CALS and ALS Canada both feel that it is important to develop Canadian Practice Guidelines for Care of Patients with ALS. Although there are other guidelines available (American AAN guidelines and European EFNS guidelines), we feel it would be helpful to have separate Canadian guidelines. We don't want to re-invent the wheel and so we will be referencing parts of the AAN and EFNS guidelines which we feel are useful and updating appropriate references. However, we would also like to include some original components to these guidelines in order to make them uniquely Canadian. One of the suggestions has been to include consensus statements on what we feel are reasonable wait times for specific components of the care of an ALS patient. For example, reasonable wait times for feeding tube insertion or BIPAP use would be considered.

We would like your help in determining what components should be included in the Canadian Practice Guidelines (CPG) and how these components should be rank ordered. If we include all the clinical questions, the final document would be quite lengthy, so we may wish to only include topics that would be useful to Canadian ALS clinicians. Please help us by answering the following questions:

Question set 1:

AAN guideline questions: Should these clinical questions be included in the Canadian CPG?

(possible answers: Definitely yes, Probably yes, Could be dropped to make room for other questions, Should not be included, Don't know.)

What is the effect of riluzole on slowing the disease process or prolonging survival in ALS?
What is the effect of enteral nutrition administered via PEG on weight stability?
When is PEG indicated in ALS?
How should a physician tell patients that they have ALS?
Does multidisciplinary management improve outcomes?
What is the efficacy of nutritional support via PEG in prolonging survival?
What is the effect of enteral nutrition delivered via PEG on quality of life?
What is the efficacy of vitamin and nutritional supplements on prolonging survival or quality of life?
What are the optimal pulmonary tests to detect respiratory insufficiency?
Does NIV improve respiratory function or increase survival?
How do invasive and noninvasive ventilation affect quality of life?
What factors influence acceptance of invasive and noninvasive ventilation?
What is the efficacy of targeted respiratory interventions for clearing secretions?
What are the most effective treatments for sialorrhea?
What pharmacologic measures reduce pseudobulbar affect?
What pharmacologic interventions reduce fatigue?
What interventions reduce cramps?
What interventions reduce spasticity?
What pharmacologic interventions reduce depression?
What pharmacologic interventions reduce anxiety?
What pharmacologic interventions reduce insomnia?
What is the prevalence and natural history of cognitive and behavioral impairment in ALS?
How is cognitive or behavioral impairment in ALS diagnosed?
What is the effect of cognitive or behavioral impairment on management of patients with ALS?

What treatments are effective for cognitive or behavioral impairment in ALS?
What treatments for dysarthria optimize communication in ALS?
What treatments reduce pain and dyspnea in the terminal phase of ALS?
Do hospice care, spiritual interventions, or advance directive improve quality of life in the terminal phase of ALS?
What is the optimal method of withdrawing both noninvasive and invasive ventilation in ALS?

Question set 2:

The following are additional topics covered by the EFNS guidelines, but not the AAN guidelines. Should these questions be included in the Canadian CPG?

(possible answers: Definitely yes, Probably yes, Could be dropped to make room for other questions, Should not be included, Don't know.)

What are the recommended investigations when investigating ALS?
Which diseases can masquerade as ALS?
What is the burden of care for ALS caregivers?
How are bronchial secretions best treated in ALS?
What is the risk of DVT in patients with ALS?
Should DVT prophylaxis be considered in patients with ALS?
Who should have ALS genetic screening?
Which genetic tests should be considered in sporadic and familial ALS?

Question set 3:
The following are questions that have been included in the AAN ALS Quality Measures.

Should ALS patients be regularly queried about falls?

Question set 4:
The following are new questions being considered for the Canadian CPGs:

What is the maximum amount of time a patient with possible ALS should have to wait to see an ALS specialist?
What is the maximum amount of time a patient with possible ALS should have to wait to have EMG studies?
What is the maximum amount of time that a patient should have to wait for BIPAP initiation after BIPAP has been clinically recommended?
What is the maximum amount of time that a patient should have to wait for REG/RIG insertion, after it has been clinically recommended?
What grief counselling should be offered to caregivers of deceased patients with ALS?
When should palliative care be invited to participate in the care of ALS patients?

Question set 5:

Please let us know of any other clinical questions that you feel would be important to include in these clinical guidelines.

If you would be interested in participating in the development of these clinical guidelines or know someone that would be interested, please enter your name or their name here.