



Prairie to Peak

ALS Society of Alberta
 March 2024 - Newsletter

SAVE THE DATE AND MARK YOUR CALENDARS!

Walk & Run Season is right around the corner!

Registration for the Walks and for Betty's Run is now open!

Betty's Run for ALS
 Inspiring Care, Hope, and Community

SAVE THE DATE

Sunday, June 9, 2024
 North Glenmore Park

[Register](#)

SAVE THE DATES

• DRAYTON VALLEY	June 1
• CAMROSE	June 1
• COLD LAKE	June 8
• EDMONTON	June 8
• RED DEER	June 15
• LETHBRIDGE	Sept 7
• HINTON	Sept 8
• WAINWRIGHT	TBD
• ALTARIO	TBD

[Register](#)

Caregivers in the Wild: *The Nature of Support*

Virtual Screening and Discussion with Award Winning Videographer,

Dr. Mike Lang PhD

Last month, a special presentation was hosted for the ALS Alberta community by health researcher, adventure guide, and award-winning director/producer, **Dr. Mike Lang**.

Using his in-depth knowledge of therapeutic recreation, his deep understanding of family caregiving, and his extensive experience facilitating adventure trips Mike takes caregivers on unique outdoor adventures, specifically designed for each caregiver.



Mike is an amazing digital storyteller and beautifully captures each caregiver's story to share on the screen. Viewers from all over the world can benefit from these meaningful moments spent in the wilderness. If you missed the screening, do not worry - you can watch the series by clicking the button below!

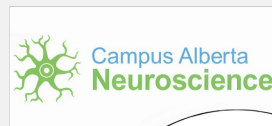
This is Caregivers in the Wild.

Watch

ALS RESEARCH IN ALBERTA ACHIEVEMENTS FOR ANN - THE BACKLUND FELLOWSHIP

**Accelerating ALS Research: Campus
Alberta Neuroscience and the ALS
Society of Alberta Unite for Postdoctoral
Fellowship**

We are pleased to announce the launch of an exciting postdoctoral scholarship competition in Alberta.



Achievements for Ann – The Backlund Fellowship Competition will support exceptional scholars in Alberta and provide them with the opportunity to contribute to the advancement of research in ALS and neuromuscular diseases. By exploring research to understand the causes, find potential treatments, and/or enhance the quality of life for those affected, these scholars will play a crucial role in combating these neurodegenerative diseases.

This post-doctoral fellowship competition is named after Mikael and Frida Backlund, whose remarkable commitment has resulted in over \$500,000 in donations to the ALS Society of Alberta. This fellowship is set to make profound contributions to ALS understanding and treatment, and is dedicated to the memory of Ann Engstrom, Frida’s mother who lived with ALS.



In addition to its direct impact on advancing scientific knowledge of ALS and the search for effective treatments, funding research in the field of ALS and neuromuscular diseases fosters innovation, knowledge translation, and a culture of education and research in the province.

Financial support through programs like *Achievements for Ann – The Backlund Fellowship* allows postdoctoral scholars to focus on their novel explorations without the worry of financial constraints. Investing in research in Alberta advances the translation of scientific knowledge into practical, evidence-based applications through dissemination to the broader scientific community, healthcare professionals, and policymakers, leading to positive impacts on the lives of Albertans. It also creates new opportunities for mentorship, training, and collaboration - deepening researchers’ expertise and nurturing a culture of lifelong learning and open knowledge sharing.

Candidates for *Achievements for Ann - The Backlund* (Postdoctoral) Fellowship Competition must hold a recent doctoral degree and have, by the time of the application deadline, secured a supervisor in Alberta for an ALS/neuromuscular disorder research project. With more details coming later this year, interested parties should expect to demonstrate their strong academic background and potential, an innovative research idea, and a strong relevance to our mission, “to make each day the best possible day for people living with and affected by ALS .”

Click here to learn more.

Click Here to Read More on Achievements for Ann - The Backlund Fellowship

Did you know?

Since 2014, the Backlunds have raised over \$500,000 for the ALS Society of Alberta AND hosted close to 96 clients and their loved ones at Calgary Flames home games.



Mikael and Frida support our ALS community in so many ways. They are true leaders in making our community a better place. They support so many important causes and truly make a difference in the lives of those living with and affected by ALS.

The ALS Alberta community is incredibly thankful for their support. Mikael and Frida host events, support families in Alberta, fund groundbreaking research, generate awareness, and host our clients from across Alberta (and their loved ones) at Calgary Flames home games.

The highlight of attending the Calgary Flames games is always when Mikael meets his guests at the end of the game. These games bring our clients and their loved ones together to create a truly memorable moment. Thank you, Mikael and Frida, for making this possible!

Mikael and Frida have hosted more than 90 families since 2014!

Parachutes for Pets: Lily & Dexter's Legacy Box

Lily and Dexter's Legacy is a ground-breaking community program of **Parachutes for Pets**, designed to assist in keeping people with their pets. In 2023, Lily and Dexter's Legacy expanded to include a Clubhouse in the organization's Pet Advocacy Center. This dedicated space allows children to have a fun-filled room to bring their pets for important meetings, counseling services, and conversations.

Love for Lily and Dexter Boxes are created for kids and pets through wonderful supporters like the Backlund Family and the Calgary Flames. Many of the boxes for kids are donated

by the public to children in the Alberta Children's Hospital Oncology Unit.



Pet boxes are often donated and delivered to other vulnerable Calgarians in need. The proceeds from the sale of these boxes are funneled into the Lily and Dexter's Legacy Fund.

We are so grateful for this organization, and honored to announce that this year, Parachutes for Pets is donating several boxes to members of our ALS Alberta community.

Thank you #ParachutesforPets and the #BacklundFamily!!

ALS Research News

Recruiting Trials – In Edmonton

*If you would like to learn more about any of the studies please contact **Kelsey Tymkow** at 780-492-7690*

Pharmaceutical **COMBAT-ALS (ibudilast)**

Evaluation of MN-166 (Ibudilast) for 12 Months Followed by an Open-label Extension for 6 Months in Patients

A Phase 2b/3 multicenter, randomized, double-blind, placebo-controlled, parallel group study to evaluate the efficacy, safety and tolerability of MN-166 given to ALS participants for 12 months followed by a 6-month open-label extension phase.

For more detailed information please visit clinicaltrials.gov -NCT04057898

Quralis (QRL-201) *A Study Evaluating the Safety and Tolerability of QRL-201 in ALS*

The primary objective of this study is to determine the safety and tolerability of multiple doses of QRL-201 in people living with ALS

For more detailed information please visit clinicaltrials.gov -NCT05633459

Observational

The Comprehensive Analysis Platform to Understand, Remedy and Eliminate ALS (CAPTURE ALS)

CAPTURE ALS, led by Dr. Sanjay Kalra at the University of Alberta, is a national ALS research platform that is developing the world's most detailed and comprehensive picture of ALS. People living with ALS and related diseases, as well as healthy controls, are invited to participate in this observational study at the University of Alberta and tell their own unique stories through their data. The data captured, including MRI scans, neurological exams, patient-reported outcome measures, cognitive and speech testing, as well as blood – will be shared with scientists across the globe to better understand ALS and to develop more effective treatments and biomarkers. Recruitment is ongoing at 4 ALS centers across Canada, including in Edmonton, where the first CAPTURE ALS participant was enrolled.

To learn more, email info@captureals.ca

The Canadian Neuromuscular Disease Registry (CNDR) is actively recruiting all individuals

diagnosed with ALS.

The CNDR is a national registry partnering with ALS clinics across the country that strives to improve access to care and therapies for people with ALS and to increase the impacts of research in the Canadian healthcare system. The CNDR works with the community to provide essential clinical data related to people living with ALS for research and planning of future studies.

The CNDR is recruiting individuals using Edaravone or Albrioz (formerly AMX0035). The CNDR is collaborating with clinicians, scientists, patient organizations, and industry on studies to evaluate the safety, tolerability, and effectiveness of ALS therapies to support access to drugs for Canadians who may benefit.

To learn more: [Click Here](#)

Understanding the prevalence, clinical features, and genetics of spinal-bulbar muscular atrophy in people of Indigenous descent

Recently, our research team found that SBMA (Kennedy's Disease) is much more prevalent than expected in people of Indigenous descent residing in western Canada.

SBMA is a genetic condition causing weakness of muscles in the face and limbs, starting in adulthood. Because it is "X-linked" it generally only affects males, but females who are carriers of the mutation may also develop a milder condition. We believe that female carriers may be more likely to develop symptoms if they have inactivation of one X-chromosome more than the other.

The purpose of this research study is to learn more about the prevalence, clinical features, and genetics of SBMA.

Ultrasound Study

This is a study that can be done during an in-clinic visit. The study is trying to determine whether diaphragm ultrasound at the bedside, which is non-invasive and only takes 5 minutes, can detect diaphragm weakness earlier and more accurately than pulmonary function testing and whether abnormal diaphragm ultrasound predicts which patients need to go on non-invasive ventilation (NIV, such as BiPAP). We are also trying to better understand how diaphragm size and strength change over time in patients with ALS.

[Learn
More](#)

Ask me Anything with Dr. Wendy Johnston

Ask Dr. Wendy Johnston Anything! (About volunteering and research). Get all your questions about participating in CAPTURE ALS and other clinical research answered. Join the webinar, **Wednesday, April 17, 2:00 - 3:00 PM GMT**.

Dr. Johnston is actively involved in ALS research, including extensive involvement in national and international clinical trials and health communication research. She is a Professor of Neurology in the Faculty of Medicine and Dentistry at the University of Alberta.

These webinars are open to CAPTURE ALS participants and their family members. Interested members of the ALS community may attend. For more information, please contact Shelagh Genuis (genuis@ualberta.ca).

Presentations will be available following the webinars on the CAPTURE ALS website: <https://captureals.ca/participant-engagement-webinars/>



ASK ME ANYTHING ABOUT VOLUNTEERING DR. WENDY JOHNSTON

WEDNESDAY, APRIL 17, 2:00 - 3:00PM GMT



How to Donate

If you would like to help us make each day the best possible day for those living with and affected by ALS, there are many impactful ways to give. Donations now, more than ever, will make a tremendous impact on our ability to support our families in Alberta. Please click the link below to help our families today with one-time, monthly, or in-memorial donations. Please call us to discuss other giving options. **Thank you!**

[Donate Today](#)



If you would like to stay up to date with the ALS Society of Alberta, follow us on social media!



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