How to Determine Your Financial Exposure and Impact to Individuals Seeking Care

For those with hemophilia, an employer's benefit plan can have a significant impact on the type, quality and timeliness of care received. Asking the right questions is key to understanding the full impact of your plan as plan design can have unintended (and sometimes dire) consequences for those with rare diseases such as hemophilia. It's never too early to pose these questions to your vendor partners, whether or not you have a current member with hemophilia on your benefit plan.

Stop-Loss Coverage

1. Does the stop-loss policy provide coverage for Hemophilia A and Hemophilia B without condition-specific exclusions?
2. Are routine hemophilia treatments (including prophylactic factor or non-factor therapy) eligible to accumulate toward the individual stop-loss deductible?
3. Are hemophilia drugs covered when billed under pharmacy, medical, or both, and are there any differences in how claims are counted?
4. Are self-administered specialty drugs treated differently than provider-administered infusions for stop-loss purposes?
5. Are manufacturer rebates, copay assistance, or other offsets deducted before claims apply toward the deductible?

Pre-Existing Conditions & Eligibility

1. Are members with a known hemophilia diagnosis prior to the policy effective date excluded from coverage?
2. Are exclusions applied differently to existing employees, new hires, or newly added dependents?
3. If a member qualifies for coverage in the first policy year, are they eligible for coverage in subsequent policy years?

Financial Limits & Policy Mechanics

1. Is hemophilia subject to any annual or lifetime maximum reimbursement limits?
2. How are claims handled if costs span multiple plan years?
3. Are hemophilia claimants subject to individual lasers, and if so, how are those determined?
4. Can lasers be removed or renegotiated over time?

Gene Therapy

1. Does your policy cover hemophilia gene therapies such as Hemgenix for Hemophilia B?
2. If gene therapies are covered, are they subject to any sub-limits, separate deductibles, or reimbursement caps?
3. Are gene therapy claims covered under medical stop loss, pharmacy stop loss, or both?
4. Is prior approval from the stop-loss carrier required before gene therapy administration?

   - If yes, what are the medical-management criteria for determining eligibility?

   - Are these criteria based on published guidelines or internally developed standards?
5. If gene therapy is denied by stop loss, do you as the employer retain 100% financial responsibility?