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NEWS RELEASE

Alberta celebrates anniversary of the #ALSIceBucketChallenge

Calgary – July 21 – In 2014, the ALS community was given an amazing gift. The ALS Ice Bucket Challenge went viral, allowing for ALS to become a commonly known disease. Alberta raised a remarkable \$2.8 million during the 2014 Ice Bucket Challenge, of which funds were allocated to national ALS research and support services within the province.

In total \$17 million was raised in Canada, with \$11.5 million allocated to ALS research and \$4.4 million allocated to support people living with ALS across the country. Brain Canada responded to the generosity of Canadians by donating an additional \$10 million to the \$11.5 million dedicated to research, bringing the total investment to \$21.5 million.

The impact of the Ice Bucket Challenge has allowed ALS Canada to accelerate the national research program. There has been a 70 per cent increase in peer-reviewed grant applications from Canadian researchers, and investments have been made in a clinical trial for the drug, pimozone.

“We are very grateful to the entire community for participating in the ALS Ice Bucket Challenge, and in particular to ALS Alberta for supporting the patients in our clinics and for contributing to the research that will allow us to find treatments and a cure for this disease,” said Dr. Lawrence Korngut, Director of the ALS and Motor Neuron Disease Clinic.

“Here in Alberta we obtained some of the first financial support for a clinical trial that is taking place in Calgary of 25 patients with ALS. We are trying to establish pimozone, which is an older medication used to treat psychiatric illnesses, that has looked very promising as a treatment for ALS.”

Due to the funds raised by the Ice Bucket Challenge, The ALS Society of Alberta has been able to work collaboratively to explore new ideas that will enrich existing programs. The equipment loan program has been enhanced with the introduction of new technologies, such as a communication device that is controlled by the gaze of the eye. In addition, the Society has been able to allocate funds for those who cannot afford transportation to the clinic or appointments.

“The ALS Society has gone above and beyond to support myself and my family with the necessary equipment and resources such as the equipment loan program and research forums to help me live a more manageable life,” said Judy Van Dresar, ALS Alberta Client. “The Ice Bucket Challenge not only increases the programs and resources available but puts much needed funding toward research in order to find a treatment, if not a cure for this horrific disease.”

An ALS diagnosis can cost a family up to \$250,000. Client support services in Alberta aim to ease the financial stress on those affected by ALS by providing communication and mobility equipment at no cost. Additional support services include home support visits, coordination of care in the community,

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support groups, support for children through the Support for Champions program and advocacy for the best possible support for people living with ALS.

One year after the ALS Ice Bucket Challenge took place, the ALS Society is encouraging Albertans to celebrate the remarkable success of the initiative. Albertans can get involved by posting a video online with the hashtags #ALSIceBucketChallenge and #ALSAB, or they can donate by visiting www.alsicebucketchallenge.ca.

“Due to the generous support we received in 2014, we were able to respond to every request for equipment and support across Alberta. This included 1,462 pieces of equipment allowing those living with ALS to stay in their homes as long as possible,” said Karen Caughey, Executive Director of the ALS Society of Alberta. “We are so grateful for the awareness and funds raised by the Ice Bucket Challenge, and we encourage Albertans to continue their support so that we can allocate further funds toward national research initiatives and to our imperative client support services.”

For more information about the research being conducted in Alberta, visit <https://vimeo.com/134113489>

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For more information please contact:

Lisa Copeland
Coordinator of Events and Special Projects
ALS Society of Alberta
Phone: 403-228-3857 ext. 109
Cell: 403-804-1248

What is ALS?

ALS (*Amyotrophic Lateral Sclerosis*) is a rapid, always fatal neurodegenerative disorder which is commonly known as Lou Gehrig’s disease. It attacks the nerves of the body that are responsible for sending messages to the brain. This results in the gradual loss of muscle control, mobility and motor skills. In time, the individual with ALS is left completely immobilized, with loss of speech and eventually an inability to swallow and breathe. Approximately 3,000 Canadians live with ALS and two to three Canadians die every day of ALS. There is no known cause or cure for this devastating disease.

ALS Society of Alberta

The ALS Society of Alberta is a nonprofit organization dedicated to making each day the best possible day for people living with and affected by ALS. We achieve our vision by providing support, facilitating the provision of care, promoting awareness, helping find a cure and advocating for change.