

# By Your Side

September 2023

Connecting Duchenne families to knowledge



**Seth,**  
*living with Duchenne;  
and his family.*

**2** GET TO KNOW  
A SAREPTASSIST  
CASE MANAGER

**4** DUCHENNE  
AND YOUR CHILD'S  
EDUCATION RIGHTS

**6** ROUTE 79  
SCHOLAR  
FEATURE



SareptAssist is standing by. Get connected with your personal Case Manager.

Call 1-888-SAREPTA (1-888-727-3782) Monday through Friday, 8:30am – 6:30pm ET



**INTRODUCING THE  
SareptAssist Newsletter**

Welcome to the new SareptAssist Newsletter, a specialized resource for relevant and timely information throughout your Duchenne journey. This quarterly publication outlines SareptAssist services, covers a range of useful topics, and highlights people living with Duchenne. Most importantly, it underscores our unique commitment to you and your family by connecting you with knowledge and resources for Duchenne.

With the new school year just getting started, this first edition offers a variety of back-to-school content. You'll find interesting topics and information that you may be able to use in your own life—including the ins and outs of Individualized Education Programs (IEPs) and 504 Plans at your child's school, profiles to celebrate winners of the annual Route 79 Scholarship, and much more!

As Duchenne families and caregivers, you understand the importance of ongoing, personalized support. Just as your healthcare provider is there for medical care and support, SareptAssist is here for many of your other Duchenne needs. Remember that our Case Managers can answer questions, help resolve insurance issues, and provide other logistical support such as access to assistance programs and education. These professionals are dedicated to help ensure that your family always feels comfortable asking questions, so you get the help you need to find answers.

With each issue of our newsletter, we will be bringing you a wide range of content on Duchenne lifestyles, community, and resources. We aim to deliver content that supports your own family experiences. So, whether it's information on World Duchenne Awareness Day or the role of Case Managers and Nurse Educators, consider this your personal resource for all things Duchenne.

—DAN MADDEN  
Vice President of Patient Services



# Get to Know a SareptAssist Case Manager

**SareptAssist offers personalized support to Duchenne families.**

## Have You Met Kate?

Kate has skydived, ziplined, and swum with sharks. Nowadays, she spends her time in Massachusetts where she lives with her husband and two young children. She enjoys nature walks, family movie nights, and convincing her kids that vegetables can give them superpowers. Let's see what she had to say about her role as a Case Manager.

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

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“ I believe that a life full of wonder is a wonderful life.

—KATE

**Our Case Managers focus on building strong relationships with each family they serve as they provide knowledge and resources.**

**Kate, a SareptAssist Case Manager, shares her story.**

**SAREPTASSIST:** Thanks for sitting down with us today, Kate! First, can you tell us what made you want to become a Case Manager?

**KATE:** Of course! And sure, I think it was the realization that sometimes the smallest act can have the biggest impact.

**SAREPTASSIST:** What about your background? How has your experience helped you in your role as a Case Manager?

**KATE:** Well, some of my most important skills—patience, compassion, and understanding—came from being a sister, daughter, wife, and mommy of two. But I was also a child protection worker for 10 years prior to Sarepta and learned that advocacy is a powerful tool. It costs nothing to be kind and empathetic, and time is always of the essence when it involves a person's well-being.

**SAREPTASSIST:** What are some of the key features of SareptAssist that are available to families?

**KATE:** Case Managers take a personal approach to support families and their children's needs because the Duchenne journey can feel overwhelming. I partner with each family I serve and help them understand insurance benefits, provide financial support options, and help coordinate logistics—and I do so on an ongoing basis, so they always have me as a resource.

**SAREPTASSIST:** How do you help your families as they access these services?

**KATE:** The first thing I do when I partner with a family is make sure that all the required insurance paperwork is completed as quickly as possible. One of the big stresses for families is just not knowing where to begin when it comes to insurance. I don't want them to feel alone or stressed, so I try to take on as many of those worries as I can. I help explain the process and stay in touch the whole time. That way, they can spend as much time with their child and continue to advocate for their needs as effectively as possible.

**SAREPTASSIST:** From your experience, what are some of the ways you've supported families at different points in their Duchenne journey?

**KATE:** I'm here to help, plain and simple. I care about getting families and their loved ones the support they deserve, so my role is to cater services to fit their needs—whether it's providing resources to the parent of a newly diagnosed child or helping families transition to at-home infusions for a more comfortable experience.

**SAREPTASSIST:** What is your favorite part of the job?

**KATE:** Getting to be a part of a team that genuinely cares about making a difference and changing lives is my favorite part of the job, without a doubt. When everyone around you is determined to use every means at their disposal to forge a better path for the Duchenne community, you can't help but feel that energy. It fuels you. It turns a job into a mission, and I'm so honored to partner with this community.

# Duchenne and Your Child's Education Rights

Your child's education needs are not only important to their learning potential—they are protected under federal law.<sup>1</sup>

- Public schools must provide equal access to education for all students with disabilities, such as Duchenne<sup>1</sup>
- Individualized Educational Programs (IEPs) and Section 504 Plans (504s) are plans that ensure students with disabilities are granted the educational access and support they are entitled to under the law<sup>2\*</sup>

## Fast facts on IEPs and 504s

What do these plans have in common?
Students living with Duchenne may be eligible for both <sup>1,3,4*</sup>
Physical accessibility accommodations such as ramps, elevators, and classes on the first floor <sup>1,5</sup>
Individualized to the student <sup>4</sup>
Can involve students, parents/guardians, teachers, school administrators/representatives, healthcare professionals, expert evaluators, and therapists <sup>4,6,7</sup>
Updated yearly <sup>8</sup>

How are they distinct?	
IEPs	504s
Specially designed instruction <sup>2</sup>	Equitable access to education <sup>2</sup>
Student progress is assessed <sup>8</sup>	Accessibility and classroom accommodations <sup>1,3</sup>
Students with an IEP are eligible for a 504 Plan <sup>1</sup>	Not all students with a 504 Plan qualify for an IEP <sup>1,9**</sup>

What types of services are provided?	
IEPs	504s
Specialized instruction tailored to meet specific learning needs, physical therapy, occupational therapy, speech therapy, behavioral therapy <sup>4</sup>	Preferential seating, extra time for assignments, physical education modifications, keyboard or note-taker for writing <sup>2-4,10</sup>

How can you advocate for IEPs and 504s?
Contact the school staff to discuss your child's needs
Identify the accommodations to best support them

## Putting an IEP and 504 Plans into place

- Learn, prepare, and have meetings with school staff to ensure your child's specific education needs are being met
- If your child's needs change over time, be proactive in having them reassessed



## Remember!

The law protects and upholds the educational rights of your child!<sup>1,2</sup>

Reach out to reputable resources and experts if you need additional support and knowledge to advocate for the right educational approach for your child's learning requirements.

## Resources to tap into throughout your child's academic journey

504 Plan Versus IEP: A Guide for Parents



Parent and Educator Resource Guide to Section 504 in Public Elementary and Secondary Schools



Letter for School Physical Limitations



\*Section 504 Plans refer to section 504 of the U.S. Rehabilitation Act of 1973 antidiscrimination law.<sup>1,4</sup>

\*\*Covered disabilities are defined under the Individuals with Disabilities Education Act (IDEA).<sup>9</sup>

**References:** 1. U.S. Department of Education. Office for Civil Rights. Parent and educator resource guide to section 504 in public elementary and secondary schools. Accessed August 14, 2023. <https://www2.ed.gov/about/offices/list/ocr/docs/504-resource-guide-201612.pdf> 2. Kassab S. 504 plan versus IEP: a guide for parents. *U.S. News and World Report*. 2021. Accessed July 26, 2023. <https://www.usnews.com/education/k12/articles/504-plan-versus-iep-a-guide-for-parents> 3. The Understood Team. 504 plans and your child: a guide for families. Accessed July 24, 2023. <https://www.understood.org/en/articles/504-plans-and-your-child-a-guide-for-families> 4. Jones C. Parents' guide to 504 plans and IEPs: What they are and how they're different. EdSource. 2022. Accessed July 26, 2023. <https://edsources.org/2022/parents-guide-to-504-plans-and-ieps-what-they-are-and-how-theyre-different/669493> 5. Muscular Dystrophy Association. Recommendations for school accommodations: physical and occupational therapy. Accessed August 14, 2023. [https://www.mda.org/sites/default/files/Teachers\\_Guide\\_PT\\_flyer.pdf](https://www.mda.org/sites/default/files/Teachers_Guide_PT_flyer.pdf) 6. CureDuchenne. Adapting education for those impacted with Duchenne. Accessed July 24, 2023. <https://cureduchenne.org/care/navigating-school> 7. McSherry C. The Individualized Education Program (IEP): A blueprint for ensuring school success. The Jett Foundation. Accessed July 24, 2023. <https://nchascn.org/wp-content/uploads/2010/03/IEPinforev.pdf> 8. Disabilities, Opportunities, Internetworking, and Technology (Do-It). What is the difference between an IEP and a 504 Plan? University of Washington. 2023. Accessed July 24, 2023. <https://www.washington.edu/doi/what-difference-between-iep-and-504-plan> 9. Lee AMI. The 13 disability categories under IDEA. Accessed July 24, 2023. <https://www.understood.org/en/articles/conditions-covered-under-idea> 10. Muscular Dystrophy Association. School accommodation recommendations. Accessed July 24, 2023. [https://www.mda.org/sites/default/files/Guide\\_SchoolAccommodations-DMD2.pdf](https://www.mda.org/sites/default/files/Guide_SchoolAccommodations-DMD2.pdf)

THE ANNUAL

# Route 79 Scholarship

## Get to know some recent recipients

Named for the 79 exons in the dystrophin gene, the Route 79 Scholarship helps students living with Duchenne continue their academic journey after high school.<sup>1</sup> We had a chance to sit down with two recent scholarship recipients, Joshua and Maanav. Based on our conversations, we learned a little about these young adults' lives and wanted to share that with you.

Here are some highlights:

As sponsor of the Route 79 Scholarship, Sarepta is committed to helping students diagnosed with Duchenne pursue their post-high school educational goals. The program also has a separate scholarship category for siblings.<sup>1</sup>

Reference: 1. Route 79 Scholarship Program: Helping students in the Duchenne muscular dystrophy community pursue post-high school education. Sarepta Therapeutics. 2023. Accessed August 16, 2023. <https://www.sarepta.com/about-us/grants-giving/route79>

Learn more about the Route 79 Scholarship using the code below



### Joshua, 22

Manassas, Va.

Graduated with honors from James Madison University



#### LIFE WITH DUCHENNE:

*"I never let it be something that got in my way or hindered me from going after my goals. I always believed that I could accomplish things like graduating college, working, and maybe eventually living by myself. Don't let your situation get in the way of going after your goals. It might be scary—I think change is difficult for a lot of people—but try your best, work with what you have, and don't be scared."*

#### CAREER PROSPECTS:

*"I majored in Intelligence Analysis. I have always been interested in investigative, detective-type police work. And I found that the job of analyst doesn't have much of a physical demand. It is mostly mental. The best way to describe it is the behind-the-scenes effort or like the 'guy in the van' from crime shows. So, you do all the research behind finding the bad guys—collecting data, tracking money and movement, and writing reports. I'm pretty good with technology, so I figured it is something I could enjoy."*

#### SUMMER HIGHLIGHTS:

*"My family and I went on a big trip in July. We headed west to see Yellowstone National Park and a lot of parks out that way like Mount Rushmore, The Badlands, Grand Teton National Park, and the Rocky Mountains—as far out as Idaho."*

### Maanav, 19

Houston, Tx.

Incoming sophomore at the University of Houston



#### LIFE WITH DUCHENNE:

*"You just have to be open-minded. The University of Houston is pretty good in terms of accessibility, but it was quite different. My high school was very small, and the University of Houston has a ginormous campus. I wondered how it was going to be in such a different place and using a scooter for the first time, and I would say it's been fairly smooth."*

#### CAREER PROSPECTS:

*"I've always wanted to be a sports journalist. I just finished my first year at the University of Houston and am majoring in Journalism. However, I had already gained some experience in high school. I created a YouTube channel and started reaching out to people that I'd always looked up to, like broadcasters and athletes, to try to get interviews. Local news outlets like the Houston Chronicle and NBC Houston have featured stories on me. It's been really cool."*

#### SUMMER HIGHLIGHTS:

*"I really enjoy travel and went to Las Vegas this summer. For the most part, though, I was focused on promoting my YouTube channel to keep building my personal brand. When I'm not interviewing athletes, I serve as an ambassador for the Muscular Dystrophy Association (MDA) and recently received the MDA Tribute Award."*

## NEWS AND EVENTS

# World Duchenne Awareness Day (WDAD) Starts With the Date Itself

September 7th has marked WDAD since 2014—raising awareness globally for Duchenne. WDAD is the seventh day of the ninth month, reflecting the 79 exons in the dystrophin gene.<sup>1,2</sup>

**WDAD continues to expand awareness in unique ways.**

## This year's theme: Breaking Barriers

For 2023, the World Duchenne Organization released a video that speaks to the physical, social, and healthcare-related challenges of Duchenne.<sup>3</sup>

### Explore How Duchenne Families Are Breaking Barriers



Watch the #WDAD2023 documentary using the QR code below.

Find additional resources at [worldduchenne.org](https://worldduchenne.org).

**References:** **1.** World Duchenne Awareness Day. The WDAD story. 2023. Accessed July 24, 2023. <https://www.worldduchenne.org/about-wdad/our-story> **2.** World Duchenne Awareness Day. Cure rare disease. 2022. Accessed July 24, 2023. <https://www.curerare.org> **3.** World Duchenne Awareness Day. 2023: Duchenne—Breaking Barriers. 2023. Accessed July 26, 2023. <https://www.worldduchenne.org/2023-duchenne-breaking-barriers>



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## CREATIVE CORNER

# Back-to-School Jams



An upbeat playlist just for you

Tune into Spotify to listen to this SareptAssist playlist!

Request a song using the QR Code, and you might just hear it!

*Playlist available on Spotify. Spotify is a trademark of its owner. Sarepta does not own the rights to any of the songs on this playlist.*

- 01** **Dynamite**  
*BTS*
- 02** **High Hopes**  
*Panic! at the Disco*
- 03** **Be the Change**  
*Britt Nicole*
- 04** **A Head Full of Dreams**  
*Coldplay*
- 05** **Happy**  
*Pharrell Williams*
- 06** **We're Going to Be Friends**  
*The White Stripes*
- 07** **On Top of the World**  
*Imagine Dragons*
- 08** **Hang Loose**  
*Alabama Shakes*
- 09** **Keep Your Head Up**  
*Andy Grammer*
- 10** **ABC**  
*The Jackson 5*
- 11** **School Day (Ring Ring Goes the Bell)**  
*Chuck Berry*

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