ALS FAQs

WHY IS THERE NOT A CURE FOR ALS?
ALS, like Parkinson's disease and Alzheimer's disease, is neurodegeneration of the aging nervous system. Although the diseases typically become apparent when people are in their 50s to 60s they probably start years or decades earlier. This means that by the time people are symptomatic the "horse has bolted the barn". This makes treatment difficult. However, there is now much effort being directed to early detection using new genetic and molecular means. This will allow intervention before the disease begins. While there is no cure for ALS, there are a variety of treatments and strategies that maximize functioning and comfort.

ARE THERE STEM CELL THERAPIES FOR ALS?
Stem cell therapy is very complicated. There are many different types of stem cell and it is not yet clear which would be best for treating neurological disease. Are they really able to replace dead cells and function as normal cells? Where do stem cells go once they are in the body and what becomes of them? These are fundamental questions that are being tackled. There is great hope for stem cells in the future but their time for human ALS has not yet come. In the meantime be very wary of those that give false hope and promise with stem cell therapy. These treatments are dangerous and uniformly fail at great financial and emotional expense.

IS THERE VALUE TO ALTERNATIVE THERAPIES?
There are many alternative therapies including vitamins, herbal medicines, massage, acupuncture, diets and so on. Some of these are harmless; some may be harmful. There are few studies that test the effectiveness of alternative therapies in people with ALS. If a treatment claims to cure a host of many different diseases it is most likely a false hope and some of these are potentially dangerous. If you are considering alternative therapies, discuss it with your GP and ALS Centre neurologist and team.

ARE ENVIRONMENTAL FACTORS RELEVANT TO ALS?
Like many other diseases, the cause of ALS is likely due to a mixture of many genetic effects interacting with environmental factors. It is difficult to isolate and identify individual triggers in disease. However, some progress is being made.

WHICH ARE THE BEST WEB SITES ON ALS?

Medical & Research Websites	**Personal Stories**
http://www.alsmndalliance.org/	www.patientslikeme.com
http://www.als.net/	www.facebook.com
http://www.als.ca/	www.myalsstory.ca

WHAT IS PLS?
PLS stands for primary lateral sclerosis. It is a variant of ALS. The course is initially much slower than typical ALS and the overall duration often much longer (sometimes 12-15 years).

ARE THERE DIFFERENT RATES OF PROGRESSION OF ALS?
Progression rate (speed) of symptoms is different for each person with ALS. However in a given person the rate remains stable (linear) or constant. Rates of progression can vary from very slow to very rapid. About 15% of people have a slow course, 10 years or more, and there is some evidence to indicate that this situation is becoming more frequent.

HOW FREQUENT IS FAMILIAL – HEREDITARY ALS?
Only about 7% of ALS is truly familial or hereditary. In other words 90+% of cases are sporadic, meaning can occur randomly in the general population. Several causative genes have been identified in Familial ALS (FALS).

WHY DOES MY FAMILY DOCTOR KNOW SO LITTLE ABOUT ALS?
ALS is regarded as rare (an orphan disease) with an incidence of 2/100,000 people. A family physician may see only one case in his/her life-time and even community Neurologists will see less than 5 cases a year. So it is to be expected that a family doctor will not be familiar with the disease.

DO YOU GET PAIN IN ALS?
Yes, pain can occur in people with ALS, although this is rather uncommon. There are different types of pain, some being quite severe. A person with ALS experiencing pain should have it assessed by a health care professional.