



ANIRIDIA EUROPE

Activity report 2014-2016

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1. The Board of Directors

During 2014-2016 the Board of Directors is composed by:

Member	Initials	Country
Asbjørn Akerlie, President	AA	Norway
Barbara Poli, vice president	BP	Italy
Ognian Petkov, secretary	OKP	Bulgaria
Denice Toews-Hennig, treasurer	DTH	Germany

Other Board Members:

Katherine Atkinson	KA	United Kingdom
Galina Gening	GG	Russia
Markku Latikka	ML	Finland
Marjorie Poyedomenge	MP	France
Rosa Sánchez de Vega	RSV	Spain

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

2014: November 26th;

2015: February 11th, June 25th, September 3rd; December 1st;

2016: January 27th, February 9th, March 4th, August 9th

The Board member Markku Latikka hasn't participated to any Board meeting, and resigned in summer 2015.

2. Status of the representatives

In summer 2016 the federation includes:

- 10 associations as full members (Bulgaria, Finland, France, Germany, Italy, Norway, Russia, Spain, Sweden and the UK);
- 8 reference persons as affiliated members (Belgium, Croatia, Denmark, Iceland, Greece, Poland, Portugal, Serbia, Switzerland);
- Contacts with patients in Hungary, Kazakhstan, Lithuania, Malta, Moldova, the Netherlands, Romania, Ukraine and Turkey.

3. Communication

- a. Website – the website was used as a platform for updating the information according the upcoming events and AE member changes.
- b. Informational brochures and flyers were distributed on several events.
- c. Social networks – the most common way of communicating between the members and patients had been through mails. Facebook had been used as an informational platform in a very minimal level. As not all of the board members were using Facebook, AE tried to implement Google social platform – Hangout in their communication, which didn't work out. AE Google account was renewed and application Google Drive was used as an official storage of the documents and protocols of AE, in order to avoid loss of information

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;
- The sponsorship agreement with the company HumanOptics was recently cancelled due to reason "Not enough information for feasibility for promoting iris implants among Aniridia patients" (BM 25.06.2016)
- A workgroup was appointed for working on fund raising, consisting of Denice Toews-Hennig, Galina Gening and Ognian Petkov. They had several meetings and worked on the topic for finding new sponsors with no specific result. Until the summer 2016 AE hasn't got a new sponsor/s.
- 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.

5. Scientific committee

During the General Assembly in Venice, September 21st, 2014, according to what is provided for in the Statutes, a Scientific Committee was elected, based on the nominations coming from the full members. The principle of not having more than one doctor per country was continued.

The SC was composed by: Dr. Tor Paaske Utheim, (Norway) - chairperson, Dr. Barbara Käsmann-Kellner, (Germany), Dr. Juan Alvarez de Toledo, (Spain); Dr. Julie Daniels (UK), Dr. Dominique Brémond-Gignac, (France), Dr. Paolo Rama, MD (Italy);

6. Research projects

AE was involved as a key partner in preparing the application for two international research projects, involving hospitals, research centres and organisations all over Europe and outside, in the framework of Horizon 2020.

Unfortunately both projects did not pass the final selection, even though they scored very high. It is possible that these projects, or part of them, will apply again in the next call for tenders.

7. Conferences and activities

a. Participation to AFI 2015 "Make A Miracle" Conference hosted by AFI and the University of British Columbia – The Board of AE gave a mandate for representing itself on the AFI conference to the President Asbjørn Akerlie and Galina Gening, and to Gaelle Jouanjan, president of the French association Gêneris. They made several contacts with professionals and non professionals, and they had an informal meeting between AE and "Vision for Tomorrow" representatives.

b. Participation in the First Russian Congenital Aniridia Conference 2-4 July 2015, Moscow - The Board of AE gave a mandate for representing itself on the conference in Russia to the Secretary Ognian Petkov. At the conference he made contact with people from Ukraine and Kazakhstan.

c. Participation in the WSPOS September 4-6 2015, Barcelona – Gaelle Jouanjan participated to the congress, representing AE and the French association. Next WSPOS congress will be hold on December 1-3 2017 in New Delhi, India.

d. Aniridia Youth Summer Camp August 4-14 2015, Italy - the camp was a co-op project between the national aniridia organizations in Norway, Spain, United Kingdom, Germany, and Italy. More information on AE website

e. EPag/ ERN project – AE became an E-Pag member and elected Gaelle Jouanjan as ePag representative for Aniridia Europe.

f. 3rd European Aniridia Conference August 26-28th 2016, Germany, Duisburg – on December 1st 2015 the Board of AE decided officially to support the 3rd European Conference in Germany. The main role as an organizer was on the German's Aniridia Association. Leader of the event is Denice Toews-Hennig. AE decided to support the conference by sharing experience from the previous conferences as well as with a reasonable amount of funds.

g. Upcoming events

A connection was established between Aniridia Europe and Albinism Europe and there was a proposal and approval from the Board for getting closer cooperation between the two organizations. As a first step in this direction there will be a joint participation on the following events – EPOS - 42nd annual meeting 23-25.09.16, Zurich, and 38th ESA meeting, 28.09-01.1.16, Budapest.

International Day of Aniridia – there was a proposal from Aniridia Network UK to create an International Aniridia Day. This would be a special day each year when individuals and aniridia associations around the world can co-ordinate their efforts to raise awareness of aniridia and/or raise funds. The proposed date was 21st June (summer solstice) because of the connection between aniridia and sensitivity to light. Aniridia Europe supported the proposal. A Facebook page of the event was created: <https://www.facebook.com/groups/aniridicfamily/permalink/855773357853601/>

The Board of Directors

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Duisburg (Germany), August 26th, 2016