



ANIRIDIA EUROPE

Activity report 2012-2014

Summary

1. The formal establishment of the federation
2. The Board of Directors
3. The enlargement of the federation
4. Community meetings
5. Communication
6. Fees, sponsorships and donations
7. The Scientific Committee
8. Research projects
9. The 1st European Conference on Aniridia 2012
10. The Scientific Symposium on Aniridia 2013
11. Participation to AFI Conference 2013
12. The 2nd European Conference on Aniridia 2014
13. Networking activities - Eurordis
14. Social projects

1. The formal establishment of the federation

During the first six months of 2012, the provisional Board of Directors worked in clearing all the administrative and financial aspects connected to the formalization of Aniridia Europe, whose headquarters were established in Oslo, Norway.

The first General Assembly was held in Oslo, on June 7th, 2012. Full members with right to vote were: Italy, Norway, Spain, Sweden, UK; Finland and Germany were absent.

After the approval of the Activity Report 2011, the acknowledgement of financial situation and adoption of the Action Plan 2012-2014, the General Assembly elected the Board of Directors, composed by 6 members.

Rosa Sánchez de Vega was elected President of the federation.

Neven Milivojevic was elected vice-president of the federation.

Sølvi Ørstenvik was elected treasurer of the federation.

Barbara Poli was elected secretary of the federation.

Katie Atkinson and Denice Toews Hennig were elected as Board members.

Hilde Hansen, Ivana Kildsgaard and Corrado Teofili were elected in the Nominating Committee, and Hilde Hansen was elected as the chairperson.

Arvid Meløy was elected as auditor.

The vice-president proposed to give an honorary membership to Rosa Sánchez de Vega. The motivation was read by the secretary:

“For her 15-year lasting commitment in the advocacy for aniridia patients

For her great commitment in connecting people in different countries

For the key role she played in building the federation Aniridia Europe

We propose that Ms. Rosa Sánchez de Vega become an honorary member of

Aniridia Europe”.

The General Assembly unanimously approved.

Report at: <http://www.aniridia.eu/2013/10/19/ae-aniridia-europe-round-table-and-general-assembly-june-6-2012/>

2. The Board of Directors

The Board of Directors has held regular meetings via teleconference and, when possible, face-to-face.

2012: January 22nd, March 25th, April 22nd, May 13th, June 7th (Oslo, Norway), July 22nd, September 23rd, November 17th (Mestre, Italy).

2013: February 10th, April 14th, June 23rd, September 1st, November 17th.

2014: February 9th, April 6th, June 19th, August 31st, September 18th.

Moreover, Board members have spent a considerable amount of time in exchanging e-mails and in face-to-face meetings with members, partners, organizations, health authorities, hospitals and research centres, as well as with doctors and researchers.

The activities performed by the Board of Directors refer not only to the administrative and financial tasks, but to a wide spectrum of actions that followed the key strategic lines stated by the Action Plan 2012-2014:

- a) Patients' empowerment and family support
- b) Advocacy and visibility
- c) Promoting research
- d) Governance and fundraising

These actions are described in the following paragraphs.

3. The enlargement of the federation

During these years, Aniridia Europe has expanded its network of associations and individual representatives. In summer 2014, 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, Greece, Poland, Portugal, Serbia, Switzerland);
- Contacts with patients in Hungary, Kazakhstan, Lithuania, Malta, Moldova, the Netherlands, Romania, Ukraine.

Aniridia Europe has also been contacted by people living in African and Asian countries, as Egypt and Iran.

4. Community meetings

After the first General Assembly (Oslo, June 7th, 2012), a face-to-face community meeting was held in Homburg/Saar, Germany, on June 1st-2nd, 2013. Report at: <http://www.aniridia.eu/2013/10/19/ae-meeting-homburg-june-1-22013/>.

Teleconference meetings were also held on December 2nd, 2012, and on December 15th, 2013.

5. Communication: website, information materials, social networks

5.1 The website

It is the most important tool for communication and visibility. During these years, its layout has been completely renewed, the content

was reorganized and new materials were added. Among them, a basic text on aniridia in 13 languages, introductory videos to Aniridia Europe in 8 languages, institutional and scientific content, news from the national associations. Information about events was constantly updated.

The Editorial staff is composed by Espen Vangsnes, Katie Atkinson, Barbara Poli, Denice Toews-Hennig, and received the support of Asbjørn Akerlie, Matteo Castelnuovo, Christian Knopke, Neven Milivojevic, Jan Moritz, Cesare Ottaviano, Rosa Sánchez de Vega, Corrado Teofili.

Editorial Staff can count on the different skills of its components and on their capability to dialogue, but the weak point is that all of them are very involved in other tasks for Aniridia Europe and their national associations, which has made almost impossible to give continuity to website maintenance.

5.2 Information materials

A flyer was developed and distributed as much as possible in European and national events. A large number of AE flyers (printed thanks to the Spanish Foundation for the Blind) were sent to ESCRS 2013 in Amsterdam.

During 2014, a brochure was developed by Ivana Kildsgaard, with the contribution of Board members and the revision and contributions of the medical content by Dr. Tor Paaske Utheim and Dr. Barbara Käsmann-Kellner. It is based on existing medical texts that were completely rearranged to address both patients and doctors. The text is very correct and very well grounded, and it is likely to serve the purpose of having a text stable enough not to need changes in a short term. The graphic layout is studied to make it readable and effective. It has been printed in 3,000 copies with financial support by the sponsor HumanOptics.

5.3 Social networks

The issue about having a Facebook page and a forum was constantly present in Aniridia Europe since its foundation and many times doubts and opportunities were discussed. Finally, both tools were implemented, but they do not seem to be very effective so far, especially if compared with national Facebook pages, that are far more active. Maybe it depends on the language challenges (families prefer to dialogue in their own language than in English) or maybe it is not easy to find time to follow the forum, where questions and answers require a deeper commitment.

The issue will require to be rethought in the next months.

6. Fees, sponsorships and donations

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

- The full membership fee is established 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;
- Eurordis grants supported the organization of the Board and SC meeting (Mestre, Italy, November 17th-18th, 2012) and the Community meeting (Homburg/Saar, Germany, June 1st-2nd, 2013); nonetheless, Aniridia Europe and the member associations had to contribute in order to cover all the expenses;
- A sponsorship agreement was signed with the company HumanOptics and has recently been renewed. The agreement consists of a direct financial support and of the availability to print AE materials (specifically, 3,000 copies of the new Aniridia Europe's brochure were printed during the summer of 2014);
- An important donation came from Doriss Land - Elite property on the Red Sea;
- Some specific contributions came from Aniridia Norway and Aniridia Italy during the Board and SC meeting (Mestre, Italy, November 17th-18th, 2012) and from Aniridia Germany during the Community meeting (Homburg/Saar, Germany, June 1st-2nd, 2013);
- A great 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.

7. The Scientific Committee

During the General Assembly in Oslo, June 7th, 2012, according to what is provided for in the Statutes, a Scientific Committee was elected, based on the nominations coming from the full members. Moreover, the principle of not having more than one doctor per country was established.

The SC was composed by: Juan Alvarez de Toledo, MD (Spain); Julie Daniels, MD (UK); Hans-Rainhard Koch, MD (Germany), who was nominated chair for one year; Paolo Rama, MD (Italy); Tor Paaske Utheim, MD (Norway).

A first face-to-face meeting was organized in Mestre (Italy), at the Veneto Eye Bank Foundation on November 18th, 2012, and resulted in a preliminary document.

Report at: <http://www.aniridia.eu/2012/12/01/report-on-aniridia-europe-board-and-scientific-committee-joint-meeting/>.

Unfortunately, the work flow inside the SC proved not to be very effective.

During the summer 2013, Dr. Koch left and was substituted by Dr. Barbara Käsmann-Kellner (Germany). Teleconference meetings were held on September 16th, 2013, and on March 4th, 2014, and a document was approved.

The next face-to-face meeting is scheduled in the framework of the 2nd European Conference on Aniridia, in Venice, and is to be held on September 18th, 2014.

French and Russian associations have expressed their candidates to enlarge the Scientific Committee. In the meantime, Aniridia Europe is collecting names and details of experts in Europe that will be contacted to become members of a network of advisers that will support the SC.

8. Research projects

The issue about developing a European project on aniridia was constantly present and discussed in the Board of Directors. Two more persons, Ivana Kildsgaard (Sweden) and Didier Colle (Belgium), were involved because of their specific skills in preparing and submitting projects in the European framework.

A document was developed to establish priorities and strategies. It is self-evident that such a project is feasible only in a long-term perspective and it requires that a lot of conditions are fulfilled, first of all the existence of an effective and well-balanced Scientific Committee. Aniridia Europe has never ceased building the grounds to get this opportunity as soon as possible.

In the meantime, Aniridia Europe has collected information and sought ways to cooperate with the existing projects in various countries (e.g. OCT project in Spain, registry of patients in Bulgaria).

9. The 1st European Conference on Aniridia 2012

The 1st European Conference on Aniridia was held in Oslo from June 8th to June 10th. It was a key moment for community and networking activities directed to patients, but it was primarily a very important step in creating scientific and medical interest around aniridia, in bringing together the best physicians from Europe, the USA and Canada and in promoting research. Even though the conference is mostly a result of Aniridia Norway's work and dedication, Aniridia Europe - at that time still in its process to formalization - could contribute by disseminating information, involving doctors and

participants and by giving the conference a broader vision and approach to the disease.

The conference was also important because it created the opportunity to receive a contribution from the Sharon Stewart Testamentary Trust that has made possible the 2nd European Conference on Aniridia in 2014.

Information, program and speakers at:
<http://2012.aniridiaconference.org/>

10. The Scientific Symposium on Aniridia 2013

The Scientific Symposium on Aniridia was held in Homburg/Saar on June 1st, during the two-days event that included Aniridia Europe's community meeting and Aniridia Germany's national meeting. It was intended as an opportunity to disseminate knowledge on the disease but also to build a network between patients and doctors to promote the best possible treatment and care for people with aniridia, not only in Germany but at European level.

Report at: <http://www.aniridia.eu/2013/10/19/ae-meeting-homburg-june-1-22013/>.

11. Participation to AFI Conference 2013

The Vice President Neven Milivojevic and the Secretary Barbara Poli participated in the *2013 Make a Miracle Conference* organized by Aniridia Foundation International in Charlottesville, Virginia.

They presented Aniridia Europe, its activities and projects, launched the 2nd European Conference 2014 and performed networking activities with doctors and patient representatives.

Report at: <http://www.aniridia.eu/2013/10/19/report-on-2013-make-a-miracle-conference/>.

12. The 2nd European Conference on Aniridia 2014

Announced in Oslo 2012 and launched in Charlottesville (Virginia, USA) 2013, the 2nd European Conference on Aniridia is going to be held in Venice (Italy), on September 19th-20th, 2014. Aniridia Italy is in charge of the local organization.

Aniridia Europe as a community expressed a great and determined commitment in designing, organizing, supporting and promoting the Conference as a unique opportunity to take one step further towards the objective of improving treatment and care of aniridia and to build the grounds for a research project.

Some topics will have a traditional treatment with a speaker relating on the subject (e.g. genetics, retina), while the most controversial topics (cataract, glaucoma, ocular surface) will have a more advanced kind of structure, with a keynote speaker relating on the

state of the art and a panel of experts discussing the topic in order to reach a consensus when possible, with the contribution of the audience.

Information, program and speakers at:
<http://2014.aniridiaconference.org/>

13. Networking activities - Eurordis

Since its foundation, Aniridia Europe has joined Eurordis, the federation of European associations on rare diseases. The President Rosa Sánchez de Vega, Eurordis Board member until May 2014, regularly attended meetings and followed all the activities in order to keep Aniridia Europe up to date about European regulations and projects on Rare Diseases and the position of Eurordis regarding the main issues (research, data protection, transparency, centres of reference, social policies, etc).

Aniridia Europe is involved in many Eurordis projects, such as the Rare Together project (support to European Federations of specific RD), Epi-Rare (common guidelines to develop European Registries for RD), EUROPLAN II (development and implementation of National Plans for RD), EU-CERD project on Social Services on RD (the President participated to the workshop in Denmark in 2013), and in the Burqol-RD project (European project on Social Burden and Quality of Life of People living with RD, Tenerife 2012).

The secretary Barbara Poli is currently appointed in a Eurordis workgroup that will work on clinical best practices in the framework of the RARE-Bestpractices project.

Many national associations participated in their respective countries to the Rare Disease Day, a Eurordis initiative.

The most recent meeting was Eurordis CEF (Council of Federations) on October 29th-30th, 2013, in Paris, where information was provided on EU plans and projects on rare diseases, and particularly about Horizon 2020.

During the same days Rosa Sánchez de Vega also met Mr. Mokrane Boussaid, director of the European Blind Union in Paris, to explore the possible ways of future collaboration. After a brief introduction of both organisations, it was clarified that EBU is mostly focused on social issues, while Aniridia Europe also faces many health challenges, due to the low frequency of the disease. EBU offered support in disseminating the 2nd European Conference and involvement in the existing working groups as well as in the future prevention projects. Other issues (such as registries or research programs) are currently beyond EBU's activities, mainly connected

to the mission of building an accessible and inclusive society with equal opportunities for blind and partially sighted people.

14. Social projects

14.1 Building new mechanisms of self-help for people affected by Aniridia

In 2013 Aniridia Bulgaria contacted Aniridia Norway to discuss the possibility of applying for a project funded by the “NGO Programme in Bulgaria under the European Economic Area Financial Mechanism” 2009 – 2014. The two associations agreed to cooperate; Aniridia Bulgaria is the project leader, while Aniridia Norway is a partner that provides its fundamental experience as a patient association.

Objectives of the project are:

- Exchange of experience through development and distribution of a Manual of good practices (already accomplished);
- Organization of two specialized trainings in Bulgaria, featuring expert speakers;
- Organization of five information seminars throughout Bulgaria in order to familiarize the disease for different groups and persons;
- Creation of a Registry in Bulgaria;
- Development and dissemination of information materials.

14.2 Youth in Europe with Aniridia

The project is funded in the framework of the EU Active Youth program and Aniridia Norway is the leading association. Young people with aniridia and their siblings, coming from Germany, Italy, Norway, Spain and UK, will participate in a summer camp in Italy in 2015.

A preliminary meeting was held in Padua, Italy, from June 24th to 28th, 2014, with 9 young people and 7 accompanying adults. The participants visited Venice, experiencing the glass-making technique in a glass factory and a gondola tour, and went to the amusement park Gardaland near the Garda Lake. They had also time to meet and draft their next summer activities, but also some leisure time to talk and stay together.

The Board of Directors

Rosa Sánchez de Vega, *President*

Neven Milivojevic, *Vice-President*

Barbara Poli, *Secretary*

Sølvi Ørstenvik, *Treasurer*

Katie Atkinson, *Board member*

Denice Toews-Hennig, *Board member*

Venice (Italy), September 21st, 2014