



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:

<b>Member</b>	<b>Initials</b>	<b>Country</b>
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 26<sup>th</sup>;

2015: February 11<sup>th</sup>, June 25<sup>th</sup>, September 3<sup>rd</sup>; December 1<sup>st</sup>;

2016: January 27<sup>th</sup>, February 9<sup>th</sup>, March 4<sup>th</sup>, August 9<sup>th</sup>

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, Belarus 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 the First Russian Congenital Aniridia Conference 2-4 July 2015, Moscow. The conference had international speakers and was organized by the association Aniridia Russia, chaired by Galina Gening. 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.

b. Aniridia Youth Summer Camp 3-15 August 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

c. Participation to AFI 2015 "Make A Miracle" Conference, 12-15 August 2015, 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.

d. Participation in the WSPOS 4-6 September 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.

e. Aniridia UK: organized 2 local conferences - in New Castle (September 2015) and in London (May 2016). Galina Gening was on the events as a Board member on behalf of Aniridia Europe.

f. EPag/ ERN project – in 2016 AE became an ePag member and elected Gaelle Jouanjan as ePag representative for Aniridia Europe.

g. 3<sup>rd</sup> European Aniridia Conference August 26-28<sup>th</sup> 2016, Germany, Duisburg – on December 1<sup>st</sup> 2015 the Board of AE decided officially to support the 3<sup>rd</sup> 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.

h. 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 38<sup>th</sup> ESA meeting, 28.09-01.1.16, Budapest.

i. 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/>

## **8. Member associations' activities**

- a. Aniridia Italy developed a brochure for schools titled "I have got Aniridia". This brochure was translated in Russian and French languages.
- b. Aniridia UK developed two "Passport for aniridic kid" (0-5 years and 5+). These passports were translated in Russian and German languages.
- c. The English translation of the Italian and Spanish Clinical Guidelines for Congenital Aniridia were published on AE website. Guidelines from Germany are ready and will be published soon. Russian and French guidelines are under developing.
- d. The French association Gêneris is helping the Belgian representatives to develop an association in their country.

### **The Board of Directors**

Asbjørn Akerlie, president  
Barbara Poli, vice president  
Ognian Petkov, secretary  
Denice Toews-Hennig, treasurer  
Katherine Atkinson  
Galina Gening  
Marjorie Poyedomenge  
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Duisburg (Germany), August 26<sup>th</sup>, 2016