



ANIRIDIA EUROPE

Activity report 2018-2020

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1. The Board of Directors

During 2018-2020 the Board of Directors is composed by:

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

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

2018: October 17th, December 17th

2019: February 13th, April 22nd, June 25th, September 13th (Paris), November 13th

2020: January 29th, April 29th, June 10th.

2. Status of the representatives

In summer 2020 the federation includes:

- 13 associations as full members: Bulgaria, Denmark, Finland, France, Germany, Italy, Lithuania, Norway, Russia, Spain, Sweden, Ukraine and Aniridia Network (United Kingdom and Ireland).
- Affiliated members and reference persons in Belgium, Belarus, Croatia, Czechia, Estonia, Georgia, Greece, Hungary, Iceland, Israel, Kazakhstan, Latvia, Malta, Moldova, the Netherlands, Poland, Portugal, Romania, Serbia, Switzerland and Turkey. Contacts with people with Aniridia from Asia and Latin America have also been made to support them create an association in their country.

3. Communication and public awareness:

- **Website:** the website was used as a platform for updating the information about the upcoming events, AE member changes and recent scientific articles.
- **E- newsletter** was published every six months, January 2019, June 2019 and January 2020, with Aniridia Europe's activities, as well as those carried out by the National Aniridia Associations.
- **Informational events. Brochures and flyers** were distributed on several events:
Eurordis GA 2019, Bucharest, Romania, represented by Oana Simerea.
Eurordis GA and ECRD 2020 online. represented by Barbara Poli and Ivana Kildsgaard, who presented a poster on Cost Action Aniridia-Net
EPOS 2019 in Rigga, Latvia, May 31-June 1st, represented by Henrihs Kigelis.
ESCRS, European Society for Cataract and Refractive Surgery 2019
Nordic Aniridia Conference, Oslo, Norway, June 7-9th 2019.

European projects meetings: Erasmus+ and Cost Action Aniridia-Net.

- **Social networks** – Aniridia Europe has been very active on facebook and other digital media, posting events, meetings and research projects. The AE board used both e-mails and Hangouts for its internal communication and meetings.
- **Aniridia Day** on 21 June 2019 and 2020 - The international Aniridia Day was a great opportunity to raise awareness on our rare condition, In 2019 videos and photos were collected to show what can be done in job, hobby, sport or education – while living with aniridia: #CanDoWithAniridia or #AniridiaDay, to improve social inclusion and quality of life for people with aniridia. More information at <https://aniridiaday.org/>

4. Fees, sponsorships and donations

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

- The full membership fee was kept minimum 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 and donations from PTC Therapeutics International, Redtree Making Projects, Eurordis, Facebook, PayPal and individuals. Some of these funds were allocated to support Pr. Julie Daniels' research project at Moorfields Hospital in London;
- A support was also given by individuals that, while participating as representatives in meetings, covered their own costs as the organization did not have enough funds. Figures are detailed in the Financial Report.
- The Christmas card campaign - based on Aniridia Network association, to raise funds for the European Aniridia Conference in London 2020 (that has finally been postponed to 2021 due to the Covid-19 emergency), with e-cards for Christmas. The cards were designed by children from around the world who have aniridia.

5. Scientific committee

Aniridia Europe Scientific Committee met in Paris, the day before the European Conference, August 21st 2018, The SC is composed by: Dominique Brémond-Gignac (France) – chairperson, Dr. Juan Alvarez de Toledo (Spain), Dr. Jon Martin Collinson (UK), Dr. Henri Copin (France), Dr. Marta Cortón, PhD (Spain), Dr. Julie Daniels (UK), Dr. Barbara Käsmann-Kellner (Germany), Dr. Neil Lagali (Sweden), Dr. Giorgio Marchini (Italy), Dr. Valeri Pavlenko (Russia), Dr. Paolo Rama, MD (Italy), Dr. Draga Toncheva (Bulgaria), Dr. Tor Paaske Utheim (Norway), Dr. Tatyana Vasilyeva (Russia), Dr. Arne Viestenz (Germany)

Committees on specific topics will be created: keratopathy, clinical management and genetics, among others.

Aniridia Europe Research Award. AE has launched the 1st *Aniridia Europe Research Award 2020*, funded by PTC and AE funds, that will be officially provided in the frame of the next European Aniridia Conference in 2021.

6. Research projects

Aniridia Europe is a partner in two European projects:

a) Erasmus+ project Looking out for a school for all: early educational inclusion for students with low vision. The project is focused on early educational inclusion for visually impaired children. It involves 6 partners from 3 different European countries. It is led by RedTree, a Spanish organisation that has a long experience in working with associations of people with visual impairment. The other partners are: Alba, the Spanish association for albinism, Aniridia Europe, Aniridi Norge, Aniridia Italiana and SmallCodes, an Italian company specialized in developing digital environments. There have been three meetings: Valencia (Spain) in March 2019, Sandefjord (Norway) in September 2019 and Florence (Italy) in February 2020. More information at: <http://www.redtree.es/projects/ka2-2018/>

b) 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 funded by the European Cooperation in Science and Technology (COST) program, a funding agency for research and innovation networks that encourages communication and research collaboration. There have been 3 meetings: MC Brussels in 2019, Paris 12th-13th September 2019 and Lisbon February 2020. More information at: <https://aniridia-net.eu/>

7. Conferences and member associations' activities, where Aniridia Europe was also represented by a board member:

a. 4th European Aniridia Conference August 24-26th 2018, France, Paris

The 4th European Conference on Aniridia, gathering more than 70 professionals and more than 130 patients, was a great opportunity to bring together experts in aniridia and people with aniridia. It contributed to strengthen the links between professionals and to push forward aniridia research. Aniridia Europe supported the conference with seed funds, grants for doctors and patients to attend the conference.

More information at: <http://2018.aniridiaconference.org/>

b. Symposium on rare eye diseases and on aniridia, Venice (Italy), February 21th, 2019
A symposium focused on the rare diseases of the ocular surface and on aniridia, in the framework of the 23rd National Congress of the Italian Society of Cornea Transplant and Ocular Surface (S.I.T.R.A.C.). The symposium was organised in collaboration with the Veneto Eye Bank, Aniridia Europe and Aniridia Italy. Pr Dominique Brémond-Gignac, chair of AE Scientific Committee, hold the introductory speech. Barbara Poli, AE Vicepresident, spoke about the role of patients' associations in research and care issues. More information at: <https://www.aniridia.eu/2019/02/28/symposium-on-rare-eye-diseases-and-on-aniridia-venice-italy-february-21th-2019/>

c. **Aniridia Centre opened in Moscow, Russia, February 2019** - A centre of expertise is now available for aniridia patients in Moscow, Russia, at the National Medical Research Center for Children's Health (an autonomous institution of the Ministry of Health of the Russian Federation), where patients receive care, not only from an ophthalmologist, but also from endocrinologist, neurologist, orthopedic, neuropsychologist, special needs specialist, pediatrician, nephrologist and ENT doctor. More information at:

<https://www.aniridia.eu/2019/04/10/aniridia-centre-opened-in-moscow-russia-february-2019/>

d. **Aniridia in the Bulgarian Ophthalmology Conference**, November 23-25th, 2018.

The conference "Novelties in Ophthalmology 2018" was held in Riu Pravets, Bulgaria, on November 23-25th, 2018.

More information at: <https://www.aniridia.eu/2018/11/28/aniridia-in-the-bulgarian-ophthalmology-conference-november-23-25th-2018/>

e. **Nordic Aniridia Conference**, 7-9 June 2019 in Hurdal near Oslo, Norway

More information at: <https://www.aniridia.eu/2019/05/25/nordic-aniridia-conference-7-9-june-2019-in-hurdal-near-oslo-norway/>

f. **Aniridia Scientific Meeting at the 95th Congress of the Spanish Ophthalmology Society**.

September 2019. Madrid. Four round tables about genetics, glaucoma; ocular surface and low vision: in Aniridia. <https://www.aniridia.eu/2019/09/30/95th-congress-of-the-spanish-ophthalmology-society-seo-madrid-25-28-september-2019/>

<https://www.aniridia.eu/2019/09/30/95th-congress-of-the-spanish-ophthalmology-society-seo-madrid-25-28-september-2019/>

g. **Aniridia Network Conference**, 1 June 2019 in Birmingham, UK

More information at: <https://www.aniridia.eu/2019/05/25/aniridia-network-conference-1-june-2019-in-birmingham-uk/>

The Board of Directors

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