



Highlights and take home messages from ENCALS 2024

To keep track of the latest developments in ALS research, EUpALS attended ENCALS 2024, held June 17-20 in Stockholm (Sweden).

Monday June 17

Opening of ENCALS 2024 by local host of ENCALS 2024 Prof. Caroline Ingre on behalf of the Karolinska Institutet, and Prof. Leonard van den Berg Chair of the ENCALS Executive Board. Thank you for having integrated our slide in welcoming presentation, highlighting EUpALS as an ENCALS collaborator.



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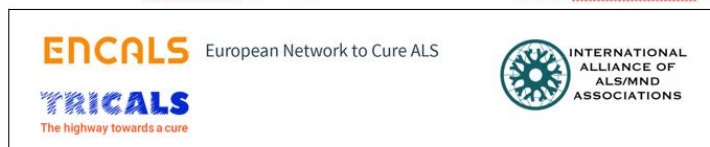
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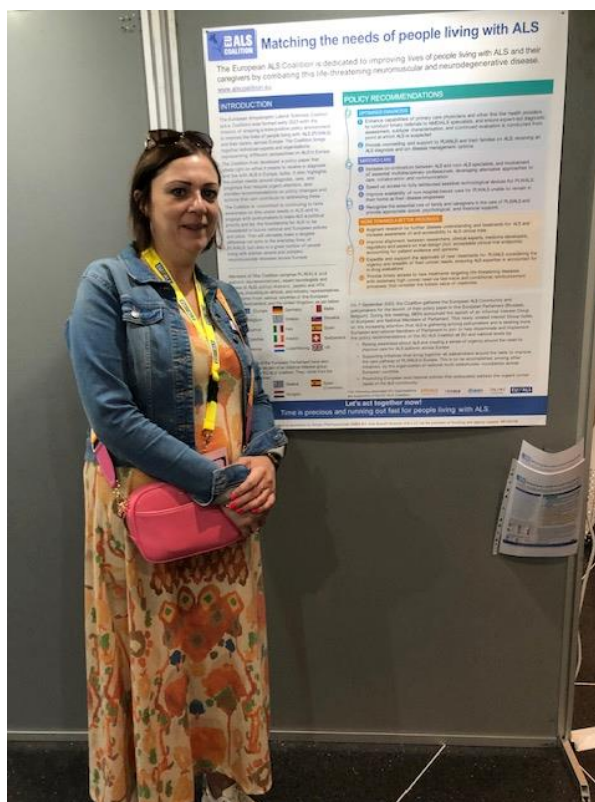
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Close collaboration



In the session on population and disease registries and epidemiology, the Swedish MND Quality Registry was presented as a tool to advance both ALS research and medical care. Also, a Swedish epidemiology study presented by Drs. Sofia Imrell showed that C9orf72 gene mutations are more common in the North region of Sweden as compared to the South. A similar observation was made in neighbouring country Norway as presented by Dr. Helle Hoyer, pointing to historical migration in the North of Scandinavia.

During the concluding poster session, Evy Reviere presented the poster 'Matching the needs of people living with ALS' describing the mission and activities of the EU ALS Coalition.



Tuesday June 18

The day started with a session on pre-symptomatic changes and imaging, in which studies focusing on detection of early signs of ALS in pre-symptomatic carriers were presented.

An equally technical session on genetics addressed e.g. multiomic analysis to identify the genetic basis of ALS, and a genome-wide screen for genetic modifiers in ALS progression.

Definitely an ENCALS 2024 highlight was the lively debate on 'The ALS future: should we go for targeted or for untargeted/cocktail treatments', moderated by Prof. Leonard van den Berg. The position aiming for a targeted approach was advocated by Prof. Angela Genge, while Prof. Pamela Shaw was in favour of the untargeted/cocktail approach. Ultimately, the audience was surveyed and spoke in favour of a targeted approach.

At the heart of ENCALS 2024 were long awaited presentations of the results of the following clinical trials:

- Data of the Amylyx PHOENIX trial with AMX0035 were presented by Prof. Leonard van den Berg. Unfortunately they did not meet the primary endpoint.
- Data of the academic trial with TUDCA were presented by Prof. Alberto Albanese. Unfortunately they did not meet the primary endpoint.
- Data of the Ferrer ADORE trial with FAB122 (oral Edaravone) were presented. Unfortunately they did not meet the primary endpoint.

In follow-up, a panel discussion was organized about the new standard of care.

Wednesday June 19

After the session on biomarkers, basic and translational research, a series of rapid fire presentations was offering young investigators the stage.

Our highlight of this closing day was the presentation by Prof. Julian Grosskreutz on The EU ALS Coalition, describing its mission, member composition, activities and delivered policy paper.

Furthermore, data from another 2 clinical trials that did not meet their primary endpoints were presented: the Biogen ALSpire study with BIIB105/ION541 (Ataxin-2 ASO), and the Sanofi Himalaya with SAR443820, a RIP1 kinase inhibitor also known as DNL788.

At the end of ENCALS, Awards were presented to

- ENCALS Young Investigator Award Gold medal: Dr. Rubika Balendra (University College London and National Hospital for Neurology, UK)
- ENCALS Young Investigator Award Silver medal: Dr. Ratko Radakovic (Cambridgeshire and Peterborough NHS Foundation Trust, UK)
- Börje Salming Award for best Rapid Fire Presentation: Dr. Karthik Bastar (University of Ulm, Germany)
- ENCALS Posters Awards: 10 young ALS researchers

Final take home message: already mark your calendars 3-6 June 2025 for ENCALS 2025 in Turin (Italy). Local host is Prof. Adriano Chio.

European organization for Professionals and People with ALS (EUpALS) ivzw

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