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The Dragonfly Digest

OFFICIAL NEWSLETTER OF THE ALS SOCIETY OF NEW BRUNSWICK & NOVA SCOTIA

Welcome to the first issue of Dragonfly Digest for 2026!

This publication from the **ALS Society of New Brunswick and Nova Scotia** is for people living with ALS and their families, as well as volunteers, donors, clinicians, and anyone who wishes to support the ALS community in New Brunswick and Nova Scotia.

In each issue, you'll learn more about our services, discover what's new, and find out how we can help people live their best lives with ALS.

If you have any questions, suggestions, or would like to get involved, please don't hesitate to reach out — we'd love to hear from you.

📩 **kcarter@alsnbns.ca**

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Check out our YouTube Channel!

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Expanding Support: Equipment Loan Program Now Includes Primary Lateral Sclerosis

The ALS Society of New Brunswick and Nova Scotia is expanding its Equipment Loan Program to include individuals diagnosed with Primary Lateral Sclerosis (PLS). This rare motor neuron disease shares several characteristics with Amyotrophic Lateral Sclerosis (ALS).

While both ALS and PLS are progressive neurological disorders, there are important distinctions:

- **Motor Neuron Involvement**: ALS affects both upper and lower motor neurons; PLS primarily affects upper motor neurons.
- **Progression**: ALS progresses rapidly, often leading to severe disability and death within a few years. PLS progresses slowly over many years.
- **Muscle Wasting**: Muscle atrophy is a hallmark of ALS; PLS does not typically involve muscle wasting.
- **Fatality**: ALS is a fatal disease; PLS, while disabling, is not.
- **Rarity**: PLS is significantly rarer than ALS.

Similarities between ALS and PLS include progressive motor impairment, increasing reliance on assistive devices, and the need for comprehensive support services.

Recognizing these shared challenges, we are pleased to now offer access to our Equipment Loan Program to people living with PLS. This program provides essential medical and mobility equipment at no cost, helping individuals maintain independence, comfort, and quality of life at home.

This expansion is made possible by our generous donors, funding from the Nova Scotia and New Brunswick Provincial Governments, and a grant provided by the Canada–Nova Scotia Aging with Dignity Funding Agreement.

Together, we continue to ensure that no one facing a motor neuron disease walks this path alone.

Expansion of Services - Feeding Tube Funding

💙 Feeding tube formula can be expensive. Starting **January 1, 2026**, people living with **ALS or PLS** who are beginning feeding tube nutrition can access a **one-time $500 subsidy** to help with the cost.

For further information:
Emily Wells, Client Services Manager
ewells@alsnbns.ca

The Purple Book - Everything You Need to Know About Building a Caregiving Team

Mike and Jan George (Soaring Families Founders) have been caring for their son for 31 years, and along the way, they've learned one very important lesson: you can't go it alone.

To support other families, Mike and Jan created a guide to help family caregivers build and train their own caregiving team. With support from the ALS Society of New Brunswick and Nova Scotia, Mike has also customized the guide specifically for families living with ALS.

If you are putting together a caregiving team for your loved one, please connect with our staff for information on how to access this service.

We've Moved!

We're excited to share that we're now settling into our new office location at:

1000 Windmill Road, **Unit 60A**
Dartmouth, NS B3B 1L7

We're still in the same building—just at the opposite end—with more space for our equipment warehouse and our growing programs.

Keep an eye on our social media for details about our Open House on Sunday, April 26th. We hope you can join us!

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Our Focus for 2025-2028

1. Building Out Loud
We're embracing an open, collaborative way of working — sharing our progress as we go. When we build out loud, our community joins us. People see the impact, contribute their expertise, and feel part of something bigger.

2. Supporting People Living with ALS
The equipment loan program, navigation support, and emotional care we offer have transformed lives — but we know there's more to do. Over the next three years, we aim to increase our revenue by $280,000, enabling us to expand services, develop a Centre of Impact and Innovation, and reach more families in need.

3. Empowering Caregivers
Caregivers give everything — their time, energy, and love. We're introducing a new program to train and connect respite workers, making it easier for caregivers to take much-needed breaks while ensuring quality care for their loved ones.

4. Growing a Culture of Philanthropy
We're redefining what it means to give. Every volunteer, family member, and supporter plays a role in building a community of generosity. By strengthening relationships, recognizing donors, and inviting new supporters to join us, we're creating a culture where giving is joyful and shared.

5. Advocating for the Future
Strong advocacy creates lasting impact. We will work toward renewing government funding year over year to ensure stability for our programs and services. We'll also support healthcare professionals in rural areas with ALS-specific training to ensure consistent, high-quality care across our region.

6. Innovating Through the Centre of Impact and Innovation
Looking ahead, we envision a Centre of Impact and Innovation — a hub for collaboration among people living with ALS, caregivers, researchers, and professionals. Whether virtual or physical, this Centre will be a place of learning, sharing, and advancing best practices in care and support.

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Join Us in Building Out Loud

This plan isn't just about goals — it's about people. It's about the families who rely on our support, the volunteers who give their time, and the donors who believe in a future without ALS.

Together, we'll continue to share our progress, celebrate our successes, and learn from our challenges. We'll build out loud — because when we share our story, others join us in writing the next chapter.

"Have a bias towards action. Let's see something happen right now. You can break that big plan into small steps and take the first step right away."
— Indira Gandhi

2026 ALS Walk Strong

ALS Walk Strong registration is now **OPEN!**

The ALS Walk Strong website is officially open for registration, and the theme of this year's walks is: Making Moments.

Whether that means more moments at home, finding moments of joy, strength, and courage, celebrating special occasions, or simply having more time with family and friends — that's what we're creating together as a community when we come together for a day of fun, fundraising, and support at this year's walks.

Save the dates for ALS Walk Strong 2026:
📍St. George. Riverside Park. June 5th
📍Truro. Victoria Park. June 6th
📍Brookfield. Brookfield Fire Hall. June 7th
📍Moncton. Centennial Park. June 13th
📍Saint John. Harbour Passage. June 14th
📍Halifax. DeWolfe Park. June 21st
📍Inverness. Inverness Racetrack. June 27th

Don't see your Walk location yet? Stay tuned, more dates to come!

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Want to host a Family and Friends Walk this year? You can do it anywhere, with anyone, in your own community. Email Trey at trussell@alsnbns.ca, and he can send you Walk materials to help you coordinate and promote your walk.

Let’s make memories together this Walk season.

✅ Register today: www.alswalkstrong.ca

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