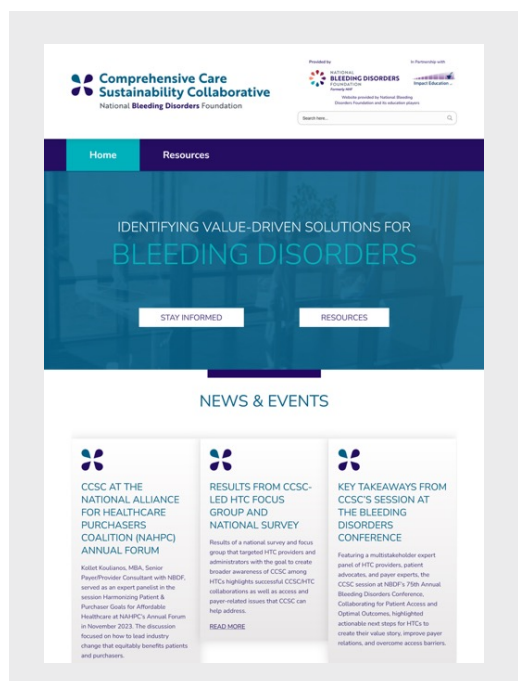


2023 YEAR IN REVIEW

New Look, Same Mission

In 2023, the National Hemophilia Foundation changed its name to the National Bleeding Disorders Foundation (NBDF). The new name and new tagline Innovate, Educate, Advocate, reflects NBDF's goal to be inclusive of all people impacted by inherited bleeding disorders.

“Our new name is one that’s inclusive, trying to represent that entire blood and bleeding disorders community based on our past. We think that this really embraces what we’re going to offer into the future by bringing everybody in and offering them something. No matter what disorder you have, you will find a home in the National Bleeding Disorders Foundation” said Dr. Len Valentino, CEO.¹



The Comprehensive Care Sustainability Collaborative (CCSC)'s mission to facilitate dialog between payers and providers to identify value-driven solutions that optimize both the total cost of care and patient outcomes, aligns with NBDF's expanded vision. Therefore, the look of CCSC has been updated to complement NBDF's new branding.

Visit www.CCSCHemo.com to review the updated site and resources.

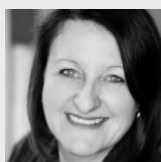
CCSC's 2023 initiatives met the following objectives to advance the sustainability of the integrated and comprehensive care model in the management of bleeding disorders:

- Implement activities that address current threats of care delivery trends on access, affordability, and sustainability of the HTC's integrated comprehensive care model and elucidate the unintended consequences of these trends
- Utilize real-world data to spotlight delivery system failures and track unintended consequences
- Inform and educate the various stakeholders involved in employer benefits decision making to fully understand the cost avoidance scenarios of current trends

CCSC Engagement with Hemophilia Treatment Centers

CCSC was able to engage directly with more Hemophilia Treatment Centers (HTCs) in 2023 through customized programming designed to meet their specific needs to improve access to care for their patients.

New HTC experts joined the CCSC Advisory Board



Julie Hayman
Director of Payer Relations
Hemophilia of Georgia



Angela C. Weyand, MD
Clinical Associate Professor
C. S. Mott Children's Hospital
University of Michigan Health



Elizabeth Solomon, MBA, MHSA
VP, Payer Solutions
Hemophilia of Georgia



Tung T. Wynn, MD
Assistant Clinical Professor
University of Florida
Director of Pediatric Hemostasis Program
and Pediatric Cancer Survivorship Program
UF Health



Michael Wang, MD
Director
Hemophilia & Thrombosis Center
Children's Hospital Colorado Anschutz
Medical Campus

HTC Survey and Focus Group

CCSC disseminated a survey to HTCs and held a focus group with HTC experts at NBDF's Bleeding Disorders Conference in August 2023. The goals were to review what CCSC is and how it can help HTCs address barriers to access, share examples of successful HTC and CCSC collaborations, and to learn about current access barriers, existing payer relations, and opportunities to collaborate with CCSC. View the [Executive Summary](#) to see the key takeaways from the survey and focus group. This valuable feedback from HTCs helped identify remaining gaps in CCSC education and outreach and served as a roadmap for setting 2024 objectives to continue to provide meaningful support and educational resources to HTCs.

CCSC Session at the Bleeding Disorders Conference

CCSC hosted a 2.5-hour session at Bleeding Disorders conference in August 2023, *CCSC: Collaborating for Patient Access and Optimal Outcomes*. The session was attended by 185 HTC providers and was led by a diverse panel of advocacy, provider, and payer experts. Notably, 88% of attendees responded that support is needed from an initiative such as CCSC to enhance the awareness among purchasers of health care (payers/insurers) regarding high quality hemophilia care that is both effective and reimbursable.

[View the CCSC e-Newsletter on key takeaways from this BDC session.](#)



“I feel that today’s session was very eye opening and powerful. This provided me with more insight into decision-making of payers.”

– Outreach Social Worker,
Hemophilia of Georgia

CCSC Reaching Purchasers of Healthcare

CCSC continued to effectively reach purchasers of healthcare in 2023 by exhibiting at two Academy of Managed Care Pharmacy (AMCP) conferences, Artia Crossroads, the Self-insurance Institute of America, Inc. (SIIA), Annual Conference, and the National Alliance for Healthcare Purchasers Coalition (NAHPC) Annual Forum. Also at NAHPC, Kollet Koulianos, MBA, Senior Payer/Provider Consultant at NBDF, participated on the panel *Harmonizing Patient & Purchaser Goals for Affordable Healthcare*. The panel presented to leaders from healthcare employer groups to discuss how to lead industry change that equitably benefits patients and purchasers.



Hearing from the Experts

Key Takeaways from the 10th Annual CCSC Advisory Board Meeting

In October 2023, CCSC hosted its 10th annual advisory board meeting in Chicago, IL. 14 HTC experts and 10 payer experts attended the 2.5-day meeting to:

- Review current threats of care delivery trends on access, affordability, and sustainability of the HTC's integrated comprehensive care model and the unintended consequences of these trends.
- Identify potential solutions to address unintended consequences of payer trends in the management of inherited bleeding disorders (IBD).
- Illustrate best practices in enhanced collaboration across multiple stakeholders (HTCs, payers, and employers) to improve access to high quality care in inherited bleeding disorder.

Through engaging panel discussions and working groups, the advisors identified goals to move CCSC forward and address barriers to access for the IBD community. The advisors agreed collaborating through data sharing is a high priority and will help HTCs emphasize their value to payers. Payers recommended risk-sharing arrangements as a means of mitigating unsustainable specialty drug spend. The advisors stressed that establishing HTC Centers of Excellence could be a solution to multiple challenges, including rural and interstate coverage and administration of gene therapies. Through CCSC, NBDF is uniquely positioned to help forge relationships between payers and providers to accomplish these goals. The Executive Summary is available upon request: ccsc@impactedu.net.

What's Next...

In 2024, CCSC will host multi-stakeholder discussions regarding the HTCs' role as more innovative therapies come to market and access issues specific to Managed Medicaid and Marketplace plans. Briefing documents, as well as new resources, will be posted on CCSCHemo.com. In addition, look for CCSC at AMCP conferences and at NBDF's 2024 Bleeding Disorders Conference.

You can also reach out to CCSC directly with any questions regarding access issues for people living with inherited bleeding disorders in your community. ccsc@impactedu.net

References:

1. National Bleeding Disorders Foundation. The National Hemophilia Foundation is Now the National Bleeding Disorders Foundation: New Name, New Look, Expanded Vision. National Harbor. August 17, 2023. Accessed December 2023. <https://www.hemophilia.org/news/the-national-hemophilia-foundation-is-now-the-national-bleeding-disorders-foundation>

Not a CCSC Member Yet? Join today at CCSCHemo.com.

NBDF encourages you to join CCSC to gain insights from clinician bleeding disorders experts and payer opinion leaders, access useful management tools and resources, and advance your collaboration with HTC providers and purchasers of healthcare.

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