

Health Equity Summit “Every Hour, Every Day: Ensuring health equity in the inheritable bleeding and blood disorders (IBD) community”

Accelerate health equity, diversity, and inclusion through an inaugural summit to identify and address barriers to access and care within the US inheritable blood disorders (IBD) community.

Why It Matters

Recent qualitative data from a survey of healthcare professionals (HCPs) who treat IBD patients suggests that multiple disparities exist and are pervasive. As National Blood Disorders Foundation (NBDF) began to explore health equity and the impact of social determinants of health in the IBD community, we realized that the data is missing. There is no national data on disparities within the IBD community. Historically, hemophilia was incorrectly viewed as only affecting white males. This is a lack of consideration for the many disparities and inequities affecting the entire IBD community. Information was needed directly from the IBD community to formulate strategies, approaches, advocacy and education initiatives to improve health equity.



Solution

Convene a Health Equity Summit to illuminate disparities and inequities for people with bleeding disorders related to access, mental health, health system navigation, and payer/policy. Gain a better understanding of lived experiences, data outcomes, and existing disparities.

At the 2022 Summit, participants included patients with lived experience, bleeding disorder patient advocacy professionals, HCPs including an expert from the CDC blood disorders team, and other partners. Four objectives were identified that drive NBDF health equity work:

- Transform organizational culture and align daily work to achieve health equity
- Address health and access needs through outcomes-focused, sustainable programs/services
- Improve access to services and quality care by integrating HCPs, payers, and public sector
- Expand partnerships for sustainable initiatives that eliminate health disparities

Recognizing that a key voice was underrepresented at the Summit, a focus group was held with NBDF’s National Youth Leadership Institute to be more inclusive of the young adult experience.



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Impact

The Summit’s output lead to development of a Health Equity and Empowerment Action Model outlining a 10-year plan for NBDF. The action model has been in progress with community roundtables and the Health Equity Task Force.



A Health Equity Task Force was established with four specialized working groups to deliver on actions identified during the inaugural summit



Three roundtables were held in 2023 to delve deeper into the health equity action model



Planning is underway for the next IBD Health Equity Summit in 2024

Practical takeaways will emerge in 2024 when strategic approaches are developed for priority populations currently being identified.

Key Learnings

The needs of the IBD community are complex. Insights and answers require multiple stakeholders representing various perspectives, cultural backgrounds, and lived experiences at the table.

