



European
Aniridia
Conference

31.05. - 02.06.
STOCKHOLM 2024



2024

**EUROPEAN ANIRIDIA
LEADERSHIP ACADEMY**

program



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2024

Welcome to Stockholm and the EALA!

It is with immense pride that I extend a warm welcome to the inaugural European Aniridia Leadership Academy. This momentous gathering marks the culmination of years of planning and dedication, bringing together a dynamic cohort of young changemakers from across Europe.

Our vision for the EALA is to empower the next generation of leaders within the aniridia community. Through this academy, we aim to equip you with the skills, knowledge, and connections necessary to drive meaningful progress and advocate effectively for our cause.

Over the next few days, you will have the opportunity to engage with experts, build bonds with fellow participants, and develop strategies for creating positive change. This is just the beginning of a transformative journey – the relationships built and lessons learned here will serve as the foundation for your ongoing leadership endeavors.

On behalf of Aniridia Sweden and Aniridia Europe, I want to express my heartfelt gratitude to each of you for your strong commitment to supporting and developing the aniridia



community. Your dedication to leading change at such a young age is truly inspirational, and I am confident that your collective creativity, compassion, and determination will shape the future of aniridia advocacy in profound ways.

Let's make the most of this opportunity and begin our journey towards a brighter future for the aniridia community. Welcome, and let's begin!

Ivana Kildsgaard
- *President of Aniridia Sweden*

31 May

Friday

DAY ONE

- | Event moderator: Ben Goodrich, Aniridia Sweden

- 10.00 ● Registration opens at the Blique by Nobis hotel
Address: Gävlegatan 18
Networking opportunity until lunch

- 12.00 - 13.30 | Lunch at the hotel restaurant Boketto

- 13.30 ● Gather in the hotel courtyard for a 10-minute walk together to the venue.
The European Aniridia Leadership Academy takes place at Birkagården.
Address: Karlbergsvägen 86B
Room: Matsalen, 4th floor

- 14.00 - 15.00 ● Welcome session – the leaders’ speed date
Session moderator: Matteo Castelnovo,
Vice President of Aniridia Italy

- 15.00 - 15.30 | Coffee break

- 15.30 - 16.45 ● What is the European Aniridia Leadership Academy?
Speakers:
Barbara Poli, President of Aniridia Europe - Introduction
Irma Byle, President of Aniridia Lithuania and Aniridia Europe’s responsible for the Erasmus+ “Together for inclusion” project
Guest from Aniridia Europe:
Marjorie Poeydomenge, Board Member of Géniris and Aniridia Europe

- 16.45 - 17.00 | Closing session

- 17.00 - 18.45 | Free time and time to travel to the Stockholm City Hall

- 18.45 ● Meet-up and check-in at Stockholm City Hall courtyard
Address: Hantverkargatan 1

- 19.00 - 21.00 ● Welcome and buffet dinner at Stockholm City Hall
Hosted by the City of Stockholm and the Region of Stockholm

01 June

Saturday

DAY TWO

- 08.45 | The venue room Matsalen opens
- 09.00 - 09.10 | Morning reflections
Speaker:
Matteo Castelnovo, Vice President of Aniridia Italy
- 09.10 - 10.30 | Becoming a superhero: the power of sports
Speakers:
Veronica Tartaglia, Italian and European fencing champion
Gianmaria Dal Maistro, Paralympic gold medalist in 2006 Turin Winter Paralympic games
Ben Goodrich, Paralympic silver medalist in 2020 Tokyo Paralympic Games
Guest from Aniridia Europe:
Denice Toews, President of Aniridia Germany and AE Board member
- 10.30 - 10.40 | Coffee Break
- 10.40 - 12.00 | Life is a matter of challenges
Speaker:
Daniel Egido, author of the book "Manual de combate del opositor" and Head of Service at the Spanish Ministry of Economic Affairs and Digital Transformation
Guest from Aniridia Europe:
Tord Håkonsen, Aniridia Europe Chief Treasury Officer
- 12.00 - 13.30 | Lunch
- 13.30 - 14.00 | Free time networking

- 14.00 - 15.00 | Daily life comparisons
Speaker:
Sølvi Ørstenvik, Aniridia Norway Board Member
Guest from Aniridia Europe:
Katie Atkinson, President of Aniridia Network and AE Board Member
- 15.00 - 15.30 | Coffee Break
- 15.30 - 16.15 | Digital is the key for accessibility
Speaker:
James Buller, Aniridia Network member and Lead/Senior Accessibility and Digital Inclusion Consultant (Grade 7) at UK Home Office
Guest from Aniridia Europe:
Galina Gening, President of Aniridia Russia and AE Board Member
- 16.15 - 17.00 | Fly away through words, sounds and voices
Speaker:
Matteo Castelnovo, Vice President of Aniridia Italy, Radio and TV Host, Podcaster, Journalist and AE Digital Team Leader
Guest from Aniridia Europe:
Elena Tsoneva, President of Aniridia Bulgaria and AE Board Member
- 17.00 - 19.00 | Free time
- 19.00 | Dinner at the hotel

02 June

Sunday

- 09.00 - 10.30 | Challenge workshop: being a volunteer is a matter of responsibility
Speaker:
Matteo Castelnovo, Vice President of Aniridia Italy
- 10.30 - 10.45 | Coffee Break
- 10.45 - 11.20 | Why and how to promote research on aniridia
Speaker:
Rosa Sánchez de Vega, Past President and Honorary member of Aniridia Europe
Guest from Aniridia Europe:
Ivana Kildsgaard, President of Aniridia Sweden and AE Board Member
- 11.20 - 11.30 | Closing session by **Barbara Poli**, President of Aniridia Europe
- 11.30 - 12.00 | Time for walking back to the hotel
- 12.00 - 12.30 | Lay summary at the scientific conference
- 12.30 - 14.00 | Closing lunch at the hotel

Empower your future and unlock new possibilities with the European Aniridia Leadership Academy (EALA)

- where rare talents come together to create a brighter tomorrow!

Practical A–Z

Conference meals

May 31st – Lunch, 12.00–13.00 in the hotel Blique by Nobis restaurant Boketto

May 31st – Reception with mingle buffet dinner, (18.45) 19.00–21.00
at Stockholm City Hall

June 1st – Lunch, 12.00–13.30 in the hotel Blique by Nobis restaurant Boketto

June 1st – Dinner, 19.00–21.00 in the hotel Blique by Nobis restaurant Boketto

June 2nd – Lunch, 12.30–14.00 in the hotel Blique by Nobis restaurant Boketto

Contact organisers

For any queries, please contact us at conference2024@aniridi.se
or send a message through whatsapp/phone to Neven Milivojevic, +46 70 639 00 68.
It is also possible to call the same number.

Directions

Maps and useful directions can be found at the conference web page:
<https://aniridiaconference.org/eac2024/logistics/>.

European Aniridia Leadership Academy venue

Birkagården: Session room – Matsalen, 4th floor
Address: Karlbergsvägen 86B

Hotel Blique by Nobis

Address: Gävlegatan 18
Phone: +46 8 557 666 00
Whatsapp: +46 8 557 666 01
E-mail: info@bliquebynobis.se

Public transport

It is easy to use the public transport in the Stockholm area. You can purchase a ticket by tapping your credit/debit card when entering the bus or train. More information can be found at <https://sl.se/en/>.

Reception at Stockholm City Hall on May 31st

The meet-up is at 18.45 in the City Hall inner yard. There is no organised transport to the City Hall. The public blue bus no 3 leaves every 10 minutes about 250 meters from the hotel and it takes you directly to the Stockholm City Hall (bus stop: Stadshuset). Make sure you take the correct direction of the bus, which should be Södersjukhuset. The bus ride takes about 15 minutes but it might take longer in rush hour. Please allow time for transportation not to miss out on the check in. At the back of the City Hall there is a small park with some statues by Carl Eldh as well as one of the most beautiful panoramic views in Stockholm, well worth exploring. Dress code for the reception is smart casual. The hosts are the City of Stockholm and the Region of Stockholm, and they have invited us to a mingle buffet dinner.

Aniridia Europe:

**Uniting compassion,
collaboration,
and innovation to
empower lives and
advance research
for a brighter future
with aniridia!**

Cooperation, support and sponsors

This conference would not have been possible without the kind and generous support and cooperation of our partners and donors. In addition to this our sponsors have contributed to making it possible for us to balance our finances. We are most grateful to all contributors!

Aniridi Norge

Aniridi Sverige

Aniridia Europe

AWS Aniridie-Wagr e.V.

Center for Rare Diseases, Karolinska University Hospital

City of Stockholm (Host Reception at City Hall)

Eurordis

Kronprinsessan Margaretas Arbetsnämnd för synskadade

Linköping University

Region Stockholm (Host Reception at City Hall)

Sigvard och Marianne Bernadottes forskningsstiftelse för barnögonvård

Synskadades riksförbund

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