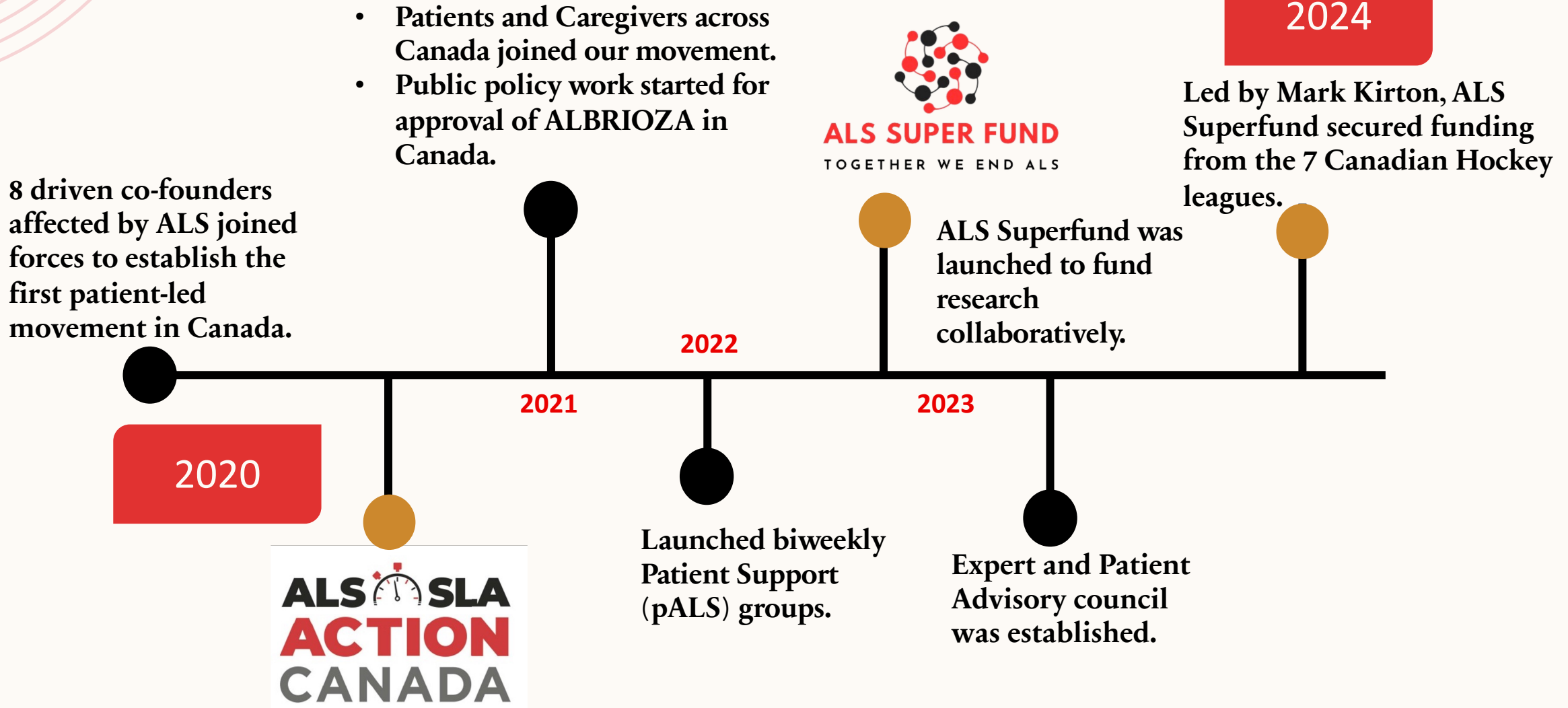


ALS ACTION CANADA

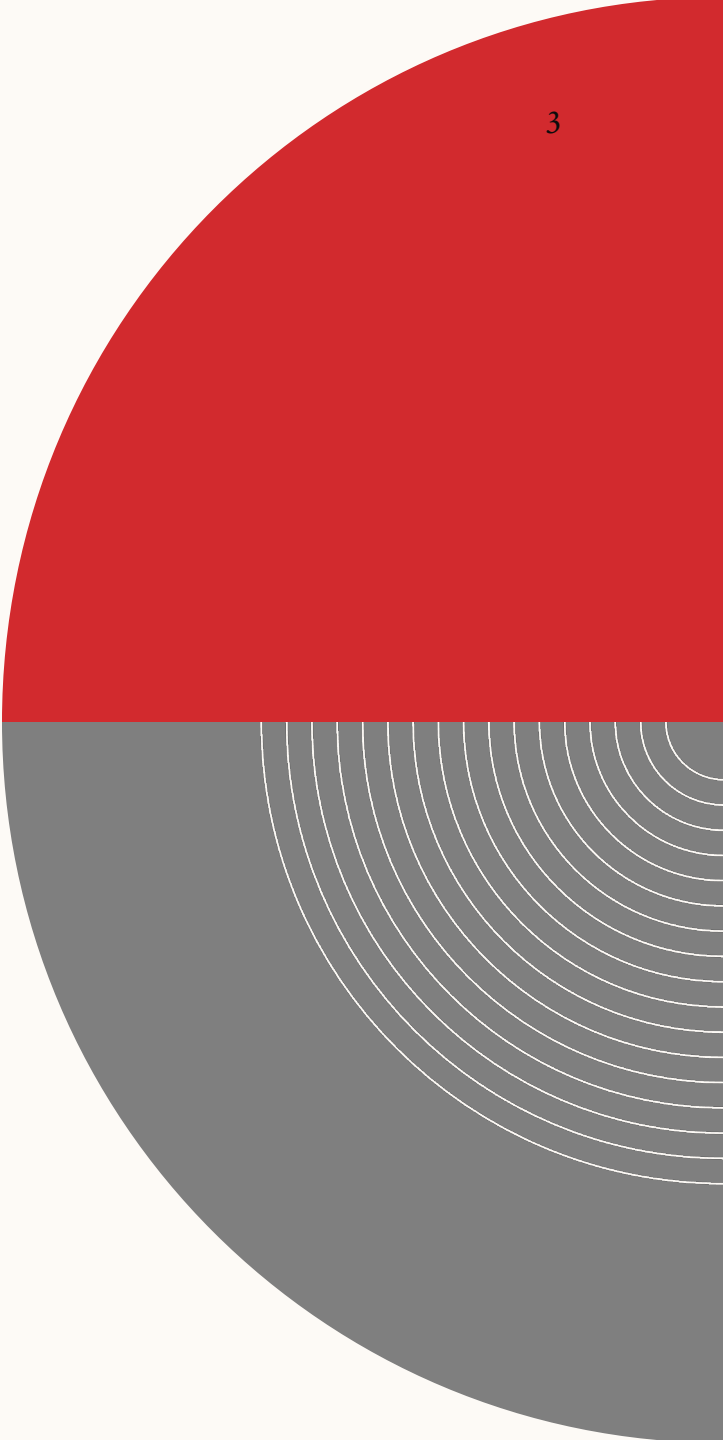
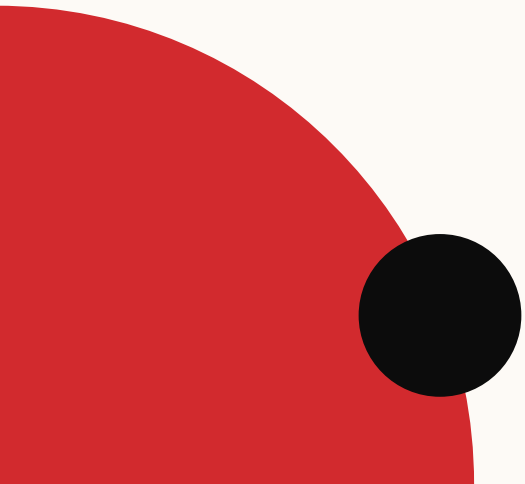
29-Nov-2023

OUR STORY



STORY OF GREG

NEED FOR ACTION



STORY OF GREG

NEED FOR ACTION

- Those diagnosed with ALS in BC are referred to the local ALS Clinic for treatment and care.
- Unfortunately, at the time, the family has come to understand that there are actually no clinical trials provided by the ALS Clinic in BC.
- Rather, while there are caring people who work at the facility, they have nothing to offer as far as experimental treatment goes. It was only through a Google search that Greg and Adrienne were able to connect with a neurologist (Dr. Genge) in Montreal and participate in drug trials.
- **Greg and Adrienne have travelled to Montreal 17 times over two years so that he can access drug trials and get treatment.**



Greg walking

STORY OF GREG

NEED FOR ACTION

- The family have come to fully realize how underfunded the set-up of care is in BC. So Greg has joined forces with people across Canada to form the first ever patient-led advocacy group called ALS Action Canada.
- Greg co-founded ALS Action Canada and poured all his heart and soul into this patient-led movement, to fight for better access to treatment, for more funding for research, but most importantly it's aimed at inspiring change
- Stories of people with ALS, as painful as they are, need to get out to the public. Action will happen when people begin to care.
- This type of movement worked for AIDS/HIV in the 1980's. We made it a livable disease. And we want the same for ALS.

STORY OF GREG

NEED FOR ACTION

“He was a kind soul who felt things deeply. He had a strong moral compass and his values dictated his decisions in life. Even when I wanted to break the rules just a little, he would always say, No, you can’t do that, it’s not right. He insisted on doing the right things. Always.” -*Adrienne M.*

Greg’s last words:



STORY OF ANDREW

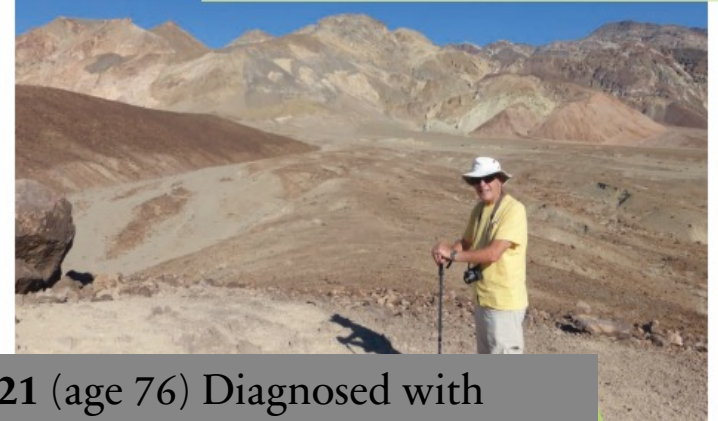
DRUG AVAILABILITY WITHOUT ACCESSIBILITY



2015/2016 (age 71) Possible UMN signs-in retrospect



2017/2018 Referred to ALS Clinic- Still racing



2021 (age 76) Diagnosed with ALS-entering Death Valley

- How long has Andrew had ALS? 8 years, 5 years, or 2 years?
- Why was Andrew not eligible for any new drugs?
- Why do ALS patients in Canada have this problem?

STORY OF ANDREW

DRUG AVAILABILITY WITHOUT ACCESSIBILITY

The answer is Triple Jeopardy linking:

1. Diagnostic EI Escorial (EE) criteria: Fewer than 50% of patient with clinically confirmed diagnosis meet the EE definition of *Definite* or *Probable* ALS (Jewett et al. 2022)

2. Clinical Trial inclusion Criteria: Restrictions according to disease duration, functional capacity, and progression rate are used for increased expediency/efficiency of new drug development and improved probability of detecting an efficacy signal.

3. CADTH reimbursement criteria: Imposing the same clinical trial restrictions for reimbursement criteria results for example in having >90% of ALS patients not able to receive Albrioza due to not meeting the criteria of EE definite 18 months of symptom onset.

STORY OF ANDREW


DRUG AVAILABILITY WITHOUT ACCESSIBILITY

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Commentary

Can I Be Honest With My Neurologist? A Problem of Health Technology Assessment in Canada

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Keywords: Amyotrophic lateral sclerosis; clinical trial methodology; doctor–patient relationship; motor neuron disease

Clinical trials of new drugs for ALS typically attempt to include patients who are considered the most likely to allow detection of an efficacy signal based on diagnostic criteria, disease duration, and functional status. Many patients are thereby precluded from participating in such trials because of the wide range of ALS phenotypes. Importantly, these criteria have also become the basis for decisions by Health Technology Assessment (HTA) agencies to restrict patients' eligibility for reimbursement of drug costs under private and publicly funded insurance plans, to only those who strictly conform to clinical trial inclusion criteria. The basis for such criteria as evident in current literature and their impact on patients' access to treatment are discussed in this commentary from the perspective of a person living with ALS (pALS).

inter-rater reliability, an incorrect implication of varying levels of diagnostic uncertainty, and their inadequate sensitivity for making the diagnosis across ALS phenotypes. Only a minority of patients meet EE criteria for “Definite” ALS at the time of their clinically confirmed diagnosis, and some may not even meet it at the time of death due to ALS. Even patients with an initial diagnosis of the lowest EE category (“Possible” ALS) may die of ALS while still categorized as “Possible.” Since a significant proportion of patients who meet the 2019 Gold Coast criteria for a confirmed diagnosis of ALS do not meet the EE definitions of “Possible” or “Probable” ALS, their replacement by the Gold Coast criteria has been proposed because they have greater sensitivity than the EE criteria with a similar level of specificity.

STORY OF MATT

NEED FOR BETTER HOMECARE



Unpleasant monthly anniversaries plague people with all rare diseases!

STORY OF MATT

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NEED FOR BETTER HOMECARE

- 1. Deteriorating Health and Home Care Struggles:** Matt's health took a significant hit in November 2022, preventing him from attending events without a wheelchair. After a hospital stay for Viral Pneumonia in May 2023, the need for home care became urgent. The transition to home care was challenging, causing strain on family members.
- 2. Inadequate Home Care Support:** The home care plan initially provided by the hospital was intensified to 9 hours a day due to gaps in care. However, when responsibility shifted to the HCCSS, they insisted on reducing it to 3 hours, causing distress. Negotiations stretched over weeks, resulting in a compromise of 4 hours per day, but challenges persisted, including inconsistent PSW attendance and suggestions that seemed to **prioritize efficiency over personal safety**.
- 3. Family Managed Program and Safety Concerns:** Opting for a family-managed program did not fully resolve the challenges. Matt's wife still feels confined to his schedule, especially during transfers with the hooyer lift. Safety requirements are sometimes overlooked, emphasizing a double standard where financial considerations appear to outweigh caregiver safety concerns in the home care system.

STORY OF MATT

NEED FOR BETTER HOMECARE

“When do I get to enjoy my final days without having to raise issues around my support for this horrible disease! I’ve unfortunately experienced huge gaps in my health care support throughout my short two year journey!” -Matt B.

Matt’s Recommendations:

1. The Home-care system should be a “wrap around model” that ensures the patient/ family are supported. Each case/ diagnosis/ person has different needs and the system must take this into account with the sole objective to keep the sick loved one at home.
2. Safety and support of the Caregiver must become a priority. The physical and mental stress a Caregiver experiences throughout a PALS journey is immense and needs to be addresses by the Healthcare system.
3. The standard 4 hours per month of respite time is not acceptable! The Caregiver must have more time for self care.
4. For the clients sake, all in-Home care agencies must try to provide consistent caregivers.

STORY OF CALI

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GAP IN EQUITY OF CARE IN CANADA



- Cali has worked in healthcare for 20 years, specifically as a clinical ambulatory care pharmacist for people with serious chronic health conditions. It was incredibly shocking to be on the other side of health care for the past 6 years while her physician husband battled ALS.
- She was astonished by the lack of local resources and assistance that she and her husband could access to, as the disease progressed. The constant search for therapies, clinical trials, equipment, suitable homecare and organizing a daily care plan consumed her every waking moment.



“I don't think I will ever forgive myself for the quality time we lost while I was trying to navigate his care.” -Cali

STORY OF CALI

GAP IN EQUITY OF CARE IN CANADA

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“ALS is often referred to as a bankruptcy disease and our case was no different.” -Cali

- She searched for peer support and guidance from other caregivers and people with ALS across Canada. She learned that not all provinces are created equally and that her province lagged in key areas. In comparison to other provinces, they had no access to local ALS clinical trials as well as certain critical equipment such a cough assist machine.
- In addition, their provincial ALS multidisciplinary clinic lacked a neurologist for over two years.
- To date, their family has spent over \$200,000 on out-of-pocket expenses, equipment and physical therapy. While we wait for meaningful ALS therapeutics, we must not forget about optimal and equitable access to care for all ALS families across Canada regardless of where they reside.

STORY OF MARK

NEED MORE COLLABORATION IN CANADA



Mark, former NHL player, was diagnosed in 2018 with ALS, prompting him to embark on a mission to raise awareness and advocacy for ALS.

STORY OF MARK

NEED MORE COLLABORATION IN CANADA



ALS SUPER FUND

TOGETHER WE END ALS

- His commitment initially manifested in producing 33 ALS promotional support videos, featuring former Hall of Famers and sports media personalities. These videos were disseminated through various social media channels and prominently showcased on the ALS Superfund website.
- ALS Superfund, led by Mark, is a unique model led by patients, guided by experts, and implemented by charitable organizations working toward common cause across the country. The Super Fund is focused on results: advancing research and ensuring equitable access to treatments and trials for all Canadians.
- But Mark's dedication did not stop there!

STORY OF MARK

NEED MORE COLLABORATION IN CANADA

- Most recently, he proactively engaged with the seven Canadian NHL teams forging a successful collaborative partnership aimed not only to amplify ALS advocacy but also to raise significant funds for research. Showing that teamwork can make a difference!
- Mark's initiative serves as a beacon, signaling to the ALS entities across Canada that a united front is the most effective path towards expediting results and ultimately finding a cure.





THANK YOU

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