

# ALS SOCIETY OF NEW BRUNSWICK AND NOVA SCOTIA

The ALS Society of New Brunswick and Nova Scotia is a non-profit organization that is committed to serving people living with ALS and their families as they navigate a difficult and confusing disease. With the generosity of our donors and the provincial governments, The ALS Society of New Brunswick and Nova Scotia is able to provide programs and services to families on the ALS journey at no cost to them.

## MISSION

The ALS Society of New Brunswick and Nova Scotia is a life-affirming advocate for people and their families, helping them navigate through a confusing and difficult disease with dignity and purpose.

## VISION

People with ALS and their families living their best lives in the face of an ALS diagnosis.

## VALUES

Advocacy, Inclusion, Knowledge, Time, Choice.

The ALS Society of New Brunswick and Nova Scotia offers an Equipment Loan Program. People living with ALS can access assistive equipment to help keep them safe, comfortable, mobile, and breathing. This equipment includes power wheelchairs, hospital beds, patient lifts, walkers, breathing machines, and more. This equipment comes at no cost to the family. The Society works with healthcare professionals and people living with ALS to get them the right equipment at the right time. The ALS Society takes care of everything from coordinating with your healthcare professionals, equipment maintenance and delivery/pick-up of the equipment.

If you are or a family member are living with ALS, would like information and support or would like to help people living with ALS, we would love to hear from you! Send us an email, give us a call, or send us a message on Facebook - any of the staff at the ALS Society of New Brunswick and Nova Scotia would be happy to assist you.



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[www.facebook.com/alsnbns](http://www.facebook.com/alsnbns)

# MEET THE TEAM



**Kimberly Carter - President & CEO**

[kcarter@alsnbns.ca](mailto:kcarter@alsnbns.ca)

Kimberly has led the ALS Society of New Brunswick and Nova Scotia since 2010, starting off volunteering before becoming permanent staff. She is responsible for the overall operations, as well as leading the staff and board members on government relations, fund development, and advocacy.



**Emily Wells - Client Services Manager**

[ewells@alsnbns.ca](mailto:ewells@alsnbns.ca)

Emily joined the ALS Society of New Brunswick and Nova Scotia in 2023. Emily takes care of all of our ALS clients and their families. Emily runs the equipment loan program, provides education and information and is the point of contact for all of our ALS families.



**Trey Russell-Johnson – Community Engagement & Events Coordinator**

[trussell@alsnbns.ca](mailto:trussell@alsnbns.ca)

Trey joined the ALS Society of New Brunswick and Nova Scotia in 2023. Trey organizes ALS Walk Strong, our biggest annual fundraiser, along with amazing volunteers. He also supports third-party fundraisers, runs our social media, and supports Kim and Emily with advocacy and raising awareness.



**Kerry Mahar - Administrative Support Manager**

[kmahar@alsnbns.ca](mailto:kmahar@alsnbns.ca)

Kerry joined the ALS Society of New Brunswick and Nova Scotia in 2022. Kerry's role includes a little bit of everything. Kerry is the first point of contact on the phones, she plays an active role in delivering client services, supporting fund development, and she takes care of our bookkeeping.



**Cecil Dixon - Equipment Technician and Delivery**

Cecil has been with the ALS Society of New Brunswick and Nova Scotia since 2012. Cecil takes care of all maintenance, repairs, and building of equipment. Cecil then delivers the equipment to the home and does any set up at the home (hospital beds) and picks up the equipment when it is no longer needed.

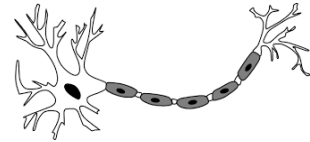
## You Are Not Alone!

Talk to any of our staff and they will help as best they can. We can connect you to others, offer advice, provide resources and education - don't know who to talk to or where to go? Feeling overwhelmed? Give us a call, write us an email, message us on Facebook, or stop by the office for a visit! We also have many caring board members and volunteers with personal ALS experience that would love to support you!

# ALS

## ALS is also known as...

- Amyotrophic Lateral Sclerosis (ALS).
- Motor Neuron Disease (MND)\* (MND is the umbrella term, ALS is just one type of MND).
- Lou Gehrig's Disease (after the famous baseball player).



## What Is ALS?

- ALS destroys the motor neurons, which are an important link in the nervous system. Motor neurons send messages to your voluntary muscles (those muscles you control, like your arms, hands, and legs) as opposed to involuntary muscles, like your heart.
- In 90% of cases, ALS occurs randomly in the general population. This is known as sporadic ALS.
- In 5% to 10% of cases, the disease is inherited. This is known as familial ALS
- Out of every 100,000 people, 6 to 8 will be diagnosed with ALS.
- ALS does not affect your five senses – sight, hearing, taste, smell, and touch.
- ALS is not contagious.
- Although ALS is most common in people over 40, people can get ALS at any age. The ALS Society of New Brunswick and Nova Scotia has seen clients from 24 to 91 years of age

## Symptoms and Signs

- Tripping, dropping things, slurred or 'thick' speech.
- Muscle cramping, weakened reflexes.
- Difficulty swallowing.
- Shortness of breath at rest.
- Decreased muscle tone.

## Life Expectancy

- Every case of ALS progresses differently. No one can predict how long you will live, not even your medical team.
- Most people will have a life span of 2 to 5 years. There have been people in Nova Scotia and New Brunswick that have lived more than 10 years.

# ALS

## What Causes ALS?

In ALS, the nerve cells that control the movement of your muscles gradually die, so your muscles progressively weaken and begin to waste away. ALS is recognized as having multiple interacting causes.

Researchers are studying several possible causes of ALS, including:

- Gene mutation. Various genetic mutations can lead to inherited ALS, which appears nearly identical to the non-inherited form.
- Chemical imbalance. People with ALS generally have higher than normal levels of glutamate, a chemical messenger in the brain, around the nerve cells in their spinal fluid. Too much glutamate is known to be toxic to some nerve cells.
- Disorganized immune response. Sometimes, a person's immune system begins attacking some of his or her body's own normal cells, which may lead to the death of nerve cells
- Protein mishandling. Mishandled proteins within the nerve cells may lead to a gradual accumulation of abnormal forms of these proteins in the cells, eventually causing the nerve cells to die.

Source: [www.mayoclinic.org](http://www.mayoclinic.org)

## Your ALS Clinic

In Nova Scotia, the ALS Clinic is run out of the Nova Scotia Rehabilitation Centre. In New Brunswick, the ALS Clinic is run out of the Stan Cassidy Centre. ALS Clinics are a multi-disciplinary team of specialists who are experienced in working with people with ALS. They can also confer with one another on the day you attend the clinic to adjust your care plan. In order to be seen at ALS Clinic, a definitive ALS diagnosis must be given, and you must be referred to the Clinic. The multidisciplinary team includes a respirologist, neurologist, physiatrist, gastroenterologist, registered nurse, speech-language pathologist, dietician, physiotherapist, and occupational therapist. When someone is referred to the ALS Clinic, they are able to access care from all of these specialists during one visit. The ALS Clinic is a great resource as these specialists have experience caring for people living with ALS. Referrals to the ALS Clinic does not mean you no longer receive care from the healthcare professionals in your community, but they can all work together to provide the best care.

**Nova Scotia ALS Clinic: 902-471-3204**

**New Brunswick ALS Clinic: 506-447-4082**

# HEALTHCARE PROFESSIONALS

## Neurologist

A neurologist is a specialist in diseases of the nervous system. Neurologists experienced in the diagnosis and care of ALS patients can work with you to rule out other conditions and provide you with specialized care.

## Occupational Therapist (OT)

Occupational Therapists help people who, through disease or injury, must adapt to how they perform everyday tasks – everything from mobility to personal care. Occupational therapists will help you perform your daily functional tasks safely and efficiently. After conducting an assessment and talking to you, occupational therapists will be the members of your healthcare team who will most often recommend assistive devices and medical equipment.

## Physical Therapist (PT)

A Physical Therapist has training in movement and function and can help you when you are experiencing difficulties with balance, walking, sitting, and standing. Physical Therapists also prescribe equipment and assistive devices. They may also teach you exercises for stretching and strategies for energy conservation.

## Physiatrist

A Physiatrist is a medical doctor who treats patients with temporary or permanent impairments due to injury or conditions like ALS. Their training focuses on the nerves, muscles, and bones—parts of the anatomy that affect mobility and physical function.

## Respirologist

A doctor who takes care of your respiratory system. They will be able to provide insight in regard to breathing equipment such as a Bi-Pap machine.

## Speech Language Pathologist (SLP)

A Speech Language Pathologist is a healthcare professional who specializes in communication. SLPs are trained to provide education and work with you to ensure you

can communicate appropriately and effectively for as long as possible. When speech becomes harder, they will work with you to find appropriate technologies to help you communicate. SLPs are also able to help with swallowing difficulties using diet modifications.

## **Continuing Care Coordinator**

A Continuing Care Coordinator acts as a guide for you and your family to navigate the healthcare system, access support, and arrange services when needed. A Continuing Care Coordinator is your first point of contact to ensure you live as independently and safely as possible.

In Nova Scotia, anyone can self-refer to Continuing Care at any time. **They can be reached by telephone at 1-800-225-7225**, 8:30 a.m.- 4:30 p.m., 7 days a week. More information can be found on their website, [www.nshealth.ca/continuing-care](http://www.nshealth.ca/continuing-care)

In New Brunswick, anyone with a health care need, that needs to be provided for at home can fill out a referral form with the Extra-Mural Program to see if they are eligible for services. Referral forms can be found on their website, [extramuralnb.ca](http://extramuralnb.ca). Please note: If you have submitted a referral form and have not heard back within 2 workdays, please call 1-(844)-982-7367. If you have submitted a referral form after hours and the referral is urgent (a service that is required within the next 24 hours), please call 1-(844)-982-7367, and the answering service will connect you with a local unit. **For any questions regarding the Extra-Mural Program, please call 1-844-982-7367.**

# PALLIATIVE CARE

Palliative care is an approach to caring for people who are living with a life-threatening illness, no matter how old they are. The focus of care is on achieving comfort, ensuring respect for the person with a terminal diagnosis, and maximizing the quality of life for the patient, family, and loved ones.

Palliative care addresses different aspects of end-of-life care by:

- Managing pain and other symptoms.
- Providing social, psychological, cultural, emotional, spiritual, and practical support.
- Supporting caregivers.
- Providing bereavement support.

Many people think that palliative care is only provided in the last weeks and months of life when curative treatments are no longer available. Palliative care is not necessarily provided by a team that only becomes involved at the end of your life. Ideally, it is provided by the people who know patients the most, working together with experts when needed. Often, our PALS (people living with ALS) and their families do not wish to access the services of Palliative Care because of the connection of the word with imminent end of life. This is not always the case. Palliative care services are broad in scope and will support your family with the goal of helping you live your best life as long as possible.

## How Do I Access Services?

Family physicians and frontline care providers, including continuing care coordinators, nurses, pharmacists, social workers, and spiritual care providers, all play a role in providing palliative care.

These providers can access support from a palliative care team who specialize in complex care planning and symptom management. Their support can complement the care that patients receive from their primary care provider and other care team members, but is not meant to replace it.

# MEDICAL MANAGEMENT

For now, there is no cure for ALS. However, the influx of research funding due to the 2014 Ice Bucket Challenge has greatly accelerated research, and it is anticipated that ALS will become a treatable, not fatal, disease in the not-too-distant future. In the past five years, new drugs have come to the market to help slow down the progression of the disease.

There are a number of treatment strategies and equipment that will help you conserve energy and live a better quality of life for a longer period of time. Early adaptation and adoption of intervention and treatment is helpful in the medical management of ALS and will make your days and your family's days a little easier.

The following is only a very brief introduction to the medical management of ALS and is designed to let you know what kind of help is available and to point you in the right direction to obtain more information.

## Breathing

In ALS, your breathing muscles and diaphragm weaken, and breathing becomes difficult. At some point, breathing difficulty will drain the energy that you want to preserve for other things. When this happens, you can choose to introduce some preventative measures. You will experience symptoms such as the inability to cough, difficulty having enough breath to speak long sentences, daytime headache, and overall tiredness. It may be time to consider what is known as non-invasive ventilation. Some testing is involved, and a bi-pap machine may be recommended. A bi-pap is a portable machine (the size of a shoe box). With a prescription, they are available for loan at no cost to you from the ALS Society of New Brunswick and Nova Scotia. A mask, humidification chamber, and tubing can be purchased through a vendor when the bi-pap is set up to your specifications.



# **MEDICAL MANAGEMENT**

## **Speaking and Swallowing (Choking) /Nutritional Support**

At some point, you may have to consider being fed through a feeding tube. Naturally, most people find this a difficult decision and believe it means that the end is near. At the ALS Society of New Brunswick and Nova Scotia, we have witnessed many people who chose this route in order to meet their goals – i.e. living longer to be with children and other family. You can still be completely mobile with a feeding tube; you can still eat your favourite things if you choose occasionally and under advice from your medical team. The care is very manageable and not as unpleasant as some might imagine. Maintaining your weight with ALS is very important to help increase length of life. You may also opt to have the feeding tube surgery while you are still able to eat and before your breathing is compromised. Your speech-language pathologist and dietician will help you with these problems, recommending therapies, food preparation, and assistive communication devices (available for loan with a prescription from the ALS Society of New Brunswick and Nova Scotia).

Being able to communicate with your spouse, family, friends, and healthcare providers is extremely important. Losing the ability to communicate with your voice is challenging and emotionally taxing both for the person with ALS and all those they need to communicate with. Patience is the key word here for everyone. Be open to discussing adaptations for communicating. Don't lose hope. There are a variety of options and technology to help you communicate. It is important to work with a speech-language pathologist to discuss a range of strategies

## **Saliva Build Up**

When tongue and throat muscles weaken in ALS, you may have difficulty expelling excess saliva and phlegm. This is the time to see a physiotherapist or a respirologist who will help you with strategies for assistive equipment such as a suctioning or cough assist machine. With a prescription, you can loan these devices from the ALS Society of New Brunswick and Nova Scotia at no charge. Masks and set-up fees are at the cost of the client.

# MEDICAL MANAGEMENT

## Mobility

Everyday activities such as getting in and out of bed, walking, and taking a shower may become difficult as ALS progresses. It can be difficult to have medical equipment such as a patient lift, hospital bed, assistive devices in the bathroom, and a wheelchair suddenly appear in your home. However, they are important for your comfort, preventing falls and injury, and will help you live as independently as possible. The decision about when to obtain equipment (available on loan at no cost with a prescription) is one that you should make with your family and occupational therapist. When making the decision to access equipment, you may also wish to consider the physicality involved in your caregiver lifting you, helping you move, etc.

## End of Life – Medical Assistant In Dying (MAiD)

The ALS Society of New Brunswick and Nova Scotia also recognizes that quality of life can only be determined by the person living with ALS. We commit to supporting those choosing physician-assisted death with information on the law, the process, and emotional support. This is not an easy topic for sure, but one that needs to be discussed with professionals (legal, finance, healthcare team) and your loved ones to ensure that people understand your wishes and why you made the decisions that you did. It helps your family fulfill your wishes, even when they may be uncomfortable with them. You can revisit your decisions a couple of times a year. As you progress with the disease, you might change your mind about certain things – getting a feeding tube or ventilation assistance, etc.

Nova Scotians seeking information about MAiD can discuss this with their primary care provider or a specialist. **They may also contact the Nova Scotia Health Authority MAiD Care Coordination Office, toll-free at 1-833-903-6243 or 902-491-5892 within the Halifax region. The Office email address is [maid@nshealth.ca](mailto:maid@nshealth.ca).**

New Brunswickers seeking information about MAiD can discuss this with their healthcare provider. **If you do not have a healthcare provider or prefer not to discuss medical assistance in dying with that health care provider, contact the Horizon Patient Representative Office by phone at 1-844-225-0220.**

# **COPING WITH ALS**

## **Give It Time and Patience**

A diagnosis of a terminal illness like ALS takes time to process both for the person diagnosed and for family and friends. Every person will process the information differently. Patience and space to process the information is required on the part of all family members and friends. Be kind to yourself and allow yourself to experience and go through the process of denial, anger, sadness, and grief. It's perfectly normal to grieve. Just don't unpack your bags and live there. Cry, scream it out, write it down, do what you have to. Then, refocus your energy on living your best life as well as you can, as long as you can. And remember, ALS Society of New Brunswick and Nova Scotia is here to help you. YOU ARE NOT ALONE.

## **ALS Does Not Define You**

ALS is part of your life - but not all of it. You are still the same person you always were. Fight for that person.

## **Maintain Positivity and Hope**

You're a normal human being, and you're not going to be able to be positive and hopeful every day. However, practicing and focusing on what is still good in your life, choosing a positive thought over a negative one, putting a smile on your face even when you don't feel like it.

“And so I began living my new life. Looking back, there are three words that summarize my new journey. The first is ACCEPTANCE. I knew that how I handled this was important to pave the way for this new road ahead. I made up a motto for myself and shared it with others, what I have, what I am and what I want. I have faith and hope, I am optimistic and I will find joy every day. I had to repeat it to myself several times during each day until I began to believe it myself.

I looked for joy - ‘unexpected happiness’ and began to find it in the most unexpected places.”

Judy Starritt

# **COPING WITH ALS**

## **Maintain a normal routine. Okay, a 'new' normal routine**

If weekly family dinners were at your house, keep hosting them as long as possible. Maybe the menu is less complicated, maybe you ask for help preparing food, or maybe you sit back and let others bring the food. Ask for help maintaining as normal a routine as possible. People want to help—you give them a gift by letting them know what help is useful. Remember, you would do the same thing for any family member or friend if the situation were reversed.

## **A New Perspective**

It is an unfortunate fact that you have a shortened life span. That fact must be acknowledged and grieved. However, many people with ALS find that it is helpful not to focus on the timeline but to embrace each day and each moment. Take time to develop deeper relationships and explore your spiritual awareness.

## **Be Proactive and Knowledgeable**

Familiarize yourself with the disease progression, the treatment, and the equipment available to reduce symptoms and make you more comfortable. Ignoring manageable problems or delaying intervention can make a difficult situation worse for you and your loved ones.

## **Seek Help from Professionals**

Seeking help (therapy or counseling) can offer a great deal of comfort and hope. Counseling and therapy sessions can be a safe place for you and/or your family to express fears, to learn how to cope with anxiety, to adapt to huge changes, and to deal with grief. Please refer to our Living the Gift Program under Programs and Services on our website ([www.alsnbns.ca](http://www.alsnbns.ca)) for more information.

## **Goals**

Setting some goals can assist you in making decisions about your medical treatment and how you wish to live your life. Be sure to consult with your Continuing Care Coordinator, Palliative Care, ALS Clinic, or family physician about your medical directives.

# **COPING WITH ALS**

## **Plan Ahead – The Difficult Decisions**

You and your family have a lot of decisions to make and plans to develop. This means you will have hard conversations and face end-of-life issues. Making these decisions early on allows you to be in control of your life and care. It gives your family members and healthcare team direction when they understand and know your goals. It reduces stress as your level of care increases. Once the hard decisions and paperwork are out of the way, you can move on with living your best life for as long as you can. And remember, you can change your mind at any time. Interventions people thought they may not want at the beginning of their journey may change as treatments develop and as you gain strength and confidence about your ability to cope.

## **Friends and Family – Breaking the News, Communication, Supporting Each Other**

Most people have the potential to have a great support system of family, friends, and co-workers. While they will not experience the physical symptoms of ALS with you, they are sharing the emotional ups and downs, the worries and fears. Ultimately, you are in control of your care and disease management. The emotional and physical well-being of your support system will play a big part in your own ability to cope. Both are interconnected and rely on good communication, emotional support, give-and-take and shared decision-making.

## **The Value of Connection and Experience**

Sometimes, people delay joining a support group or meet and talk with someone else with ALS because they don't want to know what is ahead. It can be difficult to see what is down the road, but it can also be very helpful. For example, some people with ALS may make decisions about future treatment without a full understanding of the implications of the treatment. Some people will say, when it's time for a feeding tube, I don't want to live anymore. And then they meet someone with a feeding tube that is doing very well and still engaged in life. Meeting someone living with ALS can be a great support and help you make the best decision for you. At ALS Society of New Brunswick and Nova Scotia, we have witnessed amazing friendships among our ALS families. Remember, it is not only the person with ALS who needs support but also spouses, caregivers, and children.

# COPING WITH ALS

## Let's Face It – Time Is Precious

Be open and direct with your support system in expressing your needs, wishes, fears, and emotions. In return, receive their expressions of the same without judgement. Just like it takes a village to raise a child, it will take a team of family members, friends, and healthcare workers to care for you. Encourage your team members to take care of themselves physically and emotionally. Encourage your family to be realistic in the way they can help you and ask them to do things that are in their comfort level.

Use humour to diffuse difficult situations; laughter really is the best medicine.

An ALS diagnosis can be especially difficult for children of parents living with the disease. What is more difficult for those children, however, is that when they are not kept informed at an age-appropriate level, what they imagine is usually worse than the reality.

What is important for children is their daily routine. Being able to keep a routine for them will offer safety and security. Keep them informed of changes in the daily routine. Mom is taking Dad for a check-up today, so Grandma will be here when you come home from school. Next week, Dad is getting a wheelchair to help him get around. Dad can't use his voice anymore, but he still hears and understands you.

While it is important not to overwhelm children, they can be involved in planning family activities and helping at an age-appropriate level. This helps them understand that family members support one another and that they can cope with difficult situations and be okay.

### **Additional Resources:**

Graphic Novel: Real Kids Talk About ALS

Book/Guide: The ALS Experience: It's Different and Hard

# EQUIPMENT LOAN PROGRAM

The ALS Society of New Brunswick and Nova Scotia operates an Equipment Loan Program designed to help people cope with the daily challenges of decreasing mobility and independence and help families cope with the financial challenges of ALS. Our goal is to keep people living with ALS comfortable, safe, breathing, communicative, and mobile.

The ALS Society provides equipment that can be cost-prohibitive for most families. This includes mobility equipment, basic communication devices, respiratory equipment, and bath assist equipment. Equipment will be recommended to you by your occupational or physical therapist. Prior to purchasing any equipment, please talk to Emily Wells to see if we can help.

This is a recycled equipment loan program. Our equipment serves more than one person and is used several times. It is cleaned and sanitized between uses and maintained by professionals when required. We obtain equipment by purchasing new pieces when funding allows, by assisting with co-payment of insurance deductibles, and in-kind donations.

- The ALS Society works closely with your health care team to provide various types of assistive and mobility equipment as they are required.
- We loan out equipment regardless of financial situations and there are no rental fees to access the equipment loan program.
- The equipment is delivered to your home free of charge and picked up when no longer needed.

## Accessing the Equipment Loan Program:

1. Complete a brief enrollment form (online or by email) and submit it to Emily Wells at [ewells@alsnbns.ca](mailto:ewells@alsnbns.ca) or Kerry Mahar at [kmahar@alsnbns.ca](mailto:kmahar@alsnbns.ca). To access our services, you must have a definitive or probable ALS diagnosis from your neurologist.
2. Have a member of your healthcare team submit an equipment request at [www.youarenotalone.alsnbns.ca](http://www.youarenotalone.alsnbns.ca).

The ALS Society of New Brunswick and Nova Scotia is to be notified in writing when a PAL moves into a care facility or hospital. The ALS Society will only allow mobility equipment and breathing equipment (bi-pap, cough assist, and suction units) to accompany our PALS and must remain in their possession during the term of this agreement. It is the family's responsibility and nursing facility/ hospital to ensure that all staff are properly trained on the medical equipment that our PAL accompanies. This may involve a vendor or healthcare team to properly demonstrate proper use and care of the equipment. There may be a cost for this service, and it is at the expense of the families or care facility.

The ALS Society staff works hard to ensure that the equipment is clean and working well, but we need your help. Before you contact the ALS Society to arrange equipment pick up, please ensure that all equipment has been sanitized with a disinfectant solution. We will still be cleaning the equipment, but this will help us streamline the service. By doing this, you will put the equipment in the hands of people living with ALS sooner.



# SUPPORT GROUPS

The ALS Society of New Brunswick and Nova Scotia offers a virtual support group once a month. It is open to anyone living with ALS and their family members/ caregivers. Emily Wells, the Client Services Manager, facilitates the group.

The ALS Society of New Brunswick and Nova Scotia's Support Groups is a mixture of education, discussion, and meeting other people living with ALS who share their experiences and offer advice for others. Education sessions include guest speakers such as neurologists, who talk about how they diagnose ALS, and occupational therapists, who talk about renovations to the home.

**If you would like to be added to the Support Group Contact List, please contact Emily Wells at [ewells@alsnbns.ca](mailto:ewells@alsnbns.ca) or 902-454-3636.**

# CNDR REGISTRY

As of June 2011, a new national registry for patients with neuromuscular disease– the Canadian Neuromuscular Disease Registry (CNDR)– will help patients connect with researchers to participate in clinical research that will benefit patients by offering possible new therapies, treatments and understanding of their disease.

The CNDR is a Canada-wide database of patients who have been diagnosed with a neuromuscular disease. The term “neuromuscular disease” refers to a group of more than 40 diseases that affect how muscles and nerves work. ALS is the most prominent of these diseases in adults, and Duchenne muscular dystrophy (DMD) is the most common pediatric muscular dystrophy.

The Canadian Neuromuscular Disease Registry (CNDR) includes 17 clinics across Canada located in Vancouver, Calgary, Edmonton, Ottawa, Toronto, London, Kingston, Montreal and Halifax.

## Why Participate?

The Registry is the only means by which valid national epidemiologic data about ALS can be obtained. Patients with neuromuscular disease will benefit from this new national registry. Shelagh Mikulak has ALS and joined the registry because it gives her hope that “with the information available to researchers there will be a significant increase in the number of studies leading to discovering the cause, treatment and cure of ALS”. Finding treatments for neuromuscular diseases has been challenging, as patients are scattered across the country. This registry will allow doctors and researchers to look at medical data from large groups of patients helping them to find better ways to manage each disease.

All patients, both adults and children, across Canada who have been diagnosed with a neuromuscular disease are able to join the registry. Patients living outside the cities with affiliated clinics, or those not currently seeing a neuromuscular specialist, can register by contacting the CNDR National Office at the University of Calgary. The CNDR is supported by the ALS Society of Canada, Jesse’s Journey and the Marigold Foundation.

**For more information please call 1-877-401-4494 or visit [www.cndr.org](http://www.cndr.org)**

# TELEHEALTH

## **Telehealth – New Brunswick**

The New Brunswick Telehealth Network (NBTHN) is a videoconferencing communications network that connects healthcare-focused facilities across New Brunswick. It uses videoconferencing technologies to improve patients', families', and healthcare professionals' access to health services.

Patients from across New Brunswick can meet face-to-face with healthcare professionals located anywhere on the network without leaving their home communities. This saves patients the time, stress and expense associated with travel. Barriers to health care access including travel costs or inclement weather are removed.

**For more information, including a list, by region, of facilities and programs offering this service, please visit: [www.horizonnb.ca](http://www.horizonnb.ca).**

## **Telehealth - Nova Scotia**

The Nova Scotia Tele-Health Network (NSTHN) is a video conferencing communications network available for our ALS Clients that connects healthcare focused facilities across Nova Scotia. The NSTHN uses video-conferencing technologies to improve access to health services for patients, families and healthcare professionals.

Patients from across Nova Scotia can meet face-to-face with health care professionals located anywhere on the network, without leaving their home communities. This saves patients the time, stress and expense associated with travel. Barriers to health care access including travel costs or inclement weather are removed.

**If you would like to be seen via tele-health in your community, instead of travelling to Halifax, please contact Melanie Ellerker at the ALS Clinic to make arrangements at 902-473-1245.**

# ADDITIONAL RESOURCES

## Disability Tax Credit

The Disability Tax Credit is a non-refundable tax credit that helps individuals with disabilities with disability-related costs. Eligibility for the tax credit is based on the effects of the impairment, not on the medical condition or the diagnosis.

**For more information please visit:** <https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html>

## Nova Scotia Power Critical Customer Care Program

The NSP Customer Care Program is for customers who have electric-powered medical equipment at home that is necessary to sustain life or avoid serious medical complications. Through this program customers would have access to advanced notice of planned power outages, communication during an unplanned power outage and updates on power restoration.

**For more information please call 1-800-428-6230 or visit** <https://www.nspower.ca/outages#:~:text=Our%20Critical%20Customer%20Communication%20Program%20is%20designed%20for%20customers%20whose,notice%20of%20planned%20power%20outages>

## Department of Community Services

The Department of Community Services offers a range of social services to ensure you are able to live independently. Services offered include income assistance, affordable housing and family supports.

**For more information regarding DCS please visit:** <https://beta.novascotia.ca/government/community-services/about>

**If in need of Social Supports in New Brunswick please visit** <https://socialsupportsnb.ca/en/>

## 211

211 is a service available 24/7 in Nova Scotia that helps to connect you with various programs and services in your community. 211 is a free and confidential service equipped to deal with even the most complex questions.

For more information regarding 211 in Nova Scotia, please call or text 2-1-1, email [help@ns.211.ca](mailto:help@ns.211.ca) or visit <https://ns.211.ca/>

For more information regarding 211 in New Brunswick, please call or text, 2-1-1, email [211nb@findhelp.ca](mailto:211nb@findhelp.ca), or visit <https://nb.211.ca/search/>