

The Nordic ALS Research Newsletter

This Issue's Focus:

Jumping into 2022

ALS/MND Symposium
2021 - Nordic contribution

Planning ahead for the
summer - ENCALs meeting

Welcoming 2022, a decisive year in ALS clinical research

As we are starting up with this new year, it is important to remember that more than ever, ALS clinical trials are becoming available in the Nordic countries. In Sweden only, considering current trials and upcoming trials for the spring/summer 2022, we are talking about 9 trials - a number never seen before!

However it is important to acknowledge that not all Nordic countries offer the same number of trials for ALS patients, and this is why we put so much emphasis on **communication in our community**.

We believe in a joint effort to include Nordic patients in clinical trials run in the Nordics, offering a chance to be included for patients who perhaps have less access to clinical trials in their home country. We also wish to encourage collaboration between sites and teams used to run large scale trials, and teams willing to initiate clinical trials at their hospital.

If you are thinking of starting clinical trials for your ALS patients, we recommend you reach out to the **TRICALS** network (<https://www.tricals.org/en/>) who will put you in touch with the TRICALS site closer to you.

We also recommend you initiate a discussion at your site, within your team, about ALS clinical trials: Are your colleagues aware of the clinical trials done in the Nordics? Do you know how to refer a patient for a trial? Are trials regularly discussed and offered to the ALS patients you meet? Are you able to answer your patient's questions about the trials available for them?

If you would like for the next edition of the newsletter to be focused on these questions, please reach out to juliette.foucher@ki.se



Retrospective, ALS/MND Symposium 2021

Although held virtually in December, the last International ALS/MND Symposium gathered over 1500 delegates from 44 countries across the world.

We wanted to highlight the only presentation given by a researcher based in the Nordics, Sebastian Lewandowski from the Karolinska Institutet.

His presentation, "Perivascular fibroblasts activity precedes the onset of ALS neurodegeneration with high plasma SPP1 associated with short patient survival", went over his recent findings published in Nature Medicine in April 2021.

In this study, Dr Lewandowski and his collaborators used both ALS mouse models and spinal cord samples from sporadic ALS patients and looked at cell activity patterns.

They observed a stronger survival-prediction effect when looking at plasma SPP1 (a protein marker of perivascular fibroblasts) levels compared to neurofilament levels in the CSF or bulbar onset, the 2 risk-factors that are the most looked at when talking about survival-prediction.

To follow with a close eye!

ENCALS Meeting 2022

The European Network to Cure ALS (ENCALS) will host this year's meeting in Edinburgh, Scotland, from Wednesday 1st to Friday 3rd of June 2022. It will be organized by Professors Sharon Abrahams and Siddharthan Chandran.

You can register directly from the ENCALs website under the following link: <https://www.encals.eu/meetings/encals-meeting-2022-edinburgh-scotland/>

Please keep in mind that registrations will close at 5pm on the 16th of May.

If your team wishes to submit an abstract, the deadline for abstract submission is 5pm on the 18th of March.



Keeping up with ALS EMA's application

On January 4th, Amylyx Pharmaceuticals submitted a Marketing Authorization Application (MAA) to the European Medicines Agency's (EMA) Committee seeking the approval of its lead candidate AMX0035 as a treatment of ALS.

AMX0035 is a combination of two compounds: sodium phenylbutyrate (PB) and tauroursodeoxycholic acid (TUDCA).

This submission is based on the data from the phase 2 CENTAUR clinical trial (NCT03127514), a randomized trial which continued with an Open Label Extension (OLE), following patients for three years.

In parallel, the phase 3 clinical trial with AMX0035, PHOENIX (NCT05021536) recently started recruiting in Europe and is planned to be conducted in 2 sites in the Nordics.

Machine learning and genotyping in ALS

Thanks to machine learning integrating functional genomics with genome-wide association studies (GWAS), transcriptomic and epigenetic profiling of motor neurons derived from induced pluripotent stem cells (iPSCs), Dr Michael Snyder and his team from the Stanford School of Medicine (USA) recently identified 690 ALS-associated genes that represent a 5-fold increase in recovered heritability.

We wanted to congratulate Dr Eran Elhaik from Lund University (Sweden) for his collaboration in this study, published in Neuron on January 18th.

You can access the publication following that link: <https://doi.org/10.1016/j.neuron.2021.12.019>

Tour du ALS - 10th year anniversary

The Tour du ALS is a Dutch initiative that is celebrating its 10th year anniversary this June. The Tour takes place on the Mont Ventoux, France, and aims to raise awareness and money for ALS research.

On June 9th, teams of clinicians, healthcare workers, caregivers, patients and ALS community members will climb 21km together, either biking, running or walking.

Partnering with TRICALS, we are currently in the process of building a Swedish team, as it will be the first year non-Dutch teams will join the event.

We are happy to share with you that we will partner with the Ulla-Carin Lindquist organization for this event!

You can learn more about the Tour du ALS by visiting their website: <https://www.tourduals.nl/?locale=en>

If you would like to discuss the details of the creation and organization of the Swedish team, or if you want to contribute to the fundraising feel free to reach out!



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