NATIONAL **BLEEDING DISORDERS** FOUNDATION

Personal Health Insurance Toolkit

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Quality, affordable health insurance is essential for anyone living with a bleeding disorder. Quality insurance allows you to access the health services and medications you need to preserve your health – and provides a mechanism for paying the high and ongoing costs of this care.

There are various potential sources of coverage. Private coverage is, in essence, a financial contract between a private payer and you, the policy holder. It can take the form of group insurance offered by an employer or can be purchased on an individual/family basis from health insurance companies in the private market. Public health plans (Medicare, Medicaid, and Children's Health Insurance Program (CHIP) insurance) are another important form of coverage, but largely fall outside the scope of this toolkit. For information about public health coverage, please refer to the NBDF website at bleeding.org.

Job-based coverage

Over half of all Americans are covered by group health plans offered through their employers.

Large employers typically offer self-funded plans. In a self-funded plan, the employer bears the costs and risks of health coverage (though the employer typically contracts with an insurance company to administer claims).

Smaller employers, by contrast, may offer small group/fully-insured plans, with an insurance company assuming the costs of enrollees' health care. Different laws apply (and different government agencies have jurisdiction) over self-funded versus fully-insured plans.

Self-funded large group plans	**The Employee Retirement Income Security Act of 1974 (ERISA) is the principal federal law that governs self-funded plans. Some but not all Affordable Care Act (ACA) provisions apply.** State law does not generally apply.	**Principal governmental authority**: US Department of Labor
Fully-insured and small group plans	**ACA requirements and protections apply to all plans purchased after the ACA's effective date.** State law applies.	**Principal governmental authorities**: US Department of Health; state insurance regulators

Individual and family coverage through the ACA Marketplaces

People without access to employer-provided insurance can purchase individual and family coverage on and off the ACA Marketplaces.[1] The Marketplaces (also known as exchanges) are one-stop shops for purchasing comprehensive health insurance. (You can purchase coverage off the Marketplace by contacting an insurance broker, but if you take this route, you need to exercise special care to ensure that your coverage will be comprehensive.)

Some Marketplaces are state-run and go by different names – but, wherever you live, you can access the right Marketplace for your state by starting at healthcare.gov and entering your home address. If you don't have insurance through your employer, there are good reasons to start your coverage search at healthcare.gov (the portal to the ACA Marketplace).

- Marketplace plans are comprehensive insurance, providing coverage for all 10 federally mandated essential health benefits (EHBs), including outpatient care, hospitalization, prescription drugs, mental health, and more, as well as all state-mandated benefits.
- If it looks like anyone in your household qualifies for low- or no-cost Medicaid or Children's Health Insurance Program coverage (CHIP), the Marketplace will send your information to your state agency, and that agency will contact you about enrollment.
- Shopping through the Marketplace ensures that the plans you see meet ACA standards for coverage, financial protection, and network adequacy. The Marketplace does not sell "junk" plans that don't offer all of the ACA patient protections.

[1] Even if your employer offers job-based insurance, you can still go to the Marketplace to explore other options that may be available to you and your household. However, there are some important things to consider before deciding to opt out of your group health plan. Employers typically pay a portion of the premiums associated with a job-based group plan. If you choose to obtain a Marketplace plan, the employer does not contribute to your premiums. Also, if your employer's plan meets ACA standards for coverage and affordability, you will not be entitled to premium subsidies to purchase a Marketplace plan instead of signing up for your job-based coverage.

Buyer Beware: Avoid "Junk" Plans!

"Junk" health plans are forms of coverage that don't have to comply with ACA standards for benefits covered and financial protection. They include short-term limited duration health plans, association health plans, health care sharing ministries, and Farm Bureau plans.

"Junk" plans are heavily advertised and often show up as some of the top results if you enter "health insurance" into a general internet search engine.

"Junk" plans exclude coverage for basic, essential services such as prescription drugs, specialist visits, inpatient hospital stays, and more.

"Junk" plans almost always limit how much they will pay in benefits - and generally do not cap how much you may have to pay out-of-pocket for your care. That can put you at substantial financial risk.

You can avoid "junk" plans by starting your insurance search at healthcare.gov.

Eligibility for Marketplace Coverage

Consumers are eligible to purchase health insurance coverage through the Marketplace if they:

- Live in the state in which they are applying;
- Are U.S. citizens (see footnote for non-citizen eligibility information) *https://www.healthcare.gov/immigrants/immigration-status/*
- Are not currently incarcerated.

Consumers may be eligible for premium subsidies to reduce the costs of their Marketplace plans if they:

- Have a household income equal to or higher than the Federal Poverty Level (FPL);[2]
- Lack access to affordable coverage through an employer (including a family member's employer); and
- Are ineligible for coverage through Medicare, Medicaid, or CHIP.

When can I enroll in private coverage?

All health plans have annual open enrollment periods (OEPs) – a period when people (regardless of their health history) can sign up for new or renewed coverage for the coming year. OEP dates vary, depending on where you live and whether you get your coverage from an employer, an ACA Marketplace, or another source.

For ACA Marketplace plans, open enrollment typically opens in November and ends in December or January for coverage for the next year, though be sure to search for the OEP for your state. For 2025 ACA coverage, open enrollment ran from November 1, 2024, to January 15, 2025, in almost every state; however, you generally had to enroll by December 15 for coverage that begins January 1. A few states (including California, Massachusetts, New Jersey, New York, Rhode Island and Washington DC) extended the deadline for open enrollment beyond January 15, while Idaho open enrollment is October 15th - December 15th.. Check with your state Marketplace to learn more.

It is important to note that you do not qualify for a SEP if you lose coverage because you didn't pay your premiums or because you voluntarily dropped your coverage. You must meet the specific criteria used by the Marketplace to qualify.

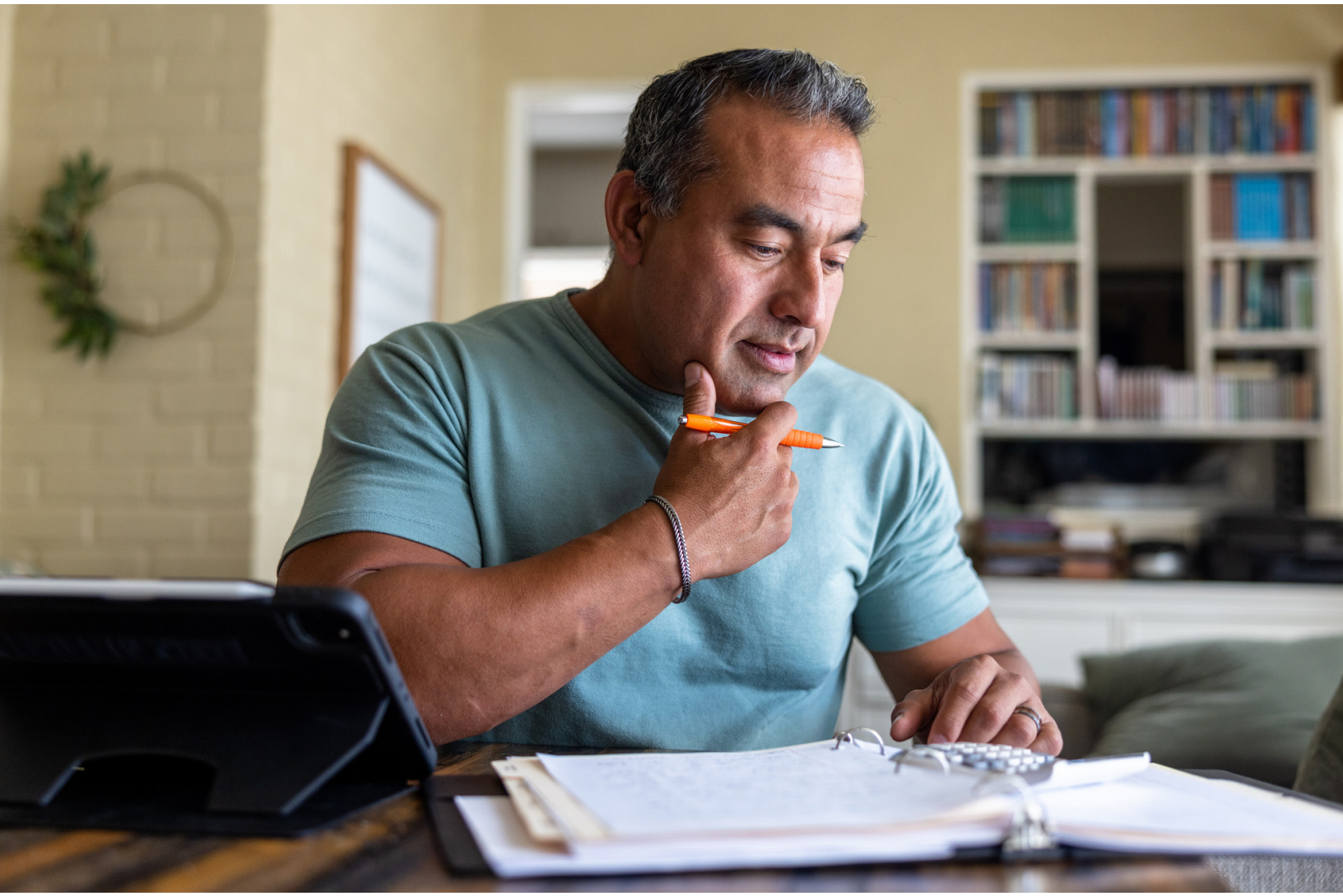
[2] The FPL for 2026 is $15,650/year for an individual, or $31,300 for a family of four.

Questions people should consider when choosing a plan include:

- What is the monthly/annual premium for the plan?
- Does it cover all the services I need?
- Are out-of-network benefits available? What percentage of the cost am I responsible for if I receive out-of-network care?
- Am I covered if I get sick/need treatment out of state?
- What is the total of my out-of-pocket costs, including medical and prescription co- pays, deductibles and coinsurance?
- Are all my physicians in network?
- Are there annual limits on the number of visits for any particular service? (For example, physical therapy is often limited to a certain number of visits per year).

Choosing a Plan

- Types of plans
- Costs of coverage
- Financial assistance



Choosing a Plan

Choosing a health plan can affect both your health and finances, so it's important to have a thorough understanding of your options and the medical and pharmacy services that you typically use.

You have the most detailed knowledge of your and your family's healthcare needs—use extreme caution when considering outside recommendations for how you should get coverage.

Types of Plans

Private plans, whether employer-sponsored or Marketplace plans, may come in various forms:

- PPO (preferred provider organization): your cost-sharing is lower if you obtain care from a provider within the health plan's network of providers, but you may also go outside the network at additional cost to you.
- HMO (health maintenance organization): you will need to get all or most of your care from within the plan's network, and will likely have to pay all the costs of non-emergency care you receive from non-network providers.
- POS (point of service plan): a hybrid of PPO and HMO gives you somewhat more ability to get out-of-network care.
- HDHP (high deductible health plan): in return for lower monthly premiums, you have to satisfy a high initial deductible before your plan starts paying for most of your care; plan may come in combination with a tax-privileged Health Savings Account.

Costs of Coverage

When calculating your coverage costs, be sure to factor in not only the costs you pay to acquire coverage (premiums), but also the costs you will have to pay to use that coverage ("cost-sharing").

- Premiums are the monthly amount you pay up front to enroll in coverage, whether or not you use care in any given month.
- Cost-sharing refers to your share of costs for any given episode of care. This category includes deductibles, copayments, and coinsurance, up to the plan and/or statutory out-of-pocket maximum.

Premiums and cost-sharing are often inversely related: lower premiums come with higher cost-sharing, and vice versa. **Cost-sharing over the course of a plan year can be substantially more than premiums.**

Cost-sharing – in general:

"Cost-sharing" refers to the share of costs (per episode of care) for which you are responsible. These are out-of-pocket costs, over and above your monthly premiums, and include:

- A deductible is the amount that you must pay for covered care before your health insurance begins to pay. Insurers apply and structure deductibles differently – sometimes, e.g., using a single deductible for all health care services, and other times setting separate deductibles for prescription drugs and medical care.
    - ACA-compliant plans are required to cover certain preventive services with no cost-sharing (i.e., even before you have satisfied your deductible).
- Copayments are flat dollar amounts you must pay for a covered service or treatment.
- Coinsurance requires you to pay a stated percentage of medical costs for a covered service or treatment, rather than a flat dollar amount.
- The out-of-pocket (OOP) maximum sets the upper limit that applies to your cost-sharing for a given year. By law, maximum OOP cost-sharing for all ACAcompliant plans (employer-provided and Marketplace) cannot exceed $10,150 for an individual plan or $20,300 for a family plan in 2026 – and your plan may have an OOP maximum that is lower than this statutory level. But note: OOP maximums only apply to in-network spending on essential health benefits. If you go outside your plan's network for care, and if you use care not covered by your health plan, your spending for those services will not count toward your OOP maximum.

Cost-sharing in Marketplace coverage:

For qualifying individuals, Marketplace plans provide financial assistance in the form of cost sharing reductions.

This financial help – only available to individuals and families enrolled in silver level plans – allows enrollees with incomes below 250% FPL to save on their deductibles, copayments, and coinsurance, and lowers their out-of-pocket maximum (i.e., reduces their overall exposure to health costs for the year).

State financial assistance/Marketplace plans:

A number of states offer cost-sharing reductions and/or premium subsidies that "stack" on top of the federal subsidies. Eligibility may vary based on income level, age of enrollee, or other factors. Check your state Marketplace to learn more.

Metal tiers:

Plans sold on the Marketplace are also categorized by metal tiers: bronze, silver, gold, and platinum.

The lowest level of coverage is called the bronze level: With low premiums but high deductibles and high out-of-pocket maximums, it is designed to cover 60% of the cost of care for a "standard" consumer.

A silver level plan will cover 70% of total average costs for covered benefits, a gold plan will cover 80%, and a platinum plan will cover 90%. Regardless of the metal level, no Marketplace plans can impose out-of-pocket maximums higher than $10,150 for an individual or $20,300 for a family in 2026.

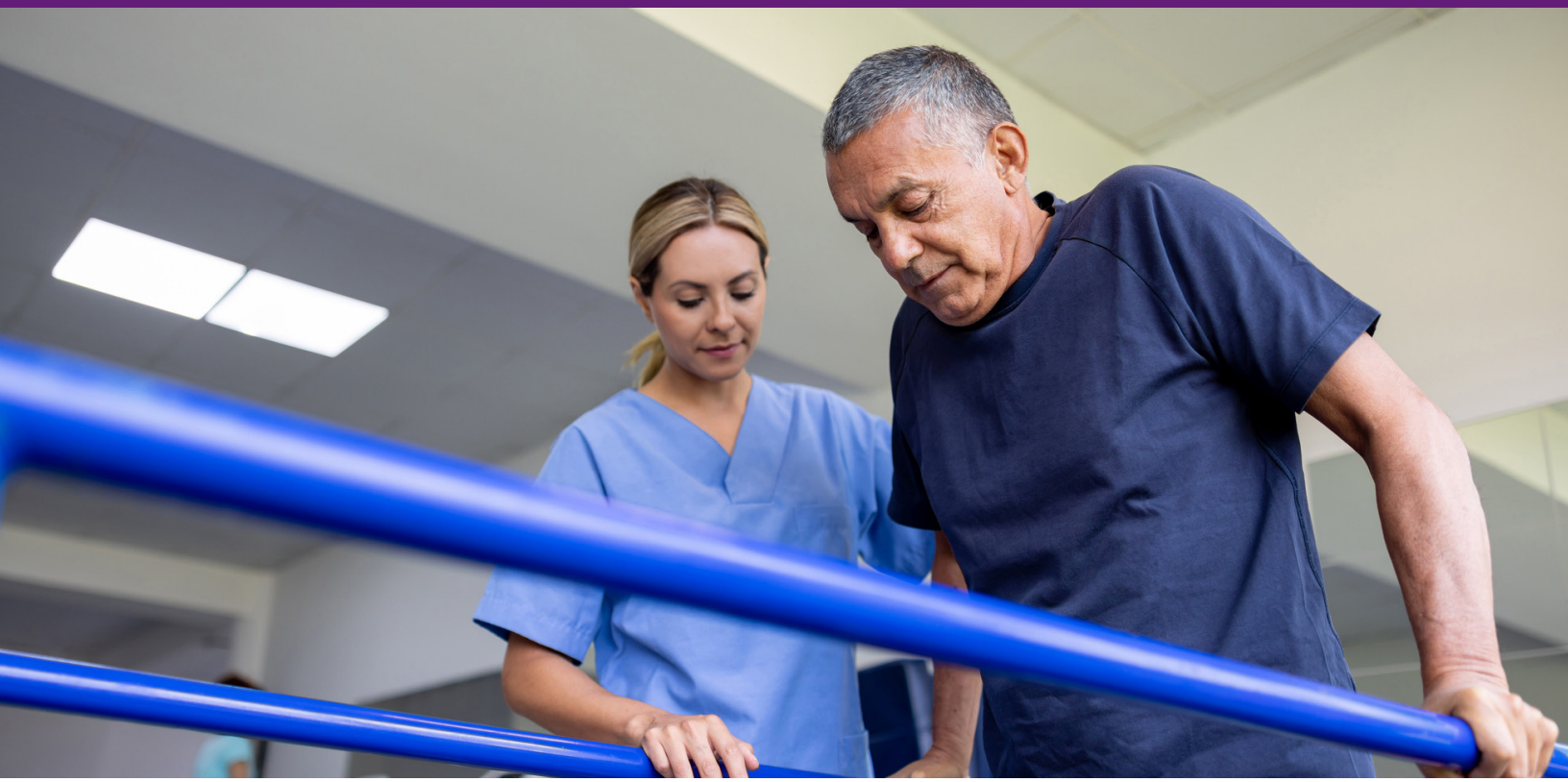
Remember that cost-sharing reductions, for those eligible based on income, are only available for silver tier Marketplace plans. Again, in most cases, higher metal tier plan will have higher premiums but lower cost-sharing.

Quick Tips

- Shop carefully! Ask questions such as: Are my prescription drugs covered? Will I have access to the providers I need? Are there limits on services or drugs?
- Don't buy a plan just because it has the lowest premiums. Low premium plans come with higher out-of-pocket costs to access care. Your total costs can be substantially higher under a low-premium plan than they would be under a plan with somewhat higher monthly premiums.
- If purchasing a Marketplace plan, make sure to check whether you qualify for subsidies that can reduce your out-of-pocket costs.
- Ask for help in weighing your choices from an unbiased source, such as your HTC social worker, a Marketplace navigator, or your local or national bleeding disorder organization. We can't make the decision for you but can guide you.
- Plans change from year to year: how much they cost (premiums and cost-sharing); what providers are in-network; what drugs are covered on formulary; and more. Don't automatically renew last year's plan without checking to see if it still meets your needs.
- Don't wait until the last minute to shop!

Evaluating Your Health Plan Options

- Scope of coverage
- Health plan cost comparison worksheet
- Questions specific to bleeding disorders coverage
- Wading through the jargon



Evaluating Your Health Plan Options: Scope of Coverage

All health plans (health insurance companies and employers offering coverage) are required to use a standardized form to describe the benefits and coverage offered under the plan. This document is known as the summary of benefits and coverage (SBC).

The SBC makes it easier for consumers to compare plans when enrolling in coverage, and to understand the benefits and costs involved with each plan. Health plans must automatically provide the SBC to a person who completes an application for coverage or to any person who requests a summary within 7 days.

A plan's SBC includes information on important elements such as the deductible, co-pays, services not covered, and whether enrollees need a referral to see a specialist. The SBC must also include "coverage examples" of some common medical conditions, which will give consumers a rough estimate of cost for each condition in order to compare plans.

The SBC should provide you with information on general questions such as:

- What is the monthly/annual premium for the plan?
- What is the upper limit on my yearly out-of-pocket costs, including medical and prescription co-pays, deductibles and coinsurance?
- Are all my physicians in network?
- Are there annual limits on the number of visits for any particular service? (For example, physical therapy is often limited to a certain number of visits per year).
- Are out-of-network benefits available? What percentage of the cost am I responsible for if I receive out-of-network care?
- Am I covered if I get sick/need treatment out of state?

Health Plan Cost Comparison Worksheet

Plan Name			
Plan type (PPO, HMO, POS, HDHP)			
Does the plan require you to choose a primary care physician (PCP)?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
If so, is your current PCP in network?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Annual Premium	$	$	$
Financial (deductible/coinsurance/annual limits)			
Deductible (in network): Individual Family	 $ $	 $ $	 $ $
Is the deductible embedded or non-embedded (sometimes called aggregate)?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Are any services (other than preventative) covered before the deductible is met?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Coinsurance (i.e. 80/20, 70/30)	%	%	%
Maximum out of pocket (MOOP): Individual Family	 $ $	 $ $	 $ $
Are there any services or costs not included in the maximum out-of-pocket?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
If so, what are they?	$	$	$
Preventive Care[5]			
Physical exam	$	$	$
Routine pediatric care	$	$	$
Immunizations[6]	$	$	$
Major Medical			

[5] For a list of preventive services that must be covered without cost-sharing under the ACA, go to: http://www.healthcare.gov. Only those services that are recommended for you by your doctor will be covered without cost-sharing. Note that this requirement doesn't apply to grandfathered plans, i.e., plans that pre-date passage of the ACA.

[6] The ACA bans cost-sharing for recommended vaccines for adults and children under the preventive services requirement.

Health Plan Cost Comparison Worksheet

Do you have a copy of the plan's provider list?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Plan Name			
In Network			
Please note: cost shares may vary when using out of network providers	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
If permitted, indicate plan's percentage of cost for out-of-network services	%	%	%
Outpatient Care			
Physician office co-pay	$	$	$
Specialist co-pay	$	$	$
Surgery	$	$	$
Laboratory services	$	$	$
Hospital Care (Inpatient services)			
Physician's and surgeon's services	$	$	$
Semi-private room and board	$	$	$
All drugs and medications			
Emergency Care			
Emergency room			
Urgent care center			
Maternity Care			
Prenatal and postnatal care (per visit)			
Hospital services (mother and child)			
Substance Abuse			
Inpatient: visits allowed per calendar year			
Outpatient: visits allowed per calendar year			

Health Plan Cost Comparison Worksheet

Mental Health[7]	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Inpatient: Visits allowed per calendar year			
Outpatient: Visits allowed per calendar year			
Pharmacy Benefit (Do you have a copy of the plan's drug formulary?)	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Yearly deductible (Note: the plan may have separate deductible for drugs)	$	$	$
Co-pay Tier 1 (generics)			
Co-pay Tier 2 (brand/preferred)	$	$	$
Co-pay Tier 3 (brand/non-preferred)	$	$	$
Are there any restrictions on obtaining drugs (e.g., fail first or prior authorization)?	$	$	$
Coinsurance Tier 4 (specialty tier) % cost share or co-pay	$	$	$
If your plan has a specialty tier with coinsurance is there a per prescription maximum?			
Is there a yearly maximum out of pocket?	$	$	$
Is clotting factor covered under the pharmacy benefit?	$	$	$
Do you have more than one choice of pharmacy provider?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Do you have more than one choice of pharmacy provider?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Other (if offered; note where there are any limits on number of covered visits or days)			
Chiropractic	$	$	$
Short-term rehabilitation: inpatient	$	$	$

[7] The Mental Health Parity and Addiction Equity Act prohibits plans from imposing higher deductibles or co-pays or tighter limits on mental health services than are allowed for medical services in the plan.

Health Plan Cost Comparison Worksheet

Short-term rehabilitation: outpatient	$	$	$
Skilled nursing facility (SNF) (Is clotting factor covered while inpatient?)	$	$	$
Home healthcare	$	$	$
Hospice care: inpatient	$	$	$
Hospice care: outpatient	$	$	$
Durable medical equipment (DME)	$	$	$
TOTAL ESTIMATED COST			

Questions Specific to Bleeding Disorders Coverage

The SBC is designed to answer general questions. It won't, however, provide detailed information on all the points important to someone seeking coverage and care for a bleeding disorder. To get that critically important information, you will probably need to dig deeper – requesting the full plan document and/or talking with health plan administrators about your specific needs and concerns.

- Is my bleeding disorder medication covered? If so, is it covered as a major medical or a pharmacy benefit?
- Do I have a choice of more than one specialty pharmacy provider?
- Is my hemophilia treatment center (HTC) in network?
- Does manufacturer-provided copay assistance count towards my deductible/out-of-pocket?
- Is durable medical equipment (DME) covered?
- Do I need a referral to see a specialist (e.g., a hematologist)?
- What services require prior authorization?
- Are physical therapy services covered? Home nursing?

Personal Health Experience Stat Sheet

Choosing a healthcare plan can be very confusing. There are many things to consider; two of the most important are network adequacy and out-of-pocket costs for care and services (benefit design). When trying to determine your potential out-of-pocket costs, it is important to determine which benefits you (and your family, if you are all on the same policy) typically use and how often you use them. This will help you project your out-of-pocket costs for the upcoming benefit year. The easiest way to do this is to ask yourself the following questions:

In the past 12 months I have:

Visited my primary care physician ___time(s).

Spouse has visited his/her primary care physician ____time(s).

Child(ren) have visited their primary care physician ____time(s).

Been seen by a specialist _____time(s).

Spouse has visited his/her primary care physician ____time(s).

Child(ren) have visited their primary care physician ____time(s).

Visited an ER _____time(s).

Spouse visited an ER _____time(s).

Child(ren) visited an ER _____time(s).

Purchased prescriptions (including for my family) at my local retail pharmacy.

(a) What was the name of the medication(s)?
(b) Was it recurring (or maintenance) medication or was it a one time use?

Used manufacturer copay assistance to cover the costs of my specialty medication?

_____ YES _____ NO

Personal Health Experience Stat Sheet

In the past 12 months I have:

Purchased bleeding disorder medication ___times per month/year from

_____(insert name of specialty pharmacy provider)

Visited an urgent care center _____time(s).

Spouse has visited an urgent care center _____time(s).

Child(ren) an urgent care center _____time(s).

Been admitted to a hospital for an overnight stay _____time(s).

Spouse was admitted to a hospital ____time(s).

Child(ren) was admitted to a hospital _____time(s).

Needed home health services (such as nursing care) _____time(s).

Spouse needed home health services _____time(s).

Child(ren) needed home health services _____time(s).

Used habilitative or rehabilitative services _____time(s).

Spouse used habilitative or rehabilitative services ____time(s).

Child(ren) used habilitative or rehabilitative services _____time(s).

Spotting hidden dangers before you buy a plan

Many people with bleeding disorders rely on copay assistance programs to help cover the out-of-pocket costs for their life-saving prescription medications. Unfortunately, health plans increasingly refuse to count copay assistance dollars toward patient deductibles and out-of-pocket maximums. Health plans or their PBMs will typically accept the patient assistance, but will then use confusing strategies ("copay accumulator adjuster programs" or "copay maximizers") to divert the funding to their own bottom line, away from the patient (the intended beneficiary of the program). These practices expose patients to high and often unexpected costs, making it hard for patients to stay on their treatment plans.

Separately or in tandem with the copay diversion tactics explained above, some employer health plans are adopting a dangerous new approach to limit their spending on high-cost medications: so-called "alternative funding programs," or AFPs. Third-party vendors promise that AFPs offer a way for employer health plans to cut specialty drug spending – without harming employees' access to their medications. In practice, though, AFPs deny or limit coverage for those drugs under the health plan, and then try to enroll the employees who use those medications into drug manufacturers' charitable Patient Assistance Programs (PAPs). Because PAPs exist to provide free drugs to people facing short-term gaps in insurance coverage, AFPs often go to great lengths to make it appear that the employee is un- or under-insured and therefore eligible for free PAP-provided product.

If the PAP nonetheless denies assistance, the AFP and the health plan may reverse course and allow coverage – or the employee may be left without access to their medication. NBDF and allied patient groups are asking lawmakers to enact patient protections against AFPs. If you are told that your plan requires you to enroll in an AFP, please contact NBDF for further consultation.

Strategy	How it works	Patient impact
Copay accumulator adjuster program	The plan accepts the copay assistance, but only counts sums paid out of the patient's own pocket toward the patient's required cost-sharing. The plan eats up the total value of available copay assistance (potentially with the patient's second or third prescription fill of the plan year). Because none of this amount counts toward patient OOP, the patient hits a "copay cliff" – and must pay a large and often unexpected amount in order to get their next prescription refill.	Once the patient's copay assistance is used up, the patient can't get their next prescription refill unless the patient pays required cost-sharing out of their own pocket. If the patient can't afford that amount, they may abandon their treatment plan – with devastating consequences for their health.
Copay maximizer program	Health plan (typically, a large group, self-funded plan) declares one or more specialty drugs a covered but "non-essential" health benefit. This designation allows the health plan to disregard ACA limits on patient cost-sharing. The health plan sets required cost-sharing for the drug(s) at level designed to deplete copay assistance; it tells the patient the only way to avoid these costs is to sign up with a third-party maximizer, which will enroll the patient in their drug manufacturer's patient assistance program. The total value of available copay assistance flows to the health plan.	So long as the maximizer program operates as intended, the patient never faces a large/unexpected bill that keeps them from getting a refill of their drug; however, the patient remains exposed to their full cost-sharing amount for all other medical services AND the patient may have to contend with additional complexity and red tape to navigate the maximizer program and continue accessing their treatment.
Alternative funding program	Health plan (typically, a large group, self-funded plan) denies or limits coverage for one or more specialty drugs; refers the employee to a third party "care representative" that instead seeks to enroll the employee into the drug manufacturer's charitable Patient Assistance Program (PAP), providing free product. Sometimes plans require employees to apply for the PAP as part of their prior authorization process. If the AFP is unsuccessful in this effort, the AFP and the health plan may reverse course and allow coverage – or the employee may be left without access to their medication.	Targeted employees face unnecessary red tape and delays, potentially harming their health. Many will not qualify for PAPs (because they are above income, or because the PAP determines that they do in fact have health insurance) and those who do qualify are not guaranteed long-term access to their medications. PAPs do not provide ancillary supplies for home administration; PAP medications are also not eligible for use in the inpatient setting, so anyone who is hospitalized will not have their treatments covered.

Current legal status: copay accumulator adjusters

As of October 1, 25 states plus the District of Columbia and Puerto Rico have passed laws prohibiting state-regulated plans from implementing copay accumulator adjusters. In addition, a 2023 court ruling holds that health plans may not apply copay accumulator adjusters to brand name drugs that lack a medically appropriate generic alternative.

Unfortunately, a recent survey shows that many plans continue to include copay accumulator adjusters even when prohibited by state law – and federal health regulators have so far declined to take enforcement action against health plans that continue to flout the 2023 federal court ruling.

Insurance shoppers should carefully read their plans for the presence of copay accumulator language and, if an accumulator is present, should follow up with their health plan, hemophilia treatment center, state regulator, and/or patient organization.

They can find draft talking points for conversations with their health plans by scanning the qr code.

Current legal status: copay maximizers.

A new federal rule went into effect for 2025, barring the use of copay maximizers in ACA-regulated health plans. (The rule states that a health plan cannot treat some drugs as essential health benefits and others as "non-essential" health benefits – to the extent that a health plan chooses to cover prescription drugs, then all those drugs are considered essential health benefits and are subject to ACA limits on patient OOP spending.)

This new rule does not automatically apply to self-funded large group plans, though the relevant federal agencies have said they will undertake rule making to remedy that gap.

Wading through the jargon

If your plan contains copay accumulators, copay maximizers, or alternative funding programs, those provisions will typically appear in your plan documents, but the relevant language can be confusing or even misleading – and hard to find. Here are some examples of language to look out for.[8]

[8] See https://allcopayscount.org/resources/how-to-spot-copay-accumulator-programs-sample-language-found-in-health-plan-policies/; https://hivhep.org/testimony-comments-letters/employers-and-issuers-using-non-essential-health-benefit-prescription-drug-vendors/ (accessed December 6, 2024).

Copay Accumulator Adjuster	"Specialty copay solutions," "out-of-pocket protection programs," "copay offset programs"
	"Discounts, coupons, or other amounts from third parties may not be used to satisfy the benefit period deductible."
	"Cost-sharing reductions for any prescription drugs obtained by you through the use of a discount card or coupon provided by a prescription drug manufacturer will not apply toward any deductible or the annual out-of-pocket maximum under your plan."
Copay Maximizer	"You can take advantage of coupons that are available through [Third Party] for certain specialty medications. With these coupons, your medication will be free. If you don't use [this] program, you'll pay 30% coinsurance. [Third Party] will contact you if your medication is eligible."
	"Please call 1-800-xxx-xxxx to participate. Once you've completed the manufacturer copay assistance program's enrollment process and consented to [Third Party] monitoring your pharmacy account, your responsibility will be reduced."
	"[Third Party] provides you with access to select specialty drugs at no cost by registering with [Third Party], which optimizes manufacturer rebates to save you and your employer money."
Alternative Funding Program	"Our goal is to obtain alternate funding for your specialty prescriptions. A Care Coordinator will be assigned to work directly with you – please prepare to have a call with them. There is paperwork that will need to be completed by you. [We] advocate on your behalf with drug manufacturers, and our Care Coordinators facilitate with multiple entities to lower the cost of your prescription drugs, Often, members end up paying nothing out of their own pockets once they are admitted into our programs."
	"If you receive a new prescription that requires Prior Authorization, you can expect an immediate Denial of Coverage BUT, DON'T BE ALARMED, that is part of the process. The Prior Authorization is immediately sent to [Third Party] to acquire the drug and find funding to reduce or eliminate your costs. [Third Party] will immediately REACH OUT TO YOU to guide you through the process and keep you informed. YOU MUST SPEAK WITH THEM SO THAT THEY CAN WORK ON YOUR BEHALF – they work for you."
	"[Third Party] is a US-based Specialty Drug Cost Containment provider who partnered with your employer to address to growing cost related to specialty medications. Our advocacy model successfully procures alternative funding for high-cost medications. Q: Is my medication still covered? A: The method of obtaining the medication has changed. Instead of going through the Pharmacy Benefit Manager, fulfillment will now go through [Third Party]. Q: Do I have to provide financial information? A: Financial information may be required at times as part of the application process."

Using Your Insurance

- Your rights
- How to advocate
- Making an appeal

Using Your Insurance: What to do when there's a problem with your coverage

During the plan year, you may encounter problems with your coverage. For example, your plan may deny coverage for a service or medication prescribed by your doctor, you may find your provider is no longer in network, or you may receive an unexpected bill for out-of-network services.

Under state and federal laws, you may have protections that apply to changes in the provider network that affect your care or unforeseen out-of-network charges.

If your plan won't cover a drug, treatment, or specific service prescribed by your doctor:

Federal and/or state law, as applicable, provide avenues for appealing adverse decisions from your health plan, e.g., when:

- The medication your doctor prescribes is not on your plan's formulary;
- The medication your doctor prescribes used to be on your plan's formulary, but your plan dropped it or moved it to a higher cost-sharing tier;
- The course of treatment recommended by your doctor is denied, either before you've received it (preauthorization denial) or after you've received it (claims denial);
    - Your plan will not approve coverage of the medication prescribed by your doctor until you first try, and "fail" on, one or more different medications ("step therapy");
- Your hemophilia treatment center or other provider is out-of-network with your health plan.

Your rights when you are denied coverage of a drug or service:

The ACA includes rules that spell out how your plan must handle your appeal (usually called an "internal appeal"). If your plan still denies coverage or payment after considering your appeal, you may have the right to an "external review" from an independent review organization. However, external review is generally available only in limited circumstances (denials on grounds of medical necessity, and disputes over surprise medical bills) and not in cases where the insurer denies payment on the grounds that the service or benefit is not covered by the plan.

The ACA rules are:

- When your plan denies a claim, the plan must provide you written notification of the following: the specific reason they denied the claim, your right to request an internal appeal of the denial, your right to an external review if your internal appeal was unsuccessful, deadlines for your appeal, and the availability of a state-established consumer assistance program (CAP) that can help you file an appeal or request a review (if your state has such a program).
- If English is not your first language, you may be entitled to receive appeals information in your native language, upon request.
- You can request an internal appeal up to 6 months from the date of your denial of coverage or payment for a specific service. When you request an internal appeal, your plan must give you its decision within:
    - 72 hours after receiving your request when you're appealing the denial of a claim for urgent care. Under the rule, the plan or insurer must defer to the attending provider in determining whether a claim is urgent or not. (If your appeals concern urgent care, you may be able to have the internal appeal and external review take place at the same time.)
    - 30 days for denials of non-urgent care you have not yet received.
    - 60 days for denials of services you have already received.

- If after an internal appeal the plan still denies your request for payment or services, you may be eligible for an independent external review. Your plan must include information on your denial notice about how to request this review. You may be able to get help with this request from your state insurance department, or, in some states, a Consumer Assistance Program (CAP). If the external reviewer overturns your insurer's denial, your insurer must give you the payments or services requested in your claim.

- How much these new rules will change your appeal rights depends on the state you live in and the type of plan you have. Some group plans may require more than one level of internal appeal before you're allowed to submit a request for an external review. However, all levels of the internal appeals process must be completed within the timeframes stated above.

Your rights when you are unable to obtain coverage of a prescription drug prescribed for you:

You can request coverage of a prescribed drug when it's not covered on your plan's formulary or appeal the denial of a covered drug based on "medical necessity."

- Requesting coverage of a non-formulary drug: Federal law requires health plans to have a process for requesting a non-formulary drug. In some states, there may be an exceptions process that is separate from the internal appeals and external review process described above. In other states, requests for non-formulary drugs are treated like all other denials of "medically necessary" health care treatments and services and the internal appeals/external review process discussed above will apply.

- Your plan documents will tell you whether to use an exceptions process or the internal appeal and external review process to request coverage of a non-formulary drug. It is very important to follow the exceptions and appeals process outlined in your plan documents. You can also contact your state's insurance department to find out what rights you have under state law. But it's important to keep in mind that federal law requires exceptions processes to:

    - Provide consumers a decision within 72 hours of the request for coverage (and within 24 hours if it's an urgent case).
    - Provide access to an independent, external review if your plan denies your exceptions request.

- Requesting coverage of a formulary drug that has been denied for you: In some cases, you may need a drug that is covered on your plan's formulary, but is denied to you based on "medical necessity" or comes with limits that your prescribing physician has said would be ineffective or inappropriate for you. In this case, you'll use the internal appeal/external review process discussed above.

Tips for advocating for coverage of the health care services and treatments you need

When you request an internal appeal of a plan denial, or coverage of a non-formulary drug, your insurance company may ask your provider for more information in order to make a decision about the claim. Your insurance company should inform you of the deadline for sending any additional information requested. If they fail to provide a deadline, call your insurer using the number provided on the back of your ID card. Remember, your health plan is required to provide you written notice spelling out the specific reasons for a denial of coverage.

How to start your appeal:

- Start by calling your plan to see if the denial is due to a simple error (e.g., coding mistake) that can be easily corrected.
- Review your plan documents. Does the service at issue fall within the terms of your coverage?
- Enlist support from your health care provider. Ask them to contact your insurer's medical management area or medical director to request a peer-to-peer review to discuss your need for the medication or treatment/service in question. This may resolve your issue without having to go through a more formal internal appeal or exceptions request process.
- If a formal appeal is necessary, work with your provider to gather supporting materials.
- These may include:
    - Your treatment records and clinical history:
    - Include information on other medications or treatment regimens previously tried that proved to be ineffective or harmful.
    - Letter of medical necessity
    - Journal articles, treatment guidelines, etc., supporting the use of the product or service at issue
    - Copies of prior authorizations, second opinions, etc.

Bear in mind that you have six months from the date of your coverage denial to request an internal appeal. The deadlines for your plan to respond to your request may not be triggered until you file a formal internal appeal or exceptions request.

You can find information on how to request an internal review or an exception in your coverage documents, or by contacting your insurer using the member services telephone number on your ID card. You can also find information on your internal appeal rights in your Explanation of Benefits or denial letter, as well as in your plan's Summary of Benefits and Coverage.

Keep the following in mind:

- If your insurer requires the prescribing physician to complete a drug authorization form, check to make sure this step was completed.
- If you received a letter of denial for the medication, read it carefully to make sure it clearly specifies the reasons for the denial.
- Remember, in crafting your appeal, that the key point to establish is "medical necessity." That is why your physician's participation and support is so important to your appeal. Your insurer may have its own definition of medical necessity, but generally, a service is "medically necessary" if it meets any one of the three standards below:
    - The service or benefit will, or is reasonably expected to, prevent the onset of an illness, condition, or disability.

- The service or benefit will, or is reasonably expected to, reduce or ameliorate the physical, mental or developmental effects of an illness, condition or disability
- The service or benefit will assist the individual to achieve or maintain maximum functional capacity in performing daily activities taking into account both the functional capacity of the individual and those functional capacities that are appropriate for individuals of the same age.

- Follow up. If your appeal is denied, take steps to pursue the next level of appeal. Do not assume this happens automatically. Make sure you communicate your desire for a second-level or independent external review. This will be a reconsideration of your original claim by professionals with no connection to your insurance plan. If the independent reviewers determine your plan should cover your claim, your health plan must cover it.

If your provider is no longer in network:

The federal No Surprises Act, signed into law in December 2020, allows certain individuals ("continuing care patients") to continue to see their provider at in-network cost-sharing, even if the provider is no longer in their plan's network – for a limited period of time.

These limits include:

- Who can benefit: "continuing care patients" are defined as individuals who are undergoing treatment with a specific provider for a serious and complex condition; those who are undergoing a course of institutional or inpatient care from the provider; those scheduled to undergo non-elective surgery with the provider; people who are pregnant; and people who are undergoing care for a terminal illness.

- Notice: health plans and issuers who terminate their contracts with network providers must give timely notification of the network change to all continuing care patients. That notice must disclose the patients' rights to elect continued transitional care from the provider.

How long the protection applies: these protections extend until the course of treatment ends, or 90 days (whichever is earlier). After that period, you will have to either find an in-network provider to continue your treatment; secure an exception from your plan prior to your next visit to continue to see the out-of-network provider; or pay out-of-network charges to continue with your original provider.

If you are "balance billed" for out-of-network care:
The federal No Surprises Act also protects consumers from balance billing, and in particular, what is often called "surprise" out-of-network charges. When consumers go out of network for care, the provider may charge the consumer for the difference between what the plan will pay and what the provider charges. This is also called "balance billing."

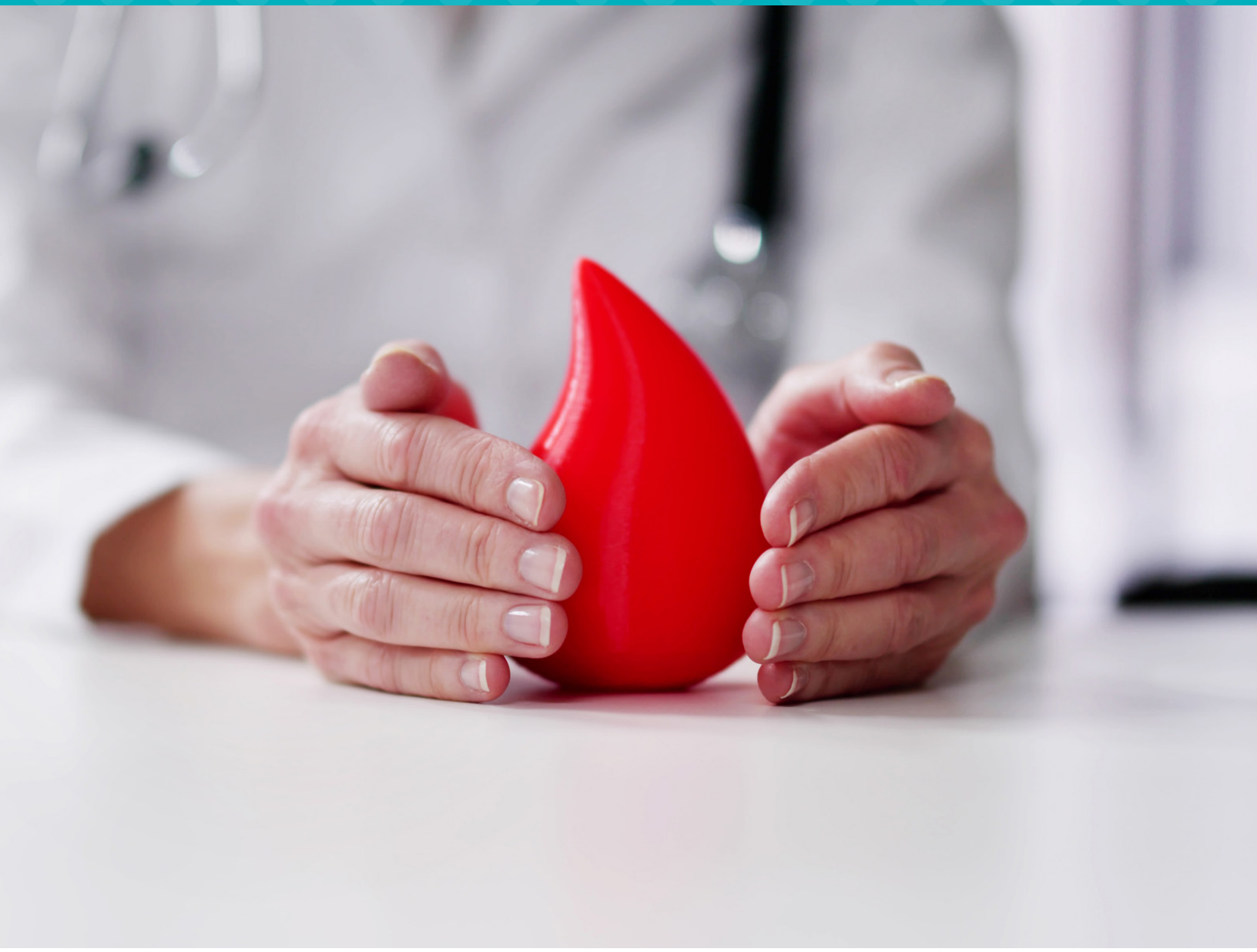
In some cases, consumers may be treated by out-of-network providers without the consumer's knowledge or permission. This can happen if a consumer uses an out-of-network emergency department. It can also happen when a consumer uses an in-network hospital with an in-network physician for surgery, but later finds out that the anesthesiologist, radiologist or assisting surgeon is out of network.

Federal patient protections against surprise medical billing went into effect on January 1, 2022.
Hospitals and other health care providers can no longer bill patients for amounts larger than their in-network cost-sharing for most emergency care, or for care from an out-of-network provider delivered at an in-network facility. Air ambulance services are also covered by the federal laws against surprise medical billing.

The surprise billing protections apply to individuals who have health insurance through an employer, the Marketplace, or other ACA-compliant individual market coverage. (Some states layer on additional surprise billing protections, e.g., prohibiting balance billing by ground ambulance services.)

The No Surprises Act does not ban all balance billing. Patients can still be charged out-of-network rates for ground ambulance services (a category of services excluded from the No Surprises Act). And, in non-emergency situations, out-of-network providers can ask patients to waive their rights under the No Surprises Act. If a patient signs such a waiver, they are effectively agreeing to pay out-of-network charges from the provider.

Patients who believe that they were incorrectly billed in violation of the federal protections can appeal using the ACA's external appeals processes. If they need additional help getting the bill resolved, they can reach out to their state department of insurance (for Marketplace and other state-regulated plans) or the U.S. Department of Labor (for self-insured employer plans).



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