

What is the Comprehensive Care Sustainability Collaborative and how can it Help You?

The Comprehensive Care Sustainability Collaborative (CCSC) is a partnership between the hemophilia treatment center (HTC) health care professionals and decision makers from the health insurance industry. National Hemophilia Foundation (NHF) created CCSC to promote high-quality, cost-effective management of bleeding disorders by supporting the sustainability of the HTC comprehensive care model. CCSC promotes the use and inclusion of HTCs into plan networks to make sure they continue to be a part of all health care systems and the services they provide remain covered by insurance plans. CCSC conducts ongoing outreach, to bring important health care decision makers together in the interest of delivering optimal patient care, in several different forms:

- Fact sheets and other educational resources for providers and plans
- Educational webcasts for clinicians
- Presentations at professional meetings that can impact coverage and reimbursement decisions and strategies
- A white paper posted on the CCSC website: www.CCSC@hemo.com

CCSC's Role in the Promotion of Affordable, Quality Care

The cost of hemophilia care can be extremely high compared with other chronic health conditions, largely due to the cost of factor replacement therapy. These costs are paid by insurers, through health coverage policies, and by patients in the form of out-of-pocket (OOP) costs, such as copays or coinsurance. Insurers have a number of methods and programs that seek to manage costs for all of their insured patients, including those with bleeding disorders. Some of these health plan strategies, such as higher cost-sharing, copay accumulator adjuster programs, and exclusive network provider contracts, may impact patient access to different components of care.

Clotting factor replacement therapy can be dispensed directly at HTCs that have an onsite pharmacy or through specialty pharmacy providers. Some health plans may have their own contracted specialty pharmacies and require patients to receive their factor replacement therapy through the plan's pharmacy rather than through an HTC, which can interfere with communication among the different health care providers and disrupt the continuity of care.

CCSC aims to minimize these disruptions in care by bringing decision makers from HTCs and health plans in a collaborative setting and advocating for patients, and in some cases directly with their individual health plans.



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CCSC is supported by charitable donations from founding supporter Takeda, and additional support from BioMarin, Biotechnology Innovation Organization, Bleeding & Clotting Disorders Institute, CSL Behring, Genentech, Inc., Gulf States Hemophilia and Thrombophilia Center, Louisiana Center for Bleeding and Clotting Disorders, Sanofi, and Spark Therapeutics. Copay Accumulator Adjustment Program (CAAP) Outreach is supported by AbbVie, Inc.

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Communicating the Vital Role of HTC

HTCs deliver family-centered, comprehensive care through a team of on-site health care providers from an array of different specialties. Whether it is doctors, nurses, social workers, physical therapists, or pharmacists, these team members are dedicated to the management of bleeding disorders and experts in the unique needs of their patients. CCSC communicates this vital role and expertise of HTCs to payers, thereby ensuring that plans are more centered on the needs of patients with bleeding disorders.

CCSC outreach aims to educate insurers by communicating that...



HTCs regularly communicate and follow up with their patients to ensure that they have the proper amount of factor available at all times.



the HTC team is available “24/7/365” via telephone support and consultation.



HTC team members provide disease-related education and infusion training, as well as support on schooling-, job-, and insurance-related matters for their patients.

In addition, CCSC communicates to insurers that patients who receive care at an HTC have better disease-related outcomes, including the following:



Fewer emergency department (ED) visits



Fewer hospital stays



Longer, fuller lives

CCSC Patient Advocacy Successes

- Overall, CCSC has pushed for including HTCs in health plan networks for their specialty pharmacy needs, including clotting factor replacement products and supplies.
- CCSC has also raised awareness about the harmful application of copay accumulator adjuster programs (CAAPs) for patients with bleeding disorders.
- In some cases, CCSC has even intervened on behalf of patients who have had their access to appropriate care hindered by the cost-management efforts put in place by their insurance plans.



To find out about how CCSC can benefit you as you navigate the financial and disease-related challenges of living with a bleeding disorder, contact: ccsc@impactedu.net

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