Key Takeaways
This webinar is a general overview of how insurance works. Plans vary from state to state and company to company. This webinar will include information and skills that can help you with whatever insurance plan you are a part of. It includes information on the following:

- How insurance is structured,
- The different parts of insurance and how that affects coverage of tests and treatments,
- The actual approval process for the sophisticated tests and treatments rare disease patients require, and
- What happens when something is denied.

How Insurance is Structured
Part 1 (or Medicare Part A)
- Covers inpatient hospital stays and most associated costs.
- Often insurers pay through Diagnosis Related Groups. This means they will pay the entire cost of the hospital stay together, instead of paying for individual expenses.

Part 2 (Major Medical or Medicare Part B)
- Covers outpatient professional and treatment fees.
- Some rare disease treatments and medications and most durable medical equipment is covered under this part of your insurance.

Part 3
- Pharmacy Plan
- Covers medication.

Depending on the structure of the plan, costs are divided differently between these parts. Each plan has its own network of hospitals, facilities, providers, and pharmacies.

Insurance 101
Ideally, the insurance process goes as follows:

Patient has a problem → Patient seeks help from provider → Provider prescribes treatment or medication → Patient on road to recovery

When your insurance covers something, your plan will send you an Explanation of Benefits (EOB). This is a document explaining how your treatment has been covered. It is important to save these documents
Insurance 101: Challenges

The following are some of the challenges you may face when seeking approval.

- Doctor or other practitioner you would like to see is not in your insurance’s network of providers.
  - It is important to note: You can go to an in-network facility and a provider at that facility might be out of network. It is important to check both the facility and provider are in network.
- There are problems with the prescribed treatments. These can include:
  - Your doctor prescribes a brand name drug and your insurance only covers generic.
  - Your insurance requires step therapy, or trying lower cost drugs that have the same outcome before moving to the more expensive therapy.
  - The most important part is to know why your medication is being denied so you can move into approval.
- Prior authorization
  - An insurance company may require prior authorization to verify your need for a test or treatment before you get it to be sure they will cover it for you.
  - The best way to determine if you need prior authorization is to call your insurance company directly.

Navigating Authorization

Call your insurance with the CPT or HCPCS code to see if a service or medication is ever in network on your plan.

Medicare has quite broad formularies, but it is sometimes difficult to get coverage for brand new therapies or tests.

- Have your provider ask for an exception to the Medicare formulary.
- Similar to the prior authorization process, you must get approval from Medicare or you will have increased out of pocket costs.

Appealing Adverse Decisions

Steps to appeal adverse decisions:

- The first step is an internal review or appeal.
  - Request your insurer contact an appropriate expert in the specialty responsible for your treatment.
  - By requesting a peer to peer review with someone who is qualified to make treatment decisions, you may end up with better results.
- The second step is an external review.
  - You have a right to an external review of any denial.
  - These reviews are handled differently depending on the state. Visit the insurance commission website for your state.
There is no magic trick to appeal a denial. Be sure to know your rights and approach your insurance company with the information they need. If you are direct about what you need, you can help initiate appeals processes or encourage your provider to do so on your behalf.

It is important that you are direct when asking for an in-specialty peer review, because that will ensure that your providers and the insurance ones are speaking the same language.

**Question and Answer Session**

With high co-insurance and deductibles, what questions can patients ask to possibly reduce costs of procedures such as injections and meds or reduce number of visits?

- **First**, have an honest conversation with your provider. Discuss with them your challenges in accessing your medications and see if there are programs or services they may offer to help.
- **Second**, speak with your insurance company and make sure that you’re receiving your medications in their preferred method. You can also ask your pharmacy about assistance programs. Many hospitals and pharmacies have these programs, but it’s not something they can advertise.
- **Third**, contact the drug manufacturer. Many manufacturer websites will have copay cards and programs that people on private insurance can use to reduce their out of pocket burden.
- **Finally**, contact NORD to see if your diagnosis qualifies for one of the many NORD assistance programs. You can find more information on those programs on NORD’s website.

We have received several questions about off label drug use. Do you have any insight or advice on off-label drug use and how to make your case to the insurance company?

- This is a tricky issue that many patients run into, because there are many drugs that manufacturers produce that can be used for a wide range of medically-accepted indications, but with rare diseases, it is not cost effective to do the clinical trials required to have these indications become on label. Discuss this with your provider and find out how they are using the drug, how their other patients are accessing it for an off-label use, and whether there is particular literature, like case studies, that can be used to make a case. Generally speaking, if your provider is able to cite specific instances, it will go a long way. This is also an instance when you might want to consider engaging an external review, because this sort of situation is when an outside reviewer is warranted to help make a determination.

I am interested in learning more about drug approval parity for Part B and Part D drugs. How do I successfully overturn the so-called "compendium issue" for off-label Part D drugs?

- This is a pretty specific question, but it has some general applications and provides the opportunity to talk through the five layers of Medicare appeals. For most drugs with these issues, you will need to apply for an exception to the Medicare formulary. Your regional Medicare Administrative Contractor, or MAC, will be who you’re appealing to. They handle the first stage of appeals processes and make local coverage determinations. The second layer of appeal is to a Qualified Independent Contractor, or QIC. If the QIC makes a negative determination, the appeal goes to the Office of Medicare Hearings and Appeals and is reviewed
by an Administrative Law Judge. The fourth level of appeal is to the Medicare Appeals Council and the fifth and final level is review by a federal district court. If you’re going through the Medicare appeals process, you basically have 60 days after any decision is made to appeal that decision using the appropriate form for an in-writing appeal. You can also engage outside help with appealing decisions. CMS allows you to appoint a representative to help guide the process. As you get into the higher levels of appeals, this outside representative can be helpful for navigating the process and making your case.

How do I receive insurance reimbursement for an infusion given with home health? When I receive it at the doctor’s or at a hospital it is paid for in full but not with home health.

- Site of care is a really important issue for patients who receive infused medications. Home health services are not covered by all insurance companies. Medicare doesn’t currently cover home care very well, unless you’re declared home bound. For private insurance, there is usually a way to get home care covered. Sometimes, it requires figuring out which in-network pharmacy will provide the service. Ask your insurance representative what pharmacies are in network for your particular infusion medication and call those pharmacies to see if you can have them do home infusions. Most private insurance plans will allow this with many medications because it is actually a lower cost option for care.

What are the qualifications for Medicare? I have been on my work disability for over two consecutive years. Would I qualify for Medicare?

- Medicare eligibility is based on two things. The first and most straightforward way to qualify for Medicare coverage is to be over 65. The second, and more difficult way, is to have qualified for Social Security disability or Railroad Retirement Board disability for 2 years. A private plan from an employer doesn’t qualify you for Social Security benefits or for Medicare as a result of disability. If you are receiving payments from a private disability plan, I would recommend applying for Social Security as soon as possible, if you have not already.

What can a case manager at insurance do?

- If you’re not comfortable with navigating your insurance, a case manager can actually help you understand your coverage determinations and help you navigate the internal appeals process. They can even help you prevent a denial in the first place by helping you understand where communications between your provider and your insurer aren’t happening in a timely way. They are often most helpful as a single point of contact for your insurance carrier for questions, as you’ll often be assigned the same case manager for all your needs. Typically, these are assigned by the insurance company, but you can actually request them as well, if you would like additional assistance.

Why some Medicare Advantage plans are so cheap?

- Medicare Advantage is an interesting combination of Medicare and private insurance. Each plan has its own pros and cons, but the way that many companies make their Advantage plans more
affordable is to limit the network of providers. So before enrolling in a Medicare Advantage plan, I would make sure your lead specialist and primary care doctor are part of your plan. That actually goes with any plan, really. Most insurance company websites will allow you to use their find a provider tool before you’re enrolled in a plan, so you can put in your plan information and find out whether your provider is in network. It’s really important to do that before enrolling in a plan.