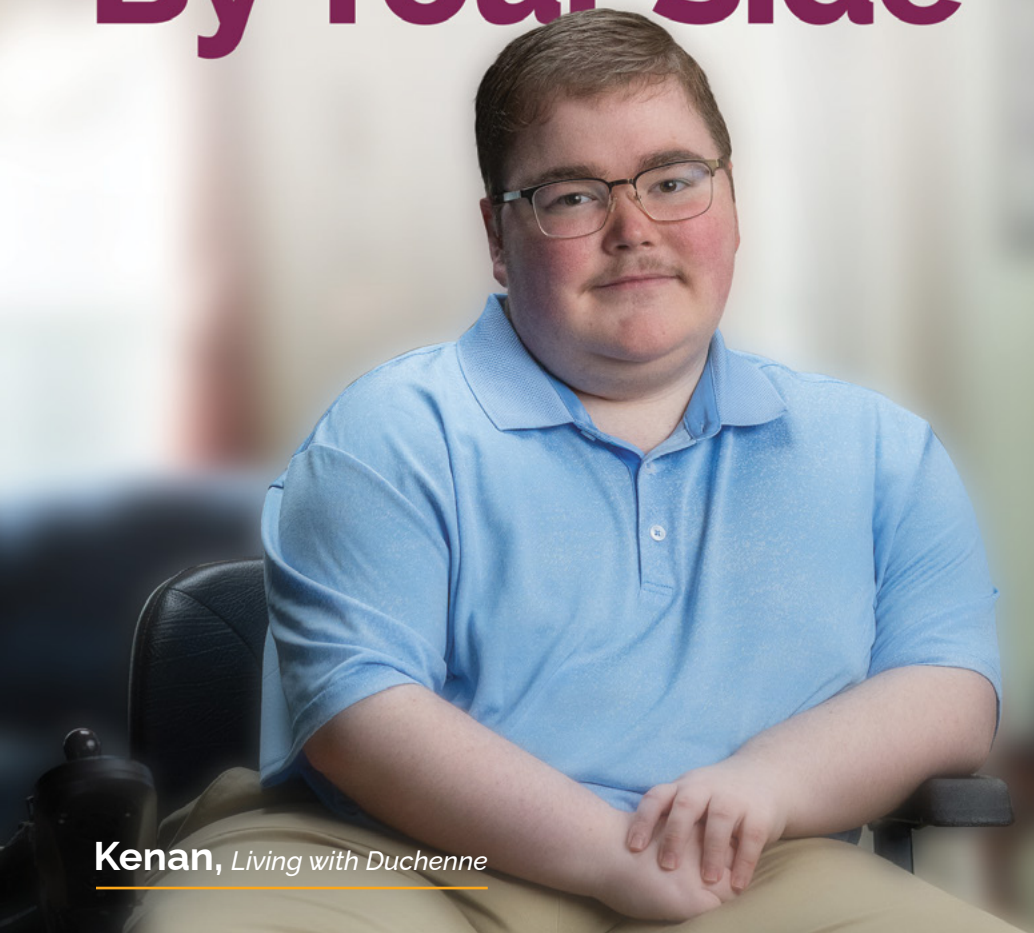


Summer 2024

# By Your Side



**Kenan**, *Living with Duchenne*

**Creating Connections  
in 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, 8:30am – 6:30pm ET

# IT'S TIME FOR A STAYCATION

IT'S IMPORTANT TO GET OUT OF YOUR ROUTINE EVERY ONCE IN A WHILE—EVEN IF IT'S IN YOUR OWN BACKYARD.

Unlike traditional vacations that may involve long journeys or strenuous activities, a staycation provides people with the chance to unwind, create lasting memories, and have fun closer to home.

## Relaxation close to home: The staycation advantage

### Mood boosting

Studies show that a break from your usual surroundings or routine can be beneficial for your state of mind.<sup>1</sup>

### Low stress

By staying close to home, you can avoid the stresses that come with jet lag, long lines, and coordinating accessible transportation.

### Tailored to you

You can plan every detail of your trip around your personal wants and needs. And because it's close to home, you might even be able to make a pit stop to a favorite restaurant, store, or another place you enjoy along the way!

#### QUICK TIP

Preparing a picnic lunch, watching an outdoor movie, or relaxing in a pool are some great ways to enjoy the day while on staycation!

**Rediscover your surroundings.** Simply enjoying quality time with loved ones in the comfort of familiar surroundings can provide a much-needed escape and give you a chance to be a tourist in your own city.



**Want to share what you did on your staycation/vacation?**

**Scan the QR code** and share your pictures or stories for a chance to be featured in a future issue!

# THE CALL OF THE WILD

IS IT TIME FOR YOUR NATIONAL PARK ADVENTURE?



## YOUR LOCAL NATIONAL PARK

### PROMOTES WELL-BEING

Picturesque views, fresh air, and tranquil settings can have a profound impact on your whole family's well-being—promoting relaxation and rejuvenation.<sup>2</sup>

### FOSTERS INDEPENDENCE

Accessible trails and facilities allow you to explore and enjoy the beauty of nature, fostering a sense of freedom and independence.

### ADVANCES INCLUSIVITY

The US National Park Service is committed to making sure facilities, programs, and services are accessible for all—including those with Duchenne.

## DID YOU KNOW?

Every US national park has an accessibility section on its website, with details about planning a trip with accessibility needs in mind. The **AllTrails** app can provide information on over 8000 accessible trails!<sup>3</sup>



The National Park Service offers a free, lifetime Access Pass to US citizens or permanent residents with a permanent disability. This pass grants access to over 2000 recreation sites,<sup>4</sup> allowing you to experience the wonders of nature while minimizing financial barriers.

**Scan to get your free Access Pass**

## SAREPTASSIST SUPPORT

### Reach out to your Case Manager before your trip

Your Case Manager can work with your specialty pharmacy to assist in locating a nurse and infusion site and coordinate the delivery of your medication to a convenient location while you're traveling. This can ensure a smoother, more enjoyable experience for you and your family.

## KENAN'S STORY:

# Independence in a new light

Getting older means taking on new responsibilities, and for young men with Duchenne, this can often mean decisions about their care.

By Your Side caught up with Kenan, who shares how he has worked with his caregivers to assume more responsibilities in his daily life.



—KENAN,  
Living with Duchenne

### How do you and your family work together to make decisions about your treatment for Duchenne?

**KENAN:** I'm older now, so my opinion matters even more. I rely on my parents for wisdom, but they trust me to make decisions. The first time I made a big decision was when we got my first wheelchair. My parents wanted me to be involved in this decision, and I knew I was at a point where I needed the help.

### Are there any tools or approaches you have for discussions with your family or doctor that help you express your care needs?

**KENAN:** I'll usually talk through my concerns to help my family and doctors understand what I am experiencing. This helps them to determine the issues that need solutions.

### Have you ever had to transition your care from one doctor to another as you have gotten older? What was that experience like?

**KENAN:** I am starting that process now by having to transition from pediatric to adult doctors. I'm asking my pediatric specialists for their suggestions [on how to have conversations] with my adult doctor.

#### SAREPTASSISTSUPPORT

#### Have questions about transitioning to a new clinic?

Give your Case Manager a call! Your Case Manager knows all the tips and tricks and can even offer guidance on organizing transportation to and from your new clinic.



*Make sure you have people you trust who can help you as you transition into making your own decisions. Be willing to listen and learn from your mistakes and take the initiative to tell others about your physical issues and how they can help.*

—KENAN, 19 years old, living with Duchenne



### How has working with your SareptAssist Case Manager helped you navigate care decisions and conversations?

**KENAN:** My Case Manager is very responsive to my needs. We talk about my physical challenges and what resources are available — she even asks about my college life and family.

### Finally, with the nicer weather upon us, do you have any recommendations for someone with Duchenne who wants to find more ways to experience the outdoors?

**KENAN:** Get outside as often as possible. When you must use a wheelchair, make sure that it can run on most surfaces like sand, grass, or even mud. Don't be afraid to get a little dirty in your chair. Also, don't do things alone. The best outdoor times are with others.

#### SAREPTASSISTSUPPORT

#### Had a recent change or disruption in insurance coverage?

SareptAssist can help you navigate coverage and financial assistance options. Reach out today—help is just a phone call away.

#### 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. Heller AS, Shi TC, Ezie CEC, et al. Association between real-world experiential diversity and positive affect relates to hippocampal-striatal functional connectivity. *Nat Neurosci.* 2020;23(7):800–804. 2. Ewert A, Chang Y. Levels of nature and stress response. *Behav Sci (Basel).* 2018;8(5):49. 3. AllTrails. Best trails in United States. Accessed May 7, 2024. <https://www.alltrails.com/us> 4. National Park Service. About us. Accessed May 6, 2024. <https://www.nps.gov/aboutus/accessibility.htm>



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