Comprehensive Care Sustainability Collaborative
National **Bleeding Disorders** Foundation

OCTOBER 2025

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

CCSC Presents: HTC/Payer Expert-Driven Solutions to Improve Access to Care

On August 21, 2025, the Comprehensive Care Sustainability Collaborative (CCSC), led by NBDF over the past 12 years, held a unique session for Hemophilia Treatment Center (HTC) providers to help identify emerging threats and opportunities that impact access to comprehensive care within the bleeding disorders community and outline actionable strategies for HTCs to overcome access barriers and improve collaboration with payers.

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, CCSC Advisory Board Meeting, and CCSC's HTC national survey.

Attendees

131 people attended the session.

49 different HTCs were in attendance

Summary

Current Threats to Care Delivery

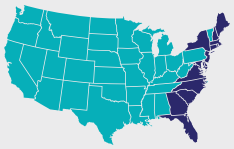
- Copay accumulated adjustment programs (CAAP), copay maximizer programs, and alternative funding programs (AFPs) have been on the rise in recent years.
- HTCs need to be aware of these programs and their impact on patients' access to care.
- AFPs have substantial adverse consequences on patients:
  - Delayed access to life-saving treatments
  - Discriminatory practices
  - Lack of direction and communication
  - Misinformation (e.g., directing patients to knowingly submit incorrect information on patient assistance foundation [PAF] applications)
  - No right to appeal
  - Negative impact on patient/caregiver mental health; potential worsening of health outcomes

"AFPs have substantial adverse consequences besides the delayed access to life-saving treatments and potential discriminatory practices."

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

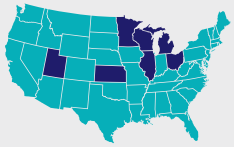
Key Insights from Payer/HTC Regional Roundtables

3 out of the 4 regional roundtables were conducted prior to BDC

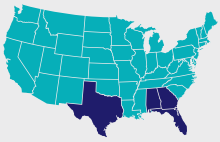


East Coast – May 6, 2025

West Coast – May 14, 2025



Midwest – July 29, 2025



South – September 23, 2025

Real-World Collaboration is Already Taking Place as a Result of the Roundtables

A national payer medical director asked to be put in contact with the chair of MASAC to develop coverage policy and ePA criteria aligned with evidence-based guidelines

"We would love to partner with HTC clinicians, because together we can think of ideas that could help reduce costs. Our ideas together also make more sense on a patient level. Collaboration directly benefits the patient, reduces waste, and makes coverage and access more efficient. I'd also like to collaborate to simplify the PA process for clinicians. That needs to happen on our end. We want treatment to be cost-effective, but we also want to serve the provider community in a better way. Prior authorization really shouldn't be something that's arduous."

- The purpose of these roundtables was to connect new HTCs, payers, and PBMs 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 and HTCs.

Key Takeaways from the 2025 CCSC Advisory Board Meeting

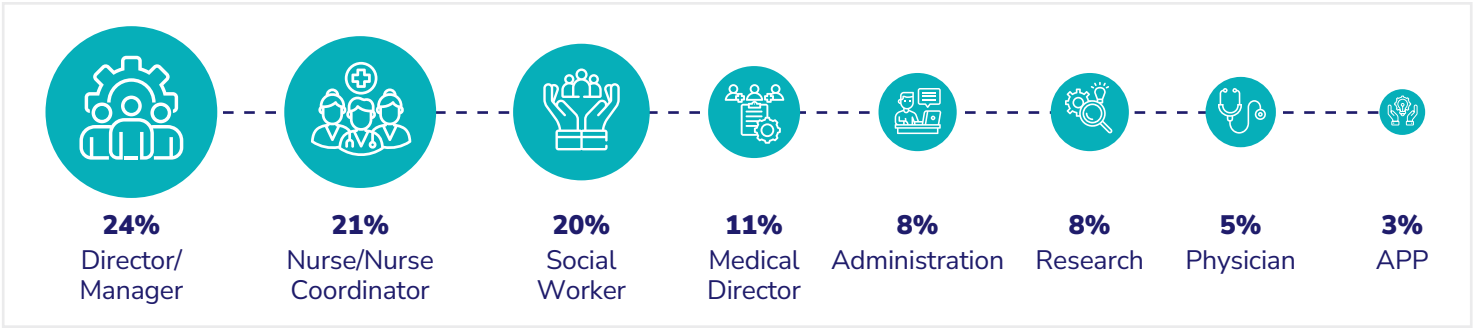
- Findings from the 2025 Advisory Board underscore the importance of **transparent data sharing, aligned clinical guidelines, and real-world case studies in establishing credibility with payers and employers.**
- New payer organizations and HTCs provided additional perspectives on **regional challenges and opportunities**. In contrast, both payer and provider advisors recognized the ongoing need for targeted education to address knowledge gaps in the management of complex clinical conditions.
- Growing interest in **expanded data sharing**, including total cost of care data, offers an opportunity to identify cost drivers and **support value-based discussions**.
- **Early payer engagement in policy development** was recognized as a critical step to foster shared understanding and align clinical guidelines with operational considerations.
- **Tailored outreach** continues to reinforce the clinical and financial benefits of integrated, outcomes-focused care, while pilot programs, shared savings models, and regional implementation offer scalable pathways for innovation.
- Addressing disruptive funding models and strengthening proactive payer engagement remain key priorities, with **CCSC positioned to serve as a convener and catalyst for ongoing collaboration and progress**.

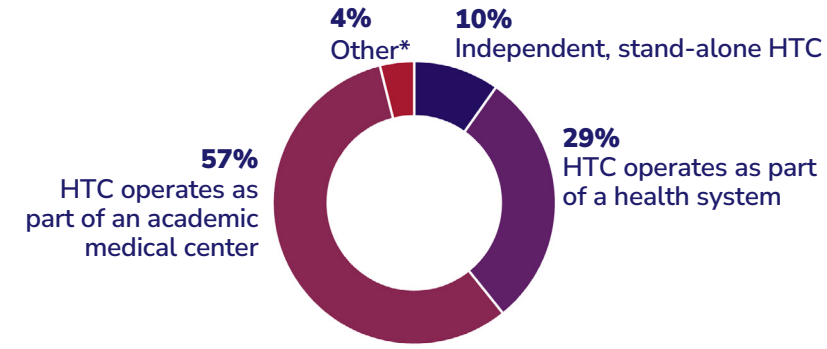
"There should be consistent proactive payer engagement by the hemophilia treatment center. Priorities should include early engagement with your payers for your patients within your HTC, particularly in navigating those medical policies and understanding the nuanced differences between different payers' policies. You want to reduce misunderstandings and demonstrate long-term value of the care that the patients get at your hemophilia treatment center."

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

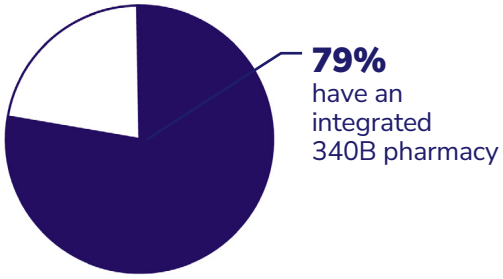
HTC Survey Results

- Survey was open and distributed May-July 2025: https://ccschemo.com/ccsc-2025-htc-survey/
- CCSC collected insights from HTCs on challenges in access to care for hemophilia and other bleeding disorders
- Survey responders came from a variety of different roles and backgrounds





*HTC operates within a state agency;
Part of a University medical center research program



- Several barriers to appropriate management were identified, with the top 3 being:
  1. Prior authorization, utilization management, and/or copay accumulator adjuster programs (CAAPs)
     - 44% of responders stated that their HTC staff spend 5-10 hours per week on prior authorizations
     - Streamlining PA and appeals would be an area of opportunity for both HTCs and payers to collaborate
  2. High cost of therapy
  3. Potential cuts to Medicaid funding
- HTC and payer communication gaps remain
  - Limited communication channels and a lack of timely information exchange are the top gaps
- Collaboration opportunities were identified for HTCs and payers
  - Streamlining PA and appeals, coordination with payer care/case management, and establishing “preferred provider” status would be among the top 3 areas of opportunity

“Prior authorizations are a huge burden on hemophilia treatment centers. They affect the timeliness of getting EOBs and being able to submit to copay assistance programs. Sometimes that is program income, then you have to write off on your program, because you didn’t have that EOB within the 60 days that’s required from the drug manufacturer to get that copay assistance for your patient.”

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

CCSC Real-world Cases to Improve Access to Care

Hemophilia Alliance and NBDF Collaboration to Enhance Care Delivery

- Hemophilia Alliance and NBDF are working together to improve access to care and support the sustainability of the HTC-integrated comprehensive care model.
- One significant barrier addressed was identifying the right decision maker at a payer who can truly influence change. Through the connections made at CCSC, providers and payers can build on these existing relationships and address problems more efficiently by reaching the right people.

"These partnerships are already benefiting our patients. I can purchase medical alert bracelets, kinesiotapes, compression stockings, and menstrual supplies for patients so families don't have to choose what they can afford to buy at the store. Some of our nurses and physical therapists have come back from educational programs, better equipped to care for our patients. The partnership is also a great resource for education and advocacy that we can all continue to have a voice and be one community."

– Hilda Ding, MD, MS, Pediatric Hematologist/Oncologist, Rady's Children's Health

Improved Access Through Employer/HTC Collaboration

- Collaborations between HTCs and employers or employer-sponsored health plans help to ensure patients have timely access to specialized care and appropriate therapies.

"You should know your provider relations representative at every payer that you work with on the fully funded side. Those reps will also help you on the self-insured side. Identify the major brokers in your area, reach out to them, and attend their meetings. That's one of the most impactful things I've seen."

– Becky Burns, Chief Operating Officer, Bleeding & Clotting Disorders Institute

"Today, there are more and more therapies for rare diseases. Things that we haven't even heard of are popping up. Employer groups who understand the trends and watch the trends and want to impact their patients have started looking for centers of excellence to partner with and learn about more efficiencies and cost savings."

- Tamara Howerton, BS, RPh, Clinical Advisor, Health Strategy, LLC

Attendee Feedback

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

"I was unaware of CCSC and its work until I attended this session. The online resources are extremely helpful and relevant to work happening with payors in our area."

- HTC Attendee

Appendix

Expert Panel

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

Becky Burns
Chief Operating Officer
Bleeding & Clotting Disorders Institute

Hilda Ding, MD MS
Director, Hemophilia & Thrombosis Treatment Center
Director, Women & Girls' Hematology-Gynecology Clinic
Associate Clinical Professor
Pediatric Hematology Oncology
UCSD Rady Children's Hospital

Tamara Howerton, BS, RPh
Clinical Advisor
Health Strategy, LLC

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

Ed Pezalla, MD, MPH
Chief Executive Officer
Enlightenment Bioconsult, LLC

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

Agenda

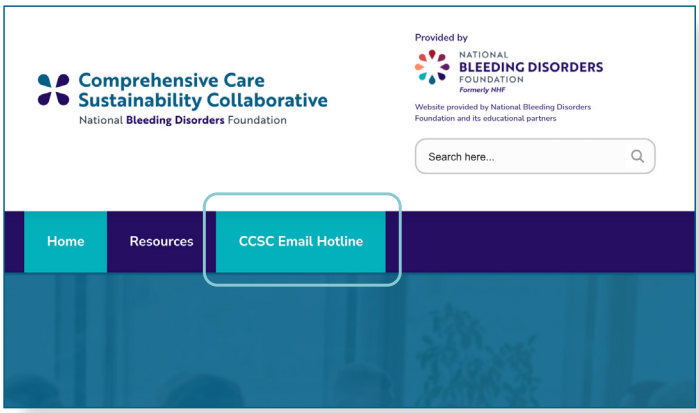
9:30 am- 9:40 am ET	**Introduction and Review Objectives** • Nathan Schaefer, MSW National Bleeding Disorders Foundation
9:40 am- 10:15 am ET	**Threats and Opportunities in Care Delivery** • Kollet Koulianos, MBA National Bleeding Disorders Foundation *Audience Q&A*
10:15 am- 11:10 am ET	**Key Insights from Payer/HTC Regional Roundtables, the 2025 CCSC Advisory Board Meeting, and HTC Survey** • Ed Pezalla, MD, MPH Enlightenment Bioconsult, LLC • Jennifer Borrillo, MSW, LCSW, MBA Hemophilia Alliance *Audience Q&A*
11:10am- 11:25 am ET	**Hemophilia Alliance and NBDF Collaboration to Enhance Care Delivery** • Hilda Ding, MD MS Hemophilia & Thrombosis Treatment Center Women & Girls' Hematology-Gynecology Clinic UCSD Rady Children's Hospital • Jennifer Borrillo, MSW, LCSW, MBA Hemophilia Alliance
11:25 am- 11:40 am ET	**Improved Access Through Employer/HTC Collaboration** • Tamara Howerton, BS, RPh Health Strategy, LLC • Becky Burns Bleeding & Clotting Disorders Institute • Ed Pezalla, MD, MPH Enlightenment Bioconsult, LLC
11:40 am- 12:00 pm ET	**Q&A and Closing Thoughts** • *Moderator:* Nathan Schaefer, MSW • *Panelists:* Jennifer Borrillo, MSW, LCSW, MBA Becky Burns Hilda Ding, MD MS Tamara Howerton, BS, RPh Kollet Koulianos, MBA Ed Pezalla, MD, MPH

Need CCSC's Help?

Check out the new **Email Hotline** on CCSC*Hemo*.com to report any patient access issues you are seeing or if you need help navigating care access for your patients or members.

You can also reach out to CCSC directly by email with any questions regarding access issues for people living with inherited bleeding disorders in your community:

ccsc@impactedu.net



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Sign Up Today at: CCSC*Hemo*.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.

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