ACTION BRIEF

Employer Strategies that Drive Health, Equity and Value

National Alliance
of Healthcare Purchaser Coalitions

MITIGATING HIGH-COST CLAIMS

A CLOSER LOOK AT HEMOPHILIA

ACTION STEPS FOR EMPLOYERS:

1. Use value-based insurance design to ensure that health plans support patients with hemophilia and their families.
2. Set expectations that health plans and other providers cover new, evidence-based treatments.
3. Ensure Hemophilia Treatment Centers are in all networks.
4. Accommodate employees with bleeding disorders by providing on- or near-site support.
5. Educate and cover health plan members with hemophilia, connecting them to the right health benefits and care management resources.

Although hemophilia is a rare disorder affecting about 25,000 people in the US, it ranks among the highest-cost healthcare conditions, averaging $270,000 per claimant annually.[1]

As with many rare diseases, hemophilia commonly requires lifelong treatment. Because of hemophilia's low incidence, employers often have little to no understanding of the disease and what makes treatment so costly. Most employers hand off the development of hemophilia cost containment strategies to intermediaries, such as pharmacy benefit managers (PBMs), carriers, TPAs or pharmacy consultants. While these vendors may develop appropriate strategies that result in the lowest total cost of care, conflicts can exist that increase employer costs unnecessarily.

When it comes to assuring optimal patient outcomes at the lowest total cost of care, employers should first consider having dialogue with hemophilia experts, before simply handing off the strategic development and implementation to vendor partners who may be conflicted. This will help them gain insight into the key cost levers that drive spend, as well as which traditional plan design strategies can create access barriers that can have a signficiant impact on spend.

> *"When it comes to rare diseases, like hemophilia, copay accumulator adjustment programs, and step therapy/fail-first language can backfire when implemented as a one-size-fits-all strategy. For patients and payers alike, the unintended consequences that can result from these obstacles can be catastrophic."*
>
> *—Kollet Koulianos, Senior Director of Payer Relations, National Hemophilia Foundation.*

UNDERSTANDING HEMOPHILIA

Hemophilia is a bleeding disorder, usually inherited, in which the blood does not clot properly. With effective treatment, most hemophilia patients can live full lives and enjoy most of the activities other people do.

Hemophilia results from a mutation in one gene that normally directs clotting factor proteins. As a result of impaired clotting, unchecked bleeding can occur within joints, causing chronic joint disease and pain; in the head, causing seizures and paralysis; or in other vital organs.

There are two types of hemophilia: Hemophilia A, resulting from a lack or deficiency of clotting factor VIII, and hemophilia B, resulting from a lack or deficiency of clotting factor IX. Hemophilia A (classic hemophilia) is four times more prevalent than hemophilia B and is often severe.

RECENT TREATMENT ADVANCEMENTS

Treatment for hemophilia is advancing. Recent developments include novel non-factor biologic agents and investigational gene therapies. In gene therapy, the patient's defective gene is replaced with a normal gene to enable the production of the active enzyme and prevent the development and progression of the disease. Advocacy groups are pushing for further care advances that can be provided at a lower cost. These include biosimilars, some of which are just finishing clinical trials and high-cost gene therapies that are coming for hemophilia.

The National Hemophilia Foundation (NHF) has advocated for the needs and interests of people affected by hemophilia and related bleeding disorders for almost 60 years. NHF advocates educate elected officials and others in healthcare and government about the unique needs of people with bleeding disorders. As a result of efforts at the federal level, millions of dollars in government funding have been used to improve medical care, services, education, and the safety and surveillance of factor replacement products.

WHAT EMPLOYERS CAN DO TO EFFECTIVELY ADDRESS RARE DISEASES SUCH AS HEMOPHILIA

Use value-based insurance design to ensure that health plans support patients with hemophilia and their families.

Care for rare diseases such as hemophilia can be very expensive. Traditional plan designs have limited flexibility in terms of deductibles, copayments and co-insurance. This type of design can have negative consequences on employee health by allocating resources to low-value care and discouraging employees from seeking high-value care for essential but expensive treatments.

The consequence can be that employees (or their dependents) do not seek adequate care for rare diseases because of unaffordable out-of-pocket costs, resulting in both a lower quality of life and ultimately more-costly care as the disease, unchecked, results in more serious consequences.

In other words, traditional plan designs can be less effective, with built-in cost barriers that discourage employees with rare diseases from seeking treatment. Instead, a "compassionate managed care" approach includes a more flexible plan design that makes treatment of rare diseases affordable and effective.

For example, consider what is happening with copay accumulator adjustment programs. These programs are designed

The Triple Aim Approach: Optimal Outcomes at the Lowest Total Cost of Care

A high-cost rare disorder like hemophilia requires a high-touch care approach. Hemophilia Treatment Centers (HTCs) are federally recognized centers of excellence that subspecialize in rare hemotologic disorders using an integrated, multi-disciplinary approach to care—the "gold standard." There are 141 HTCs in the U.S. A directory is available here.

Having a chronic disease such as a bleeding disorder often entails spending much time and effort navigating the healthcare system. At an HTC, hematologists, pharmacists, nurses, social workers, psychosocial professionals, and physical therapists provide coordinated treatment at one location with services available 24/7/365. Contracting with HTCs as in-network providers enables employers to improve patient outcomes and manage treatment costs. When HTCs are not in the plan network and specialty pharmacy is carved out to an exclusive provider, total cost of care can increase significantly.

to help employees with rare diseases reduce their out-of-pocket expenditures when they need expensive drug treatments. However, the application of these copay accumulator programs is being challenged in recent CMS rulings. As a result, employees end up paying more for the drugs they vitally need. Employers can design plans to lower copays for effective, high-cost rare disease care.

The University of Michigan Center for Value-Based Insurance Design is promoting Value-based insurance design (V-BID) principles for marketplace and employer health plans. These designs seek to eliminate the underutilization of high-value care, such as that for hemophilia, that occurs when plans allocate more resources to low-value care with no clinical benefit. With value-based plans, employers incur savings by making high-value care more accessible and affordable to employees.

Set expectations that health plans and other providers cover new, evidence-based treatments.

New treatments for hemophilia are becoming available. Often, they are safer and more effective than traditional treatments.

Payers are encouraged to make sure their benefit plans cover these new treatments. For treating hemophilia, doctors now have access to recombinant factor VIII, artificially created in a lab. Recombinant factor VIII can be used instead of factor VIII obtained from human blood (frozen plasma), avoiding the risk of viral infections, which are sometimes transmitted in human blood.

The NHF is supporting the advancement of gene therapy, as scientists better qualify who might be best suited for the therapy. Issues of cost and long-term durability, efficacy, and safety are being determined.

Ensure your health plan offerings include providers with hemophilia experience and expertise.

HTCs represent the gold-standard model of care for the management of bleeding disorders. These specialized centers provide comprehensive care for individuals with hemophilia, including the development of specific treatment plans, monitoring and follow up of affected individuals, and state-of-the-art medical care.

This care results in documented improvements in outcomes, including a lower likelihood of death, fewer hospitalizations, and lower use of emergency services.

Individuals who go to HTCs will not only receive outstanding medical care, but also benefit from an experienced, caring staff that takes time to develop comprehensive treatment care plans for patients and families. Since hemophilia is heritable, genetic counseling is included to help families make informed reproductive and other decisions.

The treatment centers not only provide specialty care but also act as a resource for primary care doctors and dentists. This approach can serve as a benchmark for other network provider options.

What is Value-Based Plan Design?

"It's the idea that insurance design should be built on the concept that high-quality treatments and providers should cost less. This kind of smart pricing is intended to improve health and minimize waste."

—Tara Bishop, MD, MPH

Accommodate employees with bleeding disorders by providing on- or near-site support.

Under the Americans with Disabilities Act, employers are obligated to accommodate employees with bleeding disorders. In particular, if asked by the employee, employers must:

- Provide the employee with a private place to self-administer infusions.
- Offer a safe place for the employee to store needles and infusion supplies.

Educate and cover health plan members with hemophilia, connecting them to the right health benefits and care management resources.

Tutorials on rare diseases and best treatment practices are available from national organizations and can be shared with employees with these conditions. For example, the NHF promotes a five-step regimen for people with hemophilia:

1. Get an annual comprehensive checkup at a hemophilia treatment center.

2. Get vaccinated—hepatitis A and B are preventable.
3. Treat bleeds early and adequately.
4. Exercise and maintain a healthy weight to protect your joints.
5. Get tested regularly for blood-borne infections.

Additionally, care management resources can be used to train individuals with hemophilia who may need to self-administer treatment, such as prophylactic (i.e., preventive) factor infusions or on-demand factor infusions, depending on disease severity.

Parents and affected individuals can be trained to administer infusions at home. Self-infusion training is a service that is provided as part of HTC-delivered comprehensive care. This is especially important for those with severe disease because infusion of factor VIII concentrate is most effective within one hour of the onset of a bleeding episode. In general, rapid treatment is important because it reduces pain and damage to the joints, muscle, or other affected tissues or organs; improves quality of life; and boosts productivity.

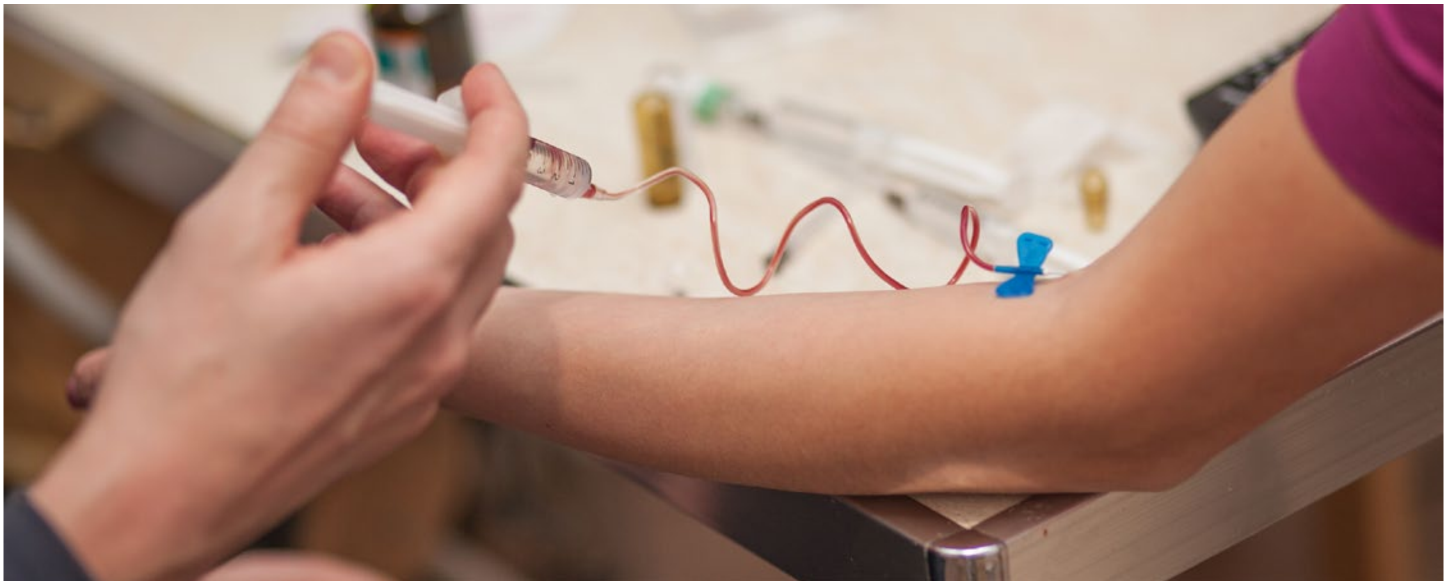
Employers can take action to ensure that employees with rare diseases get their jobs done while also managing their health at optimal levels. By understanding and honoring the rights of rare-disease patients and making resources available to help them perform their duties, employers create a supportive environment where employees with hemophilia and other rare conditions can thrive.

REFERENCE

1 Zhou ZY, Koerper MA, Johnson KA, et al. J Med Econ. 2015:18(6) 457-65..

RESOURCES FOR EMPLOYERS:

- National Hemophilia Foundation
- Midwest Business Group on Health Hemophilia and Bleeding Disorders Toolkit
- Comprehensive Care Sustainability Collaborative
- Centers for Disease Control and Prevention, Hemophilia
- Mayo Clinic: Hemophilia Best Practices



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Driving Health, Equity and Value

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