



AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF MANITOBA

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RESEARCH

Fact Sheet

The Role of the ALS Society of Canada

Founded in 1977, the ALS Society of Canada is the only national voluntary health organization dedicated solely to the fight against ALS and support for those living with ALS. The Society funds research towards a cure for ALS, supports provincial partners in the provision of quality care for those living with ALS and provides information to build awareness about the disease. The vision of the ALS Society of Canada is to find a cure for ALS.

What is ALS?

Amyotrophic Lateral Sclerosis (also known as Lou Gehrig's disease) is a fatal neurodegenerative disease. People living with the disease become progressively paralyzed due to degeneration of the upper and lower motor neurons in the brain and spinal cord. Eighty per cent of people with ALS die within two to five years of diagnosis – unable to breathe or swallow. Ten per cent of those affected may live for 10 years or longer. ALS has no known cure or effective treatment yet. For every person diagnosed with ALS, a person living with ALS dies. Approximately 2,500 - 3,000 Canadians currently live with this fatal disease.

Research commitments

ALS Canada funds a variety of research programs and ensures to attract some of the best and brightest scientists to the field of ALS research.

ALS Canada understands the importance of investing in talented Canadian ALS researchers. By contributing to research programs, ALS Canada is determined to develop effective therapies and find a cure. One of the cornerstones of our research program remains the Neuromuscular Research Partnership (NRP), a collaboration set up in 1999 between ALS Canada,

Muscular Dystrophy Canada (MDC) and the Institute of Genetics, Institute of Musculoskeletal Health and Arthritis and Institute of Neurosciences, Mental Health and Addiction of the Canadian Institutes of Health (CIHR). To date, the NRP has invested more than \$29 million to fund Canadian researchers investigating neuromuscular diseases.

ALS Canada also provides awards and scholarships to help draw young researchers to the field of neuromuscular research and seed the future for further research developments. These awards are given using a peer-review process to ensure that research funds are allocated where they will have the most impact. These include the Doctoral Research Awards, the Tim E. Noël Fellowship in ALS Research, and the Ronald Peter Griggs Memorial Postdoctoral Fellowship in ALS Research.

ALS Canada has also created the Bernice Ramsay Clinical Research Fellowship and the Bernice Ramsay Discovery Grants programs, as well as the Betty Norman Clinical Fellowship in ALS Research.

International partnerships are another focus of ALS Canada's research funding. We have partnered with The ALS Association in the U.S. to fund researchers.

Over

ALS. Three letters that change people's lives. FOREVER.

Research focus

Canadian ALS researchers funded by ALS Canada are currently exploring the following avenues of research:

- **Cell mechanisms and pathways** — protein changes including the molecules responsible for their synthesis (mRNAs), and cell pathways, including stress handling and cell death.
- **Genetics** — genes and their roles in disease predisposition and development.
- **Environmental toxins** — potentially harmful factors in the environment that may increase one's likelihood of developing ALS.
- **Immunology** — harmful inflammatory responses that are believed to contribute to the degeneration and death of motor neurons, and the development of ALS immunization or vaccination.
- **Biomarkers** — biological indicators to help diagnose or monitor the progression of ALS.

The Research Forum

Each year ALS Canada holds an annual Research Forum. The Research Forum is designed to foster the free interchange of ideas and information, to encourage the participation of Canadian ALS researchers at the senior and junior level and present a group of international experts as plenary speakers. The sharing of information, presenting of ideas and enhancing of the quality of research being conducted in the ALS community is the ultimate goal of this conference each year.

2011 Research Landmark Breakthroughs

Through the efforts of leading scientists in Canada and around the world, our understanding of ALS has increased dramatically. And, 2011 was filled with numerous research achievements, as Canadian researchers helped develop a non-invasive test, currently in clinical trials, that could potentially quicken the pace for developing effective new treatments.

In another notable achievement, a new mechanism (which may play a major role in the way this disease progresses throughout the body) was identified by ALS investigators.

In addition, researchers made a groundbreaking discovery when they identified a gene which seems to account for a significant proportion of inherited ALS – and some cases which are not inherited as well.