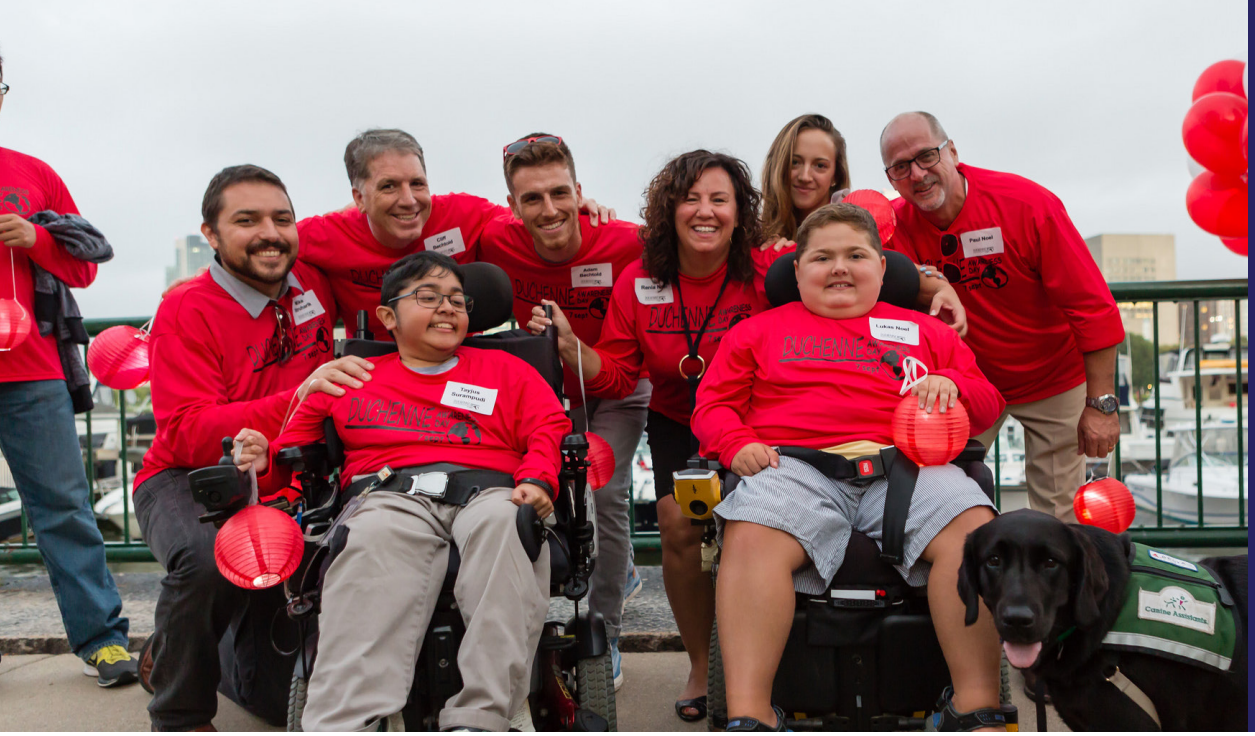
Health Insurance
FLIGHT PLAN

A Health Insurance Navigation Tool for Families Affected by Duchenne

Jett FOUNDATION

Empowering families.
Fighting Duchenne.


DUCHENNE
Canine Assistants

Taking flight together

Introduction

When caring for a child with Duchenne muscular dystrophy or when faced with a new Duchenne diagnosis, the decisions ahead can seem overwhelming - particularly when navigating health insurance and predicting your healthcare costs. Learning more about the resources available and how to navigate them is a foundational first step toward ensuring you have the most effective, appropriate, and comprehensive care for your situation.

This toolkit is designed to be a guide for maximizing your healthcare coverage and helping to ensure it meets your family's budget. It offers an overview of:

- The different types of health insurance available.
- Resources to help you understand different types of health coverage and related terms.
- The insurance eligibility profile for families impacted by Duchenne.
- How coverage works and what insurance may cover.
- How to calculate estimated costs.
- How to find help to cover costs that might not be covered by traditional health insurance plans.
- How to talk to insurers about insurance options and new treatments.

Health Insurance at a Glance

We know health insurance companies do not always understand the evolving needs of families affected by Duchenne. This makes navigating health insurance one more challenge that you may have to deal with. We hope this booklet will serve as a helpful tool for you to more easily navigate your options when it comes to health insurance.

Current law requires that all Americans (with a few exceptions) buy health insurance or be penalized. In 2017, that penalty could be 2.5 percent or more of your household income. Having health insurance is the best way to protect your family from high medical bills and avoid this penalty.

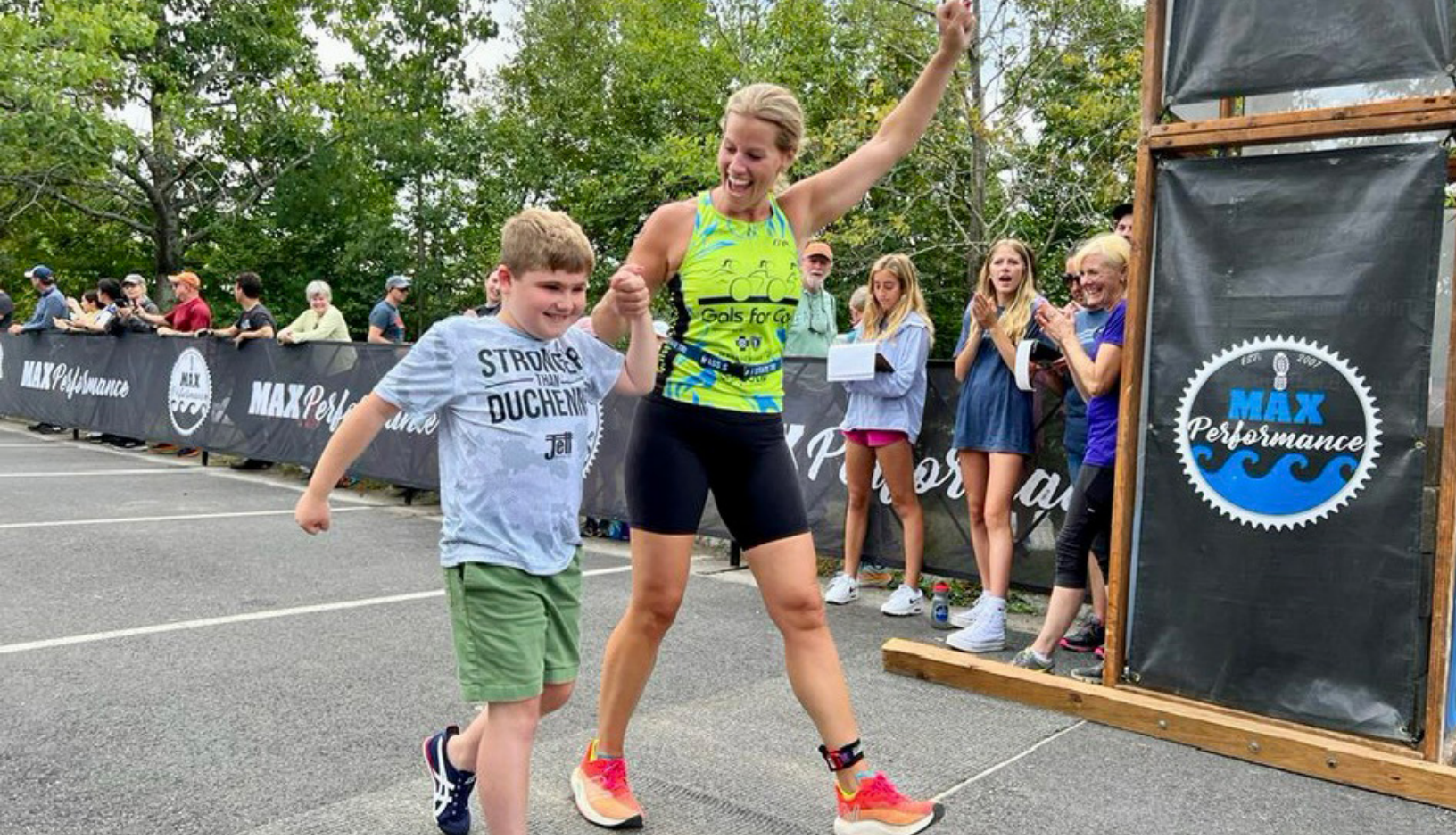
In the United States, there are **two major types** of health insurance:

- **Private health insurance** (also known as commercial health insurance), which is any health insurance plan privately purchased; often private health insurance is available through an employer
- **Government-funded health insurance**, which means insurance benefits provided through a government program such as Social Security, Medicare, Medicaid, or the Children's Health Insurance Program (CHIP)

For patients affected by Duchenne, it is helpful to have both private and government funded health insurance when possible. Having primary and secondary insurance may reduce out-of-pocket expenses.

TYPES OF HEALTH INSURANCE OPTIONS

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



About Private Health Insurance

There are many different types of private health insurance plans, also known as commercial health insurance. Each insurance plan is unique and offers different degrees of coverage. Your insurance will differ in premiums, out-of-pocket costs, out-of-network providers available, and other items. Call your insurer to learn more about what your insurance plan covers.

About Government-Funded Health Insurance

Determining the right health coverage for you and your family is important. If your child is living with Duchenne, you may have multiple insurance plans to choose from depending on where you live and your income/resource eligibility.

To find the insurance plan that works best for you and your family, some first questions to ask and answer are:

- Am I or my child eligible for government insurance?
- What insurance is offered through my employer?
- Is my or my spouse's insurance the better option for my family?

Coverage Options: Types of Private Health Insurance

Currently, private insurance plans fall into two categories: group coverage and individual coverage.

Group Plans

Group plans are provided by an employer, government agency, or worker's union while individual plans are negotiated between an individual policyholder and their insurer. Generally, group coverage is less expensive because the provider pays most of the premium for the user. If a group insurance plan is available to you, it will probably provide more comprehensive coverage than an individual plan. This is because group plans pool policies within an organization and ultimately reduce costs for insurers. Under these plans, your family is more likely to be covered for maternity care, well-baby services, preventive care, vision, and dental care. Keep in mind that the way your group plan is set up can make a difference. Group plans are either self-funded or fully insured. What this boils down to is who makes decisions regarding your coverage.

Self-Funded vs. Fully Insured Group Plans

In a self-funded plan your employer pays all medical costs and assumes all risk for its employees. Instead of paying a fat premium to a partner insurance company, self-funded plans are allowed to calculate a maximum annual risk and then keep that amount in reserve until it might be needed. For instance, if it's anticipated that a company's maximum risk is $1.5 million per year, the company is allowed to keep that money and even invest it. At the end of the year, anything that wasn't spent out of these funds goes back into the company coffers.

In what's called a fully insured plan, an employer partners with an insurance company and pays it a premium to manage its employees' health care claims. The premium amount is based on the company's maximum annual risk, and the insurer assumes all administrative and legal responsibilities related to claims management. If we use the same example as above, the $1.5 million potential risk is paid directly to the insurer, where it remains regardless of what is spent.

A key difference is that self-funded plans are exempt from state laws, which govern fully insured plans. This leaves your employer with considerable leeway in deciding what kind of coverage you get and whether an expensive procedure or treatment will be approved. If, for example, a benefit included in the plan ends up costing your employer more than they bargained for, they are freely allowed to rescind that benefit if they so choose. State mandates that dictate the breadth of coverage do not apply to these plans.

Individual Plans

Individual plans are sometimes referred to as single-payer plans. You purchase an insurance plan independently from the open market and your employer is not involved. Single-payer plans are generally much more expensive than group coverage and provide limited coverage. While some states created their own state insurance pools where consumers could buy coverage online, the vast majority sell Obamacare-approved plans through Healthcare.gov.

Before the passage of the new healthcare law, individuals who bought coverage on their own would usually have to purchase additional "riders" to cover specific conditions such as pregnancy. With the passage of the Patient Protection and Affordable Care Act (PPACA), however, all health plans are required to offer a minimum number of "essential benefits." The new essentials benefits offered by all healthcare plans in the post-Obamacare era include:

- Ambulatory patient services (outpatient care you get without being admitted to a hospital)
- Emergency services
- Hospitalization (like surgery and overnight stays)
- Pregnancy, maternity, and newborn care (both before and after birth)
- Mental health and substance use disorder services, including behavioral health treatment (this includes counseling and psychotherapy)
- Prescription drugs
- Rehabilitative and habilitative services and devices (services and devices to help people with injuries, disabilities, or chronic conditions gain or recover mental and physical skills)
- Laboratory services
- Preventive and wellness services and chronic disease management
- Pediatric services, including oral and vision care (but adult dental and vision coverage aren't essential health benefits)

On top of these essential benefits, Obamacare has broadened the scope of coverage for all Americans. Upon the passage of the PPACA, health insurers can no longer discriminate against individuals or families based on their prior medical conditions or "pre-existing conditions." In the past, someone who had cancer or diabetes would be barred from buying new coverage outside of state-sponsored, high-risk pools. But with the new law in place, everyone has access to the same health insurance plans regardless of their health.

Picking a Plan: What do you need to consider?

Are all of you or your child's needs covered? If yes, ask yourself the questions below before moving on:

1. PART OF THE MAJOR MEDICAL?

- Major medical coverage is comprehensive and long-term, and their policies last a year.
- Most major medical insurance plans offer an annual out-of-pocket spending limit that caps your expenses, even if someone on the plan needs a very expensive treatment or has a series of hospitalizations or medical emergencies.
- Major medical coverage typically include doctor's office visits, hospitalizations, medical supplies and services, prescription drugs and other healthcare expenses.
- The Affordable Care Act (Obamacare) mandates that major medical insurance covers certain preventive care services and meets the minimum essential coverage requirements.

2. ARE THE MEDICATIONS YOU OR YOUR CHILD NEED PART OF THE PHARMACY BENEFIT?

- Pharmacy benefits information includes a prescription drug list that a health insurance plan covers under its drug benefits policies. This list could be called the medical benefit formulary list or the drug list.

3. DO I NEED A REFERRAL TO SEE A SPECIALIST?

4. IS A PRE-AUTHORIZATION NECESSARY PRIOR TO ANY OF THE TREATMENTS MY CHILD OR I MAY NEED?

5. IF YOUR TREATMENT INVOLVES DRUGS, WILL YOU OR YOUR CHILD BE REQUIRED TO DO STEP THERAPY BEFORE YOU GET THE TREATMENT YOU WANT AND NEED?

It is important to be prepared that the policy you already have may require you to obtain preauthorization from the plan before moving forward with a treatment, deny coverage for a service or treatment, or may provide coverage that makes the care available, but unaffordable. Understanding your benefits, what they do and don't cover, is the best starting point to getting the best quality of care covered.

Listed are ways to get help with understanding your benefits:

- Review all of the information in your plan, even the annoyingly, small, nitty gritty print; and then make a detailed list of items that are unclear to you.
- Ask your human resources manager to assist you with the list of items that you are unclear about. If this person doesn't know the answers, ask them to contact the insurer on your behalf.
- Connect directly with the insurer's employee plan representative. To minimize confusion, ask this person if you can email her your questions and if she will answer them with an email.
- To determine your family's out-of-pocket costs in advance, ask your insurer to do a benefits investigation (BI).
- Request a benefit investigation when you need to know whether an item is covered under major medical benefits or under pharmacy benefits.
- Talk to another rare disease advocate. Even if this person has a different rare disease and a different insurance provider, they have likely dealt with similar health benefit issues of their own and those of other rare disease patients. They might have ideas or tips for working with insurers to ensure you or your child's needs are met.

Medical Equipment

Many individuals who live with Duchenne will use durable medical equipment (DME) and/or other medical supplies at one point in their life, and as you know the cost of these items can be significant.

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

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

A common and challenging issue for a patient who needs medical equipment and/or medical supplies is proving to the insurer the "necessity" for the item(s). Which is really code for, you are facing an uphill battle to convince the insurance company that the equipment you need is a medical necessity, and therefore, they should cover it.

Check your insurer's website for their DME and medical supplies benefits chart to see if the insurer currently carries all of the medical equipment your family needs. Don't be surprised to discover that some equipment is not being currently covered, and begin crafting a plan on how to obtain the equipment that doesn't appear to be covered that you or your child may need in the future.

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

Start the validation process with a prescription from your primary doctor for the medical equipment/supplies you need if at all possible. If you can't get a prescription, ask for a "justification statement" from the doctor, nurse practitioner, occupational therapist, chiropractor, other nontraditional medical professionals who treat you, including advocacy groups.

EXAMPLES OF MEDICAL EQUIPMENT INCLUDE:

- Power chairs
- Standers
- Portable commodes & shower chairs
- Medical scooters
- Walkers
- Blood and glucose monitors
- Oxygen
- Bi-pap machines
- Ventilators
- Cough Assists

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

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

Securing Government-Funded Health Coverage

You and your family may already have health insurance at the time of a Duchenne diagnosis. However, you may also be eligible for government programs to help pay for expenses not covered by your private health insurance.

The first step in becoming eligible for government assistance is receipt of an official verification of a Duchenne diagnosis by the U.S. Social Security Administration. In most states, if a person with Duchenne is eligible for Supplemental Security Income (SSI) benefits, he or she is automatically eligible for Medicaid.

Supplemental Security Income (SSI)

SSI makes monthly payments to people who have limited income (money received) and resources (owned items/property), and who are:

- Age 65 or older;
- Blind; or
- Disabled

Income includes money you receive in the form of wages from an employer, Social Security benefits, or pension payments. Income also includes such things as food and shelter. The amount of income you can receive each month and still be eligible for SSI depends partly on where you live. Call Social Security at 800.772.1213 to find out the income limits in your state. Resources used in deciding if you qualify for SSI include real estate, bank accounts, cash, stocks, and bonds. You may be able to receive SSI if your resources are worth $2,000 or less or—if you are a couple—$3,000 or less. To learn more about SSI eligibility requirements and benefits, visit socialsecurity.gov. Note: If you receive SSDI (Social Security Disability Insurance), you will be automatically enrolled in Medicare after two years for inpatient and outpatient hospital bills and other medical services.

It is important to note, even if you do not qualify for Social Security benefits, you may be eligible for other government assistance, such as Medicaid.

TO APPLY FOR SSI BENEFITS:

Review the Social Security Child Disability Starter Kit at ssa.gov/disability/disability_starter_kits_child_eng.htm. This kit answers common questions about applying for SSI benefits for children and includes a worksheet that will help you gather the information you need.

- Contact Social Security right away to find out whether your income and resources are within the appropriate eligibility limits and to start the SSI application process. You can call toll-free at 800.772.1213.
- Fill out the online Child Disability Report at ssa.gov/childdisabilityreport. At the end of the report, Social Security will ask you to sign a form that gives the child's primary care provider(s) permission to offer information about your child's diagnosis. This will allow them to make a decision on your claim.

Visit socialsecurity.gov or call toll-free at 800.325.0778, to learn more about your eligibility.

Medicaid

Medicaid is a state-run program funded with both state and federal funds. Medicaid provides low-cost, sometimes free health coverage to individuals with limited income and resources, people living with disabilities, and pregnant women. For families who have a loved one living with Duchenne, Medicaid benefits may include healthcare provider visits, medical testing, hospital visits, and transportation to visits, equipment, and other services, depending on the specific benefits and services covered by the program in your state.

Even if your income exceeds eligibility income levels, you may be able to qualify for Medicaid through "spend-down" rules. Under these rules, you are able to subtract your medical expenses from your income to become eligible for Medicaid. Currently, this program is available in 33 states for the medically needy. Find out if you qualify by visiting medicare.gov/your-medicare-costs/help-paying-costs/medicaid/medicaid.html.

In addition, it is possible to receive an income and maintain both SSI eligibility and Medicaid benefits for health insurance, up until a specified earnings threshold via Section 1619b. If you are eligible for SSI, have Medicaid for your health insurance and are employed, 1619b allows you to work and to keep Medicaid coverage without a Medicaid spend-down. You can continue to be eligible for Medicaid coverage until your gross annual income reaches a certain amount (income threshold varies annually by state). Exceptions to this work incentive are if you no longer need Medicaid, or if you accumulate more than your state's Medicaid resource limit. Visit https://www.ssa.gov/disabilityresearch/wi/1619b.htm to learn more about Section 1619b.

See if your income falls within the eligibility range for Medicaid by visiting healthcare.gov/lower-costs. Even if you don't qualify based on income alone, it is recommended you apply.

Medicaid Waiver Programs

People living with Duchenne and their loved ones may qualify for other Medicaid assistance not based on income alone. Medicaid waivers can help provide additional services and wraparound Medicaid coverage so you or your loved one can receive long-term care in your own community.

Not all states have the same rules and benefits. The federal government allows states to apply for waivers from the traditional Medicaid rules, so they can offer a range of innovative options in their state. To learn more about waivers available in your state, visit medicaid.gov/medicaid and click on "State Waivers List." Kidswaivers.org is another helpful resource to learn more about available Medicaid waivers.

Because Medicaid waivers are state-based, note that waiver services will not transfer to other states and many states have people already on a waiting list for waiver services.

What constitutes income?
Social Security uses different types of income to calculate your SSI payment and determine whether you meet the SSI resource limit.

Earned income is wages, salaries, tips, and other taxable employee pay; union strike benefits; long-term disability benefits received prior to minimum retirement age; and net earnings from self-employment.

Unearned income is derived from other sources other than work. This includes income from owning property (known as property income), inheritance, pensions, investments, interest, and payments received from public welfare.

In-kind income (income in kind) is income other than money. It includes many employee benefits and government provided goods and services, such as toll-free roads, food stamps, public schooling, or socialized medicine.

Deemed income is the portion of your ineligible spouse's income and resources that are considered to be yours, if you're married.

ELIGIBILITY FOR MEDICAID & CHIP

Eligibility for Medicaid and CHIP varies from state to state.

Note you can only be eligible for Medicaid OR CHIP, not both.

You can apply for Medicaid or CHIP in two ways:

Through the Health Insurance Marketplace by creating an account to submit an application: healthcare.gov/create-account.

Through your state Medicaid agency. Find contact information for your state at healthcare. gov/medicaid-chip/getting-medicaid-chip.

There is also no limited enrollment period for Medicaid or CHIP. If you/your loved one qualify, coverage can begin immediately at any time of year.

Note, in some states, there is no difference between Medicaid and CHIP in terms of benefits and eligibility requirements. In other states, CHIP is a separate program from Medicaid, covering children who are older or children from families with incomes above the state's Medicaid eligibility ceiling.

Learn more about Medicaid and CHIP in your state by visiting medicaid.gov/medicaid/by-state/by-state.html.

Medicare

Medicare is a federal health insurance program that provides coverage for individuals who are 65 or older and for those under 65 who have certain disabilities like Duchenne.

See if you qualify for Medicare by visiting **medicare.gov/eligibilitypremiumcalc/#eligibility.**

CHIP

Children's Health Insurance Program (CHIP) offers low-cost health coverage for children in families that exceed the income eligibility for Medicaid, but cannot afford other health insurance. Children who qualify for CHIP will not need to buy a private health insurance plan. Similar to Medicaid, CHIP can help you pay for equipment, treatment, and services needed for Duchenne care.

For families with a child living with Duchenne, Medicaid and CHIP are the programs that will most likely help you pay for the cost of your child's care. You can learn more about these programs at medicaid.gov.

Medicaid and CHIP programs may be called something else in your state. Learn the names of these programs in your state at **healthcare.gov/medicaid-chip-program-names**.

Understanding What Health Insurance Covers and How Insurers Reject/Approve Claim

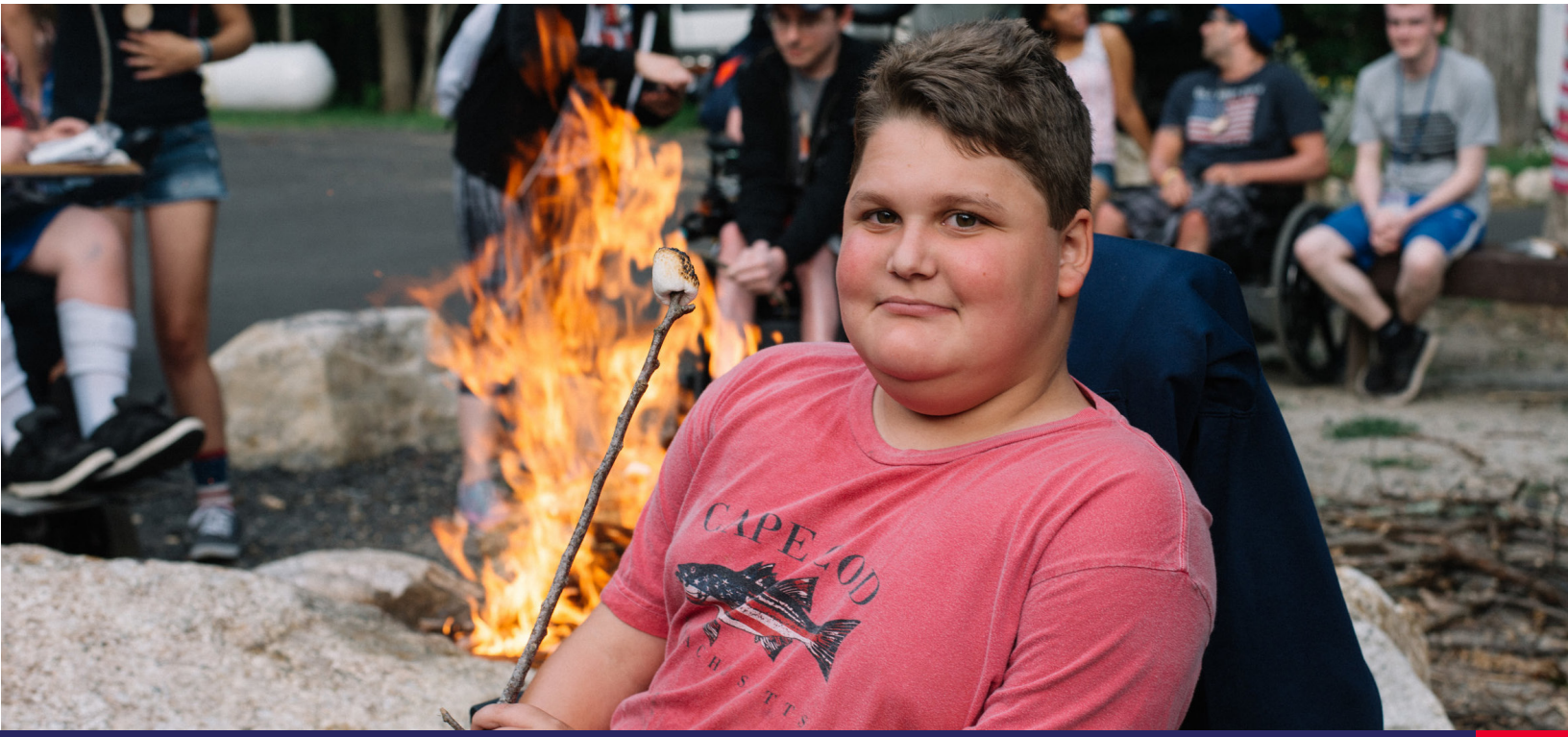
All health insurance is different and many factors can impact what services, treatment, and equipment are covered. Because managing your or your loved one's healthcare can be complex, it's helpful to have an ongoing dialogue with your insurer about coverage. To fully understand what's covered—and help predict and avoid any claims denials—be sure to ask the following questions:

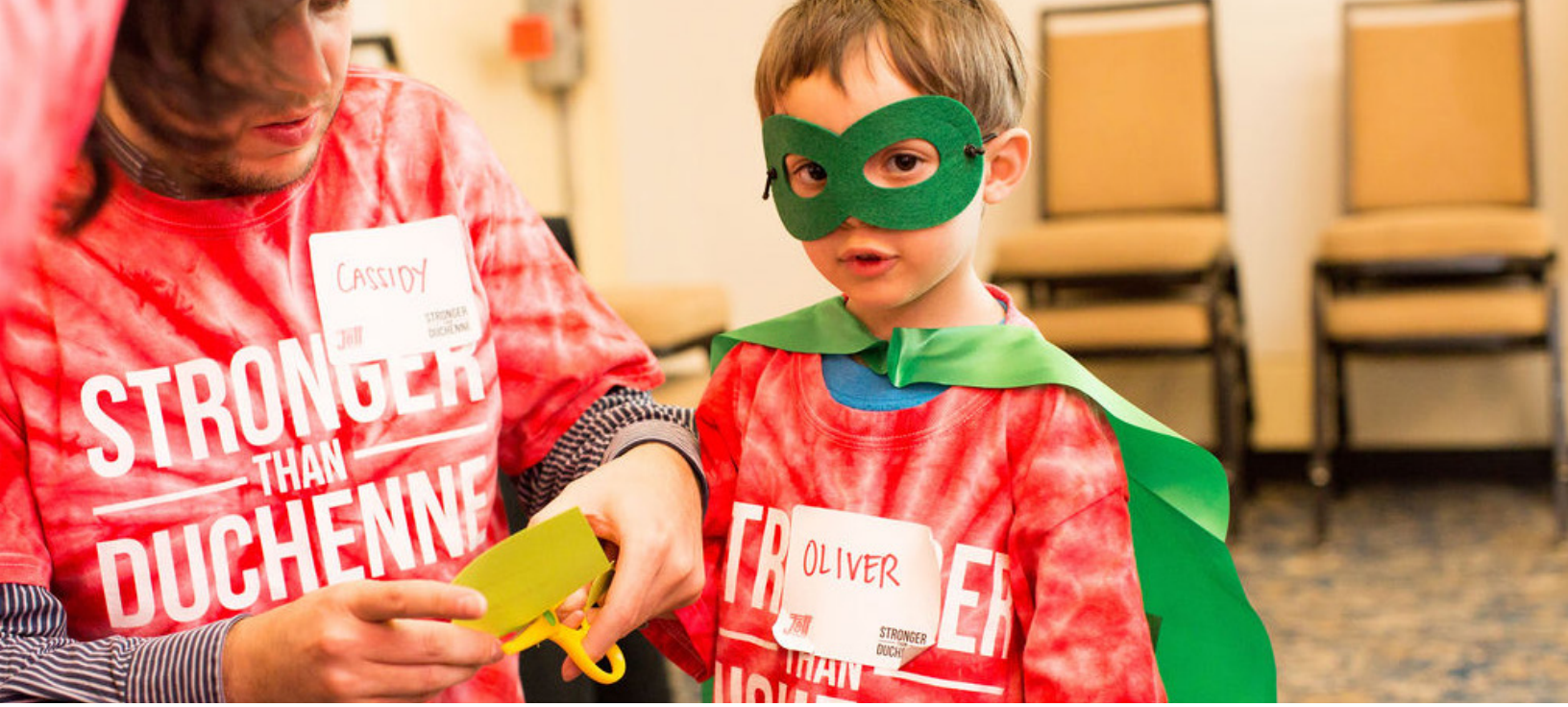
- On average, are claims for [SERVICE/TREATMENT/EQUIPMENT] generally approved under my health insurance plan?
- In general, what is your process for determining if treatment or equipment is medically necessary? What specific information and/or documentation is needed to determine if a treatment or equipment is medically necessary?
- Do you provide any exceptions for rare disorders? If so, can you give examples of such exceptions?
- If I make multiple claims for treatment or equipment, will this affect my monthly premium?
- Do you cover durable medical equipment (DME)?

Federal law requires your health insurer to respond to a health insurance claim. Required response times are:

- Within 15 days if you are seeking authorization ahead of treatment, usually referred to as "prior authorization";
- Within 30 days for medical services you've already received; and
- Within 72 hours for urgent medical matters

It is recommended that conversations with insurance companies be documented: write down the date, time, length, and details of the conversation as well as the name and/or any identification number of the individual with whom you speak. Creating a paper trail can be helpful when filing appeals for claims denials.





What to do When a Claim is Denied

Insurance denials happen for a variety of reasons. Your insurer is likely to deny a claim for anything not deemed as medically necessary. For example, a wheelchair or respiratory assistive device may be rejected if your insurer believes that durable medical equipment (DME) is not a medical necessity.

Your health insurance plan must notify you in writing of the reason they did not authorize a specific request or denied payment of a service as well as how to appeal their decision. Some of these reasons include:

- Services are deemed not medically necessary
- Services are no longer appropriate in a specific health care setting or level of care
- Services are considered experimental or investigational for this condition
- The effectiveness of the medical treatment has not been proven
- You are not eligible for the benefits requested under your health plan
- The insurance company did not receive enough information

You should be keeping a detailed and organized documentation of your conversations with your plan. Be sure that you keep track of:

- The dates and method of any correspondence (by phone, email, in writing)
- The names of insurance agents and claim reviewers with whom you speak
- Summaries of your conversations and written documents issued by your insurer

Receiving a notification that your insurer won't pay for treatment or equipment can be both frustrating and frightening. However, there are protections and laws in place that allow you to dispute your insurer's decision and demonstrate that a treatment and/or medicine is medically necessary.

While the following steps generally apply to most insurance plans, we suggest reaching out to your insurer to ensure you comply with any specific appeals requirements. Doing so can help ensure you meet their requirements, which can be critical to the appeals process.

Denial Claim Flow Chart

There are typically three levels of appeals that can happen if you are denied a medical service, treatment, or piece of durable medical equipment.

Step 1: Internal Appeal

Following the initial denial, you should be able to request an internal appeal. To file an initial appeal, write a letter to your insurer demonstrating why a particular treatment or equipment is medically necessary.

Tip: Appeals that come from your doctor using the term "medically necessary" are usually more successful.

Step 2: External Review

If your insurer denies the internal appeal, you have the right to seek an "external review" in which an independent medical professional will review your case. You must file a written request for an external review within 60 days after your internal appeal was rejected.

EXPEDITED EXTERNAL REVIEW
If you or your loved one is facing an urgent health situation, you may ask for an external review at the same time as an internal review to speed up the process. Each insurer has different rules for the external review process. Your insurance company or The Centers for Medicare & Medicaid Services—the federal agency that oversees government-funded healthcare—should provide an overview of their process.

Step 3: Fair Hearing

If you have Medicaid, Medicare, or CHIP and receive a second denial, you have the right to seek a fair hearing in writing within a certain number of days since receiving a second denial. If this is an emergency you can request an expedited fair hearing. During this hearing, which is often done over the phone, an administrative law judge will hear arguments from the medical reviewer and the patient/caregiver and their medical and legal representatives and decide whether or not to uphold or overturn the denial of a claim.

If you have exhausted all appeals options and cannot appeal a negative decision any further, you should contact your physician to inquire about assistance the developer of the treatment or medical equipment, or the hospital or clinic may provide.

Tips for a Successful Appeal Letter

- Ask your or your child's expert physician to write the appeal letter or write a letter of support that discusses the clinical reasons why a treatment, piece of equipment, or medical service is medically necessary and in line with standard of care in Duchenne.
- Peer reviewed articles from professional journals or magazines that support the treatment being recommended.
- Any current medical literature or studies documenting the medical effectiveness of the requested services for experimental or investigational treatments.
- Give examples of other plans that are covering the treatment, equipment, or medical service.
- You should do the math on the cost of acquiring the equipment or treatment and a yearly estimate of how much it will cost you to maintain, upgrade, and eventually replace it. Include these long-term costs in your appeal letter to the insurer.
- Your own personal narrative or the narrative of an authorized representative describing the need for the requested service.

Seeking Out-Of-Network Care for Duchenne

Because Duchenne is considered a rare condition, it can be difficult to find a provider that knows the ins and outs of the disorder and its related challenges. That is why it is important to know which healthcare providers and facilities are covered by your health insurance plan.

Insurers manage and predict costs by creating provider networks. This means that your health insurance plan will contract with doctors, hospitals, and other health professionals to participate within a certain network with the expectation to provide care at negotiated rates. The ability to contract with medical and health professionals provides insurers with the ability to negotiate lower prices and stabilize premiums.

Visiting a healthcare provider or hospital in your insurance network (an in-network provider) has several benefits, including lower out-of-pocket costs and more generous insurance benefits. However, insurers have been narrowing networks in recent years to keep costs low. As a result, it is likely that not every doctor, hospital, or medical treatment facility will be covered by your health insurance plan.

Your insurer offers provider directories to help understand what healthcare providers and hospitals are included in your network. These directories will allow you to search by zip code to locate the doctors, hospitals, and specialists in your area that accept your current insurance. Often, the directories also will provide an overview of the individual specialty areas and accolades of the health professionals.

Sample directories include:
- Aetna
- Anthem
- Blue Cross Blue Shield Plans
- Cigna
- UnitedHealth

If your health insurance plan is through a different insurer, be sure to call their customer service line to ask where and how you can access a provider directory online.

REASONABLE AND CUSTOMARY FEES

Reasonable and customary fees refer to charges made by your health insurance plan for a particular medical service or treatment.

A charge is considered reasonable and customary if it matches the general prevailing cost of that service within your geographic area, which is calculated by your health insurance plan. Your health insurance provider then uses this information to determine how much it's willing to pay for a given service in your area. This means that if your doctor charges above the reasonable and customary fee, you may have to pay the remainder.

Applying for Out-of-Network Care

Contact your insurer and ask about programs that will provide Continuity of Care Coverage or Gap Network Exceptions.

- Enroll or start the process to appeal to those programs.
- File a letter of concern/complaint regarding how the limited network is impacting the continuity of care, why it is cost effective to allow specialty care, and why it is the morally right decision.
- Obtain a physician, specialist, and or a geneticist letter that explains the medical need for a specialist.
- Determine if it is worth asking your insurer to pay for a doctor that is out-of-network. Don't be surprised if they ask you to get a letter of medical necessity and additional support documents. The insurer may also stipulate that the out-of-network doctor accepts its payment terms.
- Engage your network of providers, employer human resources, local media, and/or advocacy groups to help you advocate on your behalf.
- Identify the "gatekeepers" within your insurance plan and your employer human resources. Appeal directly to them.
- If all else fails, contact the provider directly to negotiate a Self Pay Rate.

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

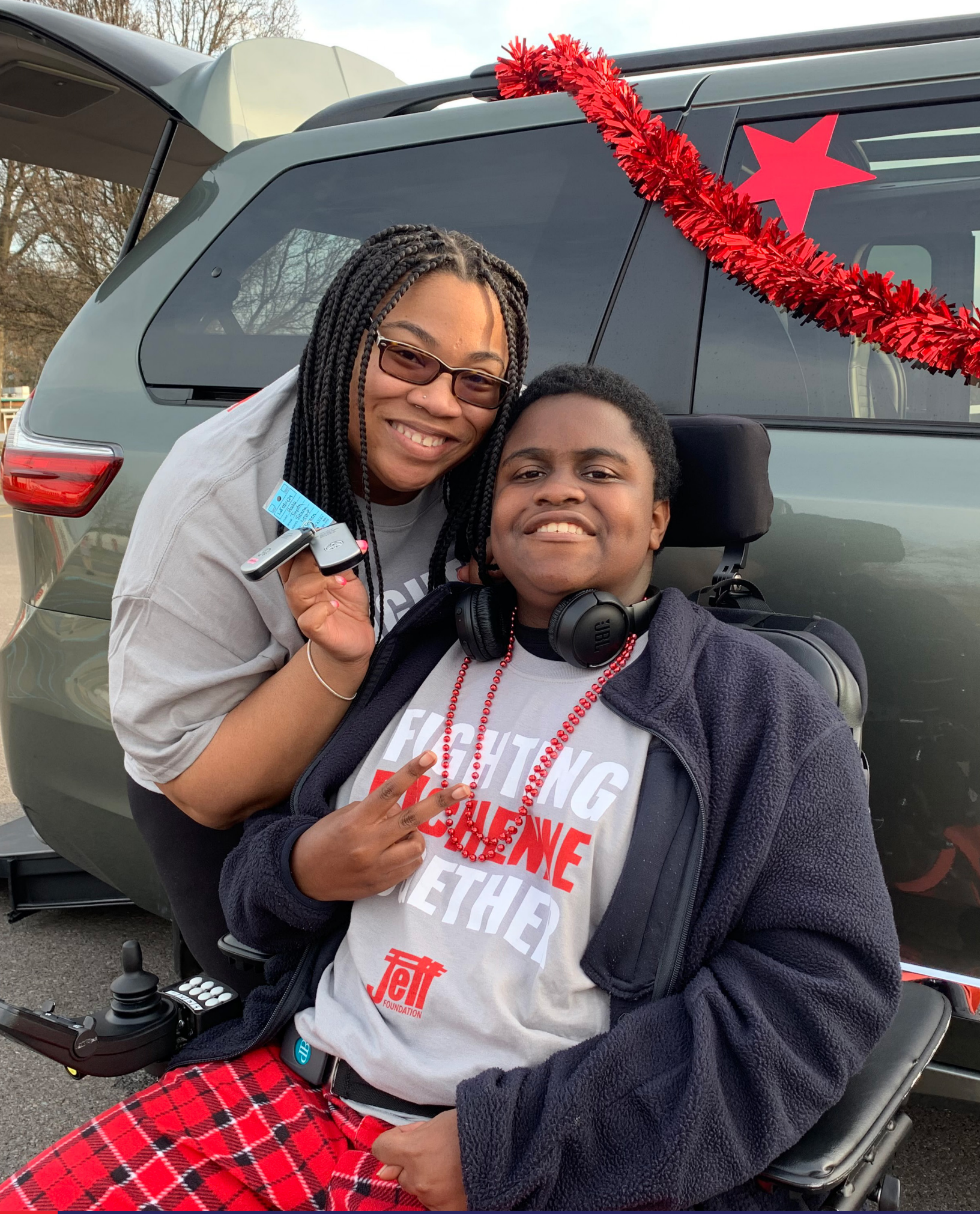
1. _____

2. _____

3. _____

To avoid or predict network restrictions, be sure to ask your insurer the following questions:

- I have always received care from [PROVIDER/MEDICAL CENTER/HOSPITAL]. Is that included in my network?
- I seek medical care quite frequently, requiring me to visit several healthcare facilities. Which health insurance plan(s) would you recommend if I want affordable access to a broad network in my area?
- Which coverage restrictions may apply for my doctors and hospitals?
- If I need to receive care from an out-of-network provider, is there an exception process? On average, how much would it cost to receive care out of my network?


FIGHTING
Jett
FOUNDATION

Understanding, Predicting, and Managing Healthcare Costs

Many health insurance plans are now charging higher premiums and imposing larger out-of-pocket costs on patients, placing greater burdens on people living with Duchenne and caregivers. However, there are resources available to help you predict and manage your family's healthcare costs. Know that your insurance company cannot deny you coverage, refuse to renew your coverage, or charge you a higher premium because of Duchenne.

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

TYPES OF HEALTH INSURANCE OPTIONS & COSTS

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

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

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

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

Out-of-Pocket Maximum
The out-of-pocket maximum is the most you will pay in deductibles, copayments, and coinsurance during a given year of coverage excluding the premium. When you reach the out-of-pocket maximum for your policy, your insurance company will pay all cost incurred for your child's care.

To illustrate how this works, let's say the Smith family's policy includes a:

- $3,000 deductible
- 20% coinsurance
- $5,000 out-of-pocket maximum

The Smiths' son, Mikey, needs a $20,000 spinal stabilization surgery. The Smiths will pay the $3,000 deductible and a portion of the coinsurance. Since the coinsurance cost is 20% of the total surgery cost, the Smiths coinsurance cost will be $4,000. However, because their policy's out-of-pocket maximum is $5,000, the Smiths only need to pay $2,000 of the $4,000 coinsurance to reach the out-of-pocket maximum. The insurance company will pay the remaining $15,000 balance.

If Mikey needs more surgery or medical procedures this year, the Smiths will not have to pay additional medical costs because they have reached their policy's out-of-pocket maximum.

Glossary

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

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

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

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

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

CHILDREN'S HEALTH INSURANCE PLAN (CHIP)
Low-cost health coverage for children in families that exceed the income eligibility for Medicaid but cannot afford other health insurance plans.

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

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

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

COINSURANCE
The percentage you pay of the cost of a covered healthcare service after paying any applicable deductible

COPAYMENT (COPAY)
A fixed dollar amount you pay for a covered healthcare service; ex. $20 per physician visit.

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

Glossary

DEDUCTIBLE
The amount you have to pay for healthcare services covered by your insurance plan before the insurance starts to pay.

DEEMED INCOME
The portion of your ineligible spouse's income and resources that are considered to be yours.

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

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

DURABLE MEDICAL EQUIPMENT
Medical equipment and supplies ordered by a healthcare provider for everyday or extended use for more than three years, such as a wheelchair or respiratory assistive device.

EARNED INCOME
Income derived from wages, salaries, tips, and other taxable employee pay; union strike benefits; long-term disability benefits received prior to minimum retirement age; and net earnings from self-employment.

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

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

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

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

IN-KIND INCOME (OR INCOME IN KIND)
Income other than money. It includes many employee benefits and government-provided goods and services, such as toll-free roads, food stamps, public schooling, or socialized medicine.

IN-NETWORK PROVIDER (OR PREFERRED PROVIDER)
A provider who has been contracted by an insurer to provide healthcare services to an insurance plan's members.

Glossary

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

MEDICAL NECESSITY
Healthcare services or supplies that meet the accepted standards of care and are needed in order to prevent, diagnose, or treat an illness, injury, condition, disorder, disease, or its symptoms.

NETWORK
The institutions, providers, and suppliers your insurance plan works with to provide healthcare services.

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

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

OUT-OF-NETWORK PROVIDER (NON-PREFERRED PROVIDER)
A provider who is not in your insurance plan's network.

OUT-OF-POCKET COSTS (SOMETIMES CALLED OOP)
The amount of money an individual may have to pay for the cost of covered healthcare services, which can vary based on the health insurance plan and can include deductibles, coinsurance, and copayments.

PRE-EXISTING CONDITION
A health condition you had prior to beginning new health insurance coverage.

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

PREMIUM
The amount that must be paid by a family or an individual to obtain coverage, usually payable on a monthly basis.

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

PRIMARY INSURANCE (OR PRIMARY PAYER)
For people with more than one source of health insurance, primary insurance is their main source of coverage that pays first, unless a particular healthcare service or product is not covered.

PRIOR AUTHORIZATIONS (OR PREAUTHORIZATION)
The requirement by a health insurance plan that, before coverage is allowed, decides if a treatment or medication is medically necessary.

Glossary

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

REFERRAL
An order, permission, or recommendation provided by the primary care provider for a patient to receive specialty care; for example, some individuals with Duchenne may need a referral to see a specialist such as a pulmonologist or an orthopedist.

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

UCR (USUAL, CUSTOMARY, AND REASONABLE)
The amount paid for a medical service in a geographic area based upon what providers in the service area charge for similar services. This information may also help in estimating what an insurer will pay for a service.

UNEARNED INCOME
Income derived from other sources other than work, including income from owning property (known as property income), inheritance, pensions, investments, interest, and payments received from public welfare.

Resource Guide

Government Resources

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

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

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

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

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

Non-profit Patient Assistance Programs

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

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

Prescription Assistance Programs

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

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

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

Rare Disease Advocacy Organizations

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

Global Genes Webinar on Navigating Insurance provides a two part informational webinar.

Your Duchenne Cost Profile

List the traditional medical services: in-office visits, tests, surgery, and other medical treatment(s) provided by your primary doctor or a specialist for Duchenne:

Type of Treatment	**Your Cost for the Treatment**
_____	_____
_____	_____
_____	_____

List the name(s) of prescription drugs you take to manage the symptoms and/or the effects of Duchenne.

Name of Prescription Drugs	**Your Cost for the Prescription Drug**
_____	_____
_____	_____
_____	_____

List the complementary and alternative medical treatments provided by alternative medical practitioners for Duchenne. Examples of alternative medical treatments include: holistic, therapeutic, acupuncture, hypnotherapy, and other similar treatments.

Treatment	**Your Cost for the Treatment**
_____	_____
_____	_____
_____	_____

List the name(s) of complementary and alternative health supplements you use to manage the symptoms and/or the effects of Duchenne. Examples of supplements are: vitamins, herbs, nutritional products, over-the-counter medicines, and salves.

Supplements	**Your Cost for the Supplements**
_____	_____
_____	_____
_____	_____

List the medical equipment and/or medical supplies you currently use to manage the symptoms and/or the effects of Duchenne.

Medical Equipment	**Your Cost for the Equipment**
_____	_____
_____	_____
_____	_____

List prescription drugs and over-the-counter (OTC) medications you use for medical conditions not related to Duchenne.

OTC Medications	**Your Cost for the OTC Medication**
_____	_____
_____	_____
_____	_____

Notes

ABOUT JETT FOUNDATION

Since 2001, **Jett Foundation** has met the needs of the Duchenne muscular dystrophy community. Our mission is to empower people and families impacted by Duchenne muscular dystrophy through the development of transformative programming, educational opportunities, and ongoing support for every stage of a Duchenne journey.

Every day, we strive to provide our community with helpful resources, interactive programs, and tools to use on a Duchenne journey. To learn more about our family-focused programs and get support, please visit our website at **jettfoundation.org**.

We aim to reach every patient and family in the Duchenne community, and invite you to engage with us as we realize a world without Duchenne.

Will you join us?

To get more involved with Jett Foundation and to help further our mission of enriching and extending the lives of individuals with Duchenne and other neuromuscular diseases, go to jettfoundation.org or contact info@jettfoundation.org.

JOIN OUR ONLINE COMMUNITY

Empowering families.
Fighting Duchenne.

connect with us

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