Gaining access to Duchenne muscular dystrophy (DMD) therapy

Your guide to understanding the road to treatment

Finn
Living with Duchenne muscular dystrophy

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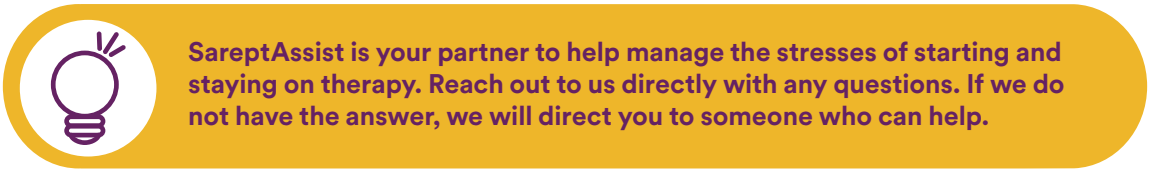
What's inside?

Once you and your doctor decide to pursue therapy for Duchenne, getting approval from your insurance company to help cover the costs of the medication can require multiple steps. This guide can help you navigate the insurance process. It has information that can help you:



SareptAssist is your partner to help manage the stresses of starting and staying on therapy. Reach out to us directly with any questions. If we do not have the answer, we will direct you to someone who can help.

Understand your insurance

Health insurance can help pay for a portion of the costs of medical care and treatment. The amount and types of costs covered vary according to the type of insurance you have.[1]

TYPES OF INSURANCE

Private (commercial) and **public (government)** are the most common types of health insurance.

PRIVATE OR COMMERCIAL

- **Private or commercial insurance can be offered through an employer or by purchasing it directly from an insurance company or state insurance exchange**
  - Employers may offer a variety of different plans during their open enrollment period, and each plan may vary in coverage, costs, and out-of-pocket expenses.[2]

Knowing the type of plan your employer has can help you understand the type of coverage offered.

PUBLIC OR GOVERNMENT-SPONSORED

- **Public or government-sponsored plans are provided at the federal and state level for people who qualify for assistance[3]**
  - Medicaid and Medicare are common types of public insurance that provide health coverage to millions of Americans

See the next 2 pages for more details on Medicaid and Medicare.

Medicaid and Medicare

Patients with Duchenne may be covered by a Medicaid or Medicare program. Below are important facts about these programs to help you know the differences. Your SareptAssist Case Manager can share information with you about the different programs and how to enroll.

MEDICAID

Medicaid is a joint federal and state insurance program that covers millions of people, including[3,4]:

- Low-income households
- Adults
- Children
- Pregnant women
- Elderly adults
- People with disabilities

Medicaid is administered by states according to federal requirements. You may hear the terms Medicaid fee-for-service or Managed Medicaid. If you are enrolled in Medicaid fee-for-service, that means the state pays physicians directly for health services. If you are enrolled in a Managed Medicaid program, that means you are part of a health care plan. In this case, the state pays the plan, and the plan then pays providers for services.[5]

All Medicaid programs provide coverage for prescription medications, typically at the lowest cost to beneficiaries.

MEDICARE

Medicare offers health insurance for people[6]:

- Aged **65 years** and older
- Under **age 65** who have certain disabilities
- Of **all ages** with **end-stage renal disease and amyotrophic lateral sclerosis (ALS)**

Within Medicare, there are different parts that cover different health care needs, such as[6]:

PART A	PART B	PART C	PART D
Hospital stays	Doctor visits	Medicare Advantage plan*	Prescription drug costs

Patients over the age of 20 with Duchenne are automatically enrolled in Medicare after receiving **Social Security Administration** disability benefits for at least 2 years.[7] For more information about how to qualify, visit SSA.gov.

*This is a managed care plan that offers both Medicare Parts A and B benefits and other supplemental benefits that may not be offered by traditional Medicare fee-for-service plans.

There are also special federal and state programs that cover the costs associated with Duchenne. For example, in addition to Medicaid and Medicare, patients may be covered by Children's Health Insurance Program (CHIP) or may qualify for disability benefits. Look to page 5 for details.

Special federal and state programs

Duchenne patients may automatically qualify for one or more of these special federal or state programs that may **cover costs of drug infusions, transportation, hospital care, doctor visits, and home health care.** It's important to know about them and how to enroll. Your SareptAssist Case Manager can help.

Supplemental Security Income or Social Security Disability

Each state has different qualification requirements for Medicaid coverage. In most states, a child with Duchenne is eligible for Social Security Administration benefits through the Supplemental Security Income or Social Security Disability Insurance programs—and automatically qualifies for Medicaid.[8]

Compassionate Allowances

The Social Security Administration Compassionate Allowances (CAL) program is available for adults with Duchenne. This program identifies severe medical diseases, including Duchenne, that automatically meet the SSA standards for disability benefits, and fast tracks the Medicaid application process for them. Today, there are more than 250 conditions on the list.[9,10]

Children's Health Insurance Program (CHIP)

CHIP is a joint federal-state program offering free or low-cost coverage for uninsured children and teens up to age 19 in families with incomes too high to qualify for Medicaid.[3]

Medicaid waiver or a Katie Beckett (available in some states)

When assessing types of Medicaid coverage for Duchenne, you may hear the term Medicaid waiver or a "Katie Beckett"—named for a young girl who required ongoing use of a ventilator at home. These are expanded programs that some states may offer to certain groups of people, based on different criteria in each state. These waiver programs often provide full or additional coverage for families of children with exceptional health needs that may otherwise not qualify for Medicaid, and often help them remain home for health services.[3,11]

Visit Medicaid.gov to learn more about Medicaid programs in your state. You can also ask your SareptAssist Case Manager about which programs may be best for you.

How costs are covered

Whichever type of plan you have (eg, private or public), your insurance company may share the costs of medications and services with you by paying a portion of the costs, and you pay the out-of-pocket expenses, if any. The structure and amount of expenses is outlined below:

PREMIUM

Amount you pay to participate in the health plan, which will vary depending on the plan and type of coverage you select (eg, individual, couple, family). You may be responsible for these costs weekly, monthly, or annually.[3]

DEDUCTIBLE

Set amount you pay each year before the plan covers a portion of the costs.[3,12]

CO-INSURANCE

After you meet the deductible, you only pay a percentage of the medical or drug expenses.[3]

CO-PAY

In addition to the deductible, you may be required to pay a co-pay—or specific dollar amount—for every doctor visit or medication. This amount will be less than the deductible and is usually paid instead of paying co-insurance.[3,13]

The Affordable Care Act set a maximum limit to the amount health plan members have to pay in out-of-pocket expenses. This limit applies to your deductible, co-insurance, or co-pay. These limits vary by plan and type of health service (eg, in-network vs out of network).[14]

How does your plan cover costs? Knowing the terms deductible, co-insurance, and co-pay can help you understand your out-of-pocket expenses for Duchenne treatment.

How plans cover specialty medications

Some drugs are known as specialty drugs. These medications require special care and are usually distributed through a specialty pharmacy or specialty distributor to ensure they are handled safely. Specialty medications may have special storage requirements or involve infusions or injections. Depending on the plan, specialty products may be covered under the medical benefit, the pharmacy benefit, or both.[15]

Both private and public insurance offer medical and pharmacy benefits. Each type of benefit covers different products and services, for example[16]:

Medical benefit often covers procedures or care received in a hospital or at a doctor's office.

- Medications administered in an outpatient setting (eg, home, hospital, doctor's office, freestanding infusion clinic) may incur additional costs for the visit[17]
- Infusions are usually covered under the medical benefit because they are administered in a clinic or office setting by a provider

Pharmacy benefit often covers medications picked up from a retail or mail-order pharmacy.

- Under the pharmacy benefit, you may hear the term "limited distribution." This means that there may only be a few, specific pharmacies that will ship the medication to the patient's home. This is most common with novel therapies that have complex shipping and handling requirements
- There are special circumstances where infusions may be covered by the pharmacy benefit, such as white bagging, which is explained later in this guide

Specialty pharmacy

A specialty pharmacy is a type of pharmacy that provides services and dispenses medications for complex health conditions like Duchenne that require specialty medications like injections or infusions. For Duchenne therapy, the role of the specialty pharmacy is to:

- **Work with the doctor's office** and your insurance company to distribute the specialty medication.
- **Provide counseling** on treatment, including managing the side effects.
- **Help with financial** assistance options.
- **Assist with setting up** home infusions and dispensing drugs and supplies.

It's a good idea to find out if your prescribed Duchenne therapy will be covered under the medical or pharmacy benefit because where the patient gets the medication can impact cost and coverage.

Before shipping the medication, the specialty pharmacy may require prior authorization paperwork that ensures the medication is being used properly and aligns with the insurance company's policies. This can sometimes delay the start of therapy.

Your SareptAssist Case Manager can help you determine how your therapy is covered and help you navigate the prior authorization process

Outpatient vs home infusion

Delivery of Duchenne medication varies by plan, coverage type, location of treatment, and your doctor's prescribing orders. In general, there are a few terms that are helpful to know[18]:

OUTPATIENT

BUY AND BILL

The doctor's office buys a bulk amount of the medication from a specialty distributor to use for different patients, when they need it. This allows for enough medication to be available in advance instead of ordering 1 unit per patient. In this case, you pay the co-pay, if applicable, to the doctor's office for treatment and administration.

WHITE BAG

The specialty pharmacy collects the co-pay from the patient, if applicable, and then sends 1 unit of the patient's medication to the doctor or clinic in time for administration. You pay a co-pay, if applicable, to the doctor's office for administration costs.

BROWN BAG

Similar to the above except the medication is sent to the patient to bring to the outpatient setting at the permission of the hospital/office/clinic.

HOME INFUSION

For patients receiving their medication at home, the billing and ordering process is very similar to white bag except that the medication gets sent to the patient's home instead of the clinic. The specialty pharmacy is responsible for delivering the medication and setting up the home health nursing. The specialty pharmacy will then collect any co-pays from the patient for the medication and administration costs.

Your SareptAssist Case Manager can help you navigate your drug delivery process.

Drug formularies, prior authorization, and reauthorization

What is a formulary?

Most health plans have a formulary as part of their pharmacy benefit. The formulary is a list of prescription drugs that is grouped into different categories or tiers. The amount you may have to pay for the drug is determined by the tier level. Typically, a drug formulary includes 4 or 5 tiers. Here's an example of a typical tier structure[13]:

TIER 1	**Generic or lowest cost drugs**
TIERS 2-3	**Brand-name drugs or more expensive generics**
TIER 4	**More expensive brand-name drugs**
TIER 5	**Specialty drugs such as infusions or the most expensive medications**

What is a prior authorization?

Most formularies include restrictions such as prior authorizations, which are processes that health plans use to ensure the drug is being used correctly and to better control the use of more expensive medications.[13]

If your health plan requires a prior authorization, it means that your doctor must submit documentation explaining why the prescribed Duchenne therapy is necessary before the plan will cover it. Prior authorization requirements vary by plan and can be different for every patient. There is no need to worry if your plan does require a prior authorization before it will cover the cost of Duchenne therapy. This is relatively common across plans for Duchenne therapies and other specialty products.

What is reauthorization?

Once a therapy goes through the process and is approved for use by your health plan, it can be administered for the amount of time it is approved for use. That time frame varies by plan and patient. When the approved time frame ends, the plan will require the treatment to be "reauthorized" for the patient to continue therapy. This is done to ensure the medication is being used correctly and continues to meet the plan's criteria for use, and requires additional documentation.

Your doctor, their office staff, and the Sarepta team can help guide you through the prior authorization and reauthorization processes. The next section provides more details on this topic.

The journey to accessing Duchenne treatment

Once you and your doctor decide that treatment is right for you or your family member, Sarepta has resources that can help you navigate the complexities of starting and staying on therapy. The process is different for everyone. It varies due to many factors, such as the type of insurance you have, your treatment needs, and financial assistance options. In this section, we provide a basic overview of the steps in the journey. Additionally, your health care team can help you with your specific situation.

Who is on your care team?

At the doctor or clinic

Doctor: prescribes medication and provides medical care.

Nurse: provides care, administers medication.

Office Staff: handles appointments and administrative issues such as billing and payments; assists with prior authorizations and appeals to help patients get access to medications.

At the health plan

Member Services: handles insurance policy questions and claims processing.

Medical Director: responsible for helping build formularies and reviewing prior authorizations and appeals.

Your Sarepta team

SareptAssist Case Manager (CM): is one of your key contacts for questions about your insurance benefits, treatment delivery, and access to medication.

Patient Access Manager (PAM): works with you and your SareptAssist Case Manager to navigate the denial and appeals process.

Director of Market Access and Reimbursement (DMAR): provides access and reimbursement support for doctors' offices and insurance companies.

Duchenne Nurse Educator (DNE): provides training for drug administration.

Specialty pharmacy

Pharmacist: coordinates medication shipment and reviews physician orders and consults with families if needed.

Nurse/Coordinator: facilitates contracts/appointments with home health agencies.

Dedicated Care Team: coordinates medication shipment to site or home, ships necessary supplies, and assists with home health care coordination.

Important steps in accessing Duchenne therapy

Once the Duchenne medication has been prescribed, there are **4 key steps to gain access** to the product and start therapy. Your SareptAssist Case Manager will be with you every step of the way.

STEP 1

BENEFITS INVESTIGATION

This is the process to determine the type of insurance you have and the expected coverage it provides for the prescribed Duchenne therapy, including prior authorization policies and out-of-pocket expenses. Your SareptAssist Case Manager will work with you to help you understand your specific insurance benefits and next steps. **Refer to the next few pages for an overview of the authorization process for Duchenne medications.**

STEP 2

TREATMENT LOCATION OPTIONS

Patients may receive infusions at an infusion center or at home. You and your doctors should discuss these options, including whether home therapy is an option for your family. Some insurance plans may only cover outpatient infusions or only cover home infusions.

STEP 3

STARTING TREATMENT

Once your insurance benefits have been confirmed and approval for infusions has been obtained, your SareptAssist Case Manager will work closely with the specialty pharmacy to facilitate treatment access and coordinate drug delivery to your treatment location. This process will vary according to the type of pharmacy and location of the infusion. Then, your Duchenne Nurse Educator will guide you and your health care team through the drug administration process.

STEP 4

ONGOING SUPPORT

Your SareptAssist Case Manager is committed to working with you during your treatment journey, and will check in with you periodically. As your needs change (eg, you have new insurance, a change of address, are planning a vacation), your SareptAssist Case Manager can keep you informed of your options to help avoid treatment interruptions.

Always consult with your physician before making any decisions about your Duchenne treatment regimen.

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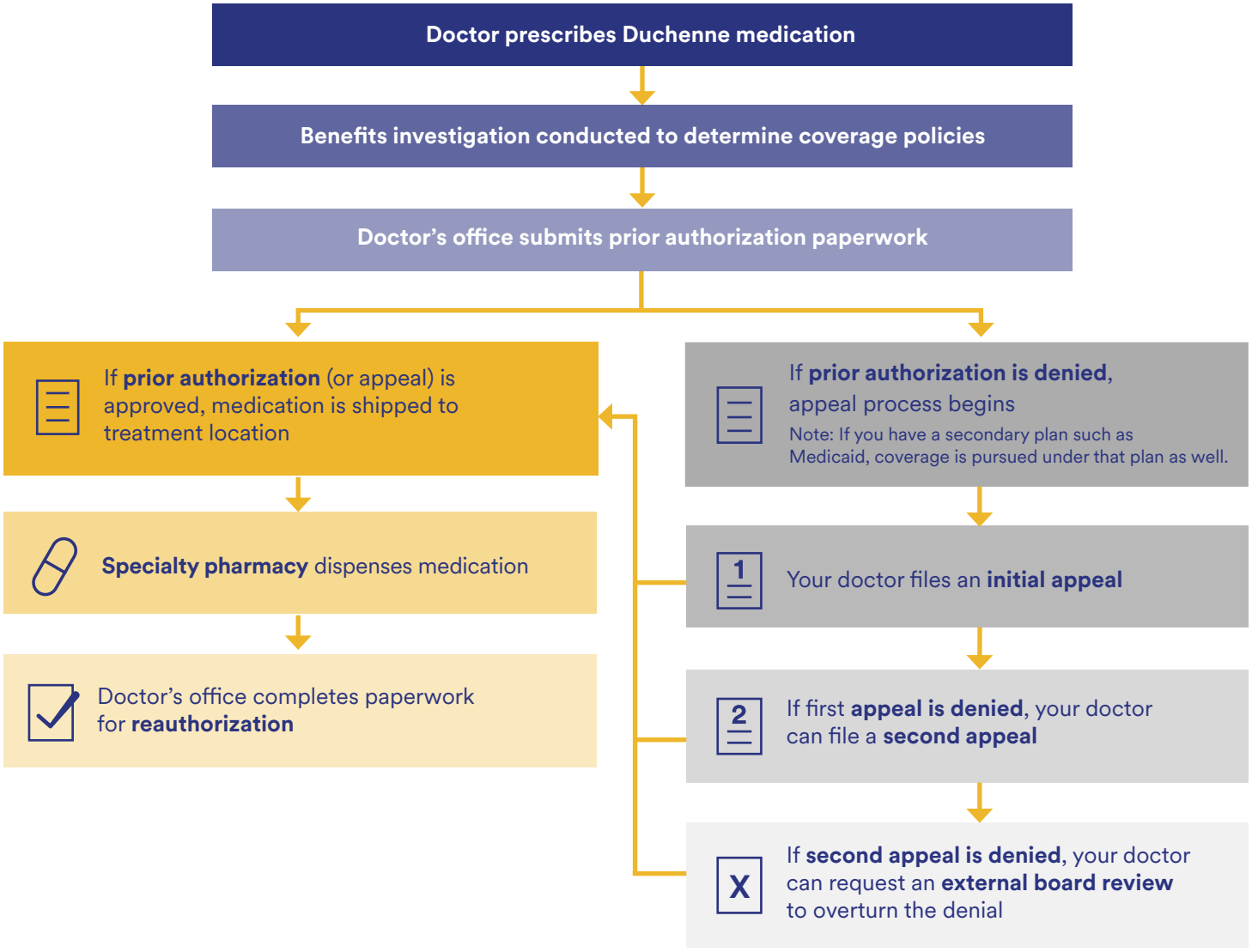
Benefits investigation: Duchenne medication authorization process

Your insurance company may require a prior authorization before the plan will cover the cost of treatment, which can delay the shipment of the drug. Below is a brief overview of what typically happens during the authorization process:



What can you do?

As a critical part of the team, you can support this process by:

- Calling your SareptAssist Case Manager
- Contacting your insurance company directly
- Checking in regularly with your doctor's office
- Reaching out to patient advocacy organizations for assistance
- Sharing your experiences on social media

Common reasons for denials

Why is a prior authorization denied?

COMMON REASONS INCLUDE:

- **Plan does not consider the Duchenne therapy to be medically necessary based on the plan's criteria. For example, the plan may:**
  - Require genetic testing to confirm a gene mutation for Duchenne[19]
  - Have specific requirements for respiratory function such as the ability to breathe without the use of a ventilator[19]
  - Require a specific score range on the 6 minute walk test (6MWT)[19]
  - Only cover medication for a specific age range
- **Incomplete information was provided, such as lack of proper clinical assessments**
- **The plan may not approve a newly FDA-approved medication**

Why is a reauthorization denied?

COMMON REASONS INCLUDE:

- **Specific assessments (eg, score on 6MWT) were not met**
- **Paperwork mistake or missing information**
- **Age may no longer be covered under plan policy**
- **Patient did not go to appointments or complete the necessary clinical assessments**

Financial assistance options

Depending on the type of insurance you have and other relevant circumstances, you may qualify for financial assistance programs. Your SareptAssist Case Manager can help provide information about the options and see if you are eligible for the following Sarepta programs.

PATIENT CO-PAY ASSISTANCE PROGRAM

This program may help with some out-of-pocket costs for Duchenne medication (not the costs of supplies or other treatment-related costs). It is for eligible individuals with commercial insurance only (not Medicaid or Medicare) in the United States who are prescribed treatment with a Sarepta product.

PATIENT ASSISTANCE PROGRAM (PAP)

This program can help uninsured patients (or those rendered uninsured) who meet certain requirements obtain access to their prescribed drug. You may be responsible for additional costs associated with administration of the drug.

MULTIPLE INDEPENDENT CHARITABLE ORGANIZATIONS

There are multiple programs that offer financial assistance, such as the Duchenne Family Assistance Program. Your SareptAssist Case Manager can provide more information and direct you to these third-party options.

You can rely on your SareptAssist Case Manager and care team to stay informed of your options and help avoid treatment interruptions as your needs change (eg, new insurance, change of address).

Real cases

Different patients, different journeys to Duchenne therapy

While you are not alone in your diagnosis, every path to therapy is unique. That's why it's so important to speak with a SareptAssist Case Manager as soon as you are prescribed your medication. Your personalized SareptAssist Case Manager has a team backed with years of knowledge and experience managing many different case dynamics and circumstances.

Following are examples of the treatment journey for our current patients, including the challenges in gaining approval, and how the Sarepta team can help—so you can see the different ways the path to access can unfold, and what you may need to consider along the way.

CM=case manager; DMAR=Director of Market Access and Reimbursement; DNE=Duchenne nurse educator; MD=doctor of medicine; MDO=medical doctor's office; PAM=patient access manager; SP=specialty pharmacy

Case Study #1

Patient: Boy, age 5 **Type of insurance:** Medicaid fee-for-service

	Access journey	Role of care team
Month 1	• Physician completed and submitted the SareptAssist START Form • Prior authorization was submitted by the doctor's office for the patient, along with the genetic testing report and clinical notes from his most recent visit with his MD—including functional assessments that the plan requires for approval • The health plan then approved his therapy, requiring reauthorization every 6 months	• CM completed welcome call with the parents and re-confirmed this patient would be getting infused at an infusion clinic near his home • CM informed parents that insurance approval may take several weeks, and kept them informed throughout the process • CM obtained insurance benefits through Medicaid • DMAR reviewed the policy and prior authorization criteria with the office and worked with the site of care to determine procurement preference and infusion plans • The infusion center preferred to white bag, so the CM helped triage necessary information to the SP • As this patient was treatment naive, the CM notified the DNE to provide further education on DMD and the infusion process to the patient and his parents
Month 2	• Patient began infusions in the outpatient infusion clinic as decided on between the family and their physician	• CM confirmed with infusion site and family that everything was ready to begin infusion • DNE performed in-service for infusion nurse at the outpatient clinic prior to first infusion
Month 8	• Reauthorization was submitted and approved every 6 months	• DMAR educated office staff on reauthorization procedures and proper documentation • CM advised the patient to make an appointment with their doctor to obtain the necessary functional assessments and updated chart notes necessary for reauthorization

CM=case manager; DMAR=Director of Market Access and Reimbursement; DNE=Duchenne nurse educator; MD=doctor of medicine; SP=specialty pharmacy.

Case Study #2

Patient: Spanish-speaking male, age 31 **Type of insurance:** Medicaid fee-for-service

	Access journey	Role of care team
Month 1	• Physician completed and submitted the SareptAssist START Form • Prior authorization was submitted by the doctor's office with the genetic testing report for the patient • Duchenne therapy was denied by the health plan due to his age and because he required further lab work documenting renal function within the last 3 months • The first appeal was submitted by office staff, which included updated lab work and a letter of medical necessity from the doctor's office	• SareptAssist CM obtained insurance benefits through Medicaid and connected with family to discuss next steps • DMAR reviewed policy and prior authorization criteria with the office • CM sent referral to the SP to start the authorization process with the doctor's office • CM included the PAM once initial authorization was denied. A Spanish-speaking PAM spoke with the patient to discuss writing a patient appeal letter to be included with the doctor's letter • PAM provided the patient with guidance, explaining how it would be necessary for the patient to obtain the required lab work to document renal function and where he could go to complete that • DMAR worked with the office to help them understand the denial and educated them on the appeal process and documentation required to support the case for coverage
Month 2	• The health plan approved therapy for in-home use per the patient's request, which required reauthorization every 3 months	• DNE performed in-service for the home health nurse prior to first infusion, and then followed up after infusion to ask how it went • CM worked with SP and family to prepare for first infusion including home health aid confirmation, appointment set up, and ensuring drugs and supplies were at the patient's home
Month 6	• Reauthorization submitted by the doctor's office with a letter of medical necessity and updated clinical notes • There was no interruption to therapy and a subsequent reauthorization was approved for 1 year	• DMAR educated office staff on reauthorization procedures and proper documentation • CM continued to check in with family and to monitor upcoming reauthorizations

CM=case manager; DMAR=Director of Market Access and Reimbursement; DNE=Duchenne nurse educator; PAM=patient access manager; SP=specialty pharmacy.

Case Study #3

Patient: Boy, age 12 **Type of insurance:** Managed Medicaid

	Access journey	Role of care team
Month 1	• Physician completed and submitted the SareptAssist START Form • Prior authorization was submitted by the doctor's office with the genetic testing report for the patient, but Duchenne therapy was denied by the health plan due to "missing clinical support (6MWT)" • Office staff then submitted the first appeal	• DMAR reviewed the policy and prior authorization criteria with the MDO • CM obtained consent connected with family to discuss the process • Insurance benefits were obtained and information was provided to the doctor's office to assist with the initial authorization submission and the first appeal • DMAR provided education to MDO on how to process prior authorization appeals and aligned upon next steps
Month 2	• The first appeal was denied because 6MWT was not included with the appeal • The patient was unable to complete the 6MWT by the time of submission so a second appeal was submitted, heading straight to an external review (some Medicaid plans only offer one internal appeal)	• CM brought in PAM to work with family on the appeal process • PAM met in person with the patient's mother to educate on documentation needs and about the external review process • DMAR educated the provider on the external review process and timelines as well as necessary documentation • Once confirmation of external review request was submitted by medical doctor's office, CM/PAM followed up on status
Month 7	• The external review board overturned the decision, allowing the patient to receive coverage for therapy and requiring reauthorization every 6 months	• DNE performed in-service for the clinic prior to first infusion, and then followed up after infusion to ask how it went. DNE then worked with an SP to identify a home health nurse • CM confirmed the infusion site received the drug shipment and family had scheduled appointments
Month 13 and beyond	• Multiple reauthorization requests have been processed, with occasional denials due to ambulation status; however, each denial was overturned after the submission of an appeal	• CM continued to check in with family and monitor reauthorizations • DMAR confirmed next appointment visit for CM and educated office on requirements for appeals • CM coordinated support for family as needed

CM=case manager; DMAR=Director of Market Access and Reimbursement; DNE=Duchenne nurse educator; MDO=medical doctor's office; PAM=patient access manager; SP=specialty pharmacy.

Case Study #4

Patient: Boy, age 9 **Type of insurance:** Commercial

	Access journey	Role of care team
Month 1	• Physician completed and submitted the SareptAssist START Form • Prior authorization was submitted by the doctor's office with the genetic testing report for the patient, but Duchenne therapy was denied because his health care policy listed it as "not medically necessary"	• DMAR reviewed the policy and prior authorization criteria with the MDO • CM obtained benefits and completed welcome call with family to discuss next steps and confirmed plan to start therapy at hospital • CM sent referral to SP to start authorization process with MDO after DMAR confirmed the site preference to accept drug from SP
Month 3	• A letter of medical necessity appeal was submitted to the insurance company • The appeal was denied again, citing the medical policy stating "medication was not medically necessary" • A second appeal was submitted, which headed straight to an external review	• DMAR educated office on appeal process and requirements based on policy • After denial, CM looped in PAM to educate family on the appeals process and steps they could take • PAM educated family on steps they could take with MD appeal • DMAR educated the provider on the external review process and timelines as well as necessary documentation
Month 5	• The external review board overturned the previous decision, allowing the patient to receive coverage for therapy and requiring authorization every 6 months	• CM helped family secure an infusion location and maintained regular check-ins to ensure information was up to date for reauthorization
Month 11	• The first reauthorization was submitted and denied, claiming the patient did not meet the plan's improvement criteria	• DMAR confirmed next appointment visit for CM and educated office on requirements for the appeal
Month 13 and beyond	• After a doctor's appointment, which allowed for the submission of recent clinical notes, the reauthorization was appealed • The health plan approved Duchenne therapy for 1 year, with reauthorization required after 1 year	• CM continued to check in with family and educate/monitor on upcoming reauthorizations

CM=case manager; DMAR=Director of Market Access and Reimbursement; MD=doctor of medicine; MDO=medical doctor's office; PAM=patient access manager; SP=specialty pharmacy.

How Sarepta can help

Prior authorization was submitted in alignment with health plan requirements; however, our patient support program, SareptAssist, is designed to provide you with information to navigate the treatment process. Our dedicated Sarepta team offers information on:

- **Insurance benefits**
- **Financial assistance options**
- **Treatment logistics**
- **Options for weekly infusions**
- **Ongoing education and support**

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Remember, while your doctor is your first point of contact for all medical needs, your **SareptAssist CM** is committed to working with you during the treatment journey and will check in regularly.
For more information, visit SareptAssist.com.

We are committed to partnering with you, your doctors, and your health plan to ease the stress of accessing Duchenne therapy, so you can focus on what's important—life with your family.

References: 1. What is health insurance? Health.org. Accessed June 13, 2022. https://www.healthinsurance.org/glossary/health-insurance/ **2.** What is self funding? Health Care Administrators Association. Accessed June 13, 2022. https://www.hcaa.org/page/selffunding **3.** Understanding health insurance options: a guide for people living with Duchenne Muscular Dystrophy and their caregivers. Accessed June 13, 2022. https://www.parentprojectmd.org/care/for-families/community-resource-center/daily-life-resources/insurance/ **4.** Medicaid. Medicaid.gov. Accessed June 13, 2022. https://www.medicaid.gov/medicaid/index.html **5.** MACPAC. Provider payment and delivery systems. Accessed June 13, 2022. https://www.macpac.gov/medicaid-101/provider-payment-and-delivery-systems/ **6.** Medicare program - general information. Centers for Medicare & Medicaid Services. Accessed June 13, 2022. https://www.cms.gov/Medicare/Medicare-General-Information/MedicareGenInfo **7.** Medicare eligibility for disabled youths. Medicare Interactive. Accessed June 13, 2022. https://www.medicareinteractive.org/get-answers/medicare-basics/medicare-eligibility-overview/medicare-eligibility-for-disabled-youths **8.** Eligibility. Medicaid.gov. Accessed June 13, 2022. https://www.medicaid.gov/medicaid/eligibility/index.html **9.** Compassionate allowances. Social Security Administration. Accessed June 13, 2022. https://www.ssa.gov/compassionateallowances/ **10.** Figueiredo M. DMD adults added to SSA compassionate allowance program. August 19, 2021. Muscular Dystrophy News Today. Accessed December 15, 2022. https://musculardystrophynews.com/2021/08/19/social-security-compassionate-allowances-program-eligibility-duchenne-muscular-dystrophy/ **11.** Shapiro J. Katie Beckett defied the odds, helped other disabled kids live longer. NPR. Accessed June 13, 2022. https://www.npr.org/sections/health-shots/2012/05/21/153202340/katie-beckett-defied-the-odds-helped-other-disabled-kids-live-longer **12.** Deductible. Healthcare.gov. Accessed June 13, 2022. http://www.healthcare.gov/glossary/deductible/ **13.** Understanding your health plan drug formulary. Verywellhealth.com. Accessed June 13, 2022. https://www.verywellhealth.com/understanding-your-health-plan-drug-formulary-1738897 **14.** Cost sharing limits overview. Cigna. Accessed June 13, 2022. https://www.cigna.com/employers-brokers/insights/informed-on-reform/cost-sharing **15.** Faust S. Pharmacy vs. medical benefit. Pharmacy Today. Accessed June 13, 2022. https://www.pharmacytoday.org/action/showPdf?pii=S1042-0991%2815%2930134-1 **16.** McCain J. The importance of a thorough benefits investigation to help navigate medical vs pharmacy benefit. National Association of Medication Access & Patient Advocacy, Inc. Accessed June 13, 2022. https://namapa.org/medical-vs-pharmacy-benefit **17.** Lotvin A. Managing specialty drug spend under the medical benefit. CVSHealth. March 30, 2017. Accessed June 13, 2022. https://payorsolutions.cvshealth.com/insights/managing-specialty-drug-spend-under-the-medical-benefit **18.** Specialty drug acquisition models. Specialty Drug Resource. Accessed June 13, 2022. https://www.specialtydrugresource.com/coverage-landscape-overview/buy-and-bill-vs-specialty-pharmacy **19.** Margaretos NM, Bawa K, Engmann NJ, Chambers JD. Patients' access to rare neuromuscular disease therapies varies across US private insurers. *Orphanet J Rare Dis.* 2022;17(1):36. doi:10.1186/s13023-022-02182-3

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