

June 19, 2023

OPEN LETTER TO COMMUNITY

RE: NHF's Summit May 2023 in Atlanta, Georgia
Women, Girls, and People with the Propensity to Menstruate (WGPPM)

By Ashley Gregory

When I arrived at the Atlanta WGPPM Summit by NHF I knew this was different. There were no event wraps on the elevator doors, no specially marked hotel key with the logo of the event and most notably, no industry partner booths. I was intrigued to learn the agenda and who else was there. I had been invited as a representative of Hemophilia Foundation of Northern California to share two things: What HFNC has been doing for WGPPM and my personal story as a woman with a bleeding disorder. It proved to be the most groundbreaking experience I have ever been a part of, and it truly was different from any other event I have attended.

Let me offer a bit of background. The bleeding disorders community has been working to educate and empower WGPPM for at least 30 years about their bleeding symptoms and how to access care. In the last 10 years, national and local programs have been focusing on WGPPM and ensuring they are aware of what symptoms are and how to keep track of them in order to report them to our providers and access the care we need. It is at these educational events that there are industry partners with booths, educators, fun activities, and lots of sessions aimed at empowering and educating our community. There was a 5,000-participant genetic study of hemophilia A patients and their female relatives called My Life/Our Future that identified the many genetic variants of hemophilia A (genotype) and has allowed researchers to study them and discover differences in phenotype (bleeding presentations, frequency, and severity of events).

Based on this education and armed with knowledge, many WGPPM's went to Hemophilia Treatment Centers (HTC's) to seek care for their symptoms. Some were offered care, some were not but not daunted and countered with written documentation of their genetic variant and symptoms and requested to be reconsidered. Many simply gave up seeking any relief from the devastating consequences of living with an untreated bleeding disorder.

In response to this, many organizations and individuals began championing the cause; WGPPM coalitions popped up and specialty pharmacies specialized in providing services to WGPPM as well as men and boys. Local organizations hosted WGPPM educational events, and they filled up with waiting lists. Industry partners implemented educational models and brought in experts to educate and empower WGPPM to obtain their diagnosis and treatment.

Once again, WGPPM went to HTC's to seek care for their symptoms. Some chose to engage in a sort of medical tourism, crossing state lines to seek HTC's that would see them in other states. There are some HTC's that understand and treat WGPPM and are willing to provide care to those able to access this resource, even from another state. Some were offered care at their

local HTC's, some were not and countered with written documentation and current research of their genetic variant and symptoms and requested to be reconsidered. Again, many simply gave up seeking any relief.

Which brings us to 2022 when the conversation had been going on for so long that I personally would talk to anyone that would listen as I professionally fielded calls, texts, emails, and personal requests for help in accessing care for WGPPM that were suffering without treatment for their bleeding disorder. I attended conferences as part of my role at HFNC as Education and Advocacy Director and wondered what could be done to overcome what seemed to be an insurmountable hurdle; to see the coming together of the new science of WGPPM and bleeding disorders and the old practice of treating bleeding disorders.

It was at one of these conferences that a blood brother approached me and suggested we work on this together using tactics effectively used by men with hemophilia in the 1980's to obtain the care needed for HIV/AIDS after being infected from factor products. I said yes, we can do this! **The FAIR Time for Women national coalition** was initially incubated by HNC, then moved to a rare disease nonprofit who now acts as our fiscal sponsor. One year in and we have been busy achieving our goals: a website where anyone can go to obtain all information about bleeding disorders (ftfw.org), an open sign on to over 1000 treaters and patients and caregivers to support the Medical and Scientific Advisory Committee's document #264 which addresses WGPPM with genetic bleeding disorders and their diagnosis, care and treatment. We have supported the creation of an algorithm created by experts to assist in diagnosing, caring for and treating WGPPM and are building a toolkit created by experts to be used to access care.

So, when I was invited to NHF's WGPPM Summit in May 2023 in Atlanta to speak, I had a decade of stories and data collected in my career to share and wondered who else would do the same. I was incredibly surprised to see a representative of every stakeholder in the room; medical experts, organizational leaders, WGPPM patients including trans males and patients of color, industry partners and treaters. We were all there to hunker down and come up with a plan; a plan to finally address the gaps in care for WGPPM with bleeding disorders!

I was enthralled as I listened to the Lived Experience Experts (LEE's) share their nightmare stories of misdiagnosis, unnecessary surgeries and procedures, prolonged bleeding, multiple miscarriages, enduring medical sexism, delayed diagnosis, and lack of treatment while many of their male counterparts have expert medical care for their bleeding disorder. As we listened and learned the entire room became steered to one goal: The time has come for WGPPM to be treated equitably in bleeding disorders.

We then broke into working groups we started having those hard conversations; what is lacking, where can we provide improvement, what needs to change? We all worked so hard but came away hopeful for this first of its kind meeting of the experts. The second day we were shown the memorialization of the sum of our work which will become a white paper in 3-6 months that will inform future policy.

I am humbled to have been part of this experience as HFNC’s Education & Advocacy Director and FAIR Time for Women’s Director and encouraged that after almost 30 years, real change is on the horizon for WGPPM.

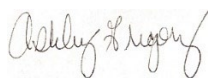
It is noteworthy that the facilitators which were brought in for this summit shared how incredibly moved they were by our stories and our collective trauma. Having it reflected to us by them was enlightening and allowed us a moment to be present with the gravity of our endeavor.

I want to thank every WGPPM that has ever been brave enough to share their story; blood brothers that witness every day the needless suffering of the WGPPM in their lives and experience guilt, anger and frustration at the inequity of it all; the organizations that have constantly been providing education and resources in this monumental undertaking and the educators that despite knowing they may face backlash from their more conservative colleagues push through and stay true to the science. WGPPM have bleeding disorders and soon the entire nation will be made aware of how to treat us based on NHF’s WGPPM Summit 2023 in Atlanta and the work done there by so many caring experts.

Below is a summary of outcomes to be expected based on my notes. Please refer to NHF’s upcoming white paper publication for actual results.

Address Access areas:	Improve Health care delivery:	Improve patient education:
<ul style="list-style-type: none"> • Provider bias • Genotype vs phenotype • Clinical trials and WGPPM • Standards and guidelines across all HTC’s • Health equity including socioeconomic, cultural, gender, race • Development of testing standards and specific recommendations 	<ul style="list-style-type: none"> • Build trust with providers • Build workforce sustainability for providers • Ongoing provider education for all disciplines • Shared decision making • Fill data gaps in WGPPM research • Cultural competence and humility training for health care providers • HTC collaboration for best outcome for WGPPM • Rating system for HTC’s 	<ul style="list-style-type: none"> • Identifying and reporting symptoms • Identifying WGPPM relatives of males with bleeding disorders (where appropriate)

Warm Regards,



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