

# CCSC e-Newsletter

November 2024

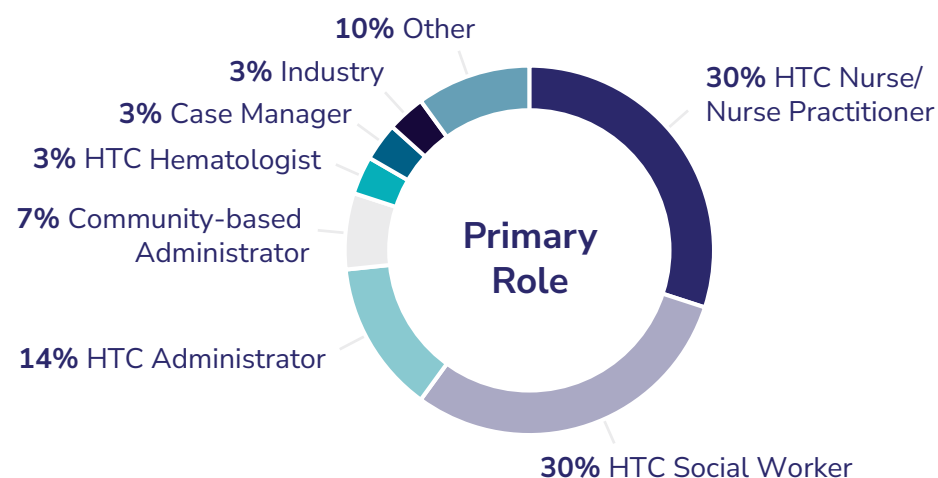
## Key Takeaways from the CCSC Session at NBDF's Bleeding Disorders Conference *HTC/Payer Collaborations to Address Current Threats to Care Delivery*

On September 12, 2024, the Comprehensive Care Sustainability Collaborative (CCSC), led by NBDF in partnership with Impact Education, LLC, over the past 10 years, held a unique session for Hemophilia Treatment Center (HTC) providers to get an update on the latest threats to care delivery and learn what HTCs can do to address barriers to access.

The session featured a multidisciplinary panel—including HTC providers, HTC administrators, payer experts, and patient advocates—to better understand perspectives from various stakeholders and offer solutions to improve patient access to care. The interactive format included four expert interviews between HTC providers and payer experts. In addition, each segment of the agenda provided a key resource/tool to which attendees could reference for more information (see Appendix).

### Attendees

135 people attended the session.



\*Other: Nurse Educator - specialty pharmacy,  
Program Manager with ATHN, Nurse and Payer Relations for Hemophilia of Georgia

## 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.
- HTC need to be aware of these programs and how they are impacting 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
- HTCs are encouraged to reach out to NBDF to help navigate these programs and overcome barriers to access. Shared patient stories can shed light on the unintended consequences of these programs for payers and employers.

“ Almost 70% of all employer-sponsored health plans are self-funded. Because they are self-funded they do not follow the same rules as a fully funded plan does. But payers use the same tools to try to control costs. They usually do it as a one-size-fits-all strategy. But it's not helpful if you're a patient with a chronic disease and have barriers to that access.”

- Kollet Koulianos-Barkhouse, MBA  
National Bleeding Disorders Foundation

### Consequences of Delays in Access to Care

- HTC physicians noted several examples of barriers patients need to overcome to get their treatment. Several specific issues were also cited: reaching patients who are far from the treatment center, getting timely approval to get tests done at specialty labs, being forced to use off-label treatments (i.e., use of von Willebrand disease [VWD] therapies in male patients, even though many of these products are only indicated for use in female patients), and having to avoid forced switching from previously approved medications and/or fail-first policies.
- There is an opportunity to further educate payers and employers to better understand providers' rationales for a treatment plan, show best practices in plan design for inherited bleeding disorders, and improve communication between payers and providers.

“ I think one of the best things we can do is show our payers how what we do in the HTCs actually saves them money. In the long run, it meets both of our goals, which are to help the patient and offer equitable care that is also financially responsible.”

- Shannon Carpenter, MD, MSCI, FAAP  
Children's Mercy Kansas City

## Employer Perspectives on Alternative Funding Programs (AFPs)

- AFP companies are going straight to employers to pitch AFPs as cost-savings tools, and the negative impact on patients is lost on employers.
- Employers, uninformed about the unintended consequences of AFPs, are demanding payers/brokers include AFPs in the plan or risk losing the business.
- HTCs can help educate payers and employers to “see the big picture” and highlight what the total cost-of-care impact is versus the short-term savings they may see with these programs.

## Presenting the HTC Value Story to the Payer

- HTCs can improve collaboration with payers through sharing their value story. HTCs should highlight how the benefits of the HTC comprehensive care model link directly to lower total cost of care. The goal is for payers to recognize that HTCs are centers of excellence in the management of bleeding disorders.

“ Access to data is super important in the ability to tell a value story. I think the value that HTCs can bring to the conversation with payers is showing how they improve outcomes. We have a lot of silos in healthcare. However, ultimately at some level, there is an understanding with people that it is important to focus on the total cost of care regardless of where you sit within the organization.”

- Dana McCormick, RPh, FAMCP  
Optum

“ Payers don’t know about hemophilia treatment centers. We like to believe that they do. But they need to hear constantly about our story, about our patients, about the services that we provide, about the value that we bring. It’s about making those constant connections.”

- Jennifer Borrillo, MSW, LCSW, MBA  
Hemophilia Alliance

## Hemophilia Alliance and NBDF Collaboration to Address Current Threats to 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 important barrier addressed was trying to reach 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.

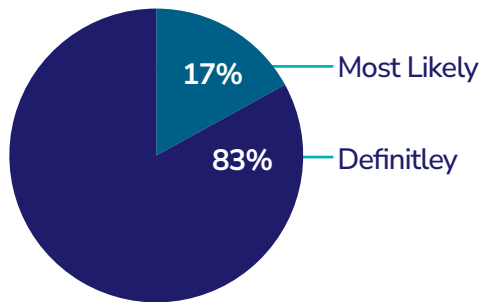
“ It’s about sustainability for our HTCs, and it’s about being able to continue to provide the excellent care that our HTCs have across the country. We don’t want to go backwards, and some of these trends that we’re seeing are going to be taking us and our patients backwards clinically. The Hemophilia Alliance feels that it’s very important to support these initiatives.”

- Jennifer Borrillo, MSW, LCSW, MBA  
Hemophilia Alliance

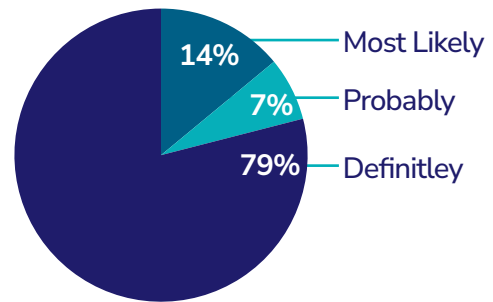
## Attendee Feedback

Participants widely agreed that initiatives such as CCSC are needed to enhance awareness of access to high-quality care that is both effective and reimbursable. Attendees also noted how CCSC can be optimally beneficial to their HTC.

Is support needed from an initiative such as CCSC to enhance the awareness among purchasers of health care (payers/insurers) regarding access to high-quality care that is both effective and reimbursable?



Is support needed from an initiative such as CCSC to advance HTC's status and access as Centers of Excellence among payers not only with currently approved treatment regimens, but also future innovative treatments?



“ Learning about the resources available was very helpful. Advocating for our patients would be very beneficial.”

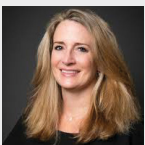
- HTC Attendee

“ Working with the Hemophilia Alliance, the regional HTC coordinators and us, in the HTCs, to collaborate on strategies to use with problematic insurance plans would be helpful. We also need help working in our larger system to improve their coordination with us.”

- HTC Attendee

## Appendix

### Expert Panel



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



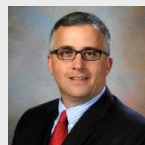
**Shannon Carpenter, MD, MSCI, FAAP**  
Chief, Section of Hematology  
Associate Director, Hemophilia Treatment Center  
Children's Mercy Kansas City  
Professor of Pediatrics  
University of Missouri-Kansas City School of Medicine



**Ryan Faden, JD, MPH**  
Director of Patient Access  
National Bleeding Disorders Foundation



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



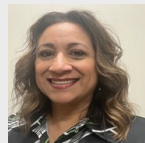
**Sal Morana, RPh, PhD**  
Executive Vice President  
Pharmacy Benefits  
Alliant Employee Benefits



**Dana McCormick, RPh, FAMCP**  
Senior Director  
Pharmacy Advisory Services  
Optum



**Elizabeth Solomon, MBA, MHSA**  
Chief Strategy Officer  
Hemophilia of Georgia



**Marisela Trujillo, MSW**  
Director of Management Operations  
Gulf States Hemophilia and  
Thrombophilia Center  
University of Texas Health Sciences  
Center at Houston

## Agenda and Key Resources

9:30 am–9:40 am ET	<b>Introduction and Review Objectives</b> <ul style="list-style-type: none"> <li>• Ryan Faden, JD, MPH National Bleeding Disorders Foundation</li> </ul>	 Key Resource: <a href="#">Latest CCSC e-News Update</a>
9:40 am–10:00 am ET	<b>Latest Threats to Care Delivery</b> <ul style="list-style-type: none"> <li>• Kollet Koulianos-Barkhouse, MBA National Bleeding Disorders Foundation</li> </ul> <i>Audience Q&amp;A</i>	 Key Resource: <a href="#">HTC Quick Guide to Alternative Funding and Copay-Centered Payer/Purchaser Initiatives</a>
10:00 am–10:25 am ET	<b>Expert Interview #1: Consequences of Delays in Access to Care</b> <ul style="list-style-type: none"> <li>• Shannon Carpenter, MD, MSCI, FAAP Children's Mercy Kansas City University of Missouri-Kansas City School of Medicine</li> <li>• Dana McCormick, RPh, FAMCP Optum</li> </ul> <i>Audience Q&amp;A</i>	 Key Resource: <a href="#">CCSC Email Hotline</a>
10:25 am–10:50 am ET	<b>Expert Interview #2: Employer perspective on Alternative Funding Models</b> <ul style="list-style-type: none"> <li>• Sal Morana, RPh, PhD Alliant Employee Benefits</li> <li>• Elizabeth Solomon, MBA, MHSA Hemophilia of Georgia</li> </ul> <i>Audience Q&amp;A</i>	 Key Resource: <a href="#">HTC Quick Guide to Alternative Funding and Copay-Centered Payer/Purchaser Initiatives</a>
10:50 am–11:15 am ET	<b>Expert Interview #3: Presenting the HTC Value Story to the Payer</b> <ul style="list-style-type: none"> <li>• Dana McCormick, RPh, FAMCP Optum</li> <li>• Marisela Trujillo, MSW Gulf States Hemophilia and Thrombophilia Center University of Texas Health Sciences Center at Houston</li> </ul> <i>Audience Q&amp;A</i>	 Key Resource: <a href="#">Value of HTCs for Payers</a>
11:15 am–11:40 am ET	<b>Expert Interview #4: Hemophilia Alliance and NBDF Collaboration to Address Current Threats to Care Delivery</b> <ul style="list-style-type: none"> <li>• Jennifer Borrillo, MSW, LCSW, MBA Hemophilia Alliance</li> <li>• Ryan Faden, JD, MPH National Bleeding Disorders Foundation</li> </ul> <i>Audience Q&amp;A</i>	 Key Resource: <a href="#">Benefits of CCSC Participation for HTCs</a>
11:40 am–12:00 pm ET	<b>Expert Panel Discussion</b> <i>Moderator: Jennifer Borrillo, MSW, LCSW, MBA</i> <b>Panelists:</b> <ul style="list-style-type: none"> <li>• Dana McCormick, RPh, FAMCP</li> <li>• Shannon Carpenter, MD, MSCI, FAAP</li> <li>• Elizabeth Solomon, MBA, MHSA</li> <li>• Sal Morana, RPh, PhD</li> <li>• Marisela Trujillo, MSW</li> <li>• Kollet Koulianos-Barkhouse, MBA</li> </ul> <i>Audience Q&amp;A</i>	
12:00 pm–12:30 pm ET	<b>Lunch and Networking</b> <b>Voices for Policy Change Presentation</b>	

## Need CCSC's Help?

Check out the new [Email Hotline](#) on [CCSCHemo.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](mailto:ccsc@impactedu.net)



## 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.

To access available resources developed by CCSC or find out how you can get involved, please visit [CCSCHemo.com](#).