



SOCIÉTÉ DE LA SCLÉROSE LATÉRALE AMYOTROPHIQUE DU QUÉBEC
AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC
LA MALADIE DE LOU GEHRIG'S DISEASE
www.sla-quebec.ca

THE ALS SOCIETY OF QUEBEC

What Is ALS?

ALS stands for Amyotrophic Lateral Sclerosis and is also known as Lou Gehrig's disease. It is a neuromuscular disorder that affects the nerve cells and spinal cord progressively leading to the total paralysis of the muscles. ALS rapidly affects the body and is usually fatal within three to five years following the initial diagnosis.

Until fairly recently, it was assumed that ALS did not affect thinking. However, researchers have found that changes in the way one thinks, perceives, processes information (cognition), and behaves will occur in some people living with ALS sometimes early on, even before an ALS diagnosis has been made. This is not to say these changes will occur in all persons with ALS as symptoms and changes vary from person to person.

At this time, there is no cure for ALS or to slow its progression.

How Does Someone Develop ALS?

In most cases the cause is unknown. In about 5-10% of cases, there is a hereditary pattern. Researchers have recently been investigating the possibilities of genetic predisposition, viral or infectious agents, toxins, and immune disorders.

Who Is The Most Vulnerable?

ALS can strike anyone, anytime, without any regard to age, gender or ethnic background. However, it seems that the usual age of onset is between 40 and 70 years of age and that ALS affects more men than women. ALS is not contagious and cannot be prevented.

What Are The Early Symptoms of ALS?

The first symptoms of ALS can be hard to notice. For example, a person may begin to trip and fall, drop small objects, have difficulty swallowing or may slur their speech. A person could also experience muscular weakness and twitching.

What Are The Effects of ALS?

ALS has a devastating effect, not only for those diagnosed but also for their family and caregivers. For some, daily losses in physical strength or ability become a reality they must learn to live with. Financial and emotional reserves may become increasingly depleted, while the afflicted individual becomes increasingly dependent on his or her caregivers and may also, in time, require more specialized care and costly equipment. Although cognitive changes occur in certain cases, people's awareness generally

remains intact. ALS does not affect the senses and therefore taste, touch, sight, smell and hearing remain unimpaired.

What Is The Future For People Living With ALS?

Because there is presently no treatment available that prolongs life significantly, those living with ALS find good planning and social and medical management crucial in easing the burden placed on themselves and their family. There may eventually be a cure for ALS. Research is helping to find a cure and ways to treat the devastating disease.

What is the mission of the ALS Society of Quebec?

The ALS Society of Quebec is a non-profit community organization whose mission is dedicated to improving the lives of people touched by ALS and the support of their family members. Promoting and subsidizing research on the causes, treatment, and cure of ALS are also integral parts of its mission which survives on donations and on proceeds from various fundraising events.

Research

Current research into the cause of ALS investigates many areas, including genetic predispositions, immune system changes, environmental toxins, infectious agents and cellular mechanisms. Research toward the development of an effective treatment for ALS is progressing more rapidly than ever before. Some of the strategies in development include drug, gene, and stem cell therapies. Because of the complex nature of ALS, it is likely that a combination of many therapeutic strategies – to attack the disease at all levels – will be the best approach to slowing, or even stopping, the course of ALS. For research updates, please visit www.als.ca

Key Facts

- Two to three Canadians die of ALS daily.
- Approximately 3,000 Canadians currently live with ALS.
- In at least 90 per cent of cases, ALS strikes individuals with no family history of the disease.
- Between 5 and 10 per cent have a familial form of ALS.
- ALS can strike anyone, regardless of age, sex or ethnic origin.
- The usual age of onset is between 40 and 70, but in rare cases it can strike people aged 20 or younger.
- Nearly 90 per cent of people with ALS die within five years of diagnosis.
- ALS affects the whole family.
- ALS is a costly disease – emotionally, physically and financially.

Contact: Claudine Cook, Executive Director
514-725-2653 ext 101 (toll free in QC: 1-877-725-7725)
ccoock@sla-quebec.ca www.sla-quebec.ca