

AGAMREE® is FDA approved to treat Duchenne muscular dystrophy (DMD) in patients 2 years of age and older.



Duchenne Journal

Caring for a child with Duchenne muscular dystrophy (DMD) means managing a lot of information. This journal is here to help. Use it to keep a clear record of treatments, routines, changes, and observations—then share important details with your healthcare team.

Whether you're tracking every day, checking in weekly, or observing monthly, each note brings you one step closer to supporting your child's health with confidence.



IMPORTANT SAFETY INFORMATION

Patients should not take AGAMREE if they are allergic to vamorolone or any of the inactive ingredients in AGAMREE.

Please see Important Safety Information on page 26 and accompanying full Prescribing Information.

This journal belongs to:

Name: _____

Date: _____

Contact information:

Catalyst Pathways®: 1-833-422-8259 AnovoRx Specialty Pharmacy: 1-844-288-5007

Patient Access Liaison (PAL): _____

Medication details:

AGAMREE® dose: _____ Date started: _____

Any previous treatment(s): _____

Reason for switch (if applicable): _____

Medicine

Tracking your child’s medicines helps you remember what they’re taking and how each one makes them feel. It’s also a good way for you to share clear information with your healthcare team. **Use the spaces below to track details about your child’s medicines.**



DATE STARTED	MEDICATION	DOSE	NOTES
___ / ___ / ___			
___ / ___ / ___			
___ / ___ / ___			
___ / ___ / ___			
___ / ___ / ___			
___ / ___ / ___			

Is your child experiencing any side effects? Explain here to discuss with your healthcare team.

Appetite and growth

As with any corticosteroid treatment, your child may experience weight changes, particularly in the beginning of treatment. Instead of focusing solely on the number on the scale, it can be helpful to consider other signs of change, like overall eating habits and growth patterns.

Share these details with your healthcare team—both at the start of treatment and over time—to better manage treatment overall and give you the opportunity to discuss potential dose adjustments if your child is experiencing weight gain. **Use the prompts below to fill in the spaces.** Add in notes and comments where necessary.



DATE	APPETITE (Increased, decreased, normal)	MEAL & SNACK FREQUENCY (No. of meals/snacks per day)		CHANGES IN EATING HABITS (Portion sizes, food choices, cravings)	BELT ADJUSTMENTS (Also consider changes in waist size)	CHANGES IN CLOTHES SIZE/FIT (Feeling tighter, staying the same)
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___ / ___ / ___						
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___ / ___ / ___						

Appetite and growth

Have you seen any significant changes in your child's eating habits or growth patterns?

Write them here to discuss with your healthcare team.

ADDITIONAL NOTES



Behavior

You may notice changes in your child’s behavior during treatment—or you may notice no differences at all. Use this assessment to track any changes you may want to discuss with your healthcare team. There are no wrong or right answers—it’s just an honest look at how your child has been feeling.

During the last month, how often have you seen the following behaviors in your child? In the spaces below, write down never or rarely (NR), sometimes (S), often (O), or always (A). Add in notes and comments where necessary.



DATE	SAD OR UPSET	RESTLESS OR TENSE	UNRESPONSIVE TO DISCIPLINE		UNABLE TO MAKE DECISIONS	SHOWS LITTLE OR NO INTEREST IN THINGS	ACTS OUT	APPEARS LISTLESS AND/OR APATHETIC
___ / ___ / ___								
___ / ___ / ___								
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___ / ___ / ___								

Behavior

Have you seen any significant changes in your child's mood or behavior?

Write specific examples here to discuss with your healthcare team.

ADDITIONAL NOTES



Muscle strength and movement

Your child’s muscle strength and movements can change over time—sometimes in small ways. Writing it down can help you and your healthcare team see what may be improving with treatment, and what may be more challenging over time.

How often do you notice the following signs or symptoms in your child? In the spaces below, write down never or rarely (NR), sometimes (S), often (O), or always (A). Add in notes and comments where necessary.



DATE	DIFFICULTY CLIMBING STAIRS	DIFFICULTY STANDING FROM SITTING POSITION	DIFFICULTY LIFTING OBJECTS		DIFFICULTY WALKING	FEELING TIRED OR WEAK	HAVING PAIN (Specify location)	HAVING TROUBLE BREATHING	DIFFICULTY TALKING OR SWALLOWING
___ / ___ / ___									
___ / ___ / ___									
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Muscle strength and movement

Have you seen any significant changes in your child's ability to move or get around?

Write specific examples here to discuss with your healthcare team.

ADDITIONAL NOTES



Questions to ask your child's healthcare team

CHANGES SINCE MY CHILD'S LAST VISIT

How has my child's health and mobility changed overall?

Have there been changes in my child's lung or heart health?

Are there any new concerns around my child's spinal posture or curvature?

MY CHILD'S MEDICINE

What are potential short- and long-term symptoms we might expect from taking corticosteroids for DMD, and how can they be managed?

Are there other medications to consider for my child at this stage of DMD?

How can my child's current treatment help even after loss of mobility?

BEHAVIOR AND BONE HEALTH

Are there behavioral specialists or psychologists in the office, center, or hospital who can help assess and manage my child's potential mood and behavior changes? If not, is there someone you recommend?

How is bone health monitored in DMD, and how do we prevent or treat scoliosis?



ADDITIONAL COMMENTS AND QUESTIONS

Based on the information you have logged in your journal—considering your child’s appetite and growth, behavior, and muscle strength and movement—what other comments or questions do you have for your healthcare team?

Achievements or aspirations

This section is for mapping out achievements or aspirations that matter to you and your child—whether they’re about health, hobbies, school, friendship, or everyday life. Take some time to write down what you both want to achieve, and any steps you’re taking to get there.

ACHIEVEMENT OR ASPIRATION:

ACHIEVEMENT OR ASPIRATION:

ACHIEVEMENT OR ASPIRATION:



Has your child experienced any positive changes or “wins” recently?

Write specific examples to discuss with your healthcare team.



Meditation moment: Breathe with intention
Following your breath refocuses your mind, shifting your attention away from daily stresses to the present moment. Try counting each inhale and exhale. For example, breathe in and out, and count “1.” Continue this pattern until you reach 10, and then start again. **Learn more meditation techniques on page 23.**

At-home stretching

Daily stretching can help delay muscle tightness and support your child's ability to move and stay independent for longer. The stretches that follow can be done with your help or independently, depending on abilities and comfort level. A little time each day can make a meaningful difference.

Talk with your healthcare team for medical advice before starting a new stretching routine.

Stretches for the lower body



Hamstring

Lie down at the corner of 2 walls. Place a heel on the wall and the other leg along the wall on the floor. Slowly move closer to the wall until a stretch is felt in the back of the thigh. Hold for 60 seconds and repeat 1-2 times.



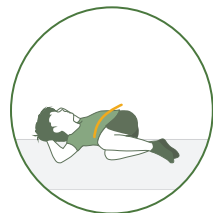
Gastrocnemius (upper calf)

While standing at a wall, position one foot in front of the other. Lean forward while keeping the back knee straight and toes pointed forward. Hold for 60 seconds, relax, then repeat.



Soleus (lower calf)

While standing at a wall, position one foot in front of the other. Slowly lean forward while bending the back knee and keeping toes forward and heel on the ground. Hold for 60 seconds, relax, then repeat.



Trunk rotation

While lying on the back with knees bent, swing legs to one side, allowing the hips and lower back to rotate in the same direction. Hold for 10-20 seconds, then rotate to the opposite direction and hold for 10-20 seconds. Repeat on each side 10-20 times.



Meditation moment: Stretch slowly

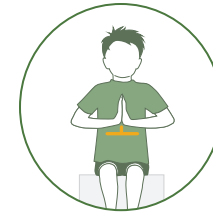
Being a caregiver takes strength. Take a few minutes to stretch your neck, shoulders, back, or hips—wherever you hold stress. Move gently and breathe deeply. **Learn more meditation techniques on page 23.**

Stretches for the upper body



Wrist extension

While seated, place palms down on each side. Slowly move hands backward until a stretch is felt. Hold for 60 seconds, relax, reposition, and repeat.



Wrist and finger extension

While seated, place palms together in front of chest. Slowly lower hands, keeping elbows out until a stretch is felt. Hold for 60 seconds, relax, reposition, and repeat.



Neck extensor

While lying on the back, position neck in a comfortable position looking forward.



Tuck the chin down while extending the back of the neck. Hold for 5-10 seconds, relax, and repeat 5-10 times.

Adapted from CureDuchenne.
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Reference: Self-stretching. CureDuchenne. Accessed November 3, 2025.
<https://cureduchenne.org/wp-content/uploads/2019/11/self-stretches-english.pdf>

Nutritional needs

Making healthy food choices can help your child with Duchenne feel better overall. There’s no specific diet—but keeping a few simple habits in mind can make a big difference over time.

Here are a few general guidelines to consider:



Protein is an important part of any diet, especially in DMD. Eating more protein can help your child stay full longer, which can help prevent unhealthy snacking. The most common way to satisfy protein requirements is through lean meat, like chicken, grass-fed beef, lamb, and fish, and other foods like beans, yogurt, and nuts.



Heart health is important for people with DMD. Limit foods like saturated fats (commonly found in animal products and processed foods) or high amounts of salt (sodium).



Bone health is important for people with DMD. Be sure your child is getting enough calcium and vitamin D, which are essential nutrients for bone health. Ask your healthcare team about the right doses.



Drinking enough water helps remove waste from the body, maintain a normal body temperature, keep the joints moving, and maintain healthy tissue. The general guideline for how many ounces of water to drink daily is your child’s weight divided by 2.
For example: 100 lb / 2 = 50 oz of water daily

Talk with your healthcare team about the suggested daily values that are right for your child.

References: 1. Proper nutrition for people with Duchenne muscular dystrophy. CureDuchenne. Accessed November 3, 2025. <https://cureduchenne.org/care/nutrition-duchenne> 2. Ward LM, Hadjiyannakis S, McMillan HJ, Noritz G, Weber DR. Bone health and osteoporosis management of the patient with Duchenne muscular dystrophy. *Pediatrics*. 2018;142(Suppl 2):S34-S42.

5 meditation techniques

Caring for a child with Duchenne is both deeply meaningful and highly demanding. Taking just a few minutes each day to check in with yourself can help lower stress and refill your tank. These quick mindfulness practices are easy to try, even on your busiest days.



Mindfulness meditation *(Stay present and notice without judgment)*
Sit or lie comfortably, breathe naturally, and observe your thoughts and sensations; gently return to the moment if your mind wanders.
Benefits: Improves focus, emotional balance, and stress management



Loving-kindness meditation *(Create compassion for yourself and others)*
Close your eyes, send positive wishes to yourself, then extend them to others.
Benefits: Boosts empathy, mood, and self-love



Body scan meditation *(Tune into your body’s sensations)*
Move your attention slowly from head to toe, noticing tension or relaxation.
Benefits: Reduces physical tension and grounds your awareness



Breath awareness *(Anchor your mind with your breath)*
Focus on each inhale and exhale, or count your breaths.
Benefits: Calms the nervous system and supports emotional stability



Progressive muscle relaxation *(Release stress through physical relaxation)*
Tense each muscle group for 5 seconds, then release, starting from your toes and moving upward.
Benefits: Relieves stress and promotes deep relaxation



Make it a habit
Set a reminder on your calendar and start with a few minutes daily. Consistency matters more than duration. Short, daily practice is more effective than occasional long sessions.

References: 1. Riopel L. 15+ meditation exercises & activities to practice today. PositivePsychology.com. September 25, 2019. Accessed November 3, 2025. <https://positivepsychology.com/meditation-exercises-activities> 2. What is the best type of meditation? Medical News Today. Updated May 24, 2023. Accessed November 03, 2025. <https://www.medicalnewstoday.com/articles/320392>

Find your community

Caring for a child with Duchenne can feel overwhelming at times—but you don’t have to do it alone. Whether you’re looking for emotional support, trusted information, or connection with others who “get it,” there’s a strong and welcoming community ready to support you.



CureDuchenne.org

Organization committed to finding a cure for Duchenne using innovative venture philanthropy to fund groundbreaking research, early diagnosis, and treatment access



MDA.org

Organization started by a concerned group of caring families. Since 1950, the MDA has relentlessly pursued their promise to free families from the life-threatening effects of muscular dystrophy and muscle-debilitating diseases



TheAkariFoundation.org

Focuses on educating and empowering the Hispanic community on rare diseases, helping with resources, awareness, advocacy, and education specializing in Duchenne



JettFoundation.org

Empowers people and families impacted by Duchenne through the development of transformative programming, educational opportunities, and ongoing support for every stage of Duchenne



ParentProjectMD.org

The largest Duchenne-specific patient advocacy organization whose mission is to end Duchenne by accelerating research, raising awareness to impact policy, demanding optimal care for every single family, and striving to ensure access to approved therapies



TeamJoseph.org

Fights for all children and young adults battling Duchenne and is committed to ensuring every child with Duchenne receives the care, medical equipment, and support they need to live a full life, regardless of their financial situation

“It makes it a little easier when you know somebody is out there, families that are just like us that have gone through this before.” – Holly, mother of Grant, actual AGAMREE® patient



Seek out new friendships at summer camp



Jett Foundation’s Camp Promise — CampPromise.org

Gives children and teens with neuromuscular conditions, including DMD, a chance to enjoy a traditional, fully accessible summer camp—at no cost to families



Muscular Dystrophy Association’s Summer Camp — MDA.org/summer-camp

A place for kids and young adults with neuromuscular disease, including DMD, to develop friendships, learn to self-advocate, and harness potential—at no cost to families

Try a mentor program

Sometimes the best support comes from someone who has walked a similar path.

ACESMentorProgram.com

The AGAMREE, Connect, Educate, and Support (ACES) Mentor Program gives you the opportunity to connect with a mentor by phone or video to address your questions based on their experiences with DMD and treating with AGAMREE

Jett Foundation Community Ambassadors — JettFoundation.org/Community-Ambassadors

Connect with community ambassadors, who are individuals impacted by Duchenne, moms, dads, grandparents, siblings, and more. They are advocates, educational resources, and pillars of emotional support

Parent Project Muscular Dystrophy Connect Programs — ParentProjectMD.org/Get-Involved/Connect

Led by volunteer parents and grandparents, PPMD’s Connect groups serve as regional points of contact for families and individuals affected by Duchenne



Scan for more community support groups
Or visit YourCatalystPathways.com/dmd/your-resources

Important Safety Information

What is AGAMREE?

AGAMREE is a prescription medicine used to treat Duchenne muscular dystrophy (DMD) in patients 2 years of age and older.

IMPORTANT SAFETY INFORMATION

Patients should not take AGAMREE if they are allergic to vamorolone or any of the inactive ingredients in AGAMREE.

What is the most important information I should know about AGAMREE?

- **Do not stop AGAMREE, or change the amount taken, without first checking with your healthcare provider.** There may be a need for gradual dose reductions to decrease the risk of adrenal insufficiency crisis, which can be fatal.
- **There is an increased risk of infection when taking corticosteroids like AGAMREE.** Tell your healthcare provider if the patient has had recent or ongoing infections or has recently received a vaccine. Seek immediate medical advice in the case of fever or other signs of infection. Some infections can be severe, and sometimes fatal. Patients should avoid exposure to chickenpox or measles; alert your healthcare provider immediately if exposure occurs.
- **Corticosteroids, including AGAMREE, can cause an increase in blood pressure and water retention.** Your healthcare provider may monitor for these increases during treatment.
- **There is an increased risk of developing a hole in the stomach or intestines in patients with certain gastrointestinal disorders when taking corticosteroids like AGAMREE.**
- **Corticosteroids, including AGAMREE, can cause severe behavioral and mood changes.** Seek medical attention if behavioral or mood changes develop.
- **There is a risk of osteoporosis with prolonged use of corticosteroids like AGAMREE,** which can lead to vertebral and long bone fractures.
- **Corticosteroids like AGAMREE may cause cataracts or glaucoma.** Your healthcare provider should monitor for these conditions if AGAMREE treatment continues for more than 6 weeks.

- Immunizations should be up to date according to immunization guidelines prior to starting therapy with AGAMREE. Live-attenuated or live vaccines should be administered at least 4 to 6 weeks prior to starting AGAMREE. Live-attenuated or live vaccines should not be administered in patients taking AGAMREE.
- Rare instances of severe allergic reaction have occurred in patients receiving corticosteroid therapy.

Before taking AGAMREE, tell your healthcare provider about all medical conditions, including if the patient:

- has decreased liver function.
- is pregnant or planning to become pregnant. AGAMREE can harm an unborn baby.
- is breastfeeding or planning to breastfeed. AGAMREE may appear in breastmilk and could affect a nursing child.

Certain medications can cause an interaction with AGAMREE. Tell your healthcare provider about all the medicines the patient takes, including prescription and over-the-counter medicines, dietary supplements, and herbal products.

What are the possible side effects of AGAMREE?

The most common side effects with AGAMREE include facial puffiness (cushingoid features), psychiatric disorders, vomiting, weight gain, and vitamin D deficiency. These are not all the possible side effects of AGAMREE.

Call your doctor for medical advice about side effects.

Please see accompanying full Prescribing Information for additional Important Information.

To report SUSPECTED ADVERSE REACTIONS, contact Catalyst Pharmaceuticals, Inc. at 1-844-347-3277 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

ADDITIONAL NOTES





**Hear how
AGAMREE® has
impacted lives—
from actual
patients and
their families**



GAVEN

Actual AGAMREE patient.



Scan to watch their stories

Or visit

AGAMREE.com/patient-support/agamree-resources

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