



Midwest Business Group on Health *2019 PBMI Excellence Award Submission* *Hemophilia: What Employers Need to Know*

Overall Description

MBGH serves as one of the nation's leading 501(c)(3) non-profit employer coalitions of mid, large and jumbo self-funded public and private companies. MBGH offers members education, research and community-based activities that increase the value of health benefits and health care services. We serve 125 companies who provide health benefits to more than 4 million lives and spend over \$8.8 billion on health care each year.

About Hemophilia

Hemophilia is a genetic disorder preventing the blood from clotting normally. If left untreated or undermanaged, it can lead to permanent, painful joint disease, disability and sometimes death. According to the CDC, the number of people in the US with hemophilia is estimated at 20,000. Because of the low prevalence of hemophilia, employers have very little knowledge of and experience with hemophilia.

Although a rare condition, hemophilia is a disproportionate driver of health care spend, placing a significant economic burden on health care payers, patients and caregivers. Indirect costs come from diminished work productivity and absenteeism. Some direct costs are the result of unnecessary hospitalizations, outpatient and ER visits. However, it is estimated that 90% of total direct medical costs result from the specialty drugs necessary to treat and manage the condition. The average annual cost of medication to treat hemophilia is more than \$270,000. With complications, this can increase to over \$1 million. Delivery and administration of these drugs is often not appropriately managed, resulting in thousands of dollars in increased cost, often due to waste.

Hemophilia: What Employers Need to Know

Although employers are uniquely qualified to support employees with hemophilia, they can only do this effectively if they are armed with the right information. This includes having an awareness of the prevalence of hemophilia in their population and the related health care spend, available treatment options, effective plan design strategies and what's covered under the medical and pharmacy benefit that can support the medical and clinical aspects of care delivery.



To equip employers with appropriate information, tools and resources to help manage their hemophilia spend, MBGH created a three-phased approach to hemophilia awareness, education and action.

Phase 1: Employer Advisory Board

- MBGH conducted an advisory board meeting, including several large and jumbo self-insured employers, to gain a better understanding of the current perspectives and attitudes of employers related to supporting employees and family members with hemophilia
- A pre-meeting survey was conducted to establish baseline knowledge and gauge employer perceptions, beliefs and benefits-related activities; a post-meeting survey was conducted to gather feedback, identify if perceptions and beliefs had changed and determine if employers will make changes to their benefits-related strategies (e.g. plan design, formulary)
- Representatives from the National Hemophilia Foundation and the Hemophilia Alliance provided an overview of hemophilia, including information about ways to mitigate risk, primary cost drivers and how employers can improve outcomes by using federally recognized Hemophilia Treatment Centers, recognized as the gold standard in caring for people with hemophilia

Phase 2: Online Employer Toolkit

- The [Hemophilia Toolkit](#), an online resource, was created to help employers better understand how hemophilia impacts their organization and provides support for creating new strategies to manage costs, prevent unnecessary waste, and improve outcomes
- This comprehensive hemophilia resource is designed to help employers build a business case for better hemophilia management, and learn about the related economic impacts, productivity implications, strategies for benefit plan design and coverage, available treatment options, and employer best practices

Phase 3: Employer Education & Awareness

- MBGH hosted a webinar, titled [Hemophilia & Bleeding Disorders: Plan Design Strategies that Address Cost, Waste & Improve Outcomes](#), to create awareness about hemophilia among MBGH members, prospective members, sister coalitions and vendor partners, and to launch the Hemophilia Toolkit as a free resource
- A promotional campaign around the Hemophilia Toolkit is ongoing and includes:
 - Information sent to members, prospective members and vendor partners in the form of weekly email updates and the MBGH quarterly newsletter
 - MBGH media manager regularly soliciting media coverage related to the Hemophilia Toolkit
 - Sharing the Hemophilia Toolkit and other related resources with sister/employer coalitions at meetings, via phone and through email communications



Achieved Outcomes

MBGH Advisory Board

- Meeting discussions, along with survey results, helped to inform the development of the toolkit online resource and subsequent webinar
- Advisory Board participants noted the value of learning about this disease, which flies under the radar for most employers; they gained clarity on the importance of plan design and contract language related to hemophilia when dealing with PBM, specialty pharmacies and health plans
- Two participating companies, Caterpillar and Walgreens, agreed to conduct a retrospective analysis to determine hemophilia-related medical and pharmacy claims spend and identify potential waste; MBGH is working with these organizations on next steps

Hemophilia Toolkit

- The toolkit provides a checklist, titled [Hemophilia: Gathering Meaningful Data](#), a step-by-step guide for employers to evaluate the impact of hemophilia on their organizations
- This type of evaluation leads to meaningful changes in strategy and ultimately cost savings, especially related to vendors including PBMs, specialty pharmacies and health plans
- The toolkit contains case studies that demonstrate the value of benefit design strategies including the use of the Hemophilia Treatment Center (HTC) model for clinical care and integrated pharmacy services for hemophilia management – these case studies help quantify predicted savings for employers
- One example is a case study that follows a patient who transitioned from a specialty pharmacy to an HTC for care and condition management:
 - A specialty pharmacy was dispensing clotting factor between 5% and 10% above the prescribed target, which is not unusual for specialty pharmacies
 - The HTC's assay management intervention resulted in dispensing at 1% to 4% below the target
 - This translated into **cost savings of \$287,000 per month** for the patient's health plan
 - **An additional \$460,000 in savings** came from precise management of clotting factor fills and expert medical management received through the HTC's integrated comprehensive care

MBGH-hosted Webinar

- The webinar had 52 participants, bringing awareness of this important issue to a broad audience of employers, vendor partners, and other employer coalitions
- During the webinar, member companies including Caterpillar and Boeing offered examples of what employers can achieve with hemophilia management. Their message encouraged employers to take these critical steps:



- Gather data to understand the impact of hemophilia on your medical/pharmacy claims costs
 - Have discussions with carriers to get the right network in place, so people can get to high-quality low-cost providers (including Hemophilia Treatment Centers)
 - Negotiate with specialty pharmacies/PBMs to put assay (clotting factor) management and dose optimization in place to reduce waste
 - Require carriers and specialty pharmacies to communicate with one another
 - Use the resources and tools available in the new Hemophilia Toolkit to guide this process
- Feedback showed the webinar was highly valuable to participants, especially information about employer plan design considerations, cost management approaches, and available resources; the Q & A was also noted as an informative feature
 - Access to the Hemophilia Toolkit is now available to free-of-charge to 125 MBGH member employers representing more than four million lives, as well as non-member companies across the country
 - Following the webinar, an article appeared in [Radar on Drug Benefits](#), a bi-weekly publication that includes readership from health plans, employers, PBMs and pharmaceutical companies, providing even more visibility to this resource

Lessons Learned

Hemophilia consistently ranks among the top-10 high cost claims conditions. However, because of the low prevalence of hemophilia, employers as a key payer group have very little experience with this genetic bleeding disorder. They lack awareness of the overall cost impact, including that related to tremendous waste of clotting factor by middlemen (e.g. PBMs and specialty pharmacies) involved in the delivery and administration of the factor, which ultimately carries a big price tag for employers.

Learning about hemophilia from the National Hemophilia Foundation and Hemophilia Alliance and gathering employer insights including current practices, plan design strategies and existing knowledge regarding hemophilia were instrumental and informed various elements of the MBGH Hemophilia Toolkit. For example, employers reported the following pain points related to hemophilia:

- No understanding of the disease
- Limited understanding of how related specialty drug costs can be managed
- Detailed reports and information on hemophilia claims are not routinely provided by PBMs
- Do not have the tools to better manage costs and don't know where to turn

This demonstrates the need for good quality resources to help employers better manage all aspects of hemophilia in their covered populations. Total cost of care can skyrocket when members with hemophilia are unmanaged or undermanaged.



High cost drivers can be addressed through a variety of strategies, including use of a benefit plan design that drives members to the highest quality, most cost-effective site of care for treatment and ensuring health plans and PBMs are appropriately managing clotting factor treatment for each patient. MBGH is committed to continued employer education on this topic.