Comprehensive Care Sustainability Collaborative
National Bleeding Disorders Foundation

OCTOBER 2026

Key Takeaways from the CCSC Session at NBDF's Bleeding Disorders Conference

CCSC Presents: From Solutions to Sustainability: HTC–Payer Alignment to Protect and Advance Comprehensive Care

On August 13, 2026, the Comprehensive Care Sustainability Collaborative (CCSC), led by NBDF over the past 13 years, held a unique session for Hemophilia Treatment Center (HTC) providers to explore emerging challenges and opportunities affecting comprehensive care, examine strategies to improve coverage, network access, and prior authorization processes, and strengthen collaboration with payers, employers, and other stakeholders to protect and advance sustainable access to high-quality care for people with bleeding disorders.

The session featured a multidisciplinary panel—including HTC providers, HTC administrators, payer experts, and patient advocates—and highlighted key takeaways from the latest NBDF-led payer/HTC regional roundtables and the CCSC Advisory Board Meeting.

111 people attended the session

Summary

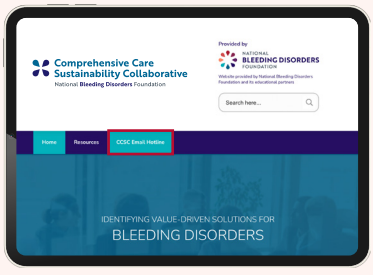
Current Threats to Care Delivery

- Payers continue to focus on managing high-cost specialty medications, with bleeding disorders remaining among the highest-cost disease categories.
- Growing utilization of:
  - Prior authorization requirements
  - Quantity limits
  - Step therapy protocols
  - Copay accumulator and maximizer programs
  - Alternative funding programs (AFPs)
- AFPs, however, were highlighted as a major concern due to:
  - Delays in treatment access
  - Patient administrative burden
  - Potential disruption of continuity of care
  - Increased risk of adverse outcomes and emergency care utilization
- Continued advocacy efforts are underway to:
  - Combat accumulator and maximizer programs
  - Address inappropriate alternative funding arrangements
  - Improve oversight of specialty drug importation scheme
  - Protect access to essential bleeding disorder therapies
- CCSC stakeholders emphasized the need for stronger federal action, employer education, and coordinated patient advocacy.
- Potential progress was reported around efforts to improve drug classification and formulary protections for bleeding disorder therapies.

CCSC Email Hotline

ccschemo.com

HTCs are encouraged to reach out to NBDF for help navigating these programs and overcoming access barriers. Shared patient stories can highlight the unintended consequences of these programs for payers and employers.

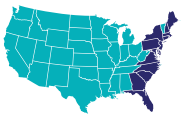


Key Insights from Payer/HTC/Employer Regional Roundtables

4 regional roundtables were conducted



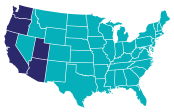
Employer/Broker
May 5, 2026



East Region
May 18, 2026



Midwest Region
June 16, 2026



West Region
June 23, 2026

- The purpose of these roundtables was to connect new HTCs, payers, PBMs, and employers in engaging discussions on regional issues and potential collaborations to address access barriers to high-quality care.
- Regional challenges were brought to light, and opportunities were discussed to enhance collaboration between payers, employers, and HTCs.

Major Findings from Regional Roundtables

HTC access remains highly variable across regions due to:

- Geographic barriers
- Rural access challenges
- Local payer policies
- Network restrictions

PBM and benefit design decisions continue to create barriers through:

- Exclusive specialty pharmacy arrangements
- Fragmented pharmacy and medical benefits
- Restrictive utilization management practices

Employer and Broker Engagement

A new employer/broker roundtable revealed significant knowledge gaps:

- Many employers and brokers were unfamiliar with HTCs and the comprehensive care model.
- Participants expressed interest in educational resources and tools.

Priority Opportunities Identified

- Develop a standardized HTC value-reporting framework.
- Improve routine HTC-payer data sharing.
- Expand employer, broker, and PBM education efforts.
- Strengthen communication regarding the clinical and economic value of HTC care.

Key Takeaways from the 2026 CCSC Advisory Board Meeting

Three major workstreams were identified:

Policy & Access

- PBM engagement
- HTC network gap assessments
- HTC contracting resources
- Payer literacy resources for HTC staff

Data, Outcomes & Value Demonstration

- HTC value case studies
- Real-world evidence initiatives
- Standardized metrics and benchmarks
- Pharmacy inclusion advocacy

Employer Engagement

- Employer toolkits and action briefs
- Broker engagement strategies
- Patient story collection and advocacy resources
- Employer-focused educational initiatives

Improving Access & Reducing Barriers

Prior Authorization Challenges

Participants identified several recurring friction points:

- Repeated authorization requirements for chronic therapies
- Administrative burden from payer-specific processes
- Network and PBM restrictions that fragment care
- Variability across plans and regions

Potential Solutions

- Explore standardized prior authorization frameworks informed by MASAC guidance.
- Promote more consistent clinical criteria and documentation requirements.
- Increase use of electronic prior authorization pathways.
- Develop payer-recognized HTC attestations and streamlined review processes.

Network Access Priorities

- Preserve patient access to HTCs and HTC specialty pharmacies.
- Reduce fragmentation of care resulting from pharmacy carve-outs.
- Increase recognition of HTCs as bleeding disorders Centers of Excellence.
- Expand telehealth and outreach clinic models to address geographic barriers.

Demonstrating HTC Value

Stakeholders emphasized the need to communicate:

- Reduced ER visits and hospitalizations
- Improved treatment adherence
- Better long-term outcomes
- Lower total cost of care
- The significant value of non-billable services provided by HTC teams

Strengthening Cross-Stakeholder Collaboration

Building Stronger Partnerships	Participants stressed that sustainable progress depends on ongoing dialogue among HTCs, payers, PBMs, employers, brokers, and patient advocates
Strategies for Moving Forward	• Develop regional payer and employer relationships before access issues arise. • Create case studies demonstrating HTC impact on outcomes and costs. • Package HTC value propositions using metrics meaningful to employers. • Leverage patients, brokers, and HR teams as advocates when coverage barriers occur. • Collect and share real-world examples of unintended consequences from restrictive policies.
Key Themes	• Employers generally want to support patients but often lack awareness of HTC services. • Education remains one of the greatest opportunities for advancing HTC inclusion. • Greater transparency in PBM practices may create new opportunities for HTC engagement. • HTCs should proactively communicate both: – The value of their integrated care model – The critical role HTC pharmacies play in sustaining comprehensive services.
Action Priorities	• Expand engagement with payers, consultants, brokers, and employer groups. • Create employer-facing case studies and one-page value tools. • Continue gathering patient stories and access barrier examples. • Strengthen awareness that comprehensive HTC care depends on maintaining access to both HTC clinical services and HTC pharmacy services.

Why Timely Access Matters

The unintended consequences are real. You cannot put an obstacle in the way of access to care. There are consequences both for the patient and for the payer, and those costs continue long into the future.

~ Kollet Koulianos, MBA

Employers As Partners

Helping the patient be an advocate for themselves in a constructive, respectful way is important. I've seen instances where patients raised concerns and programs were canceled because employers wanted to do the right thing once they understood the impact.

~ Sal Morana, RPh, PhD

The Value of HTC Care

The highest quality care for our patients is going to be the most cost-effective care as well. Those two things are absolutely connected, and we need to make sure that is clearly understood. We all have the same goal at the end of the day: to keep patients from bleeding, being in the hospital, or being in the ER. That's in everybody's best interest.

~ Mark Reding, MD

Attendee Feedback

Participants widely agreed that initiatives such as CCSC are necessary to increase awareness of access to high-quality, effective, and reimbursable care.

When care is made affordable, a large barrier is removed, making it possible for patients to receive life-saving care. CCSC is an amazing resource to approach the conversation with the payers opening up the possibility of removing that barrier.

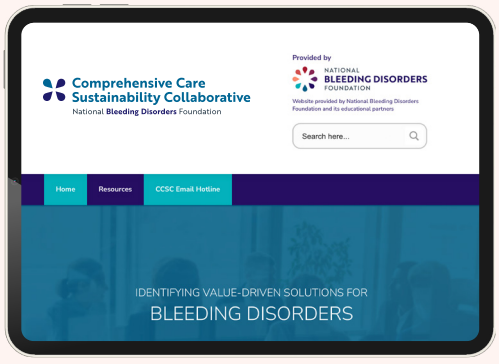
~ Patient/MASAC Member

Not a CCSC Member Yet?

Join today at CCSCHemo.com

ccschemo.com

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



Appendix

Expert Panel



Aaron Blocker, MS
Senior Director of Patient Access
National Bleeding Disorders Foundation



Jennifer Borrillo, MSW, LCSW, MBA
Senior Vice President
Member and Community Relations
Hemophilia Alliance



Becky Burns
Chief Operating Officer
Bleeding & Clotting Disorders Institute



Estay Greene, PharmD, MBA
Vice President of Pharmacy Management
BlueCross BlueShield of South Carolina



Maissaa Janbain, MD
Director
Louisiana Center for Bleeding and Clotting Disorders



Kollet Koulianos, MBA
Senior Payer/Provider Relations Consultant
National Bleeding Disorders Foundation



Sal Morana, RPh, PhD
EVP, Pharmacy Practice Lead
Alliant Employee Benefits



Mark Reding, MD
Professor of Medicine
Division of Hematology, Oncology and Transplantation
Director, Center for Bleeding and Clotting Disorders
University of Minnesota



Nathan Schaefer, MSW
Senior Vice President of Public Policy & Access
National Bleeding Disorders Foundation

Agenda

9:00 am–9:30 am
Registration

9:30 am–9:40 am
Introduction and Review Objectives
Nathan Schaefer, MSW

9:40 am–10:00 am
Update on Threats and Opportunities in Care Delivery
Kollet Koulianos, MBA

10:00 am–10:10 am
Q&A

10:10 am–10:40 am
Key Insights from Employer/Payer/HTC Regional Roundtables and the 2026 CCSC Advisory Board Meeting
Aaron Blocker, MS, GBA | Maissaa Janbain, MD

10:40 am–11:00 am
Q&A

11:00 am–11:20 am
Improving Access & Reducing Barriers: Aligning Payers and HTCs on Coverage, Network Access, and Prior Authorization
Estay Greene, PharmD, MBA
Jennifer Borrillo, MSW, LCSW, MBA

11:20 am–11:40 am
Strengthening Cross-Stakeholder Collaboration: Building Practical Tools, Relationships, and Real-World Implementation Pathways
Becky Burns | Sal Morana, RPh, PhD | Mark Reding, MD

11:40 am–12:00 pm
Q&A
Closing Thoughts
Panel | Moderated by Aaron Blocker, MS, GBA

Provided by

NATIONAL BLEEDING DISORDERS FOUNDATION

In Partnership with

Impact Education LLC

CCSC is supported by charitable donations from founding supporter Takeda, and additional support from Biotechnology Innovation Organization (BIO), Bleeding & Clotting Disorders Institute, CSL Behring, Genentech, Inc., Gulf States Hemophilia and Thrombophilia Center, Hemophilia Alliance, Louisiana Center for Bleeding and Clotting Disorders, Mary M. Gooley Hemophilia Center, Sanofi, and Western New York BloodCare.

© 2026 National Bleeding Disorders Foundation. All Rights Reserved.