



ANIRIDIA EUROPE

ACTIVITY REPORT 2016-2018

According to the goals and priorities set in our Action Plan 2016-2018, Aniridia Europe AE took the following actions, over the last two years.

1. To support and empower our members (national organisations and individuals with aniridia) wherever they live, increase our membership and promote patients' networks, to grow as an umbrella organization

Networking: Aniridia Europe has had a very active participation on digital media (in different Facebook groups, Twitter, Instagram, Whatsapp groups, that provided us the chance to contact people with aniridia from countries beyond Europe, like Iran, Egypt, Dubai, Ethiopia, Philippines, India, Israel, Turkey and Latin-American countries.

Membership. AE has increased its membership with two new full members and many affiliated members: 12 national associations as full members in Bulgaria, Denmark, Finland, France, Germany, Italy, Norway, Russia, Spain, Sweden, UK-Ireland, Ukraine and a support group in Belgium. AE has currently affiliated members or representatives in Belarus, Czech Republic, Croatia, Estonia, Georgia, Greece, Hungary, Iceland, Kazakhstan, Latvia, Lithuania, Malta, Moldova, the Netherlands, Poland, Portugal, Romania, Serbia and Switzerland (see: <http://www.aniridia.eu/in-your-country/>).

Support and empowerment: AE participated in some events of our National Associations, like **Aniridi Denmark General Assembly** in April 2017 with an online presentation: *How can Aniridia Europe support you?* And also at **the Irish group of Aniridia Network meeting**, on April 2017, both represented by Rosa Sánchez de Vega, President of AE.

Individuals with aniridia from countries where there is no association, were also supported, physically, for ex. by Galina Gening in Greece, or online, to inquirers on AE website. Galina Gening, AE board member, also participated in **Aniridia Network UK Conference**, organised by Aniridia Network, that on April 2018 in London.

2. To promote research

Scientific Committee meetings. AE participated in the different online meetings of AE Scientific Committee over the last two years, providing administrative & technical support, represented by Ivana Kildsgaard, Board member and Rosa Sánchez de Vega, President. The Scientific Committee will meet presentially in Paris, August 24th, the day before the 4th European Aniridia Conference.

Letters of support were sent to different research projects, developed by Prof. Julie Daniels or Prof. Neil Lagali, upon request. We hope some of them will succeed to be funded by the EU and then, can be carried out in the near future.

3rd European Conference on Aniridia. Duisburg, Germany, August 26-28th 2016, organised by the German Aniridia Association, AWS-Aniridie WAGR e.V, together with the University Klinik in Saarlands, led by Prof. Barbara Käsmann-Kellner. Professionals and researchers met to push forward knowledge and research on Aniridia. An Abstract Booklet with the presentations was also published and disseminated.

- **4th. European Aniridia Conference** will take place in Paris, August 25-26th 2018, organised by the French Aniridia Association, GENIRIS and OPHTARA (Reference Center for Rare Diseases in Ophthalmology, with the support of Aniridia Europe: financially, in the communication strategy and as advisor and link with the medical community in the world. AE provided more than 30 grants to support people with aniridia and their families, to attend the conference, with a particular focus on young people with aniridia.

A youth meeting will be organised for the young people the day before the conference, August 24th and a cultural/social event will take place on August 25th in the evening. This meeting will be coordinated by Prof. Semina (geneticist) and Galina Genning (psychologist), AE Board member.

3. External communication: To raise awareness & provide information about the disorder and the organisation

Aniridia Day 2017. Aniridia Europe celebrated Aniridia Day on June 21st 2017, for the first time ever. The Organising Committee proposed online actions, like: a Poetry Contest and a Shining Success campaign, that had a great impact on digital media. Friends and families joined people with wearing sunglasses and took pictures that were widely shared. An official video for the campaign was recorded and a website was developed for the day. See at: www.aniridiaday.org. Many National associations organised different activities that day, such as interviews, publications, meetings, info tables at hospitals, etc. Some well known sportsman/women and celebrities supported the campaign.

Aniridia Day 2018. There were Webinars online all over the day on topics related to aniridia by doctors and people with aniridia about different topics and in different languages. The presentations were recorded and will be posted on AniridiaDay website Youtube Channel. An online #AniridiaSight Campaign, was also developed, with descriptions about how a person with aniridia can see, compared to a person with normal visual acuity. Both activities were led by James Buller and Glen Turner from Aniridia Network.

An official video by Prof. Dominique Bremond-Gignac, AE Scientific Committee Chair, was shared online, in which she conveyed her congratulations and hopes for a better future for people with aniridia.

Activities at different hospitals were carried out by the different National aniridia associations.

Rare Disease Day, February 28th. National Aniridia Associations organised and participated in different events in their respective countries in 2017 and 2018, to celebrate Rare Disease Day, organised by EURORDIS. Aniridia Europe supported this campaign, sharing the message and logo on the digital media, as well as a message from Prof. Barbara Käsmann-Kellner, Chair of Aniridia Europe's Scientific Committee in 2017 about the slogan of the Day: *With Research, possibilities are limitless*, as well as from Prof. Dominique Bremond-Gignac in 2018, current Scientific Committee Chair, on the slogan of the Day *#ShowYouRare,showYouCare*.

Aniridia Europe website. It was rearranged and updated, fo facilitate the access to the content. Coming events as well as new scientific articles and publications were posted by Barbara Poli, Vice-President of Aniridia Europe and Espen Vangsness, member of Aniridi Norge.

Apart from scientific publications, new ones on Aniridia at School and Aniridia in Sport were posted. Please, see www.aniridia.eu

4. Advocacy and participation in events. To participate in meetings of umbrella organisations and professional conferences.

Umbrella Organisations:

EURORDIS. AE participated as EPAG (European Patient Advisory Groups) in the meetings of ERN-EYE (European Reference Network for Rare Eye Disorders), represented by Gaelle Jouanjan, President of Geniris, in Tübingen (Germany), Budapest (Hungary) and Vienna (Austria) as well as in EURORDIS General Assemblies in Budapest (Hungary) in 2017 and in Vienna (Austria) in 2018, where the European Conference on Rare Disoeases and Orphan Drugs also took place. AE also took part in EURORDIS webinars and training courses on data protection, ERN, clinical trials for small populations, RD registries, volunteering, social rights, etc.

Rare Diseases International RDI General Assembly , organised by EURORDIS, Barcelona June 4th 2017, represented by Rosa Sanches de Vega, President of AE, who participated together with the Spanish Rare Diseases Federation FEDER. In order to find people with aniridia, wherever they live, letters and information about aniridia and AE were delivered to the different National Blind Unions and Rare Disorders Organisations from different parts of the world.

Tifloinnova 2017. We also visited Tifloinnova 5.0 exhibition November 2017 in Madrid (Spain), organised by the Spanish Blind Organisation ONCE. where information about our organisation was disseminated to the exhibitors. This event brought together the top companies from all parts of the world, working in the last advances on low vision devices and apps, that could contribute to improve the quality of life of people with aniridia.

Participation in Professional & Scientific Congresses.

We were present at EPOS and ESA Congresses, at an information booth, together with Albinism Europe and provided information in different European professional conferences:

- **EPOS 2016** (European Paediatric Ophthalmological Society) meeting in Zurich, Switzerland. September 2016, represented by Ognian Petkov, AE Board member.
- **EPOS 2017** (European Paediatric Ophthalmological Society) in Oxford (UK) August 31st 2017, represented by James Buller, Aniridia Network Board member and Katie Atkinson, AE Board member.

- **ESA 2016** (European Strabismology Association) meeting in Budapest (Hungary) September, 2016, represented by Ognian Petkov, AE Board member.
- **ESA 2017** (European Strabismology Association) in Porto (Portugal) September 13-16th, Porto 2017, represented by Rosa Sánchez de Vega, President of AE.
- **ESCRS 2017**. Information was sent to be disseminated to the attendees at (European Society for Cataract and Refractive Surgery) in Lisbon (Portugal) 2017.
- **RARE Best Practices Conference** , Rome, Italy, November 2016, coordinated by the Italian Health Institute, represented by Barbara Poli, Vice-President of AE. A platform for sharing best practices for rare diseases management. It is also a EU project on guidelines and best practices.
- **Telethon Convention**, March 2017, represented by Barbara Poli, Vice-President of AE .TC is an organization for research in the field of congenital rare diseases and cooperates a lot with patient associations.
- **5th International Summer School on Rare Disease and Orphan Drug Registries**, Rome, Italy, September, 2017, represented by Barbara Poli, Vice-President of AE.
- **WOC 2018** (World Ophthalmology Congress), Barcelona June 2018. AE had the opportunity to be present at an information booth, together with the Spanish Aniridia Association, represented by Rosa Sánchez de Vega, President of AE.

As a result of our presence in all these professional congresses/meeting, AE has created a Scientific Network, with more than 400 professionals, who provided us their contact details.

5. Governance and Fundraising

Organisational issues:

Action Plan: AE new elected board in 2016, in its first meeting, approved a routemap for the next two years, with 5 strategic lines, with goals to be accomplished and responsables for the different established working groups.

Meetings: A schedule of board meetings every other month was adopted and put into practice, with a call for the meeting with an detailed agenda, that was sent to board members within the days stated in our Statutes.

Norwegian ID registration: A key issue was to get every ID board members registered at the Norwegian Administration, what is compulsory for NGOs, according to the laws in Norway, where we are officaly based.

Internal regulation for the Scientific Committee is developed to be more specific in the governance of the SC than what our Statutes states.

Fundraising activities: A data base with more than 150 companies, as potential sponsors, was developed by a volunteer, Edina Schmidt, with the support of Ognian

Petkov, AE board member. Letters were sent with information and calls were made to some of them as a follow-up.

As a result of this action, **PTC Therapeutics** got in contact with us and considered their financial support. They finally funded AE with a 5,000 € in 2017 and 6,000 € in 2018.

We were also granted by **Eurordis project Support to European Federations**, after sending our application with the plan of activities, 2,000 € in 2018. We were also granted in 2017 with 2.200 € for a Scientific Committee face-to-face meeting, but as it was not held, we lost the grant.

We also got funds from **Union Berlin Football Team** by crowd funding.

TAHNK YOU: All these activities could only be done, thanks to our PTC Therapeutics sponsorship and to all volunteers, not only from Aniridia Europe Board, but also from members of the different National Aniridia Associations, that “rowed in the same direction and worked as a team”. We also thank the professionals, members of our Scientific Committee, for their generous work in benefit of the aniridia community.