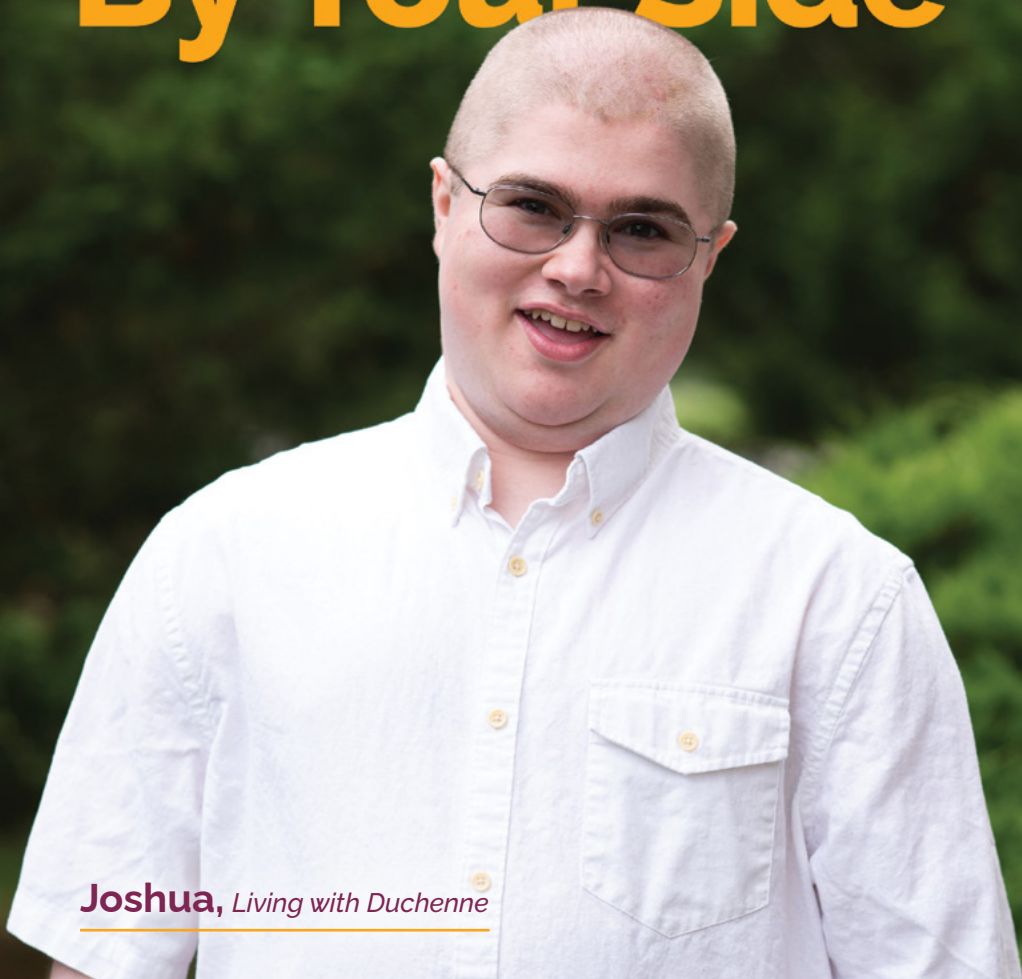


Fall 2024

By Your Side



Joshua, *Living with Duchenne*

Embracing the
community dedicated
to Duchenne



SareptAssist is standing by. Get connected with your personal Case Manager.
Call [1-888-SAREPTA \(1-888-727-3782\)](tel:1-888-SAREPTA) Monday through Friday, 8:30 am – 6:30 pm ET

CREATING CONNECTIONS

Finding support in all corners of the Duchenne community

A lot goes into the daily management of Duchenne, and having a care team you can lean on is critical to getting the most out of treatment. Together with others in the Duchenne community, you have more support than you may realize.

Social Tips from Joshua

Living with Duchenne

“



The more you interact with other people, the more comfortable you're going to be. It's easier for me to just put myself out there.

”

Nurturing social relationships is a crucial part of a healthy and productive life for anyone.¹ Connecting with others over a hobby or special interest can be a great place to start.



Care Team Tips from Timothy Estilow

Occupational Therapist

"It's extremely important to have a multidisciplinary team to discuss what the priorities and needs are for care."

Having a well-rounded team of specialists in your corner can help you gain and maintain your independence.²



Support Tips from Dawna Kraft

Associate Director, Patient Services

"If anything comes up, call us. Because if we can't help you, we usually can put you on the path to finding the help you need."

Your SareptAssist Case Manager is there to support you. Whether you need help with your pharmacy, coordinating treatment while traveling, or finding resources, they are always ready to jump in.

SEPTEMBER IS WORLD DUCHENNE AWARENESS MONTH

Did you know? September 7th, 2024 is the first annual World Duchenne Awareness Day recognized by the United Nations.³ It's a day to put your community connections into action and empower individuals and their families impacted by Duchenne around the globe.

COME TOGETHER TO TAKE ACTION

Say it on social. Spread the word about Duchenne across social media using **#DuchenneAwarenessMonth** and **#WDAD2024** (World Duchenne Awareness Day 2024).

Using these hashtags is a great tool for sharing information about the other ways you may be raising awareness. See below for more community-based ideas.



Raise research funds

Invite others to support ongoing Duchenne research by creating an online fundraiser.



Get in on game day

Connect with local high schools or community sports teams to host a charity game on September 7th.



Celebrate and educate

Work with school administrators to take advantage of the back-to-school season by bringing Duchenne education into the classroom.

SAREPTASSISTSUPPORT

Navigate support groups with help from your Case Manager

There are many Duchenne organizations and advocacy groups that are available to you. They are a great starting point for connecting with peers and other families impacted by Duchenne. Contact your Case Manager to see if some groups may be able to assist with finding local solutions to your specific needs.



CRITTER CORNER

Finding comfort in an animal companion

Spending time with animals can have many benefits. Whether they offer comfort, companionship, or a means to accessibility, they can be the perfect addition to your Duchenne circle.⁴

— TRISTAN,
Living with Duchenne

To find the right fit for you, it's important to know what you're looking for. You have options beyond the friendship of a family pet, depending on your needs, circumstances, or preferences.

Enlisting the help of a service dog⁴

A service dog is more than a companion—they are specially trained to do a number of jobs that help you participate more fully in your day-to-day life. For those with Duchenne, service dogs can assist with:

- Standing up from being seated
- Bringing medication to you
- Walking or taking the stairs
- Alerting others to medical emergencies
- Picking up items

You and your service dog are a team. You take care of their needs and keep an eye on how they are behaving. In turn, your service dog puts your interests first and can be depended on to do the tasks they're trained to do.

SAREPTASSISTSUPPORT

Navigating your needs

It can be hard to know exactly where to look for specific support. Your Case Manager is there to help. They can help connect you with the right Duchenne organization or advocacy group for your needs.

Finding an emotional support friend⁴

Unlike service animals, emotional support animals (ESAs) aren't trained to do specific tasks. Beyond companionship, they are there to offer therapeutic support like reducing anxiety or boosting mental health.

ESAs can be any kind of animal, so long as they are trained to behave in public. To the right is a list of potential ESAs that may be right for you.

POTENTIAL ESAs

- Dogs
- Cats
- Rabbits
- Birds
- Miniature horses

You may find that there are places where pets are not allowed but ESAs are. For example, if you rent a home with rules against having pets, the Fair Housing Act allows you to keep your ESA there. A licensed mental health professional can provide you with a letter or prescription that certifies your animal as an ESA, which may help in these situations.



It's important to understand your rights when it comes to using a service dog. They are allowed to be where other animals are not, including on public transportation like airplanes.

Visit [ADA.gov/topics/service-animals/](https://www.ada.gov/topics/service-animals/) to learn more.

Get connected with your dedicated Case Manager

SareptAssist Case Managers are experts on Duchenne, insurance plans, and healthcare networks. They can help you learn, connect, and get answers.

Call **1-888-SAREPTA** (1-888-727-3782)
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References: 1. Orben A, Tomova L, Blakemore SJ. The effects of social deprivation on adolescent development and mental health. *Lancet Child Adolesc Health*. 2020;4:634-40. 2. Birnkrant DJ, Bushby K, Bann CM, et al. Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis and neuromuscular, rehabilitation, endocrine, and gastrointestinal and nutritional management. *Lancet Neurological*. 2018;17(3):251-267. 3. PR Newswire. United Nations officially designates September 7 as World Duchenne Awareness Day. Accessed Jul 30, 2024. <https://www.prnewswire.com/news-releases/united-nations-officially-designates-september-7-as-world-duchenne-awareness-day-302001169.html> 4. Muscular Dystrophy News Today. Pet project: service animals for Duchenne muscular dystrophy. Accessed August 14, 2024. <https://muscular dystrophynews.com/duchenne-muscular-dystrophy-service-animals/>



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