



**National patients organisation
for people affected by aniridia,
rare pathologies of iris,
with or without associated syndromes**

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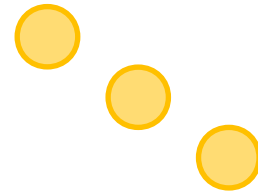
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FB : Association GENIRIS – Aniridie Maladies Iris

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A patients organisation

- ⊙ Created by patients to serve patients, 17 years ago
- ⊙ General interest
- ⊙ 220 members from France, Switzerland, Belgium, Luxembourg, North Africa, ...
- ⊙ 1 governance board with 15 peoples
- ⊙ 1 Scientific Committee with 17 members, created 7 years ago
- ⊙ Work with French Rare Diseases Centers of Reference
- ⊙ Work with 5 French Rare Diseases Networks
- ⊙ Work with INSERM, French national institute for medical research
- ⊙ Work with ERN Eye and in EMA
- ⊙ Work with Cost Action « aniridia net » and Ejprd « AAK insight »

- ⦿ 2019 : Development of the first national guidelines in France on aniridia with the aniridia center of reference OPHTARA Necker in Paris
- ⦿ 2020 : Beginning of development of the first european CCS/ guidelines on aniridia with AE and the aniridia center of reference OPHTARA Necker in Paris @ERN EYE and @Cost action anirdia net
- ⦿ 2021 : Development of the first national guidelines in France and in Europe on Wagr spectrum with the aniridia center of reference OPHTARA Necker in Paris
- ⦿ 2021 : Creation of the world's first therapeutic education program (TEP) for patients with congenital aniridia with the aniridia center of reference OPHTARA Necker in Paris

- ⊙ 2022 : French call for research projects devoted to congenital aniridia, wagr spectrum and ARS, 60ke for 3 projects.
- ⊙ Every year, an annual meeting organized
- ⊙ Patient representative in 2 French Rare Diseases Centers of Reference in 2 French Rare Diseases Networks
- ⊙ Patient representative @INSERM from 2016
- ⊙ Patient representative in a French aniridia research project for tear film gene therapy
- ⊙ Patient representative @European level in ERN Eye from 2016 and in EMA from 2021
- ⊙ Patient representative in Cost Action « aniridia net » and Ejprd « AAK insight »

PATIENTS EXPERIENCE TO VOLUNTEER PATIENTS ORGANISATION ACTION

TO PATIENTS AND FAMILIES
AFFECTED OR CONCERNED BY :

- ANIRIDIA, IRIS MALFORMDE,
COLOBOMA
- WAGR, GILLESPIE, AXENFELD-
RIEGER, PETERS, VON HIPPEL
- MACULA UNDER DEVELOPPED
- OPTIC NERV MALFORMED
- CONGENITAL CATARACT AND
GLAUCOMA
- STRABISMUS AND NYSTAGMUS
- DRY EYE AND OCULAR SURFACE
DISEASES
- CORNEAL PROBLEMS ANS
TRANSPLANTS
- ORBITOPALPEBRAL DISEASES
- PHOTOPHOBIA
- LOW VISION AND BLINDNESS
- COMPENSATION OF IMPAIRMENT

TO NATIONAL PATIENTS
ORGANISAITONS AND ADVOCACY
GROUPS

**PATIENTS
ORGANISATION :
GLOBAL SUPPORT**

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**RISK MANAGEMENT AND
RISK BEHAVIORS**

TO PROFESSIONNALS OF :

- HEALTHCARE
- VISUAL CARE
- PARAMEDICAL CARE
- SOCIAL CARE
- RESEARCH
- EDUCATION
- IMPAIRMENT
- EMPLOYMENT
- HANDICAP

- FRENCH AND EUROPEAN
RARE DISEASES
NETWORKS

- INSTITUTIONS OF HEALTH
IN FRANCE AND EUROPE

