



DECEMBER 2022

Understanding and Navigating Medicare



About Global Genes®

Global Genes is a 501(c)(3) non-profit organization dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally. In pursuit of our mission we connect, empower, and inspire the rare disease community to stand up, stand out, and become more effective on their own behalf—helping to spur innovation, meet essential needs, build capacity and knowledge, and drive progress within and across rare diseases. We serve the more than 400 million people around the globe and nearly 1 in 10 Americans affected by rare diseases. If you or someone you care about has a rare disease or is searching for a diagnosis, you can *contact us by submitting our confidential form*. A Patient Services Guide will provide you with a personalized response within 2-3 business days that will include information, resources, and connections that address your specific needs.

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Acknowledgments

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Introduction

In addition to the physical, mental, and emotional hardships of living with a rare disease, the costs can be astronomical. According to the [*National Economic Burden of Rare Disease Study*](#),¹ conducted by the EveryLife Foundation for Rare Diseases, the economic cost of 379 rare diseases reached nearly \$1 trillion in 2019. One study from the National Center for Advancing Translational Sciences found that health care costs for individuals living with rare diseases are 3 to 5 times greater than the costs for people without a rare disease.

One way to ease this burden is to take full advantage of the Medicare benefit program, which is available to people over the age of 65 and those who qualify for Social Security Disability Insurance (SSDI). Although many adults with rare diseases qualify for Medicare, figuring out how to do this can be incredibly challenging, time-consuming, and frustrating.

This toolkit is intended to make it easier for you to receive all the benefits you deserve. It's a high-level, "how-to" guide designed specifically for people living with rare diseases and rare disease advocates. It answers questions about Medicare and other options for financial assistance that are especially relevant to people with disabilities, including:

- Can I receive Medicare before I'm 65?
- Is it available for my child?
- How do I apply?
- What types of Medicare insurance are available?
- Are there other health and financial assistance programs I should consider?
- Are there differences in coverage depending on the state I live in?
- What else should I know to expedite and optimize my benefits?

The toolkit also features tips and advice from rare disease professionals and people who have first-hand experience navigating a slow and often frustrating process. Their insights can help you make informed decisions and avoid common and costly mistakes.

If you want to dig deeper, you'll find links to many reliable sources of information and support from organizations such as the [*Patient Advocate Foundation*](#). And, of course, Global Genes is always here to help you. [*Contact RARE Concierge Patient Services*](#) by filling out our confidential form.

Medicare Basics

What is Medicare?

Medicare is a federally administered health insurance program for people who are 65 years of age or older or who qualify for Social Security Disability Insurance (SSDI). You can qualify for SSDI if you have a disability, End-Stage Renal Disease (ESRD) or ALS (also called Lou Gehrig's disease).

What types of Medicare insurance are available?

Most people enrolled in Medicare (also called **Original Medicare**) choose to have both hospital insurance (Part A) and medical insurance (Part B). Medicare Part A is free for most people, and the government usually pays 75% of Medicare Part B costs.

Medicare Part A covers hospital stays, care in skilled nursing facilities (SNFs), hospice care, and some home healthcare.

Medicare Part B helps pay for visits to doctors and other healthcare providers (HCPs), outpatient care, durable medical equipment (DME), and home healthcare.

For both types of coverage, you can see any doctor, HCP, and hospital that takes Medicare (and most do) anywhere in the country without needing to get any prior authorization.

Once you have Medicare Parts A and Part B, you can then purchase *Medicare Part D*, which offers prescription drug plans from private insurers.



RARE TIP

You can search *this FDA database* to find out if your orphan drug has been approved.

What are my other Medicare insurance options?

Two other types of alternative or supplemental plans are available from private insurers. **Medicare Advantage (Part C)** combines Medicare Part A and Part B and typically includes Part D (prescription drug coverage). These “bundled plans” are approved by Medicare but are run by a private company, and may have different requirements and benefits.

- In most cases, you can only use doctors who are in the plan's network.
- In many cases, you may need to

get prior approval from your plan before it covers certain drugs or services.

- Plans may have lower out-of-pocket costs than Original Medicare.
- Plans may offer some extra benefits that Original Medicare doesn't cover—like vision, hearing, and dental services.

With Medicare Advantage, you can find the type of coverage and benefits that fit your needs. Your options include Health Maintenance Organizations (HMOs), Preferred Provider Organizations (PPOs), Private Fee-for-Service (PFFS) plans, or Special Needs Plans (SNPs), which are tailored for people with certain health conditions.



Medicare Advantages or Part C

Supplemental Insurance (Medigap)

Since Medicare does not cover all healthcare expenses, many people purchase Supplemental Insurance (also called Medigap), which can help cover the cost of co-payments, co-insurance, and deductibles. To enroll in these plans, you must have Original Medicare Part A and Part B. People who are enrolled in Medicare Advantage plans do not qualify for Medigap.

Although all Medigap plans are required

to offer certain benefits, their coverage and costs vary. Medicare can help you compare policies online, and you can contact your [*State Health Assistance Program \(SHIP\)*](#) for free counseling on the available options.



RARE TIP

The best time to get a policy is during your Medigap Open Enrollment Period. It's the 6-month period that starts the month you turn 65 and you first have both Medicare Part A and Part B. During this time, you can buy any Medigap policy sold in your state, even if you have health problems. If you're under 65, you may not be able to get a Medigap policy, or you may have to pay more.

[*Learn more about Medicare Supplemental Insurance*](#)



Choose the Best Plan for You

Get tips on selecting the right Medicare coverage for you in *this video* from Erin Bradshaw, Chief of Mission Delivery for the *Patient Advocate Foundation (PAF)*, a non-profit that provides direct services to patients with chronic, life-threatening, and debilitating disease.



PAF's Case Management program is an intervention that helps you understand health insurance coverage options, address problems you run into with your coverage, and connect you to resources that may help with financial challenges you have with paying for care, household expenses, and income replacement benefits such as disability.

Connect to PAF services by calling 800-532-5274.

PAF also offers helpful resources on topics like “how to appeal denials” and “how to avoid financial stress,” including the following:

Choose Wisely: Tips for Medicare Open Enrollment

Engaging with Insurers: Appealing a Denial

Health Insurance: How to Avoid Financial Stress

Understanding How SSI and SSDI Can Help You

How do I apply for Medicare?

You can apply online ([Medicare.gov](https://www.Medicare.gov)), on the phone (1-800-633-4227), or at your local Social Security Administration (SSA) office. If you're about to turn 65, it's recommended you apply three months before your birthday because there are penalties if you miss the initial enrollment period, which begins three months before you turn 65 and ends three months after the month you turn 65.

If you qualify for SSDI, there is a 24-month waiting period before you are eligible for Medicare. During this time you must find other sources of insurance. You will automatically be enrolled in Medicare after you have been on SSDI for 24 months.

How are Medicare claims submitted?

- That depends on what type of plan you have. If you have Original Medicare, the law requires doctors and suppliers to file Medicare claims for covered services and supplies you receive.
- If you have a Medigap policy, your healthcare providers will file claims to cover additional costs (co-pays, deductibles, etc.) for services and supplies you receive.
- Out-of-network providers are not required to file claims, although some may do it as a courtesy. If the provider does not file, you will need to file your own claim. Note that the reimbursement rate (if any) will be less than in-network providers.



RARE TIP

Here are some additional resources that will help you learn more about your options.

Medicare.gov

Medicare Health and Drug Plans

Medicare Supplemental Insurance Plans

State Health Insurance Assistance Program (SHIP)

Understanding Medicare Advantage Plans

10 Things You Should Know about Medicare

- Choose wisely when selecting Medicare plans and supplemental coverage – your decisions will affect the benefits you receive, who will provide your care, and your out-of-pocket costs.
- *Medicare.gov* can help you find and compare your options.
- Take advantage of your local *State Health Insurance Assistance Programs*.
- Medicare coverage is the same for people who qualify based on disability as for those who qualify based on age.
- Make sure you know the window when you can apply for Medicare and take action promptly to avoid late enrollment penalties.
- Choosing Part D when you first enroll in Medicare is recommended, since there are permanent penalties added to your Part D monthly premium if you delay and enroll later.
- Although Medicare Advantage Plans offer more benefits, they typically have restrictions that limit your choices for doctors and hospitals.
- You can only purchase Medigap supplement insurance if you enroll in Original Medicare A and B, not if you enroll in Medicare Advantage.
- You can change your coverage only when you have a *qualifying event* or at certain times designated as “open enrollment” periods (usually occur between October and December), which allow you to switch from Original Medicare to a Medicare Advantage plan (or vice versa) and change your Part D prescription drug plan provider.
- Medicare covers care at a skilled nursing facility only when you need skilled nursing care or therapy services to treat, manage, observe, and evaluate your care for a limited time period. Medicare does not cover most dental care, eye exams, hearing aids, acupuncture, any cosmetic surgeries, and long-term care.

How does Medicare differ from Medicaid?

Medicare is federal health insurance for anyone age 65 and older and some people under 65 with certain disabilities or conditions. **Medicaid** is a joint federal and state program that provides free or low-cost coverage to help people pay for healthcare if they have a low income and/or a disability and receive Supplemental Security Income (SSI). Medicaid offers benefits and nursing home care, personal care services, and assistance paying for Medicare premiums and other healthcare costs.

3 Things You Might Not Know about Medicaid

- Since each state can set up its own Medicaid program (within parameters set by the federal government), eligibility criteria and benefits will depend on where you live.
- Medicaid may cover expenses not paid by Medicare, such as dental care and transportation to medical appointments, but coverage varies by state.
- If you qualify, you can receive benefits from both Medicare and Medicaid. To qualify, you must meet the income requirements in your state for Medicaid and be eligible for Medicare based on age or disability.

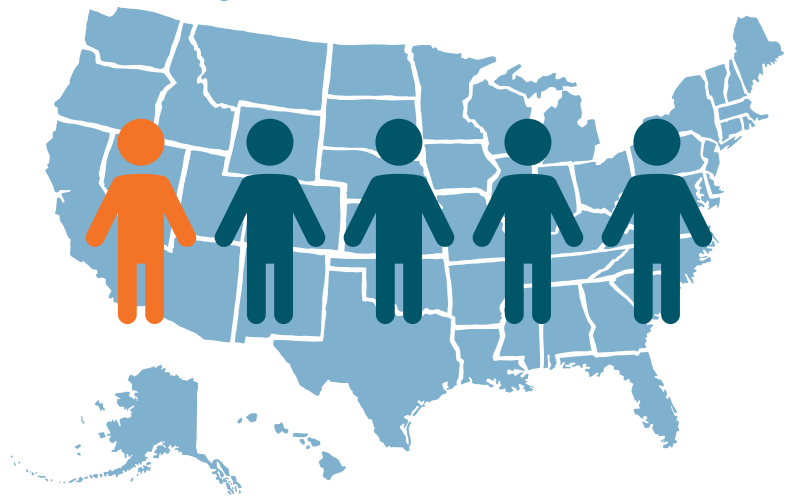
Learn more

Understanding and Navigating Medicaid

State Medicaid office websites

Healthcare.gov

Medicaid is the largest health insurer in the United States and provides health coverage for **one in five** Americans.²



RARE TIP

"If you are sick, don't wait to apply to benefit programs such as Medicare, Medicaid, and Social Security Disability Insurance to see what you might qualify for. I wish someone had told me that if you wait too long and go years without working, you could lose your benefits."



– MARY MORLINO, GLOBAL GENES RARE CONCIERGE PATIENT SERVICES MANAGER

Medicare for People with Disabilities

Many people think of Medicare as a program that covers health care costs only for senior citizens. But people under 65 years of age can also receive Medicare benefits if they qualify for Social Security Disability Insurance (SSDI). There is, however, a waiting period before coverage begins. If you become eligible for Medicare because of a disability, and have been receiving SSDI benefit payments for 24 months, you should automatically be enrolled in Medicare Parts A and B at the start of your 25th month. Generally, you'll receive a packet of information in the mail several months before coverage begins. If you aren't automatically enrolled, or have questions about the process, contact [Social Security](#).

What are the SSDI eligibility requirements for adults?

The number of work credits you need to qualify for disability benefits depends on your age when your disability begins. Generally, you need 40 credits, 20 of which were earned in the last 10 years ending with the year your disability begins. In 2022, workers were awarded one credit for each \$1,520 earned through wages or self-employment; you can only get up to four credits each year.

However, younger workers who become disabled may qualify with fewer credits. You can get more [details on the number of work credits needed at different ages](#) from the Social Security Credits page on SSA.gov.

When you start receiving SSDI, certain family members may qualify for benefits based on your work history. More information can be found on the [Family Benefits page](#) on SSA.gov.

How does the Social Security Administration (SSA) define "disability"?

The SSA defines adult disability as a medically confirmed physical or mental impairment that results in "an inability to



do any substantial gainful activity,” and 1) can be expected to result in death, or 2) has lasted or can be expected to last for at least 12 months.



RARE TIP

Compassionate Allowances are a way to quickly identify diseases and other medical conditions that, by definition, meet Social Security’s standards for disability benefits.

SSA has a list of diagnoses that automatically qualify eligible people (those who have the work credits for SSDI or income to qualify for SSI).

How do I apply for SSDI?

Visit this [SSA website](#) to learn more about the SSA’s disability benefits and apply for its SSDI or Supplemental Security Income (SSI) programs.

Keep in mind that it is not uncommon to be denied initially. You can appeal this decision in writing to the SSA and must do so within 60 days of the denial letter. You can also go online to request a hearing with an administrative judge, where an attorney can represent you and witnesses, such as doctors, can speak on your behalf.



RARE TIP

N. Leah Fink, an attorney specializing in SSI and SSDI, shares her insights on applying for SSDI.

- Let SSA know everything about all your health-related problems; don’t just focus on your rare disease.
- Include lists of all the doctors you’ve visited (and their addresses) in the last year.
- Tell SSA about all your medications; emergency and urgent care visits; physical or occupational or therapy visits; or any mental health problems you may have.



“Let SSA know what your worst days are like, how often you have them, and all the negative ways they affect your life.”

– N. LEAH FINK



Can my child qualify to receive Medicare or SSDI?

Under some circumstances, children can receive Medicare. For example:

- Children under the age of 20 can qualify for Medicare if they have End-Stage Renal Disease (ESRD), need dialysis or a kidney transplant, and have at least one parent who qualifies for Social Security.
- If you are 18-21 years of age, you can apply for Social Security Disability (SSDI) under your parents' earning record even if you have never worked. You would be eligible for Medicare 24 months after SSDI benefits start.

Another option for children 18 or younger who do not qualify for Medicare is the Children's Health Insurance Program (S-CHIP), a partnership between the federal and state governments that provides low-cost health coverage to children in families that earn too much money to qualify for Medicaid. [Check with your state](#) to apply and find information about covered services.

Understanding Medicare coverage and following the guidelines can be complicated. It may take a good deal of research. But remember you can get help from organizations like the [Patient Advocate Foundation](#) and [Global Genes](#).

Learn more

How to Access and Maintain Social Security Benefits

Medicare for People Under 65

Medicare Eligibility for Disabled Youths

InsureKidsNow.gov

Social Security Disability Programs

Another Option: Supplemental Security Income (SSI)

If SSDI and Medicare are not options for you and/or your child, an alternative pathway to receiving healthcare benefits (and getting financial assistance) is Social Security's Supplemental Security Income Program (SSI). It provides monthly payments to adults and the parents of children who 1) meet SSA's definition of disability and 2) meet the criteria for income and resources (what you own). These criteria will vary depending on the state where you live.

How does SSI differ from SSDI

SSI determination is based on age/disability and limited income and resources. SSDI determination is based on disability and work credits. In most states, an SSI recipient will automatically qualify for health care coverage through Medicaid.

Learn more about [Supplemental Security Income](#) (SSI)

How can I get SSI?

You can screen eligibility and apply for SSDI or SSI at your local SSA office online **after** you have created a [mySocialSecurity](#) account, or by calling 800-772-1213. The application

usually takes about 5-10 minutes to complete, and you may need to give the SSA permission to contact your bank and medical providers. An SSA representative will usually contact you within two weeks to schedule an appointment to help you apply for benefits.

Who decides whether you qualify for SSI?

After you submit your disability application to SSA, it is sent to a state disability agency, usually called Disability Determination Services (DDS). The application is then reviewed by claims examiners as well as medical and psychological consultants, who determine whether it is approved. If a DDS office decides it doesn't have enough information, it may direct you or your child to attend a consultative examination (CE), which is a brief doctor's visit, usually under one hour, paid for by the DDS.

It can take 3 to 5 months before you receive their initial decision.



RARE TIP

It may be a fast route to obtaining Medicaid coverage. In many states, a child who receives SSI benefits will automatically be placed in his or her state's Medicaid program. Other states may require that you apply after SSI approval.

Resources from Global Genes

You'll find more information on disability, Medicaid, and Supplemental Social Security Income in these Global Genes toolkits:

Understanding and Navigating Medicaid

How to Access and Maintain Social Security Benefits

5 Things to Know about SSI

- Not everyone receives the same payments. You may get more if you live in a state that adds money to the federal SSI payment. You also may get less if you have other income such as wages, pensions, or Social Security benefits. Find out how much you will be eligible for *using these guidelines*.
- SSI can be complicated. SSA offers advice on *where to get help with the process*.
- If you receive SSI, you may be able to get additional help from your state or county. For example, you may be able to get Medicaid or buy food through the Supplemental Nutrition Assistance Program (SNAP). Call your local social services department or public welfare office for information about the services available in your community. Every state has a Disability Determination Services (DDS) agency, but some states call their agencies by slightly different names. You can find your DDS on your state's website.
- You have to report any changes in income or circumstance within 10 days. If not, penalties of \$25 to \$100 can be deducted from your monthly SSI payment.
- If DDS sends you a notice to go to a consultative examination CE, make sure that you attend. If you don't, the agency could deny your claim due to lack of cooperation.

Medicare Costs and Savings Opportunities

If you or your spouse are 65 or older and have paid Medicare taxes for at least 10 years, you don't pay a premium for Part A. If you are disabled and have been receiving Social Security benefits, you also may not have to pay any monthly premium. However, you will be responsible for paying a hospital deductible, which will be \$1,600 in 2023 for each inpatient hospital benefit period, as well as co-insurance for hospital stays longer than 60 days. You can find an explanation of benefit periods in this [Medicare glossary](#).

In 2023, most people enrolled in Part B of Original Medicare will have to pay a monthly premium of \$170 (though it could be higher depending on your income) and a \$226 deductible before Medicare starts to pay. Part B also requires a 20% co-insurance payment for medical services, including physician inpatient care, which could be substantial.

Keep in Mind

There is no annual limit for what you may have to pay in out-of-pocket expenses if you are enrolled in Original Medicare, which is a big reason why many people buy



supplemental insurance. You can cap costs with a Medicare Advantage plan, but you may have a more limited provider network. To help you sort out what is best for your unique situation, here is a [comparison chart of average costs](#).

Money-saving Healthcare Programs

In addition to Medicaid (see previous section), here are some other ways to lower your health care expenses.

- [Medicare Savings Programs \(MSP\)](#): Your state may help you pay for Medicare premiums, deductibles, and co-insurance. To qualify for

an MSP, you must have Medicare Part A and meet *income and asset guidelines*, which will vary from state to state. To see if you are eligible, contact your state's *State Health Insurance Assistance Program (SHIP)*.

- Low-cost health centers and clinics: You may pay less for Medicare-covered services if you receive them through low-cost health centers and clinics in your state. For more information, contact your *State Health Insurance Assistance Program (SHIP)*.
- Here is a *glossary that lists additional programs* that help people with limited incomes pay Medicare costs.



RARE TIP

The *Inflation Reduction Act*, signed into law in August of 2022, will provide financial relief for people on Medicare in some situations. The new law will be implemented in phases from 2022 to 2025.

Money-Saving Prescription Drug Programs

A recent *study* found that the average annual cost for orphan drugs (used to treat, prevent or manage rare diseases) was more than \$123,543, which is 25 times more expensive than traditional drugs. Here are some financial assistance programs that can help reduce these and other prescription expenses.

- The *Extra Help program*, also known as the Part D Low Income Subsidy (LIS), helps pay for a portion of Part D costs, including premiums, deductibles, and co-payments. You will receive Extra Help automatically if you get full Medicaid coverage, receive help from your state's Medicare Savings Program in paying your Part B premium, or receive Supplemental Security Income (SSI) benefits. The SSA estimates the average annual value of LIS is \$5,000 per person.
- *State Pharmaceutical Assistance Programs (SPAPs)*: Some states offer this program, which helps pay for the Part D premium and cost-sharing expenses. Most SPAPs have income guidelines and some may also pay for drugs excluded from Medicare Part D or those not in your plan's formulary.

Other options for getting financial help include:

- **Patient Assistance Programs (PAPs)**, which can offer free or low-cost drugs directly from the company that makes them. Not all PAPs allow you to participate in their programs if you are eligible for Part D. Contact the company that manufactures your rare disease drug for more information. For help finding the maker of your medication and application forms, visit *Needy Meds* or the *Medicine Assistance Tool*.
- **Safety net providers**, which are pharmacies in certain government-funded hospitals and community

health centers (such as federally qualified health centers (FQHCs)) that provide healthcare for underserved populations and rural health clinics (RHCs). Some of these providers may waive co-pays for drugs covered by your Part D plan if you request assistance. Use this [tool](#) to find FQHCs by state.

- **National Charitable Co-pay Programs.** These programs provide direct payment for co-pays, co-insurance, and deductibles, and some premium assistance. You can find programs based on diagnosis on [Needy Meds](#) or visit these program websites:

- » [Co-Pay Relief](#) 866-512-3861
- » [CancerCare](#) 866-55-COPAY
- » [Good Days](#) 877-968-7233
- » [Healthwell Foundation](#)
800-675-8416
- » [National Organization for Rare Disorders](#) 800-999-6673
- » [Patient Advocate Foundation](#)
800-532-5274
- » [Patient Access Network Foundation](#) 866-316-7263
- » [The Assistance Fund](#)
855-845-3663

Learn more

[State Pharmaceutical Assistance Program chart](#)

[State Pharmaceutical Assistance Programs \(ncsl.org\)](#)

[How to Access and Maintain Social Security Benefits](#)

[Glossary of programs that help pay Medicare costs](#)



RARE TIP

Take Advantage of ABLE Savings Accounts

An ABLE account is a tax-advantaged savings account available to individuals diagnosed with significant disabilities before the age 26. Contributions can be made to this account to meet the qualified disability expenses of the owner, or designated beneficiary. These expenses can include costs related to accessible housing and transportation, personal assistance services, assistive technology, and health care not covered by insurance, Medicaid or Medicare.



“ABLE accounts are underutilized in the rare disease community, in part because people don’t realize that the funds can be used for much more than the direct costs associated with the disease or disability.”

– MINDY CAMERON,
RARE DISEASE ADVOCACY
CONSULTANT

Learn More

[SSA spotlight on Achieving a Better Life Experience \(ABLE\) accounts](#)

Know Your Rights Concerning Applications and Claims

The appeals process for government benefits programs can be exhaustingly complicated, slow, and frustrating. Whether you're appealing an application or claim, whenever feasible you should seek professional help from legal counsel, a patient advocacy organization, or someone who's "been there and done that" successfully. But if you're on your own, here is some basic information on how the appeals process works, what you should know, and how to find the resources and people you need.

What Happens During an Appeal?

As noted earlier, appeals to the SSA to qualify for SSDI or SSI disability benefits are sent to a state disability agency, usually called Disability Determination Services (DDS). The DDS process typically has four stages of review:

1. Your initial application is reviewed by the DDS.
2. If DDS denies your request (which happens about 65% of the time), you can ask for a different DDS claims examiner to review your file. This process is called reconsideration.
3. If you're denied after reconsideration, you can request a hearing in front of an administrative law judge, a process handled by the Social Security Office of Hearings Operations (OHO).
4. If your request for a hearing is dismissed or you disagree with your hearing decision, you may ask the [SSA Appeals Council](#) to review the decision.

If DDS finds that you qualify for disability benefits during the first two stages of review, you will automatically begin receiving payments.



7 things to Know about the Appeal Process and Your Rights

- You have 60 days from the date you receive the notice of a decision to ask for an appeal.
- If you decide you want a lawyer or someone familiar with SSA programs to be your representative, this person cannot charge or collect a fee from you without first getting written approval from the SSA. One way to locate an attorney is to [use this referral service](#).
- If you receive a decision that you no longer have a qualifying disability, you will need to file a Request for Reconsideration – Disability Cessation Right to Appeal (SSA-789). This form is not online, but you can download it at www.ssa.gov/forms.
- Be aware that the hearing process may be lengthy, so it is critical to keep SSA informed if your contact information changes.
- If a claim is denied, make sure your provider is using the right ICD code for the services.
- You can keep track of your claim by opening a [my Social Security account](#).
- If you must travel more than 75 miles from your home or office to attend your hearing, SSA can pay certain costs. An Administrative Law Judge may also approve payment of similar travel expenses for your representative and any witnesses.



RARE TIP

ICD Codes

Some claims for rare diseases are denied because the provider did not use the right *International Classification of Diseases* (ICD) code, which is used to document a person's medical condition and determines reimbursement. If a claim is denied, check your billing statement and look up the code for your diagnosis on the National Center for Health Statistics [ICD-10-CM browser tool](#).

Patient advocacy groups are working on getting ICD codes for gene variants that cause phenotypes but do not yet have an ICD code. Check regularly to see if your gene has received an ICD code, since the list changes over time.

Learn more
[ICD Code Roadmap](#)



Rare Intel

N. Leah Fink, an attorney specializing in SSI and SSDI, shares her insights and counsel about the appeals process.

- Although the SSA initially denies about two of every three disability applications, don't get discouraged. It's just an expected hurdle that needs to be cleared to get a hearing before an Administrative Law Judge.
- The hearing is where you can explain to the judge that you can't do any type of work on a full-time basis because of your physical and mental limitations, which is why it's important to talk about your mental health in your SSDI application.

"The hearings are where most SSDI cases are won."

Learn More

Medicare Rights Center

Appealing an SSA Disability Decision

SSA Hearings and Appeals

Best Practices for Claimants' Representatives



RARE TIP

"It's important to know your rights and stand your ground. I know that's not easy for some people but remember that Social Security exists to serve people like you."



– AUSTIN LECLAIRE, PATIENT ADVOCATE

Rare Patient Story

Mary Morlino, Global Genes' RARE Concierge Patient Services Manager, offers tips on Medicare and disability gleaned from her personal experience navigating life with a rare disease.

- *Mary Morlino's Story*
- *Mary's Medicare Tips*
- *Disability Work Credits*
- *Working While You're On Disability*

For more support related to financial advocacy and other challenges faced by people living with rare diseases, complete this confidential *form for RARE Concierge Patient Services*.

Glossary

ABLE Account: A tax-advantaged savings account for people with disabilities. It protects and can help you grow financial resources.

Medicaid: A joint federal-state program that provides healthcare coverage for low-income people. Medicaid programs vary by state.

Medicare: A federally administered health insurance program for people who are 65 years of age or older or who qualify for Social Security Disability Insurance (SSDI).

Medicare Advantage (also known as Medicare Part C): A type of Medicare plan sold by a private insurer that offers hospital, medical, and, in most cases, prescription drug benefits.

Medicare Part A: Hospital insurance available for free for most people who are aged 65 years or older and those who qualify based on their ability to meet the SSA's definition of disability.

Medicare Part B: A plan that can be purchased by a Medicare beneficiary to cover medical expenses, such as doctor visits. For most people, the federal government pays for 75 percent of the cost of Part B.

Medicare Part D: A plan that can be purchased by a Medicare beneficiary to cover prescription drug expenses.

Medicare Supplement Insurance (Medigap): An insurance policy you can buy to help lower your share of certain costs for Medicare Part A and Part B services.

Social Security Administration: The federal agency that oversees Social Security retirement benefits, Supplemental Security Income and Social Security Disability Insurance.

Social Security Disability Insurance: A program within Social Security that provides monthly payments to people who meet requirements for length of work history and the federal definition of disability.

Supplemental Security Income (SSI): An SSA benefit program for some low-income retirees, working-age adults with limited resources who are blind or have a disability that prevents employment, and to children who are blind or have a disability.

Find more definitions in this
Medicare Glossary

Resources

Global Genes Toolkits

Understanding and Navigating Medicaid

Navigating Health Insurance

How to Access and Maintain Social Security Benefits

Other Resources

Medicare Glossary

Medicare Cost-Saving Programs

Medicareresources.org

State Health Insurance Assistance Programs

SSA Hearings and Appeals

ICD Code Roadmap

ICD-10-CM browser tool

Medicare Rights Center

Patient Advocate Foundation

Center for Medicare Advocacy

FDA searchable database of approved orphan drugs

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