

Walk to End ALS

presented in BC and the Yukon by



&



Top Level Sponsor



Through the Walk to End ALS in BC our **TEAM ALS BC & Yukon** volunteers and donors help to fund the Canadian ALS Research Program and to support patient services programs provided by the ALS Society of BC. 60% of the funds raised at the Walks go to support patient services in BC and the Yukon and 40% go to ALS research in Canada. We are excited to see in 2019, \$1.4M invested in fueling the scientific discoveries that will bring hope for #aFuturewithoutALS.

The projects funded will answer questions that will help to accelerate research discovery contributing to the development of potential ALS therapies:

- **How do unique protein interactions explain TDP-43 behaviour in different people with ALS?** \$100,000 awarded to Dr. Mohan Babu at the University of Regina.
- **How do environmental marks on RNA play a role in how ALS is caused?** \$100,000 awarded to Dr. Patrick Dion at the Montréal Neurological Institute at McGill University.
- **Does prior exposure to common viruses influence ALS onset and disease progression?** \$100,000 awarded to Dr. Matthew Miller at McMaster University.
- **Does a substance in gut or oral bacteria influence the disease course of ALS?** \$100,000 awarded to Dr. Minh Dang Nguyen at the University of Calgary.
- **Can a new ALS mouse model provide important information for understanding and treating ALS?** \$100,000 awarded to Dr. Jeehye Park, at the Hospital for Sick Children (SickKids) Research Institute.
- **Are the same faulty nerve-muscle connections in ALS mice also occurring in humans?** \$100,000 awarded to Dr. Richard Robitaille at the Université de Montréal.
- **What is the role of the annexin A11 gene in ALS disease processes?** \$100,000 awarded to Dr. Peter St. George-Hyslop at the University of Toronto.
- **Can advanced technology reveal the role of multiple cell types affecting ALS in humans?** \$98,400 awarded to Dr. Stefano Stifani at the Montréal Neurological Institute at McGill University.
- **Can earlier palliative care consultation improve patient and caregiver quality of life?** \$55,437 awarded to Dr. Jocelyn Zwicker and Dr. Christine Watt at the Ottawa Hospital.

- **Can speech-recognition technology help diagnose ALS?** In partnership with Orangetheory Fitness, \$100,000 awarded to Dr. Yana Yunusova at the Sunnybrook Research Institute.
- **Can an animal model provide new insights into the formation of stress granules?** \$75,000 awarded to Alicia Dubinski, a PhD student in Dr. Christine Vande Velde's lab at the Université de Montréal.
- **What is the role of a newly discovered protein in ALS?** La Fondation Vincent Bourque | ALS Canada – Brain Canada Ph.D. Studentship of \$75,000 awarded to Myriam Gagné, a PhD student in Dr. Christine Vande Velde's lab at the Université de Montréal.
- **Is the loss of normal function of C9ORF72 in a particular cell type a key driver of ALS disease processes?** \$75,000 awarded to Rahul Kumar, a PhD student in Dr. Peter McPherson's lab at the Montréal Neurological Institute at McGill University.
- **Is an experimental drug that can prevent abnormal protein behaviour in ALS already out there?** La Fondation Vincent Bourque | ALS Canada – Brain Canada Ph.D. Studentship of \$75,000 awarded to Marc Shenouda, a PhD student in Dr. Janice Robertson's lab at the University of Toronto.
- **Could newly discovered tags on TDP-43 protein explain its abnormal behaviour in ALS?** In partnership with Brain Canada, \$75,000 awarded to Terry Suk, a PhD student in Dr. Maxime Rousseaux's lab at the University of Ottawa.
- **Can new understandings about nuclear speckles lead to new treatment options for ALS?** \$165,000 awarded to Dr. Ulises Rodríguez Corona, a post-doctoral student in Dr. Marlene Oeffinger's lab at Institut de recherches cliniques de Montréal (IRCM).

The funding of the 16 research projects followed a competitive peer-review process, which engaged global ALS experts to identify projects grounded in scientific excellence and with the potential to most quickly advance the field of ALS research. The peer review was observed by people who have personal experience with ALS.

Patient Service Programs provided by the ALS Society of BC include:

- **EQUIPMENT LOAN PROGRAM:** With over 3,030 pieces of medical equipment our Equipment Loan Program is designed to help people cope with the daily challenges of decreasing mobility and independence, through obtaining basic and essential assistive equipment. This includes mobility equipment, lift equipment, beds & accessories, communication devices, and bathroom aids, if needed. All equipment loaned is available at no charge to registered ALS patient members.
- **SUPPORT GROUPS:** Support groups provide an open, friendly and safe environment for ALS patients, family members, caregivers and friends to discuss issues related to living with ALS. Groups are facilitated by experienced volunteers.
- **PSYCHOLOGICAL TREATMENT SERVICES:** Psychological treatment services are available free of charge at locations across BC. Registered Psychologists and Clinical Counselors provide much needed therapy and counseling to ALS Patients, their families and caregivers at any stage of the illness. Services will be provided throughout the disease and up to one-year following.
- **DAY OF CARING FOR CAREGIVERS:** Held every Fall in communities around BC, THE Day of Caring for Caregivers is a chance for the full-time primary caregivers of ALS Patients to have a day of respite. This event allows for people who devote themselves to the care of their loved ones to come together and share experiences. It also provides the opportunity to learn how to

take better care of themselves and how to cope with grief.

- **CAMP ALOHI LANI:** In July or August ALS BC hosts a camp for youth who have a Parent (or Grandparent in a significant role) Living with ALS. ALS BC is extremely pleased to be able to offer this weekend retreat at no cost to families. Camp Alohi Lani, which means 'Bright Sky' in Hawaiian, is a safe setting in which youth aged 8-17 years can come together and receive support for their own journey. Most importantly Camp Alohi Lani offers campers an opportunity to meet other youth from across BC and make connections with peers.
- **CARE CONNECTIONS:** The primary purpose of forming a Care Connection is to reduce caregiver responsibilities and reduce the worry the person with ALS has about their caregiver. By caring for the caregiver, the person with ALS is helped as well. The ALS Society of BC's Care Connection is a program to aid your own group of caring family and friends to help their loved ones with ALS and their caregivers.
- **MOBILE CLINICS:** In partnership with Vancouver Coastal Health and the ALS Centre @ GF Strong Rehab Centre, the ALS Society of BC provides Mobile Clinics to outlying communities. ALS Centre healthcare professionals and an ALS Society of BC representative travel to clinic locations to provide follow-up appointments for people challenged to travel.

All that is required to access these programs is the patient's registration with ALS Society of BC. No fees are charged. Services available to people living with ALS in British Columbia and the Yukon.

For more information, contact:

Wendy Toyer, Executive Director

ALS Society of BC ; 1228 – 13351 Commerce Parkway; Richmond BC V6V 2X7

Email W.toyer@alsbc.ca

Office (604) 278-2257 ext. 222

Cell (778) 999-6257

www.alsbc.ca