPPM with bleeding disorders today?” The answers were clear. The participants need:

- ◆ A clear and structured pathway to diagnosis
- ◆ Access to appropriate treatment at HTC's
- ◆ Provision of more education about WGPPM with bleeding disorders, particularly for health care providers

As a result of listening to lived experience experts, health care providers and other attending stakeholders across the bleeding disorders community, key areas for action were identified. These are not in any priority order. Prioritizing within these is a potential next step for the bleeding disorders community moving forward.



NBDF would also like to acknowledge that there are unique needs and challenges faced by trans and gender non-binary people with bleeding disorders and while some were brought up in this forum, further understanding is needed to collaborate to improve outcomes and care.

Potential action steps that aim to address these priorities were made:

 <p>Create an 'Ideas Box' of shared educational resource library for national and local organizations housing materials and campaign tactics</p>	 <p>Using best practice and experience of other organizations, agree what gold standard bleeding disorder clinics should look like; develop list of accredited clinics and award accordingly</p>	 <p>Convene an interdisciplinary screening and testing working group to develop guidelines to feed into a recognized WGPPM diagnosis pathway</p>	 <p>Building on existing experience within the BD community, develop a universal tool kit to be used to educate and train individuals to self-advocate effectively</p>
 <p>Patient expert trainers: create a panel of LEEs to participate in training and inspiring student doctors in bleeding disorders and cultural diversity; develop accompanying case-study based learning packs</p>	 <p>Create a communications tool kit to improve WGPPM / HCP conversations and enhance share decision-making</p>	 <p>Garner information on clinical studies and research being undertaken in WGPPM and create a registry (eg International Clinical Trials Registry)</p>	 <p>Continue work to revise non-appropriate WGPPM nomenclature ('carrier', 'mild' etc)</p>
 <p>Extend bleeding disorders educational events to more general medical conferences – make relevant to other disciplines</p>	 <p>Research funding – think 'outside the box' to identify sources to cover areas that pharma companies and for-profits are unable to fund</p>	 <p>Build a LEE speaker bank, train up members to support educational initiatives and publicity campaigns</p>	 <p>Create a national campaign to encourage WGPPM, including WGPPM of color and transgender/nonbinary to participate in clinical trials; lobby the scientific community and government to make inclusion a criterion of study design</p>
 <p>Continue to break down period stigma by intensive public health announcements, social media, celebrity endorsement</p>	 <p>Organize pop up, mobile clinics to meet and treat people where they are to combat geographic isolation</p>	 <p>Create skin tone tools to act as guides to HCPs to help them recognize bruising on a variety of skin colors</p>	<p><i>These are potential action ideas, not just for one organization or person to take the lead on, but for the overall community with its varied stakeholders to work better together to coordinate, collaborate and address.</i></p>

CONCLUSIONS

The WGPPM Summit was a highly ambitious undertaking.

Setting ourselves the task of overcoming barriers to diagnosis for WGPPM and identifying strategic priorities and improvement areas for the care of WGPPM with a diagnosis was no small feat.

Thanks to the passion, commitment and total engagement of the attendees, and their determination to create a better world for WGPPM with bleeding disorders, huge steps forward were made, not only in identifying the unmet needs that WGPPM face daily, but also coming up with practical suggestions and solutions that can be implemented at local, national and global levels.

There were some recurring themes that kept coming up: education about WGPPM with bleeding disorders at all levels, awareness of unmet needs, the need for attitudinal changes amongst the professional community, the power of advocacy, the need for inclusive research mindful of gender and racial differences and the absolute need for all partner organizations and stakeholders to collaborate and work together for a better future for WGPPM with bleeding disorders.

So, what does a better future look like? The most important messages are from our LEEs and we'll let their powerful voices deliver them.

“

Believe women, believe your patients. Don't be held back by dogma from decades ago. Women with bleeding disorders are here.

Rose (She, Her, Hers)

“

Women need to be believed when they say they are having a bleed despite what our levels say. We are trusted with our sons' bodies but not our own.

Participant in pre-Summit survey

“

My greatest hope is that WGPPM are not only heard but listened to.

Mason (He, Him, His)

“

Knowledge is power – I’ve always felt that. If you want change, you can’t sit back and wait for everyone else to do it for you. You have to find your voice. Change won’t happen without you.

Stormy (She, Her, Hers)

“

To local and national organizations serving the bleeding disorders community: “Please work on awareness of signs and symptoms / abnormal bleeding in your outreach, with the goal of reaching those inside and OUTSIDE the bleeding disorders community.

Participant in pre-Summit survey

“

To government agencies: “I think WGPPM is a major issue around the country that has not been recognized to its full capacity and would be in their favor to make sure that access to healthcare becomes a priority in their political agenda.

Participant in pre-Summit survey

ACKNOWLEDGEMENTS

NBDF would like to thank all of the WGPPM Summit lived experience experts, panelists, participants, and workshop facilitators who generously gave of their time, expertise and passion to move forward together.



ABOUT THE NATIONAL BLEEDING DISORDERS FOUNDATION

The National Bleeding Disorders Foundation (NBDF) is dedicated to finding cures for inheritable blood disorders and to addressing and preventing the complications of these disorders through research, education, and advocacy enabling people and families to thrive.

Today, the National Bleeding Disorders Foundation serves people across the US with all bleeding disorders, including hemophilia, von Willebrand disease, rare factor deficiencies, and platelet disorders. We support a network of more than 50 chapters across the country. We have given more than 22 million dollars to bleeding disorders research. We provide education and support to countless families with bleeding disorders, seek to find resources for undiagnosed women with bleeding disorders, and work tirelessly to protect access to healthcare on the state and local level. Each year, we also award the best and brightest in our community.

The NBDF is committed to the cause of health equity through a variety of efforts, including but not limited to: the creation of an annual health equity summit; various research fellowships geared toward diverse populations and/or researchers; research designed to aid diverse communities, and more, the organization hopes to make a positive difference in the community's equity and future.

More than 75 years after the creation of the NBDF, we honor the legacy of the founders by ensuring the bleeding disorders community remains at the heart of everything we do.

For more information contact [HANDI – NBDF's Information Resource Center](#).

WGPPM SUMMIT RESOURCES

The following materials and resources were distributed at the WGPPM Summit and highlight the experiences, insights and work of participants and their organizations.

- WGPPM Summit Resources: Consumer Patient Education & Awareness
- WGPPM Summit Resources: Health Care Provider Education and Awareness
- WGPPM Summit Resources: Policy / Advocacy
- WGPPM Summit Resources: Research
- WGPPM Summit Pre-survey results

In addition, the LEE's shared videos of their stories, and each was played throughout the WGPPM Summit to keep the conversations centered on the LEE experience. The LEE videos and these resources can be found at [Women | NBDF](#).

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