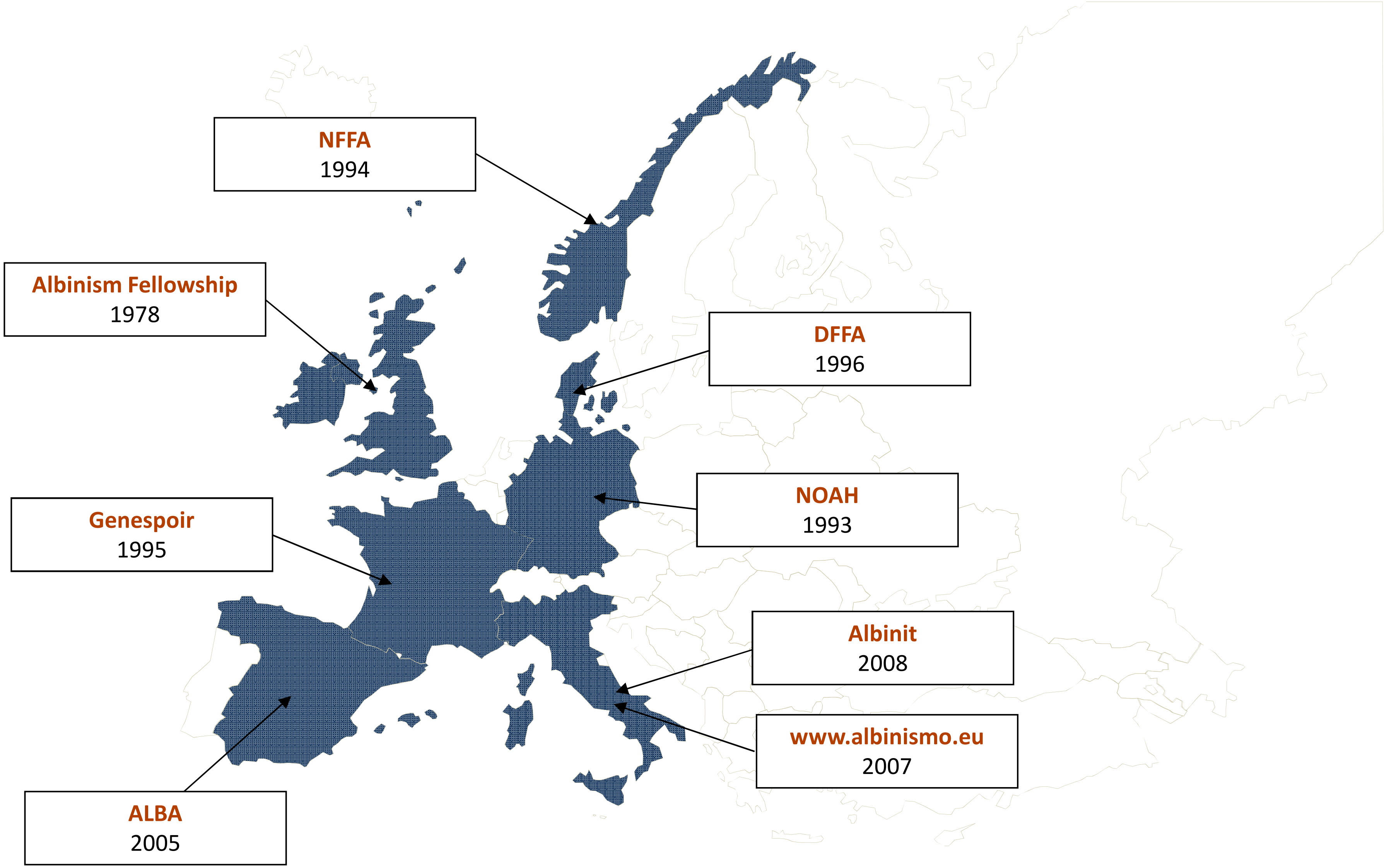
1ST EUROPEAN DAYS OF ALBINISM

October 27th & 28th 2012
Paris, FRANCE

Overview of the European patients' organisations

Landscape of patients' organisations



NFFA
1994

Albinism Fellowship
1978

DFFA
1996

NOAH
1993

Genespoir
1995

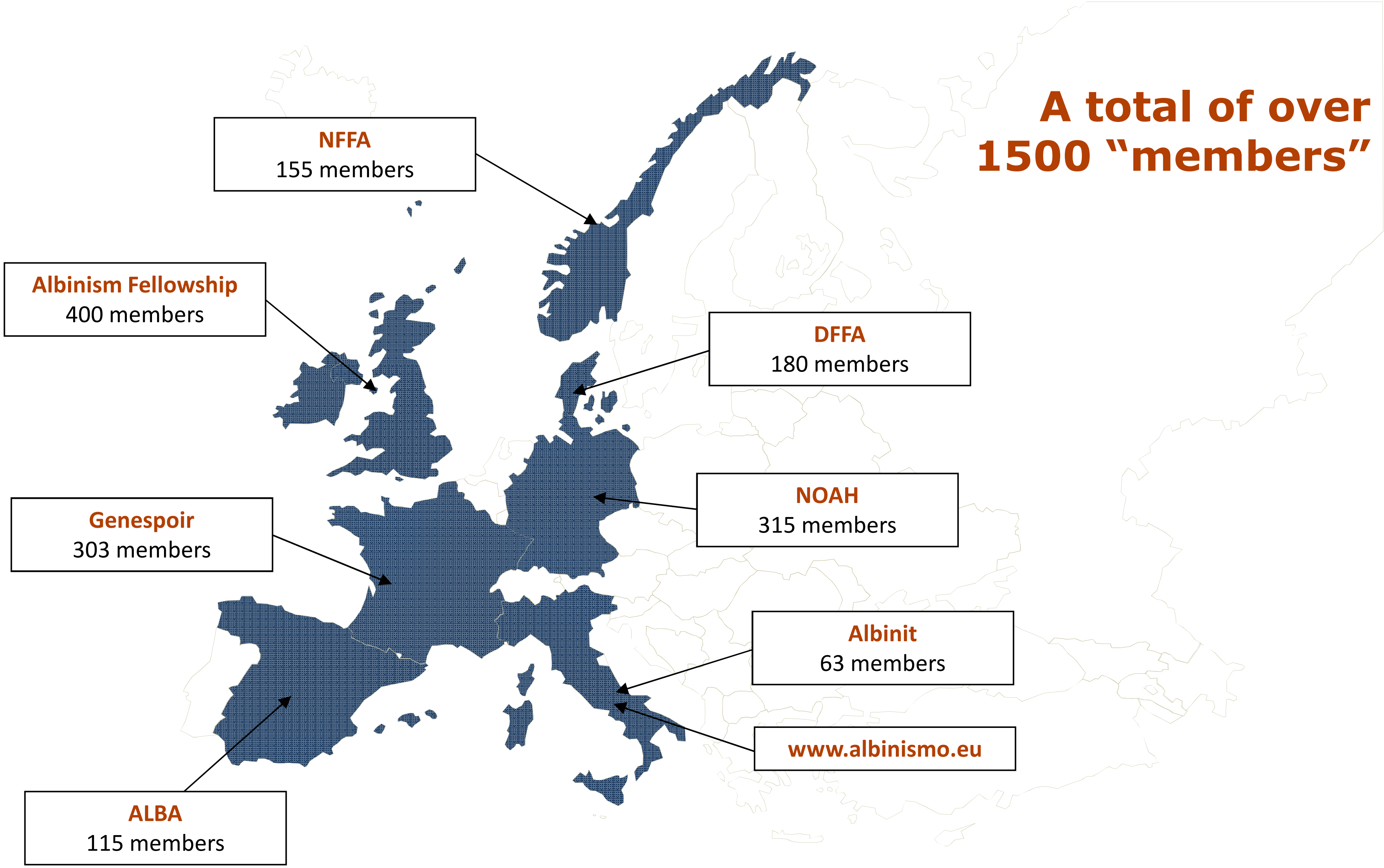
Albinit
2008

www.albinismo.eu
2007

ALBA
2005

Landscape of patients' organisations

A total of over 1500 "members"



NFFA
155 members

Albinism Fellowship
400 members

DFFA
180 members

NOAH
315 members

Genespoir
303 members

Albinit
63 members

www.albinismo.eu

ALBA
115 members

Key areas of activity

- **Informing, assisting, supporting families:**
  - Post-diagnosis support
  - Exchange of experience, social interaction, psychological support
  - Internet (website, forum, Facebook)
  - Meetings and gatherings
  - **Challenges:** value of membership, balance parents + children / grown-ups, retention of members, distance

Key areas of activity

- **Healthcare and medical world:**
  - Information on assistance and benefits to members
  - Contacts with medical practitioners (specialised hospitals, “expert” centres, conferences)
  - **Expectations:**
    - **Good practices for diagnosis (and announcement of diagnosis)**
    - **Concentration of expertise and knowledge**
  - **Challenge: how to engage with the medical world?**

Overview of missions

- **Research:**
  - Contacts with researchers (Denmark, France, Italy, Spain, UK)
  - Funding of research projects (France)
  - **Messages:**
    - All organisations see **research as vital**
    - Need for community of patients to stand united and be **visible to back the research community**
    - **Coordination of research community** needed
    - **Research agenda** and prioritisation?
    - Need to **communicate on research** to members of our organisations

Conclusions of yesterday’s meeting

- Commonalities in the missions, challenges and expectations
- Work on the following collaboration opportunities:
  - Exchange of experience (community building and “management”)
  - Data- and knowledge-sharing (e-infrastructure)
  - Humanitarian projects (?)
  - Consolidating knowledge and good practices on medical aspects
  - Research:
    - Visibility of the community of patients
    - Strong connection with research community
    - Support through fund-raising (“Horizon 2020” as a funding opportunity to target)