



ANIRIDIA EUROPE

**Activity report 2020-2022**

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## 1. The Board of Directors

During the mandate 2020-2022 the Board of Directors is composed by:

<b>Member</b>	<b>Initials</b>	<b>Country</b>
Barbara Poli, President	BP	Italy
Ognian Petkov, Vice president	OP	Bulgaria
Sanna Söderlund, Secretary	SS	Finland
Tord Håkonsen, Treasurer	TH	Norway
<b>Other Board Members:</b>		
Katie Atkinson	KA	UK
Galina Gening	GG	Russia
Ivana Kildsgaard	IK	Sweden
Marjorie Poeydomenge	MP	France
Rosa Sánchez de Vega	RSV	Spain

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

2020: September 1<sup>st</sup>, October 10<sup>th</sup>

2021: January 20<sup>th</sup>, March 28<sup>th</sup>, May 8<sup>th</sup>, June 8<sup>th</sup>, September 21<sup>th</sup>, December 14<sup>th</sup>

2022: January 24<sup>th</sup>, March 7<sup>th</sup>, May 3<sup>rd</sup>, 14<sup>th</sup> June

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## 2. Status of the representatives

In summer 2022 the federation includes:

- 14 associations as full members: Bulgaria, Denmark, Finland, France, Germany, Italy, Lithuania, Norway, Romania, Russia, Spain, Sweden, United Kingdom and Ukraine
- individuals as affiliated members or contact persons in Belgium, Croatia, Czechia, Estonia, Georgia, Greece, Hungary, Iceland, Ireland, Israel, Kazakhstan, Latvia, Moldova, the Netherlands, Poland, Portugal, Serbia, Switzerland and Turkey.

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## 3. Communication and awareness

**a. Website** – the website was completely renewed and made compliant with the GDPR provisions, and constantly updated with the information about events and relevant scientific information about aniridia.

**b. Newsletter** - an e-newsletter was published every six months, July 2020, January 2021, July 2021 and January 2022, with Aniridia Europe's activities, as well as those carried out by the National Aniridia Associations. On Rare Disease Day, 28<sup>th</sup> February 2022, a newsletter with updates on the scientific literature about aniridia was sent to the network of doctors and to the members. A new advanced tool for newsletters was adopted and integrated with the new website.

**c. Social networks** – A digital team composed by young volunteers began working in 2020 and gave a great support to the Board in starting to develop an overall communication strategy for Aniridia Europe and in producing contents. Apart the already existing Aniridia Europe's Facebook page and Twitter profile, a LinkedIn profile and an Instagram page were created. The communication through these channels was reorganized and integrated with the use of advanced digital tools. All this was facilitated by a Eurordis grant focused on digital development, that allowed to buy IT equipment and tools. Many videos and recordings were made available on the YouTube channel.

**d. Participation to meetings** - Since 2020 it has not been possible to distribute informational brochures and flyers because most events were cancelled or performed only online; nonetheless, Aniridia Europe participated online to all the relevant events, such as:

- **Eurordis General Assemblies**
- meetings of the **Eurordis Council of Federations**
- meetings of the Eurordis **e-PAG** (European Patient Advisory Groups) **at the ERN-EYE** (European Reference Network for the eye rare diseases)
- **Erasmus+ “A school for all”** educational project: Aniridia Europe has participated to all the meetings and has organised the final online multiplier event, contributing to the successful conclusion of the project
- meetings of **Cost Action Aniridia-Net**.

**e. Aniridia Day** - The international Aniridia Day is a great opportunity to raise awareness on our rare condition, to share information and experiences, and to improve social inclusion and quality of life for people with aniridia. On 20<sup>th</sup> and 21<sup>st</sup> June 2021 Aniridia Europe organised two webinars:

- *Breaking Barriers with Aniridia*, focused on learning how to move past barriers, how to think “outside the box” and use perseverance and creativity to achieve objectives. This activity was matched with the video *Breaking Barriers – Aniridia Day 2021* (<https://www.youtube.com/watch?v=KYb-9pPEXnk>), created in collaboration with the young American influencer Brooke Kuehl, to share our vision on how people break down barriers in their life

- *Managing aniridia: dos and don'ts from infancy to adulthood*, organised in collaboration with the COST Action Aniridia-Net and with the speakers Prof. Dominique Brémond Gignac and Prof. Barbara Käsmann-Kellner

On Aniridia Day 2022 Aniridia Europe promoted the meeting *#AniridiaDay Global Connection*, a round table that gathered for the first time aniridia representatives from Asia, Africa, Europe, North and South America.

**f. Aniridia-Net calendars** – Thanks to the support of the COST Action Aniridia-Net, funded by the European Union, it was possible to create the 2021 and 2022 Aniridia calendars.

The calendar 2021 displayed the beautiful and touching drawings created by aniridia children from all over the world.

The following year, the photographs gathered thanks to the aniridia families around the world that participated to the competition launched on Aniridia Day

2021 by Aniridia Europe were used to create a beautiful calendar for 2022 to convey the message: “Working together to build a brighter future for aniridia patients”, that describes the main objective of the COST Action Aniridia-Net. In both cases, the aim was to create awareness on the condition and at the same time to show how beautiful, strong, joyful and resilient our kids can be in celebrating life in spite of all the challenges they face.

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#### **4. Fees, sponsorships and donations**

Aniridia Europe’s financial resources come from various persons and institutions.

- The full membership fee was kept to 30 euros per year, affiliated membership does not have any compulsory fee. Both full and affiliated members can decide to add a donation according to their possibilities, as some did;
- There were sponsorships, grants and donations by Redtree Making Projects, Eurordis, Facebook, PayPal and individuals donations.
- Support was also given by individuals that covered their own costs while participating as representatives in meetings.
- Figures are detailed in the Financial Report.

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#### **5. Scientific Committee and scientific activities**

**a. Aniridia Europe's Scientific Committee** - it could not meet face-to-face during these years, but most of its members have continued to cooperate in a very intense manner, especially in relation with the activities of the COST Action Aniridia-Net and with the organisation of the 5<sup>th</sup> and 6<sup>th</sup> *European Conference on Aniridia*, as well as supporting Aniridia Europe in the organisation of a series of webinars since February 2021.

**b. Aniridia Europe Research Award** - launched in 2020, it awarded three research projects.

Unfortunately, all projects were delayed by the limitations due to the pandemic. The preliminary results of the project: *A cross-border study on the functional consequences of PAX6 missense mutation. A collaborative study between Russia and Italy*, by Dr. Tatyana Vasilyeva (Moscow, Russia) and Prof. Giuseppe Damante (Udine, Italy), were presented during the 6<sup>th</sup> *European Conference on Aniridia*, in Alicante (Spain) 3-5 June 2022.

The other projects (*A retrospective register study of keratoplasty outcomes in aniridia from across Europe*, by Dr. Mor Dickman, Maastricht, and *A questionnaire about the ocular surface in aniridia in European countries*, by Dr Alejandra Daruich, Paris) are still suspended.

For this reason, it was decided not to launch a second edition of the award, in the perspective of launching it again whenever possible.

**c. Scientific webinars** - since February 2021, thanks to the support of a grant by Eurordis for the digital development, Aniridia Europe organised a series of webinars targeted to professionals and/or patients.

Most of them were performed in partnership with the COST Action Aniridia-Net:

- *News from the frontier: a dialogue on Aniridia-Net COST Action to improve aniridia clinical management and promote innovative research*, 27-02-2021

- *Eyes open on stem cells: dynamics, signatures and niche*, 26-05-2021

- *Managing aniridia: dos and don'ts from infancy to adulthood*, 01-06-2021

- *A fresh look to aniridia pathophysiology with a focus on translational implications*, 22-10-2021

- *Regulatory Framework on Orphan Medicinal Products for Rare Diseases*, 20-05-2022

Other webinars were organised on different topics:

- *Digital rebels against distance*, about how to break the distance caused by the pandemic through the smart use of the digital media, 24-04-2021

- *The digital therapeutics value*, about the home measurement of the intraocular pressure, 26-04-2022

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

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## **6. Social and research projects**

Aniridia Europe is a partner in various European projects:

**a. The Erasmus+ project “Looking out for a school for all”: early educational inclusion for students with low vision** was successfully concluded in 2021, with the release of two intellectual outputs: the *Virtual training course for nursery school teachers* and the application VISAPP, an ICT tool for the educational inclusion of low vision students. Information at: <http://www.schoolforall.eu/>

**b. The Erasmus+ project “Seeing the invisible”: inclusive digitalization of students with low vision in school education** was accepted and funded at the beginning of 2022. Its purpose is to generate digital and adapted tools to enable students with low vision in the primary school to achieve full inclusion in the classroom and educational success, regardless of whether their teaching is on-site or online.

The partners are: Alba, the Spanish association for albinism, Aniridia Europe, Aniridi Norge, Aniridia Italiana, SmallCodes, an Italian company specialized in developing digital environments, and Greta du Velay, a French centre for the life-long learning. The kick-off meeting was held on 16<sup>th</sup> May 2022 in Valencia (Spain).

**c. Cost Action CA18116 Aniridia-Net - Aniridia: networking to address an unmet medical, scientific, and societal challenge.** ANIRIDIA-NET is a pan-European network of researchers, ophthalmologists, trainees, aniridia patient

organizations, industry and special interest groups. It is funded by the European Cooperation in Science and Technology (COST) program, a EU funding agency for research and innovation networks that encourages communication and research collaboration. [www.aniridia-net.eu](http://www.aniridia-net.eu)

**d. Aniridia – novel therapeutic tools to treat or prevent progressive corneal opacification (AAK-INSIGHT)**, 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).

It will last until 2024 and will have a budget of 1.4 million Euro. Its overall objective is to find a drug able to induce the production of PAX6 protein in the eye and cornea; the drug will be tested in cells and eye models of aniridia. Aniridia Europe will be in the Patient Advisory Board of the project, as well as our member associations Gêneris, Aniridi Sverige and Asociación Española de Aniridia.

**e.** Aniridia Europe is an active partner in the application for other projects both in the scientific research and social field, that are currently pending.

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## **7. EAC – European Aniridia Conference**

a. The 5<sup>th</sup> EAC was planned in London in 2020 but due to the pandemic it had to be postponed to 31<sup>st</sup> July - 1<sup>st</sup> August 2021, and it was held completely online. The conference was organised by the local association Aniridia Network, that made a great effort to offer a high quality event in spite of all the challenges. Aniridia Europe supported Aniridia Network as much as possible in fundraising initiatives and in promoting the event. The conference had a great participation by professionals and patients, and the talks were of a very high scientific level. All the recordings are available at: <https://aniridiaconference.org/eac2021/>

b. After the 5<sup>th</sup> EAC, a new website for the European Aniridia Conferences was created, with the purposes of providing the programme and the registration tools for the current conference, while keeping the relevant information about the past conferences. The website will remain silent in-between the conferences, and will be given to the next conference organisers in due time. Social channels dedicated to the conference were also created, and the logo developed for the 5<sup>th</sup> EAC was acquired as the official logo of all EACs for the future. These achievements were made possible thanks to the great support of Aniridia Network and Aniridi Norge. See at: <https://aniridiaconference.org/>

c. The 6<sup>th</sup> EAC was held in Alicante (Spain) from 3<sup>rd</sup> to 5<sup>th</sup> June and was organised by the Spanish association (Asociación Española Aniridia) as a face-to-face event, which proved to be a great opportunity to have talks and meetings in addition to the programme. The scientific quality was judged very high and

many opportunities have been established for future and fruitful collaborations among professionals and with the patient representatives.

See at: <https://aniridiaconference.org/eac2022/>

On Friday 3<sup>rd</sup> June 2022, in the framework of the conference, Aniridia Europe held the Networking Meeting of AE members, with the participation of ANA (Aniridia North America) representatives; in the first part of the meeting, all participants described the situation in their respective countries, their challenges, activities, and plans/ambitions, while Aniridia Europe's President talked about AE activities and ongoing projects.

The second part of the meeting was a workshop on the topic: *The power of patient driven research - how do we join forces to give the best support to research, in terms of input to ongoing projects, filling in the gaps and identifying new areas where research is needed?*

The participation to the conference and to the networking meeting was partially supported by a Eurordis grant.

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## 8. Partnerships

Since its very beginning, Aniridia Europe has always considered very important to develop strategic partnerships with the relevant players in the field of rare diseases and specifically aniridia.

Through the well established relationships with **Eurordis**, the umbrella organization for rare diseases associations in Europe, Aniridia Europe could get some grants for developing its networking and digital activities.

In the same framework, Aniridia Europe has elected a representative as **e-PAG** (European Patient Advisory Groups) at the **ERN-EYE** (European Reference Network for the eye rare diseases), Ms. Gaëlle Jouanjan until the end of 2021, followed by Ms. Rosa Sánchez de Vega since the beginning of 2022.

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

The establishment of relevant relationships with hospitals, research centres and individual professionals is fundamental to give us the possibility to organise the European Aniridia Conferences, as well as to become a partner in research projects, where we have the opportunity to bring the patients' needs and expertise in order to advocate and create awareness on our condition.

Recently, Aniridia Europe was invited to participate to an organ composed by patient representatives, provisionally called **CLEO: Council of Lived Experience in Ophthalmology**, established by the EU-EYE (European Alliance for Vision Research and Ophthalmology).



A special and very important partnership concerns the other aniridia organisations all over the world. This is why Aniridia Europe has warmly welcomed the creation of **ANA - Aniridia North America**, in late 2021. Talks about the possibility to cooperate in many areas and to promote aniridia research have already started.

**The Board of Directors**

Barbara Poli, President  
Ognian Petkov, Vice president  
Sanna Söderlund, Secretary  
Tord Håkonsen, Treasurer  
Katie Atkinson  
Galina Gening  
Ivana Kildsgaard  
Marjorie Poeydomenge  
Rosa Sánchez de Vega

Sandefjord (Norway), 25<sup>th</sup> June 2022