



ANIRIDIA EUROPE

# Aniridia Europe: looking out for the aniridia community

Networking meeting, Alicante (Spain), 3<sup>rd</sup> June 2022, 15-18 CEST

*Barbara Poli, President of Aniridia Europe*





ANIRIDIA EUROPE

# Our history, our members

Informal meetings in 2003, 2007, 2008, 2011

Formal establishment in late 2011

General assemblies in 2012, 2014, 2016, 2018 and 2020

In summer 2022 the federation includes:

- 14 associations as full members: Bulgaria, Denmark, Finland, France, Germany, Italy, Lithuania, Norway, Romania, Russia, Spain, Sweden, United Kingdom and Ukraine
- individuals as affiliated members or contact persons in Belgium, Croatia, Czechia, Estonia, Georgia, Greece, Hungary, Iceland, Ireland, Israel, Kazakhstan, Latvia, Moldova, the Netherlands, Poland, Portugal, Serbia, Switzerland and Turkey



ANIRIDIA EUROPE

# EACs: who would have believed it?

**2012 Oslo (Norway)**

**2014 Venice (Italy)**

**2016 Duisburg (Germany)**

**2018 Paris (France)**

**2020 (2021) London (UK) – online**

**2022 Alicante (Spain)**

**2024 Stockholm (Sweden)**

In 2020-2022 a logo, a specific website and dedicated social channels were developed for the conference thanks to the work of many people

6th European Aniridia Conference, 3-5 June 2022, Alicante (Spain)



ANIRIDIA EUROPE

# Digital: a new way to communicate, involve, share

Webinars in partnership with the COST Action Aniridia-Net:

- *News from the frontier: a dialogue on Aniridia-Net COST Action to improve aniridia clinical management and promote innovative research*, 27-02-2021
- *Eyes open on stem cells: dynamics, signatures and niche*, 26-05-2021
- *Managing aniridia: dos and don'ts from infancy to adulthood*, 01-06-2021
- *A fresh look to aniridia pathophysiology with a focus on translational implications*, 22-10-2021
- *Regulatory Framework on Orphan Medicinal Products for Rare Diseases*, 20-05-2022

Other webinars were organised on different topics:

- *Digital rebels against distance*, about how to break the distance caused by the pandemic through the smart use of the digital media, 24-04-2021
- *The digital therapeutics value*, about the home measurement of the intraocular pressure, 26-04-2022

... and the new website, the newsletter, the social channels, all the recordings on the YouTube channel... steps towards an overall communication strategy



ANIRIDIA EUROPE

# Ongoing projects

Cost Action CA18116 Aniridia-Net - *Aniridia: networking to address an unmet medical, scientific, and societal challenge, 2020-2024*

> **guidelines, patient-driven research, quality of life**

*Aniridia - novel therapeutic tools to treat or prevent progressive corneal opacification (AAK-INSIGHT), 2021-2024*

*The Erasmus+ project “Seeing the invisible”: inclusive digitalization of students with low vision in school education, 2022-2023*

Aniridia Europe is an active partner in the application for other projects both in the scientific research and social field, that are currently pending

6th European Aniridia Conference, 3-5 June 2022, Alicante (Spain)



# Partnerships

- **Eurordis**, the umbrella organization for rare diseases associations in Europe:
  - grants for developing Aniridia Europe's networking and digital activities
  - a representative as **e-PAG** (European Patient Advisory Groups) at the **ERN-EYE** (European Reference Network for the eye rare diseases)
- Aniridia Europe is invited to participate to an organ composed by patient representatives, provisionally called **CLEO: Council of Lived Experience in Ophthalmology**, established by the EU-EYE (European Alliance for Vision Research and Ophthalmology)
- **ANA - Aniridia North America**, created in late 2021. Talks about the possibility to cooperate in many areas and to promote aniridia research have already started



# A look into the future: what shall we do next?

## Strengths

National associations  
Volunteers  
Reputation

## Weaknesses

Funds  
Human resources  
Low involvement of young people

## Opportunities

Partnerships (ANA, Eurordis)  
EU projects (new drugs, genetics)  
EYE ERN (guidelines, registries)

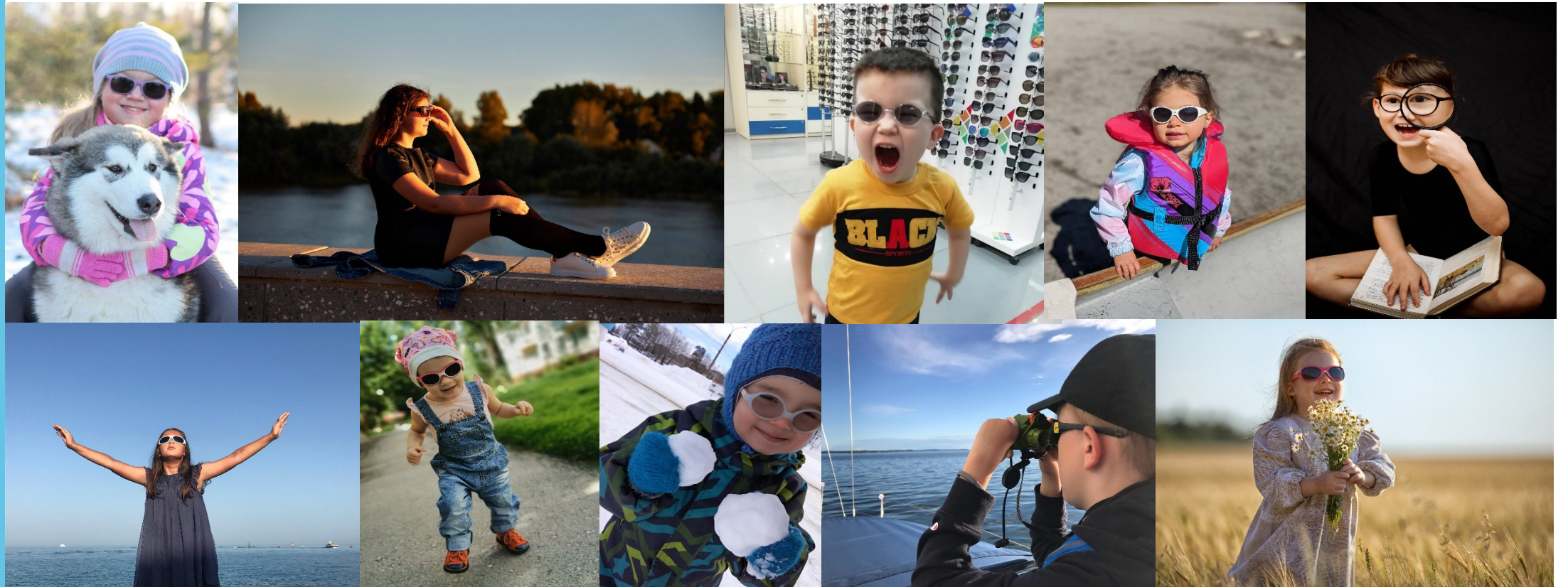
## Threats

International situation  
Priorities (decreased interest in RD?)  
Aniridia, just one among thousands...



ANIRIDIA EUROPE

# THANKS!



[www.aniridia.eu](http://www.aniridia.eu)  
[info@aniridia.eu](mailto:info@aniridia.eu)