



ANIRIDIA EUROPE

Main activities

Spanish Aniridia Association

Aniridia Europe Networking Meeting
3rd June 2022, Alicante, Spain
Rosa Sánchez de Vega

Strengths & weaknesses

- 5 board members
- 3 staff members
- 10 Regional representatives
- National and regional call for grants/projects

Four main areas

- *1.- Social support/care*
- *2.- Awareness and Communication*
- *4.- Innovation & Research*
- *5.- Fundraising*

Social support/care

- *Information service SIOAS, answered by professionals tel. e-mail, website (form), social networks and presentially.*
- *Grants for school and to purchase visual aids*
- *Agreement with Ophthalmology and Genetics Clinics (lower fee) and Low Vision Opticians, Pharmaceutical Companies (free eye drops)*

Awareness campaigns & Communication

- Campaign ***“We look through your eyes”*** (White book for low vision)
- Campaign ***“Look at us, look at them”*** (for paediatricians and social-health professionals)
- Campaign ***“We are not invisible, we have low vision, for Schools***
- Accessible hotels, Accessible Bank offices
- Webinars Aniridia every Month
- Vision Day. WAGR Syndrome Day
- Communication: E-newsletter, whatsapp , social media, etc.

www.aniridia.es

Innovation & Research

Ongoing research studies

- Genetic advice
- Autologous serum
- Photophobia study
- Eye drop study
- Rare Disease Registry-Eye Disorders-ONERO
- OCT in Aniridia
- PEGF Plasma Enriched with Growth Factors

Research promotion & involvement

- ANIRIDIA-NET
- *AAK insight*
- *Research Award: Juan Murube del Castillo-
National Ophthalmology Society Congress*
- *6th European Aniridia Conference. Spain.*
- *Scientific blog. Science at hand (by
professionals Univ. Valladolid).*

Fundraising

- ***Public calls for projects (regional /national). Alone or with other platforms (FEDER, Visión España).***
- ***Private donations (foundations, ophthalmo clinics, opticians, etc.***
- ***Own funds:***
 - ***Members annual fee***
 - ***Christmas Lotto***
 - ***Helpfreely Plattform***
 - ***Teaming online tool.***
 - ***Merchandising***