

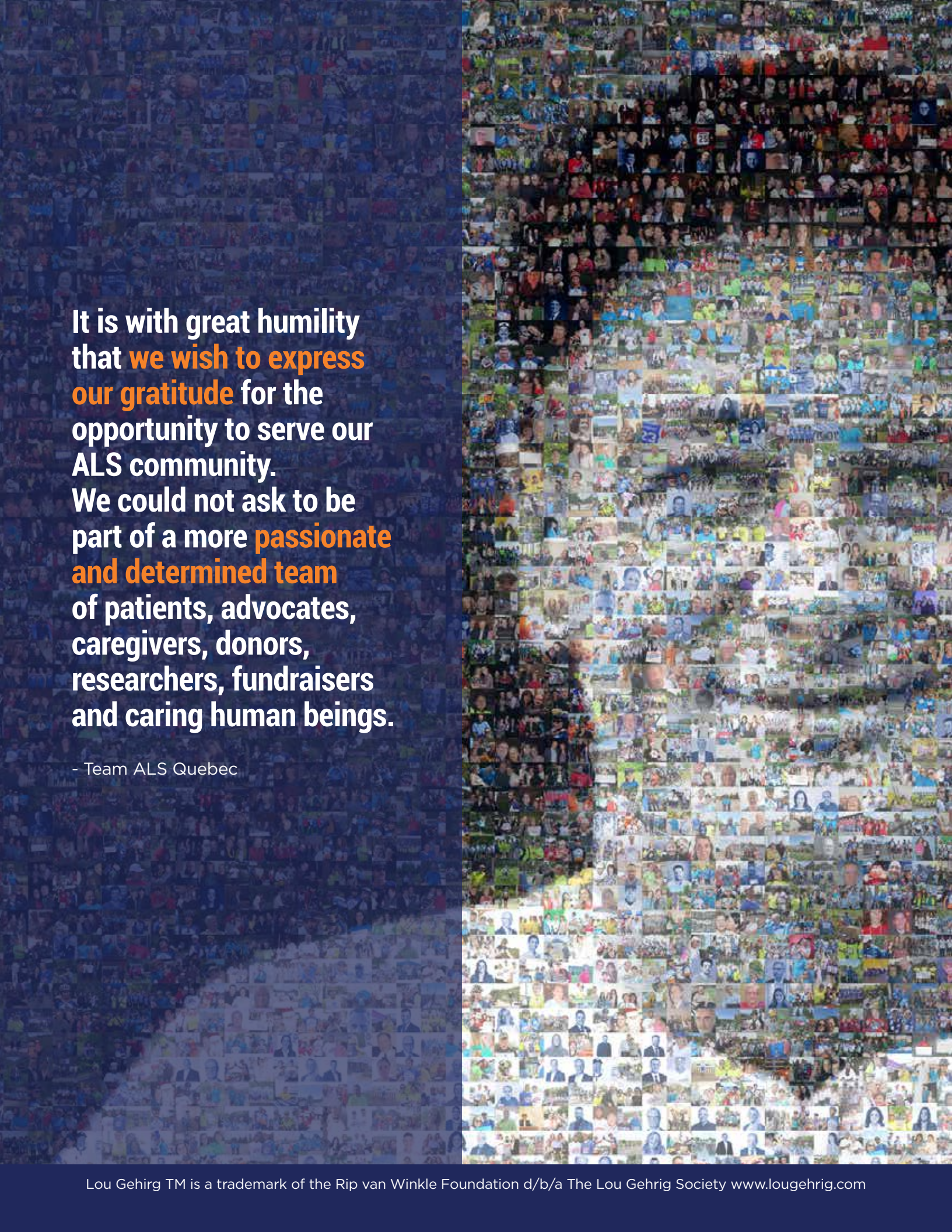


# UNITED TO STRIKE OUT ALS

2020-2021 ANNUAL REPORT







It is with great humility  
that **we wish to express  
our gratitude** for the  
opportunity to serve our  
ALS community.  
We could not ask to be  
part of a more **passionate  
and determined team**  
of patients, advocates,  
caregivers, donors,  
researchers, fundraisers  
and caring human beings.

- Team ALS Quebec



## WE ARE A TEAM UNITED TO STRIKE OUT ALS

Tough times often bring people together. Our families tell us this. We, as a community, also know this to be true.

During this second challenging year navigating ever-changing Covid-19 protocols and restrictions, many of our communications with families, our fundraising events, and our efforts to raise awareness have remained virtual. We all miss the chemistry of meeting face-to-face, but through it all, we have not lost sight of our common goals and our burning desire to keep the momentum strong.

We did it Team! Whether we were huddled in the dugout or out on the mound, our players were united to support families, to raise awareness, and to collect much needed funding so we can continue to offer our programs and services and contribute to leading-edge research.

There were many victories along the way and we are so proud to share our highlights with you in our Annual Report. We saw growing numbers of participants in our virtual support programs responding to our families' various needs and a growing number of ALS Ambassadors raising their voices in the traditional media and on social media. More than 100 sports, entertainment, and media personalities leveraged their networks to celebrate the first annual Lou Gehrig Day with Major League Baseball,

including our own unveiling of the Lou Gehrig Mosaic of Hope filled with more than 3,000 photos of people we honour with every action we take.

Perhaps one of the most joyful highlights of 2021 was to participate in person in the Ride to Fight ALS. It was just so wonderful to be among members of our community again, and a reminder, that when it becomes safe for all of us, we will all be together in person once again.

There is so much to look forward to! The many promising therapies in clinical trials give us hope that we are on the cusp of new discoveries that will change the trajectory of the disease and improve the quality of life for people diagnosed with ALS. We will be ready! We have been working on our new strategic plan that will articulate our vision, mission and objectives for the next three years. Together, we know we will reach our milestones.

Thank you all – donors, partners, volunteers, program participants – for making our work together a constant source of inspiration. And thank you, too, for the efforts of our wonderful board members and staff whose deep passion and tireless dedication are constantly on display. We are the luckiest players on this incredible team!



*Susan Kennerknecht*

**Susan Kennerknecht**

President, Board of Directors



*Claudine Cook*

**Claudine Cook**

Executive Director  
ALS Society of Quebec

# ABOUT AMYOTROPHIC LATERAL SCLEROSIS (ALS)



Also known as Lou Gehrig's disease, ALS is a fatal neurodegenerative disease with no cure.



Each year, 1,000 Canadians are diagnosed with ALS— for each person diagnosed, someone else dies.



Communication between the brain and the motor muscles is cut off, and people gradually lose their ability to walk, talk, swallow, and, finally, breathe.



ALS can affect anyone: 90% of cases are sporadic, 10% are hereditary.



80% of people diagnosed with ALS die within 2 to 5 years.



ALS impacts the whole family on emotional, physical and financial levels.

## OUR MISSION

The ALS Society of Quebec is a non-profit community organization whose mission is to support people touched by ALS and their families through every step of their journey. It also promotes and funds research, while raising awareness of the disease with the public, government and healthcare professionals. The Society survives on donations and **the proceeds** from various fundraising events.

## 2020-2021 BOARD OF DIRECTORS OF THE ALS SOCIETY OF QUEBEC

### ADMINISTRATORS



ISABEL CYR  
Director of Policy and  
Government Relations,  
Taiga Motors, Former Caregiver



VINCENT GAGNÉ  
Director, Governmental  
Relations,  
TELUS



MARIO HUDON  
Former sports commentator  
Person living with ALS

### EXECUTIVE COMMITTEE



SUSAN  
KENNERKNECHT,  
Chair  
President, Conseil BKK  
Consulting Inc.



ANDRÉ FALARDEAU  
Treasurer  
Former caregiver



TANYA LUTTRELL  
Consultant at SSMIK  
Culture d'impact



DIANE TKALEC  
Nurse Clinician  
Former Caregiver



NORMAN MACISAAC  
Executive Director, Léger  
Foundation, retired  
Person living with ALS



DENIS VANDAL  
Marketing consultant



DR. RICHARD ROBITAILLE  
Neurologist and Professor  
of Neuroscience Université  
de Montréal



LUC VILANDRÉ  
Former President,  
TELUS Health, SLA QC  
Co-Founder of the  
Ride to Fight ALS

# UNITED TO SUPPORT FAMILIES WITH ALS

For people with ALS, the experience of losing independence, movement and speech can be very isolating. Adapting to these losses through a pandemic with ongoing restrictions can make it even harder to feel connected. Throughout 2021, we sustained and increased our efforts to stay in touch with members of our community. Despite working remotely, ALS Quebec staff teamed up and collaborated in unison with other stakeholders to continue to offer a full range of supportive programs and services from diagnosis to end-of-life care to bereavement support.

In spite of the many Covid-19 related challenges over the past year, we remain united in our goal. No one affected by ALS should be left on the sidelines. No one should feel alone in their ALS battle.

For the health and safety of our community, we have continued to deliver our programs and services virtually without compromising the needs of those without online access. We have offered: virtual support groups where families can share their concerns and feel heard; web-based resources, informative online conferences, webinars; e-newsletters and social media posts. Zoom technology has also helped us increase our outreach to members in remote parts of the province. At the same time, we have continued to provide attentive listening and up-to-date information via telephone, and shared pertinent print materials by postal mail for members who are not otherwise able to connect technologically.

United in our goal to reach every ALS family that requires support means we also need to respond to individual circumstances that differ based on personal social and

financial resources and the programs and services offered by Quebec's healthcare and social services system that vary from region to region. We are here to close the gap, whether that means providing financial assistance to vulnerable families or connecting families together for emotional comfort and mutual support.

We are also here to ensure that healthcare professionals can provide the best possible quality of care by answering questions and facilitating discussion forums that allow for peer to peer dialogue about relevant issues and foster a better understanding of the emerging needs of those living with ALS who are placed in their care.

All of this customized support requires a team motivated by passion, the desire to make a meaningful difference, and the ability to work side-by-side with many key players: members of the Programs and Services Committee and related sub-committees; our wonderful volunteers; ambassadors; and professionals within Quebec's health network whose contribution is essential to our mission. We are tremendously grateful to all of these essential collaborative partners.

Most importantly, the courageous families we support bring us all together to unite within a common cause. Every person affected by ALS inspires us to give the best of ourselves, to do better, to keep moving forward. We are thrilled to be able to stay connected with you by virtue of technology and look forward to the day where we can be an ALS community that is reunited together in person, face-to-face, in the moment. Until then, we wish to express our genuine thanks to each and every one of you! Thank you everyone!



*Diane Tkalec*

**Diane Tkalec**  
Nurse clinician  
Former caregiver  
Board member



*Véronique Pignatelli*

**Véronique Pignatelli**  
Director of Programs and  
Support Services  
ALS Society of Quebec

## COMMUNITY SUPPORT PROGRAM EVALUATION COMMITTEE

- Chair: Diane Tkalec (nurse clinician, former caregiver, Board member)
- ALS Society of Quebec team: Kate Busch (coordinator of services), Véronique Pignatelli (social worker, director of services)
- Public-system occupational therapist: Ann-Marie Léporé (CIUSSS-ODIM)

## CHSLD COMMITTEE

- Chair: Paula Stone (occupational therapist, retired)
- ALS Society of Quebec team: Kate Busch (coordinator of services), Véronique Pignatelli (social worker, director of services)
- Maryse St-Gelais (former caregiver, doctor specialized in family medicine)

# SUPPORT COMES FULL CIRCLE IN CHATEAUGUAY



At a small party to celebrate Tony Archer's 70th birthday after he was diagnosed with ALS, he said, "Do not feel sorry for me because I don't feel sorry for myself." He lived for five years with ALS at his home in Chateaugay, never losing his vibrancy, his strong will, and his positivity, even when the treatments he received failed and when he became ineligible to participate in promising new ALS clinical trials that might have had the potential to change the course of his life. "He always had the attitude, 'I'm not sick. I just have ALS,'" says Ordeen, his wife of 45 years.

Tony's daughter, Shauna, also remembers the tremendous impact he had on others. "My parents are fortunate. We have a huge family, and many good friends and neighbours who would come by often to see him. At the time, Dad couldn't shake their hands to

greet them or stand up to greet them, but it was incredible how he touched them with positive words. They came to give him an encouraging word and they were the ones who went away feeling encouraged!"

A strong and loving community gives us strength in difficult times. Ordeen Archer and her three grown children, Shauna, Michelle, and Shayne know the power of community from first-hand experience. In addition to their own close-knit circle of friends and family, they received ongoing support from ALS Quebec at every stage of their ALS journey, from the time Tony was diagnosed in 2015, and still today, more than a year after his passing.

"ALS Quebec was always preparing us ahead for the next stage. We didn't know how fast the disease would progress, but they made sure everything was in place. For a long time, Tony resisted the idea of a wheelchair, but when he really needed it, it was already there," remembers Ordeen. In addition to receiving home visits and equipment provided to help Tony remain comfortable at home, the family participated in the annual Walk to End ALS, caregiver support groups, and social events such as apple-picking and a Western-themed evening that helped strengthen their ties to the community.

Looking back, Shauna believes the kindness of people who visited and prayed for her dad may have helped keep him going for as long as he did. Caring and compassion have also been a constant source of comfort for Ordeen, who continues to look forward to bereavement support groups hosted by ALS Quebec on Zoom. "When you hear other people's stories and we learn and we cry together, it helps me," she explains. "When I realize what others have gone through, someone who lost a young person only after a year, and I had five years... it really does something for me." Ordeen received a special gift this past Christmas when she spoke one-on-one with a grief counsellor who was invited to attend one of the group meetings. An image that stayed with her was a presentation slide illustrating the predictable ups and downs associated with grief, like an ocean, surging with rough swells then calming to still waters, and then back and forth again and again.

Despite the fact Tony passed away in the hospital during the pandemic, his family were by his bedside to hear him say 'I love you' before he took his last breath. "Without the BiPAP machine covering his face, he gave me that smile I will always remember," says Ordeen. "I know he was at peace."

## WE HELP YOU TO BE BETTER INFORMED AND BETTER EQUIPED AT EVERY STAGE OF THE DISEASE

### INFORMATION



Documentation



Conferences



Internet site and online, on-demand resources



Newsletters

### PSYCHOSOCIAL AND COMMUNITY SUPPORT PROGRAMS



Orientation and reference



Personalized support and toll-free line



Support groups



Short-term financial support\*



Bereavement support

### AWARENESS, SOCIAL AND NETWORKING ACTIVITIES



Social activities and events



Online community



Professional networking activities



Interaction with ALS research community

### OPPORTUNITIES TO GET INVOLVED



Advocacy



Volunteer



Ambassador's club

\* Certain conditions apply.



# SUPPORT FROM THE TENAQUIP FOUNDATION OFFERS TIGHTKNIT FAMILY CHANCE TO “SEIZE THE DAY”

Seize the Day was launched in 2018 with the generous support of the Tenaquip Foundation with the purpose of granting a special wish to someone living with ALS. The program has been a resounding success, creating lasting memories for families during a time of anticipatory grief and duress. In 2021, the ALS Society helped facilitate meaningful experiences for 10 individuals and their loved ones affected by ALS.

THE **TENAQUIP** FOUNDATION

Nicole Richer, who passed away on December 9, 2021, was one of the beneficiaries of ALS Quebec's Seize the Day program. "We catered a dinner for family and friends," wrote her beloved life partner, Pierre Joly. "It was her way to say goodbye and thank them for their support during her journey."

Families also took a Spa day together, spent a day boating on the lake, and travelled to spend time with their loved ones who live far from them.

Bringing joy and delight into the lives of families with ALS is the number one goal of the program, but it also benefits our counsellors and the whole team to be part of something so uniquely rewarding. Reading the different requests, seeing the photos, and hearing back from families is heartwarming for all of us.



## SOME OF OUR ACHIEVEMENTS

**5000+**

Members (persons diagnosed with ALS, caregivers, bereaved loved ones, and healthcare professionals)

**500+**

Families living with ALS, received timely individualized support and counselling by phone, Zoom or email, without a wait list

**175**

Families with a recent ALS diagnosis, were welcomed and provided with emotional support and accurate, practical information and resources

**8**

Virtual discussion forums for healthcare professionals,

**288**

participants

**40**

Community Support Program requests (for short-term financial, technical and social aid)

**150**

Bereaved members received a personalized follow-up support phone call

**210**

Online resources available

**19**

Themed conferences in real time,

**531**

participants

**45**

Bilingual virtual support group meetings,

**456** participants

**NEW**

*Culinary Care in ALS - Nutritional Toolkit*, available in both French and English in digital format

**20+**

other new and updated resources added to the online platform



# UNITED TO MAKE A DIFFERENCE



## CHSLD COMMITTEE MEMBER ADVOCATING FIERCELY FOR ALS CLIENTS LIVING IN LONG-TERM CARE

Paula Stone is a retired occupational therapist and long-time volunteer. She grew up with parents who both volunteered in the community, and a father with MS who was legally blind. Choosing a career in healthcare where she helped patients adapt to using assistive technology, and volunteering to support people with limited mobility, came naturally.

For 20 years, Paula has volunteered with the Association Québécoise de Voile Adaptée (AQVA) helping people with physical disabilities learn how to sail. She has also been involved with ALS Quebec for several years, initially, as a member of the Programs and Services Committee to help establish a respite program for caregivers.

Today, Paula has a burning desire to address the pressing needs of people with ALS living in long-term care facilities, where she says staff are often ill-equipped to provide specialized care and services. As a professional, Paula encountered dozens of patients with ALS in their homes as

well as institutional settings. It was a face-to-face meeting in 2015 with a former client who wanted his ventilator unplugged that was the catalyst for Paula to shift into high gear to make a difference for ALS patients in long-term care.

As an active member of the ALS Quebec CHSLD Committee, Paula is building a case for educating staff (including nurses, doctors, respiratory therapists and personal support workers), and for providing online resources so they acquire knowledge and skills to attend to the specialized needs of people with ALS. These can have an enormous impact on common daily tasks that allow for greater independence, such using a telephone or computer, or turning lights on and off. Eventually, Paula would love to help develop a pilot project in a unit within a long-term care facility that would demonstrate the value of providing specialized care to people with ALS and other related diseases.

"I look forward to the day when I see the same smile from ALS patients living in long-term care that I have witnessed in my work teaching people with physical disabilities to sail," says Paula. "That would be my greatest reward."

## SPECIAL THANKS TO OUR VOLUNTEERS

With your help, we can provide the best support and care to a community of people living with ALS. We thank you for giving your time to such an important cause, and helping us continue our fight against ALS.

Arunasalampillai, Madura  
Bastien, Yves  
Beaulieu, Phyllis  
Biljan, Morgan  
Boivin, Louise  
Boudreau, Anne  
Boudreau, Roger & Fabienne  
Cardinal, Jacques  
Cardinal, Karina  
Cardinal, Julian  
Carignan, Thérèse  
Cartier, Nancy  
Charest, Clément  
Colagiacomo, Nancy  
Côté, Michael  
Cyr, Isabel

Décarie, Patricia  
Delambre, Dominic  
Diep, Ty  
Dinarzo, Nick  
Doucet, Angèle  
Duchaine, Martin  
Ducharme, Isabelle  
Duchesneau, Mylène  
Dumas, Pansy  
Durand, Jacques  
Falardeau, André  
Faucher, Frédéric  
Fortin, Roger  
Freitas, Zeldá  
Gagné, Vincent  
Gaudreault, Claude  
Germain, Isabelle

Giroux, Amélie  
Gosselin, Julie  
Grenier, Stephan  
Grenier, Justine  
Grenier, Émilie  
Grenon-Nyenhuis, Chantale  
Harvey, Florence  
Hidalgo, Monica  
Hudon, Mario  
Jack, Barry  
Kennerknecht, Susan  
Lacroix, Odette  
Lajoie, Sylvain  
Lanno, Mia  
Lapierre, Christine  
Laporte, Yvan

L'Arrivée, Bernard  
Léporé, Ann-Marie  
Létourneau, Denise  
Luttrell, Tanya  
MacIsaac, Norman  
Madore, Nathalie  
Mantovani, Sylvie  
Martineau, Odette  
Michaud-Dinarzo, Joanne  
Miron, Dominique  
Mongrain, Alain  
Montesi, Anna  
Montesi, Julie  
Morpeau, Valérie  
Ouellet-Bernier, Roxanne  
Peters, Martine

Pinault, Patricia  
Piotte, France  
Poirier, Jeanine  
Powel Smith, Carol  
Richard, Marie-France  
Robitaille, Richard  
Salas, Prochat  
Sekhri, Ines  
St-Gelais, Maryse  
Stone, Paula  
Tanguay, Michelle  
Tkalec, Diane  
Tremblay, Nelle  
Vandal, Denis  
Vézina, Louis  
Vilandr , Luc  
Vilandr , Christiane

# UNITED TO RAISE AWARENESS

ALS has become a better-known disease since the Ice Bucket Challenge in 2014. However, we still have a lot of work to do to educate the public about the enormous challenges facing families affected by ALS. Raising a strong, united voice to build awareness is a critical part of our ongoing work as a community.

## TWO OUTSPOKEN ALS ADVOCATES TEAM UP TO ACCELERATE ACCESS TO NEW TREATMENTS



Mario Hudon first contacted Norm MacIsaac ten days after he received his ALS diagnosis in December 2020. He knew about the e-petition Norm had launched to accelerate access to innovative treatments approved by Health Canada, and he wanted to get on board as a way to turn his situation into something positive to help others.

Mario knew he could raise awareness by leveraging contacts made over the course of his 20-year career as a sports commentator in the Quebec media. In the midst of the pandemic, it was difficult to meet in person, but Norm and Mario teamed up over the phone to expand their campaign into the francophone community. Their goal was to send a strong message to the Minister of Health to address the urgent needs of patients whose prognosis is typically two to five years. The response was overwhelming. Together, Mario and Norm collected more than 26,000 signatures across Canada, 10,000 of them right here in Quebec!



Mario calls Norm MacIsaac his “mentor.” Seeing all he has done to raise awareness during seven years living with ALS – including the publication of his book *The Best of the Worst News: Tales of Inspiration from Around the World* and *My Life with ALS*, his bilingual blog, his Facebook group and numerous interviews and talks he has given in his role as an ALS Society Ambassador – Mario feels inspired to push things forward. “We are not afraid to talk about ALS,” he says, “We both have the same goal: speaking up and speaking out on behalf of everyone affected by this disease so we can all sustain hope. It may not be for Norm or for me, but we have to keep moving steadily towards the day when ALS will be treatable.”

We invite our community to join our team of Ambassadors and learn how your voice can make an impact.

## STRENGTH IN NUMBERS IN THE FIGHT AGAINST PROGRESSIVE NEUROLOGICAL DISEASES

For the 5<sup>th</sup> year in a row, The ALS Society of Quebec is pleased to team up with the MS Society of Canada (Quebec Division), Parkinson Quebec, Muscular Dystrophy Canada (Quebec Division), and the Huntington Society of Quebec, to form Partenaire Neuro. The objectives are to join forces and educate Quebec elected officials about the challenges of people living with a progressive neurological disease, and to discuss topics of interest to them such as home care, housing and support for caregivers. Thank you for joining us in this conversation, which is so vital for the ALS community and for all the families touched by a progressive neurological disease.



**Neuro Partners**  
Progressive Neurological Diseases

## UNITING OUR VOICES TO AFFECT CHANGE

We are pleased to rally with ALS Societies from across Canada to make our community voices even louder. As part of that united effort, Norman MacIsaac and Claudine Cook take part in ALS Canada’s Advocacy Committee whose main goals are to ensure people living with ALS and their families throughout Canada receive the best possible standard of care and to ensure equitable and timely access for all Canadians living with ALS to treatments that improve quality of life and extend lifespan.





## ALS AWARENESS MONTH: TEAMING UP TO STRIKE OUT ALS

### JUNE IS ALS AWARENESS MONTH

We are so proud of how our community came together during ALS Awareness Month to help Strike Out ALS!



### THANK YOU

to Pierre Arcand for recognizing #ALSAwarenessMonth in his declaration at the National Assembly of Quebec.



Launched on June 1<sup>st</sup>, The Lou Gehrig Mosaic of Hope is a tribute to the baseball legend whose name has become synonymous with ALS, and whose grace and courage in the face of his own diagnosis continues to inspire hope 80 years after he passed away. We would like to thank Major League Baseball for inaugurating the 1<sup>st</sup> Annual Lou Gehrig Day on June 2<sup>nd</sup> across North America. Quebec may not have its own major league baseball team, but our baseball community hit a home run this year! Our Lou Gehrig Mosaic of Hope was a vast public awareness campaign to educate the public about the disease and raise money for research and the highest standards of care for people with ALS and their caregivers.

The animated photo mosaic is a testament to the strength of our ALS community here in Quebec. It showcases 3,000 photographs from members across the province - people living with ALS, their family members and caregivers,

bereaved family members, donors, volunteers, ALS researchers, staff members, friends and advocates. We would like to thank the 100+ celebrities from the sports, entertainment and media who helped us spread the word via their social networks. Every action helps!



We have come a long way. Together, we are making progress at an unprecedented rate. We are filled with hope.

To view the live mosaic or to learn more, please visit [als-quebec.ca](http://als-quebec.ca).

## BUILDINGS LIT UP IN BLUE FOR ALS

On the night of June 1-2, several buildings were lit up in blue to mark ALS Awareness Month and Lou Gehrig Day. Thank you to the Olympic Stadium in Montreal, the City Hall in Sherbrooke, the footbridge on the Petite Décharge River in Alma, Saguenay, the Basilica Sanctuaire Notre-Dame-du-Cap in Trois-Rivières, and the Fairmont Le Château Frontenac in Quebec City.

## #WINTERBLASTTOENDALS

Inspired by Snowman Joe and the Boucher family during the lockdown, we invited our families to build a snowman to honour a loved one affected by ALS. Our hearts melted with every picture and story shared on social media! We truly love the spirit of our community and every story shared helps us to raise awareness.



# UNITED TO FIND ANSWERS

## CONNECTING FAMILIES AND RESEARCHERS IS A WIN-WIN PROPOSITION FOR ALL

Dr. Richard Robitaille, ALS researcher and professor in the Department of Neurosciences at the Université de Montréal, is investigating how to slow down disease progression by keeping muscles stronger for longer. In ALS patients, faulty nerve-muscle connections at tiny sites called neuromuscular junctions (NMJ) prevent muscles from receiving signals to contract or relax. Dr. Robitaille is hopeful learning how and why this occurs will lead to new treatments that could improve the quality of life, and even prolong life, for people diagnosed with ALS.



The excitement among members of Dr. Robitaille's team is tangible. In a relatively short time, they have a discovery in the lab they want to bring to the clinic. That excitement is being shared with families affected by ALS who are invited to the lab so they can learn more about the research being conducted, ask questions, and talk about their own first-hand experience with the disease.

"Seeing the energy of patients with ALS, their will to fight back, it's just so impressive" says Dr. Robitaille, "I say to my students, 'Think about who we're doing this for. Think about how hard they are working. We must keep up the fight no matter what.' We are going to figure out a way. We're going to find solutions because there's strong motivation, for sure."

Beyond the scope of his own research, Dr. Robitaille sees leading edge scientific inquiry within the Canadian ALS research community that is exemplary in terms of expertise, a willingness to collaborate, and a steadfast commitment to finding effective new treatments. "The ALS community has never been so dynamic. We are increasing our understanding about ALS and improving scientific models and clinical trials at an unprecedented pace," he says. Progress cannot come fast enough, but the ALS community is poised to make promising new discoveries that could be a game changer for families affected by ALS.



*"The day I visited Dr. Robitaille's research lab with my wife, my son and daughter, and their partners, we didn't know quite what to expect. The quality of the information that was shared and the amount of work that went into preparing the visit was all so impressive. The young doctoral and post-doctoral students each gave a detailed presentation, demonstrated their individual work under the microscope, and answered our questions with great care. There was a lot of dialogue and learning on both sides. I think what stood out most for me was their passion for the research. That really stayed with me. We could see these young researchers were pushing the limits to find solutions despite operating with very limited funds. I know we are in good hands! The challenge now is to secure more funding so we can really move the dial on ALS with new treatments and therapies."*

- Claude Lapierre  
Living with ALS since 2016

## RESEARCHER UPDATE

In 2020, Dr. Silvia Pozzi received a \$250,000 La Fondation Vincent Bourque-ALS Canada Career Transition Award for her work developing antibody-based strategies aimed at delaying or stopping the progression of ALS. Since receiving the award Dr. Pozzi has achieved an Assistant Professor position at Université Laval enabling her to become a permanent ALS research contributor and leader. In 2021, she also received the prestigious Paulo Gontijo Award, an international award given to top young researchers dedicated to finding the cause and cure of ALS. Dr. Pozzi is just one example for the talented researchers committed to ALS, supported in part to the fundraising efforts of Walk to End ALS participants, including donors like you from Quebec, and the generosity of partners like Vincent Bourque Foundation.



FONDATION  
VINCENT BOURQUE



Thank you to The Fondation Vincent Bourque and the Lessard Family who continue to support families affected by ALS and research through ALS Canada's Research Program. Your active participation in everything we do is truly inspiring.





The Tony Proudfoot Training Fellowships in ALS Research were established in 2008 to support outstanding master's and doctoral students or post-doctoral fellows pursuing research training in ALS research at the Montreal Neurological Institute and Hospital. The fellowships are made possible by the Tony Proudfoot Fund at the ALS Society of Quebec in honour of Montreal Alouette and McGill physical education instructor Tony Proudfoot who campaigned tirelessly to help raise the profile of ALS after his own diagnosis in 2007. The fellowships are also made possible through the generosity of Wendy Clarke in memory of her father, A. George Alexander.

This year's recipient is Maria Gobbo whose research focuses on the development of biomarkers using newly acquired technology, gene discovery and genetic testing protocols, and the development of new outcome measures for drug development for ALS.

## DONOR SUPPORTS TONY PROUDFOOT RESEARCH FELLOWSHIPS IN HONOUR OF HER BELOVED FATHER

Former Montreal Alouette and McGill physical education instructor Tony Proudfoot became a fierce advocate for ALS awareness after he was diagnosed in 2007. He wrote about his illness in a series for the Montreal Gazette, spreading his story across Canada. Tony passed away in 2010.

More than a decade later, his legacy lives on in a fund that helps train and support the next generation of leaders fighting this disease. The Tony Proudfoot Training Fellowships in ALS Research were established in 2008 to support outstanding master's and doctoral students or post-doctoral fellows pursuing research training in

ALS research at The Neuro. The Fund also supports the Society's mission to improve the living conditions of people with ALS and provides support for their family members across the province.

In 2021, the Tony Proudfoot Fund at the ALS Society of Quebec and Wendy Alexander Clarke in memory of her father, A. George Alexander, were pleased to support Maria Gobbo whose focus is the development of biomarkers using newly acquired technology, gene discovery and genetic testing protocols, and the development of new outcome measures for drug development for ALS.

*In 1988, as I was holding our infant daughter, my father quietly told me the doctors at The Neuro had given a name to the muscle weakness he had been experiencing for months. I can still feel my heart dropping when I learned he had ALS. My adored father, widowed three years prior and in his late 70's, was stricken with this horrible disease. He faced it with his usual grace and the stoicism of his generation. A good man, a gentleman, gone far too soon, and unable to hold his baby granddaughter.*

*Since then, I have learned about young women and men diagnosed as they enter the most wonderful years of their lives, facing the unknown and unimaginable. It was one thing to have the father I loved so fiercely taken from me, but younger people deserve to live full lives, to love and be loved. Somehow, this disease must be stopped.*

*If my donations can help researchers find a cause/cure, then the money I inherited from my father will have served a purpose. This may not happen in my lifetime, but I know it will happen, and future generations will not know the heartbreak of losing their loved ones to this devastating disease.*

- Wendy Alexander Clarke

# ALS CANADA RESEARCH PROGRAM OVERVIEW

The ALS Society of Quebec is proud to have contributed to the ALS Canada Research Program to unlock answers to mysteries about the causes and progression of the disease and to support the development of promising therapies.

The ALS Canada Research Program is the only dedicated source of ALS research funding Canada. Thanks to the support of donors, it provides sustainable funding for ALS research in Canada which is even more critical now with the pandemic creating challenges for health research funding. Donors like you enable us to invest in the ALS Canada Research Program, accelerating the impact of high-quality ALS research investments, fill important knowledge gaps in our understanding of ALS, ensure a strong pipeline of ALS researchers and strengthen Canada's infrastructure for ALS clinical trials.

Whether it happens in the lab or the clinic, ALS research provides hope to a passionate community with an urgent need: to see treatments that change the reality of living with the disease. And awarding research grants on an annual basis means that there is a steady pipeline of work underway.

Through the Discovery Grant Program and in partnership with the Brain Canada Foundation\*, the ALS Canada Research Program invests in leading edge research focused on pursuing innovative new areas of ALS research including genetics, biomarkers, pathways for future therapies and quality of life. By fuelling scientific discovery and furthering our understanding of ALS, these grants enable ALS researchers across Canada and around the world to collaborate on projects that push the envelope and will one day have a positive impact on people living with ALS and their families, bringing hope for a future without the disease.

Support from donors here in Quebec also helps provide crucial funding for young researchers in the field of ALS, helping to ensure that Canada continues to have a strong community of talented ALS researchers committed to answering the remaining unknowns about ALS, so new therapies can be developed to improve quality of life and extend lifespan for people diagnosed with this challenging disease. The Career Transition Award enables talented early-career lab researchers to become permanent ALS research contributors and leaders. The Clinical

Research Fellowship provides early-career clinical researchers with specialized training in clinic-based research, increasing capacity for ALS clinical trials and care. The ALS Canada Trainee Awards invest in the brightest young minds to ALS research, bringing new ideas to the field and maintaining Canadian ALS research excellence into the future.

All projects funded by the ALS Canada Research Program are supported by the generosity of provincial ALS Societies, ALS Canada donors, and community-based fundraising efforts, including 40 per cent of net proceeds from the Walk to End ALS. Before grants are awarded, prospective projects undergo a peer-reviewed grant competition that engaged a panel of global ALS experts in prioritizing projects grounded in scientific excellence and with the potential to most quickly advance the field of ALS research.

*\* The Canada Brain Research Fund is an innovative partnership between the Government of Canada (through Health Canada) and Brain Canada*

## YOUR DONATIONS AT WORK:

One example of how Discovery Grant recipients are making an impact is the interdisciplinary team led by Dr. Eric Shoubridge and Dr. Gary Armstrong of The Neuro (Montreal Neurological Institute-Hospital). With a discovery grant awarded in 2020, Dr. Shoubridge and Armstrong have teamed up to understand the connections between a recently linked pair of proteins and how they contribute to neurodegeneration in ALS - and their most important helpers are thousands of tiny striped fish. And additional 2020 Discovery Grant recipient, researchers Dr. Alex Parker (Department of Neuroscience, CRCHUM, Université de Montréal) and Dr. Matthieu Ruiz (Department of Nutrition, Université de Montréal and co-director of the metabolomics platform at the Montreal Heart Institute) are investigating what the brain-gut connection could mean for the development of future ALS therapies.



Dr. Gary Armstrong



*"I cannot emphasize how important this discovery support is to furthering ALS research in Canada. It funds relevant ALS research with a translational approach, that might not yet be considered for a conventional grant, and it brings projects to the next critical stage."*

- Dr. Alex Parker, recipient of a 2020 Discovery Grant



# UNITED DESPITE THE DISTANCE



**Hundreds**

of walks held  
across the  
province

**60%**

of money  
raised goes to  
direct services for  
**families**



**40%**

of money raised  
goes toward  
**research\***



\*Matched by Brain Canada



## WALK FOR ALS IN BAS-SAGUENAY A FIRST-TIME TRIUMPH

Lise Bernier, 71, lives in the small community of Petit-Saguenay with a population of under 1,000 people. Diagnosed shortly after New Year's 2021, she is the first person in the Bas-Saguenay region of Quebec to organize the Walk to End ALS event for ALS Quebec.

As the date for the Walk approached last June, Lise was overjoyed by the positive response: a team of more than 100 supporters including friends, family, local businesses, and municipal government representatives, who collected more than \$10,600 in donations and raised the profile of ALS in the region.

ALS is a "sneaky disease," says Lise. At the beginning, she noticed a troubling decrease in strength in her right hand and right leg. No one can predict exactly how the disease will progress, but as someone who has always been active, Lise can only describe life with ALS as a "complete 360-degree turnaround." Even so, she is determined to step up to the plate to help strike out ALS.







Our flagship event,  
powered by  
**TELUS Health,**  
in collaboration with  
MT PHARMA

**50 to  
1,000 KM**  
cycled over the  
summer and in  
person!

**2.75  
million**  
raised since 2008

**2022**  
We can't wait to  
celebrate  
**15<sup>th</sup>** Anniversary!

## TOP FUNDRAISER EXPRESSES PROFOUND GRATITUDE FOR SUPPORT FROM ALS QUEBEC



Last August, André Besner organized Quebec's top fundraising team in the Ride to Fight ALS, powered by TELUS Health. He did so in memory of his beloved wife, Dominique, who passed away in November 2020. For two years, André was a devoted caregiver. "For me, it was the ultimate gesture of love for a woman I adored. I would have done it for any amount of time," says André. "And I was not alone.

There were many of us encouraging Dominique in our circle of care – our two daughters, Dominique's mother and her brothers, friends and colleagues. We all did what we could to make her days as pleasant as possible."

As the disease progressed, André and Dominique focused on living in the present moment to avoid dwelling on all the grief and pain ahead. A final trip to the Périgord region of France with Dominique's mother remains a cherished memory. "What beautiful moments we spent together there," remembers André. "Dominique chose a path of courage and love over bitterness and despair. She knew happiness, even in the face of such a terrible disease."

Organizing the Ste-Hyacinthe ride in Dominique's honour was deeply satisfying for André, and even more so because

it was an in-person event held in the midst of the pandemic. He had no trouble recruiting participants for the 80km ride. One of Dominique's friends, Isabelle Doray, was so inspired by Dominique's resilience that she decided to step outside her own comfort zone and accept the challenge even though she had never ridden before. "Hats off!" says André. "It took such a huge effort for Isabelle to complete the ride that day. She truly honoured Dominique's energy and determination to carry on."

Although ALS is still rare, André has noticed that it is not uncommon to run across someone whose life has been touched by ALS. If there are relatively few people living with ALS at any given time, it is partly because of the poor prognosis for patients who are typically given only 2-5 years to live. Raising awareness is critical. The more we talk about the disease, the better our understanding of how quickly it progresses, and the impact it has on whole families.

André is tremendously grateful for the vital support provided by ALS Quebec, including the presence of an ALS Quebec volunteer at every one of Dominique's visits to the ALS clinic in Montreal. Since the diagnosis in 2018, he has worn an ALS Quebec bracelet on his wrist as a symbol of his gratitude. He will always feel part of the ALS community because, in his words, "together, we learn to understand all the stages of the journey and we support each other every step of the way."

Looking forward to celebrating the 15<sup>th</sup> Anniversary of one of our key signature events!



# UNITED TO GAIN MOMENTUM



## TWO BROTHERS DOUBLE THEIR IMPACT WITH BACK-TO-BACK SPORTS CHALLENGES

Steeven and Maxime Plante recently lost their father, Jacques, who was diagnosed with bulbar ALS in January 2021. Looking back, they are deeply moved by the import and the many positive outcomes of organizing back-to-back fundraising events that raised \$23,000 for people affected by ALS in Quebec. Under the banner, “Derrière L’Objectif” in homage to their father’s professional career as a photographer, Steeven challenged six of his friends and colleagues to tackle the local mountains and collectively climb 8848 metres, equal in height to summiting Mount Everest; Maxime organized (and completed) his first marathon run which started at the ALS clinic in Quebec City and ended at the church in St-Lambert-de-Lauzon where his dad resided.

Initially, Steeven and Maxime wanted to raise money to assist Jacques directly for any costs he might incur such as retrofitting his home and acquiring assistive devices and equipment. However, Jacques was far more interested in raising money to serve a broader purpose by raising awareness about ALS and supporting critical ALS research and support services for families affected by the disease.

*“As we began organizing the events,” says Maxime, “we could see dad light up.”* In fact, he was so motivated that he set his own personal goal to participate by covering 500 km of the route in his motorized wheelchair. Despite his failing health, Jacques came very close to achieving that goal, living each day with renewed courage and determination.

*“The most magical moment was arriving at the church at the end of the run,” says Maxime. “Hearing the church bells ringing, seeing so many people turn out to greet us at the finish line, it was the most beautiful present the community could have given my father.”* Coming together for such an important cause was profound, and proof of what can happen when people unite under one banner: the power of community to effect change sustains hope in dark times.



## LET’S MAKE TOMORROW BETTER

Christian Alain and his daughter Marie-Josée Alain were deeply moved by the tremendous response to their online campaign in 2021. Together, their family, friends, and colleagues donated \$57,600 to support the work of ALS Quebec, providing much needed funds, inspiration and hope for a better future.

Sadly, Mr. Alain passed away from ALS on December 17, 2021. We extend our most sincere gratitude for all he did for the cause, and our deepest sympathy to Marie-Josée and the family who mourn his loss.

## ALS TAKES CENTRE STAGE AT THÉÂTRE LA LICORNE

A very special thank you to playwright and actor Steve Gagnon, Quebec’s favorite actress Guylaine Tremblay, stage director Édith Patenaude, the Théâtre La Licorne (founded by La Manufacture), and everyone who purchased sweatshirts specially designed for the play *Les Étés Souterrains*. Your efforts helped raise \$12,000 for ALS Quebec.



## EXXEL POLYMERS HOSTS FIRST ANNUAL ALS GOLF TOURNAMENT AT DOMAINE CHÂTEAU-BROMONT

Exxel Polymers’ vice-president and co-owner, Charles Bourdeau, hosted the first annual Exxel Polymers Golf Tournament at the prestigious Domaine Château-Bromont this September, raising \$12,800 for ALS Canada in honour of his father, Denis, who has been living with ALS since March 2021.



## TRANSPORT DSQUARE'S SOFTBALL TOURNAMENT HITS IT OUT OF THE PARK FOR ALS!

Many thanks to everyone who turned out to participate in Transport D'Square's inaugural co-ed softball tournament in Châteauguay in August, raising more than \$8,000 for ALS Quebec.



## MARC SARRAZIN AND RH EQUIPMENT ARE BUILDING A BETTER FUTURE THROUGH RESEARCH

Marc Sarrazin, 58, was diagnosed with familial ALS in March 2021, just as the first Covid-19 lockdown in Quebec was ending. Marc knew that his own personal quarantine would continue, having witnessed his own father struggle with the disease, but he was determined to stay positive. His employer, RH Equipment, was quick to jump on board, helping to raise \$12,350 towards leading edge ALS research that will continue to sustain hope for Marc and others with ALS waiting for the next clinical breakthrough.



## BROMONT ULTRA ENCOURAGES PERSONAL BEST

The Bromont Ultra is a one-of-a-kind event that challenges runners to run the longest distance of their lives. Trail runs from 6km to 160 km are designed to help everyone achieve their personal best. This year, the event raised \$352,000 for 31 participating organizations, and more than \$16,000 for ALS Quebec which has been part of this inspiring event since 2014.



## CHANTAL'S RIDE REVS UP THE ENGINES FOR ALS

For the second year, Chantal's Ride gathered motorcycle enthusiasts to cover a 130 km ride through the beautiful region of Lanaudière, stretching from the Saint Lawrence River just north of Montreal toward the Laurentian Mountains. The event raised more than \$7,000 for ALS Quebec and was a great motivator and source of hope for Chantal, who has been living with ALS since 2013.



# THANK YOU FOR THE INCREDIBLE COMMUNITY EVENTS YOU ORGANIZED!

Our amazing community organized a host of fundraising events in 2021 despite the challenges of constantly changing restrictions. As the pandemic continued to play havoc with our plans, you showed tremendous initiative by holding virtual events as diverse as music concerts, honey and almond sales, and ultra-marathons. Your significant financial contribution allowed us to continue serving families affected by ALS the best way we know how.

Thank you, each and every one of you, for all the time and effort it took to put together your unique event. You truly showed what it means to be part of a strong and united team building a future without ALS!



## MANON PÉPIN IS TURNING THE PAGE FOR A BETTER TOMORROW

The pandemic hasn't stopped Saint Hyacinthe's Walk Coordinator, Manon PÉPIN from continuing her fundraising efforts inspired by and in memory of Pierre Lemieux. On top of rallying her community for the walk, in 2021, she hosted a book sale and continued her campaign to raise awareness about ALS in Quebec. Thank you, Manon for your tireless dedication and your generosity!

## MYLÈNE AND CATHERINE TEAM UP AGAIN TO DRIVE HOME THEIR MESSAGE OF HOPE

Once again this year, Walk Team Les Ondes Positives organized a drive to collect beer cans and wine bottles to return in Ontario for the deposit refund. Mylène Boudreault and her teammate, Catherine Panelli, also created a Haunted House on Halloween to raise funds and heighten awareness about the needs of people with ALS. We can't thank you enough for your priceless efforts and for inspiring everyone around you!



## FACEBOOK FUNDRAISING

Martin Fecteau	Diane Lacombe
Mario Hudon	Pier-Luc Deschatelets
Benoît Guindon	Pauline Gévry
Fannie Parizeau Lamoureux	Viviane Giguère
Luc Bienvenue	Laurie-Anne Lenarduzzi Chasles
Danielle Desharnais et Sarah KD	Nathalie Chouinard
Raphaëlle D'Amour	Sophie Fortin
Julien Abenhaim	Evelyn Piche
Akim Bourassa Houle	Aliza Perez
Anne Jolicoeur	Pierre Daigneault
Claudine Morin	Petrouse La Frousse
Stéphanie BC	Andrew Luttrell
Sonia Martineau	Suzie Vallières
Marie-pierre D'Amour	Daniel Grosleau
Mariève Lévesque	Andrée Paquette
Marie-Claude Monette	Sylvio Faucher
Mariline Levesque	Luce Arsenault
Laurence Lafond	Manon Millette
André Denis	Sofia Shnd
Lucie Thériault Denis	Véronique Lapointe
Jessica Michaud	Sébastien Côté
Mario Poulin	Chantal Joannis
Valérie Théberge	Cynthia Blake

## 3<sup>RD</sup> PARTY EVENTS

ALS fundraiser - Team Lady Di (David Lussier)	Collecting refundable cans and bottles (Mylène Boudreault & Catherine Panelli)	Fundraising activity (Antonia Iagallo)	Michael Soles Bowl (Randy Burns)
ALS Lac St-Jean 2 <sup>nd</sup> Edition (Suzie Bouchard)	Dsquare'S Annual ALS Softball Tournament (Natalie Smith)	Fundraising activity (Marc-Antoine Gagnon)	Music show (Laurent Bégin)
Annual fundraising in memory of Francine Pharand (Suzie Pharand & Geneviève Lalancé)	Exel Polymers Golf Classic (Geneviève Carrier)	Fundraising activity (Paul Régimbal)	Online sale of used books (Manon PÉPIN)
Beers sale for ALS (masoif.com)	Football game - Cégep St-Jean-sur-Richelieu (Véronique Charbonneau)	Fundraising activity for France Dupuis (Dominic Lamothe)	Ride for the cause (Shella Hubert)
Bromont Ultra (Gilles Poulin)	Fundraising activity in memory of Michèle Boussaroque (Ingrid Boussaroque)	Goats 2021 Golf Classic (Hugues Choquette)	Sport challenges "Derrière l'objectif" (Steeven & Maxime Plante)
Carole's yearly fundraising (Victoria Harrison)	Fundraising activity - Maxi - SJE Quebec students	Let's make tomorrow better (Christian Alain)	Sweaters sale_ Théâtre La Licorne (Steve Gagnon)
Chantal's ride (Jocelyn Théorêt)	Fundraising activity - Petites Maisons de Cap-aux-Oies (Yvon Perron)	Lou Gehrig Day Draw (Perry Giannas)	Tour de l'île à la course pour la SLA, (Anne-Lise Nadeau, Doudja Mekamcha & Isabelle Desjardins-David)
Christmas light sale (Jocelyn Dorion)		Marc and les Équipements RH united for research (Julie Martineau)	
Christmas trees sale (André Martel)			

THANK YOU TO OUR DEVOTED VOLUNTEERS, TIRELESS PARTICIPANTS, LOYAL PARTNERS AND GENEROUS DONORS.  
 YOUR SUPPORT FUELS THE HOPE OF A FUTURE WITHOUT ALS,  
 WHILE PROVIDING THE BEST CARE FOR OUR COMMUNITY.



#### DONORS \$2,000+

9315-1876 Québec Inc.	Daniel Brosseau Fund	Kennerknecht, Susan	Pharmascience inc.
Bahri, Noha	Delorme, Danièle	Laprise, Roger	Raymond, Gilles
Bradshaw, Mark	Djoukhadjian, Manouk	Ledoux-Perreault, Louise	Senécal, Suzanne
Caisse de bienfaisance des employés et retraités du CN	Dorion, Jocelyn	Les Entreprises Lachance inc	St-Germain, Antoine
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Artiste Paul Giroux	Décary, Julien	Lecours, Janique	Rucher et miellerie Reine Fabiola
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Chef Andrea Telaro	Fairmont Banff Springs	O2V	Travelway
Chef Dino Cordileone	Motter, Frank J	On a Roll Records	Trium mobilier de bureau inc
Clinique Dentaire Petite-Patrie	Ken Hall - Fairmont Château	Orangetheory Fitness Griffintown	West Jet



# WE THANK ALL OUR DONORS. EVERY DONATION COUNTS!

## DONORS \$500+

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## ANDRÉ DELAMBRE'S LASTING LEGACY: MAINTAINING FORWARD MOMENTUM

When André Delambre was diagnosed with ALS in 2003, he approached his client and friend, impresario René Angélil and Céline Dion to help raise the initial one million dollars that would launch the André-Delambre Foundation hoping it would be the “spark that would light up the way to a cure for ALS.”

The first Foundation grants made to ALS Quebec truly ignited the organization's programs and services and helped grow awareness about the disease across the province. One of the successful initiatives of the Foundation was the annual ALS Symposium that gathers some of the most highly regarded international scientists in the field of ALS research to share their latest thinking in an atmosphere of collaboration and congeniality.

André's son, Dominic Delambre, has been equally involved in the cause in various capacities, honouring his father's legacy by maintaining the forward momentum André set in motion while he was still alive.

“When my dad was living with ALS, most people, even general practitioners, simply did not know about the disease or how to diagnose it,” says Dominic. Thanks to visionaries like him and those who followed him, progress is accelerating, bringing hope to families burdened by the devastating impacts of ALS.

As the André-Delambre Foundation winds down its operations, we would like to thank them for their generous legacy gift in memory of André. “Our families' hope is that his light will continue to shine with the work that ALS Quebec does. We know he would be so proud to learn about how the Society developed over the years and the promising new treatments that are on the horizon!”



# FINANCIAL SUMMARY

Financial year from November 1<sup>st</sup> 2020 to October 31<sup>st</sup> 2021

## REVENUE

2020-2021

2019-2020

Fundraising	\$850 842	\$447 293
General Donations	\$676 412	\$525 935
l'Appui pour les proches aidants	\$161 240	\$206 274
Health Partners Quebec & Canada	\$81 897	\$100 984
Bequests	-	-
Government Grants	\$128 628	\$158 917
Tony Proudfoot Fund	\$61 030	\$13 627
Team Stock Fund	\$1 280	\$1 675
Other	\$10 661	\$10 990

## TOTAL

\$1 971 990

\$1 465 695

## EXPENSES

2020-2021

2019-2020

Programs and services	\$326 667	\$493 239
l'Appui pour les proches aidants	\$184 201	\$195 688
Fundraising	\$226 594	\$234 702
Administration	\$108 040	\$125 145
Awareness	\$87 879	\$63 887

## RESEARCH CONTRIBUTION

Contribution to research	\$215 541	\$95 183
Contribution to the Neuro (Tony Proudfoot Fund)	\$55 325	\$6 689
Contribution to research conferences	\$1 803	\$1 176
	\$272 669	\$103 048

## TOTAL

\$1 206 050

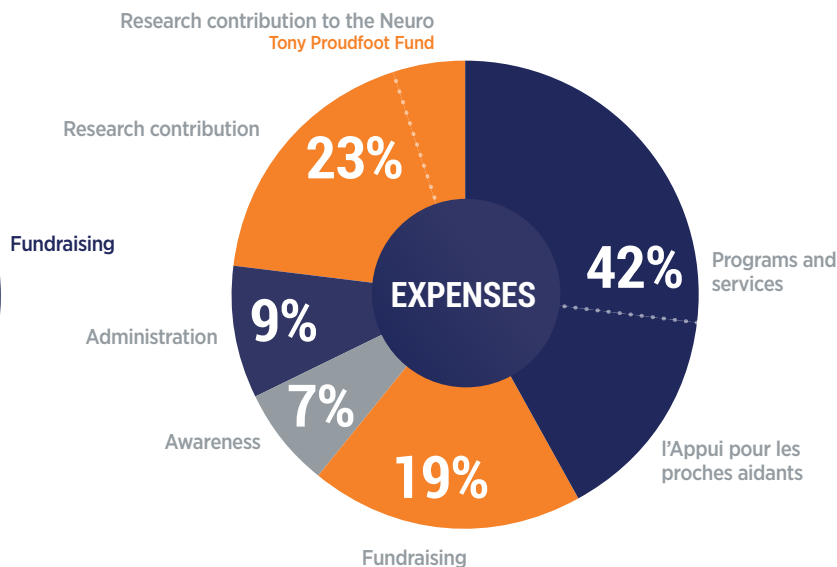
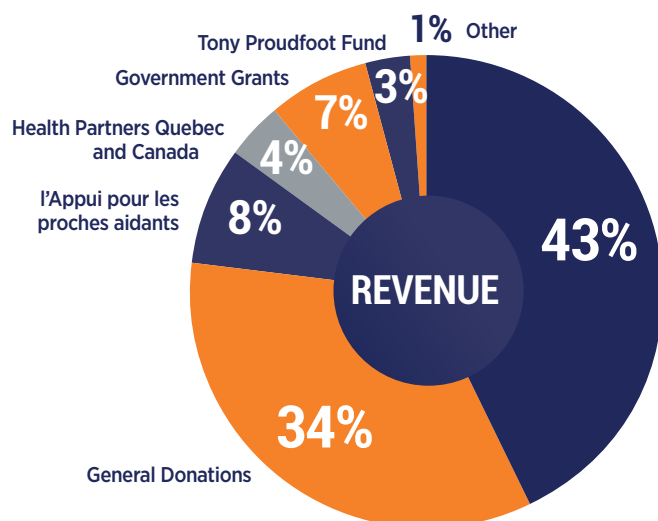
\$1 215 709

Excess (deficiency) of revenue over expenses

\$765 940

\$249 986

The Board of Directors are pleased to confirm the creation of \$500K Research Fund. Details to follow in 2022.



Please visit our website to view a detailed version of our audited statements.





Following the death of my twin sister Christiane, I would like to thank you all for your support. Christiane enjoyed meeting people with the same disease. The Snowman Challenge brought a bit of joy to her days. Each time a picture of a snowman was sent to her, the thoughts and encouragement of these people touched her greatly.

Thank you for your support,  
Christine Veilleux, Vicky & Jean-François D'Amours (Christiane's children)

Following my mother's death, my father wanted to encourage your organization to continue its wonderful work with families affected by this unjust and cruel disease. My parents were extremely grateful to have found you along their path. You made a big difference in their daily lives and helped them face this disease with courage and dignity.

On my behalf, on behalf of my father and in memory of my mother, I sincerely thank you for being there for them.

Sylvie Renaud  
Person living with ALS

What I loved most about the virtual meetings was knowing that I was not alone and that I had support at my fingertips if I need it. It was wonderful to see that each person has a story to share. Thank you for allowing us to do this.



# AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC

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who tirelessly dedicates  
her time and talent,  
in memory of  
her father.



This report is also available in French.