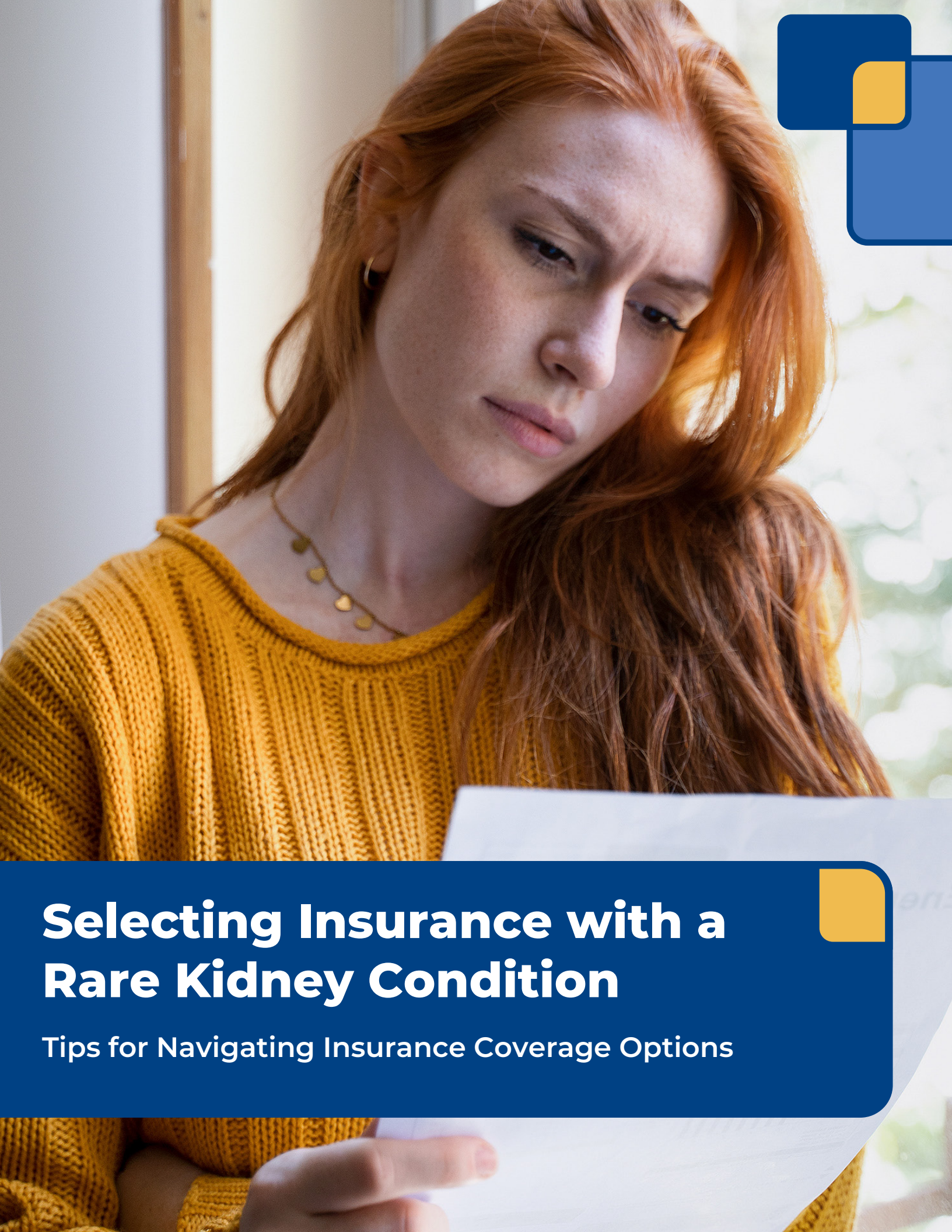

Selecting Insurance with a Rare Kidney Condition

Tips for Navigating Insurance Coverage Options

Introduction to Insurance

Choosing a health insurance plan can be confusing. You will need to:

- Know what healthcare specialists and services you might need
- Determine if your doctor or specialist is a part of the insurance plan you are considering
- Understand common insurance terms
- Compare different kinds or levels of coverage

This process is even more complex for someone with a rare condition; some insurance plans may not cover your specific needs.

What is Health Insurance?

Health insurance pays for some or all of your health-related expenses.[1] You buy health insurance and pay a certain amount of money each month. That monthly payment is called the premium. The cost of health insurance and the services it will pay for, or cover, are different for each plan. Your monthly cost is typically related to the percentage of your care your insurance will cover.[1] Most health insurance covers basic healthcare needs (for example, dealing with the flu, pain, or a broken bone).

These are the most common services typically partly or fully covered by health insurance (some or all related costs).[1]

- Doctor visits
- Procedures, like biopsies
- Medications
- Emergency services
- Lab tests
- Medical equipment, like hemodialysis machines

Did you know that most insurance companies have specialized care managers?

They can help you understand your unique needs, advocate for yourself, explain your benefits, and assist in getting your medication covered.

Factoring in a Rare Kidney Condition

Rare kidney conditions can require care different from other, more common conditions. This may include:

- Specialty medicines, some of which may be expensive[2]
- More visits to the doctor or clinic
- Lab tests, like blood or urine tests, that may need to be done regularly
- New health and lifestyle habits to help you manage your condition[3]

All of these factors may affect which insurance plan you choose. Be sure to talk to your doctor about the level of care you might need before you select an insurance plan.

Common Types of Insurance Providers

There are many different types of health insurance provided by different organizations. One of the big differences between them is how they are offered and who they are available to.

Employer Group Health Plan (EGHP): Insurance provided by a person's employer or a union. The employer pays part of the monthly premium for these plans, and the employee pays the rest.[1] This is commonly called commercial insurance.

Individual Plans: A self-employed person, a person who works for a company that does not provide insurance, or a retiree not accessing Medicare/Medicaid can purchase an individual plan separately or through the Marketplace, which was created as part of the Affordable Care Act.[1] Individual plans can also be called commercial insurance.

Medicare: Federal government health insurance for people more than 65 years old and certain younger people with disabilities. Medicare also covers people with end-stage kidney disease (ESKD).[1]

Medicare Advantage Plans (Medicare Part C): Insurance plans offered by companies that partner with Medicare to provide your Medicare benefits. Many Medicare Advantage Plans (MAPD Plans) offer coverage for prescription drugs.[1]

Medicaid: An insurance program run by state governments that offers free or low-cost coverage to people with low income and their families, pregnant women, senior citizens, and people with disabilities. Check with your state to see if you qualify for Medicaid.[1]

Children's Health Insurance Program (CHIP): A federal program that provides coverage at a low cost for children of families that earn too much for Medicaid coverage but cannot afford to buy insurance.[1]

Indian Health Service (IHS): The primary care provider for the American Indian and Alaska Native Medicare population. Coverage includes clinical and preventive health services.[4]

TRICARE: A health insurance program for active-duty military service members, retired service members, active and retired members of the National Guard and Reserve, and their families and survivors.[5]

Selecting an Insurance Plan

Once you know the type of insurance you will use, you need to decide on a plan. The main differences between the different plan types are whether you can use providers considered out-of-network and whether you need to get a referral from your primary care provider to see specialists or for certain medical services. Let's learn more about what this means.

In-network and out-of-network

All plans have a list of providers, facilities, and suppliers that they prefer. Plans have negotiated a contract with them to pay a certain rate for their services. Providers on this list are considered in-network. Providers not on the list are out-of-network. Plans that allow you to use out-of-network providers offer more flexibility. Out-of-network visits will typically cost more than they would if you visited a provider in-network.[1]

If you have a rare kidney condition, there may be few specialists in your area that provide treatment. Because they are not local, they may not be in your plan's network. Be sure to factor in the cost of seeing out-of-network doctors when choosing a plan.

Referrals

Some plans require you to get a referral before seeing specialists or receiving certain medical services. A referral will come in written form from your primary care provider.

Since people with rare kidney conditions may need to see one or more specialists, the referral requirement may add time and complexity as you manage your condition.

Here are some plans you might come across as you search for insurance. The chart below outlines how these plans handle out-of-network services and referrals.[1]

Insurance plan types	Covers out of network services	Requires referrals for certain medical services
Preferred provider organization (PPO)	Yes	No
Health maintenance organization (HMO)	No	Yes
Point of service (POS)	Yes	Yes
Exclusive provider organization (EPO)	No	No

Checklist When Determining Coverage and Considering Your Specific Needs

As you compare plan types, keep these considerations in mind.

- If you already have a doctor who specializes in rare kidney conditions, check to see if they are in-network with insurance plans you are considering.
- A rare kidney condition may require specific care or specialists in addition to your nephrologist. If you need to find a doctor who specializes in rare kidney conditions, check your insurance provider's directory of physicians for a list of possible specialists to see.
- Pay close attention to a plan's prescription drug coverage. Does it cover specialty medicines, which you may need as someone with a rare condition? Is this coverage different from coverage for other, more common medicines? Does it cover brand-name medications?
    - **Some insurance plans will deny coverage of brand-name medications if there are generic medications available. Talk with your primary care physician or kidney specialist about your prescribed medications. If your coverage is denied, they can help you request an appeal.**
- Does the plan cover different dialysis treatments needed?
- When selecting coverage, be sure to check any prior authorization (see glossary) requirements for:
    - The nephrologist you are currently seeing
    - Other specialists you may need to see
        - **It may help to ask your primary care physician or nephrologist about the types of specialists that may join your healthcare team.**
    - Medical equipment coverage
    - Second opinions from other specialists
    - Lab tests

Call the insurance provider's customer service line and ask any questions you may have.

Do you know your open enrollment dates?

Open enrollment is a period during which you choose new insurance providers for the following year. Be sure to allow enough time to research the insurance plan offerings before the open enrollment deadline.

Calculating Costs

To find the plan that is right for you, it's important to look at more than just the monthly premium cost. A plan with a low monthly cost may seem like a good option, but plans with low premiums can have higher costs for:

- **Deductibles** (the amount you are required to pay before you can access your plan's benefits)
- **Coinsurance** (the percentage you pay for a medical expense after you reach your deductible)
- **Copays** (the amount you pay out-of-pocket for a medical service, like a doctor's visit)

Let's compare sample costs for a low-premium plan and a high-premium plan for Jennifer.

Expenses	Plan 1 (low-premium)	Plan 2 (high-premium)
Premium cost per month	$200 ($2,400 for 12 months)	$400 ($4,800 for 12 months)
Copay for primary care physician	$25	$15
Copay for specialist appointments	$50	$25
Coinsurance responsibility	40%	20%
Deductible	$2,000	$1,000

Jennifer has a rare kidney condition. She visits her primary care physician twice a year and sees her nephrologist, a specialist, six times a year. She also has four blood tests per year that cost $200 per test and is expecting to have a kidney biopsy that costs $8,000. Jennifer calculates her coinsurance responsibility for the blood tests and the kidney biopsy for each plan. She then adds the out of-pocket-expenses for each plan, including the premiums, deductibles, copay costs, and coinsurance costs. Jennifer notices that while plan 1 has a lower premium each month, plan 2 actually provides the care she needs at a lower annual cost as outlined in the chart below.

Jennifer's costs per year		
Expenses	**Plan 1 (low-premium)**	**Plan 2 (high-premium)**
Premium per year	$2,400	$4,800
Deductible	$2,000	$1,000
Copay cost for primary care physician (2 visits yearly)	$50	$30
Copay costs for specialist visits (6 visits yearly)	$300	$150
Coinsurance for blood tests (4 tests/year at $200/test)	$320	$160
Coinsurance for a kidney biopsy that costs $8,000	$3200	$1600
Total annual cost	$8,270	$7,740

The costs of services listed here are examples. The cost of the actual services you need will depend on the services, their frequency, and your healthcare plan options.

Glossary of Insurance Terms to Know

Appeal: A request for your health insurance company to review a denial of a benefit or payment.[1]

Coinsurance: The amount you pay for a medical expense after you reach your deductible. The amount will be a percentage of the total cost and differs by insurer and coverage.[1]

Copayments: Also referred to as copay. The amount you pay out of pocket for a medical service, like a doctor's visit. After you've met your plan's deductible, you pay the copayment amount.[1]

Deductible: The amount of money you are required to pay before you can access your plan's benefits. Deductible amounts vary by insurer and coverage.[1]

Denial: A decision by an insurance company to not cover the costs of a doctor's visit, prescription, or procedure. A denial may result from a service not covered under the insurance plan or an appointment or a procedure with a doctor not in the plan's network of providers.[1]

In-network: The providers, facilities, and suppliers that your healthcare plan covers.[1]

Out-of-network: The providers, facilities, and suppliers that are not covered by your healthcare plan. Depending on the plan, you can use out-of-network healthcare providers, but you will pay more than if you saw a provider in your plan's network.[1]

Out-of-pocket maximum: The highest amount you will pay for healthcare services per year, including the money that you spent on coinsurance, copayments, and deductibles for in-network services. If you reach the maximum, your plan will cover all additional costs for covered benefits.[1]

Premium costs: The amount you pay for health insurance regularly, usually monthly. In addition to this cost, you will also need to pay for copayments, coinsurance, and deductibles. The premium amount and additional costs vary by coverage, plan type, and insurer.[1]

Prescription drug coverage: The amount your plan covers for a particular prescription medicine. Coverage may require you to use a generic, if available. Some more expensive treatments may require prior authorization from your healthcare provider.[1]

Prior authorization: Approval from your insurance provider to cover the cost of a certain medication or procedure before you receive it.[1]

Referral: Written approval from your primary care provider to see specialists or for certain medical services.[1]

References

1. Glossary. HealthCare.gov. Accessed April 28, 2025. https://www.healthcare.gov/glossary. 2. Specialty Pharmaceuticals. AMCP.org. Accessed April 28, 2025. https://www.amcp.org/concepts-managed-care-pharmacy/specialty-pharmaceuticals. 3. IGA nephropathy. National Institute of Diabetes and Digestive and Kidney Diseases. November 2015. Accessed April 28, 2025. https://www.niddk.nih.gov/health-information/kidney-disease/iga-nephropathy. 4. Medicare & You, 2023: The Official U.S. Government Medicare Handbook. CMS, Centers for Medicare & Medicated Services; 2022. 5. TRICARE 101. Accessed April 28, 2025. https://www.tricare.mil/Plans/New.