



*Ensuring health equity in the inheritable blood disorders
community*



National Hemophilia Foundation

Health Equity Summit White Paper

Keri Norris, Marissa Melton, Lisa Colquhoun

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Executive Summary

The National Hemophilia Foundation aims to better understand all the health inequities and disparities that affect the inheritable blood disorders (IBD) community. To gain insight, we held our inaugural Health Equity Summit “**Every Hour, Every Day: Ensuring health equity in the inheritable blood disorders community**”.

Issue and Solution

In the absence of quantitative data to illuminate disparities and inequities that exist within the IBD community, we sought out an opportunity to bring stakeholders together to discuss existing and emerging issues within access, mental health, health system navigation and payer/policy issues. The Health Equity Summit aimed to better **understand the lived experiences of people living with inheritable blood disorders, missing data outcomes and existing disparities and to identify where each stakeholder group can intervene to make changes resulting in health equity for all.**

Objectives of the Meeting:

1. Transform organizational culture and align daily work to achieve health equity.
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 partnerships that lead to sustainable initiatives that eliminate health disparities

Our keynote speaker, Dr. Italo M. Brown (Admission Impossible, LLC) was dynamic, insightful, and provided us with probable solutions regarding starting and sustaining health equity work. Panels of subject matter experts and chapter leaders provided us with information on navigating individual and community needs, where challenges are and possible solutions. Small group break outs gave us the opportunity to explore qualitative data that was put together in themes and begin prioritizing for future initiatives, programs, and suggested services.

Call to Action

Results from the Health Equity Summit have led to the formation of the NHF Health Equity Task Force with four subgroups (access, mental health, health system navigation, payer/policy), an NHF Equity and Empowerment Action Model (3–5-year plan to address health equity), in 2023 three community roundtables to follow up on findings, and creation of 2 graphical representations of our health equity work. All these actionable items will lead to the 2024 Health Equity Summit for which we hope you will join us!

Background:

The National Hemophilia Foundation's mission is focused on addressing and preventing the complications of inheritable blood disorders (IBD) through research, education, and advocacy, enabling people and families to thrive. Established in 1948, NHF has 52 chapters across the United States. In 2020, NHF recognized the need for an increased focus on health equity, diversity, and inclusion (HEDI). To that end, we have expanded our team to include persons with expertise in these areas. To drive diversity, equity, and inclusion (DEI) within NHF and to address health inequities within the IBD community, we must have an initiative that identifies and addresses barriers to access and care within the IBD community, thus increasing quality treatment overall. Within this initiative was born our first inaugural Health Equity Summit, which took place June 1 & 2 in Atlanta, GA. We titled our NHF Health Equity Summit "**Every Hour, Every Day: Ensuring health equity in the inheritable blood disorders community**", as we intend to always use our health equity lens and DEI strategies in everything that we do.

Issue:

According to the American Public Health Association, all definitions of *health equity* include a focus on ensuring opportunities for everyone to attain their highest level of health. *Health inequities* are created when barriers to quality *healthcare, treatment, education, safe air and water, adequate housing, transportation, and healthy food* prevent individuals and communities from reaching their full potential. They reflect unequal distributions of social and economic resources that impact an individual's healthⁱ. Health inequities are further complicated by health disparities, which are "a difference in health that is closely linked with social, economic, and/or environmental disadvantage"ⁱⁱ.

Often times, health inequities stem from structural racism, disenfranchisement and/or discrimination of particular marginalized groups, including racial and ethnic minorities, low-income populations, and members of the LGBTQI+ community, and result in health disparities.ⁱⁱⁱ These groups have historically been discriminated against, resulting in the inability to obtain vital resources needed to achieve optimal health and are disproportionately exposed to poverty, violence, poor neighborhood conditions, and environmental health hazards. We recognize that historically, hemophilia brings to mind the image of only white men and boys; however, we know by our community work and interactions, that our community is much more diverse. With this diversity throughout the US, comes challenges of the circumstances in which our community members live – policy, racism, poverty, insurance status, competing interests, transportation, and food insecurity – work, and play.

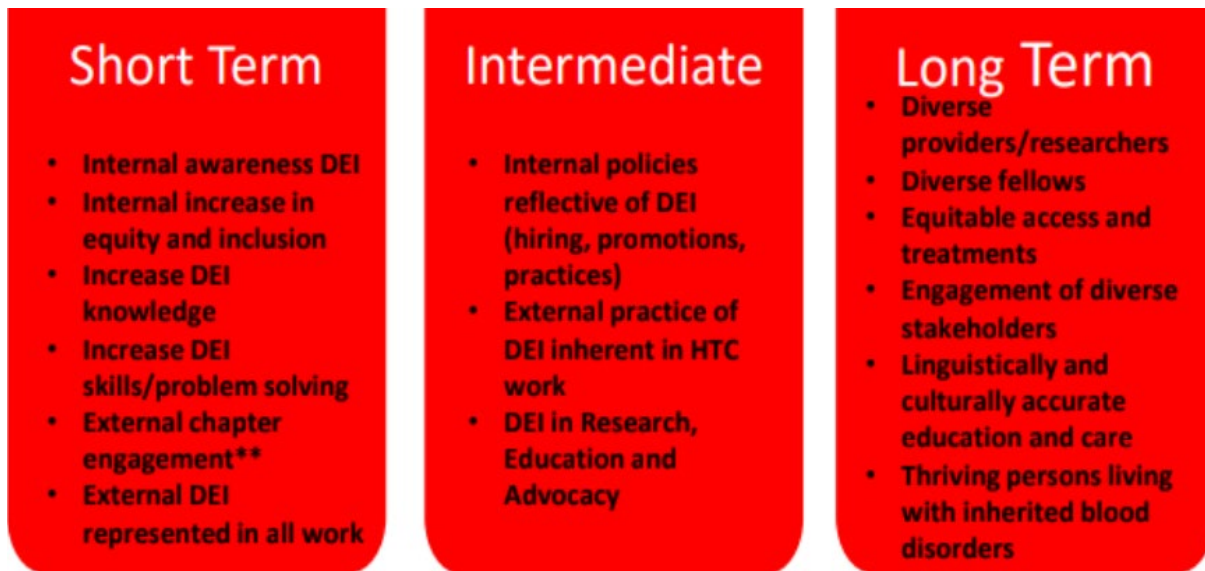
As illustrated in a study of the hemophilia community^{iv}, multiple disparities exist and are pervasive. The findings of the study led to suggestions of continued research with qualitative input. Much like other chronic diseases, we see disparities in health outcomes for our communities but less on qualitative data, stories from affected persons that inform the science, or finding themes that are recurring amongst multiple communities within our realm of influence. Our health equity summit was put in place to illuminate the themes for people with hemophilia and other bleeding and blood disorders around access, mental health, health system navigation, and payer/policy.

Development of Health Equity, Diversity, and Inclusion Department (HEDI)

NHF's commitment to DEI and Health Equity was a two phased approach. Phase one involved successfully onboarding a qualified and dedicated Vice President of Health Equity, Diversity, and Inclusion (HEDI) in 2021. Phase 2 involves the VP of HEDI NHF further developing, providing, and overseeing the following programs, activities, and initiatives to address community, clinical, and organizational-level barriers to health equity:

- i. Apply the following values across all internal and external strategies:
 - **Diversity** – A team that is reflective of the diverse experiences of the communities we serve.
 - **Equity** –An environment where equity exists, and our communities and employees thrive.
 - **Inclusion** – A safe space for policies, processes, and efforts where our employees and community are valued, included, and have a sense of belonging.
- ii. Infuse anti-racism, anti-discrimination and equity measures into our mission and company policies, enforcing racially equitable hiring practices, providing cultural awareness and sensitivity training to staff, and aligning our strategic imperatives with these goals.
- iii. Ensure diversity and inclusion in all research and outreach efforts to increase the likelihood that all consumer needs are equitably addressed.
- iv. Reduce employment barriers.
- v. Strengthen retention of quality employees, cross team collaboration, and sustainability of the organization.
- vi. Supporting mental health wellness and recovery by collaborating to increase health equity in mental health.
- vii. Deliver dialogue and strategies that raise awareness surrounding diversity, equity, and inclusion issues.

Figure 1 NHF Logic Model for HEDI



HEDI departmental efforts include being a resource and providing resources to our departments, chapters, community members, industry, partners, and other organizations to ensure that DEI and Health Equity are happening at all levels. Building our internal capacity is just as important as building our external capacity. It was important to work on the foundations of diversity, equity, and inclusion internally as it was to build the foundation of health equity externally, simultaneously. Engagement across teams with cross collaborative functioning to strengthen DEI and health equity efforts for current programs and initiatives was imperative to building out future efforts. The basics of understanding the difference between equality, equity, social justice, and belonging was important to our team in our efforts and in reaching our impactful goals.

We understand that in our quest for equity, we must acknowledge the historical past of unfair access and treatment of those who are impoverished, racial and ethnic minorities, communities with limited resources, uninsured and underinsured, living in rural or mountainous areas, or low literacy. Diversity is beyond race/ethnicity, and therefore, we gathered to hold a conference in Atlanta with discussions around access, mental health, health system navigation, and payer/policy issues to gain a better understanding of stakeholders with lived experiences and those who work directly with them and on behalf of them. It is imperative to make strides that ensure optimal health outcomes for *all*. To ensure these optimal outcomes, we must understand the root cause of health inequities and health disparities which lead us to the social determinants of health and their domains (see Figure 2, below).

Figure 1

Social Determinants of Health

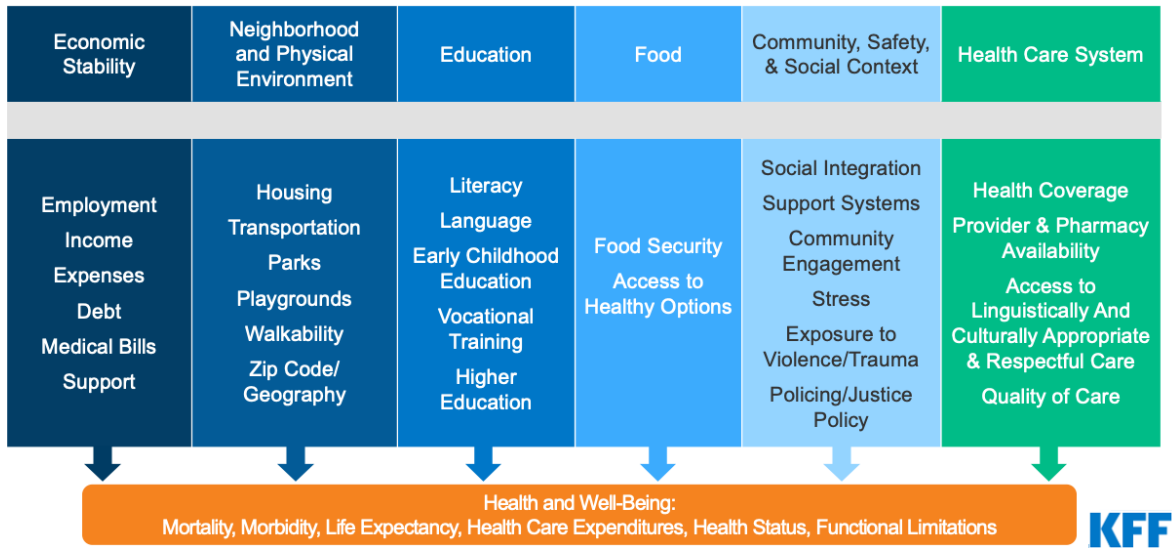


Figure2. Social Determinants of Health^v

Social Determinants of Health

Understanding the challenges of the social determinants of health across multiple health outcomes, gives us insights into the root causes of health inequities. There are many factors that contribute to maintaining good health such as physical activity, nutrition, and seeing a health provider regularly. However, there are additional non-medical factors called social determinants of health (SDOH) that influence health outcomes. These are the conditions in the places where people live, learn, work, and play that affect health risks and outcomes^{vi}. Examples of SDOH include safe housing, transportation, racism, discrimination, educational attainment, language and literacy skills, and access to nutritious foods. Unfortunately, SDOH are more influential in influencing health and account for 30-55% of health outcomes^{vii}. When not properly addressed, SDOH have a significant impact on people’s health, well-being, and quality of life.

Healthy People 2030 provides data-driven national objectives to improve health and wellbeing^{viii}. They identified five areas of focus: healthcare access and quality, education access and quality, social and community context, economic stability, and the neighborhood and built environment. These areas influence a person’s ability to optimally engage with their health and present barriers to care. For example, individuals who have less economic stability and do not have access to grocery stores with healthy foods are more likely to have poor nutrition, increasing chances of developing conditions such as heart disease, diabetes, or obesity. Addressing SDOH is important to improving health and reducing longstanding health inequities.

Need

As NHF began to explore the SDOH, health equity and current health equity efforts in the agency and through its partners, we realized that the data is missing. We can point to health disparities and health inequities data for other chronic or infectious diseases^{ix}; however, there is no existing national data on disparities within the bleeding disorders community. Perhaps this is because historically, hemophilia is viewed as only affecting white males then the assumption is that the lack of diversity (narrowly defined) is the reason no one considered the plethora of disparities and inequities affecting the *entire* community. In addition, we must note that there is more than hemophilia in the inheritable bleeding disorders realm, including VWD, and rare factor deficiencies that need further investigation. To formulate strategies, approaches, advocacy, and education strategies we had to 'go back to the drawing board' and get the information directly from the community. We decided a Health Equity Summit would be the best way to get the information directly from a segment of invited stakeholders who would help us put the missing pieces of the puzzle together to move the needle on health equity within the bleeding disorders community.

Health Equity Summit Overview and Findings

The summit brought together stakeholders to discuss themes around access to care, mental health, navigating health systems, payers/policy for a better understanding of lived experiences, data outcomes and existing disparities that are within the realm of our influence. We identified where each stakeholder's group can intervene and work towards permanent changes resulting in health equity for all.

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

1. Transform organizational culture and align daily work to achieve health equity.
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 quality care by supporting integration and coordination of health services, health care providers, payers, and the public health sector.
4. Expand stakeholder partnerships that lead to sustainable initiatives that eliminate health disparities.

Landscape of health equity was set by members of the National Hemophilia Foundation, Hemophilia Foundation of America, and Genentech, our executive partner. The CDC's Blood Disorders Team Lead, Dr. Vanessa Byams provided us with an overview of CDC's approach to health equity, which covers all divisions and is comprehensive. The C.O.R.E. strategy (**Cultivate** comprehensive health equity science; **Optimize** intervention; **Reinforce** and expand robust partnerships; **Enhance** capacity and workplace diversity, inclusion, and engagement) was laid out for attendees to understand the ways in which CDC had strategized to address and implement evidence-based approaches to health equity. Dr. Melissa Creary, a University of Michigan professor and former Senior Director, Office of Public Health Initiatives, ATHN gave some insight on health equity within the Sickle Cell community and lessons we could learn from them.

Our keynote speaker, [Dr. Italo Brown](#), Assistant Professor in Emergency Medicine, and Health Equity & Social Justice Curriculum Thread Lead at Stanford University School of Medicine brought us a powerful message about going “Against the Grain” in order to reach health equity. He cautioned about illusion of equity and justice often will have us thinking we are moving the needle when we are not and that we must have all voices represented, pointing out the lack of youth/young adults in attendance. He spoke about acknowledging the painful past of racism and its influence on access and health outcomes. Dr. Brown further illuminated the fact that ER physician’s limited knowledge can be problematic for BD community members, representation within the provider community, underdiagnosis of mental health issues can be problematic as well, in addition to the need for more pain management studies. Dr. Brown also offered us some tangible solutions for health equity work and what it looks like:

- Solutions:
 - *Expand understanding of including all systems of oppression/restorative justice*
 - *Advanced policy reform – engage opposition; increase awareness of advanced development*
 - *Prioritize pathway programs – engage Subject Matter Experts (SMEs)*
 - *Invest in equity initiatives – Return on investment (ROI)*
 - *Increase community engagement – engage hard to reach populations, everyone must be included*
- It looks like:
 - *Collaborating – with other organizations that are doing the same work, no more silos*
 - *Partnering – all stakeholders must be involved, and a multidisciplinary team is effective to reach equity*
 - *Centering – focus the work on the affected persons and allow them full partnership from initiation to dissemination*
 - *Amplifying – work your channels and extend the message*

Two panels were held to provide insight into the wins and obstacles of the bleeding disorders community, a subject matter expert panel and chapter executive directors. The panels were moderated by NHF HEDI Champions, and the discussions were rich and engaging. We had the wonderful opportunity to hear from subject matter experts, Fel Ehandi, Mosi Williams, and Chelsee Nabritt. We also were honored to hear from chapter leaders, Nooshin Kosar, Sue Martin and Rich Pezzillo. Here are some meaningful insights into some of what each speaker had to share:

Chelsee: *She spoke about obtaining **meds and insurance varies from carrier to carrier**, it is important to know and **understand your coverage** and that there is not a generic brand for all medicines. She also encourages us to help those with bleeding disorders **learn how to speak up and advocate** for themselves with insurance companies and providers.*

Fel (a parent of a son with Hemophilia B): *It is important to **engage diverse communities and Spanish speaking communities** (to educate them and provide systems of support). He also emphasized the*

importance of educating outsiders – teachers, babysitters, etc. and providing them with easy-to-understand information.

Mosi: *He emphasized the need for partner sessions on different topics of **mental health and treatment** and how it is important to have these sessions in the community. He also highlighted the issue of **reaching your maximum allowed with insurance companies** and copays accumulating.*

Nooshin: *She spoke about how nothing happens overnight when trying to ensure **health equity (change takes years)**. She also offered that we all should step back and realize these are bigger picture items and to move towards them with simpler things like **inclusive language and continuing to provide cultural materials and language variety**.*

Sue: *She emphasized that we should note that **everyone doesn't have access to a computer/digital means**. When engaging hard to reach populations we should **reach people where they are, ask them to bring others along**. She suggested that we continue small group sessions with communities and consider **"NHF on the road"**.*

Rich: *He spoke about understanding the differences with resources and access for **rural versus urban** communities, **bridging the gaps in access and treatment**, and the need for better understanding and **empathy in practice**. He briefly spoke about our need to **elevate pain management treatment** and the need to **help with financial barriers** especially for those requiring financial assistance.*

Small Group Breakouts

When working in health equity at NHF, we kept hearing the same overarching themes of access, mental health, navigating health systems (especially the ER and non-HTC providers), and payer/policy. We used the small group breakouts to allow for stakeholders to freely discuss and talk about the equity issues for each of the four categories. Each table discussion was facilitated by an NHF HEDI Champion or HFA Health Equity Summit Planning Committee Member, except the one table for NHF Senior Staff (who were separated out so that stakeholders could freely speak and to test if our leadership is on par with what the community believes are the foremost issues around equity). Here are the results for each group (answers from each of the 9 tables have been grouped into themes):

Access

- Transportation; time to HTC; not having access to different specialists; lowering costs; better understanding of community needs and comprehensive care; all chapters need to have newsletters; having payers in for more patient education meetings; staff need to be hired to do outreach; funding issues; transportation to provider appointments; education
- Location of HTCs (spread); you don't know what you don't know; insurance; fear of medication being expensive; language barriers; racial bias; treatments; ER not educated; lots of mistrust in providers; having more patient navigators; more education on insurance, translators needed; community councils; the need for roundtables to share stories

- Robust HTC versus rural HTCs; wanting to get more resources to providers in ER and hospitals; pre-planning plan in place; continuum of care; data resources are needed; improving resources for LGBTQIA+
- Transportation to HTCs; promoting chapters more; older folks disconnected; inconsistency amongst HTCs; patients feel like lab rats at clinical trials; rural areas need resources; youth plan for engagement and sustainability; chapters need to find new people; expand partnerships; regional meetings to share knowledge
- **Direct table notes:**
 - **Barriers** proximity to HTCs, coverage issues, income level, transportation, time off from work, education/literacy, you don't know what you don't know (providers included), insurance in marketplace is a big issue, fear of medical expenses, language barriers, racial bias in prescription pain meds, , language and citizenship barriers, ER treat and street approach, mistrust of providers, use of patient navigators, holding pharma more accountable, designing clinical trials around community needs/obstacles, lack of education on resource/tools, bills for HTC are not cheap (funding), time off work, not having access to different specialists, immigration/legal status, childcare, cost of care and treatment, complicated insurance, universal EMRs, increase education and specialties represented, tech systems, rehab facilities and medicine for pain, new immigrants not knowing how to access the health system, satellite clinics paused during covid, education around hospitals/ER, all hospitals should have a baseline knowledge of what hemophilia is, more comprehensive HTCs, insurance/prior authorizations, preplanning with local ER, health app that share data with other systems, access to rehab facilities/pain meds, trans access issues, guidance for patients who cannot get infusions at hospital
 - **Actionable items:** better PTO policies, effective telehealth services, policies around access to affordable internet services, telehealth across state lines, additional funding for providers to receive more education around disparities, stigma, bias around bleeding disorders, more education on insurance, reliable translators, more HTCs spread around the country, community councils with patients included, pharma council with everyone sharing how they plan to do their part, recruit adult hematologists to specialize in BD, lowering costs, better understanding of community needs in comprehensive way (sharing info widely), referrals to chapter, policy around insurance access, templates for chapter newsletter for resources, having payers in for more patient meetings, more stories on the impact of not getting care, data, designated clinics (IV infusion),

Mental Health

- More trainings for psychologists and social workers; how are we tapping into other conditions (chronic) and learning from them; we need a virtual national network; innovative social work or psychology interns to BD camp; in person support groups; unmet needs of mental illness and decrease mental health stigma; long term impact; national collabs on mental health first aid; competing interests are everything
- Need more social workers for IBD community; need a national campaign for equity; mental health into smaller groups like anxiety; ensure that Narcan is readily available not in certain area; mental health services paired with substance abuse; competing interest transportation; language barriers; cultural issues

- Training of physicians, first responders, MH crises; how to deal with patients and not gaslighting; more education to generations; MH talks with men; stigma is the biggest issue and cultural issues
- Some talk about reluctance to seek help; HIPAA; perception that resources are leading to machines and robots; role of the social worker is important, but it should be a team approach; serving the underserved; broaden definition to include other stressors in life; rapid response is key; MH trainings.
- **Direct table notes:**
 - **Barriers:** Education resources for mental health, culture issues around mental health, NHF meet the gaps at HTC, pain/addiction services need to be available (Narcan on hand if needed), HTCs are not standardized, providing more opportunities to talk in a group about mental health, provider directory for mental health is not available, educational content, elevate mental health stories so we can eliminate stigma, distrust of services, insurance issues covering mental health, financial stressors, stigma, intergenerational education about mental health, racial gaslighting, mental health first aid training, experience of children with infusion & trauma & long term impact, consider competing interests: life, school, work, covid, rising costs, safety, social media;
 - **Actionable items:** therapists who see bleeding patients, its ok to have mental health problems, removal of stigma, deal with culture issues, awareness campaigns/different languages, talk about experience and tell stories, counseling services for caregivers/parents, more sessions on the topic of mental health, assessments of diagnoses in the community, extend education about mental health to family of affected persons, acknowledge that mental health issues exist in the community, map out family history of mental health issues, therapist/provider education on cultural stigma/beliefs, talk to HTC/chapters about mental health support, support for teens/more mental health talks with teens, behavioral management goes hand in hand with treatment, talk about mental health with boys in camps, more community support to battle the feeling of isolation, training on how to deal with the “angry” patient, more trained psychologists with experience in BD community, bring SW/psych interns to camps, virtual network created for BD psychologists, support groups, collaborate with SCD and other MH orgs

Health System Navigation

- Barriers with access to care, paying for parking, where agencies are located, new hospitals being built far away, communication, advocacy and collaboration will help to improve navigation; Spanish and other languages are needed; seeing representation in your provider as a means of building trust.
- Barriers with front office staff who don't understand IBD; HTC understaffed; actionable items more outreach to educate patients on quality of care; break down cultural barriers; insurance is key; education on what is available to them; promote insurance toolkit more
- Barriers – settings, limited resources at locations; more on provider education for non-HTC providers (ER dept); OBGYN outreach and testing (VWD); develop handouts for providers; proactive action plan with questions to ask; give patient advocacy education for talking to providers; talk more about resources around pain.

- Barriers (NHF SLT) meeting people where they are; lack of adult providers (peds in some states); patient bill of rights; money and funding; awareness; standards and criteria dissemination (HOW)
- Barriers time off policies for patients; transportation; have effective telehealth services across state lines; provide additional funding models; providers education around SDoH; better investment in tech so that information is accurate and reliable
- Direct table notes:
 - Barriers: assumptions of patients, types of insurance, limitations of insurance, different settings and services at HTC, limited resources, limited locations, PBMs add to the problem, find ways to get all NHF resources out, front office staff education, HTCs rejection of females as patients unless they are severe type 3 VWD, young adult transition is not great, hard to get appointments, welcome packets and transfer of care, too much research and not enough patient care, inconsistencies with how medications are reimbursed,
 - Actionable items: provider education for non-HTC providers, OR visit no hematologists, ER education, resources for patients when they go to ER in correct languages, cultural sensitivity, digital, OBGYN outreach, proactive action plan asking the right questions, patient advocacy, pain and its role in BD, insurance education, need navigators, promote insurance tool kit, listen intently & will allow people to be authentic, appreciate patients and be attentive to sharing, standards of care for BD patients regardless of provider, public health CLIA labs and minimum standards of care, ER Coordination with HTCs, more outreach to education on quality of care, breakdown cultural barriers, telehealth services, elevate women's voices,

Payer/Policy

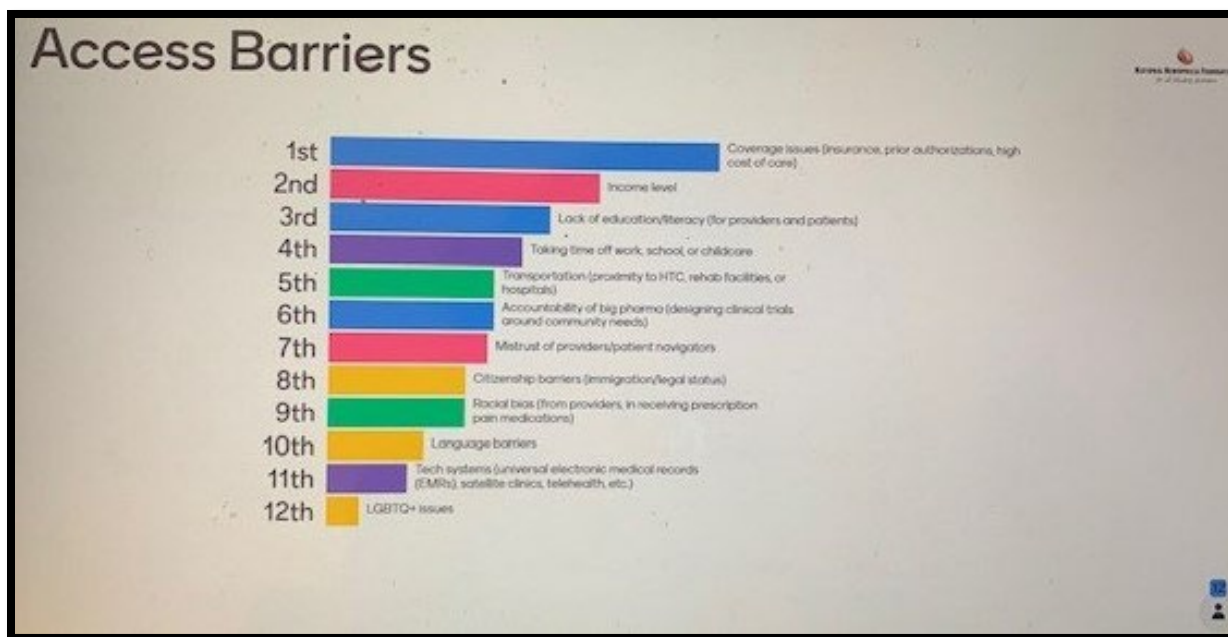
- Spectrum of understanding of payers and policy out there; really look at copays; legislation on what more can we do; IBD diagnosis should let you see specialist; patient reported outcomes should drive care; importance of women's voices; challenges with payers not always educated on IBD – urologist may make decisions about an IBD patient (overseeing claims); high cost of medications; find ways to get resources out to the bigger community
- Continue the work of the CCSC, grow that group, get more payers at the table, re-evaluate the sustainability of the HTC models, lack of uniformity, inequity of care, lack of policy, access in general.
- Federal legislation to limit out of pocket cost, variability in treatment, payers need to know there is no generics – products are not interchangeable; short term decision have long term consequences; gene therapy keeps them up at night; eligible doesn't mean access to gene therapy; lack of care for quality of life
- NHF (SLT) copay accumulators' accessible education; TikTok videos to engage younger populations; HTC don't understand copay accumulators; 30% pts use Medicaid which differs from state to state; enforced poverty to qualify for Medicaid; not all states have expanded Medicaid (33 have)
- **Direct table notes:**
 - Barriers: payer community not educated on BD, coordination of care needs to take place, need virtual trainings, high cost of meds, PBMs add to the problems, no generics,

products are not interchangeable, short-term diagnosis can have long term consequences – target joint development of inhibitors, gene therapy how payers will respond to cost structure, equity in gene therapy, payers not valuing quality of life, preserving the integrity of the essential health benefits

- Actionable Items: insurance is key, navigators can help, promote insurance toolkit, listen intently, get all NHF payer/policy resources out into the community, federal legislation, copays shifting costs to patients – limit out of pocket costs, variability in treatments, payers need to know that no generics available

How We Addressed the Missing Voice

The responses were very informative but not inclusive of all voices so on July 11, 2022, we had a focus group with the National Youth Leadership Institute (NYLI) group to be inclusive of the young adult experience and provided them the overarching themes to prioritize for NHF. The result of their prioritization is below in graphical representation.



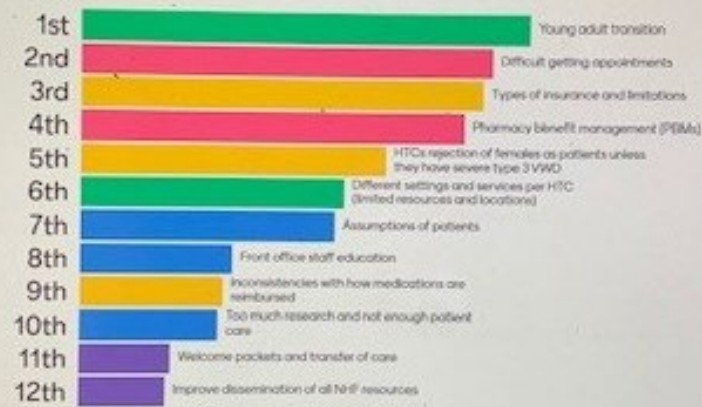
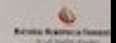
NYLI members were able to prioritize the access barriers according to their and their friends’ experiences as members of the BD community. They ranked top access issues of concern: coverage issues (insurance, prior authorizations, high cost of care), income levels (costs), and lack of education/literacy for providers and some patients.

Mental Health



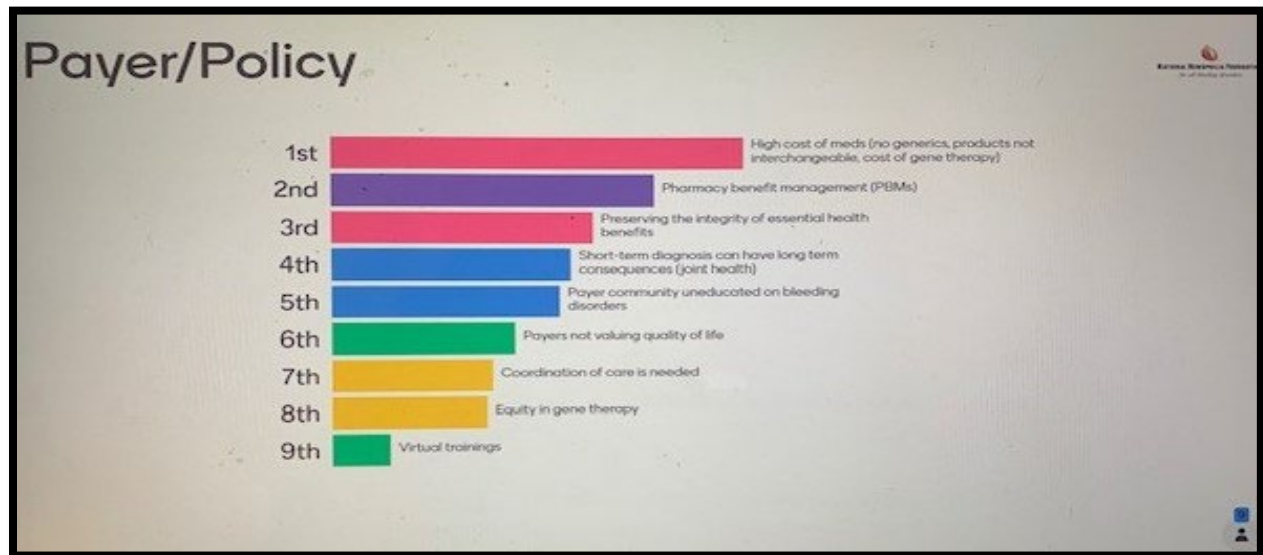
NYLI members were able to prioritize the mental health barriers according to their and their friends' experiences as members of the BD community. They ranked top mental health issues of concern: consideration of competing interests (life school, work, COVID, costs), coverage/insurance issues, and HTCs are not standardized across the US.

Health System Navigation



NYLI members were able to prioritize the health system navigation barriers according to their and their friends' experiences as members of the BD community. They ranked top health system navigation issues

of concern: young adult transition (provider engagement, knowing insurance and other issues), difficulty getting appointments, types of insurance and the limitations of that insurance.



NYLI members were able to prioritize the payer/policy barriers according to their and their friends' experiences as members of the BD community. They ranked top payer/policy issues of concern: high cost of medications, pharmacy benefit management, and preserving the integrity of essential health benefits.

Another NYLI was an unfounded barrier from the summit but one worth mentioning, especially for women with VWD where diagnosis is difficult and there are gender barriers as well. We know that it takes on average 18 years for a woman with VWD to get diagnosed so it's highly likely that this falls within young adults' specific issues (it may affect other age groups as well).

Call to action

In summation, as a result of the 2022 NHF Health Equity Summit and its findings, the following will happen:

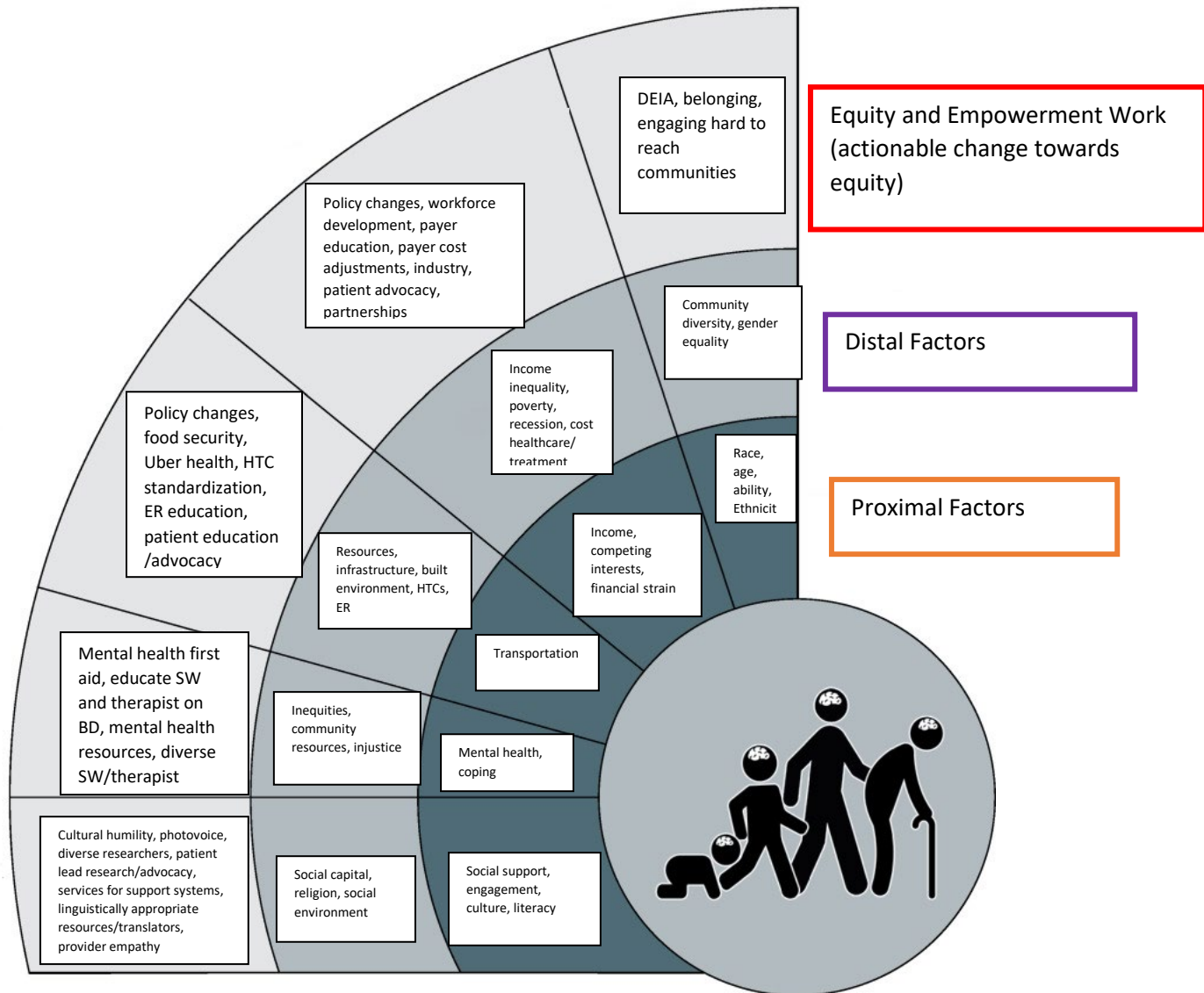
- **Health Equity Task Force** (with 4 subgroups and 20 members per group) that will start meeting in Q3 of 2022,
- **3 roundtables** throughout the country (will want to partner with 3 chapters) in 2023 and planning of the 2024 Health Equity Summit
- **2 graphical representations** of our HEDI work (by November of 2022)
- Creation of **an NHF equity and empowerment model** (outlining our work for the next 3-5 years)

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

1. Transform organizational culture and align daily work towards achieving health equity.

2. Address emerging IBD community health needs, including issues with access to care, by supporting adaptable, innovative, outcome-focused, patient centered, sustainable programs and services.
3. Improve access to services and quality care by supporting integration and coordination of health services, health care providers, payers, and the public health sector. Expand stakeholder partnerships that lead to sustainable initiatives that eliminate health disparities.

Dr. Norris incorporated the social determinants of health, systemic issues unveiled from the health equity summit and NYLI prioritization, and possible solutions and adapted this graphic from another source^x to fit NHF health equity plan for action.



ⁱ Braveman P, Arkin E, Orleans T, Proctor D, and Plough A. (2017). What Is Health Equity? And What Difference Does a Definition Make? Princeton, NJ: Robert Wood Johnson Foundation.
https://www.rwjf.org/content/dam/farm/reports/issue_briefs/2017/rwjf43739

ⁱⁱ Klein R, Huang D. (2010). Defining and measuring disparities, inequities, and inequalities in the Healthy People initiative. National Center for Health Statistics. Center for Disease Control and Prevention.
https://www.cdc.gov/nchs/ppt/nchs2010/41_klein.pdf

ⁱⁱⁱ U.S. Department of Health and Human Services. The Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020. Phase I report: Recommendations for the framework and format of Healthy People 2020. Section IV: Advisory Committee findings and recommendations.
http://www.healthypeople.gov/sites/default/files/PhaseI_0.pdf

^{iv} Arya, S., Wilton, P., Page, D., Boma-Fischer, L., Floros, G., Dainty, K. N., Winikoff, R., & Sholzberg, M. (2020). Healthcare provider perspectives on inequities in access to care for patients with inherited bleeding disorders. *PLoS one*, 15(2), e0229099. <https://doi.org/10.1371/journal.pone.0229099>

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