



ANIRIDIA EUROPE

Activity report 2011

Aniridia Europe was officially founded in September 25th, 2011. The main activities of this year were therefore connected to this event.

Background

It is useful to briefly remind the history of the international relationships among the member of the European Aniridia community.

First contacts came in 2002, when some Italian representatives participated in Madrid to the International Conference organized by the Asociación Española de Aniridia.

Then in 2003 a first meeting was held in Paris, at Eurordis' offices, whose participants came from Belgium, France, Italy, Liechtenstein, Norway, Spain; at that time, there were associations only in France and Spain.

In the following years contacts continued and the network was enlarged; in many countries associations were formally founded.

Face-to-face meetings were held in the following years: in Paris (2007), in Mallorca (2008), during the European Workshop on Aniridia organized by the Asociación Española de Aniridia, and in Paris again (2010), involving a growing number of countries.

Fundamental was in this process the encouragement and constant support of Eurordis.

Steps towards the formal establishment

Starting from February 2011, teleconferences among all the representatives were held on a regular basis.

Some were entrusted to clear up all the administrative and legal aspects necessary to found a European federation; a proposal for Statutes was prepared and the procedure for formal registration in Norway was performed.

Others worked on the enlargement of the network, looking for aniridic people in other countries, encouraging and supporting the



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development of new associations, building mailing lists to facilitate communication and sharing of ideas.

By the end of the year the network included formally established associations in seven countries (Italy, Norway, Spain, Sweden, United Kingdom, with Finland and Germany in the process of formal registration) as well as representatives in other twelve European countries (Belgium, Bulgaria, Croatia, Denmark, France, Greece, Lithuania, The Netherlands, Poland, Portugal, Serbia, Ukraine).

As a final step, in September 25th, during a teleconference participated by representatives of 16 countries, the federation Aniridia Europe was officially founded, the Statutes approved and the provisional organs of the federation (Board of Directors, Nominating Committee and Auditor) were elected. The provisional organs will last until the first General Assembly, that will be held in Oslo, in June 7th, 2012.

The first European Conference on Aniridia

Aniridi Norge, the Norwegian association, started the process of organizing the first European Conference on Aniridia in Oslo in 2012 and constantly shared information and consensus within the network. All AE members actively participated in supporting the organization and in spreading information in their countries.

The definition of mission and objectives

In November, a Board and Networking meeting was held in Paris. Participants focused on key issues, such as the definition of AE mission, the establishment of short and medium term objectives, the development of an *Action Plan* for the next years.

A fundamental passage was the decision of creating a Scientific Committee to assist the federation in orienting the research on the disease and in preparing projects on it. Criteria were discussed and the participants started contacts in their countries to find candidates for the Scientific Committee.

The website and the logo

2011 was a fundamental year for the development of the website. An Editorial Staff was constituted and tasks were assigned.

The website was conceived as a tool to spread information especially in those countries where there weren't associations already established; a document of basic information on aniridia was



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developed and made available in eleven languages (Bulgarian, Croatian, Danish, Dutch, English, Greek, French, Italian, Portuguese, Serbian, Spanish).

Scientific medical articles on the disease were provided in English in a specific section of the website, that will be constantly updated, as well as information about the federation, its organs and statutes and its meetings.

At the same time, AE logo was designed, discussed and finally adopted; it represents a Moebius band with iris colours on one side and black colour on the other side. As the two sides are in fact one only continuing boundary, this may represent at the same time the difference and the closeness of the two aspects, as well as an uninterrupted quest for improvement of aniridia people's condition.

Read, approved and signed
Oslo, June 7th, 2012

The President
Rosa Sánchez de Vega

The Secretary
Barbara Poli