

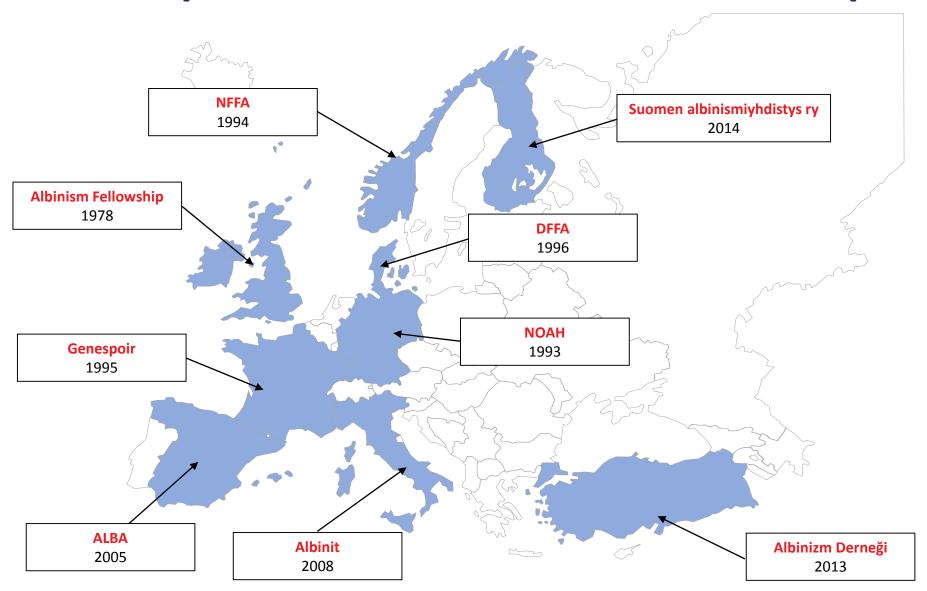


## Albinism Europe

**General Presentation** 

To the 3<sup>rd</sup> YPA participants

## 2018 - 9 patients' associations accros Europe



### The story started in 2010

- Genespoir decides to get in contact with the other albinism organisations existing in Europe
- Our views:
  - We have similar goals and activities
  - We face similar difficulties
  - We have lots to share
  - We are geographically close
  - We would be stronger together
- Goal: bringing together the actors of albinism in Europe in order to launch joint projects and be more efficient
- First step: 2011-2012, Genespoir goes around Europe in order to meet the other associations











### **March 2012**





**June 2012** 

### 2011 – encounter with Prof. Montoliu



- Spanish researcher
- Member of ALBA (Spanish albinism organisation)

How about a European conference?

## October 2012 - 1<sup>st</sup> European Conference

1<sup>st</sup> EDA

October 27<sup>th</sup>-28<sup>th</sup> 2012, Paris - France

- A meeting of associations
- A scientific conference
- A joint session with associations and scientists



October 27th & 28th 2012 Paris, FRANCE





## **About 60 participants**

First meeting of the European associations (Germany, Italy, Spain, Denmark, Norway, France, UK & Ireland)



Organized by

October 27th & 28th 2012

Paris, FRANCE

#### A Conference for

- Physicians,
- Researchers,
- Patients' organizations

#### Scientific Committee:

Robert Aquaron, Marseille, France Benoît Arveiler, Bordeaux, France Glen Jeffery, London, UK Barbara Käsmann-Kelner, Homburg,

Germany Lluis Montoliu, Madrid, Spain Maria-Vittoria Schiaffino, Milan, Italy Alain Taïeb, Bordeaux, France

#### Co-sponsored by:

### Other speakers:

Brian Brooks, Bethesda, MD, USA Enrico Maria Surace, Naples, Italy

### Invited patients' organizations:

ALBA, Spain Albinism Fellowship, UK & Ireland ALBINIT, Italy DFFA, Denmark NFFA, Norway NOAH Albinismus, Germany













Contact: conference@genespoir.org www.genespoir.org

## Seven associations represented



- First meeting of the European associations (Germany, Italy, Spain, Denmark, Norway, France, UK & Ireland)
- First meeting of the European scientists working on albinism (ophtalmologists, dermatologists, geneticists, biologists...)
- An outstanding scientific conference
  - 2 new genes announced





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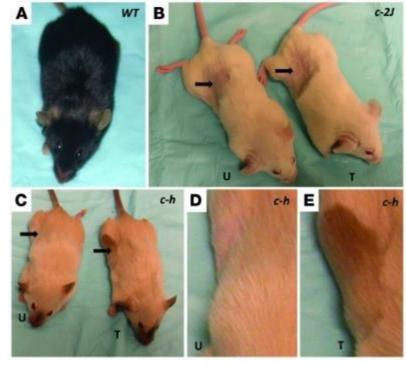




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- An outstanding scientific conference
  - 2 new genes announced
  - Participation of Pr Brian Brooks
    (USA nitisinone research project)
- An opportunity for the associations to exchange with the best specialists of albinism in Europe





## April 2014 – 2<sup>nd</sup> European Conference

### 2<sup>nd</sup> EDA

April 5<sup>th</sup>-6<sup>th</sup> 2014, Valencia - Spain

- A meeting of associations
- A scientific conference
- A joint session with associations and scientists
- A meeting of young Europeans with albinism



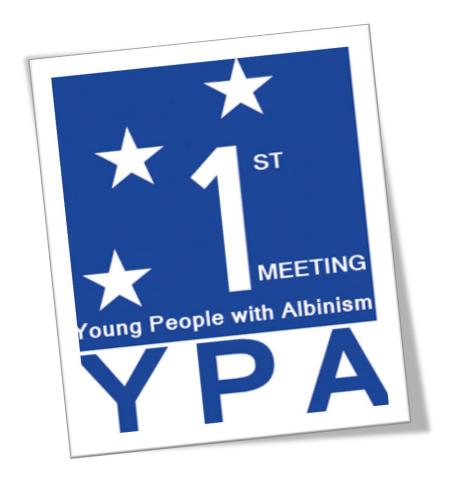




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- A new association represented: Turkey
- The European scientific conference becomes a world event (participants from Europe, Japan, USA, Australia, Colombia)



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- A new association represented: Turkey
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- First meeting of young
  Europeans with albinism (13 participants, 5 countries)





## April 2016 – 3<sup>rd</sup> European Conference

3<sup>rd</sup> EDA

April 7<sup>th</sup>-8<sup>th</sup> 2016, Milan - Italy



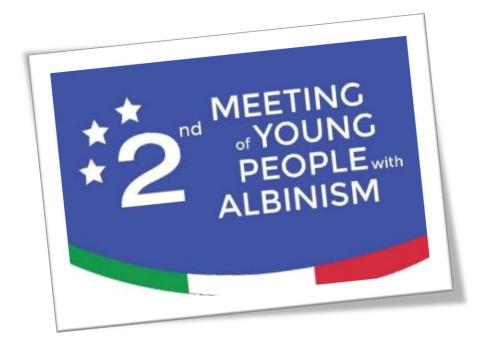
- A meeting of associations
- A scientific conference
- A psycho-educational meeting (in Italian)
- A joint session with associations and scientists
- A meeting of young Europeans with albinism (2<sup>nd</sup> YPA)

The event gets bigger!





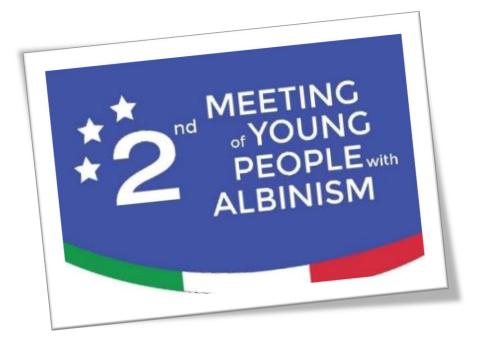
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  - 25 participants
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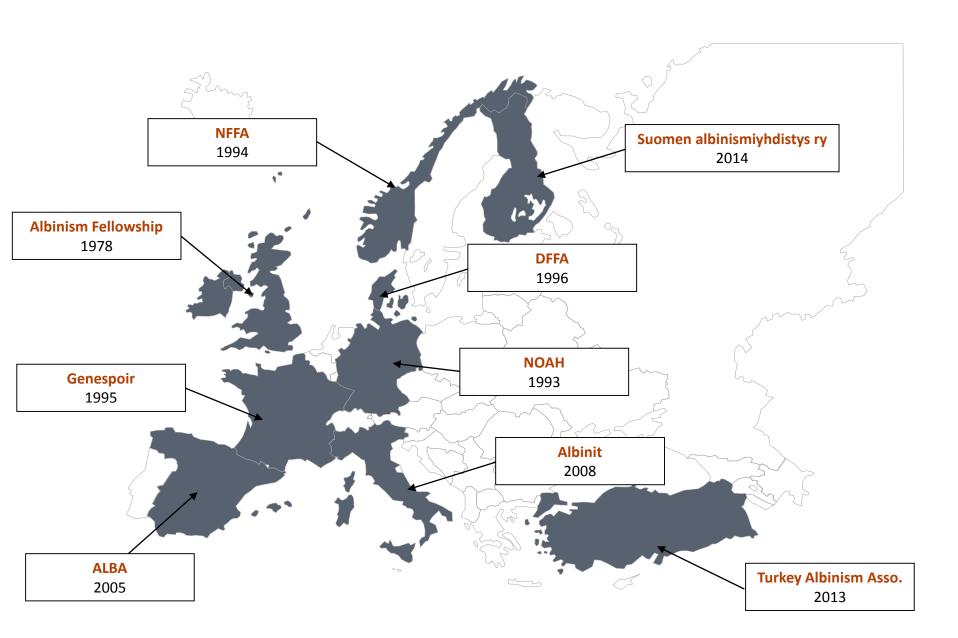


- The event gets bigger!
- A new association represented: Finland
- The YPA becomes bigger:
  - 25 participants
  - 9 countries represented
  - 5 days
- The collaboration between European associations grows:
  - Exchange of experience
  - Discussions on common projects

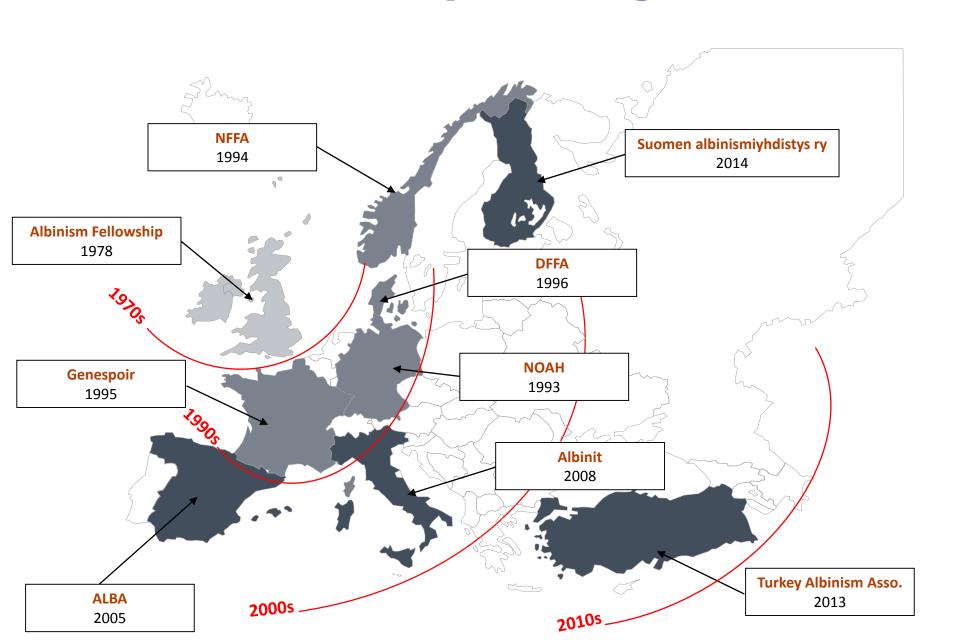




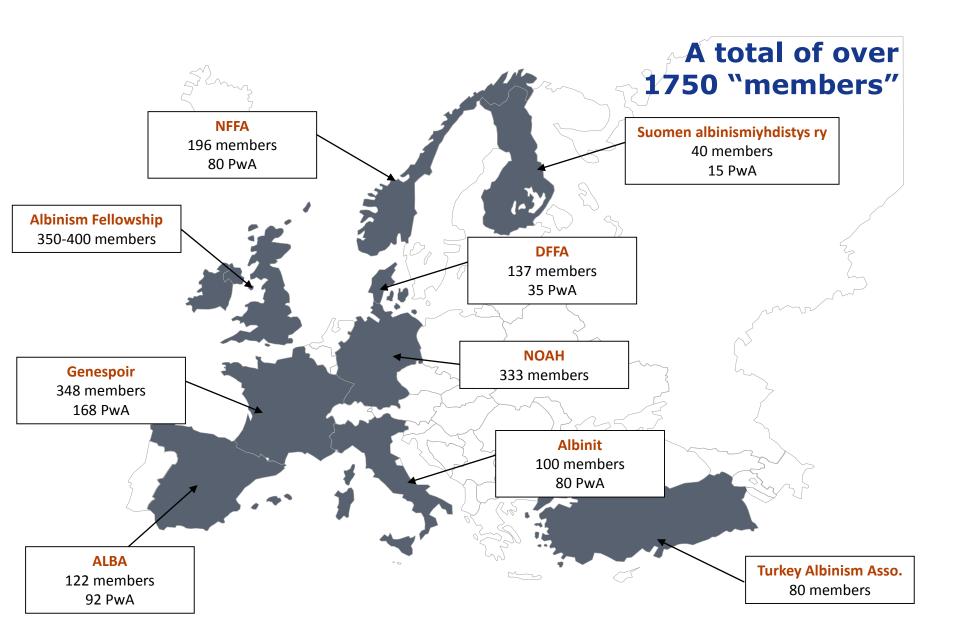
## Landscape of organisations



## Landscape of organisations



## Landscape of organisations



### Recent and on-going activity

A name and a logo!



## **ALBINISM** EUROPE

### Recent and on-going activity

- A name and a logo!
- A European scientific Committee

### Scientific Committee

- Benoit Arveiler (CHU, Bordeaux, France) co-chair
- Lluis Montoliu (CNB-CSIC and CIBERER-ISCIII, Madrid, Spain) co-chair
- Brian Brooks (National Eye Institute, NIH, Bethesda, MD, USA)
- Maria Mies van Genderen (Bartimeus, Diagnostic Centre for Rare Visual Disorders, Zeist, The Netherlands)
- Irene Gottlob (University of Leicester, UK)
- Karen Gronskov (Kennedy Center, Clinical Genetics, Copenhagen, Denmark)

- Michael Hoffmann (University Eye Clinic, Magdeburg, Germany)
- Barbara Kaesmann-Kellner (University Eye Clinic, Homburg, Germany)
- Alessandra Del Longo (Niguarda Hospital, Milano, Italy)
- Michael Marks (Philadelphia Children Hospital and UPENN, Philadelphia, PA, USA)
- Fanny Morice-Picard (CHU, Bordeaux, France)
- Maria Vittoria Schiaffino (San Raffaele, Milano, Italy)
- Maria Jose Trujillo (FJD Hospital, Madrid, Spain)

### Recent and on-going activity

- A name and a logo!
- A European scientific Committee
- A website: www.albinism.eu



HOME ALBINISM EUROPE Y

EDA & YPA ~

ALBINISM SCIENTIFIC COMMITTEE CONTACT US

Q Search ....

### Welcome to ALBINISM EUROPE website

Albinism Europe is an European network of albinism patients organizations

### Successful Face-to-Face meeting in Milan

News - 17 October 2017 - Hits: 13

ALBINISM EUROPE



On 30th September 2017, representatives from "Albinism Europe" met face-to-face in Milan (Italy) to discuss the development of several common projects and to complete organization details of the 4th European Days of Albinism (EDA) and the 3rd Meeting of Young Europeans with Albinism (YPA) in Norway.

> Read more ....

#### UPCOMING EVENTS



3YPA - 3th Young People whit Albinism

#### POPULAR TAGS

SPAIN ALBINISM EUROPE EDA ERASMUS+ CONFERENCE ITALY YRA GERMANY TURKEY NORWAY FRANCE EDUCATION

#### MOST READ

- > ALBINISM EUROPE
- > Albinism Europe Scientific Committee
- ) EDA & YPA

### Recent and on-going activity

- Organisation of the:
  - 4<sup>th</sup> European Days of Albinism conference
  - 3<sup>rd</sup> YPA meeting



Oslo, Norway – March 7th -11th 2018

## A new country represented!



## Want to get involved?





















albinism fellowship