

Winter 2024

By Your Side



JOHN, living with Duchenne

New Year, New Adventures Await!



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

SETTING GOALS FOR A BRIGHT NEW YEAR

As we welcome in the new year, it's the perfect time to think about the goals you want to achieve in 2025. Just like New Year's resolutions, goal setting can help us stay motivated, inspired, and connected. Whether it's exploring new hobbies or connecting with friends, now's the time to dream big and make it happen.

Meet Nicole

Nicole Reynolds - SareptAssist Case Manager



By Your Side checked in with Nicole, a SareptAssist Case Manager, who shared valuable tips for families on staying organized and motivated in their journey with Duchenne.

What resources and strategies would you recommend for families to stay motivated and on track with their goals throughout the year?

NICOLE: Something that's really helped me is writing everything down to stay on track. Grab a journal, mark a calendar with all your appointments, list all your healthcare providers in one place with their contact information, stay up to date with how your insurance covers you and your medical conditions, and take note of the trends and changes you see over time. And then most importantly, give yourself grace if you don't get it perfect.

How can families best utilize the services of SareptAssist to help successfully achieve their New Year's goals?

NICOLE: As Case Managers, we offer all kinds of support services ranging from understanding your insurance benefits and your financial assistance options—whether they be through us or externally—to helping with the more logistical factors around starting on therapy. For example, helping you find a specialty pharmacy that's in your network, or helping you organize infusions in an outpatient infusion facility. That's why we're here.

There's no one right way to utilize the support of your Case Manager. It's based on what's going to work best for you. No concern is ever too big or too small. If it's something that I can't help with, then I will help find the right person who can.



Your SareptAssist Support team is just a call or email away.

BUILDING YOUR PATH FOR A SUCCESSFUL NEW YEAR

WHY SET GOALS?

Goals give you direction and focus. They can be hobbies, day-to-day activities, or long-term goals. They help you organize your dreams into achievable steps, making it easier to celebrate your success along the way. Remember, all progress counts!

TIPS FOR EFFECTIVE GOAL SETTING:

Be specific: Instead of saying, "I want to spend more time outside," try, "I will go outside for one hour every day."

Make it measurable: Set criteria to track your progress. For example, "I'll read one book a week" gives you a clear target.

Set realistic goals: Choose goals that are achievable and fun. Setting short-term goals can offer immediate satisfaction, and selecting an activity you enjoy, like gaming, means that you're more likely to follow through and have fun along the way.

Write it down: Putting your goals on paper makes them feel more tangible and helps you stay committed.

Celebrate milestones: Recognize your progress, no matter how small. Celebrating achievements boosts motivation!

For more in-depth strategies and tips, check out our Goal Setting Guide on [Duchenne.com](https://www.duchenne.com), specifically designed for people living with Duchenne. It's filled with helpful advice to inspire and support you on your journey.



Think about the things you can do. Focus on those things. Do your best at everything and be happy in what you're doing.

—KENAN, living with Duchenne



Thank you for being part of our journey

As we take a pause from this newsletter series, we want to thank you for being a part of our community. Stay connected and find helpful resources by following SareptAssist on social media. Visit <https://bit.ly/4ibni2p> to continue accessing updates, tips, and community stories.

Chasing dreams with Duchenne

We caught up with John, a junior at Boise State University, who shared how he's embracing new challenges in his life and the importance of having a strong support system as he pursues his goals.



— JOHN, living with Duchenne

What goals have you set for yourself this year, and why are they important to you?

JOHN: One of my big goals this year has been to get good grades. I have straight A's right now, so that's really exciting. Another is that I moved into a new apartment recently. Just getting settled into a new environment, that was a big goal of mine. To get used to the new situation and be able to figure things out.

Can you share a recent experience where you met a goal that you set?

JOHN: I recently got an almost perfect score on a history midterm and that really was inspiring to me.

How do you stay motivated and focused on achieving your goals?

JOHN: Well, one thing that really motivates me is just trying to stay on top of everything. This is more specific to school, but taking good notes in classes and trying to be on top of everything that I'm learning.

SAREPTASSISTSUPPORT



Your Case Manager can share their knowledge on insurance plans, healthcare networks, and financial assistance programs. Let their expertise work for you.



Your Duchenne Nurse Educator specializes in Duchenne education and therapy information and is ready to answer your questions.



What role has your support system played in helping you reach your goals?

JOHN: My family is very supportive of my goals and allowing me to continue to further my education. My dad, my mom, my brother, they all help me out physically with things that are hard for me to do, like getting ready for my day and having help throughout the day. So that's really beneficial to me being able to have a full life, and to be able to do everything that I do because it would be really hard to do all those things without them. They also helped a lot with the move into my new apartment. It was a complicated process getting it all set up. Luckily for me, it wasn't that far, because I lived in the dorms at Boise State University before moving.

What advice would you give to other young people with Duchenne who are setting their own goals?

JOHN: I would advise them that they shouldn't be afraid to put themselves out there. Even if you're in hard or stressful situations, or you feel awkward, you should still be willing to put yourself out there and push through those feelings. They are just feelings, and if you push past them, you're able to do a lot of great things. I think I apply that to the way I live. In everything that you do, just always doing your best and putting your best foot forward, even if it feels stressful or difficult at times.

SareptAssist Support, By Your Side.

SareptAssist is a support program committed to patients and caregivers in the Duchenne community.

www.SareptAssist.com

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