

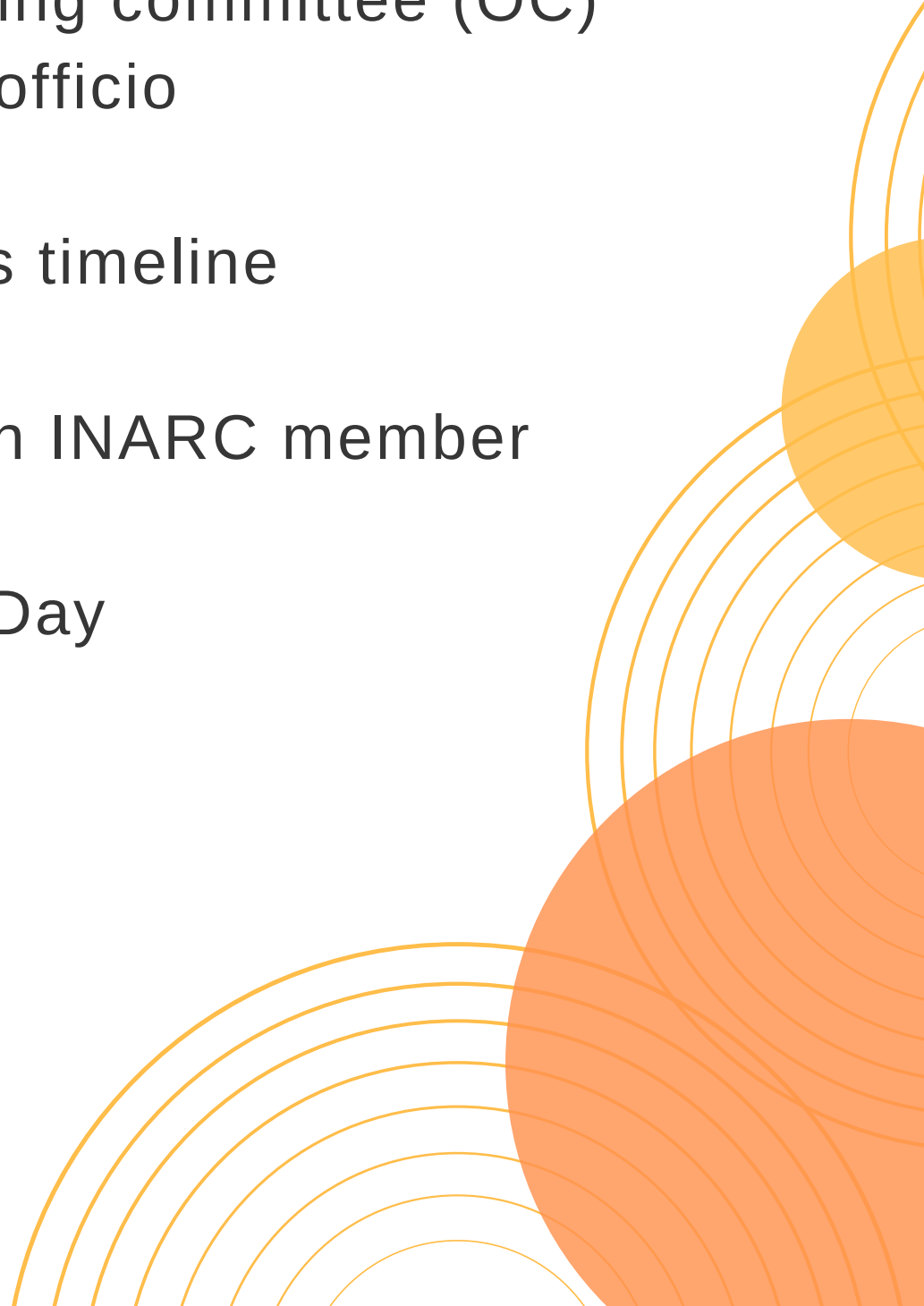
# INARC

## 2024 Brochure

*The first international network for  
ALS care and research  
professionals who are not medical  
doctors*



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# Our goals

- **Connect** the different ALS research and care staff members together
- Organize **networking** events at global conferences
- Organize **workshops** and satellite meetings
- Streamline the **communication** between ALS research and care staff members
- Create a **platform** and a space to exchange skills and expertise
- Increase our **problem solving skills** when facing common challenges in the ALS clinical research fields
- **Empower** our members and experience-based training



***To better serve ALS patients, both in care and in research!***

# Organizing committee and Ex-officio



## **Tommy Bunte (OC)**

- Tommy acts as a TRICALS trainer for outcome measures. He has a nursing background and then specialized to become a physician assistant at the University Medical Centre Utrecht, where he is now leading the ALS trials conducted there.
- Affiliations: UMC Utrecht.



## **Juliette Foucher (OC)**

- Juliette is currently working at the Karolinska University Hospital where she is coordinating ALS trials, developing partnerships, handling communication, supervising students and supporting their growing team. In parallel she is conducting her PhD at the Karolinska Institute, focusing on how cognitive and behavioral impairment can impact ALS trial access. She is also acting as Nordic patient liaison for TRICALS.
- Affiliations: Karolinska Institutet (Department of Clinical Neuroscience), & Karolinska University Hospital (Department of Neurology)



## **Mathias Couillard (OC)**

- Mathias has experience coordinating ALS clinical trials, and then evolved to managing the Montreal Clinical Research Unit. Since then, he has transitioned to the Genge Partner Inc., a clinical trial unit exterior to the hospital environment, where he is building a team specialized in the conduct of neurological trials in general, with a focus on ALS.
- Affiliations: Genge Partners Inc., & Montreal Neurological Institute and Hospital, McGill University

# Organizing committee and Ex-officio



## **Vanessa Bertone (OC)**

- Vanessa started her involvement in ALS through clinical trial coordination and has since then progressed to the role of Disease Lead at the Montreal Clinical Research Unit, focusing on ALS and neuromuscular disorders. She is evolving in an environment focusing on neurological diseases, as her unit is running over 100 trials in neurological clinical trials.
- Affiliations: Clinical Research Unit, Montreal Neurological Institute and Hospital, McGill University



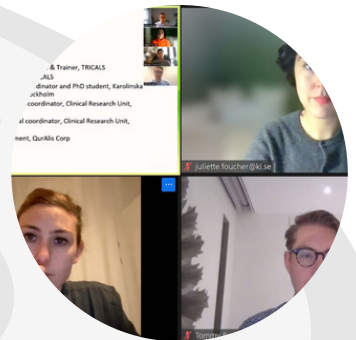
## **Corey Straub (Ex-Officio)**

- Corey got involved in the ALS community through administrative support with the director of the Montreal ALS clinic and program. Since then, Corey has transitioned to be a senior executive assistant in the ALS start-up QurAlis. Corey is acting as an Ex-Officio member for INARC, working on developing partnerships between INARC and pharmaceutical companies.
- Affiliations: Montreal Neurological Institute and Hospital, McGill University, & QurAlis

# INARC's timeline



**Preliminary INARC meeting**  
ENCALS 2022



**INARC launch**  
APF 2022



**INARC poster**  
PACTALS 2023



**INARC meeting**  
ENCALS 2023



**INARC talks**  
APF 2023



**INARC networking dinner,**  
ALS/MND 2024



**INARC presentation**  
TRICALS Masterclass

# Being an INARC member



## For who?


Are invited to be INARC members all staff members involved either in the clinical care of ALS patients or in clinical research with ALS patients. As other networks might be more specific to physicians, INARC focuses on all the other members involved in ALS research and care: nurses, research nurses, study coordinators, occupational therapists, physiotherapists, speech and language pathologists, assistant nurses from both research and care, and more!

## How much does it cost to become a member?

Becoming an INARC member is free of charge!

## How do I become a member?

If you wish to become an INARC member, you simply need to send an email at [inarc@tricals.org](mailto:inarc@tricals.org) asking to be added to our members list.



# Being an INARC member

## What's in it for me?

Joining INARC will allow you to connect with other professionals who are facing the same challenges than you are at your site/center/hospital. But as they come from different perspectives, and with different contexts, meeting them will allow you to improve your own practice, and increase your capabilities to think outside the box! What we have observed at INARC is that the richest conversations usually happen between small centers and large centers, when large centers may provide advice on how to optimize certain tasks to save time, and smaller centers on how to be very resourceful with less resources. INARC events also offer lectures, training on outcome measures, workshops, and contribute to our evergoing education and training.





# Being an INARC member

## Who will I meet during INARC meetings and events?


During INARC events you will meet professionals from care and research teams, coming from North America, Europe and South America. We are currently working on establishing relationships and memberships with professionals from Africa and Asia, and if you know of teams who might be interested please let us know of them! All events are run in English, but English is not the 1st language of most of our members. As our goal is to exchange, we ask every INARC member to leave their concerns on their abilities in English at the door! This allows for all our members to be comfortable during INARC meetings, for it to be a judgment-free zone when it comes to speaking in English.

## Can I be sponsored to attend INARC events?

Each country has options to support and sponsor care and research professionals to attend conferences and meetings, and we encourage you to investigate this within your own networks. However, if you are coming from a country with very limited resources and are struggling to attend an INARC event, we encourage you to reach out to us and we will see if we can find a solution.

# INARC Day



- Every year en marge of ENCALS, INARC organizes a **full day of satellite meeting**. This year, it will take place on June 20th, on the Karolinska Institutet (KI) campus, room Franklinsalen. The topic of this year's meeting is "**End of Life in ALS**".
  - The room is located behind the KI Library, you can find guidance to the room via this link: <https://medarbetare.ki.se/franklinsalen>
  - This year, INARC members can enjoy a **reduced registration fee** for the ENCALS conference. Each INARC member can, for 50e, access the full ENCALS conference and of course the INARC satellite meeting on June 20th. Note that the INARC Satellite meeting must be attended if you register using the INARC reduced fee.
  - To proceed with this reduced registration, INARC members must email at **inarc@tricals.org**, asking for an INARC membership certificate. Once you have received this certificate you need to upload it in the ENCALS registration portal, selecting the INARC member fee.
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# Contact information



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*If you wish to sponsor an INARC event, please reach out to Corey and to **[inarc@tricals.org](mailto:inarc@tricals.org)***