



NATIONAL
BLEEDING DISORDERS
FOUNDATION
Formerly NHF

NBDF'S HEALTH EQUITY SUMMIT 2024

*"Every Hour, Every Day: Access and
Political Determinants of Health"*



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September 2024



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EXECUTIVE SUMMARY

The National Bleeding Disorders (NBDF), formerly National Hemophilia Foundation, is committed to continuing the conversation about health equity within the bleeding disorder community. A large part of our commitment in addressing health equity is discovery, investigation, assessment, and action.

To effectively carry out these tasks, we convened a set of stakeholders to explore how to improve our health equity efforts through access, education, advocacy, and research. In May 2024, NBDF hosted their 2nd National Bleeding Disorders Foundation (NBDF) Health Equity (HE) Summit ***“Every Hour, Every Day: Access and Political Determinants of Health”*** on May 30th and 31st in New Orleans, LA. It was attended by 82 stakeholders.

The mission and the objectives of the Health Equity Summit were as followed:

To bring together stakeholders around the topics of access to care and the political determinants of health for a better understanding of lived experiences, data outcomes and evidence-based practices where each stakeholder group can intervene to make changes resulting in health equity for all.

Objectives:

1. Transform organizational culture and better understand the political determinants of health.
2. Address emerging inheritable bleeding and blood disorders community health needs, including issues with access to care, by supporting adaptable, innovative, outcome-focused, sustainable programs and services.
3. Improve access to services and treatment by supporting integration and coordination of health services, health care providers, payers, and the public health sector.
4. Expand stakeholder leadership that results in shared decision making as a way forward for sustainable initiatives that eliminate health disparities.

Our keynote speaker, Dr. Omar Escontrias, Senior Vice President of Equity, Research and Programs at the National Health Council discussed the historical and systemic inequities that perpetuate health disparities in marginalized and minoritized communities. Furthermore, Dr. Escontrias emphasized the importance of addressing social determinants of health, political determinants of health, and voting rights to promote equitable representation and access to healthcare. Panels of Chapter Executive Directors provided us with challenges and strategies for addressing health equity and diversity in the bleeding disorders community, thus emphasizing the importance of community engagement, education, and collaboration with other organizations to overcome language and communication barriers among marginalized communities. Small roundtable discussions gave us the chance to explore qualitative data put together in themes to prioritize future initiatives, programs, and suggested services.

Call to Action

Results from the Health Equity Summit will lead to three community roundtables in 2025 to follow up on findings, training and technical assistance of the E3 Model | Engage, Empower, Elevate. These actionable items will lead to the 2026 Health Equity Summit for which we hope you will join us!

“Outstanding summit. HEDI should be a "must" topic that should be taught in every medical school. Thanks for allowing me to attend this most important and interesting meeting.”

- Summit attendee

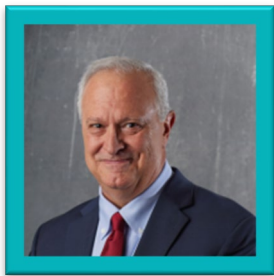
FOREWORD

Dear Friends and Colleagues,

All of us at the National Bleeding Disorders Foundation (NBDF) continue to strengthen our shared commitment to advancing the principles of health equity, diversity and inclusivity (HEDI) into every aspect of our mission and operation. We believe that fostering and celebrating a diverse and inclusive community is essential to advancing health equity and improving the lives of all those living with inheritable blood and bleeding disorders. Our dedication to these values is unwavering. By embracing diverse perspectives and ensuring that every voice is heard, we will better understand and more effectively address the unique challenges faced by our community. Inclusivity strengthens us and drives innovation, allowing us to create and implement more meaningful and effective programs and services.

As we continue to champion our HEDI principles, I invite you to join us in this vital work. Together, we will build a more equitable, diverse, and inclusive future for everyone in the inheritable blood and bleeding disorders community.

With sincere appreciation,



Phil Gattone, M.Ed.
President and CEO
National Bleeding Disorders Foundation (NBDF)

BACKGROUND

With the recognition of the work done since the [2022 Health Equity Summit](#), we realized the importance of understanding political determinants of health as one of the true drivers of health disparities. By focusing on these political factors, it becomes possible to create more equitable health policies and improve health outcomes for the inheritable bleeding and blood disorders community.

Political Determinants of Health

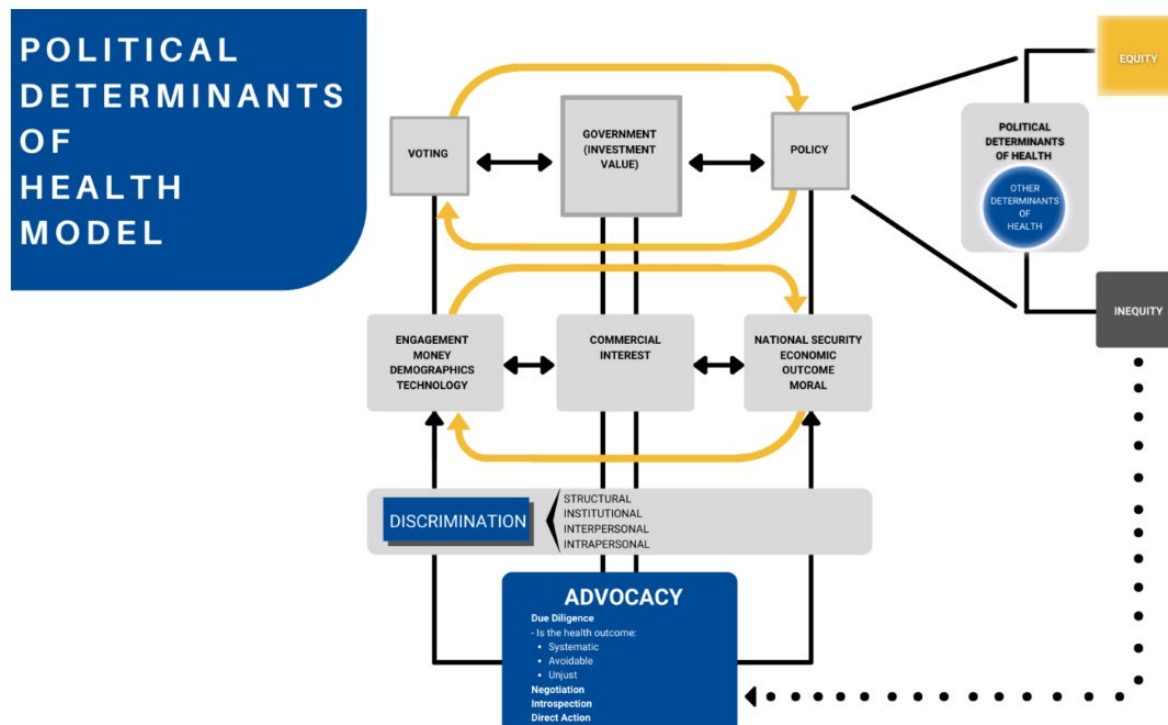
As defined by Daniel Dawes, political determinants of health “involve the systematic process of structuring relationships, distributing resources, and administering power, operating simultaneously in ways that mutually reinforce or influence one another to shape opportunities that either advance health equity or exacerbate health inequities⁷.” The political determinants create the social determinants/drivers of health, including poor environmental conditions, unsafe neighborhoods, inadequate transportation, and lack of healthy food options, which affect other aspects of health. To put into context how social determinants of health differ from political determinants of health, let’s take the example of housing security and quality. Having a safe and clean home to live in is a social determinant of health, whereas the political determinant is the redlining practice that led to people of color living in more disenfranchised neighborhoods⁸.

The political determinants of health model created by Daniel Dawes is split into three factors: voting, government, and policy (Figure 1).

1. **Voting:** As explained by Dr. Dawes, “voting puts in place or allows you to bypass the decision makers, the people charged with creating or executing policies that effects everyone, regardless of whether you have engaged in the political process”⁷. While voting is a fundamental civic duty, many fail to recognize or take for granted how voting can impact their health, well-being, and life expectancy. Nonetheless, the less healthy individuals are less likely to vote which in return are less likely to have their concerns addressed⁷. Voting rights, access to polling places, and gerrymandering can affect the ability of marginalized populations to influence policies that directly impact their health⁷.
2. **Government:** The structure and function of government institutions play a crucial role in shaping health policies. This includes the actions of legislative bodies, the implementation of laws by executive agencies, and the interpretation of laws by the judiciary⁷. As described by Daniel Dawes, “it provides a mechanism for decision makers to keep, enforce, or change the status quo by reinforcing existing policy at the local, state, regional and federal levels⁷.” If a person only votes and does not continue to engage in the political process, their needs will not be meaningfully addressed. Government decisions determine the allocation of resources, the prioritization of health issues, and the enforcement of health-related regulations⁷.
3. **Policy:** This factor essentially concretizes or codifies the final decision or action⁷. Public policies, both within and outside the health sector, significantly impact health outcomes. Policies on housing, education, employment, environmental protection, and criminal justice, among others, all have direct and indirect effects on health. Health policies themselves, including those on healthcare access, quality, and funding, are central to determining health disparities⁷.

These three factors are affected by advocacy/grassroots efforts that help to drive the agenda forward on health equity; thus, making it the glue that binds the model.

Figure 1: Political Determinants of Health Model



Daniel E. Dawes (2020), The Political Determinants of Health, Johns Hopkins University Press

Current State of Access to Care:

Access to care for people with bleeding disorders varies widely, influenced by factors such as geographic location, socioeconomic status, and healthcare access (or lack thereof). Many patients face significant barriers to receiving timely and adequate care, including:

- **Geographic Barriers:** Patients in rural or underserved areas may have limited access to hemophilia treatment centers (HTCs) given their uneven distribution (e.g., people who live in Guam need to take a 7-hour flight to their closest HTC in Hawaii). A recent systematic review included a qualitative survey on the perspectives of Canadian healthcare providers, who revealed that rural location was felt to be a significant contributor to both delayed diagnosis and decreased access to care^{1,2}. Such barriers impact the ability to advocate and engage patients to empower them to influence their elected officials.
- **Financial Barriers:** High costs of treatment and medications can be prohibitive, even for those with insurance coverage. A literature review conducted by Okide et al., found that many community-dwelling adults with hemophilia may choose to work in jobs that are unsuitable for them to obtain or maintain insurance coverage³. At the same time, many with insurance coverage face rising costs of co-payments and lifetime. Programs such as copay accumulators jeopardize a patient's access to lifesaving medication and may drive up health care costs as patients turn to more expensive emergency departments to obtain their clotting factor therapy⁴.
- **Systemic Barriers:** Fragmented healthcare systems and lack of coordination between providers can result in gaps in care and delayed treatments. Therefore, NBDF proposes that the comprehensive care delivered in HTCs can serve as the model for other chronic illnesses and medical conditions, including

fostering open communication and collaboration with multidisciplinary teams, with primary care providers¹.

Available data reveals stark disparities in access to care for people with bleeding disorders. For example, data from NBDF's Community Voices in Research (CVR) registry found that people diagnosed with von Willebrand Disease (vWD) often experience prolonged diagnostic delays of 10+ years⁵. Furthermore, the World Federation of Hemophilia (WFH) World Bleeding Disorders Registry found that the age of diagnosis of people with hemophilia in low- and low-middle-income countries is delayed by 3 decades compared to patients in upper-middle-income countries and by 4 decades compared to patients in high-income countries; thus, exacerbating health outcomes and increasing the burden of the disease⁶.

For people with bleeding disorders, several key political factors influence their access to care:

- **Historical Context:** Historically, healthcare policies have often overlooked rare diseases, leading to inadequate funding and support for bleeding disorder programs. For example, before the Affordable Care Act (ACA) in 2010, many insurance plans did not cover pre-existing conditions which disproportionately affected individuals with rare diseases⁴. Additionally, before the enactment of the Orphan Drug Act (ODA) in 1983, there were few incentives for pharmaceutical companies to develop treatments for rare diseases in the U.S. due to the small market size and high cost of drug development⁹.
- **Current Policy Landscape:** Current legislation and healthcare policies can significantly impact access to care. For instance, the ACA continues to provide pre-existing condition exclusions and eliminating lifetime and annual limits on insurance benefits which is a significant consumer protection for people with bleeding disorders⁴. Nonetheless, a loophole under the ACA allows many employer health plans to deem certain categories of prescription drugs as “non-essential,” even when they are life-saving or necessary for people with serious pre-existing and chronic conditions¹⁰. It is important to note that insurance coverage policies, funding for bleeding disorder research, and the availability of patient assistance programs are all shaped by political decisions.
- **Advocacy and Policy Change:** Patient advocacy groups, testimonies from patients, State Based Advocacy Coalitions (SBAC), and the All Copays Count Coalition (ACCC) have played a crucial role in shaping policies that improve access to care¹¹. However, ongoing efforts are needed to address remaining gaps and ensure equitable treatment for all patients.

Achieving health equity for people with bleeding disorders requires concerted efforts from various stakeholders, including policymakers, healthcare providers, and patient advocacy groups. NBDF is committed to ensuring that people with bleeding disorders have timely access to quality medical care, therapies and services, regardless of financial circumstances or where they live¹². As part of the call to action at the Health Equity summit, we encouraged attendees to attend NBDF's largest bleeding disorders advocacy event in the U.S., Washington Days, in Washington, DC¹³. Additionally, we also asked all summit attendees to participate in their respective state advocacy days, and to go and vote in the upcoming elections. Engaging with political determinants empowers communities to advocate for their rights and influence decisions that affect their health. This empowerment is essential for driving systemic change and holding policymakers accountable.

NBDF's HEDI Department Initiatives to Address Health Disparities

- **E3 Model | Engage, Empower, Elevate:** After the conclusion of the 2022 Health Equity Summit, NBDF's HEDI team held focus groups, chapter roundtables, and informed interactions with different stakeholders to discuss barriers that were brought up at the summit and to come up with potential solutions (Figure 2). Such insightful exchanges led to the creation of the E3 model (Figure 3). The model covers barriers to care affecting people across their lifespan, from birth to death. It starts with proximal determinants which are those that are closer to us and have a direct influence on our health (e.g., age, culture, transportation, income). The model also focuses on the distal determinants which are further away from us and have an indirect influence on our health and health outcomes (e.g., cost of healthcare/treatment, and community diversity). The model aims to provide promising practices and/or evidence-based solutions at different levels (individual, community, organizational, and institutional). Stakeholders can use the model to implement realizable action plans within their reach/capacity with the resources available to them. This model exemplifies the idea of meeting community members where they are at; thus, enabling people and families to thrive.
- **NBDF's HEDI Priority Populations (2024-2034):** Towards the end of 2023, the HEDI team prioritized the populations that were continuously mentioned during informed interactions with lived experience experts (see Figure 2). It was decided that the five populations that will be prioritized of interventions for the next ten years will be: bilingual/multilingual, minoritized and marginalized, rural residents/geographically challenged, Women, Girls, and People who have or had the Potential to Menstruate (WGPPM), and young adults (Figure 4). However, it is up to the states and chapters to decide which specific population under each category they will focus on and work with. Furthermore, the 10-year plan recommended specific strategies to advance health equity within the five priority populations, again, given the capacity and resources of different stakeholders.

Figure 2: Creating the E3 Model



Figure 3: E3 Model

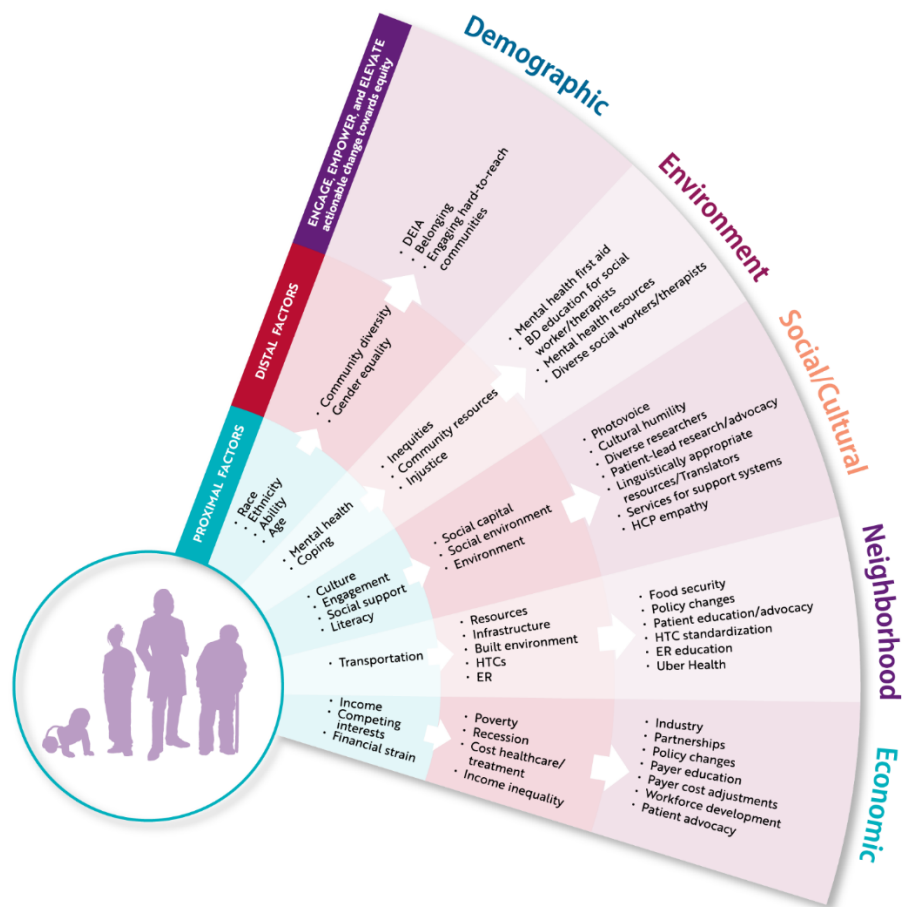
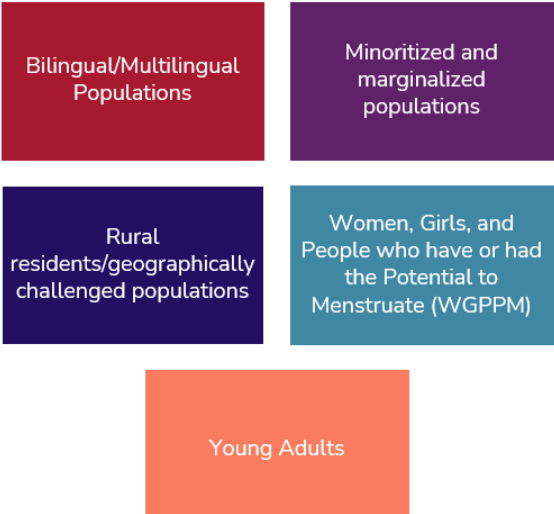


Figure 4: NBDF's HEDI Priority Populations (2024-2034)



SUMMIT OVERVIEW AND FINDINGS

Breakdown of Summit Attendees

Total Attendees



82
Attendees
*(Lived Experience Experts- LEEs,
Chapter leaders, speakers,
Government/Industry, NBDF
Board Members, NBDF Staff,
and NYLI members)*

Gender



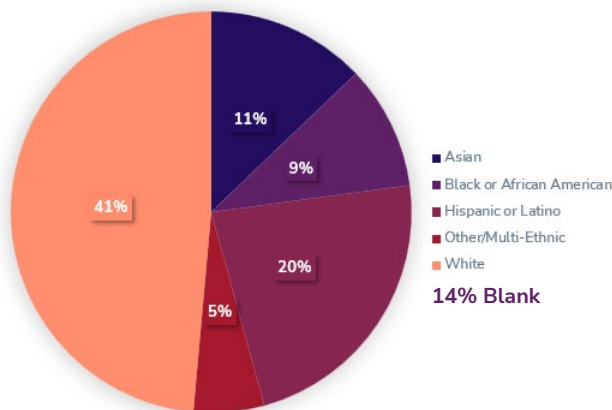
Female
66%



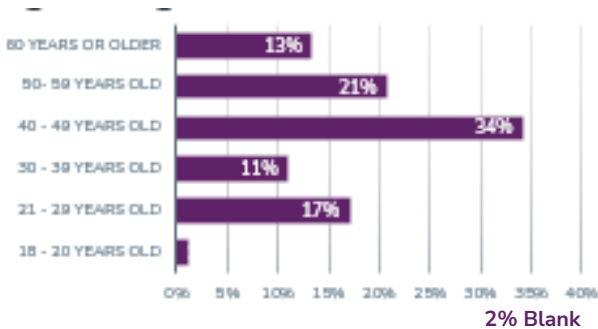
Male
32%

1% Prefer to describe
1% Blank

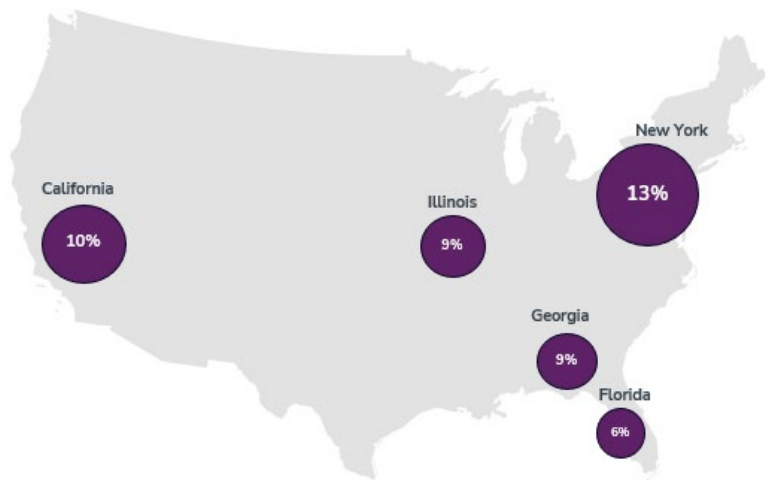
Racial/Ethnic Background



Age Range



Top 5 Cities Represented



Mission and Objectives

The summit brought together stakeholders to discuss topics of access to care and political determinants of health for a better understanding of lived experiences, data outcomes, and evidence-based practices where each stakeholder group can intervene to make changes resulting in health equity for those living with inheritable bleeding and blood disorders.

Four objectives were identified to drive our work over the next 12-18 months:

1. Transform organizational culture and better understand the political determinants of health.
2. Address emerging IBD community health needs, including issues with access to care, by supporting adaptable, innovative, outcome-focused, sustainable programs and services.
3. Improve access to services and treatment by supporting integration and coordination of health services, health care providers, payers, and the public health sector.
4. Expand stakeholder leadership that results in shared decision making as a way forward for sustainable initiatives that eliminate health disparities.

Highlights of Speaker Presentations

Thursday, May 30th

- **Welcome, Phil Gattone, M.Ed., NBDF's President and Chief Executive Officer**
Phil spoke on NBDF's shared commitment to advancing the principles of HEDI into every aspect of our mission and operation. He ended with a quote by Mahatma Gandhi "our ability to reach unity in diversity will be the beauty and the test of our civilization" to reinforce that "what makes us unique is what brings us together."
- **Ice Breaker, Brendan Hayes, MPH, CPH, NBDF's Senior Director of Education, Innovative Therapies and Kristi Harvey-Simi, NBDF's Senior Director of Chapter Training**
The ice breaker activity of "This or That?" asked attendees' questions such as whether they preferred summer or winter/map or GPS. They were also asked about topics to discuss at their table such as where they were on their journey learning about HEDI concepts or what was their why for attending the Health Equity Summit. Attendees were asked to revisit where they see themselves on the journey to learning about diversity concepts at the conclusion of the summit. The purpose of the activity was to illustrate that although people are different and diverse, we all have things in common.
- **Political Landscape for NBDF's Advocacy, Nathan Schaefer, MSW, NBDF's Senior VP of Public Policy & Access**
Nathan discussed the challenges faced by Hemophilia Treatment Centers (HTCs), limited representation in Congress, and challenges faced by NBDF in advocating for diverse patient populations. He emphasized the importance of chapter staff to encourage community members to vote and engage with candidates either through NBDF's Washington Days event or state advocacy days.
- **A Word from our Sponsors- Sanofi and Takeda**
Representatives from our Executive sponsors, Alison Clifford (Takeda) and Jane Cavanaugh-Smith (Sanofi) discussed what their respective organizations are doing in the health equity space regarding bleeding disorders. They emphasized the importance of listening to and learning from diverse communities, investing in programs addressing health disparities, and fostering a culture of inclusivity.

- **Keynote Presentation, Omar A. Escontrías, DrPH, MPH, Senior Vice President, Equity, Research and Programs at National Health Council**

Dr. Escontrías discussed the historical and systemic inequities that perpetuate health disparities in marginalized communities, including the placement of hazardous facilities in predominantly black and brown neighborhoods. Furthermore, he explained how social determinants of health are influenced by political decisions, citing Freedmen's Bureau of 1865 as an example. Dr. Escontrías highlighted the interplay between environmental, social, and behavioral factors contributing to health disparities and the need for community engagement and advocacy to create impactful and meaningful change. He also spoke on the importance of addressing social determinants of health, political determinants of health, and voting rights to promote equitable representation and access to healthcare, thus highlighting important factors such as:

- Non-profit organizations have an important role in voter mobilization
- Community voice is crucial in advocating for policy change
- Affirmative action in education and healthcare promotes diversity and equal opportunities
- Stakeholders must work together to collectively address social drivers of health

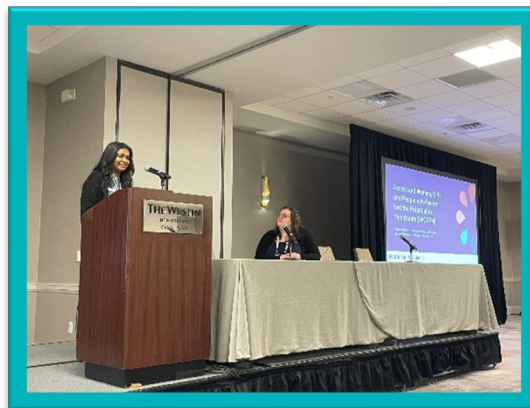


“Vote is one of the strongest powers that we have now in order for us to set the agenda that will move forward in our communities.”

- Omar A. Escontrías, DrPH, MPH, Senior Vice President, Equity, Research and Programs at National Health Council

Friday, May 31st

- **Welcome, Adeli Lopez, PHR, SHRM-CP, NBDF's Vice President of Human Resources**
Adeli challenged attendees to think about which values they will share throughout the summit and to bring those values as their identity—she shared her own values of authenticity, humility, and joy.
- **Access and Gender Identity, Marissa Melton, MPH, NBDF's Health Equity, Diversity, and Inclusion Program Specialist**
Marissa discussed gaps in care for persons who identify as members of the LGBTQIA+ community and the related health outcomes affected by disparities in care for trans and other gender diverse people. Recommendations were made to attendees, such as getting more involved in gender identity research to address representation gaps.
- **Access and Social Drivers of Health, Karina Lopez, MPH NBDF's Health Equity, Diversity, and Inclusion Program Specialist**
Karina's presentation centered around the crucial role of addressing social drivers of health in improving health outcomes, particularly for marginalized communities. The need to empower lived experience experts and provide training and preparation to make them effective advocates was also discussed. To address social drivers of health, attendees were encouraged to participate in NBDF's Washington Days or State Advocacy Days, to make use of the E3 model, and to sign up for Community Voices in Research (CVR).
- **Access and Women, Girls, and People who have or had the Potential to Menstruate (WGPPM), Natalia Winberry, MNLM, Senior Manager of Education and Jasmine Pauldurai, MPH, Education Specialist**
Natalia and Jasmine spoke about the unique intersectional issues that women and girls with bleeding disorders face, such as sexism, stigma, and inadequate care. They emphasized the need for increased awareness and education and advocacy efforts to address these issues and ensure equal access to care and diagnosis. The importance of centering the voices of women and girls with bleeding disorders and addressing genetic testing and diagnosis was also highlighted.



- **Poster Presentation: Climbing Mountains: Trailblazing New Tactics to Enhance Health Equity, Perry Jowsey III, MA, CFRE, Executive Director, Colorado Chapter, NBDF**
Perry's poster presentation focused on the challenges of addressing health equity in the rural and frontier communities in Colorado, where the state's rugged terrain, lack of resources, and systemic disparities create significant barriers. One tactic to enhance health equity was that staff in the Colorado chapter provided programming to 11 unique counties over an 18-month period, innovating their approach to reach a wider and more inclusive audience. He emphasized the need to innovate and expand the

chapter's reach, provide education and advocacy, and for programming to be made more inclusive to improve health outcomes in underserved communities.



- **Poster Presentation: Breaking Down Communication Barriers for the Nevada Bleeding Disorders Community, Jacob Murdock, Executive Director, Nevada Chapter, NBDF**

Jacob's poster highlighted the importance of inclusivity in community outreach, citing that 22% of Nevada's community members primarily speak Spanish. Therefore, the team implemented a three-part project to improve inclusivity, including translating communications into Spanish and providing interpreters for in-person events. Jacob's poster was shared with attendees in both English and Spanish.

- **Unveiling the E3 Model | Engage, Empower, Elevate, Keri Norris, PhD, JM, MPH, MCHES, NBDF's VP of Health Equity, Diversity, and Inclusion**

Dr. Norris started her presentation by speaking on the importance of HEDI, citing data gaps and systemic oppression. To address such data gaps and disparities, Keri outlined NBDF's HEDI team 10-year strategic approach to prioritize marginalized and minoritized populations in health equity efforts. She ended her presentation by unveiling the E3 model which outlines practical and evidence-based solutions for addressing social determinants of health into proximal (circumstances of daily life that have a direct influence on health) and distal factors (circumstances of life that have an indirect influence on health). *Please note that the model has not been made public yet.*

- **Improving Access through Health Equity Efforts, Danielle Bell, former Program Manager for NBDF's Nevada Chapter, Perry Jowsey III, MA, CFRE, Executive Director for NBDF's Colorado Chapter, Ashley Castello, former Executive Director for Louisiana Hemophilia Foundation, and Rigoberto Garcia III, MPH, Executive Director for Hemophilia Foundation of Southern California**

This panel discussion centered around the challenges and strategies for addressing health equity efforts in the bleeding disorders community at local and regional levels. Some of the challenges discussed were lack of knowledge on who they are serving, and barriers faced by families including financial, transportation, and housing. Panelists shared experiences and strategies for expanding outreach efforts to underserved communities in rare disease advocacy, including the use of volunteer advocates and collaboration with other healthcare providers.



- Breakout Discussions: The Way Forward**
 Attendees participated in roundtable discussions facilitated by NBDF's HEDI champions. This activity offered stakeholders to weigh in on the most important challenges and thoughts around health equity as it pertains to shared decision making and mitigation bias, real world data, gender issues in access, and policy and access.
- Group Report Outs, Angelina Wang, NBDF's Director of Medical Programs and Information**
 Angelina moderated the small group report outs and helped attendees share their feedback based on the roundtable discussions that were held around the different themes.
- Call to Action, Kristi Harvey-Simi, NBDF's Senior Director of Chapter Training**
 Kristi discussed the tangible outcomes to be delivered post-summit, including a white paper summarizing the findings, three community roundtables, and technical assistance on the E3 model, as requested. She challenged attendees to engage with underrepresented groups in the bleeding disorders community and to make a difference in addressing social drivers of health. Lastly, she encouraged them to continue working towards health equity every hour of every day.
- Meeting Adjourned, Dawn Rotellini, NBDF's Chief Operating Officer**
 Dawn closed out the meeting with emphasizing the need for collective action and trust among stakeholders to address health disparities.

“We’re trying to make sure that we are providing fair and just opportunities for healthcare, and that is not just only access, but being able to provide information in the language that the person can learn in.”

- Rigoberto Garcia III, MPH, Executive Director for Hemophilia Foundation of Southern California

Roundtable Discussions

Based on the feedback received from community roundtables held in 2023, the overarching themes that were going to be discussed amongst stakeholders at the summit were: real world data, shared decision and mitigating bias, policy and access and gender issues and access. We had 15 roundtables that allowed attendees to freely discuss the equity issues for each of the four themes. Each table discussion was facilitated by an NBDF HEDI champion (13) or NBDF senior leadership staff (2). We provided each facilitator with a facilitation guide that included rules of engagement, the definition of the specific theme, and guiding questions to ask the group. Here are the results for each group:

Real World Data: Considered observational data, and it can come in the form of electronic health records, medical claims and billing, and product and disease registries.

Considerations:

- Data sensitivity
- Trust: some demographics may be more apt to sharing
- Data accuracy and ideally would connect to electronic medical records (EMR)
- Ethical considerations

Data points of interest:

- Diagnosis, treatment, socioeconomic status/need, family composition, areas of interest, underserved populations, clinical trial options and engagement, emergency visits, quality of life, missed appointments, access to care, bleed history, regional info, insurance, genetic counseling opportunities, health outcomes, psychosocial, treatment at an HTC or non-HTC, dental, transitions for young adults from pediatric to adult clinics.

Actionable items:

- Make data accessible
- Build partnerships between chapters, HTCs, NBDF, school nurses, community health centers, and other places where patients seek treatment
- There are data collection efforts in place (e.g., CDC's Community Counts, NBDF's Community Voices in Research, and ATHNdataset)- should find a way to share data seamlessly
- Chapters noted they ideally would like databases like that of hemophilia treatment centers—potentially having a chapter “intranet”

“Chapters crave data to help make challenging budget and programmatic decisions for optimal impact and service to the community.”

Prevalent gender issues:

- For VWD, women are oftentimes dismissed and told their periods are too mild or they're told they're making up their symptoms.
- Medication not made for women—exclude women who are pregnant, may be pregnant, and post-menopausal
- Huge gap in data in this area
- Samples in research may not be significantly significant
- Time off during menstrual issues
- Consistency of diagnosis: If you move, you have to be re-diagnosed
- The history of women of color were often dismissed and told it was hysteria or anxiety
- Seeing late diagnoses is all too common
- Factor level being the “end all, be all” can ignore their symptoms, their stories, their experiences
- Testing is very expensive, and we need to work with insurance companies
- There is no standard of care for a diagnosis
- Talking with families because you are not a “family of bleeders” – you could have a bleeding disorder
- Symptoms look different in women in color, and they are not listened to or heard in comparison to their white peers
- Access to insurance as a WGPPM is very difficult
- Higher cost for medication
- You face obstacles in getting a diagnosis as a WGPPM even if you have family history and bleeders in the family
- Not easy to set up an appointment with a specialist
- It's hard as a young adult because providers can make you feel uneducated and dumb for asking questions about your BD

Ways to advocate for change:

- Keep talking about it! Open about these conversations with providers and other healthcare professionals – also include BIPOC in that conversation
- Education to providers; empower patients who feel that they are not heard
- Find legislative advocates—HTC needs more funding for staff and education
- Legislative appropriations
- Chapters hiring lobbyists—get a group at WD to speak specifically for WGPPM
- Focused efforts on WGPPM
- Healthcare providers to listen to the recommendations made by MASAC—raises awareness; how to begin addressing barriers
- Prevention- prevent issues from down the road, pro-active approach
- Period poverty- psychologists, providers talk to patients about their periods; own discomfort; some women don't want to talk to a male; woman period lasted more than 50 days; “normal” heavy bleeds from generation to generation
- Address the root cause
- HTCs should encourage genetic testing for family members when they treat men/boys with bleeding disorders
- Meet people where they're at and don't place the burden on them to seek out better care
- Summits/educational events catered towards provider education and ensuring they are up to date with WGPPM and bleeding disorders
- Helping providers understand that mild/moderate looks different in boys and men and in WGPPM

Actionable items:

- We all have a responsibility to create a safe space
- Help our patients navigate the system
- Help patient advocate for themselves and they have our help
- Explore more ways to shift the power dynamic and explore ways to empower WGPPM and other diverse gender identities seeking treatment and care.
- Promote health advocates to support, educate, and empower WGPPM and other diverse gender identities to overcome barriers to access
- Taking steps to address/remove outdated nomenclature.
- Don't hold conference in places that are not friendly to women and trans/gay people—ensure people are protected traveling and while in attendance at the conference—safety and precautions
- Inclusion in research/clinical trials
- Advocacy team at WD's to prioritize WGPPM
- Reach out and meet people where they are—school, nurses
- Education/cultural sensitivity
- Figure out funding—how to make these things a priority

“For VWD, women are oftentimes dismissed and told their periods are too mild or they’re told they’re making up their symptoms.”

Policy and Access: Covers the spectrum of current policies and understanding insurance coverage/copay accumulators and the influence of policy on other social determinants of health.

Political determinants of health to address:

- Implementing policies- task forces are not what we want
- Lawmakers listening to providers
- Leveraging your LEEs
- Government and insurers should stay out of patient care and decision making, leave to patient and provider
- More directly enter politics; run for office to influence from inside
- Collaborate with state health department
- How to bring data to life in a compelling way to influence policy makers at different levels—interweave data and stories
- Learn from/collaborate with others chronic/rare disorders areas to help move all forward

Literature or advocacy toolkit to promote policies:

- E3 Model
- Consumer programming that is accessible to all and easy to understand and interpret
- Chapter toolkits for elections; voter registration
- NBDF/HFA/ATHN to create a super PAC: hard to raise money and challenging to be a part

- Giving people an easy way to start; complacency when there is so much to do
- Using regions, working groups, partnerships to disseminate information and share ideas
- Use available data to bring light, trends, how to improve outcomes through treatment
- Communicate economic benefit of providing quality care- live longer, can contribute as healthy workers, productive members of society,

Actionable items:

- NBDF should advocate for a carve out policy from government to help cover BD; happens in other countries
- NBDF to reach out to ten insurers that prevent patients from getting factor and care.
- Create a compounding of resources so treaters are armed when denied
- NRB efforts: Continue to create a comp model similar to COG
- Legislative templated approach for passing legislation-similar to copay accumulators--building connections and relationships with lawmakers—especially those who you disagree with
- Engage more young people (especially younger than 26) on the critical importance of policy matters and access vis a vis bleeding disorders
- Glossary of important key terms – or how/where to best direct advocacy concerns
- Actively seek to build coalitions – look for inroads and allyship across health conditions – blood, chronic diseases, women’s reproductive health

“Building connections and relationships with lawmakers—especially those who you disagree with.”

Shared Decision Making (SDM)/Mitigating Bias: Using evidence-based practices and considering the patient's capacity, this occurs when providers and patients work together to decide the best course of action for treatment and cost.

Ways to get more stakeholder buy-in to SDM:

- Showcase how better outcomes from SDM could lead to increased adherence to treatment
- Teach people to not be afraid of their physicians
- Explain that SDM is not about accusing, blaming, bias, assumptions
- Being prepared before there is an emergency:
- Awareness/Education of the resources that are available
- Getting/sharing factual information with patients
- Being calm even when stressed
- Learning from our mistakes
- Helping healthcare providers to see a person and not a “patient”
- Making sure that HCPs are talking to the PERSON, the LEE, with the bleeding disorder – not above their head, not to the mom, directly to the person

Real biases that we need to mitigate in SDM:

- If physicians already have a bias against the patient – cultural, ageism, language, education level or think that they know more about the patient's experience than the patient
- If the patient has bias against HCPs - I've had bad experiences previously so all physicians will treat me badly so I'm going to go in strong and set expectations
- Women don't experience pain the same way men do
- Women don't bleed the same way men do
- Substance use assumptions when dealing with pain – you are a seeker of drugs

Actionable items:

- MASAC should develop the best practice model using NBDF's HEDI team and the leaders/drivers to ensure we are mitigating bias and inclusive of underserved populations.
- HTC regional directors/administrators: This influential group of industry leaders can be the best route in the implementation of a best practice shared decision-making model
- More awareness and understanding of our own community and communities around us (understanding and listening how to reach people where they are)
- HCPs to empower your patients to be honest about their needs

“Educate yourself on shared decision-making, so that you can have conversations with providers.”

CALL TO ACTION

In summation, as a result of the 2024 Health Equity Summit and its findings, the following will happen:

- **Community roundtables (3):** These will occur throughout the country in partnership with three chapters in 2025.
- **Training and technical assistance for the E3 model, as requested.**

Let's not forget that addressing not only the social determinants of health, but also the political determinants of health allows for tackling the underlying power structures and policies that shape health outcomes for people with bleeding disorders, leading to more comprehensive and sustainable improvements in public health.

We must continue to work towards health equity every hour of everyday--each small step counts towards impactful change!

“With the E3 model, we plan to empower you, we plan to help you elevate your voices, and advocate for what you want.”

*-Keri Norris, PhD, JM, MPH, MCHES, NBDF's
Vice President of Health Equity, Diversity,
and Inclusion*



Thank you to all who
attended the Summit!



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Left to Right: Keri Norris, Dawn Rotellini, Adeli Lopez, Sonia Roger, Angelina Wang, Samantha Carlson, Natalia Winberry, Maria Santaella, Brendan Hayes, Michael Craciunoiu, Nick Kallinicou, Kristi Harvey-Simi, Danielle Bell, and Karina Lopez

(Missing: Marissa Melton, Kate Nammacher, Jasmine Pauldurai, Maureen Grace, Nikole Scappe)

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