

The Nordic ALS Research newsletter



This Issue's Focus:

A new name for our newsletter!

The ALS/MND International Symposium

The Nordic approach

A new name, for a larger audience!

Since our first edition back in June, many new readers joined our mailing list - welcome to all of you, and thanks for joining our rapidly growing community!

In order to better reflect our readers, we decided to rename this communication the Nordic ALS Research Newsletter, to better reflect you all receiving it. Indeed, most of our new members are coming from Norway, Finland and Denmark - toward a stronger Nordic ALS Research cooperation!

Who is the newsletter designed for ?

The newsletter is aimed for the Nordic ALS community who wants to keep in touch with what is currently being done in ALS research - a way to keep up with recent updates in the field and better inform your patients !

May you be a physician, the member of a multidisciplinary clinic team seeing ALS patients, a researcher, please reach out to us if you wish someone from your team to be added from our mailing list.

How to build a strong cooperative network ?

As you already now, we do not build a strong and a cooperative network by receiving a newsletter 3 times a year. It takes a bit of planning, time and effort, but it's definitely all worth it. Here are 3 tips designed to give you keys on how to continue keeping this newsletter alive in between editions:

1

Adopting an active approach - this means mentioning or relaying the information you receive to your colleague and your own network in your institution, to help create ALS research discussions

2

Contributing - suggest themes, ideas, projects, you would like to see in this newsletter ! Get involved so this newsletter reflects the info YOU want to read!

3

Don't be shy ! - ask questions, send emails, reach out to colleagues and start projects, we'll be happy to relay them!

Time to think about dysphagia

Ann-Sofie Eriksson, who is a SLP working in Västerås (Sweden), is currently completing her Master's degree and focusing on dysphagia in ALS.

Her goal is to come out with a standardized approach in the care of dysphagic ALS patients, by implementing a checklist to support healthcare workers in the field.

This project will also allow to observe how dysphagia is currently handled in Sweden, especially how interventions are introduced (such as PEG,...).

Ann-Sofie's project will allow us to have a better grasp of the Swedish ALS/dysphagia landscape, as well as highlighting any inequalities in terms of care.

ALS Clinical Trials: more than ever

This Fall marks the busiest time ALS clinical trials have ever seen in the Nordic countries.

Several sponsors have already announced sites selected for the trials starting this Fall and Winter, including the Nordics into their plan.

It is essential for our community to work together and united during these exciting times, to offer Nordic ALS patients the information and opportunities they deserve.

If you are not conducting any ALS trials at your site, please consider referring your patient to a trial-conducting site for a trial consultation. The team will then make sure patients fit the criterion of the study.

If you would like to start ALS clinical trials at your site, feel free to reach out so we can share our expertise and experience with you!

A Fall like no others for the Nordic ALS community !

The Nordic approach

Even if more and more ALS clinical trials are starting in the Nordic countries, we are still in the situation where we have a lot of patients, and only a handful of sites offering trials. This means that for the vast majority of patients, there is no site nearby, and sometimes, no site in their country running a trial they might be eligible for.

In the last few years, we have been receiving and increasing amount of requests from patients coming from outside of Sweden, asking to be screened for the trials we were conducting.

This lead us to open an important discussion with the trial sponsors: we need to open ALS trials inclusion to **ALL NORDIC PATIENTS**, and not only to patients from the country where the trial is being done.

We believe that if Sweden is the only country in the Nordics offering a specific ALS trial, then we should be able to open inclusion to patients from Iceland, Norway, Denmark and Finland as well.

It is our collective responsibility to open this dialog with the trial sponsors, as we all have a roll to play to offer the best chances to the Nordic ALS patients.

32nd international symposium on ALS/MND

The annual symposium organized by the MND Association (MNDA) will take place virtually from the 7th to the 10th of December.

Registrations are open until the 1st of December on the MNDA website, and will allow you to have access to all the talks and poster sessions offered by the Symposium. Last year's edition was also virtual and the MNDA did a great work at making sure we could also network and discuss via the symposium's platform. Our group from the ALS Clinical Research Center at Karolinska will present 6 posters on various subjects, and we hope to see you there!



Launch of the Swedish version of the TRICALS website

As you all probably know, TRICALS is the largest European network to find a cure for ALS, with 6 TRICALS sites in the Nordics (located in Norway, Denmark and Sweden). Their website recently launched a Swedish version, making the information even more accessible for our community!

<https://www.tricals.org/sv>

EMS Training in ALS, a standardized methodology?

Expiratory Muscle Strength Training, also called EMST, was implemented by the SLP team of the Karolinska Hospital in November 2018. Since then, the team has been offering EMST to patients. If you are interested in implementing this method in your clinic as well, feel free to reach out!

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Please note that you can opt-out of this newsletter at any time. If you do not wish to receive this newsletter anymore, feel free to reach out and we will remove you from our mailing list.