



ANIRIDIA EUROPE



The 2nd European Conference on Aniridia Venice (Italy), 19/20 September 2014

Report

The Conference lasted two days, with a total of more than 20 hours of presentations and discussions on the most relevant topics for aniridia: glaucoma, cataract, posterior segment, ocular surface, the genetic bases of the disease. Each session consisted of one or more keynote lectures that were then discussed by a panel of experts. A full session was dedicated to the clinical management of pediatric patients, with the aim of providing useful knowledge for promoting a better treatment, the prevention of complications and a comprehensive approach to the child.

Friday and Saturday morning sessions were directed to physicians and researchers (even though some patients' representatives were also present), while the Saturday afternoon session was specifically designed to be open to patients and parents of affected children, who could make questions and interact with doctors.

The faculty was composed of 35 persons, 30 professionals (chairs, speakers and panelists) and 5 patients' representatives; 16 among them came from Italy, 14 from other European countries and 5 from the USA. A representative of the Italian National Health Institute was also present. Attendees were 113, including 47 doctors and 66 patients. Among the professionals, 20 came from Italy and 27 from abroad. Among the patients, 40 came from Italy and 26 from other countries. The Conference was therefore attended by 77 professionals, including physicians and researchers in the faculty and among the attendees. This is quite a relevant number for a meeting on this rare disease. The organizing committee received many positive feedbacks from the professional attendees about the high scientific level of the medical discussion as well as about the organization. Some of them said that they "learned a lot", which was one of the Conference's aims.

The abstracts submitted were 18 (13 with a clinical content, 5 with a genetic topic), and all of them were published before the event on the Conference website. 12 abstracts were selected for oral presentation during the Conference. The acknowledgement for the best abstract was given to *Aniridia associated keratopathy - is it time to evaluate treatment?* by Dr. Per Fagerholm et al. from Sweden. The scientific committee reserved a special mention also to *"Living with aniridia" - One voice!*, presented by Wibeche Inngskog from Norway, and to *PAX6 mutation in French patients: an update* by Dr. J.M. Rozet et al. from France.

Jill Nerby launched and promoted the next AFI Conference in Vancouver 2015 while illustrating the great job done by her organization during these years in favor of the "aniridia community" of patients, physicians and researchers.

The Conference also offered the opportunity for other important collateral meetings to take place: on Thursday September 18th the Scientific Committee of Aniridia Europe met at Fondazione Banca degli Occhi del Veneto, to dialogue and work on the creation of a network of doctors in Europe as a fundamental basis for any research project on the disease.

During the Conference, a group of geneticists met in a room provided on purpose, to discuss the possibility to create a consortium among the Departments of Genetics and Research Centers dealing with aniridia in order to facilitate communication and standardization of their procedures.

Coffee breaks, lunches and the Gala Dinner on the charming island of San Servolo, in the Venetian lagoon, also proved to be wonderful opportunities for informal talks and information exchanges. Most participants expressed their gladness to be offered these possibilities.

On Saturday evening there was also a meeting with the organizers of the project *Youth in Europe with Aniridia*, a summer camp for young people from 5 different countries that will take place in summer 2015 in Italy and whose value is going to be really relevant as far as the empowerment and social inclusion of visually impaired youngsters are concerned.

On Sunday September 21st the General Assembly of Aniridia Europe was held in Venice to elect the new Board of Directors of the federation and discuss the main strategic lines of its action.

Articles about the Conference were published on three newspapers, *Il Gazzettino*, *La Nuova Venezia* e il *Corriere del Veneto*, and the local department of the Italian national television broadcasted an interview and a report.

After the conference a publication on the pathology was released by the international publisher Springer. Most of the speakers agreed in collaborating to it and therefore the medical and scientific outcomes discussed during the Conference on the different topics were taken into account and made available to the public.

The publication details are:

Aniridia: Recent Developments in Scientific and Clinical Research, Springer 2015

Editors: Stefano Ferrari, Mohit Parekh, Barbara Poli, Diego Ponzin, Corrado Teofili

ISBN-13: 978-3319197784

ISBN-10: 3319197789

Finally, as it was announced during the Conference, the scientific quality of the event attracted a donation of 40,000 euros to the Fondazione Banca degli Occhi del Veneto to be used for a research project on aniridia.

The administrative and accounting aspects were constantly monitored, and the objective of making the most effective use of the financial resources was a constant guide and concern. The provisional budget was respected and the final budget did not show any deficit.