



DECEMBER 2022

Understanding Career Opportunities and Employment Benefits



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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Introduction

Being able to work means so much more than the money we earn. Having a career can give our lives a sense of purposeful accomplishment while providing countless opportunities to learn, grow, and develop fulfilling relationships. The employment benefits you receive, in addition to your salary, can also provide you and your family with an important financial safety net.

But finding the right career (and employer) can be especially complicated and challenging for adults with rare diseases. This toolkit is designed to help you understand and evaluate the work-related options and employment benefits that will best suit your abilities, healthcare needs and financial resources, whether you:

- Have recently been diagnosed with a rare disease
- Are looking for a new job while living with a rare disease
- Are returning to work after a health crisis or disease progression
- Receive disability payments but would like to work without losing this benefit
- Or already have a career but are not taking full advantage of employer benefits programs



The toolkit also features tips and advice from rare disease patients and experts to help you make smart decisions and avoid common and costly mistakes.

Consider this a high-level guidebook for making the most of the many opportunities for part-time, full-time, and remote work available to people living with a rare disease. If you want to dig deeper into any of the topics, we provide links to many reliable sources. And, of course, Global Genes is always here to help you in any way we can. To contact us, [fill out our confidential Patient Services form](#). Within 2-3 business days, you will receive a personalized response that will include information, resources, and connections that address your specific needs.

Finding the Job That's Right for You

Technology and changing attitudes about how and where we work have opened the door to countless employment opportunities for people living with rare diseases. For example, more and more employees are now able to work remotely, and employers are doing more to accommodate their disabled workforce.

Although there's good reason to be optimistic about your prospects, you also need to be clear-eyed about what to expect in the job market. Consider:

- While 17% of the global population lives with some form of disability, the *World Economic Forum* reports that employed people with disabilities often experience unequal hiring and promotion standards, unequal pay for equal work, and occupational segregation.
- Although 90% of companies claim to prioritize diversity, only 4% of businesses are focused on making offerings inclusive of disability.¹

To advocate for your needs, you should consider such factors as:

- The unique contributions you have to offer a potential employer.
- How much time you can work each week without adversely affecting your health.
- Your options for working remotely and/or part-time.
- What accommodations you will need.
- What to consider when evaluating your benefits package, which, for many adults with rare diseases, can be even more important than salary.
- How your employment will impact other income you receive from government benefits programs (Medicare, Medicaid, Social Security Disability Insurance, Supplemental Security Income).



RARE TIP

“Knowing who you want to serve, help, work with, etc., benefits you in several ways. It helps you market yourself and your services, and it helps the people in your life refer business or job opportunities to you. Furthermore, knowing who you’d like to work with, or for, will help you identify organizations where you might find these opportunities, and even help you in the interview process, as you’ll be able to talk authentically about your desire to work for the company.”



– JOAN FRIEDLANDER, AUTHOR OF *BUSINESS FROM BED: THE 6-STEP COMEBACK PLAN TO GET YOURSELF WORKING AGAIN AFTER A HEALTH CRISIS*

Your personal ambitions, needs, and abilities are always of utmost importance. Before you contact any employer, ask yourself:

- What do I want from work besides having a source of income?
- What type of work will give me the most fulfillment?
- Do I want to spend more time with other people or work alone?
- What are my strengths and limitations?
- Do I have any special skill sets or talents I want to cultivate?
- What do I offer that would make me a great employee?

No matter what your skills, interests or impairments, your employment opportunities will continue to grow as you gain experience. Whether you’re entering or re-entering the workforce, looking for a new career, or want more from your current job, the ideas, tips, and resources in this toolkit can help put you on a path to a meaningful and rewarding career.



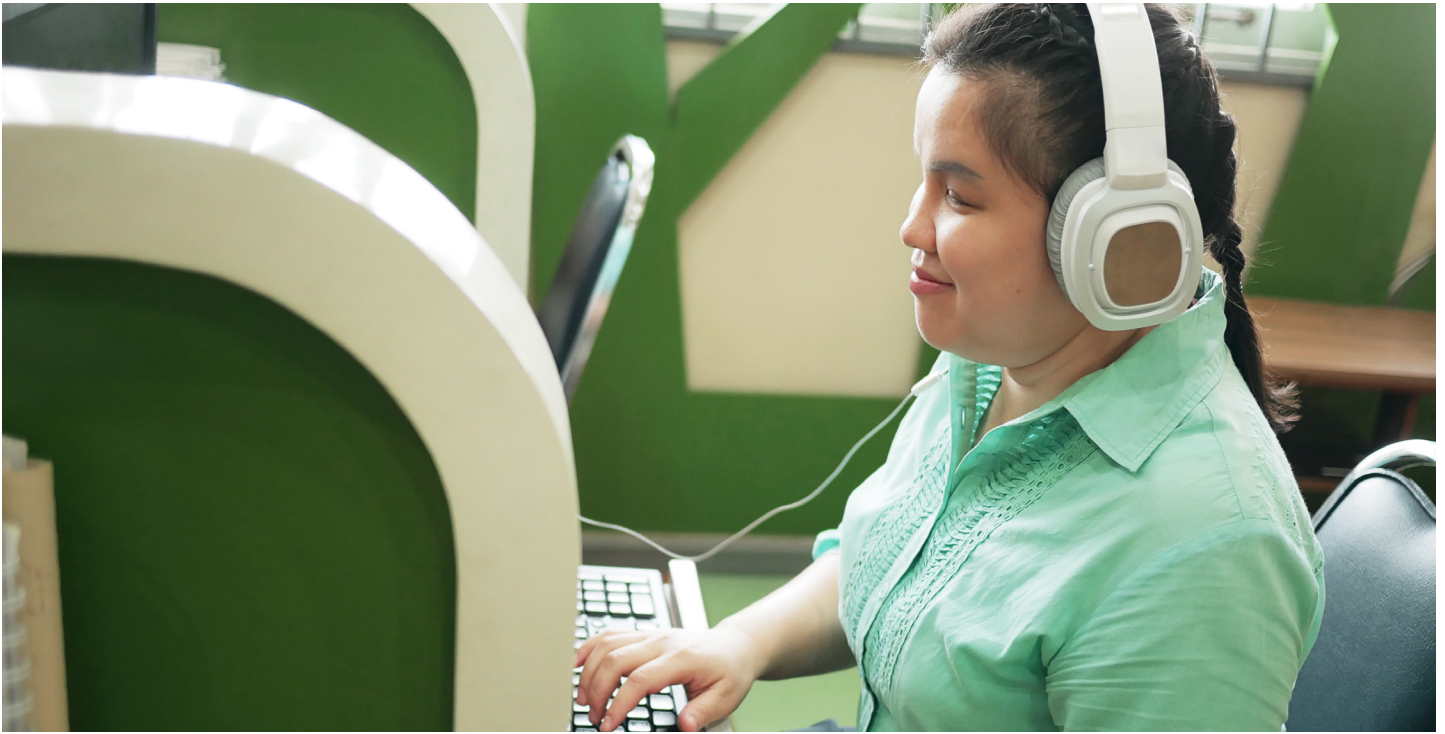
RARE TIP

According to the U.S. Census Bureau, between 2019 and 2021 *the number of people who primarily worked from home nearly tripled* and now represent roughly 18% of the workforce (more than 27 million people)².



10 Things You Should Know about Finding a Job

1. Depending on the severity and type of your rare disease, employment benefits could be the most important factor in choosing an employer. (Note: This will be covered in more detail in the Benefits section).
2. For many companies, a commitment to diversity applies primarily to gender and racial inequalities. When evaluating job offers, consider finding out what percentage of the workforce has a disability and request to speak to one of these employees.
3. Whether you're applying for a job or already have one, ask for what you need. *The Americans with Disabilities Act (ADA)* of 1990 requires employers to provide "reasonable accommodations" to qualified job applicants or employees.
4. If you receive Social Security disability benefits and would like to work, check out the free support services available from the Social Security Administration's *Ticket to Work program*.
5. Take advantage of disability advocacy and support groups that offer job placement assistance. For example, the *Job Accommodation Network* provides free information and consulting services for individuals with all types of medical conditions, including one-on-one consultation on job accommodation solutions.
6. Networking events or forums offering jobs for people with disabilities can help you find companies with excellent facilities and support systems already in place. For example, *Chronically Capable* provides information about flexible jobs and includes a professional community where you can find events, resources, and a 24/7 private forum.
7. If you're a young adult, take advantage of *The Workforce Recruitment Program*, which connects federal and private-sector employers nationwide with highly motivated college students and recent graduates with disabilities seeking summer or permanent jobs.
8. Self-employment is another option to consider if you are able to access *healthcare benefits* and *disability insurance*. A *Gallup survey* found that more than 28% of workers were self-employed at some point during a given week, and 14% said being an independent contractor was their primary job³.
9. Honesty and confidence are two of your most valuable attributes. Employers hire people whom they feel are trustworthy and capable of doing whatever it takes to contribute to a company's success.
10. The path to the "perfect job" is rarely a straight line. It's good to be flexible and willing to try different types of jobs, knowing that many of your skills can be applicable in many different situations and industries.



Social Security's Ticket to Work Program

This program supports career development for people ages 18 through 64 who receive Social Security disability benefits and want to work. If you meet the eligibility requirements, you can use this *Find Help tool* to contact providers who offer free support services such as job coaching, job counseling, training, benefits counseling, and job placement.

These services include Employment Networks, Workforce Employment Networks, State Vocational Rehabilitation (VR) Agencies, Work Incentives Planning & Assistance (WIPA) Projects, and Protection and Advocacy for Beneficiaries of Social Security (PABSS).



RARE TIP

You're not alone if you're worried about being stigmatized by prospective employers because of your disability. Such fears are common and, even in well-intentioned work environments, well-founded. According to *Jonathan Kaufman*, a career coach and psychotherapist who focuses on disability issues and has cerebral palsy, "Even if you're highly qualified for a job, you might be self-conscious about your disability."

Tips for Your Job Search

In *this video*, Dakota Fisher-Vance, Global Patient Advocacy Associate Director for BioCryst Pharmaceuticals, shares job search advice for people living with a rare disease, drawn from her personal experience. Dakota is also the co-founder of Young Adult Cancer Connection.

“What I hated most about my disease was that it made me miss the first three years of my career. At first, I felt there was no point in trying. But I found that as long as you can translate whatever experience you have into what you want to do, you’re going to be ok.”

“If you are just recovering from a health setback, starting part-time work may be the way to go. I know that if I had taken on a full-time job right away, I probably would have concluded that I wasn’t meant to work. There’s no shame in first dipping your toes in the water, and a part-time job can help you figure out what would be best for you.”



RARE TIP

If you want to test the waters to see if you have the physical capacity to work at this time or determine potential workplace accommodation needs, or if you want to explore a new path, consider starting with a volunteer job.

Learn More

[*Job Accommodation Network*](#)

[*Workforce Recruitment Program*](#)

[*Chronically Capable*](#)

[*Social Security Ticket to Work Program: Discover Who's Hiring Now*](#)

[*Social Security Ticket to Work Program: Find Help*](#)

[*Tips to Find Jobs for People with Disabilities*](#)

Know Your Rights: Job Accommodations and Disclosing Your Disease

Whatever limitations your condition may create, if you're qualified to perform the essential functions of a job, you have a right to equal treatment regarding employment opportunities. You also have a right to decide whether or not you disclose information about a disability.

Here are things you should know about your rights, employers' obligations, and how to get the help you need to advance your career.

Requesting Accommodations

Perhaps the most important thing to remember about your rights is that your employer has a legal obligation to accommodate your specific needs associated with your disability. As noted earlier, the *Americans with Disabilities Act* (ADA) requires employers with 15 or more employees to provide "reasonable accommodations" to all qualified job applicants or current employees. According to the *ADA National Network*:

"A reasonable accommodation is any change to either the application or hiring process; the job; the way the job is done; or the work environment that allows a qualified person with a disability to perform the essential functions of his or her job and enjoy equal employment opportunities. Accommodations are considered "reasonable" if they do not create an undue hardship or a direct threat."

Examples of accommodations usually considered reasonable include:

- Allowing a flexible work schedule
- Providing reserved parking
- Improving accessibility in a work area (for example, wider hallways for a wheelchair)
- Providing specialized equipment or software such as visual or auditory aids

Be aware of exactly what accommodations you will need and discuss them with your prospective or current employer. For example, if you need to have several infusions each month, make sure it's ok for you to work remotely. Or perhaps you need to start work an hour later or have extra time at lunch to rest.

All participants involved in these talks must agree to maintain confidentiality.

7 Keys to Success When Requesting Accommodations

1. Before approaching your employer, decide which accommodations are realistic and would be most effective in resolving the functional limitation(s) caused by the disability.
2. Research as much as you can about your legal protections afforded by the [ADA](#) so you know your rights and can help navigate conversations with your employer. [The Job Accommodation Network](#) has a website page that provides a practical guide to requesting and negotiating reasonable accommodation under the ADA.
3. If you are currently employed, ask for accommodations as soon as you are aware you need them, so your employer has time to make changes before any barriers interfere with your performance.
4. If you're concerned about privacy, consider submitting your request through your human resources (HR) department, which has protocols for dealing with such requests. But if you're comfortable sharing your needs with your direct supervisor, you can keep this person in the loop. Initially, you can request reasonable accommodations (such as time off for monthly infusions) without explicitly declaring your diagnosis.
5. The goals of your accommodation discussion are to help your employer understand what barriers you are experiencing, why it is a problem, and what needs to be done to address it.
6. Document the dates and other notes about your requests, including the company's responses and commitments, especially if you have concerns that your employer may not be amenable to the changes you proposed.
7. When making a request, emphasize how your accommodations will empower you to be a more efficient and productive employee.



RARE TIP

When requesting accommodations, be as specific as possible. Dan Ryan, author of the *Job Search Handbook for People with Disabilities*, says that knowing what technologies would help you excel on the job can make you more attractive to prospective employers.

Learn More

[ADA National Network](#)

[Job Accommodation Network](#)

[How To Ask for Accommodations at Work](#)

[JAN Searchable Online Accommodation Resource \(SOAR\)](#)

Disability Disclosure

Whether to disclose your disability and medical history to prospective or current employers is a personal decision. Some people are open and forthright about sharing all their life experiences. Others consider this strictly a private matter. And many are still on the fence, not yet sure what would be best for them in their particular workplace situation.

Whatever your preferences, the first thing every job seeker with disabilities should know is that the ADA makes it illegal for employers to ask job candidates about their medical history during a job interview.

Although every person and situation is unique, here is some general information about what to consider in deciding whether, what, when, and how to disclose your health information.

Disclosure Pros and Cons

Most people with disabilities have first-hand knowledge of why someone would be hesitant to disclose their disability to job interviewers, coworkers, or managers. Unconscious bias and discrimination are prevalent in any social setting, including the workplace, and it's hurtful to feel stigmatized as "different." Workers also don't want to be perceived as less capable or unable to meet the same performance standards as their coworkers.

On the positive side, disability disclosure is essential if, as previously noted, you want to receive reasonable accommodations necessary to effectively perform your job functions. It also can be helpful when applying to companies or organizations with robust affirmative action programs focused on hiring, retaining, and advancing qualified workers or in patient-centric fields.

Also keep in mind that disclosure is not an all or nothing proposition. For example, if you want your colleagues or supervisor to understand your frequent bathroom visits during team meetings or why you need to be hospitalized, you can tell them the difficulties you encounter because of your medical condition without mentioning your specific symptoms or challenges.

Being secretive about a disability can make some people feel shameful or that they have something to hide, which can drain them mentally and emotionally. One way to ease this distress is to disclose your condition only to close friends at work or a supervisor whom you can trust. If you don't want others to know, ask those you tell to keep the information private.



5 Things to Know about Disclosing Your Disability

1. You are not required to notify an employer of your disability on a job application or during an interview, and not doing so will not affect any future requests for accommodations.
2. If your disability does not prohibit you from performing essential job functions, there's no reason to disclose it before you get an offer. This will eliminate the possibility of unconscious bias and ensure the employer focuses solely on your qualifications.
3. If you are requesting an accommodation during the hiring process, you only need to tell the employer that you have an *ADA-protected disability* and what you are asking for.
4. Don't be surprised if you see a disability question on a job application. Some companies are required to collect and submit disability survey information to the Equal Employment Opportunity Commission. The form should say that survey participation is voluntary and you don't have to answer any questions.
5. Although the decision on when and how much to disclose is up to you, keep in mind that it's best to do so before it causes performance problems.



RARE TIP

Rare Tip: Social Media
When thinking about disclosure, remember that whatever you are sharing about your disability on social media will likely be seen by employers who are considering hiring you.

How Do You Decide When and How Much to Disclose?

Find out in *this video* conversation with Dakota Fasher-Vance, Global Patient Advocacy Associate Director for BioCryst Pharmaceuticals and co-founder of Young Adult Cancer Connection.

“The question I suggest asking is, ‘What is the value to me from sharing that I am a rare disease patient?’ For some people, sharing that part of themselves is essential to letting an employer know who they are and what they have to offer a company.”

Learn more

How To Disclose a Disability to Your Employer



Working While Receiving Social Security Disability Benefits

While everyone can use the money earned from a new job, keep in mind that this can also reduce the payments you receive from Social Security.

For example, if you qualify for Social Security's *Supplemental Security Income (SSI) program*, your cash benefits can be suspended if your earnings exceed "substantial levels." In 2022, average earnings of \$1,350 or more per month were usually considered substantial.

The good news is that Social Security also has special rules, called work incentives, that enable people receiving disability benefits or SSI payments to work and still receive monthly payments.

Trial Work Period (TWP) incentives

- TWP helps beneficiaries enter, re-enter, or continue in employment by protecting their eligibility for cash payments and/or health care coverage until they achieve self-supporting employment.
- There are no limits on what you can earn for the first nine months of your TWP -- you will receive your full

Social Security disability benefits as long as you report your work and continue to have a disability.

- The TWP continues until you have used nine cumulative trial work months within a 60-month period. In 2022, a trial work month was any month in which your total earnings exceeded \$970.
- After your trial work period ends, you can work for 36 months and still receive benefits for all months during which your earnings weren't "substantial."

Work Incentives Planning and Assistance Projects (WIPA)

- This free service is part of Social Security's *Ticket to Work program* and provides benefits counseling to eligible Social Security and SSI beneficiaries who have a disability to help them make informed choices about work.
- WIPA projects are staffed by Community Work Incentive Coordinators who provide in-depth counseling and analysis on how

work and earnings may impact your SSI, Social Security Disability Insurance (SSDI), health care, and other public benefits.

Other Ticket to Work employment team service providers and programs include:

- *Employment Networks (ENs)*, which are private or public organizations that can help with career counseling and assistance with job placement, including helping you understand how benefits may be affected by work. This also includes employment networks that are part of a state's public workforce system commonly referred to as *Workforce ENs*.
- *Vocational Rehabilitation* agencies usually work with individuals who need more significant services. In some states, their services may include intensive training, education and rehabilitation. These agencies may also provide career counseling, job placement assistance, and counseling on the effect that working may have on Social Security disability benefits.
- *Protection and Advocacy for Beneficiaries of Social Security* organizations, which represent eligible Social Security beneficiaries in removing barriers to successful employment and can help you understand your employment rights.



Learn more

How to Access and Maintain Social Security Benefits

Working While Disabled: How SSA Can Help

Choose Work: SSA Ticket to Work Program

Considering Company Culture

Workload pressures or feeling uncomfortable in a work environment can make living with a rare health condition even more stressful. A [Psychology Today article](#) cited studies that showed people with rare diseases need better social support, and that the lack of support may explain why adults with rare disorders report significantly greater anxiety and depression, and poorer quality of life, than the general public and even people with more common disorders.⁴

That's why it's especially important to pay close attention to the company's culture when researching a potential employer or deciding whether to accept a job offer. Here are some questions you might want to ask to determine whether an organization walks the talk when it comes to being inclusive and welcoming for people with disabilities.

- Does the company have programs or work groups for people with disabilities?
- Are its leaders and workers authentic, understanding, empathetic, and supportive?

- Is it involved with any groups or organizations to improve access and inclusivity in the workforce?
- How do employees feel about working there?

If possible, ask to speak to disabled employees or potential colleagues about their opinions of the company and whether they feel they get enough support.



RARE TIP

Chronically Capable is a good resource to find companies that care about helping you be successful. Its platform has a wide range of full-time, part-time, and contract roles from leading companies across the globe who are dedicated to supporting the rare disease community.

⁴ People With Rare Diseases Need Better Social Support. Kathleen R. Bogart Ph.D. *Psychology Today*, October 14, 2020.

Leveraging Your Experiences to Help Others

The hardships and pain of living with a rare disease can often be debilitating. But if you're looking for a job, familiarity with the challenges of having such a condition does have an upside: your life experiences and expertise are highly valued in a large and growing marketplace.

Hundreds of non-profit patient support and advocacy organizations work tirelessly to help the more than 30 million Americans living with rare diseases. Thousands of healthcare providers, pharmaceutical companies, and other businesses and organizations are also committed to improving health and workplace opportunities for those living with rare disease. All are interested in gaining deeper insights and ideas about what they can do to make more meaningful contributions to the rare disease community.

As you consider your work options, ask yourself this: Do I have the knowledge, skills, and/or communication capabilities that could benefit these organizations? If so, you may want to consider a career that is a win-win for you and your employer. Few things in life are as rewarding as doing work that will better the lives of others.

Rare Intel

A recent [Indeed.com search](#) listed more than 2,000 rare disease jobs.

Learn more

[Rare Disease Patient Organizations](#)

[Rare Disease Job Search](#)



What You Should Know about Benefits

Finding the right benefits package is often as important to people living with a rare disease as finding the right job – with good reason. *According to a recent study*, medical issues resulting in high healthcare costs and time out of work are a leading cause of bankruptcy in the United States.

This section will provide a brief overview of employer-based health insurance and other benefits as well as counsel and tips specific to people with rare diseases. It is not, however, meant to be comprehensive. Since there's an abundance of great information about how to assess your benefit options, we strongly encourage you to thoroughly review all the resources included here to inform and guide your decisions. Two good starting points are the Global Genes toolkit, *Navigating Health Insurance*, and the Patient Advocate Foundation's *Understanding Workplace Benefits*.

Primer on Workplace Benefits

In *this video*, you'll meet 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 or *request help online*.

Health Insurance

The Affordable Care Act (ACA) requires large employers with more than 50 full-time employees (or full-time equivalent employees) to offer medical coverage. The ACA also has the Small Business Health Options Program (SHOP) that enables companies with fewer than 50 employees to cost-effectively offer this coverage.

Depending on the employer, workers might have a wide array of options that include different types of plans and programs with varying levels of coverage, access to providers, and employee costs. Yes, deciding what will be best for you is complicated and can take longer than you'd like. But it's worth the effort, especially for people with rare diseases who require specialized care, expensive medications, and/or frequent or long hospitalizations.

In fact, for many, choosing the right health plan can be even more important than the salary and bonuses you receive. Here is some basic information you should know to get started.



Rare Insights on Employment Benefits

In *this video*, Dakota Fasher-Vance, Global Patient Advocacy Associate Director for BioCryst Pharmaceuticals and co-founder of Young Adult Cancer Connection, shares what she has learned about getting the most from employment benefits when you're living with a rare disease.

"The thing to remember about health plans is that each year everything can change. New enrollment periods are my least favorite time because any changes to my plan can be scary. Although most companies try to maintain consistency, if you do have any surprises be sure to go over them with your HR manager and talk about how they might impact any health emergencies you might have."

Types of Health Insurance Benefits

- **Comprehensive Group Insurance Plans** (also known as 'Major Medical' plans), which cover a wide range of medical expenses, including physician visits, in-patient and out-patient treatment, and pre- and post-hospitalization costs.
- **Supplemental Health Offerings**, which is optional insurance coverage you pay for yourself and can help reduce the financial impact of a serious accident, illness, or care not covered by the health plan.

- **Medical Savings Options**, including tax-free deduction programs such as Flexible Spending Accounts (FSAs) and Health Savings Accounts (HSAs).
- **Health & Wellness Programs**

Common Comprehensive Insurance Plans

- Preferred Provider Organization (PPO) plans – these can be attractive to people with rare diseases because they do not require referrals to see a specialist and allow out-of-network care, although this usually means higher Out-of-Pocket (OOP) costs.
- Health Maintenance Organization (HMO) plans – these require that 1) care is coordinated through a primary care provider, and 2) you must get a referral to see other health care professionals except in an emergency. They also typically are less expensive than PPOs but do not cover the costs of care received outside of the HMO's network.
- Point of Service (POS) plans – these are a hybrid of the PPO and HMO models since they require coordination through a primary care provider and require referrals but also allow the use of out-of-network providers at an additional cost.
- High Deductible Health Plans (HDHP) – these have lower premiums but higher deductibles than traditional health plans. You would be responsible for most healthcare costs (except

for preventive services) until you meet the deductible but are still required to pay co-pays and/or co-insurance for medical services and prescriptions.

Formularies and Drug Tiers

Since many people with rare diseases take multiple and/or highly expensive medications, it's critically important to see if the medicines you need are included on a health plan's list of covered drugs, called a formulary. If it's not in the formulary, the insurance company will not pay any of its costs. Also be aware that drugs can be removed or added to the formulary at any time, and coverage levels also can change throughout the year.

The plan formulary typically sorts medications into 4 to 5 tiers, which determines how much you have to pay for them. Higher tiers (called "non-preferred" groups) have higher costs. Specialty drugs are the most expensive, and you may have to try other medication options before the plan will cover your drugs.

Cost Considerations and Savings Opportunities

For most employer-based health plans, you still must pay a share of the costs for health services and prescription drugs. The most common expenses are:

- **Premiums**, which are the monthly fee you pay for coverage. Keep in mind that plans with lower premiums will likely require you to pay more in deductibles and co-payments when needing medical services.

- **Deductibles**, which is the out-of-pocket amount you pay for your medical care before the insurer pays its share. Some healthcare plans cover the entire cost of certain preventive services.
- **Co-payments**, which are the fixed dollar amounts you pay for a specific service, procedure, or drug each time you receive care or fill a prescription.
- **Co-insurance**, which is a fixed percentage of the cost of all services and prescription drugs you are required to pay. Some insurers use co-insurance rather than co-payments, while others use a combination of the two.
- **Out-of-Pocket Maximum**, which is the most you would have to pay for covered services in a plan year. After you spend this amount on deductibles, co-payments, and co-insurance for in-network care and services, your health plan pays 100% of the costs of covered benefits.

Coverage if You Lose Health Benefits

Losing a job and the health benefits that come with it can be terrifying for people living with rare diseases. So, it's a good idea to learn a bit about the *Consolidated Omnibus Budget Reconciliation Act (COBRA)*, which gives workers and their families who lose their health benefits the right to choose to continue group health benefits provided by their group health plan for limited periods of time under certain circumstances such as voluntary or

involuntary job loss, reduction in the hours worked, transition between jobs, death, divorce, and other life events. COBRA can be expensive. Qualified individuals may be required to pay the entire premium for coverage up to 102% of the cost to the plan. It also has strict enrollment deadlines, and only lasts for a certain period of time. But it's reassuring to know it's there as an option.

Flexible Spending Accounts (FSAs) and Health Savings Accounts (HSAs)

Cafeteria plans give employees and their spouses and dependents access to plans that offer tax and savings benefits. Here are the two most popular health-related plans that use pre-tax funds deducted from your paycheck to pay for services while reducing your overall taxable income.

Flexible Spending Accounts can be used to pay for co-payments, deductibles, over-the-counter drugs, medical items and other out-of-pocket medical and dental expenses. Both you and your employer can contribute pretax dollars into your FSA account. There's an annual limit to the amount of contributions that can be made, and this money must be used within the plan year.

Health Savings Accounts are similar to FSAs but are only available if you are enrolled in a high deductible plan. Unlike FSAs, the contributions from you and your employer can carry over from one year to the next.

10 Rare Tips for Evaluating Healthcare Benefits

1. Every insurance plan has a list of benefits called a Summary of Benefits and Coverage, which you can use for side-by-side comparisons. Take the time to carefully review your options and don't be hesitant to ask a lot of questions.
2. Check to see if the doctors, drugs, tests, and/or medical facilities you want to use are included in your employers' health plan. If not, see if the plan allows you to use providers outside of its network and how much this will cost you.
3. Compare which tiers your medications fall into on the different plans you are considering and choose the one that maximizes your benefits.
4. If you belong to a support group for your disease, ask its members about their experiences with your employer's health insurance plan (or plans) as well as other insurers they like or dislike.
5. A plan with a low premium is not necessarily the least expensive -- its terms regarding deductibles, co-payments, etc. could mean you will pay significantly more during the year for your care.
6. When evaluating costs, always consider whether you will be protected from financial disaster if a worst-case health scenario occurs.
7. Reach out directly to pharmaceutical companies. Some pharmaceutical companies have established programs that can help with getting access to specific rare disease medications you are currently on or may need in the future. They can also inform you on which insurers' plans cover these medications.
8. Know your rights to appeal a denied claim. If your health insurance company doesn't pay its share of the costs for your care (or doesn't let you know in advance that it will not cover all or some of the expenses for the care you need), you have the right to request in writing to reconsider its decision. Your physician can help you do this.
9. Keep in mind that healthcare insurance is just one factor to consider as you evaluate the salary and benefits package you are offered. Get the complete picture – including paid time off, medical leave, disability insurance, life insurance, etc.
10. Use inadequate benefits as a negotiating tool. If you're not fully satisfied with the benefits package or consider it subpar, consider using this to negotiate a higher salary or increase your signing bonus.

Learn more

Navigating Health Insurance

Understanding Workplace Benefits

Finding a Health Plan With More Coverage

Disability Insurance

Some employer benefit packages may pay a portion of the premiums for short- and/or long-term disability insurance that provides you with income if you cannot work due to an accident or injury.

Short-term disability insurance

coverage generally lasts from 9 weeks up to one year if you meet medical requirements. Payments provide a set percentage (usually around 60%) of the wages you earned before you were disabled.

Long-term disability insurance also replaces some of your income (again, typically about 60% of your wages) for up to 5 years when you cannot work at all or only part-time because of a disability. These policies provide you with a daily benefit when you can no longer take care of yourself, whether living at home or in a skilled care facility or nursing home.

5 Things to Know about Long-term Disability Insurance

- Even if your employer provides this benefit and you have medical documentation that supports your inability to work, it doesn't guarantee you will be covered. These types of employer-provided policies have very specific eligibility requirements that include time limits for length of employment and exclusion of workers in certain positions. Under the Employee Retirement Income Security Act, you have the right to be provided with

all policy-related documents free of charge.

- Some plans have a pre-existing clause or look-back period. This can be crucial to determine before accepting a job.
- Also keep in mind that insurers can have different definitions of "disability." For example, a disability is usually defined as any type of physical or mental health condition that prevents you from performing tasks at your specific job. But some policies specify that, to be eligible, your condition must prevent you from performing *any* job.
- Expect to wait between 90 days and one year after leaving work before you receive your payments.
- Most Long-Term Disability (LTD) policies will require you to apply for Social Security Disability Insurance (SSDI) benefits. If you're approved for SSDI benefits, the insurance company will then look to offset your LTD disability benefits with your SSDI benefits. If you receive any past-due or retroactive Social Security Disability benefits, you may be expected to pay back any LTD benefits you received during that time period.

Questions to Ask Employers about Other Health-related Benefits

Paid Time Off (PTO)

- Do you have a separate policy for paid sick days or does PTO include sick days, vacation time, and personal time off?
- Can unused PTO carry over from one year to the next?
- Do you offer sick leave time for caregivers?
- What, if any, restrictions do you have for taking PTO days?

Life Insurance

- Does your life insurance policy include “living benefits,” which allow me to immediately use a portion of insurance to help pay medical bills or other expenses?
- What are the criteria for becoming eligible to receive this type of insurance?
- How would having this policy affect my eligibility for government benefits?
- Once I’m signed up, will it be easy for me to later increase my insurance coverage? Would this require additional medical information?



RARE TIP

Family Medical Leave Act

Remember, the Family Medical Leave Act (FMLA) entitles eligible employees to take unpaid, job-protected leave for specified family and medical reasons, including a serious health condition that makes the employee unable to perform the essential functions of his or her job.



Resources

Global Gene Toolkits

How to Access and Maintain Social Security Benefits

Navigating Health Insurance

Finding and Choosing a Job

Workforce Recruitment Program

Chronically Capable

Social Security Ticket to Work program

Social Security Ticket to Work Program: Discover Who's Hiring Now

Social Security Ticket to Work Program: Find Help

Tips to Find Jobs for People with Disabilities

ADA National Network

Rare Disease Patient Organizations

Rare Disease Job Search

Accommodations

Job Accommodation Network

How To Ask for Accommodations at Work

JAN Searchable Online Accommodation Resource (SOAR)

Disclosure

How To Disclose a Disability to Your Employer

Financial Considerations: Work Incentives

Trial Work Period (TWP) incentives

Work Incentives Planning and Assistance Projects (WIPA)

Benefits

Understanding Workplace Benefits

Finding a Health Plan With More Coverage

Other Resources

Working While Disabled: How SSA Can Help

Patient Advocate Foundation

The Americans with Disabilities Act (ADA)

Family Medical Leave Act (FMLA)

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