



RARE TOOLKITS™

Navigating Health Insurance





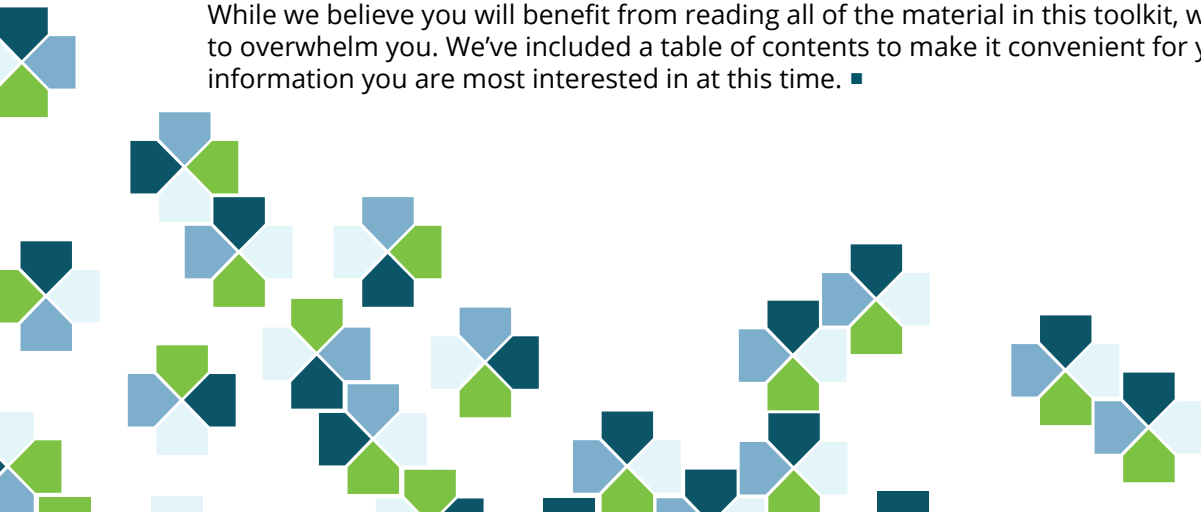
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Thank you for including us on your journey! Most likely you have a need for this: Navigating Health Insurance because you or a loved one has a rare disease. As you prepare to use the tools in this kit, we want you to know that you are not alone. We are in this together. It is our hope that the personal stories, resources, tips, and suggestions for self-reflection in this guide will make the road to advocacy for your rare disease more manageable.

We know, all too well, that a lack of information and support for people living with RARE diseases can lead to feelings of dis-ease. Please know, it's not just you—feeling depressed, anxious, and isolated are common conditions in the RARE community. Fortunately, RARE Advocates see these challenges as opportunities to take control back from their disease by filling the void with support groups, knowledge, and advocacy.

While we believe you will benefit from reading all of the material in this toolkit, we don't want to overwhelm you. We've included a table of contents to make it convenient for you to find the information you are most interested in at this time. ■



 Paper and pen indicate an interactive exercise



It's All About You!

There are a gazillion situations in daily life, at work, at home, or in line behind 20 other irate people at the post office, that are often about somebody else. Well, that's about to change. We designed this toolkit to give you the information and tools you need, as a rare disease patient or caregiver, to make an informed decision about health insurance.

We know you are many things to many people, which is why this toolkit is all about you! So, like a Hollywood celebrity or a sports superstar you should have an "it's all about you" team of personal assistants. Unfortunately, your assistants live only on the pages of this toolkit, so they can't stand in line at the post office for you. But, they can make it easier for you to identify specific subject areas in the toolkit; and if it were possible, they would give you a big group hug every day.

Without further delay, let's meet your Navigating Health Insurance Toolkit personal assistants.



Advocate Amy, with her permanent headset, is next to advocate tips, how-to info, and listed suggestions for next step solutions.



Doc Mc Martin is on call 24-7 in the doctors' lounge next to medical information.



Banker Beverly is all about the benjamins, which is why she is next to money matters information.



Detective Deeva is on the case next to some topics that extend beyond the scope of this toolkit and that you may want to investigate further.

Now that you've met your assistants it's time to create your personal health insurance profile. Your completed profile will make it easier for you to match your health insurance needs to health insurance options and plans.

In addition to your health insurance profile there are interactive prompts for some topics. Your answers to these prompts helps to further personalize this toolkit; making it a valuable, reference for your continued use.

Your Health Insurance Profile

Name: _____

Date of birth: _____

Gender: (M/F/TG) _____

Social Security number: _____

Name and phone number of medical emergency contact:

Name of current health insurance provider(s); account number; phone number

Rare Disease Brief Medical History

Name of my rare disease: _____

Year of my diagnosis: _____

My diagnosis is still undetermined as of: (M/D/Y) _____

Name and phone number of primary doctor: _____

Name and phone number of primary specialist: _____

Other Condition(s) Brief Medical History

List other medical conditions, not related to your rare disease, you have been diagnosed with by your primary doctor or a medical specialist.

Other medical condition diagnosis: _____

Navigating Health Insurance Toolkit: SECTION 1

Star Treatment: Getting the Best Plan for You!

Star treatment! Hollywood has a purpose and health insurance has a purpose. Most people would agree, maybe not insurance nerds, the purpose of health insurance is not to be sexy or entertaining like Hollywood. "Who you gonna call?" when you need a thumbs up to receive an expensive medical treatment, probably, not the Hollywood studio that produced "Ghostbusters."

The primary purpose of health insurance, since its inception in the early 1900s, is to assist people with the cost of healthcare: doctors, drugs, preventive care, medical services, and so forth. The healthcare provider you use: employer provided, government (Medicaid/Medicare), privately purchased, or your cousin Vinny, may affect the terms of your care, but not the purpose of it.



Advocate Amy thinks this list will make you feel like the sharpest tool in the shed! Listed is a basic overview of health insurance:

- Health insurance is a way to pay for healthcare
- Protects individuals from paying the full costs of medical services
- You choose a plan with defined benefits
- You pay the insurer a premium on a defined basis (monthly, quarterly, or annually)
- Insurer agrees to pay a portion of your covered medical costs

Health insurance can take many forms and the specifics of what an individual policy covers, the cost of premiums, the level of deductibles, and the requirement for copayments will all vary from policy to policy. If your rare disease requires the care of specialized physicians and long-term therapy, you really want to choose a plan that helps you to continue being the star that you are!

Speaking of stars, talented as she may be, actress Meryl Streep knows an Academy Award nomination does not guarantee a win; at last count she's been nominated 19 times and has only won 3 of those times! Such is the way of health insurance.

There is no guarantee that the plan you choose will have every option you want or that over time it will deliver on every need you have. But, you should expect to be treated like all the other nominees the company insures. Look for Advocate Amy to quickly find tips and resources that address patient-provider conflicts.



Picking a plan is now more complicated than it used to be. This is especially true if you or a family member has a rare disease. Listed are two crucial things to consider when choosing a health insurance plan:



1. Benefit design

- General health care needs
- Rare disease specific care needs



2. Cost

- **Premium:** The premium is the monthly fee you pay for coverage. Policies with lower premiums will likely require you to pay more in the form of deductibles and copayments when you make use of medical services. Examine the terms carefully; a policy with a low premium does not mean it is the least expensive.
- **Deductible:** The deductible is the out-of-pocket amount you pay for your medical care before the insurer pays its share. There are exceptions to this. Some healthcare plans (including those obtained through the insurance Marketplace) cover the entire cost of certain preventive services. A policy may also have different deductibles for certain aspects of the plan, such as prescription drugs.
- **Copayment:** A copayment is a fixed dollar amount you pay for a specific service, procedure, or drug each time you receive care or fill a prescription.
- **Coinsurance:** A fixed percentage of the cost of all services and prescription drugs a policyholder is required to pay. The coinsurance for certain services or prescription drugs may vary. Some insurers use coinsurance rather than copayments, while others use a combination of the two. ■



Patient Protection & Affordable Care Act Intro

The passage of the Patient Protection and Affordable Care Act (ACA), is the landmark health insurance reform legislation passed under the Obama administration; and it is often referred to as Obamacare.

What Will ACA Plans Provide?

Coverage

- Guaranteed issue and renewal of coverage regardless of health status
- Young adults may remain on their parents' plan until age 26
- Essential Health Benefits
- Ambulatory patient services;
- Emergency services;
- Hospitalization;
- Laboratory services;
- Maternity and newborn care;
- Mental health and substance use disorder services, including behavioral health;
- Prescription drugs;
- Preventive and wellness services and chronic disease management;
- Rehabilitative and facilitative services and devices; and
- Pediatric services, including oral and vision care.
- Premiums
- Premium rating based on health status is prohibited.
- Premiums are allowed to vary by: age (3:1), tobacco use (1:1.5), policy type (individual or family), and geographic location.
- May provide 30 percent discount if enrolled in a qualified wellness program.

There are many health insurance options listed in this toolkit. Including plans that are part of the Affordable Care Act Marketplace. Carefully consider the pros and cons of each option to determine which one is best for you.

Pros of ACA:

ACA provides new protections to patients and improves access for people who were not previously able to obtain healthcare coverage, some of whom are people with pre-existing conditions like a rare disease.

Cons of ACA:



Some ACA plans have very restricted networks. A restricted network can make access to a rare disease specialist difficult or unavailable to you. ■

Prepare for Liftoff!

Health insurance is a complex topic for most people. Even a brilliant rocket scientist may find it hard to figure out; and likely more so, if she has a rare disease. Finding the best health insurance policy for your circumstances will depend on many factors, including: age, eligibility, and whether or not you have access to coverage through an employer.

Before you launch into the toolkit take a spin around the glossary to familiarize yourself with commonly used insurance terms. Don't worry; there won't be a pop quiz! But, being familiar with these commonly used terms will make the information easier to understand. ■

Benefits are the services and items covered under a health insurance plan.

 **Your Insurance Interactive** 

List the three most important benefits you want/need your health insurance plan to offer.

1. _____

2. _____

3. _____



Health Insurance & Rare Disease

We know health insurance companies do not always fully understand the evolving needs of people living with rare medical conditions. Which makes navigating health insurance one more challenge that you may have to deal with over the course of your lifetime. In response to this challenge, we want you to have tools that will make you feel knowledgeable and confident about your ability to navigate the health insurance universe.

Accessing Care



Advocate Amy thinks these tips are the bee's knees for getting information on policy details:

Reports from rare disease advocates confirm that the health insurance playing field is not always level. And, you're probably not surprised that a lack of education about rare disease patients' needs is the reason why.

Anyone who has been part of the rare disease community is acutely aware of the need for more medical specialists who have experience treating rare disease patients. They also know that to overcome rare disease healthcare obstacles requires assertive action by medical researchers, physicians, pharmaceutical companies, lawmakers, and patient advocacy groups.

In the meantime, whether you have a rare disease diagnosis or not, your healthcare needs won't wait for the next Age of Aquarius (sing along time...“when Jupiter aligns with Mars...”). Therefore, it is important for you to be informed before you choose a policy.

- If you already have a rare disease diagnosis or you are waiting for a diagnosis, and you want access to specific doctors, drugs, tests, and/or a particular medical facility review the policy first to determine if these wants are included in a plan before you select it.
- Ask other patients in your doctor's waiting room to share with you which plans they use and why. If they are reluctant to do so, ask your doctor if he can connect you to patients who are willing to share info with you about the good, the bad, and the ugly of their insurance coverage.
- Connect in-person or online with support groups for your rare disease. If you are waiting for a diagnosis connect with people who have similar symptoms. Ask members of these groups about their health insurance plans.
- Reach out directly to pharmaceutical companies if you currently need or want future access to specific rare disease drugs. Some pharmaceutical companies have established programs that help patients gain access to the rare disease drugs they make. These companies and programs may also help you identify insurers who cover the drugs they produce. ■



Plans & Friends with Benefits

It helps to know in advance of a medical dilemma what benefits your health insurance provides. As a patient with a rare disease you should be prepared to respond if Doc Mc Martin wants to include you in a clinical trial, or refers you to an out-of-network specialist, or wants you to get costly lab work done—today!

If you are seeking access to a specific drug, the drug manufacturer may have a program in place that will contact your insurance company on your behalf to determine your eligibility. It will save you a barrel of heartache if you understand beforehand what your responsibility for the cost of a specific treatment will be. If you are unable to afford your portion of the cost, there are programs that may be able to help you.

Rare disease benefits considerations

Is your specific rare disease treatment covered? If yes, is it:

1. Part of the major medical?
 - Major medical coverage is comprehensive and long-term.
 - Major medical policies last a year.
 - Most major medical insurance plans offer an annual out-of-pocket spending limit that caps

your expenses, even if you need very expensive treatment.

- Major medical coverage typically includes doctor's office visits, hospitalization, medical supplies and services, prescription drugs and other healthcare expenses.
 - Obamacare mandates that major medical insurance covers certain preventive care services and it meets the minimum essential coverage requirements (listed in this toolkit under "Patient Protection and Affordable Care Act Intro").
2. Part of the pharmacy benefit?
 - Pharmacy benefits information includes a list of prescription drugs a health insurance plan covers under its drug benefits policies. This list may be called the medical benefit formulary list or the drug list.
 3. Do I need a referral to see a specialist?
 4. Is a preauthorization necessary prior to treatment?
 5. If your treatment involves drugs, will you be required to do step therapy before you get the treatment of choice?

Your policy may require you to obtain preauthorization from the plan before moving forward with a treatment, may deny coverage, or may provide coverage that makes the care available, but unaffordable.



Listed are ways to get help with understanding your benefits:

- Review all of the information in your plan, even the annoyingly, small, fine print; and then make a detailed list of items that are unclear to you.
- Ask your human resources manager to assist you with the list of items that you are unclear about. If this person doesn't know the answers, ask them to contact the insurer on your behalf.
- Connect directly with the insurer's employee plan representative. To minimize confusion, ask this person if you can email her your questions and if she will answer them with an email.
- Ask your insurer to do a benefits investigation (BI) to determine your out-of-pocket cost in advance.
- Request a benefits investigation when you need to know whether an item is covered under major medical benefits or under pharmacy benefits.
- Reach out to a rare disease advocate. Even if this person has a different rare disease and a different insurance provider, she has likely

dealt with similar health benefit issues of her own and those of other rare disease patients. As an advocate she may be willing to contact your insurer for you to get answers about your benefits or refer you to other advocates who can better help you.

- Ask family and friends who have chronic medical conditions for help. Managing long-term illnesses generally includes ongoing interactions with health insurers about benefits. Their health insurance experiences may provide answers for you. ■

Step therapy is when your insurance plan wants you to use a less expensive, alternate therapy to see if it works before approving the use of a more expensive drug.

Limited & Out-of-Network Benefit Issues

A **provider** network is a network of providers that have a contract with an insurance plan. The plan sets the reimbursement, pricing, and range of coverage.

A **limited** provider network has a smaller subset of providers within the overall medical network. Members covered under a LIMITED network generally must receive services from a provider within this identified subset.

An **out-of-network** provider has not contracted with your insurance company for reimbursement at a negotiated rate. Some health plans, like HMOs, do not reimburse out-of-network providers at all, which means that you would be responsible for the full amount charged by your doctor.

Challenges:

- If Doc Mc Martin is out of your insurance provider's network you may have to pay more to see him.
- Limited access to specialists for diagnosis and treatment of specific rare diseases.
- Out-of-network increase in financial responsibility to receive specialized care.
- Out-of-network specialist copayments and charges may not count toward maximum out-of-pocket spending.
- Rare diseases have few therapeutic options which are provided by specific specialists.
- Out-of-network care can potentially cost 5 to 6 times as much as in-network covered provider care; also, deductible and out-of-pocket maximum are significantly higher.

Resolutions:

- Contact your insurer and inquire about any programs that will provide Continuity of Care Coverage or Gap Network Exceptions.
- Enroll or start the process to appeal to those programs.
- File a letter of concern/complaint regarding how the limited network is impacting the continuity of care, why it is cost effective to allow specialty care, and why it is the morally right decision.
- Write additional letters to support your claim for Continuity of Care Coverage.
 - Write a disease specific advocacy group letter.
 - Obtain a physician, specialist, and or a geneticist letter.

Out-of-pocket maximum is the most you will pay in deductibles, copayments, and coinsurance during a given year of coverage excluding premiums.

Keep it in perspective: What is the worst-case scenario in terms of out-of-network cost?

- Determine if it is worth asking your insurer to pay for a doctor that is out-of-network. Don't be surprised if they ask you to get a letter of medical necessity and additional support documents. The insurer may also stipulate that the out-of-network doctor accepts its payment terms.
- Engage your network of providers, employer human resources, local media, and/or advocacy groups to help you advocate on your behalf.
- Identify the "gatekeepers" within your insurance plan and your employee human resources. Appeal directly to them.
- If all else fails, contact the provider directly to negotiate a Self Pay Rate.



Banker Beverly adds that choosing an out-of-network provider may have financial ramifications that you should consider. ■

Finding a Provider



If it's easier for you to find a gift for the person who has everything, than it is to find a doctor who has experience treating your rare disease, listed are some resources worth trying:

- Contact a patient organization in your rare space for experts in the field in your state, or nationally if you are willing to travel.
- Contact the National Institutes of Health's Genetic and Rare Disease Information Center for advice on how to find a specialist.
- Ask your primary care physician to direct you to an appropriate specialist.
- Search online to see if there is a patient advocacy group for your rare disease, and ask members to refer you to their specialist.
- Find out who is conducting research on your disease by checking Clinicaltrials.gov or the medical journal website PubMed.
- Contact a university health center in your area. These health centers may have doctors who are involved in clinical trials or who may be working in your disease area.



Doc Mc Martin wants you to know that communication is key to making health related decisions. He offers these suggestions for finding the right doctor:

- Choose a doctor who will meet your needs and who will listen to your concerns as a rare disease patient.
- Ask a family member or friend to accompany you on the first appointment to get their feedback on the doctor.
- Pay close attention to the doctor's bedside manner.

Primary care physician is a doctor who provides care and coordinates specialists for a specific patient.



Detective Deeva knows finding the right provider is one of the most crucial parts of your healthcare needs. She knows you don't have to be Sherlock Holmes to get the facts on a doctor, just start with these tips:

- Search online for reviews by former and current patients.
- Search online for news stories about the doctor and about the doctor's medical practice.
- Ask other people in your rare disease community if they have information and/or experience with the doctor.
- If possible, get the opinions of other medical professionals who have worked with the doctor in the past (former employees may be more willing to share their opinions, than someone currently working with the doctor). ■

What to Do When Elements of Care are Not Covered



Your Insurance Interactive

Based on your current medical needs what three things concern you most about health insurance coverage?

1. _____
2. _____
3. _____



Advocate Amy offers this throwback gem, “a stitch in time saves nine.” If you discover a hole in what should be the warm, fuzzy, blanket of your health insurance coverage here are some Amy approved tips for mending the hole before it gets any larger:

Contact your insurer representative when you are unsure whether a doctor, hospital, procedure, or drug is not covered. You want to verify that you understand why an element of care is not covered by the policy.

Ask the representative if there are potential changes to your policy in the next enrollment year that will affect the status of the items you need covered.

Engage your rare disease patient advocacy organization.

Accept positive advice from other patients who have successfully traveled the same road.

Anticipate that every year there may be changes to your policy by your insurer and/or your employer that can affect, for better or for worse, the terms of your coverage.

Leave behind anger and “principles.”

Ask the representative to send you an email or snail mail with the instructions and forms for submitting information about the item(s) you need covered.

Stay calm when there is a sudden change in a plan or new people involved in administering a plan.

Ask your HR personnel for help.

Take a deep breath and remain hopeful that “no” is often part of the process of getting to “yes.”

Maintain close relationships with your doctors’ staff.

If there is one, engage with biotech or pharmaceutical companies that are developing or producing the drug.

Tom's Story

When insurance company procedures defy logic it can make you feel like you are swimming in sand. Consider Tom, who has homozygous familial hypercholesterolemia, or HOFH. The rare condition, caused by a genetic mutation, elevates his cholesterol and puts him at risk for cardiovascular disease.

When he didn't respond to statins to control the elevated cholesterol levels his doctors prescribed Juxtapid, a drug approved for his rare condition. The drug was effective, but expensive at \$1,000 a day.

After being on the drug for three years, his insurance company notified him that it would no longer cover the drug because there was a new class of drugs—PKCS9 inhibitors—that they thought would be more cost effective. But, there was a catch; when he asked the insurance company to cover the new drug, they denied his claim. "They are making the rules and changing the rules as they go," he said.

While his doctor fights with the insurance company to get the new drug covered, Tom is using an older, less effective therapy and once every two weeks must undergo LDL aphaeresis, a four-and-a half hour process where his blood is run through a machine that filters out the LDL cholesterol.

"I'd really like to have the insurance company meet my kids and tell them, 'It doesn't matter if your dad dies. It doesn't matter if he has a heart attack,'" he said. "I'd like them to meet my wife, who would be a single mother. I want them to understand it's more than a piece of paper."

"Only if we understand can we care. Only if we care will we help." Jane Goodall

Each insurance company has its own process; but some of the requirements by insurers are the same or similar. It is common for the approval process to begin with a request for prior authorization to pay for something not covered by your health plan such as:

- A drug not on its formulary
- A higher dose of a needed drug than the plan will cover
- An out-of-network specialist
- An out-of-network hospital
- Medical supplies and devices for rare disease care
- The cost of an experimental therapy



Detective Deeva fraud alert! Closely investigate online and snail mail offers for consumer supplemental healthcare and pharmacy discount programs or cards. Start with the Better Business Bureau website to see if there are consumer complaints about the company. Also check your state's government insurance website for a list of companies being investigated for insurance fraud. ■

Dave Caponera, a veteran in the rare disease community, is currently vice president of patient engagement and access for Catalyst Pharmaceuticals, notes that because of the nature of many rare diseases, insurance companies may not be familiar with your rare disease or its treatment.

"A lot of these insurance companies will not have heard of these diseases," he said. "They will not know about all that has gone on, so you are doing a lot of educating about the disease, the ramifications of the disease, the prevalence, the incidence, and all of that to give them an understanding. You are also talking about the treatment that you have an FDA approval for and explaining how the drug fits into the overall treatment."



Medical Equipment & Supplies

Making a case for a patient's need for a specific drug or a specialist may be easier to establish than the need for certain medical equipment. If you are a rare disease patient who uses durable medical equipment (DME) and/or medical supplies you know the cost of these items can be significant.

DME is also called home medical equipment (HME). In general, insurers define or classify DME as durable and reusable medical equipment intended for long-term use in your home. The equipment is deemed necessary for you to move about and function at home.

From the world of insurance lingo, there is a difference between a DME, assistive technology (AT), and assistive devices (AD). The last two are defined as electrical or mechanical equipment that helps an individual with the activities of daily living. The Assistive Technology Act of 1998 says the difference between DME and AT is that an AT is: "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities."

One of the most common and often most challenging issues for a patient who needs medical equipment and/or medical supplies is proving to the insurer the "necessity" for the item(s). Which is really code for, it may take you and a large flash mob to prove to your insurer that the equipment you need is a medical necessity; and therefore they should cover it.

Check your insurers website for their DME and medical supplies benefits chart to see the current coverage status for the equipment/supplies you

need. Don't be surprised to discover that some equipment that is needed for the same medical condition may not be covered. For example, if it's difficult for you to walk, the insurer may pay for you to have a chair lift installed in your home, but not for grab bar rails.

Therefore, before you drive your new medical scooter off the showroom floor, find out if your insurer requires members to validate necessity for medical equipment/supplies and what you need to prove necessity. The validation requirements as well as the denial and approval process for medical equipment/supplies may not be the same for every item or for every insurer, so don't rely on past experiences.



Doc Mc Martin advises you to start the validation process, if possible, with a prescription from your primary doctor for the medical equipment/supplies you need. If you can't get a prescription, ask for a "justification statement" from your doctor, a rare disease specialist, nurse practitioner, occupational therapist, chiropractor, other nontraditional medical professionals who treat you, and rare disease advocate groups.

Examples of medical equipment and supplies includes:

- Wheelchairs
- Portable commodes
- Medical scooters
- Walkers
- Blood and glucose monitors
- Oxygen
- Ventilators
- Gauze/ bandages
- Catheters

Medical supplies that are considered disposable or one-time use items like gauze and bandages may be denied initially. If they are denied respond with an appeal letter from your doctor that explains in plain language your ongoing medical necessity for these supplies as it relates to your rare disease. The ability to pay for medical equipment/supplies that are not covered by your insurer is another challenge you may face, if not today, in the future.



Banker Beverly advises you to do the math on the cost of acquiring the equipment and a yearly estimate of how much it will cost you to maintain, upgrade, and eventually replace it. Include these long-term costs in your appeal letter to the insurer.

If you have a necessity for medical equipment/supplies that your policy will absolutely not cover:

- Contact your state's health and human services department to find out if you qualify for financial assistance through Medicaid to pay for the items.
- Reach out to religious and charitable organizations for help. They may be able to assist you with finding the equipment through a donation or at a better price than retail.
- Write a letter explaining your circumstances to your state representative and your state's attorney's office. With the letter also include your communications with the insurer: telephone calls (who you spoke with and when), emails, financials, and the denial and appeals documents. ■



The Prior Authorization Process

Let's get this party started! Doc Mc Martin has written you a prescription for a promising, new medication for your rare medical condition. Now what? Realistically, you should prepare yourself for the possibility that the insurance company is going to crash your celebration party.

It's been a few weeks since Doc Mc Martin wrote the prescription, but you're still waiting to hear when you will have it. So, you call Doc Mc Martin for answers. His office manager tells you there is a delay on the delivery of your promising, new prescription because they are working on the prior authorization for it.

Which basically means Doc Mc Martin and his staff are diligently preparing documents that explain your rare disease, your treatment, and why you need a particular medication, treatment, and/or medical equipment and supplies. He may also include a Letter of Medical Necessity, lab work and your health history notes to help secure the authorization for your medication.



From the desk of Doc Mc Martin, notes on prior authorization:

- The prior authorization process can vary from plan to plan.
- Whatever the process is, it will likely require your doctor to get involved in explaining to the insurance company your diagnosis and prescribed treatment.
- This may require your doctor to fill out a specific form, submit a letter of medical necessity, or participate in a peer-to-peer review where your

doctor speaks to a medical professional who represents your insurance plan.

- In all cases, your doctor will need to explain your condition, the basis for the diagnosis, and justification for the therapy prescribed.
- In many cases insurers will deny a prior authorization request because a physician didn't provide all of the required information.
- It is important to understand what the plan wants in the prior authorization, and, if your request is denied, specific reasons for the denial.
- It is important to note that prior authorization does not guarantee that your health insurance will cover the cost.

Your insurance plan may require you to use a less expensive, alternate therapy to see if that works before approving your use of a more expensive drug. This is known as step therapy.

Your doctor will need to document that you have already used and failed the step therapy the insurance plan wants you to use instead of what the doctor is prescribing. Alternatively, your doctor can make a case why step therapy is not appropriate and why the more expensive drug is necessary.

If you are issued a denial, you will need a copy of the denial letter, the plan's evidence of coverage that clearly states the plans benefits, as well as guidelines from the plan as to what constitutes medical necessity. The key in an appeal is to show that the care that you

are being denied should be covered by the plan based on its rules, that it is appropriate, and is medically necessary. ■

Prior authorization (also called prior approval and preauthorization) is a decision by your health insurer or plan that a service, treatment, prescription drug or durable medical equipment is medically necessary, except for in an emergency.





Denials & Appeals

Denials

There is the “traffic was a nightmare and the office coffee sucks this morning” bad day. And then there is the “traffic was a nightmare, the office coffee sucks this morning, and I received a denial of coverage letter” bad day.



Off-the-record, Advocate Amy thinks dreamy Doc Mc Martin made the bad coffee today. More importantly, she wants you to take a look at this list of typical reasons why your coverage may have been denied:

- Out-of-network provider issues
- Preauthorization or referral required
- Wrong insurer billed/billing errors
- Errors in your personal billing info
- Noncovered service or item

Now that you may have an idea why coverage was denied you can contact your provider and move forward with the appeals process to see if you can convince the insurer to reverse the denial.

Appeals

Whatever the answer is for the denial of coverage you should ask the insurer representative for (if you haven't received it) an explanation of benefits (EOB) and what the process is for appealing the denial with them.

Most insurance plans offer two stages of appeals. In the case of Medicare, there is a federal review process. If you fail with your insurance plan's review, your state may offer an external review process.

Self-advocacy appeal actions:

- Ask your doctor to initiate the appeals process (it can be done several times).
- Educate the insurer about your rare disease and why your circumstances may fall into the “exception to the rule” category of approval.
- Use your history of medical reports to provide evidence of your need.
- Make sure to submit the right paperwork to the right people.
- File an expedited appeal if the need for a medication or service is urgent.

Appeal if your insurance company says it will not pay for a specific service or drug, you have a right to appeal the decision.

- Check your state's department of insurance when coverage is denied.
- Work with your patient advocate organization.
- Work with your provider rep in an assertive but professional manner.
- Work with manufacturer's patient support team.
- Be persistent. Case managers, medical directors, and others in the insurance world can be very busy.
- Call or email frequently until response is elicited.
- Continue to rely on the specialist's office, physician, and the patient advocacy organization for support.
- Contact local and state officials. Share your story. Let the insurance company know you will be contacting officials.
- If necessary, talk to the press. Most towns have local blogs or newspapers. Get in touch and share your story. Tell the insurance company you will be contacting the press.

Group advocacy Medicaid specific appeal actions:

- Gather policy information for that state.
- Reach out to manufacturers to understand potential issues and changes .
- Sign up for public testimony.
- Identify physician(s) in that state for testimony/ letter.
- Get a letter from an association.

Group advocacy commercial insurance appeal actions:

- Gather specifics for the patient's case.
- Gather policy information for that plan.
- Reach out to manufacturers to understand potential plan issues.
- Schedule a call with the health plan medical director.
- Arrange a Medical Advisory Board member call.
- Accompany with a letter or an email. ■

Katie's Story

Katie is the mother of a teenage son with a peroxisomal biogenesis disorder, a rare genetic disease that causes a build-up of long chains of fatty acids that can cause damage to organs, lead to hearing and vision problems, and result in the loss of muscle tone. She works part-time in a medical practice, which helps her to have a better understanding of the medical billing and insurance process than most people. Even with her job experience, she still has challenges with getting Medicaid to meet her son's needs. “It's difficult even when you know the game,” she said.

Katie said she tries to be proactive by reaching out directly to doctors before they order medical equipment. She wants them to make sure they can provide a strong diagnosis and reason why the equipment is a medical necessity. When Katie has to file an appeal she provides the doctor with a sample “necessity” letter or a list of bullet points as to what needs to be communicated to the insurance company. Providing the doctor with this information is her way of helping doctors who already have plenty of other paperwork and many patients to service.

Katie is fighting with Medicaid to provide her son, who is losing muscle strength, with a gait trainer to help with his walking and an adaptive trike to provide him with exercise to maintain muscle strength. Her advice for learning how to navigate the process is to talk to other patients and caretakers who have already done it. “You learn more in a waiting room talking with other parents than speaking to a case worker or using Google,” she said. “If you just open up and say, ‘I'm struggling with this,’ someone will speak up and give you tips. They've been there. They know the ins and outs.”

“Although the world is full of suffering, it is full also of the overcoming of it.”
-HELEN KELLER



All Hands on Deck: Where to Get Help

There will be times when you hit choppy seas with some part of your insurance coverage. This is when you may need all hands on deck to help right the boat. The situation may be something complex like getting prior authorization for a medication or seemingly simple like a billing error.



Advocate Amy suggest that in most circumstances asking the insurer for help is a smart cookies don't get eaten first step. Insurance plan representatives and customer service staff are on the insurer's payroll to help you get answers about their plans, products, and procedures.

Insurer help:

- When you enroll in your employer's insurance plan you should get the name and contact information of the plan representative from your HR manager.
- Contact the plan representative by phone or email and introduce yourself. Explain that you may need assistance with understanding the plan and want to schedule a time when you can get answers.
- Don't feel as if the insurance plan representatives are the enemy. Be respectful when you talk to them and document your conversations.
- If you reach a dead end with the person you

are dealing with, politely ask to speak to a supervisor or someone else who may be able to help resolve your problem satisfactorily.

Medical help:

- Contact your doctor for help when you need to appeal the insurer's denial of coverage, services (in or out-of-network) medications, and medical equipment/supplies. Ask him to help you educate the insurer about your rare disease needs.
- Contact your doctor's administrative staff when there is a billing error or dispute regarding paying for services they provided.
- Contact your primary doctor when a specialist recommends a procedure or medication that may not be covered by the insurer. You will want your primary doctor on board with the recommendation if you have to appeal a denial.
- Contact your primary doctor when there are changes to your plan that may affect his care for you, the billing process, and outcomes of pending decisions on claims and appeals.
- Contact the pharmaceutical company if you need help getting coverage for a drug they make.
- Ask your rare disease specialist to connect you with a support group and to arrange an introduction to other patients she treats with your rare disease.

Prescription assistance programs:

- Partnership for Prescription Assistance is a resource to connect patients who qualify and are without prescription drug coverage access to medicines for free or at minimal cost.
- RxAssist offers a comprehensive database of patient assistance programs, as well as practical tools, news, and articles so that healthcare professionals and patients can find the information they need.
- Medicare.gov Pharmaceutical Assistance Programs Listing.
- The U.S. government's Medicare website offers a directory of pharmaceutical assistance programs searchable by drug name.

Human resources help:

- Ask your HR manager to let you know when open enrollment occurs, so you can assess new plans.
- Ask your HR manager to give you an overview of how the plan works.
- Ask HR if the company will assist you with filling out paperwork for appeals and similar issues.
- Ask HR to share with you how the insurer has responded to issues similar to yours with other employees.
- If you reach an impasse with the insurer's rep ask HR to intervene on your behalf. The HR manager's authority; influence on who the company chooses to get health insurance coverage from; and good rapport with the representative may get you better results.

Patient advocacy help:

- Ask patient advocate groups to help you to publicly and privately petition your insurer for areas of coverage that they have traditionally denied you and others.
- Ask rare disease advocates to pressure and educate your insurer about the necessity for areas of coverage that you have been denied.
- Ask patient advocates for advice and recommendations for how to connect with clinical trials, pharmaceutical companies, and legislators.
- Ask patient advocates for their help in working for changes in healthcare legislation at the state and federal level.
- Ask patient advocates for help with legal assistance if you need it to take action against your insurer.
- Ask patient advocates for help connecting with non-profit patient assistance programs.

Your state's department of insurance help:

- Get help with qualifying for and enrolling in Medicaid and Medicare insurance programs.
- Get help with understanding and enrolling in your state's Affordable Care Act insurance plans.
- Contact and petition state legislators to make laws that advance healthcare insurance for patients with rare diseases.
- Get help about what to do if you believe your insurance provider is breaking the law.
- Find out if an insurance company or prescription drug program is on your state's insurance fraud watch list.

Non-profit patient assistance help:

- Contact non-profit patient assistance programs for help if you need financial assistance to get medications and/or insurance coverage.
- Contact non-profit patient assistance for help understanding insurance coverage policies.

Media help (last resort):

- Ask your local media (newspapers, TV stations, radio stations, and local healthcare bloggers) for their help in bringing awareness and public attention to your insurer conflict. ■

Kevin Rohrbach Jr., vice president of rare disease for Dohmen Life Science Services, which operates rare disease patient service programs on behalf of drugmakers to support specific products, said that persistency is essential. "If a patient is navigating the plan on their own behalf, if you hear a response that's not favorable, continue to pursue it. There are alternate routes that may or may not be shared by the plan's representative that the patient can pursue to have their voice heard," he said. "There may be other departments or areas within the health plan that have representatives that you can speak to."

Drug Company Industry Sponsored Patient Assistance Programs

Patient assistance programs (PAP) provided by drug companies can help to alleviate some of the stress and work of interacting with your insurance company. Listed are just a few of the ways these programs can assist you:

- They will assign you a case manager who will contact the insurer, determine whether the drug is covered, what your benefits are, and determine the process for getting prior authorization or appeal a denial if necessary.
- They will also work with your doctor to get the insurance company the information they need that explains your diagnosis, tests results, treatment decisions, and why a specific drug is needed.



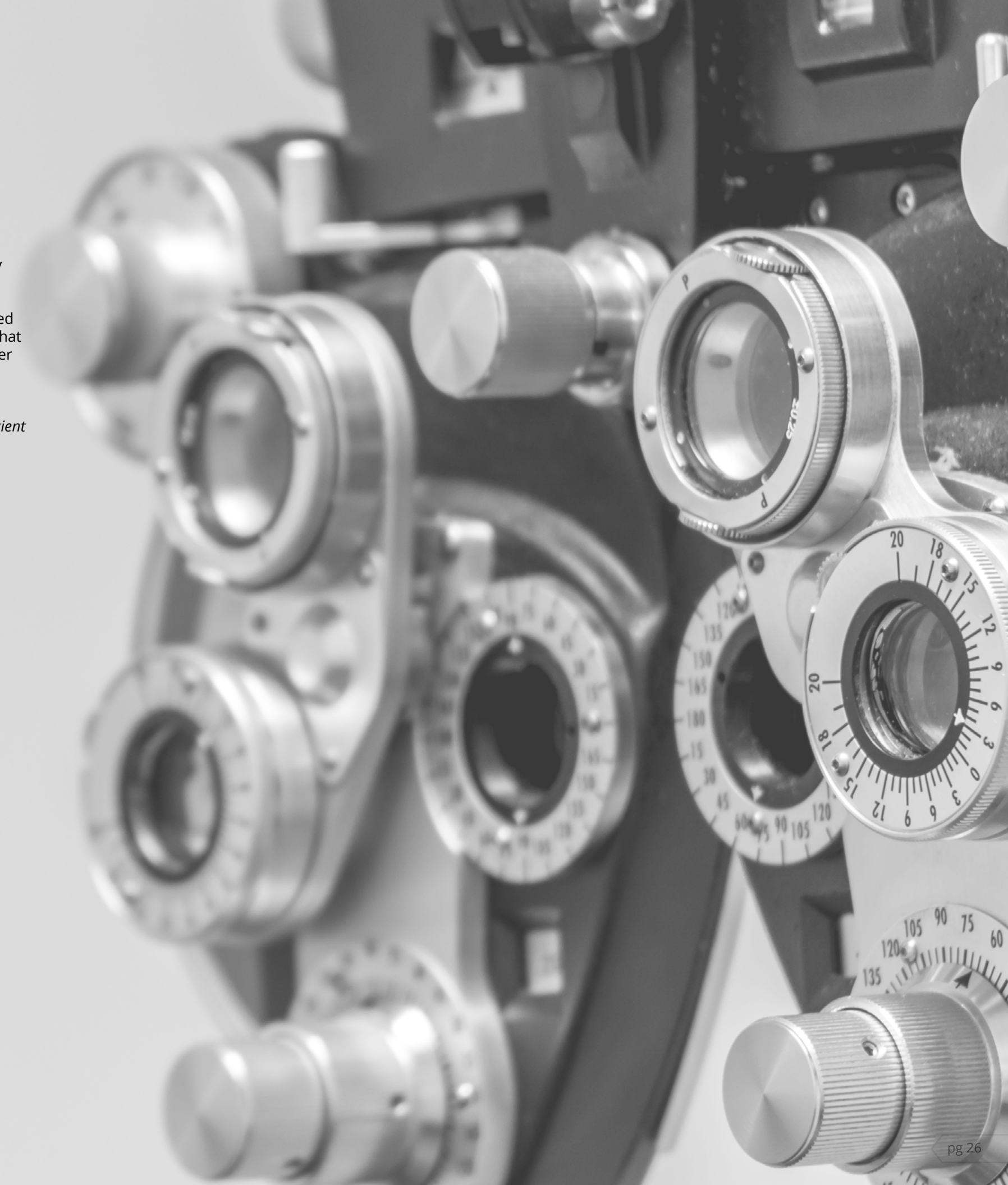
To demonstrate a drug company patient assistance program, we'll use Banker Beverly's denial of coverage experience.

Doc Mc Martin prescribed Banker Beverly a 90-day prescription of a costly eye medication she needed after her eye insertion surgery. She had a good response to the medication, but her insurance would not cover it. Because the insurance company denied coverage of the drug Doc Mc Martin prescribed another medication that the insurer covers.

Unfortunately, after 45 days of use Banker Beverly did not have a good response to the covered medication. With no other option to get the more costly medication, she applied for and was accepted into a drug company patient assistance program that has a drug *copay. The PAP copay is helping Banker Beverly afford the costly eye medication that her insurer will not cover. ■

**Copays are not a benefit of every drug company patient assistance program.*

"The payers for the most part want to do the right thing," said Dan Counihan, senior director of sales for Genzyme. "Take advantage of services that are free from the various companies that are out there. Because people are knowledgeable, understand the system, understand the obstacles, and work with the insurance companies."



Patient Advocacy Groups & Non-Profit Patient Assistance Programs

Patient advocacy groups are your go-to crew when you need help with your insurance plans and other related issues including healthcare legislation. Find out if there is a patient advocacy group for your rare disease.

What these groups may lack in staffing and financial resources, they have in experience with the healthcare system. Ask for their advice and assistance when you have insurance challenges that are too complicated for you to handle alone. They may also be able to connect you with other patients who have navigated similar challenges.

There are a number of non-profit groups focused on helping rare disease patients gain access to needed therapies. Some of these groups are focused on specific diseases while others have a broader mission of supporting rare disease patients.

These groups can help you navigate the insurance process to get coverage for medication; and in some cases help you pay for drugs when you don't have insurance or can't meet your financial responsibilities under your coverage.



Advocate Amy says, you won't find her secret, homemade mayonnaise recipe in the Resource Guide of this toolkit; but you will find a listing for the Patient Advocate Foundation (PAF) and other useful resources.

The following information is from the PAF website www.patientadvocate.org. It explains PAF's mission, services, and a partial list of partnerships with other patient support programs. (Please visit the PAF website for their complete list of support programs). ■



Patient Advocate Foundation is a national 501 (c)(3) non-profit organization that provides professional case management services to Americans with chronic, life threatening and debilitating illnesses. PAF case managers serve as active liaisons between the patient and their insurer, employer and/or creditors to resolve insurance, job retention and/or debt crisis matters as they relate to their diagnosis also assisted by doctors and healthcare attorneys.

Patient Advocate Foundation seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of their financial stability.

In addition to PAF's core services, we are proud to operate these additional dedicated programs to meet the needs of specific groups of patients, caregivers and providers. These programs are supported through grants, partnerships and targeted donations."

MedCareLine Programs

The MedCareLine is a division of Patient Advocate Foundation staffed with a team of nurses and case managers who provide individualized case management services to a specific group of patients, caregivers and providers.

The team can assist with understanding insurance policies and appeals, providing educational resources and researching clinical trials. These case managers can also assist with facilitating referrals to co-payment programs, finding financial assistance resources and providing guidance to the uninsured patients to learn how to access necessary care and apply for public and charity assistance as needed.

Aetna Clinical Appeals CareLine

A patient and provider hotline to help Aetna patients with insurance navigation issues as well as denials associated with off-label medication use, pre-existing health condition, non-covered benefit or benefit exclusions, experimental/investigational denials or not medically necessary, out-of-network benefits, and coding or billing errors.
(877) 401-3944
aetnaclinicalappeals.pafcareline.org

Colorectal CareLine

The Colorectal CareLine is designed to provide customized case management assistance to patients who have been diagnosed with a colorectal cancer and are seeking education and access to care. Colorectal cancers include colon cancer, bowel cancer, cancer of the rectum, large intestine or appendix.
(800) 532-5274
www.colorectalcareline.org

Heart Valve CareLine

The Heart Valve CareLine is designed to help patients, providers and caregivers who need assistance navigating the insurance world and accessing needed healthcare when dealing with the complications of a valvular condition. In addition, CareLine staff may be able to connect heart valve patients to a one-time \$1,000 grant program that helps to cover expenses associated with heart valve treatments and transportation costs getting to and from treatment.
(866) 318-7892
www.heartvalve.pafcareline.org




Navigating Health Insurance Toolkit: SECTION 2



Understanding Health Insurance: The Big Picture

The first section of this Navigating Health Insurance Toolkit covers many of the benefits and challenges of health insurance a person with a rare disease may encounter. This second section covers the big picture details of health insurance.

Some of the general information about health insurance may be familiar to you; while other information about the Patient Protection and Affordable Care Act (ACA), also called Obamacare, is new and still a work in progress. We believe both sections of the toolkit and the self-help resources at the end will help you make informed choices about how your healthcare needs fit into the big health insurance picture.

 Advocate Amy, knows having a grocery list makes shopping a breeze at the Piggly Wiggly Superstore. Use this list of general health insurance benefits to make it breezier for you to shop for health insurance.

- What services does the plan cover?
- Are my physicians in the network?
- Are there annual limits to the number of visits for any particular service (for example, physical therapy)?
- Are out-of-network benefits available?
- What percentage of the cost am I responsible for if I receive out-of-network care?
- Am I covered if I get sick or need treatment out of state? ■

Your Insurance Interactive

Write three questions that you have about health insurance today.

1. _____

2. _____

3. _____

Types of Health Insurance

Like 31-flavors of ice cream and counting there are many types of health insurance. You may have insurance coverage through government sources, employer-sponsored plans, a self-funded employer plan, or directly through a provider. If you don't have insurance through an employer and you are not eligible for government-sponsored health plans, the health insurance marketplaces created under the Affordable Care Act may be an option for you to have access to health insurance.

Depending on eligibility and if you have access to health insurance through an employer, there are a variety of ways to have access to healthcare. ■



Open for Business: The Affordable Care Act Marketplace

Types of Health Insurance Options		
<p>Private health Insurance: Plans marketed by the private health insurance industry (Aetna, Blue Cross, Cigna, and others). Coverage includes policies obtained through employer-sponsored insurance.</p>	<p>Employer sponsored: Insurance provided as a benefit of employment.</p>	<p>Individual plans: Individual insurance purchased outside of the workplace from private health insurers.</p>
<p>COBRA: Government legislation that allows an employed person to take his/her group health insurance policy when leaving employment.</p>	<p>Medicare: Medicare Insurance Program for people who are 65 years or older, certain younger people with disabilities and people with ESRD.</p>	<p>Medicaid: Social insurance program for families and individuals with low incomes; federal and state partnership.</p>
<p>Affordable Care Act/ Obamacare: Provides new protections to patients and improves access for people who were not previously able to obtain healthcare coverage.</p>	<p>Katie Beckett or TEFRA Waiver: gives states the option to extend Medicaid to children with severe disabilities by only counting the income of the child with a disability.</p>	<p>SCHIP: State and federal insurance partnership aimed at covering uninsured children in states.</p>
<p>Home and Community Based Services (HCBS) Waivers: for people with intellectual and other disabilities.</p>	<p>TRICARE: Health insurance coverage through the United States military for retirees and their dependents.</p>	<p>Veterans Association (VA) Benefits: Health benefits for U.S. military veterans.</p>

The passage of the Patient Protection and Affordable Care Act (ACA), the landmark health insurance reform legislation passed under the Obama administration and often referred to as Obamacare, provides new protections for patients and improves access for people who were not previously able to obtain health care coverage.

The ACA created health insurance marketplaces to help individuals shop, compare, and find health insurance. The Federal Health Insurance Marketplace can be found at healthcare.gov. There is also a list on the website with links to the healthcare marketplaces in the states that have chosen to create their own plans under the act.

The plans available through the Health Insurance Marketplace run the gamut of insurance options available for individuals and businesses looking to access health insurance in the private marketplace. With all of these plans, regardless of whether you use any medical services, you are responsible for paying the monthly premium and additional fees including a deductible.

In addition to the minimum essential coverage, which is available through the federal government and many states, all of the plans are rated as either being in one of four categories (Bronze, Silver, Gold, or Platinum). Each of these broad categories reflects the expected costs of premiums, deductibles, and copayments for the plans within those categories.



Banker Beverly advises you to do the math on premiums versus out-of-pocket medical costs based on your typical healthcare needs. Premiums for policies in each category increase while the amount of deductibles and copayments decrease.

- Bronze rated plans have the lowest premiums, but users pay 40 percent of their medical costs.
- Silver rated plan users pay 30 percent of their medical costs.
- Gold rated plan users pay 20 percent of their medical costs.
- Platinum rated plan users pay 10 percent of their medical costs.

When shopping for health insurance through the ACA Marketplace, you will likely have a choice of several types of healthcare plans. Some of these plans will restrict the pool of doctors, hospitals, and pharmacies you can access, generally those within their networks. Others may allow you to use resources outside of their networks, but the out-of-pocket costs will vary.

When comparing plans, review the summary of benefits for each plan. If there are doctors and drugs you want/need to have access to, check the provider directory of the plan and list of covered drugs. This information is available through the ACA Marketplace. ■

Shopping Marketplace Plans

The number and variety of ACA Marketplace plans available will, largely, depend on where you live. The options include several different types of health insurance.



Doc Mc Martin hopes you will continue to use him under a new policy. Make sure doctors you want to use are contracted to provide care under a specific plan. If they are not, see whether the plan allows you to use providers outside of its network and how much it will cost you. When checking to find out whether a specific doctor is within a specific plan's network, make sure you are checking the actual plan you are considering. The doctors in an insurer's network may differ within the various plans it offers.



Exclusive Provider Organization (EPO)

An Exclusive Provider Organization is a type of managed care plan that restricts services only to doctors and hospitals in the plan's network (except in an emergency). Under this plan, patients who use doctors or hospitals outside of the network pay for this care themselves.

Point of Service (POS)

A Point of Service plan provides greater flexibility for patients to use doctors outside of its network. Under a POS plan your primary care physician can refer you to a doctor in or out of the network, however, using doctors in the network cost less than using doctors outside the network.

Government-Funded Health Insurance

There are a variety of government-funded health insurance plans available to people who are eligible based on age, disabilities, income, military service, or other qualifications. Listed is a description of three of the major plans: Medicare, Medicaid, and The Children's Health Insurance Plan.

Medicare

Medicare is a federally-funded plan that provides health coverage to people 65 and older and for some younger people who have permanent disabilities. People with end-stage renal disease are also eligible for Medicare.

Medicare has several components. Original Medicare includes Part A as well as Part B for a monthly premium based on income. Medicare also includes a number of supplemental options. These options are provided by private companies and have additional costs and rules. Medicare includes:

- Medicare Part A, covers hospital stays, care in skilled nursing facilities, hospice care, and some home healthcare
- Medicare Part B, covers doctor's visits, outpatient care, medical supplies and preventive services.
- Medicare Part C, is also known as Medicare Advantage Plans. This is a health plan provided by a private company that contracts with Medicare to provide Part A and Part B benefits. This can be a Preferred Provider Organization, Private Fee-for-Service plan, Health Maintenance Organization, Special Needs Plans, or Medicare Medical Savings Account.
- Medicare Part D, which provides prescription drug coverage. Medicare Part D is a plan offered by private insurance companies approved by Medicare. This coverage may also be included under some Medicare Advantage Plans.

Supplemental Insurance

Supplemental Insurance, also known as "Medigap" or "Secondary Coverage," can help cover costs not covered under Original Medicare (Medicare Part A and Part B). Supplemental policies are sold by private insurance companies and can help cover the cost of copayments, coinsurance, and deductibles. Supplemental plans issued after January 1, 2006 do not cover prescription drug costs. These plans generally don't cover services Medicare doesn't cover. Instead, they are usually used to cover Medicare deductibles.

For the average person covered under Medicare it may be difficult to see the monthly cost of a Medigap policy as a good investment. However, rare disease patients who have a higher level of utilization of medical services and the possibility of hospitalization at a greater rate may find this coverage beneficial.

Medigap policies can offset the copayments and deductibles people with Original Medicare incur. The features of these plans and their costs can vary widely, therefore, shop carefully for this type of policy. You should also do some calculations about your likely use to determine if they are worth the costs.

Banker Beverly adds, while it may feel like counting ants on a log, it's worth the time to do the math. You want to understand the monthly cost of a supplemental policy and the number of doctor visits, hospitalizations, diagnostic tests, and other services you will need to offset those costs.

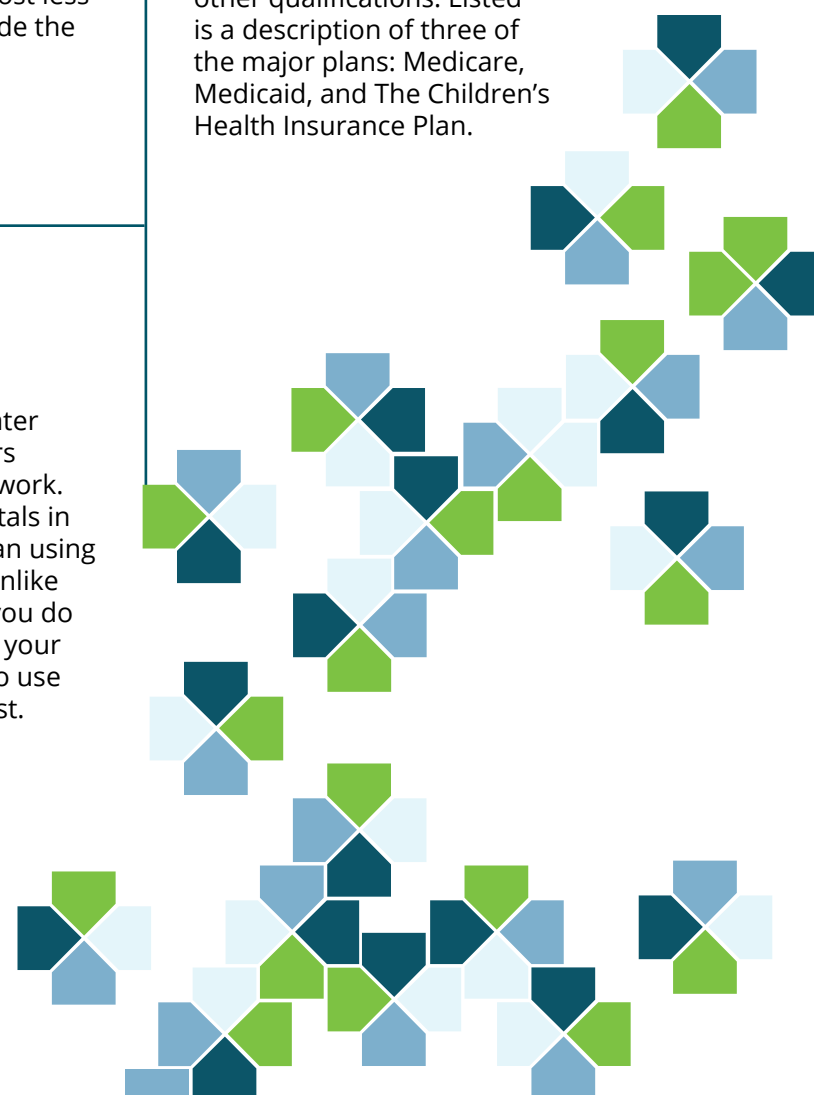
Rare disease patients will likely have more predictable use of healthcare services and may be able to determine if these policies are worth the additional investment. If you have a Medicare Advantage plan, supplemental coverage should not be purchased because it duplicates coverage provided by your Medicare Advantage Plan.

Health Maintenance Organization (HMO)

A Health Maintenance Organization usually limits coverage to care from doctors who work for or who contract with the HMO. These plans generally won't cover out-of-network care except in an emergency. HMOs often provide integrated care and focus on prevention and wellness. Patients are required to have a designated primary care physician, who will direct you to specialists as needed. If you use doctors or hospitals outside of the network, you may have to pay the full cost of these services.

Preferred Provider Organization (PPO)

Preferred Provider Organizations allow greater flexibility to use providers outside of the plan's network. Using doctors and hospitals in the network cost less than using those outside of it; but unlike a Point-of-Service plan, you do not need a referral from your primary care physician to use the services of a specialist.



Medicaid

Medicaid is a joint federal and state program that helps some people with lower incomes pay for medical care. Each state has different requirements for eligibility. The Medicare.gov website provides help in determining your eligibility based on the state you live in.

People who have incomes that exceed the limits set by the state in which they live, may qualify for eligibility under "spend down" rules that allow them to subtract medical expenses from income to gain eligibility. Some people may be eligible for dual coverage of both Medicare and Medicaid. In those cases, Medicare pays before Medicaid kicks in to cover costs not covered by Medicare.

Medicaid Expansion

Under the Affordable Care Act, several states have expanded eligibility for Medicaid to include people with incomes up to 138 percent of the federal poverty line. The intent is to provide health insurance to a greater number of people who would otherwise be without it.

Detective Deeva advises you to keep an ear to the ground about the Affordable Care Act in your state. The ACA has been a politically-charged process and many states have chosen not to implement it, yet. The Kaiser Family Foundation provides a regularly updated list on the status of Medicaid Expansion from state to state. When this toolkit went to print, Medicaid Expansion had been adopted by 32 states.

Children's Health Insurance Plan (CHIP)

The Children's Health Insurance Plan offers parents who qualify access to low-cost health coverage for their children. If the parent's income is too high to qualify for Medicaid a CHIP plan may be the answer. The qualification rules and what the plans cover vary from state to state.

The good news is all CHIP programs in all states cover routine check-ups, immunizations, doctor visits, prescriptions, dental and vision care, inpatient and outpatient hospital care, laboratory and X-ray services, and emergency room services. For details about coverage in a specific state visit the InsureKidsNov.gov websites

Employer-Sponsored Health Plans

In the United States, 49 percent of people get health insurance through an employer, according to the Kaiser Family Foundation. An employer may offer a single health insurance plan, a selection of different types of plans, or a self-insured plan.

These plans can include coverage in the form of Health Maintenance Organizations, Preferred Provider Networks, and other types of coverage. Increasingly, employers are shifting a growing percentage of the cost to employees. They are also starting to use Health Savings Accounts more, where money is set aside to cover the medical cost of an employee.

Self-Funded Employer Health Plans

Instead of using an insurance company some employers fund their employees' healthcare through a program of the employer's own creation. As a way to control costs these plans may require employees to use only specific providers. Most of these programs must conform to rules under the Employee Retirement Income Security Act of 1974, which set regulations for these programs. Several subsequent laws have amended this legislation.

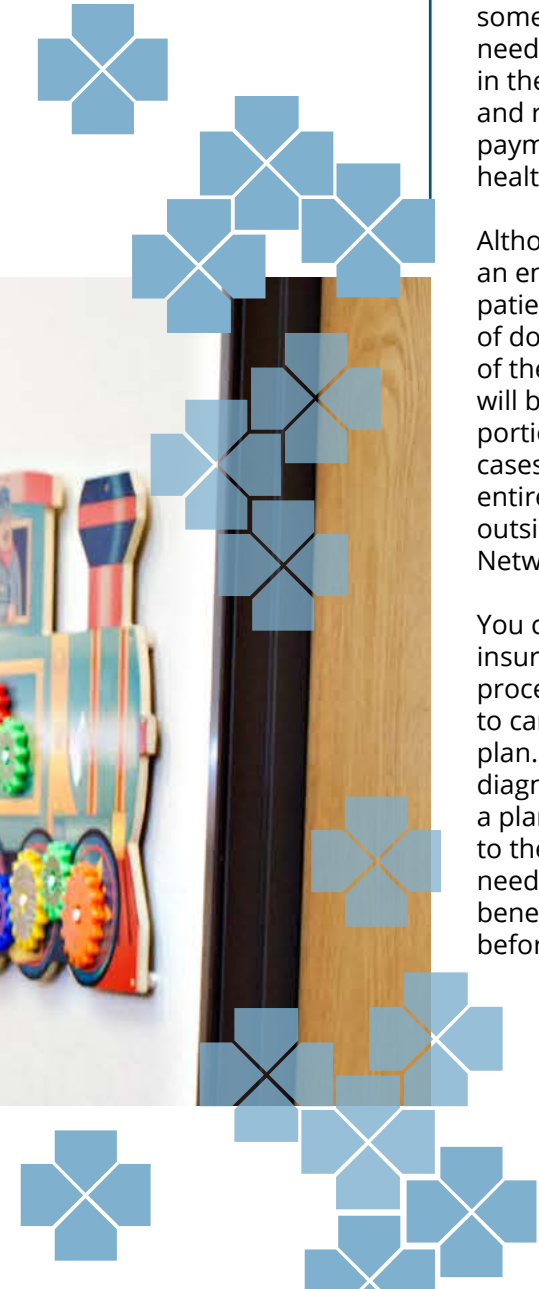
Limited Provider Networks

The rising cost of healthcare has led payers to take steps to do their best to control costs. One way they do this is through Limited Provider Networks. Limited Provider Networks have become a popular strategy for creating plans with affordable premiums. These networks rely on a smaller pool of doctors and hospitals available to patients under the plan.

In essence these networks provide a better price to payers in exchange for gaining access to more patients under the plan than they would otherwise have in a larger network. In some cases, services and drugs needed by rare disease patients in these plans may be tiered and require larger coinsurance payments than other types of healthcare.

Although lower premiums are an enticement, rare disease patients who want the services of doctors and hospitals outside of the network may find they will be responsible for a large portion of the cost. In some cases they may have to pay the entire cost when they get care outside of the Limited Provider Network.

You can avail yourself to an insurance plan's appeals process if you need access to care not covered by your plan. If you have a rare disease diagnosis it is best to select a plan that provides access to the doctors and drugs you need. Review the network, plan benefits, and plan formulary before selecting a plan. ■





Health Insurance Rewind



While Advocate Amy is not willing to share her secret, homemade mayonnaise recipe, she is willing to share this rewind of helpful tips about health insurance:

Health insurance basics

- Health insurance is a way to pay for healthcare.
- Health insurance protects individuals from paying the full costs of medical services.
- Before you choose a plan ask if you will need a referral to see a specialist?
- Before you choose a plan ask if you will need preauthorization for treatments?
- Before you choose a plan ask if you will be required to do step therapy before you get the drug treatment of choice?
- Choose a health insurance plan with defined benefits that best meet your healthcare needs.
- You pay the insurer a premium on a defined basis (monthly, quarterly, or annually) for access to care.
- The Insurer agrees to pay a portion of your covered medical costs (doctors, treatments, prescriptions, hospital costs, emergency room visits, etc.)

Choose a doctor

- Select a doctor from the insurance provider's directory of physicians.
- Contact a patient organization in your rare space for the names of specialists.
- Contact the National Institutes of Health's Genetic and Rare Disease Information Center for advice on how to find a specialist.
- Ask your primary care physician to direct you to an appropriate specialist.
- Ask your doctor what the process is for receiving a medication for your rare disease. The steps from prescribing to receiving the

medication may be more complicated than simply getting it filled at your neighborhood pharmacy.

Ask for help

- When you enroll in your employer's insurance plan get the name and contact information of the plan representative from your HR manager.
- Ask human resources if the company will assist you with filling out paperwork for appeals and similar issues.
- Contact your doctor for help when you need to appeal the insurer's denial of coverage, services (in or out-of-network) medications, and medical equipment/supplies. Ask your doctor to help you educate the insurer about your rare disease needs.
- Partnership for Prescription Assistance is a resource to connect patients who qualify and are without prescription drug coverage access to medicines for free or at minimal cost.
- Ask patient advocates for advice and recommendations for how to connect with clinical trials, pharmaceutical companies, and legislators.
- Get help from your state's insurance programs about qualifying for and enrolling in Medicaid and Medicare insurance programs.
- Get help with understanding and enrolling in your state's Affordable Care Act insurance plans.
- Contact non-profit patient assistance programs for help if you need financial assistance to get medications and/or insurance coverage.
- Protect yourself from health insurance fraud. Contact your provider directly if there are discrepancies with your billing. If you receive unsolicited inquiries from third-parties about your healthcare ask questions before you give answers.

Health insurance coverage will vary from policy to policy, but the basic mechanisms of how policies work are generally the same from one policy to the next. The shared components of health insurance policies include:

Types of Health Insurance Options

Premium

The premium is the monthly fee you pay for coverage. Policies with lower premiums will likely require you to pay more in the form of deductibles and copayments when you make use of medical services. Examine the terms carefully; a policy with a low premium does not mean it is the least expensive.

Deductible

The deductible is the out-of-pocket amount you pay for your medical care before the insurer pays their share. There are exceptions to this. Some healthcare plans (including those obtained through the insurance marketplace) cover the entire cost of certain preventive services. A policy may also have different deductibles for certain aspects of the plan, such as prescription drugs.

Copayment

A copayment is a fixed dollar amount you pay for a specific service, procedure, or drug each time you get care or fill a prescription.

Coinsurance

A fixed percentage of the cost of all services and prescription drugs a policyholder is required to pay. The coinsurance for certain services or prescription drugs may vary. Some insurers use coinsurance rather than copayments, while others use a combination of the two.

Out-of-Pocket Maximum

The out-of-pocket maximum is the most you will pay in deductibles, copayments, and coinsurance during a given year of coverage excluding the premium. When you reach the out-of-pocket maximum for your policy, your insurance company will pay all cost incurred for your care. To illustrate how this works, here's a look at Banker Beverly's health insurance policy in action.



Banker Beverly's policy has a:

- \$3,00 deductible
- 20 percent coinsurance
- \$5,000 out-of-pocket maximum

Banker Beverly has eye insertion surgery that cost \$20,000. She will pay the \$3,000 deductible and a portion of her coinsurance. Banker Beverly's coinsurance cost (20 percent of \$20,000) is \$4,000. Since she is paying the \$3,000 deductible, she will only have to pay \$2,000 of the \$4,000 coinsurance to reach the policy's \$5,000 out-of-pocket maximum. The insurance company will pay the \$15,000 balance.

If Banker Beverly has more facial feature surgery or other medical services this year she will not have to pay any additional medical costs, because she has reached the policy's \$5,000 out-of-pocket maximum.



Superstar: Best Practices



Advocate Amy and the crew believe duct tape, a swiss army knife and these best practices from the field will help you navigate the rest of your superstar journey without them.

What are some best practices?

- Over communicate with your doctor and your specialty pharmacy or whoever is responsible for delivering your medications to you.
- SPP may call from a private number. Please keep in mind they are trying to make sure they can deliver your medication. Respond to their calls immediately to ensure you continue to receive your medication or to answer questions they may have.
- Expect the unexpected. If you know your medication is due to be shipped from a location that is expecting a major weather event, call them before the event to see if it can be shipped earlier. You always want to avoid a delay in taking your medication.
- Know how many refills you have left on a prescription. Make an appointment with your doctor before you need a refill.
- Plan for travel. Know where to go in the event of a medical emergency. If it's an extended trip will you need to have medication shipped to a different location?
- Have a list of important numbers in a place where they can easily be accessed by family members, coworkers, and first responders. Include: your doctor's numbers, your specialty pharmacy number and your RX number, your local pharmacy number, your patient organization number/email, and two emergency contacts.
- Be prepared to advocate for yourself or someone you love living with a rare medical condition.
- Breathe. ■



"Sometimes, reaching out and taking someone's hand is the beginning of a journey. At other times, it is allowing another to take yours."

-VERA NAZARIAN



Looks Like a Duck: Health Insurance Fraud



Detective Deeva cautions, if it looks like a duck, quacks like a duck, and taste like chicken, it's a duck. If you start receiving unsolicited third-party insurance inquiries by phone or by mail requesting your medical or financial information; or there are unfamiliar items on your billing statement, this may be a sign of insurance fraud.

Use the listed information from healthcare.gov and Medicare to protect yourself from being a sitting duck for insurance fraud:

- Protect your private healthcare and financial information.
- Never give your banking, credit card, or account numbers, to someone who calls or comes to

your home uninvited; even if they say they represent your insurance provider.

- Don't give your Medicare card, Medicare number, Social Security card, or Social Security number to anyone except your doctor or other authorized Medicare provider.
- Never give your personal health information, like your medical history or specific treatments you've received, to anyone who asks you for it. (If you apply for certain Affordable Care Act Marketplace exemptions, you may be asked for medical documentation.)
- Don't let anyone persuade you to see a doctor for care or services you don't need.
- Check your pills before you leave the pharmacy to be sure you have the correct medication, including whether it's a brand or generic and the full amount.
- Do educate yourself about Medicare. Know your rights and know what a provider can and can't bill to Medicare.
- Check your Medicare statements carefully to make sure you received each service listed and that all the details are correct.
- Don't accept medical supplies from a door-to-door salesman. Medicare and Medicaid will not send representatives to your home to sell products or services.

- To view your Medicare claims, login to MyMedicare.gov, or call 1-800-MEDICARE. For more information on protecting yourself from fraud, visit STOP Medicare Fraud

It's time to take action and report suspected fraud if:

- Someone other than the insurance company you've chosen contacts you about health insurance and asks you to pay – or asks for your financial or personal health information.
- Someone contacts you and claims to be from the government or Medicare – and asks you to pay for a new "Obamacare" insurance card.
- You give your personal health, bank account, or credit card information to someone who calls you and says they're from the government.
- If you receive health insurance information that is confusing or sounds fishy. Check out HealthCare.gov to verify things or call the Marketplace at 1-800-318-2596 (TTY: 1-855-889-4325). ■

Fraud and the Affordable Care Act Marketplace

The Affordable Care Act Marketplace has trained assisters in every state to help you at no cost. You should never be asked to pay for services or help to apply for Marketplace coverage. After you apply you may get a phone call from the Marketplace asking you to verify or provide more information. If we don't have this information we may not be able to process your application.

Follow these tips to help prevent fraud: If your phone has caller ID, check the number. The display may show one of these:

1. Health Insurance MP
2. InsMarketplace
3. 701-264-3124
4. 844-477-7500

The customer service representative will say they are calling from the Marketplace and provide a first name and agent ID number. Write them down. A Marketplace representative may leave a message on your answering machine. If this happens, you won't be able to call back. If the Marketplace can't reach you after 3 tries, you'll get a letter in the mail telling you what to do next.

The Marketplace representative may ask you the following:

- To verify your identity, using information you provided on your application, including your full name and address.
- To provide or verify your Social Security number, application ID, policy ID, user ID, date of birth, or phone number.
- To verify or provide income, household, and employment information, but NOT personal financial information, like a bank name and account number. They will also not ask about any personal health information, like your medical history or conditions. (If you're applying for certain Marketplace exemptions, you may be asked to provide medical documentation.)

If you don't want to answer over the phone, ask the representative to mail you a letter with instructions for completing your application. In certain cases, the Marketplace may request additional documentation.

The address to mail correspondence is:
Health Insurance Marketplace
465 Industrial Blvd.
London, KY 40750-0001

**Navigating Health
Insurance Toolkit:
SECTION 3**



GLOSSARY

Lost in Translation: The Language of Health Insurance

In addition to knowing what premiums, deductibles, and copayments are, there are several other insurance terms that are helpful to know. Listed are some key industry terms you may come across in insurance documents and promotional materials. A full glossary is available on the Healthcare.gov website.

Annual Limit

Some policies carry an annual limit on the total benefits the insurance company will pay under the policy in a given year. The policy may carry separate annual limits for different areas of care, such as hospital stays and prescription drugs. If the annual limit is reached under a policy, you will be responsible for all subsequent costs during that year.

Appeal

If your insurance company will not pay for a specific service or drug, you have the right to appeal the decision. Insurance companies must explain why they denied a claim and explain how you can dispute the decision. This is also true if a company decides to terminate your policy.

Benefits

This includes the services and items covered under a health insurance plan. This information is available in the health insurance plan's coverage documents.

Benefit Year

The benefit year of an individual health insurance plan coincides with the calendar year. For policies that began after January 1, the benefit year will still end on December 31.

COBRA

Consolidated Omnibus Budget Reconciliation Act (COBRA) is a law that allows you to temporarily continue your employer-sponsored healthcare after employment ends. Under COBRA, you are responsible for the full cost of premiums, as well as administrative fees.

Claim

A claim is a request for payment that you or your healthcare provider submits to your health insurer after you receive medical services and/or other items like medical equipment.

Cost Sharing

The amount you are responsible for paying out-of-pocket under your plan for covered services, excluding the cost of premiums and non-covered services.

Coordination of Benefits

A means of determining which health plan is responsible for paying a claim when your healthcare is covered by more than one policy.

Denial

Is the decision by a health insurer to refuse payment for a specific service, treatment, drug, and certain medical equipment/supplies.

Drug List

Is a list of prescription drugs a health insurance plan covers under its drug benefit policies. This is also known as a "formulary."

Exclusions

Healthcare services that your health insurance plan doesn't cover like single-use medical supplies (gauze, bandages, incontinence pads, and similar items).

Explanation of Benefits

A statement from your health insurance plan stating what portion of a provider's services are eligible for coverage after a claim has been submitted. This is also referred to as an "EOB."

Formulary

Is a list of prescription drugs a health insurance plan covers under its drug benefit policies. This is also known as a "drug list."

Grievance

A formal complaint filed by you against your health insurance plan, such as when coverage for a specific procedure, specialist, or drug is denied.

Letter of Medical Necessity

A letter from a doctor in response to a health insurance plan's requirement for prior authorization of a drug/equipment or procedure, or in response to a denial to cover a drug/equipment or procedure. The letter explains why the procedure, drug, or equipment is necessary.

Non-Cancellable Policy

A health insurance policy that the insurer cannot cancel and that it must renew without changing the terms or raising the premium.

Open Enrollment Period

The period each year when you can enroll in a health insurance plan. You are able to enroll in health insurance plans outside this period if you qualify for a special enrollment period because of certain life events, such as getting married, having a baby, or losing healthcare coverage. You can apply for Medicaid or the Children's Health Insurance Program any time of year.

Pre-existing Condition

A health condition you had prior to beginning new health insurance coverage.

Preauthorization/Prior Authorization

Advance approval from the insurance company before you get a particular service, procedure, or prescription if you want the insurer to pay for it.

Primary Care Physician

Is a doctor who provides primary care and coordinates specialists and other medical services for a patient.

Provider

A term used to describe anyone providing care to a patient including doctors, nurses, physician assistants, and others.

Third-party Payer

Is an entity, such as an insurance company, government agency, employer, or other third-party that provides payment or reimburses costs for your healthcare expenses.

UCR (Usual, Customary, and Reasonable)

The amount paid for a medical service in a geographic area based upon what providers in the service area charge for similar services. This information may also help in estimating what an insurer will pay for a service. ■

Welcome to Something Bigger!

You are a part of something bigger—THE RARE COMMUNITY! Building connections within your specific disease community is absolutely the most vital part of your efforts. Members will tell you that the depth of the connection they feel with others in their rare disease community is hard to describe. There is an innate sense of closeness and empathy that comes with a rare disease diagnosis.

Like we said in the beginning you are not alone. You are part of an estimated 30 million Americans and 350 million people worldwide that are affected by a rare disease. While the diseases and the symptoms may be different, people in the rare community often share the same challenges and fight for the same changes. This is a powerful thing! Rare is everywhere and is frankly not-so-rare.

*"It's not in the stars
to hold our destiny,
but in ourselves."*

- WILLIAM SHAKESPEARE

Resource Guide

Government Resources

HealthCare.gov is the federal government's insurance marketplace for health insurance policies for individuals, families, and small businesses.

Medicare.gov is the website for the federal health coverage program for the elderly and certain people with permanent disabilities.

Medicaid.gov is the website for the state-administered government health coverage for people who have low-incomes.

Federal Trade Commission's online Complaint Assistant to report suspected fraud. You should also contact your local police department. Visit www.ftc.gov/idtheft to learn more about identity theft.

Health Insurance Marketplace call center: 1-800-318-2596 (TTY: 1-855-889-4325).

Non-Profit Patient Assistance Programs

Caring Voice Coalition provides financial support, therapy appeals, alternate coverage and other services to qualified individuals who have one of the life-threatening, chronic diseases on its list of supported diseases.

NORD RareCare provides assistance programs that provide medication, financial assistance with insurance premiums and co-pays, diagnostic testing assistance, and travel assistance for clinical trials or consultation with disease specialists.

Patient Advocate Foundation provides professional case management services to Americans with chronic, life threatening, and debilitating illnesses.

Patient Services, Inc. provides financial support and guidance for qualified patients with specific, rare chronic diseases.

Prescription Assistance Programs

Partnership for Prescription Assistance is a resource to connect patients who qualify and are without prescription drug coverage access to medicines for free or minimal cost.

RxAssist offers a comprehensive database of patient assistance programs, as well as practical tools, news, and articles so that healthcare professionals and patients can find the information they need.

Medicare.gov' Pharmaceutical Assistance Programs Listing

The U.S. government's Medicare website offers a directory of pharmaceutical assistance programs searchable by drug name.

Rare Disease Advocacy Organizations

Listing of U.S. based rare disease advocacy organizations compiled by the National Institutes of Health's Genetic and Rare Disease Information Center

Global Genes Webinar on Navigating Insurance, Part I Part II



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Let's Stay Connected!

Global Genes is invested in collecting and then sharing best practices and lessons learned as well as devoted to celebrating successes of the rare disease community.

Submit questions, feedback and your action steps here:
www.globalgenes.org/toolkitfeedback

Follow us @globalgenes



If you are interested in contributing to a future toolkit topic, please email:
advocacy@globalgenes.org.

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