



ANIRIDIA EUROPE

Activity Report

2022 - 2024

Aniridia Europe is committed to supporting individuals and families affected by aniridia. The organisation has been actively involved in initiatives to raise awareness, advocate for better healthcare, and foster community support. The following report outlines Aniridia Europe's key activities and achievements.

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1. The Board of Directors

During the mandate 2022-2024, the Board of Directors is composed of:

Member	Initials	Country
Barbara Poli, President	BP	Italy
Galina Gening, Vice President	GG	Russia
Tord Håkonsen, Treasurer	TH	Norway
Elena Tsoneva, Secretary	ET	Bulgaria
Other Board Members:		
Katie Atkinson	KA	United Kingdom
Irma Byle	IB	Lithuania
Ivana Kildsgaard	IK	Sweden
Marjorie Poeydomenge	MP	France
Denice Toews	DT	Germany

The Board of Directors has held regular meetings via teleconferences as follows:

- 2022 September 14th, November 22nd.
- 2023: February 15th, June 30th, October 25th, December 20th.
- 2024: March 5th, May 27th, May 31st, 17th June

2. Status of the representatives

In the summer of 2024, the federation includes:

✓ Full members - 14 National Associations:

Bulgaria, Denmark, Finland, France, Germany, Italy, Lithuania, Norway, Romania, Russia, Spain, Sweden, United Kingdom, and Ukraine

✓ Affiliated members - 16 reference persons:

Belgium, Croatia, Czechia, Estonia, Georgia, Greece, Iceland, Ireland, Latvia, Moldova, the Netherlands, Philippines, Poland, Portugal, Serbia, and Switzerland

✓ Contacts with patients:

Belarus, Egypt, Iran, Israel, Hungary, Kazakhstan, Malta, and Turkey

3. Communication and awareness

a. Website

The website was constantly updated with information about events and relevant scientific information about aniridia.

- As a project partner, the AE Board prepared the Aniridia Europe Framework according to the sustainability and social responsibility requirements. It is a new content structurally present in a new section created as a part of the “**About**” section in the main menu called “**Our Values**” <https://www.aniridia.eu/our-values/>, including the following content:

Table of Contents

- [Our guiding principles](#)
- [Our objectives](#)
- [Our commitment to sustainability](#)
- [Social responsibility](#)
- [Environmental responsibility](#)
- [Economic sustainability](#)
- [Code of Ethics](#)

The Code of Ethics will be available as a form that every AE member can confirm as part of their membership approval.

- **The Handbook of Good Practices** is a shared experience from the Association Aniridia Norway that can help patients establish and run new national associations worldwide. It was initially written for a joint project with the Association Aniridia Bulgaria 10 years ago, but now it is available in English.

b. Newsletter

An e-newsletter covering Aniridia Europe’s activities and those carried out by the National Aniridia Associations was published in September 2022 and August 2023.

c. Social networks

Social Media Campaigns: Aniridia Europe continued to leverage social media platforms to raise awareness about aniridia. Engaging content, including

personal stories, informational graphics, and updates on research, reached a broad audience, fostering understanding and empathy. Many videos and recordings were made available on the YouTube channel.

d. Participation in meetings

Aniridia Europe participated online or in place at all the relevant events, such as:

- ✓ **EURORDIS General Assemblies**
- ✓ meetings of the **Eurordis Council of Federations**
- ✓ participation **at the Brussels Rare Disease Week 2023**
- ✓ meetings of the Eurordis **e-PAG** (European Patient Advisory Groups) **at the ERN-EYE** (European Reference Network for Eye Rare Diseases)
- ✓ **Erasmus+ Educational Project "Seeing the Invisible"**
- ✓ meetings of **Cost Action Aniridia-Net**.
- ✓ meetings of the **Restore Vision Project**
- ✓ participation in **EPOS Congress** in Munich, 8-9 October 2022
- ✓ **Erasmus+ Project "Together for Inclusion"**
- ✓ participation in the **WAGR Weekend** in Overpelt, Belgium, July 2023

e. International Aniridia Day

Aniridia Europe organised and promoted International Aniridia Day on June 21 each year. The awareness campaign garners significant attention through online events, webinars, and collaboration with partner organisations. It highlights the challenges those living with aniridia face and advocates for improved support and resources.

On the evening of Tuesday, 21st June 2023, we broadcast some videos on our channels:

- ✓ ***An international greeting*** - people connected from all over the world: Europe, North and South America, Asia, and Africa. The greetings are in many languages: English, Chinese, Arabic, French, Spanish, and Malayalam.

- ✓ **The Aniridia-Net Journey** - an interview with Prof. Neil Lagali (Linköping University, Sweden) and Dr Stefano Ferrari (Veneto Eye Bank Foundation, Italy) about the COST Action Aniridia-Net, a networking project aimed at improving aniridia clinical management and promoting innovative research and development of new alternatives for its diagnosis and treatment. The project's final meeting was in Venice (Italy) on 29th-30th June 2023, and it was a good time to report on its outcomes.
<https://www.youtube.com/watch?v=aXtn5rnjG0>

Aniridia Day, June 21, 2024, has been marked by the Motto: **We can do it together!**

- ✓ Flyer is created for this purpose.
- ✓ It was translated into several languages.

f. Aniridia-Net calendars

The 2023 and 2024 Aniridia calendars were created with the support of the COST Action Aniridia-Net, funded by the European Union. The calendars displayed beautiful and touching pictures of aniridia children from all over the world. The photographs were gathered thanks to the aniridia families worldwide who participated in the competition launched on Aniridia Day. The beautiful 2024 calendar conveys the message, "Working together to build a brighter future for aniridia patients," which describes the main objective of the COST Action Aniridia-Net. It was disseminated to the participants of the 7th EAC in Stockholm. The aim was to raise awareness of the condition and show how beautiful, strong, joyful, and resilient our kids can celebrate life despite their challenges.

g. Comic book

It is a COST Action Aniridia-Net Project. The comic book "Aniridia - a journey to a brighter future" was created by WG3. The aim is to provide information about Aniridia in a fun and easy-to-understand way. It is a beautiful product for children and parents with aniridia. It has been translated into over ten languages and is available for download in all languages at aniridia-net.eu. Aniridia Sweden disseminated the printed version to the participants of the 7th EAC in Stockholm.

4. Scientific Committee and scientific activities

a. Aniridia Europe's Scientific Committee

Most of its members have continued to cooperate very intensely, especially concerning the activities of the COST Action Aniridia-Net, Restore Vision project, and the organisation of the 7th European Aniridia Conference. They also support Aniridia Europe in organising a series of webinars.

b. Scientific webinars and interviews

Thanks to the support of a grant by EURORDIS for digital development, Aniridia Europe organised a series of webinars and interviews targeted to professionals and patients. Most of them were performed in partnership with the COST Action Aniridia-Net:

- ✓ ***COST Action 2018-2023:***
 - *Interview with Prof. Thomas Ritter*
 - *Interview with Prof. Dominique Brémond-Gignac*
 - *Interview with Prof. Elizabeth Simpson*
 - *interview with Prof. Francisco Figueiredo*
 - *Interview with Prof. Ken Nischal*

- ✓ ***The Restore Vision Project***
 - *webinar with Prof. Thomas Ritter, Prof. Giulio Ferrari, and Barbara Poli – **March 21st, 2024: Advancing treatments for rare eye diseases***
 - *Interviews with the work package leaders during the Restore Vision Consortium meeting in Stockholm on **3rd June 2024.***
 - *Interview with Prof. Thomas Ritter*
 - *Interview with Prof. Giulio Ferrari*
 - *Interview with Prof. Claus Cursiefen*
 - *Interview with Prof. Neil Lagali*

Other webinars were organised on different topics:

- ✓ ***"Seeing the Invisible"***
 - *webinar - **February 2024.** The final meeting of the RedTree project, "Seeing the Invisible," was held successfully with more than 50 participants.*

All recordings are available at:
<https://www.youtube.com/user/AniridiaEurope>

5. Social and research projects

Aniridia Europe is a partner in various European projects:

a. Cost Action CA18116 Aniridia-Net - Aniridia: networking to address an unmet medical, scientific, and societal challenge.

Aniridia-Net is a pan-European network funded by the European Cooperation in Science and Technology (COST) program. Its goal is to improve aniridia clinical management, promote innovative research, and develop new alternatives for its diagnosis and treatment. www.aniridia-net.eu

✓ European consensus document

This is a Clinical Consensus Statement about Aniridia prepared by 13 European experts. It includes clinical questions and answers.

✓ Patient-driven research

The working group in this project is dedicated to addressing not only the medical aspects but also the social aspects of living with aniridia. The last survey was a testament to our commitment, involving a diverse group of almost 300 patients with aniridia from various European countries. The results were presented during the 7th European Conference on Aniridia in Stockholm (Sweden) from 31 May to 2 June 2024.

✓ Experimental treatments for congenital aniridia-associated keratopathy

A project granted by the EU is conducted by a consortium of researchers from several countries, led by Prof. Neil Lagali (Linköping University, Sweden) and Prof. Daniel Aberdam (CNRS, Biologie, Inserm-Technion, France). The project aims to evaluate promising pharmacological and gene therapy/microRNA approaches for treatment in cells and transgenic mouse models to assess their potential for treating this rare sight-threatening disease. Aniridia Europe is on the Patient Advisory Board of the project, as well as our member associations Gênis, Aniridi Sverige and Asociación Española de Aniridia.

b. The Erasmus+ Program, RedTree Project “Seeing the invisible”: inclusive digitalisation of students with low vision in school education

It generated digital and adapted tools to enable students with low vision in primary school to achieve full inclusion in the classroom and educational success, regardless of whether their teaching is on-site or online. The project’s App is handy for children with aniridia and albinism at school for different subjects. It offers the teachers everything they need, regardless of whether teaching is face-to-face or virtual.

The final meeting of the RedTree project was held successfully, with more than 50 participants. RedTree has a three-year commitment to the project's output.

c. The Erasmus+ Project “Together for Inclusion”: Young people with low vision for active participation, awareness and associationism worldwide.

This project aims to train young people with low vision to lead the creation and management of associations in European and Latin American society. The project leaders are ALBA, the Spanish Association for Albinism, and RedTree, the agency developing the project. Other partners are Aniridia Italy, Aniridia Europe, and two South American organisations of people with albinism from Chile and Argentina.

Two multiplier events were held in Stockholm: one with the EALA participants on 31st May and one with the Nordic Meeting participants on 1st June 2024.

<https://www.aniridia.eu/2024/06/12/multiplier-events-of-the-erasmus-project-together-for-inclusion-held-in-stockholm-on-31-may-and-1-june-2024/>

d. Horizon Europe – (2021-2027), Restore Vision Project (2023-2027)

EU research and innovation funding program with a budget of €95.5 billion. The most ambitious program ever implemented is to address the ills of society. “**Restore Vision**” is the biggest project ever funded to develop and test new treatments and drugs for seven Rare Eye Diseases, one of which is aniridia. The total available amount is € 8 million. The project combines expertise from six research institutions in Ireland, Sweden, Italy, Spain, France, and Germany, plus three companies and Aniridia Europe, a patient organisation. It will last for four years.

Aniridia Europe is an active partner in the application process for other pending projects in scientific research and the social field.

6. EAC – European Aniridia Conference

a. **The 7th EAC** was held as a face-to-face event in Stockholm from 31st May to 2nd June 2024. The local association Aniridia Sweden organised the conference as a high-quality event. The scientific quality was judged very high, and many opportunities have been established for future and fruitful collaborations among professionals and patient representatives. Aniridia Europe supported Aniridia Sweden as much as possible in fundraising initiatives and promoting the event. The conference had significant participation by professionals and patients.

All the recordings are available at: <https://aniridiaconference.org/eac2024/>

b. In the conference framework, Aniridia Europe has held **the European Aniridia Leadership Academy (EALA)** in English for young European diagnosis carriers. These activities are part of the Erasmus+ Program, RedTree Project **“Together for Inclusion”**: Young people with low vision for active participation, awareness and associationism worldwide.

c. Parallel to the European Aniridia Conference, **a Nordic Aniridia Meeting** (Nordiskt möte) was held in Scandinavian languages for diagnosis carriers, their families, and others interested in aniridia and its related conditions. This meeting was for members of the Nordic aniridia associations only.

d. Meeting of AE Board members with Aniridia North America (ANA) representatives, to discuss the Registry (Questionnaire) they have created to be launched on Aniridia Day 2024. As a collaborative effort, AE decided to inform the aniridia community about this study's existence, the Registry's purpose, and how and what data will be used. The registry will foster a better understanding of all aspects of the disease, which is critical for improving care in the future.

e. The website for the European Aniridia Conferences provides the program and registration tools for any current conference while keeping relevant information about past conferences. The website remains silent between conferences and will be given to the following conference organisers in due time. The conference's social channels and official logo for all future EACs are the same.

Participation in the conference and networking meetings was partially supported by a Eurordis grant.

7. Fees, sponsorships and donations

Aniridia Europe's financial resources come from various people and institutions.

- The full membership fee was kept to 30 euros per year; affiliated membership has no compulsory fee. Both full and affiliated members can decide to add a donation according to their possibilities, as some did.
- Sponsorships, grants, and donations were made by RedTree Making projects, EURORDIS, COST Aniridia Net, Restore Vision project, Facebook, PayPal, and individual contributions.
- Support was also given by individuals who covered their costs while participating as representatives in meetings.
- Figures are detailed in the Financial Report.

8. Partnerships

Since its beginning, Aniridia Europe has always considered it essential to develop strategic partnerships with the relevant players in rare diseases, specifically aniridia.

Through well-established relationships with Eurordis, the umbrella organisation for European rare diseases associations, Aniridia Europe could get some grants to develop its networking and digital activities.

In the same framework, Aniridia Europe had a representative as an e-PAG (European Patient Advisory Group) at the **ERN-EYE** (European Reference Network for the Eye Rare Diseases): Ms. Rosa Sánchez de Vega from the beginning of 2022 to the end of 2023, when she decided to resign. The AE Board selected Oana Simerea as a representative to submit a new application for the role of an e-PAG. AE is waiting for ERN-EYE to approve her application.

The partnership with the **Cost Action CA18116 Aniridia-Net - Aniridia: networking to address an unmet medical, scientific, and societal challenge** - allows Aniridia Europe's Board members to participate in the working groups on clinical guidelines and patient-driven research.

Establishing relevant relationships with hospitals, research centres, and individual professionals is fundamental to our ability to organise the European Aniridia Conferences and become partners in research projects. This allows us to address the patient's needs and expertise and advocate for and create awareness of our condition.

A unique and essential partnership concerns the other aniridia organisations worldwide.

Aniridia Europe has a relationship with **ANA** (Aniridia North America), created in late 2021. There are possibilities of cooperating in many areas and promoting aniridia research, which has already started.

Also, AE has a relationship with **IWSA** (International WAGR Syndrome Association), a collaboration that assembles researchers, practitioners, and patients.

9. Conclusion

From awareness campaigns to advocacy efforts and research initiatives, Aniridia Europe has been dedicated to improving the lives of individuals affected by aniridia. The organisation strives to create a more supportive and inclusive environment for those with this rare eye condition through collaboration, education, and empowerment.

This report highlights Aniridia Europe's and its partners' collective efforts to work towards a brighter future for individuals and families impacted by aniridia.

The AE Board of Directors:

1. Barbara Poli, President
2. Galina Gening, Vice President
3. Tord Håkonsen, Treasurer
4. Elena Tsoneva, Secretary
5. Katie Atkinson
6. Irma Byle
7. Ivana Kildsgaard
8. Marjorie Poeydomenge
9. Denice Toews

8th June 2024