



Personal Health Insurance Toolkit



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

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Personal Health Insurance Toolkit

Having the tools you need to select the right health plan for you and your family is very important. The Affordable Care Act (ACA) has led to significant changes in the way individuals and families can receive health care coverage. Historically, those affected by chronic conditions had limited opportunities to obtain healthcare coverage in the individual market. The ACA created health insurance Marketplaces (also referred to as Exchanges), which are intended to be transparent and competitive markets where individuals and small businesses can buy qualified health plans that meet certain benefit and cost standards. Every state has a Marketplace that offers a variety of health plan options in four categories (tiers) – bronze, silver, gold and platinum. In the Marketplace, you can compare coverage options based on price, benefits, quality and other features important to you. The ACA also applies new consumer protections to large employer plans.

Regardless of how you and your family obtain your health insurance, it is ultimately your responsibility to choose the plan that is right for you. It is essential to understand your family's health care needs and the medical services used most often in order to properly evaluate your options. The selection of an appropriate health plan can affect both your health and your finances. The National Hemophilia Foundation's Personal Health Insurance Toolkit was designed to provide you with the information and resources you need to help you make the best possible choice in selecting the plan that is right for you and your family.

This toolkit reflects rules and protections already in place under the ACA as of January 2019. For unfamiliar acronyms or terms, see the Glossary of Commonly Used Healthcare Terms and Acronyms section that begins on page 17.

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HealthPlan Comparison Guide

Determining which health plan is most appropriate for your needs can often be a difficult process, regardless of whether it is an individual or family policy you buy on your own or a plan offered through your employer (a group health plan). There are many things to consider when reviewing your options. These considerations fall under two categories: cost and benefit design. Most people first consider the cost of a plan when making a decision. Our goal is to provide you with a tool to help you evaluate the cost of the plan so that you can select plans with comparable benefits.

Questions typically asked by people when choosing a plan include:

1. What is the monthly/annual premium for the plan?
2. What is the total of my out-of-pocket costs, including medical and prescription co- pays, deductibles and coinsurance?
3. Does it cover all the services I need?
4. Are all my physicians in network?
5. 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)
6. Are out-of-network benefits available? What percentage of the cost am I responsible for if I receive out-of-network care?
7. Am I covered if I get sick/need treatment out of state?

For those affected by a bleeding disorder, there are often additional, more specific, questions we must ask that relate to what benefits are covered and how, such as:

1. Is clotting factor covered? If so, is it a major medical or a pharmacy benefit?
2. Do I have a choice of more than one specialty pharmacy provider?
3. Is my hemophilia treatment center (HTC) in network?
4. Do manufacturer copay cards count towards my deductible/out-of-pocket?
5. Does the plan accept third (3rd) party premium assistance?
6. Is durable medical equipment (DME) covered?
7. Do I need a referral to see a specialist (i.e., a hematologist)?
8. What services require prior authorization?
9. Are physical therapy services covered? Home nursing?

Answers to many of these questions, relative to cost and covered benefits, can be found by reviewing a plan's summary of benefits, drug formulary list and provider network directory. While this is often considered a tedious process, it is one of the most important steps you can take to ensure that a plan meets your needs. It is important to remember that **ONCE YOU CHOOSE A PLAN, YOU CANNOT CHANGE UNTIL THE NEXT OPEN ENROLLMENT PERIOD** unless you experience a qualifying life event.

You may find that you have the option to choose between multiple plan types and designs such as HDHP, HMO, PPO, POS or EPO. The National Hemophilia Foundation's Personal Health Insurance Toolkit was developed to assist you in evaluating your plan options. The Health Plan Comparison Chart was designed to help in performing a side-by-side comparison of your plan options by helping to identify covered benefits and out-of-pocket costs associated with each. The chart can be used in two ways: to make general comparisons between health plans or highlight the costs and benefits specific to your individual needs.

To begin a personalized evaluation of your health plan options, follow the steps on page 10.



Getting Started

Step 1

Complete the Personal Health Experience Stat Sheet. This document was designed to identify and quantify the health services used by you and your family in the previous 12 months, providing you with a list of benefits your new plan should include.

Step 2

Have a copy of the Glossary of Commonly Used Healthcare Terms and Acronyms document at hand.

Step 3

Collect from your human resources representative, insurance agent, or Marketplace the following documents for each health plan offered. (Note: often you will be provided a link to this information on the insurance carrier's website)

A) Summary of Benefits and Coverage (SBC) – Health insurers and group health plans are required to provide you with an easy-to-understand summary of a health plan's benefits and coverage. For more information on what should be included in your SBC, please see the fact sheet section of the toolkit. You may also want to get a copy of other plan documents from your plan or employer for information not included on your SBC, including more detail on excluded benefits and plan rules.

B) Drug Formulary – Health insurers maintain a formulary (sometimes referred to as a preferred drug list or PDL), which is a list of prescription drugs, both generic and brand name, that are covered through your plan. Formularies classify drugs by different cost tiers that define the plan member's co-payment (co-pay) amount and/or coinsurance levels. Typically, generic drugs require the lowest co-pay from plan members. Brand name drugs will cost more and specialty tier drugs will cost the most and sometimes require you to meet certain requirements such as "fail first" or step therapy, or prior authorization. The formulary may have that information. However, it must be included in formularies for Marketplace plans.

C) Provider Network Booklet – A provider network is a group of providers (such as physicians, hospitals, skilled nursing facilities, pharmacy or other licensed, certified institutions, or health professionals) that have contracted with the health plan to provide healthcare services to plan members at agreed upon billing rates. Depending on the plan's design, members who receive care from a provider not included in the network may have less or no coverage for that provider and/or service received.

Members who get care out-of-network may also be subject to "balance billing," in which the out-of-network provider charges the patient for his or her charges above what the plan will pay. Please see the fact sheets section of the tool kit for more information on balance billing. It is important to note that many insurers offer several different plan options, each of which may have a different provider network. It is important to review the current provider network for EACH plan.

Step 4

Begin using your Health Plan Cost Comparison Worksheet. One way to evaluate your potential cost is to base your review on your previous year's medical experience. Using the information included on your Personal Health Experience Stat Sheet, the plan's SBC, provider directory, and drug formulary list, fill in each section that applies on the worksheet.

It is important to remember that unexpected medical needs often arise. Their costs are typically unpredictable. The toolkit is designed to provide a general idea of predictable costs associated with your health plan based on your family's known health situations.

While these documents may answer many of the questions important to choosing the appropriate plan, there may be some questions that require additional resources. To answer these questions, begin by contacting your human resources/benefits administration department, broker or your health plan's customer service representative. There are many resources available to consumers who need additional help. For more information and/or a list of available resources, you can contact NHF, your local chapter, and/or your HTC social worker.



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 cost and 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:

1. Visited my primary care physician ____ time(s).
 - a) Spouse has visited his/her primary care physician ____ time(s).
 - b) Child(ren) have visited their primary care physician ____ time(s).
2. Been seen by a specialist ____ time(s).
 - a) Spouse ____ time(s).
 - b) Child(ren) ____ time(s).
3. Visited an ER ____ time(s).
 - a) Spouse ____ time(s).
 - b) Child(ren) ____ time(s).
4. 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? _____

5. Utilized a manufacturer copay assistance card to cover the costs of my specialty medication?

6. Purchased hemophilia clotting factor _____ times per month/year from _____ (insert name of factor/specialty pharmacy provider).
7. Been admitted to a hospital for an overnight stay _____ time(s).
 - a) Spouse _____ time(s).
 - b) Child(ren) _____ time(s).
8. Needed home health services (such as nursing care) _____ time(s).
 - a) Spouse _____ time(s).
 - b) Child(ren) _____ time(s).
9. Visited an urgent care center _____ time(s).
 - a) Spouse _____ time(s).
 - b) Child(ren) _____ time(s).
10. Used rehabilitative or rehabilitative services _____ time(s)
 - a) Spouse _____ time(s)
 - b) Child(ren) _____ time(s)

The following is a list of all doctors (including specialists) and facilities that I/my family used in the past 12 months:

Primary Care Physician(s): _____

Specialist(s): _____

Urgent Care Center(s): _____

Lab Facility: _____

Hospital Facility: _____

Ophthalmologist: _____

Dentist: _____

Retail Pharmacy: _____

Specialty Pharmacy: _____

Other: _____



Health Plan Cost Comparison Worksheet

Plan Name			
Plan type (EPO, HDHP, HMO, PPO, POS)			
Does the plan require you to choose a primary care physician (PCP)?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
If so, is your current PCP in network?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Annual Premium	\$	\$	\$
Financial (deductible/coinsurance/annual limits)			
Deductible (in network):			
Individual	\$	\$	\$
Family	\$	\$	\$
Deductible (out-of-network):			
Individual	\$	\$	\$
Family	\$	\$	\$
Is the deductible embedded or non-embedded (sometimes called aggregate)?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Are any services (other than preventative) covered before the deductible is met?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> 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?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
If so, what are they?	\$	\$	\$
Preventive Care²			
Physical exam	\$	\$	\$
Routine pediatric care	\$	\$	\$
Immunizations ³	\$	\$	\$
Major Medical			
Do you have a copy of the plan's provider list?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Plan Name			
In Network			
Please note: cost shares may vary when using out of network providers			
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 Care⁴			
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	\$	\$	\$
Mental Health⁵			
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?)	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> 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)?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Coinsurance Tier 4 (specialty tier) % cost share or co-pay	\$ or %	\$ or %	\$ or %
If your plan has a specialty tier with coinsurance is there a per prescription maximum?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Is there a yearly maximum out of pocket?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No

Is clotting factor covered under the pharmacy benefit?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Do you have more than one choice of pharmacy provider?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Do you have more than one choice of pharmacy provider?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
Other (if offered; note where there are any limits on number of covered visits or days)			
Chiropractic	\$	\$	\$
Short-term rehabilitation: inpatient	\$	\$	\$
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			

² For a list of preventive services that must be covered without cost-sharing under the ACA, go to: <http://www.healthcare.gov>. Only those that are recommended for you by your doctor will be covered without cost-sharing. Note that this requirement doesn't apply to grandfathered plans.

³ The ACA bans cost-sharing for recommended vaccines for adults and children under the preventive services requirement.

⁴ For group plans and individual policies created or issued after 3/23/2010, the ACA bans higher co-pays or coinsurance for out-of-network ER services. The ACA prohibits insurers from charging out-of-network cost sharing for emergency services, regardless of whether you use an in-network or out-of-network ER. Note, however, that the prohibition does not apply to grandfathered plans and doesn't protect enrollees from balance billing.

⁵ The Mental Health Parity and Addiction Equity Act prohibits plans from imposing higher deductibles or co-pays or tighter limits on visits than are allowed for medical services in the plan.



Healthcare and Insurance Related Acronyms

AAC	Actual Acquisition Cost	CON	Certificate of Need
ACA	Affordable Care Act	CO-OP	Consumer Operated and Oriented Plan
ACO	Accountable Care Organization	CSHCNs	Children with Special Health Care Needs
APTC	Advanced Premium Tax Credit	CSR	Cost-Sharing Reduction
AV	Actuarial Value	DUR	Drug Utilization Review
CAC	Certified Application Counselor	DME	Durable Medical Equipment
CAP	Consumer Assistance Program	EAC	Estimated Acquisition Cost
CCIO	Center for Consumer Information and Insurance Oversight	ECP	Essential Community Provider
CDC	Centers for Disease Control and Prevention	ED	Emergency Department
CHC	Community Health Center	EHB	Essential Health Benefits
CHIP	Children's Health Insurance Program	EMR	Electronic Medical Record
CHIPRA	Children's Health Insurance Program Reauthorization Act of 2009	EOB	Explanation of Benefits
CMS	Centers for Medicare & Medicaid Services	EPO	Exclusive Provider Organization
COB	Coordination of Benefits	EPSDT	Early Periodic Screening, Diagnostic & Treatment Services
COBRA	Consolidated Omnibus Budget Reconciliation Act	ERISA	Employee Retirement Income Security Act
		ESI	Employer-sponsored Insurance

FDA	Food and Drug Administration	P4P	Pay for Performance
FFM/FFE	Federally Facilitated Marketplace/ Federally Facilitated Exchange	PA	Prior Authorization
FFS	Fee-for-service	PBM	Pharmacy Benefit Manager
FPL	Federal Poverty Level	PCCM	Primary Care Case Management
FQHC	Federally Qualified Health Center	PCMH	Patient-centered Medical Home
FSA	Flexible Spending Account	PCIP	Pre-existing Condition Insurance Plan
HCR	Health Care Reform	PCORI	Patient-Centered Outcomes Research Institute
HCBS	Home and Community-Based Services	PCP	Primary Care Provider
HDHP	High Deductible Health Plans	PDL	Preferred Drug List
HHS	U.S. Department of Health and Human Services	PDP	Prescription Drug Plan under Medicare Part D
HIPAA	Health Insurance Portability and Accountability Act	POS	Point-of-Service Plan
HIM/HIX	Health Insurance Marketplace/ Health Insurance Exchange	PMPM	Per-member Per-month
HMO	Health Maintenance Organization	PPO	Preferred Provider Organization
HRP	High Risk Pool	QHP	Qualified Health Plan
HRSA	Health Resources and Services Administration	SPA	State Plan Amendment
HSA	Health Savings Account	SBC	Summary of Benefits and Coverage
HDHP	High Deductible Health Plan	SBM/SBE	State Based Marketplace/ State Based Exchange
HTC	Hemophilia Treatment Center	SEP	Special Enrollment Period
IPA	In-Person Assistants Program	SHOP	Small Business Health Options Program
LTC	Long Term Care	SNF	Skilled Nursing Facility
MAGI	Modified Adjusted Gross Income	SPM/SPE	State Partnership Marketplace/ State Partnership Exchange
MA	Medicare Advantage	SPP	Specialty Pharmacy Provider
MCO	Managed Care Organization	SSDI	Social Security Disability Income
MLR	Medical Loss Ratio	SSI	Supplemental Security Income
MOOP	Maximum Out-of-Pocket	TPA	Third Party Administrator
OEP	Open Enrollment Period	UCR	Usual, Customary and Reasonable Charges
OON	Out-of-Network	WAC	Wholesale Acquisition Cost
OOP	Out-of-Pocket		



Glossary of Commonly Used Healthcare Terms

#

340B Program

The 340B Drug Pricing Program enables eligible health care organizations (known as covered entities) to purchase drugs from manufacturers at reduced prices. It is called 340B since that is the section of the Public Health Service Act that establishes the program. Eligible health care organizations/covered entities include hemophilia treatment centers as well as community health centers, children's and other types of hospitals, Ryan White clinics, and other safety net providers.

A

Accountable Care Organization (ACO)

A group of healthcare providers that gives coordinated care for chronic disease management with the goal of improving the quality of patient care. The "organization's" payment is tied to achieving healthcare quality goals and outcomes that result in cost savings. ACOs can include various types of doctors – primary care, specialists, etc. – as well as other medical providers (nurses, physician's assistants, etc.) and institutions (hospitals, multi-physician practices).

Accreditation

This is the "seal of approval" given to the plan by an independent organization to show that the plan meets national quality standards.

Accumulator

Refers to the running total amount of money you have paid towards your out-of-pocket maximum for covered services. This includes the amount you have paid towards your deductible, copays and coinsurance, but not your monthly premium payments.

Accumulator Adjustment Programs

A program used by pharmacy benefit managers (PBMs) which allows them to identify when a manufacturer copay card has been used and prohibits it from counting towards your deductible or OOP maximum.

Actual Acquisition Cost (AAC)

An estimate of the actual price a pharmacy provider pays for the drug.

Actuarial Value (AV)

The percentage of total average costs for covered benefits that a plan will cover. Example: if a plan has an actuarial value of 70%, on average, people enrolled in the plan would be responsible for 30% of the costs of all covered benefits. However, your own share of costs could be higher or lower depending on your actual healthcare needs and terms of your insurance policy. The AV is a rough measure of how generous a plan's coverage is, but it won't tell you your own costs over the year or for any given service. Under the ACA, coverage must be offered in four categories, Bronze, Silver, Gold and Platinum, (sometimes called metal tiers) based on the actuarial value of providing essential health benefits to members. Two plans may be in the same metal tier, but that does not mean that they will cover the same benefits in the same way. (See Bronze, Silver, Gold and Platinum Health Plans and Fact Sheet).

Advanced Premium Tax Credit (APTC)

Also referred to as a premium tax credit, this new tax credit provided for in the Affordable Care Act helps make coverage purchased in the Marketplace/Exchanges more affordable for consumers. Advance payments of the tax credit can be used right away to lower monthly premium costs. Qualified consumers may choose how much advance credit payments to apply to their premiums each month, up to a maximum amount. If the amount of advance credit payments a consumer gets for the year is less than the tax credit due, the consumer will get the difference as a refundable credit when they file their federal income tax return. If the consumer's advance payments for the year are more than the amount of their credit, they must repay the excess advance payments with their tax return.

Affordable Care Act (ACA)

Also known as the Patient Protection and Affordable Care Act (PPACA), health care reform (HCR) and Obamacare, it is the comprehensive healthcare reform law enacted in March 2010. The law was enacted in two parts: PPACA was signed into law on March 23, 2010. It was amended by the Health Care and Education Reconciliation Act on March 30, 2010. Affordable Care Act refers to the final, amended version of the law.



Affordable Coverage (as it relates to the APTC)

Employer coverage is considered affordable - as it relates to the Advanced Premium Tax Credit (APTC) - if the employee's share of the annual premium for self-only coverage is no greater than 9.66% of annual household income in 2016 (this amount will grow annually). Individuals offered employer-sponsored coverage that's affordable and provides minimum value won't be eligible for a premium tax credit if they choose to purchase health insurance in the Marketplace.

Allowed Amount

Discounted fees that insurers will recognize and pay for covered services. Insurers negotiate these discounts with providers in their health plan network. Network providers agree to accept the allowed charge as payment in full. Each insurer has its own schedule of allowed charges. If you go out-of-network to obtain care, you may be asked to pay the difference between the allowed amount and the provider's charge, known as balance billing.

Annual Limit

A cap on the benefits your insurance company will pay in a year while you're enrolled in a health insurance plan. Annual caps are sometimes placed on particular services such as prescriptions or hospitalizations. Annual limits may be placed on the dollar amount of covered services or on the number of visits for a particular service. After the annual limit is reached, you must pay all associated healthcare costs for the rest of the year.

Appeal

A request for a health insurer or plan to review a decision to deny coverage for a service, either the payment for services received or prior approval for a service, your doctor has recommended for you.

Association Health Plan

Health insurance plans that are offered to members of an association. These plans are marketed to individual association members, as well as small businesses members. How plans are structured, who they sell to, and whether they are state-based or national associations determines whether they are subject to state or federal regulation, or both. More importantly, they are largely exempt from regulations and are not considered ACA compliant.

B

Balance Billing

The practice of billing a patient for charges not paid by his/her insurance plan because the charges exceed covered amounts. Balance billing amounts will often be charges that are above the usual and customary rates. Balance billing may occur when an individual goes out of network for care, whether intentionally or unintentionally. Some states ban balance billing, particularly when individuals obtain out-of-network care unintentionally, known as "surprise billing."

Benefits

The healthcare items or services covered under a health insurance plan. Covered benefits and excluded services are defined in the health insurance plan's coverage documents. In Medicaid or CHIP, covered benefits and excluded services are defined in state program rules.

Biologic

A biologic (also known as a biological product) is a type of complex medication such as a vaccine, blood or blood product, or other treatment that mimics proteins naturally present in the body. Rather than being created chemically like drugs, biologics are based off of recombinant, cell or tissue-based proteins. Clotting factor is a biologic.

Biosimilar Biological Products

A biosimilar is the "follow-on" or subsequent version of a biologic. Biosimilars and biologic products have the same relationship that generic drugs have with brand name drugs, with an important distinction that due to their complexity, biosimilars are not identical to the original biologic product.

Bronze Health Plan

A plan in the health insurance Marketplace/ Exchanges where the percentage the plan pays of the average overall cost of providing essential health benefits to members is 60%.

C

Capitation

A method of paying for health care services under which providers receive a set payment for each person or "covered life" instead of receiving payment based on the number of services provided or the costs of the services rendered. These payments can be adjusted based on the demographic characteristics, such as age and gender, or the expected costs of the members.

Care Coordination

The process of organizing your treatment across several healthcare providers. Medical homes and Accountable Care Organizations (see definition) are two common ways to coordinate care.

Catastrophic Plan

A high deductible healthcare plan (HDHP) that only covers expensive care, like hospitalizations. Under the ACA, catastrophic plans must cover 3 primary care visits and preventive services before the deductible. For other care, your plan will only pay for services after you've first paid up to a certain amount for covered services. Only individuals who are under 30 years old or cannot find affordable coverage are able to purchase a catastrophic plan.



Center for Consumer Information and Insurance Oversight (CCIIO)

Located within the Centers for Medicare & Medicaid Services (part of the Department of Health & Human Services), the Center is the federal agency tasked with implementing many provisions of the Affordable Care Act related to private health insurance.

Centers for Disease Control and Prevention (CDC)

The federal agency responsible for protecting health and promoting quality of life through the prevention and control of disease, injury, and disability. The CDC's National Center on Birth Defects and Developmental Disabilities' hemophilia homepage provides consumers with access to the most up-to-date resources including the complete hemophilia treatment center (HTC) directory, videos, brochures, fact sheets and numerous other health education and outreach resources. The HTC directory provides the names and contact information of treatment center staff who are part of the federally-funded HTC network.

Centers for Medicare and Medicaid Services (CMS)

The federal agency that administers the Medicare, Medicaid, and Children's Health Insurance Programs, and implements many provisions of the ACA related to private health insurance Marketplaces.

Certificate of Need (CON) Program

CON programs are aimed at restraining health care facility costs and facilitating coordinated planning of new services and facility construction. Many CON laws initially were put into effect across the country as part of the federal Health Planning Resources Development Act of 1974. Despite numerous changes, most states retain some type of CON program, law or agency.

Certified Application Counselor (CAC)

An individual (affiliated with a designated organization) who is trained to help consumers, small businesses, and their employees as they search for and enroll in health insurance options through the Marketplace created by the ACA. CAC services are free to consumers.

Children's Health Insurance Program (CHIP)

Insurance program jointly funded by state and federal government that provides health insurance to low-income children. In some states, it covers pregnant women in families who earn too much income to qualify for Medicaid but cannot afford to purchase private health insurance coverage.

Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA)

Reauthorized CHIP This legislation provided states with significant new funding, new programmatic options, and a range of new incentives for covering children through Medicaid and CHIP.

Children with Special Health Care Needs (CSHCN)

Maternal and Child Health Bureau's (MCHB) defines CSHCN as those children that have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

Claim

A request for payment that you or your healthcare provider submits to your health insurer after you receive covered items or services.

Consolidated Omnibus Budget Reconciliation Act (COBRA)

A federal law that may allow you to temporarily keep health coverage if your employment ends or you are no longer eligible for coverage, you lose coverage as a dependent of the covered employee, or if there is another qualifying event. COBRA requires you pay 100% of the premiums, including the share the employer used to pay, plus a small administrative fee.

Coinsurance

A form of medical cost sharing in a health insurance plan that requires an insured person to pay a stated percentage (rather than a set dollar amount) of medical expenses after the deductible amount, if any, was paid.

Community Health Centers (CHC)

Public and private, nonprofit organizations providing comprehensive, culturally competent, quality primary and related health care services to medically underserved communities and vulnerable populations. The centers are managed and governed by a community board, which is primarily comprised of patients and community members. There are several different types of CHCs: Federally Qualified Health Centers; non-grant supported health centers; and outpatient health programs/facilities operated by tribal organizations.

Consumer Assistance Program (CAP)

State programs available to assist consumers with problems or questions concerning health care coverage. Consumers with questions can usually access the programs through phone or e-mail. See <https://www.cms.gov/CCIIO/Resources/Consumer-Assistance-Grants/>.

Consumer Operated Oriented Plan (CO-OP)

Created by the ACA, a type of non-profit health insurance organization for which its insured people are also the owners. Cooperatives can be formed at a national, state, or local level and can include doctors, hospitals, and businesses as member-owners. Co-ops offer insurance through the Marketplace/Exchange but are not available in every state.

Coordination of Benefits (COB)

A way to figure out who pays first when two or more health insurance plans are responsible for paying the same medical claim.



Copayment

A flat dollar amount you must pay for a covered program. Example: you may have to pay a \$15 copayment for each covered visit to a primary care doctor.

Copay Maximization Allowance Programs (also known as Copay Allowance Maximization Programs, or Variable Copay Programs):

Generally, target a narrow list of specialty medications allowing plans to take advantage of the full annual value of the manufacturer copay coupons available on those drugs by increasing the beneficiary's monthly specialty copay amount, up to the monthly value of the copay coupon (annual face value of manufacturer copay coupon, divided by 12). Unlike the copay accumulator adjustment programs, the amount collected doesn't count towards the out of pocket. Given that this type of program changes the copays on some drugs (drug specific copays), health plans are required to update their summary plan description, making it more challenging for plans to implement. The uptake on these programs has been far more limited than that of the copay accumulator adjustment programs.

Cost Sharing

The share of costs covered by your insurance that you pay out-of-pocket. This share is commonly referred to as out-of-pocket (OOP) costs. The ACA sets an annual limit on out-of-pocket costs, which includes deductibles, coinsurance and copayments, or similar charges, but it doesn't include premiums, balance billing amounts for non-network providers, or the cost of non-covered services. For 2016, the annual limit on out-of-pocket costs is \$6,850 for an individual and \$13,700 for a family; this amount grows annually. Note that separate cost sharing limits apply in Medicaid and CHIP, which include premiums.

Cost-Sharing Reduction (CSR)

A discount that lowers the amount you have to pay out-of-pocket for deductibles, coinsurance, and copayments. You can get this reduction if you get health insurance through the Marketplace/Exchange, your income is below a certain level, and you choose a Silver Health Plan (See "Metal Tiers" and "Silver Health Plan"). If you're a member of a federally recognized tribe, you may qualify for additional cost-sharing benefits.

D

Deductible

The amount you must pay for covered care before your health insurance begins to pay. Insurers apply and structure deductibles differently. Example: under one plan, a comprehensive deductible might apply to all services while another plan might have separate deductibles for benefits such as prescription drug coverage.

Deductibles for family plans may be embedded or non-embedded. Under an embedded deductible, each family member must meet his or her own deductible until the overall family deductible amount has been met. Under a non-embedded deductible, the overall family deductible must be met before the plan begins to pay.

Department of Health and Human Services (HHS)

The federal agency charged with protecting the health of all Americans. Its agencies include the Centers for Medicare and Medicaid Services (CMS), Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA).

Dependent

A child or other individual for whom a parent, relative, or other person may claim a personal exemption tax deduction. Under ACA, individuals may be able to claim a premium tax credit to help cover the cost of coverage for themselves and their dependents.

Dependent Coverage

Insurance coverage for family members of the policyholder, such as spouse, children or partners. Under the ACA, all plans offering dependent coverage must cover dependents up to age 26, regardless of whether they are a tax dependent, live at home, or are a student.

Disability

A limit in action, restriction or impairment that can be physical and/or mental. Different state, federal or private programs may have different disability standards. A legal definition of disability can be found at: www.ada.gov/pubs/ada.htm

Donut Hole, Medicare Prescription Drug

Most plans with Medicare prescription drug coverage (Part D) have a coverage gap, called a donut hole. This means that after you and your drug plan have spent a certain amount of money for covered drugs, you have to pay all costs out-of-pocket for your prescriptions up to a yearly limit. Once you have spent up to the yearly limit, your coverage gap ends and your drug plan helps pay for covered drugs again. The donut hole is being phased out and will be closed entirely by the ACA in 2020.

Drug List

Also referred to as a formulary, it is a list of prescription drugs covered by a prescription drug plan or another insurance plan offering prescription drug benefits.



Drug Utilization Review (DUR)

Is an ongoing review of prescribing, dispensing and use of medication. It is often used as utilization management tool to control and promote more efficient use of scarce health care resources.

Dual Eligibles

A term used to describe an individual who is eligible for Medicare and for some level of Medicaid benefits. Most duals qualify for full Medicaid benefits including nursing home services, and Medicaid pays their Medicare premiums and cost sharing. For other duals Medicaid provides the "Medicare Savings Programs" through which enrollees receive assistance with Medicare premiums, deductibles, and other cost sharing requirements.

Durable Medical Equipment (DME)

Equipment and supplies ordered by a health care provider for everyday or extended use. Typically, DME may be considered a separate category under a health insurance plan. Coverage for DME may include: oxygen equipment, wheelchairs, crutches or blood testing strips for diabetics.

E

Early Periodic Screening, Diagnostic & Treatment Services (EPSDT)

The comprehensive set of benefits covered for children in Medicaid.

Electronic Medical Record (EMR)

A digital version of a paper chart that contains all of a patient's medical history from one practice.

Eligible Immigration Status

An immigration status that's considered eligible for getting health coverage through the Marketplaces. The rules concerning eligible immigration status differ for Medicaid and Marketplace coverage.

Emergency Department (ED)

Medical treatment facility that provides emergency room services.

Emergency Room Services

Evaluation and treatment of an illness, injury, or condition that needs immediate medical attention in an emergency room.

Employer Mandate

The ACA requires certain employers with at least 50 full-time employees (or equivalents) to offer health insurance coverage to their full-time employees and their dependents (but not spouses) that meets certain minimum standards set by the ACA. Employers that don't offer coverage or offer coverage that fails to meet minimum standards will have to pay a penalty, if an employee qualifies for Marketplace coverage with premium tax credits

Employer-Sponsored Insurance (ESI)

This is health insurance provided by an employer, who typically covers a portion of the costs. Sometimes called group health insurance. Plan options may include HMOs, PPOs, and EPOs, among others.

Employee Retirement Income Security Act of 1974 (ERISA)

A federal law that establishes standards for employer-sponsored health insurance, particularly for self-insured employer-sponsored plans. (See Self-Insured Plan). Some employer plans are subject to state health insurance laws, in particular, small employer plans. Most large employer plans (sometimes referred to as "ERISA plans") and all self-insured plans are only subject to this federal law and not state health insurance laws. In the context of the ACA, ERISA plans are exempt from some of the private health insurance reforms.

Essential Community Providers (ECP)

The ACA designates certain providers as Essential Community Providers, including those that are included in section 340B(a)(4) of the Public Health Service Act. This list includes CHCs, disproportionate share hospitals (DSH), and other providers eligible to participate in the 340B program, including HTC. Plans offered through the Marketplace are required to include some ECPs in their networks.

Essential Health Benefits (EHB)

A set of healthcare service categories that must be covered by certain plans. The Affordable Care Act defines essential health benefits to "include at least the following general categories and the items and services covered within the categories: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care."

EHB services are defined differently in each state, based on what is covered by a benchmark plan. Private health insurance policies that are not grandfathered and are sold to individuals and small employers must cover these benefits, regardless of whether the policy is offered inside or outside the Marketplaces. Medicaid plans must cover a comprehensive bundle of services as well. Health plans are no longer able to impose a lifetime or annual dollar limit on spending for these services. Only grandfathered individual health insurance policies may still impose an annual limit.

Exclusions

Items or services that aren't covered under a contract for insurance and which an insurance company won't pay.



Exclusive Provider Organization (EPO) Plan

A managed care plan in which services are covered only if you go to doctors, specialists or hospitals in the plan's network (except in an emergency). EPOs are like HMOs except that individuals may not need a referral from a primary care physician to see a specialist.

Explanation of Benefits (EOB)

A form sent by an insurance company to an insured that includes a such items as a summary of the claims processed for an insured since their last claim, a summary of what the insurer paid for the claim and what the insured's responsibility may be, and a summary of the person's year-to-date costs in the plan.

External Review

A review of a plan's decision to deny coverage for or payment of a service by an independent third-party not related to the plan. If the plan denies an appeal, an external review can be requested. In urgent situations, an external review may be requested even if the internal appeals process isn't yet completed. External review is available when the plan denies treatment based on medical necessity, appropriateness, health care setting, level of care, or effectiveness of a covered benefit; when the plan determines that the care is experimental and/or investigational; or for rescissions of coverage. An external review either upholds the plan's decision or overturns all or some of the plan's decision. The plan must accept this decision.

F

Federally-Facilitated Marketplace/ Federally-Facilitated Exchange (FFM/ FFE)

One type of Marketplace option for states under the Affordable Care Act. States opting for an FFM/FFE will have a Marketplace that is run by the federal government. All FFM/FFEs will meet federal rules. States that operate their own Marketplace may have different rules but must meet federal minimum standards.

Federal Poverty Level (FPL)

A measure of income level issued annually by the Department of Health and Human Services. FPL is used to determine eligibility for certain programs and benefits. FPL varies based on family size. For more information on FPL please visit: <http://aspe.hhs.gov/poverty/index.cfm>. Many public health insurance programs set eligibility based on a percentage of the FPL.

Federally Qualified Health Centers (FQHC)

Federally-funded nonprofit health centers or clinics that serve medically underserved areas and populations. Federally qualified health centers provide primary care services regardless of your ability to pay. Services are provided on a sliding scale fee.

Fee for Service (FFS)

A reimbursement plan in which doctors and other healthcare providers are paid for each service performed, such as for tests and office visits.

Flexible Benefits Plan

Offers employees a choice between various benefits including cash, life insurance, health insurance, vacations, retirement plans and child care. Although a common core of benefits may be required, you can choose how your remaining benefit dollars are to be allocated for each type of benefit from the total amount promised by the employer. Sometimes you can contribute more for additional coverage. Also known as a Cafeteria Plan or IRS 125 Plan. Note that these plans generally do not qualify as minimum essential coverage.

Flexible Spending Account (FSA)

Accounts offered and administered by employers that allow employees to set aside pre-tax dollars out of their paycheck to pay for the employee's share of insurance premiums or medical expenses not covered by the employer's health plan. The employer may also make contributions to a FSA. Typically, benefits or cash must be used within the given benefit year or the employee loses the money. Flexible spending accounts can also be provided to cover childcare expenses, but those accounts must be established separately from medical FSAs.

Food and Drug Administration (FDA)

Is responsible for protecting the public health by assuring the safety, efficacy, and security of human and veterinary drugs, biological products, medical devices, our nation's food supply, cosmetics, and products that emit radiation. The FDA also provides accurate, science-based health information to the public.

Formulary

Sometimes referred to as a "drug list," it is a list of drugs your insurance plan covers and may include how much you pay for each drug. If the plan categorizes drugs into different groups with different co-pays, also known as tiers, then the formulary will list drugs by these tiers. Formularies may include both generic drugs and brand-name drugs. The formulary may not include drugs that are administered under the major medical benefit of a plan.

Fully Insured Job-based Plan

A plan in which the employer contracts with another organization to assume financial responsibility for the enrollees' medical claims and for all incurred administrative costs.

G

Gold Health Plan

A plan in the health insurance Marketplaces/ Exchanges where the percentage the plan pays of the average overall cost of providing essential health benefits to members is 80%. (See Actuarial Value)



Grandfathered Health Plan

As defined in the ACA, a group health plan that was created—or an individual health insurance policy that was purchased—on or before March 23, 2010. Grandfathered plans are exempt from many changes required under the ACA.

Plans or policies may lose their grandfathered status if they make certain significant changes that reduce benefits or increase costs to consumers. A health plan must disclose in its plan materials if it is a grandfathered plan. It must also advise consumers how to contact the U.S. Department of Labor or HHS with questions. (See New Plan)

Grievance

A complaint an insured communicates to his or her health insurer or plan.

Guaranteed Issue

A requirement that health plans must permit you to enroll regardless of health status, age, gender or other factors that might predict the use of health services. However, you can generally only enroll in coverage during an annual open enrollment period.

Guaranteed Renewal

A requirement that your health insurance issuer must offer to renew your policy as long as you continue to pay premiums.

Habilitative/Habilitation Services

Health care services that help you keep, learn, or improve skills and functioning for daily living. Examples include therapy for a child who isn't walking or talking at the expected age. These services may include physical and occupational therapy, speech-language pathology, and other services for people with disabilities in a variety of inpatient and/or outpatient settings. Habilitative services are one of the 10 essential health benefits (EHBs).

Department of Health and Human Services (HHS)

HHS, also known as the Health Department, is a cabinet-level department of the U.S. federal government with the goal of protecting the health of all Americans and providing essential human services.

H

Health Care Reform (HCR)

Also known as the Patient Protection and Affordable Care Act (PPACA), the Affordable Care Act (ACA) and Obamacare, it is the comprehensive healthcare reform law enacted in March 2010. The law was enacted in two parts: PPACA was signed into law on March 23, 2010. It was amended by the Health Care and Education Reconciliation Act on March 30, 2010. Health Care Reform refers to the final, amended version of the law.

Health Insurance Exchange (HIE)

Also known as a Health Insurance Marketplace, these are new transparent and competitive health insurance Marketplaces where individuals and small businesses can buy qualified health plans that meet certain benefit and cost standards. Every state has a Marketplace.

Health Insurance Marketplace (HIM)

Also known as a health insurance Exchange (HIE), these are new transparent and competitive health insurance Marketplaces where individuals and small businesses can buy qualified health plans that meet certain benefit and cost standards. Every state has a Marketplace.

Health Insurance Portability and Accountability Act (HIPAA)

HIPAA is a 1996 law that eliminated discrimination by health insurers for those with pre-existing medical conditions. It also sets important privacy and security standards for health care entities so that consumers' health information is protected.

Health Maintenance Organization (HMO)

An insurance plan that usually limits coverage to care from doctors who work for or contract with the HMO and will require you to get a referral from your primary care physician to see a specialist. Generally, won't cover out-of-network care except in an emergency, and may require you to live or work in its service area to be eligible for coverage.

Health Resources and Services Administration (HRSA)

An agency of the U.S. Department of Health and Human Services that works to improve access to health care services for people. HRSA's Maternal and Child Health Bureau administers the National Hemophilia Program, which coordinates activities at and provides funding to the national network of HTC's located throughout the country. HRSA also administers the 340B program. (See 340B Program)

Health Savings Account (HSA)

A tax-exempt medical savings account that can be used to pay for current or future qualified medical expenses. The funds contributed to the account aren't subject to federal income tax at the time of deposit. Employers may make HSAs available to their employees or individuals can obtain HSAs from most financial institutions. In order to open an HSA, an individual must have health coverage under an HSA-qualified high deductible health plan (HDHP). Unlike a Flexible Spending Account (FSA), funds roll over year to year if you don't spend them.

Health Status

Refers to your medical conditions (both physical and mental health), claims experience, receipt of healthcare, medical history, genetic information, evidence of insurability and disability.



Hemophilia Treatment Center (HTC)

A diagnostic and treatment facility comprised of a comprehensive, multidisciplinary team of medical professionals who specialize in treating individuals with hemophilia and related bleeding disorders. HTCs treat the whole person and the family, through continuous supervision of all the medical and psychosocial aspects of bleeding disorders. HTC multidisciplinary teams may include hematologists, pediatricians, orthopedists, physical therapists, nurses, dentists, social workers and other mental health professionals. HTCs can refer patients to other specialists for services that are not provided in-house. HTC care can reduce or eliminate complications in patients with bleeding disorders.

High-Deductible Health Plan (HDHP)

A plan with a higher deductible than a traditional insurance plan. The monthly premium is usually lower, but you pay more of the healthcare costs yourself before the plan starts to pay its share (your deductible). An HDHP that meets federal standards for a minimum deductible can be combined with a health savings account (HAS) to allow you to pay for qualified out-of-pocket medical expenses on a pre-tax basis.

High-Risk Pool (HRP) Plan (State): High-risk pool plans offer health insurance coverage that is subsidized by a state government. Not all states offer high-risk pools, and those that do have distinct rules in terms of cost, eligibility and benefits. Many high-risk pools will be phased out following the implementation of plans in the Marketplaces.

Home and Community-based Services (HCBS)

Services and support provided by most state Medicaid programs in your home or community that gives help with such daily tasks as bathing or dressing. Covered when provided by care workers or, if your state permits it, by your family.

Home Healthcare

Healthcare services and supplies in your home that a doctor prescribes.

Hospital Readmission

A return by a patient to the hospital following discharge for the same or related care within 30, 60 or 90 days. Hospital readmissions are often used in part to measure the quality of hospital care.

Individual Health Insurance Policy

Policies for people who aren't connected to job-based coverage. Individual health insurance policies are regulated under state and federal law. Note that the phrase "individual policies" when used in this way – policies that are unconnected to employment – can be used for policies that cover a single person or multiple people (families, mother and dependent child, husband and wife, etc.).

Individual Mandate

Also known as "individual responsibility," under the ACA, you must be enrolled in a health insurance plan that meets basic minimum standards, known as Minimum Essential Coverage (MEC). If you aren't enrolled in MEC, you may be required to pay a penalty. Exempt from this are people with very low income for whom coverage is unaffordable, or for other reasons, including religious beliefs. The Summary of Benefits and Coverage for your plan must tell you if the plan is considered MEC.

In-Network Coinsurance

The percent (i.e., 20%) you pay of the allowed amount for covered health care services to providers who contract with your health insurance or plan. In-network coinsurance usually costs you less than out-of-network coinsurance.

In-Network Copayment

A fixed amount (i.e., \$15) you pay for covered health care services to providers who contract with your health insurance or plan. In-network copayments usually are less than out-of-network copayments.

In-Network Provider

A physician, certified nurse midwife, hospital, skilled nursing facility, home healthcare agency, or any other duly licensed or certified institution or health professional under contract with your insurance provider.

In-Person Assisters (IPA)

Individual or organizations that are trained to provide help to consumers, small businesses, and their employees as they look for health coverage options through the Marketplace/Exchanges. IPAs help consumers complete eligibility and enrollment forms and are required to be unbiased. Their services are free to consumers.

L

Lifetime Limit

A cap on the total lifetime benefits your insurance policy will cover (also known as a lifetime cap). Before passage of the ACA, many insurers set a lifetime dollar limit on benefits (like \$1 million) and would not pay for covered services once the limit was hit. As of September 2010, non-grandfathered health plans can no longer set lifetime dollar limits on the Essential Health Benefits (EHBs). Plans can continue to limit specific benefits by number (for example, covering only a certain number of visits).

Long-Term Care (LTC)

Medical and nonmedical services provided to people who are unable to perform basic activities of daily living such as dressing or bathing. Long-term supports and services can be provided at home, in the community, in assisted living or in nursing homes. Individuals may need long-term supports and services at any age. Medicare and most health insurance plans don't pay for long-term care.



M

Managed Care Organization (MCO)

A group or organization that provides managed care plans.

Managed Care Plan

A plan that generally provides comprehensive health services to its members, and offers financial incentives for patients to use the providers who belong to the plan. Examples include: health maintenance organizations (HMO), preferred provider organizations (PPO), exclusive provider organizations (EPO) and point of service plans (POS).

Managed Care Provisions

Features within health plans that provide insurers with a way to manage the cost, use and quality of healthcare services received by group members. Examples of managed care provisions include:

- Preadmission certification - Authorization for hospital admission given by a healthcare provider to a group member prior to hospitalization. Failure to obtain a preadmission certification in non-emergencies reduces or eliminates the healthcare provider's obligation to pay for services rendered.
- Utilization review - The process of reviewing the appropriateness and quality of care provided to patients. Utilization review may take place before, during or after the services are rendered.

Managed Care Provisions (cont.)

- Preadmission testing - Requirement designed to encourage patients to obtain necessary diagnostic services on an outpatient basis prior to nonemergency hospital admission. The testing is designed to reduce the length of a hospital stay.
- Nonemergency weekend admission restriction - A requirement that imposes limits on reimbursement to patients for nonemergency weekend hospital admissions.
- Second surgical opinion - A cost-management strategy that encourages or requires patients to obtain the opinion of another doctor after a physician has recommended that a nonemergency or elective surgery be performed. Programs may be voluntary or mandatory in that reimbursement is reduced or denied if the participant does not obtain the second opinion. Plans usually require that such opinions be obtained from board-certified specialists with no personal or financial interest in the outcome.

Maximum Out-of-Pocket (MOOP)

A yearly cap on the amount of money individuals are required to pay out-of-pocket for health care costs, excluding the premium cost.

Medicaid

A state-administered health insurance program for low-income families and children, pregnant women, the elderly, people with disabilities, and in some states, other adults. The federal government provides a portion of the funding and sets guidelines. States also have choices in how they design their program, so Medicaid programs and eligibility vary from state to state, and may have a different name in your state. Under the ACA, states have the option to expand Medicaid coverage to all individuals with income under 138% of the FPL.

Medical Loss Ratio (MLR)

A financial tool that measures the percentage of premium dollars taken in by a health insurer that are spent on customers' medical claims and quality improvement activities as compared with money spent on overhead expenses, including salaries, administrative costs and agent commissions. The Affordable Care Act sets minimum medical loss ratios for different markets, as do some state laws. If your plan does not meet an applicable MLR, then you or your employer could receive a refund.

Medically Necessary

Services or supplies that are needed for the diagnosis or treatment of your health condition and meet accepted standards of medical practice.

Medical Underwriting

A process used by insurance companies that uses your health status when you're applying for health insurance coverage to determine whether to offer you coverage, at what price and with what exclusions or limits. Under the ACA, all non-grandfathered plans are prohibited from using medical underwriting to deny coverage or determine premiums.

Medicare

A federal health insurance program for people who are age 65 or older and certain younger people with disabilities. It also covers people with End-Stage Renal Disease (ESRD)/ Medicare is composed of four parts:

Medicare Part A

Hospital insurance that helps cover inpatient care in hospitals, skilled nursing facilities, hospice and home care. Most beneficiaries are enrolled in Part A automatically.

Medicare Part B

Medical coverage that helps to cover medically necessary services like doctors' services, outpatient care, home health services and other medical services. Part B also covers some preventive services, and physician-administered drugs like clotting factor. Most beneficiaries are enrolled in Part B automatically.



Medicare Part C/Medicare Advantage (MA)

A type of Medicare health plan offered by a private company that contracts with Medicare to provide you with all your Medicare Part A and Part B benefits. There are many types of Medicare Advantage Plans (MAP) include HMOs, PPOS, Private Fee-for-Service Plans, Special Needs Plans and Medicare Medical Savings Account Plans. If you're enrolled in an MA plan, Medicare services are covered through the plan and aren't paid for under Parts A and B Most Medicare Advantage Plans offer prescription drug coverage.

Medicare Part D

An optional program that provides prescription drug coverage. There are two ways to get Medicare prescription drug coverage: through a Medicare Prescription Drug Plan or a Medicare Advantage Plan that includes drug coverage. These plans are offered by insurance companies and other private companies approved by Medicare.

Minimum Essential Coverage (MEC)

The type of coverage an individual must to have to meet the individual responsibility requirement under the ACA. This includes policies sold through a Marketplace, job-based coverage, Medicare, Medicaid, CHIP, TRICARE and certain other coverage. The summary of benefits and coverage (SBC) for your plan must tell you if the plan is MEC. Note that some plans sold outside the Marketplace to individuals do not meet these standards and will not count toward the requirement to have coverage. Check with the insurance company for the plan to confirm whether it is "minimum essential coverage."

Minimum Value

A health plan meets this standard if it's designed to pay at least 60% of the total cost of medical services for a standard population. Individuals offered employer-sponsored coverage that provides minimum value and that's affordable won't be eligible for a premium tax credit if they choose to purchase health insurance through the Marketplace.

Modified Adjusted Gross Income (MAGI)

The figure used to determine eligibility for lower costs in the Marketplace/Exchange and for Medicaid and CHIP. Generally, modified adjusted gross income is your adjusted gross income plus any tax-exempt Social Security, interest, or foreign income you have.

N

Navigator

An individual or organization that's trained to help consumers, small businesses, and their employees as they look for health coverage options through the Marketplaces established pursuant to the ACA. Navigators assist consumers with completing eligibility and enrollment forms. These individuals and organizations are required to be unbiased and their services are free to consumers

New Plan

As referenced in the ACA, a health plan that is not grandfathered and therefore subject to the reforms in the ACA. In the individual health insurance market, a plan that your family is purchasing for the first time. In the group health insurance market, a plan that your employer is offering for the first time. New employees and new family members may be added to existing grandfathered group plans – so a plan that is new to you and your family may still be a grandfathered plan.

In both the individual and group markets, a plan that loses its grandfathered status will be considered a new plan. This happens when it makes significant changes to the plan, such as reducing benefits or increasing cost-sharing for enrollees. (See Grandfathered Plan).

Nondiscrimination

A requirement that job-based insurance not discriminate based on health status by denying or restricting health coverage, or charging more. Job-based plans can restrict coverage based on other factors such as part-time employment that aren't related to health status.



Open Enrollment Period (OEP)

The time period set up to allow you to choose from available plans, usually once a year.

Out-of-Network (OON) Coinsurance

The percentage (for example, 40%) you pay of the allowed amount for covered health care services to providers who don't contract with your health insurance or plan. Out-of-network (OON) coinsurance usually costs you more than in-network coinsurance. The amount of coinsurance you pay may be more when you use an out-of-network provider.

Out-of-Network Copayment

A fixed amount (for example, \$30) you pay for covered health care services from providers who don't contract with your health insurance or plan. Out-of-network (OON) copayments usually are more than in-network copayments. The copayment you pay may be more when you use an out-of-network provider.

Out-of-Network Providers

A duly licensed or certified institution or health professional not under contract with your insurance provider.

Out-of-Pocket (OOP) Limit

The maximum amount you will be required to pay for covered services in a year, before the plan covers 100% of all costs. Generally, this includes the deductible, coinsurance, and copayments (varies from plan to plan), but not premiums. Plans can set different out-of-pocket limits for different services, and some plans do not have out-of-pocket limits.



P

Patient-centered Medical Home (PCMH)

The patient centered medical home (PCMH) is a model for transforming the organization and delivery of primary care. It is also referred to as primary care medical home, advanced primary care, and the healthcare home.

Patient-Centered Outcomes Research Institute (PCORI)

Institute authorized by the ACA to conduct comparative effectiveness research (CER).

Pay for Performance (P4P)

A health care payment system where providers receive incentives for meeting or exceeding quality, and sometimes cost, benchmarks. Some systems also penalize providers who do not meet established benchmarks. The goal of pay for performance programs is to improve the quality of care over time.

Per-member Per-month (PMPM)

Applies to a payment or cost for each enrolled plan member each month. For capitation payments, like in an HMO (Health Maintenance Organization), an insurance company pays a PMPM amount to a physician based on the number of members on the plan, regardless of whether the physician has an encounter with the patient that month or not. For cost, it is the average cost to cover each plan member each month.

Pharmacy Benefit Manager (PBM)

Health plans and sponsors contract with Pharmacy Benefit Managers to handle the claims processing and administrative functions involved with prescription drug programs. In addition to processing and paying claims, PBMs develop and maintain a program drug formulary, contract with participating pharmacies and negotiate discounts and rebates with drug manufacturers.

Plan Year

A 12-month period of benefits coverage under a health plan. This 12-month period might be different than the calendar year, depending on when your health plan renews.

Platinum Health Plan

A plan in the health insurance Marketplaces where the percentage the plan pays of the average overall cost of providing essential health benefits to members is 90%.

Policy Year

A 12-month period of benefits coverage under an individual health insurance plan. This 12-month period might be different than the calendar year.

Point-of-Service Plan (POS) Plan

A type of plan in which you pay less if you use doctors, hospitals and other healthcare providers that belong to the plan's network. POS plans may also require you to get a referral from your primary care doctor in order to see a specialist.

Preauthorization

A decision by your health insurer or plan that a health care service, treatment plan, prescription drug or durable medical equipment is medically necessary. Sometimes called prior authorization, prior approval or precertification. Your health insurance or plan may require preauthorization for certain services before you receive them, except in an emergency. Preauthorization isn't a promise your health insurance or plan will cover the cost.

Pre-Existing Condition

With certain limited exceptions, a pre-existing condition is any condition (physical, mental or a disability) for which medical advice, diagnosis, care, or treatment was recommended or received within the 6-month period before you enrolled in a health insurance plan. Before passage of the ACA, insurers could either not offer health insurance to you if you had a pre-existing condition or could refuse to cover any services related to a pre-existing condition (known as a pre-existing condition exclusion). Under the ACA non-grandfathered health insurance plans can't refuse to cover you or charge you more just because you have a pre-existing health condition.

Pre-Existing Condition Insurance Plan (PCIP)

High-risk pool operated by the states and the federal government that provided coverage for individuals who have been denied coverage for a pre-existing condition or have a pre-existing condition. Individuals must have been without health insurance for at least six months. Ended in 2014.

Preferred Drug List (PDL)

A PDL is a list of medications that are covered without the need to obtain prior authorization. Drugs are designated as either preferred or non-preferred.

Preferred Provider Organization (PPO)

A type of health plan that contracts with medical providers, such as hospitals and doctors, to create a network of participating providers. You pay less if you use providers who belong to the plan's network. You can use doctors, hospitals and providers outside of the network for an additional cost.

Premium

A monthly or annual payment you make to your insurer to get and keep insurance coverage. Premiums can be paid by employers, unions, employees or individuals or shared among different payers.

Prescription Drug Coverage

Health insurance or plan that helps pay for prescription drugs and medications.

Preventive Services

Routine healthcare that includes screenings, checkups, and patient counseling to prevent illnesses, disease or other health problems.



Primary Care

Health services that cover a range of prevention, wellness and treatment options for common illnesses. Primary care providers (PCP) include doctors, nurses, nurse practitioners and physician assistants. They often maintain long-term relationships with you, and advise and treat you on a range of health-related issues. They may also coordinate your care with specialists.

Primary Care Provider (PCP)

Includes doctors, nurses, nurse practitioners and physician assistants; they provide health services for a wide range of common illnesses, wellness and prevention.

Primary Care Case Management (PCCM)

A model of Medicaid managed care that is outlined in the Medicaid statute. In PCCM programs, state Medicaid agencies contract with primary care providers to provide, locate, coordinate, and monitor primary care services for Medicaid beneficiaries who select them or are assigned to them by the state. The primary care provider – usually a physician or a physician practice, but sometimes a nurse practitioner, physician assistant, or other provider – serves as a beneficiary's "medical home" for primary and preventive care. Under their contracts with primary care providers, states pay them a small monthly case management fee in addition to regular FFS payments.

Prior Authorization (PA)

A decision by your health insurer that a health care service, treatment plan, prescription drug or durable medical equipment is medically necessary. Sometimes called preauthorization, prior approval or precertification. Your health insurance or plan may require preauthorization for certain services before you receive them, except in an emergency. Preauthorization isn't a promise your health insurance or plan will cover the cost.

Q

Qualified Health Plan (QHP)

An insurance plan that is certified by a Marketplace, provides essential health benefits, follows established limits on cost-sharing (like deductibles, copayments, and out-of-pocket maximum amounts) and meets other requirements. A qualified health plan will have a certification by each Marketplace in which it is sold.

Qualifying Event

Any event or occurrence such as death, termination of employment, divorce or a terminal illness that changes an employee's eligibility status and permits an acceleration or continuation of benefits or coverage under a group health plan. The term is most frequently used in reference to COBRA eligibility.

R

Rate Review

A process that allows state insurance departments to review rate increases before insurance companies can apply them to you.

Referral

A written order from your primary care doctor for you to see a specialist or get certain medical services. In many Health Maintenance Organizations (HMOs), you need to get a referral before you can get medical care from anyone except your primary care doctor. If you don't get a referral first, the plan may not pay for the services.

Rehabilitative/Rehabilitation Services

Health care services that help you keep, get back, or improve skills and functioning for daily living that have been lost or impaired because you were sick, hurt, or disabled. These services may include physical and occupational therapy, speech-language pathology, and psychiatric rehabilitation services in a variety of inpatient and/or outpatient settings.

Rescission

The retroactive cancellation of a health insurance policy. Insurance companies will sometimes retroactively cancel your entire policy if you made a mistake on your initial application when you buy an individual market insurance policy. Under the Affordable Care Act, rescission is illegal except in cases of fraud or intentional misrepresentation of material fact as prohibited by the terms of the plan or coverage.

Rider (Exclusionary Rider)

An amendment to an insurance policy. Some riders add coverage while other riders exclude coverage (known as exclusionary rider). Example: You buy a maternity rider to add coverage for pregnancy to your policy. An exclusionary rider is an amendment permitted in individual policies that permanently excludes coverage for a health condition, body part or body system (such as a certain disease state or disability). Under the ACA, no exclusionary riders will be permitted in non-grandfathered health insurance plan.

Risk Adjustment

A statistical process that takes into account the underlying health status and health spending of the enrollees in an insurance plan when looking at their healthcare outcomes or healthcare costs.

S

Self-Insured Plan

Type of plan usually present in larger companies where the employer itself collects premiums from enrollees and takes on the responsibility of paying employees' and dependents' medical claims. These employers can contract for insurance services such as enrollment, claims processing, and provider networks with a third party administrator, or they can be self-administered. Self-insured plans do not follow state insurance rules. They are regulated under the federal rule known as ERISA and overseen by the U.S. Department of Labor.



Silver Health Plan

A plan in the health insurance Marketplaces/ Exchanges where the percentage the plan pays of the average overall cost of providing essential health benefits to members is 70%.

Skilled Nursing Facility (SNF) Care

Skilled nursing care and rehabilitation services provided on a continuous, daily basis, in a skilled nursing facility. Example: Physical therapy or intravenous injections that can only be given by a registered nurse or doctor.

Short-Term, Limited Duration Health Plans

These plans are low-cost, limited coverage insurance plans that are meant to help individuals who have a temporary gap in health insurance coverage. Insurers could offer a short-term plan for up to three (3) years. While the premium is lower, many of these plans come with high deductibles. These plans typically do not cover pre-existing conditions, prescription drugs, or maternity care.

Small Business Health Options Program (SHOP)

The Marketplace available to small businesses under the ACA. Small businesses buying plans in the SHOP select the plan and decide how much they pay toward employee premiums. Participating small businesses may qualify for a small business health tax credit worth up to 50% of their premium costs.

Social Security Disability Income (SSDI)

Income payable by the federal government to individuals who are determined to be totally disabled.

Supplemental Security Income (SSI)

Social Security administers this program. We pay monthly benefits to people with limited income and resources who are disabled, blind, or age 65 or older. Blind or disabled children may also get SSI.

Special Enrollment Period (SEP)

A time outside of the open enrollment period during which you and your family have a right to sign up for health coverage. Job-based plans must generally provide a special enrollment period of 30 days following certain life events that involve a change in family status (such as marriage or birth of a child) or loss of other job-based health coverage. Plans sold to individuals, including Marketplace plans, must provide 60 days to enroll.

Special Healthcare Need(s)

The healthcare and related needs of children who have chronic physical, developmental, behavioral or emotional conditions. Such needs are of a type or amount beyond that required by children generally.

Specialty Pharmacy Provider (SPP)

A pharmacy that is designated to provide specialized medication for complex, genetic, rare, and chronic health conditions. Specialty pharmacy providers may provide home health or nursing services.

State Based Marketplace/State Based Exchange (SBM/SBE)

One type of Marketplace option for states. States opting for an SBM/SBE will manage their own Marketplace in accordance with applicable federal laws.

State Continuation Coverage

A state-based requirement similar to COBRA that applies to group health insurance policies of employers with fewer than 20 employees. In some states, state continuation coverage rules also apply to larger group insurance policies and add to COBRA protections. Example: in some states, if you're leaving a job-based plan, you must be allowed to continue your coverage until you reach the age of Medicare eligibility.

State Partnership Marketplace/State Partnership Exchange (SPM/SPE)

One type of Marketplace option for states under the ACA. States opting for an SPM/SPE will have a Marketplace that is run by the federal and state government jointly.

State Plan Amendment (SPA)

A process to change administrative aspects of a state Medicaid plan. Every state has a Medicaid state plan that outlines the details of its Medicaid program. Each state plan is different, reflecting the level of flexibility that states have in their Medicaid programs. If a state wants to change its Medicaid program, one option is to file a SPA.

Summary of Benefits and Coverage (SBC)

The ACA requires plans to offer this easy-to-read summary that lets you make apples-to-apples comparisons of costs and coverage between health plans. You'll get the "Summary of Benefits and Coverage" (SBC) when you shop for coverage on your own or through your job, renew or change coverage, or request an SBC from the health insurance company.

Supplemental Security Income (SSI)

A monthly benefit paid by Social Security to people with limited income and resources who are disabled, blind, or 65 or older. SSI benefits are different than Social Security retirement or disability benefits.

T

Third Party Administrator (TPA)

An individual or firm hired by an employer to handle claims processing, pay providers and manage other functions related to the operation of health insurance. The TPA is not the policyholder or the insurer. The TPA may often be a company you associate with health insurance, such as Aetna or Blue Cross, but in this role it is not the actual insurer but simply managing the plan on behalf of the employer.

TRICARE

A health care program for active-duty and retired uniformed services members and their families.



U

Uncompensated Care

Healthcare or services provided by hospitals or healthcare providers that don't get reimbursed. Often uncompensated care arises when people don't have insurance and cannot afford to pay the cost of care.

Urgent Care

Care for an illness, injury or condition serious enough that a reasonable person would seek care right away, but not so severe as to require emergency room care.

Usual, Customary and Reasonable (UCR) Charges

A healthcare provider's usual fee for a service that does not exceed the customary fee in that geographic area, and is reasonable based on the circumstances. Instead of UCR charges, PPO plans often operate based on a negotiated (fixed) schedule of fees that recognize charges for covered services up to a negotiated fixed dollar amount. Conventional indemnity plans typically operate based on UCR charges.

V

Veteran's Health Benefits

Veterans may be eligible for a broad range of services, including health care benefits, through the Veteran's Administration.

W

Waiting Period (Job-Based coverage)

The time that must pass before coverage can become effective for an employee or dependent, who is otherwise eligible for coverage under a job-based health plan. Applies to all new employees, and is not based on health status. Under the ACA, employer plans cannot impose a waiting period of more than 90 days

Well-Baby/Well-Child Visits

Routine doctor visits for comprehensive preventive health services that occur when a baby is young and annual visits until a child reaches age 21. Services include physical exam and measurements, vision and hearing screening, and oral health risk assessments. Under the ACA's rules for preventive services, well child visits may be covered without cost-sharing.

Wellness Programs

A program intended to improve and promote health and fitness that's usually offered through the work place, although insurance plans can offer them directly to their enrollees. The program allows your employer or plan to offer you premium discounts, cash rewards, gym memberships and other incentives to participate. Examples: programs to help you stop smoking, diabetes management programs, weight loss programs and preventive health screenings.

Wholesale Acquisition Cost (WAC)

The manufacturer's list price for the drug to wholesalers or direct purchasers, excluding discounts, rebates pay or reductions in price. This price is defined by federal law.

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Health Insurance Marketplaces: An Overview

The Affordable Care Act (ACA) created health insurance marketplaces, sometimes called exchanges, which provide individuals and small business owners with a "one-stop-shop" online marketplace to shop for, compare and purchase health insurance. Qualified individuals may be able to obtain premium tax credits and cost-sharing reductions to make marketplace coverage more affordable.

The marketplace for small businesses is called the Small Business Health Options Program, or SHOP, and is open to businesses with 2 to 50 employees (up to 100 employees in some states). Eligible small businesses may qualify for tax credits to lower the employer's cost of buying coverage for employees.

Each state has a marketplace for individuals and families, and a SHOP for small businesses to buy coverage. Marketplaces may be operated by the federal government, the state government, or by a partnership of both. In most ways, the marketplaces won't differ based on who operates the marketplace; they all must perform the same functions and plans will have to meet a minimum set of standards set by the federal government. However, state-based marketplaces may apply more consumer-protective requirements for participating plans, such as a requirement to offer standardized benefit designs, or offer different tools for consumers, such as decision support tools.

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 a citizen of the U.S. (or are lawfully present); and
- Are not currently incarcerated.

Consumers will need to go through additional eligibility screening to determine whether they are eligible for premium tax credits or cost-sharing reductions to help make their marketplace plan more affordable.

Marketplace plans: Federal rules establish: minimum standards for benefits and cost sharing, limit the factors that may be used to set premiums, and require plans to meet network adequacy standards.

All marketplace plans must meet the following requirements (states can apply stronger standards):

- **Essential Health Benefits (EHBs):** Insurers are required to cover a minimum set of benefits within at least the following 10 categories: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care.
- **Key patient services and protections:** Health plans must cover recommended preventive care at no cost-sharing (co-payments, coinsurance and deductible), and allow individuals to use emergency services without prior authorization or higher cost-sharing for out-of-network emergency room care.
- **Prohibition on discrimination based on health status:** Insurers cannot refuse to accept applicants, omit benefits for a pre-existing health condition, or impose a waiting period based on health status.
- **Standardized tiers of coverage:** Plans must provide a minimum level of financial protection for health costs, at least 60 percent of total average costs for covered benefits. In addition, plans must be offered at specified coverage levels, known as "metal levels," so that individuals can more easily compare them. The lowest level of coverage (60 percent) is called the bronze level. A silver level plan will cover 70 percent of total average costs for covered benefits, a gold plan covers 80 percent, and a platinum plan covers 90 percent. Individuals under age 30 or who cannot find "affordable" coverage are eligible to purchase catastrophic coverage.



- **Modified community rating:** Insurers are no longer allowed to charge higher premiums based on the health status or claims experience of an individual. However, insurers may charge more if the individual is older than average (up to three times more) or if he or she uses tobacco products. Premiums can also vary by geography.
- **Prohibition on annual and lifetime limits:** Health plans can no longer impose annual or lifetime dollar limits on essential health benefits (EHBs).
- **Limits on out-of-pocket costs:** Health plans must limit out-of-pocket costs for essential health benefits obtained in-network to no more than \$6,850 for an individual or \$13,700 for a family in 2016 (this amount will grow each year to track increases in medical costs).
- **Dependent coverage to age 26:** Health plans must allow families to keep their adult children on the family plan up to age 26. This applies even if the child isn't a student, doesn't live at home, or is not financially dependent on his or her parents.
- **Sufficient access to providers:** Marketplace plans must meet federal standards for network adequacy, ensuring access to primary care doctors, specialists, and "essential community providers" such as community health clinics and hemophilia treatment centers (HTCs) without unreasonable delay.

Tools available to Marketplace shoppers: The tools available to consumers shopping for coverage will vary depending on whether the state or federal government is operating the exchange. All federally run Marketplaces allow consumers to estimate annual out-of-pocket costs using a cost calculator, to look up which plans include a consumer's preferred providers, and search plans based on covered prescription drugs. Many state- administered Marketplaces offer similar tools.

Note that the metal levels of coverage provide a rough way to evaluate the relative generosity of a plan; individual costs will vary based on actual health care use. The out-of-pocket cost calculator will help refine the comparison of plans based on an individual's expected health care use, based on high, medium and low levels of health care use. However, for a more precise comparison, use the Health Plan Cost Comparison Worksheet in this toolkit.

Buying coverage in the Marketplace vs. shopping in the outside market: In most states, consumers will continue to be able to buy health coverage outside the Marketplace. For the most part, health insurers selling coverage outside the Marketplace will have to provide many of the same consumer protections that insurers inside the health insurance Marketplace provide. However, some types of coverage sold outside the Marketplace are exempt from the new rules, and consumers should fully review the terms of their coverage to ensure it provides adequate protection. For example, some plans sold outside the Marketplace may still discriminate based on health status, won't provide essential health benefits, and may not meet the federal limit on out-of-pocket costs. In addition, not all coverage sold outside the Marketplace meets the federal standard for "minimum essential coverage" and consumers could face a tax penalty if they do not have this minimum coverage.

Furthermore, financial assistance can only be obtained with Marketplace plans, and some special enrollment periods (SEP) for enrolling in or changing plans outside the open enrollment period are only available to Marketplace plan enrollees.

However, plans sold outside the Marketplace that comply with the ACA's consumer protections may be a better option for some consumers, particularly if a preferred provider is not part of any Marketplace plan network and/or the consumer is ineligible for financial assistance and doesn't expect a mid-year drop in income (which, if enrolled in the Marketplace, would qualify them for a SEP to enroll in coverage with financial help).



Making Benefits Easier to Understand

Under the Affordable Care Act (ACA), all health insurance companies and employers offering coverage must use the same standard form to summarize the benefits and coverage offered under the plan. With standardized forms, consumers are able to compare plans when enrolling in coverage, regardless of whether it's available through an employer or Marketplace, and better understand the benefits and costs under the plan once enrolled.

The standard format, known as the summary of benefits and coverage (SBC), includes information on important elements of the coverage, such as the deductible, co-pays, services not covered, and whether enrollees need a referral to see a specialist. These are presented in a way that makes it easier for consumers to make comparisons of their coverage options. 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, but won't provide specific information on what an individual's actual costs may be. All health insurance companies and employer plans must also provide consumers with a uniform glossary of terms commonly used in health insurance coverage, such as "deductible," "non-preferred provider" and "coinsurance."

Some additional points to keep in mind:

- If an employer offers some benefits under a separate policy, such as prescription drug coverage or mental health services, it can provide multiple forms. Be sure you have all the SBCs for your coverage so you can get a complete picture of your total benefits and costs.
- The SBC requirement applies to all plans, whether you buy yours on your own or get it through an employer.
- The SBC must tell you if your coverage qualifies as minimum essential coverage (MEC). If your plan provides MEC, it will meet the requirement to have coverage and you won't owe a penalty.
- The SBC must also tell you if your coverage provides minimum value. Employees that are offered job-based plans that fail to provide minimum value may be eligible for financial assistance for a Marketplace plan.
- Health plans must automatically provide the standard summary to a person who completes an application for coverage or to any person who requests a summary within 7 days. Employers must provide the summary when coverage renews (30 days prior to renewal) and upon request within 7 business days. Employers must also provide an updated summary if there is substantial mid-year change in coverage that would affect the content of the SBC.

For a sample of the summary of coverage [click here](#), or go to:

www.cms.gov/CCIIO/Resources/Forms-Reports-and-Other-Resources/Downloads/sbc-template-accessible.pdf

To see the uniform glossary of terms [click here](#), go to:

<http://www.cms.gov/CCIIO/Resources/Files/Downloads/uniform-glossary-final.pdf>



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Which ACA Requirements Apply to My Plan?

Standards for Health Insurance Plans, by Plan Type	New Employer-sponsored plan	Self-insured plan	Individual Market/Exchange plan	Grandfathered plan
No lifetime or annual limits: Plans are prohibited from limiting the lifetime dollar value of benefits effective now. Only grandfathered individual plans may impose an annual limit.	✓	✓	✓	✓
Dependents under age 26: Plans must allow adult children under age 26 to enroll in a parent's plan effective now.	✓	✓	✓	✓
Plan administrative costs: Plans must provide rebates to consumers if the percentage of premiums spent on medical services falls below 85 percent for large group plans or 80 percent for small group and individual plans (or higher standard set by state, if applicable) effective now.	✓		✓	✓
Preventive services: Plans must offer first dollar coverage (no co-payment or deductible) for certain preventive services effective now.	✓	✓	✓	
Patient protections: Plans are prohibited from requiring a referral to see an OB-GYN and from requiring prior authorization or higher cost sharing for out-of-network emergency services, effective now.	✓	✓	✓	

Standards for Health Insurance Plans, by Plan Type	New Employer-sponsored plan	Self-Insured plan	Individual Market/Exchange Plan	Grandfathered Plan
Out-of-pocket maximums: Plans must limit out-of-pocket costs to \$6,850 for single coverage and \$13,700 for family coverage effective in plan year 2014.	✓	✓	✓	
Pricing: Medical underwriting is prohibited and rating variation is only allowed based on age (3:1 ratio), tobacco (1.5:1.0), family composition and geography effective in plan year 2014.	Small group only		✓	
Minimum services covered: Plans must cover preventive and primary care, emergency, hospital, physician, outpatient, maternity and newborn care, pediatric (including dental and vision), medical/surgical care, prescription drugs, lab, and mental health and substance abuse, effective in 2014. States set benchmarks within each category.	Small group only		✓	

Adapted from UC Berkeley Center for Labor Research and Education, "Affordable Care Act: Summary of Provisions Affecting Employer-Sponsored Insurance," July 2014, Accessed: January 11, 2016. Other sources include ACA text, guidance and implementing regulations.



Subsidies to Buy Coverage in a Health Insurance Marketplace

Under the Affordable Care Act (ACA), individuals who purchase coverage through a health insurance Marketplace may be eligible for financial assistance if their household income is less than 400% of the federal poverty level (FPL) and they don't have "minimum essential coverage."¹ The ACA provides two forms of financial assistance, both of which are only available through a health insurance Marketplace: a monthly premium tax credit, which will lower the premium amount an individual or family must pay, and cost sharing subsidies, which will limit an insured's maximum out-of-pocket costs.

Premium Tax Credits: To be eligible for the premium tax credit, an individual must meet all of the following criteria:

- Be enrolled in a plan through the health insurance Marketplace
- Is not eligible for other minimum essential coverage, other than coverage offered in the individual market, and
- Has a household income between 100 and 400% of the FPL.

Premium tax credits are determined on a sliding scale, based on income, so that individuals at the lower end of the income scale get the most financial assistance. Premium tax credits can be used at the time an individual must pay their monthly premium, so the amount they owe is automatically lowered.

¹ In 2019, 400% FPL is \$48,560 for an individual and \$100,400 for a family of four. The poverty level varies by family size and is adjusted annually to reflect inflation. "Minimum Essential Coverage" includes most types of coverage, including Medicare, Medicaid, and employer-sponsored coverage that is considered affordable and adequate.

The subsidy is based on the premium for the second lowest cost silver plan available in the Marketplace, known as a benchmark plan. The tax credit can be used to purchase any plan in the Marketplace, but an individual or family who wants a more expensive or higher tier plan (i.e., gold or platinum), must pay the difference. For example, if John has income of 100% FPL (\$11,770), his premium would be capped at 2.03% of his income, or \$271. If the benchmark plan costs \$5,000 a year, John would owe \$271 and the credit would cover \$4,729.

However, if John chose to buy a plan with a higher premium (i.e., either a higher cost silver plan or a gold plan), he would pay more than \$271. For example, if the premium for the plan he buys is \$5,500, John would pay \$771 (\$5,500 minus the \$4,729 credit based on the benchmark).

PREMIUM LIMITS FOR CONSUMERS BASED ON INCOME, 2019	
INCOME	PREMIUM LIMIT
Up to 133% FPL	2.08% of income
133 - 150% FPL	3.11 - 4.15% of income
150 - 200% FPL	4.15 - 6.54% of income
200 - 250% FPL	6.54 - 8.36% of income
250 - 300% FPL	8.36 - 9.86% of income
300 - 400% FPL	9.86% of income

Note: These amounts will increase annually

Premium tax credits are adjusted to take into account premium differences because of age, family size, and geography. However, premium tax credits will not take into account a premium surcharge for tobacco use. Tobacco users must pay that surcharge out-of-pocket, without the help of premium tax credits.



Cost-Sharing Subsidies Individuals and families with income below 250% FPL may also qualify for help paying out-of-pocket costs for services covered by their plan. This financial help, which is only available with a silver level plan, comes in two forms: a lower out-of-pocket limit and a higher actuarial value.² First, the cost-sharing subsidy will lower the out-of-pocket limit for eligible individuals to a fraction of what would apply otherwise.³ Second, the cost-sharing subsidy will increase the actuarial value of the silver level plan in which an individual enrolls. Where the standard value of a silver plan is 70% of total average costs for covered services, individuals eligible for the cost-sharing reduction will get a silver plan that covers 73%, 87% or 94% of total average costs for covered services, depending on income. This subsidy goes directly to the insurer to reduce an enrollees' out-of-pocket costs at the time the covered service is received.

Cost-Sharing Subsidies for Consumers Enrolled in a Silver Level Plan Based on Income, 2019

COST SHARING SUBSIDIES FOR CONSUMERS ENROLLED IN A SILVER LEVEL PLAN BASED ON INCOME, 2019		
INCOME	ACTUARIAL VALUE	OUT-OF-POCKET LIMIT
100 - 150% FPL	94%	\$2,600 individual; \$5,200 family
100 - 150% FPL	87%	\$2,600 individual; \$5,200 family
200 - 250% FPL	73%	\$6,300 individual; \$12,600 family

Reconciling premium tax credits: Individuals who receive premium tax credits must file taxes for the year in which they receive that financial assistance and reconcile the amount received with the amount they should have received based on actual income. Individuals whose actual income ends up lower than expected, would receive too few credits and would be entitled to a refund. Conversely, individuals whose actual income ends up higher than expected would receive too much in tax credits and would owe the difference on their taxes.

Individuals who have a change in income or mistakenly report income for purposes of calculating eligibility for cost sharing reductions, however, are not required to reconcile that financial help and are not expected to pay back any extra assistance received.

² The ACA requires insurers to offer four standardized levels of coverage: Bronze, Silver, Gold and Platinum. The four plan levels will vary based on the share of covered services paid by the plan. They range from the least generous level (bronze, with an actuarial value of 60%) to the most generous level (platinum, with an actuarial value of 90%).

³ The out-of-pocket limit for all plans in 2019 is \$7,900 for an individual plan and \$15,800 for a family plan.

What to Do When There's a Problem with Your Coverage

During the plan year, you may encounter problems with your coverage. For example, you may find your provider is no longer in network, or you are billed for out-of-network services when you weren't expecting that. 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 provider is no longer in network:

Some states have laws that allow consumers in certain circumstances to continue seeing their provider at in-network cost-sharing even if the provider is no longer in their plan's network. This may include medical or pharmacy providers. These protections may also apply to consumers who are newly enrolled in a plan that doesn't cover the providers the consumer has been seeing under a previous plan. Known as "continuity of care" laws, these protections are not available in every state. In addition, even those states that have such protections may limit the circumstances under which they apply.

These limits include:

- **Who can benefit:** most state laws limit "continuity of care" protections to consumers with very specific health care needs, for example, those who are in the middle of a course of treatment, are undergoing care for a terminal illness, or are pregnant.
- **How long the protection applies:** most state laws limit how long the protection applies. The limit may be for a specific period of time (i.e., 90 days), or until the completion of the course of treatment (i.e., a course of chemotherapy or completion of a pregnancy).
- **Which plans must provide the protection:** many states limit the type of plan that must provide this protection, for example, Health Maintenance Organizations (HMOs) but not Preferred Provider Organizations (PPOs).



State regulated plans: To figure out if your state has "continuity of care" protections for individuals enrolled in state-regulated plans (i.e., individual plans or small employer coverage), contact your state department of insurance. You can find the contact information here: http://www.naic.org/state_web_map.htm. If your state requires continuity of care protections, you'll need to find out who is eligible for those protections and for what period of time.

Under federal rules, plans participating in Federally Facilitated Marketplaces must offer some protection against network changes that affect your care. If your provider leaves your plan's network in the middle of your plan year, federal rules require the plan to allow certain enrollees to continue seeing that provider at in-network cost sharing.

- **Who can benefit:** those in "active treatment" can get this protection, which includes those in: an ongoing course of treatment for a life-threatening condition; an ongoing course of treatment for a serious acute condition; the second or third trimester of pregnancy; or, an ongoing course of treatment for a health condition for which a treating physician or provider attests that discontinuing care by that physician would worsen the condition or interfere with the anticipated outcome.
- **How long the protection applies:** Until the treatment is complete or for 90 days, whichever is shorter.

If your state has stronger protections for consumers who lose access to an in-network provider in the middle of the plan year, those will apply. These federal rules for Marketplace plans will apply where there are no state protections and where the state protections are weaker. To see if your state has applicable consumer protections (as of April 2016) [click here](#) or visit this resource: <http://www.commonwealthfund.org/publications/blog/2016/apr/continuity-of-care-protections>

If you qualify for "continuity of care" protections, note that it will be your responsibility to either find an in-network provider to continue your treatment or obtain permission from your plan prior to your next visit to continue to see the out-of-network provider.

Coverage through a large employer plan or self-insured employer plan: you may not have any legal protections. However, contact your human resources (HR) department and/or your plan to find out if your coverage includes any similar types of protections for you.

If you are billed for surprise out-of-network care:

Some states have laws that protect 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.

State laws that protect against these surprise charges may limit the circumstances under which they apply. These limits include:

- Who can benefit: the amount in dispute may need to meet a threshold for triggering state protection, for example, \$500 in balance billed charges. Or state law may require the consumer to request mediation to resolve the dispute. Other states, require the plan and provider to resolve the difference and protect the consumer from any additional charges.
- Which plans must provide the protection: many states limit the type of plan that must provide this protection, for example, Health Maintenance Organizations (HMOs) but not Preferred Provider Organizations (PPOs)

To find out if balance billing protections apply to you, contact your state department of insurance. You can find the contact information by [clicking here](#) or visiting: http://www.naic.org/state_web_map.htm.

If your plan won't cover a drug, treatment or specific service recommended for you by your doctor: You have options under federal law for getting that denial reconsidered. See Fact Sheet on **Appeals and Grievances**.



What If I Am Denied Coverage? Appeals and Grievances

Dealing with insurance companies can be complicated and frustrating, especially if you have a chronic illness, such as hemophilia or von Willebrand disease (VWD). Medications and treatments needed to manage your health can be overly burdensome, but are manageable. However, should your insurance plan deny coverage of a medically necessary prescription drug or other treatment or service, you could be left in an anxious situation not knowing how and when you will get the care you need. Fortunately, there are now options that allow you to appeal your insurance company's decision.

Your rights when you are denied coverage: The Affordable Care Act (ACA) includes rules that spell out how your plan must handle your appeal (usually called an "internal appeal"). If your plan still denies payment after considering your appeal, the ACA permits you to have an independent review organization decide whether to uphold or overturn the plan's decision. This final check is often referred to as an "external review."

Note that these ACA rules apply only to new (non-grandfathered) plans. Grandfathered plans do not have to comply with the new rules. However, over time all plans will lose that status and have to comply.

The ACA rules are:

- When your plan denies a claim, the plan must notify you of the following: the reason the claim was denied, your right to request an internal appeal of the denial, your right to an external review if your internal appeal was unsuccessful, and the availability of a 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 can ask 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. 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), and
- 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 to send any additional information requested. If a deadline is not given, call your insurer using the number provided on the back of your ID card. Remember, you should also receive the denial in writing. Be proactive and call your insurance company if you do not.

Where to start: You may want to start by contacting your prescribing/treating physician and ask him/her to contact your insurer's medical management area or medical director to request a peer-to-peer review to discuss the specific reason why you need this type of medication or treatment/service. This may resolve your issue without having to go through a more formal internal appeal or exceptions request process.

However, do keep in mind that you have 6 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 without a more formal internal appeal or exceptions request.

If your physician has already had the peer-to-peer review with the medical management staff, and the request continues to be denied, you have the right to appeal this decision in writing to the appropriate department or to more formally request an exception to the formulary. 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**.

When you request an internal appeal or exception, be sure to write a clear and simple letter providing the following:

- Pertinent clinical information regarding your health and medication history, including any medical records documenting your health history. If you're requesting a medication, include:
 - Information on other drugs or drug dosages you may have tried or considered but were or would have been ineffective or cause harm, or, based on sound clinical evidence and knowledge of the patient, are likely to be ineffective or cause harm.
 - History of any adverse reactions or side effects you have had to similar medications (over the counter or prescribed), or generic equivalents that were not effective.
 - Your treating physician should have copies of these.

Keep the following in mind:

- If your insurer requires the prescribing physician to complete a drug authorization form, you should make sure this has been done in compliance.
- If you received a letter of denial for the medication, ensure that the information provided explicitly addresses the reasons for the denial.
- If the dispute is over the "medical necessity" of the service, your physician's support in the form of a letter, including any relevant studies supporting the benefit of the treatment in question could be invaluable. Request that your physician write a letter of "medical necessity." 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, go to 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 think your plan should cover your claim, your health plan must cover it.



Where Do I Go for Help?

Consumer Assistance

Many states offer direct help with problems or questions about health insurance, either through Consumer Assistance Programs or the state Department of Insurance. The U. S. Department of Labor can provide help on employer-sponsored coverage, particularly if you are in a self-insured plan. To find out where to get help, you can [click here](#) or visit <https://www.healthcare.gov/how-can-i-get-consumer-help-if-i-have-insurance/>

In addition, the Marketplace offers several kinds of assistance to help you apply for coverage and choose a plan that meets your needs, [click here](#) or visit - <https://www.healthcare.gov/contact-us/> for information online and through a toll-free call center:

- 1-800-318-2596
- TTY 1-855-889-4325

Local help will be available through insurance agents and brokers as well as government agencies such as State Medicaid and Children's Health Insurance Program (CHIP) offices. All states will have additional in-person assistance through trained and certified individuals and organizations that can help you understand your health coverage options and enroll in a plan. Depending on which state you live in and who is providing the service, these organizations may be known as Navigators, In-Person Assistors or Certified Application Counselors. A list of the enrollment assistors and agents and brokers available in your area can be found by [clicking here](#) or visiting <https://LocalHelp.HealthCare.gov> or view the **Consumer Resources** section of this toolkit.

Consumer Resources

The Centers for Medicare & Medicaid Services Center for Consumer Information and Insurance Oversight (CCIIO), part of the Department of Health and Human Services (DHHS), provides national leadership in setting and enforcing standards for health insurance that promote fair and reasonable practices to ensure that affordable, quality health coverage is available to all Americans. The center also provides consumers with comprehensive information on coverage options currently available so they may make informed choices on the best health insurance for their family. Visit CCIIO at: <http://cciio.cms.gov>.

The Centers for Disease Control and Prevention National Center on Birth Defects and Developmental Disabilities Hemophilia Homepage provides consumers with access to the most up-to-date resources including the complete hemophilia treatment center (HTC) directory, videos, brochures, fact sheets and numerous other health education and outreach resources. The HTC directory provides the names and contact information of treatment center staff who are part of the federally funded HTC network. For a comprehensive listing of programs and resources visit: <http://www.cdc.gov/ncbddd/hemophilia/index.html>.

Families USA is a national nonprofit, nonpartisan organization dedicated to achieving high-quality, affordable healthcare for all Americans. For more than 30 years, it has been a highly effective consumer advocate organization at the national, state and community levels. In addition to providing user-friendly consumer resources, it offers extensive tools for state and local advocates, including state budget, healthcare-related legislation and implementation efforts. For access to the complete list of resources visit: <http://www.familiesusa.org>.



Healthcare.gov is the Web site managed by the U.S. Department of Health and Human Services that educates Americans about the Affordable Care Act (ACA). The Web site has a tool to find individual state's Consumer Assistance Programs, which states have established them, and other helpful sources for health insurance. Visit: www.healthcare.gov.

The Health Resources and Services Administration National Hemophilia Program Homepage assists people with hemophilia and other bleeding disorders and their families by coordinating activities and care at the national network of 130 hemophilia treatment centers (HTCs) located throughout the country. The program existed since 1975, and with HRSA support, HTCs provide diagnostic and educational services for individuals with bleeding disorders. The website is: <http://mchb.hrsa.gov/programs/hemophilia/index.html>.

Kaiser Family Foundation Web site provides access to reports, surveys, issue briefs, charts, slides and fact sheets about health policy-related issues such as the number of uninsured, Medicare, Medicaid, healthcare costs, and health reform. Through the main site one can access the Health Reform Source, a site devoted entirely to health reform implementation, including explanations of the health reform law, public policy issues and easy access to relevant data, studies and developments. The main Web site is: www.kff.org.

HANDI, the National Hemophilia Foundation's Information Resource Center HANDI's mission is centered on service—answering specific questions, fulfilling information requests, providing quality educational publications, making referrals to additional sources of assistance and immediately responding to the needs of the bleeding disorders community. HANDI's collection of more than 13,000 articles, textbooks, and educational publications is the definitive source for information about hemophilia and other inherited bleeding disorders. Call 1.800.42.HANDI or e-mail: handi@hemophilia.org.

The National Hemophilia Foundation's Steps for Living Web site is a one-stop resource for information on bleeding disorders for kids, adolescents, parents and health educators to promote healthy living for the whole family. The site provides information and resources to help consumers, family members and caretakers adjust to life with a bleeding disorder as a child grows and matures. There is information and activities for all age groups, including insurance and treatment guidelines. For further information visit: www.stepsforliving.hemophilia.org.

National Hemophilia Foundation's Web site advocacy section includes information to help the community stay informed. It enables consumers to respond to emerging issues through such resources as links to response letters to state and federal policymakers on preferred drug lists (PDLs), sole source provider contracts, Medicaid managed care and other health reform regulations. There are also resources available to assist consumers with healthcare coverage options in their state, a downloadable Personal Health Insurance Toolkit, information about state hemophilia programs, and A-PLUS webinars. Visit NHF's Web site: www.hemophilia.org and select "Advocacy."

Georgetown University's Center on Health Insurance Reforms has developed an online resource for Navigators and others seeking information on the private insurance reforms of the ACA. The resource has close to 300 searchable FAQs on everything from the individual mandate, Marketplace plans and premium tax credits, to employer coverage and preventive services. The resource can be found at <http://navigatorguide.georgetown.edu/>

Navigators: To find enrollment assisters, including Navigators, for in-person help, go to <https://localhelp.healthcare.gov/#intro>. You can also find agents and brokers at that site. If you live in a state with a State-Based Marketplace, you will be directed to your state's website for coverage and local help.

Patient Services Incorporated (PSI) evaluates an individual's financial, medical and insurance situation to determine who is eligible for premium or co-payment assistance including COBRA. It provides help for many illnesses and offer many types of financial assistance. For more information, call: 800.366.7741 or visit: www.patientservicesinc.org.

PAN Foundation is an independent, national 501 (c)(3) organization dedicated to helping federally and commercially insured people living with life-threatening, chronic and rare diseases with the out-of-pocket costs for their prescribed medications through disease specific programs. For more information, call 866-316-7263 or visit www.panfoundation.org.

The Assistance Fund is an independent charitable patient assistance foundation that helps patients and families facing high medical out-of-pocket costs by providing financial assistance for their copayments, coinsurance, deductibles, and other health-related expenses through disease specific programs. For more information, call 844-282-5802 or visit www.tafcares.org.

*Many manufacturer or therapy providers have a division or third party group that is designed to assist you with insurance questions/concerns. Please check with your provider.



State Specific Resources

Every state has a bureau/agency that may be contacted for assistance. The name of the agency may differ from state to state. Examples are: Department of Insurance; Insurance Commission's Office; Office of Insurance Regulation, etc.

In addition, local consumer advocacy organizations dedicated to serving the bleeding disorders community exist in most states. (See: hemophilia.org for a listing of local hemophilia advocacy organizations)

Additional Helpful Links

Hemophilia Federation of America: <http://hemophiliafed.org>

LA Kelley Communications: www.kelleycom.com

Hemophilia Treatment Center Network: to find the one closest to you visit:
www.cdc.gov/ncbddd/hemophilia/HTC.html