EB-CLINET
Connection | Communication | Collaboration

4th EB-CLINET CONFERENCE
26-27 Sept 2017, Salzburg, Austria

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University Hospital of Dermatology | EB House Austria | EB Academy
EB-CLINET – Clinical Network of EB Centres and Experts

- **EB House Austria (Centre of Expertise)**
  - EB Clinical Unit: Dr. Anja Diem
    - Counselling
    - Treatment
    - Clinical projects
  - EB Research Unit: Dr. habil Julia Reichelt
    - Diagnostics
    - Basic research
    - Specific research fields and groups
  - EB Academy Unit: Dr. Gabriela Pohla-Gubo
    - Training & education
    - Networking
    - Fundraising & public relations

- **University Hospital of Dermatology**

- **EB Academy**
  - To share experience & knowledge
  - To build and maintain networks
  - To support DEBRA Austria in FR & PR

- **EB-CLINET**
  - Project of the EB Academy (since 2011)
  - Platform for connection, communication and collaboration
Why do we need EB-CLINET?

- Experts are as rare as the disease
- Specialists need to be informed about the latest news and developments
- Health care professionals need to be connected
- New/more experts need to be recruited and trained
- Patients need to be directed to competent (local) health care professionals
- Patients need to be sufficiently educated about the specifics of their (individual) disease
- Patients need to be informed about the latest developments

EB-CLINET to serve....
What can EB-CLINET provide?

- Information
- Worldwide contacts
- “Collective (swarm) intelligence”...

... shared or group intelligence that emerges from the collaboration, collective efforts, and competition of many individuals and appears in consensus decision making (Wikipedia)

EB-CLINET provides a cross-border networking platform

EB-CLINET collaborates with specialists around the globe
How does EB-CLINET facilitate collaboration and support?

- **Recruitment of partners**
  - Personal contacts (clinicians, patients, DEBRAs...)
  - Meetings

- **Collection of data (EB-CLINET partnership)**
  - General Questionnaire
    - (mailto:office@eb-clinet.org)

- **Direct contacts**
  - Interactive maps

→ Annual update!

→ Anonymised EB-CLINET E-mail addresses!
Connection | Communication | Collaboration

**Connection**
- Assistance for any EB related questions and needs – from patients or experts
- Direction of specific enquiries to a certain person in charge/selected country

**Communication**
- Information about trainings, meetings
- Updates concerning the EB-CLINET work streams
- Information on recent developments regarding treatments and research
- Updates on clinical trials, or calls for recruitment of collaborators

**Collaboration**
- EB-CLINET partners – advice and assistance
- DEBRAs – registry, CPGs, meetings
- EBWB – patient support, recruitment of partners, education & training
- ERN-Skin – sub-thematic group on EB (advisory board)
EB-CLINET – Partners (September 2017)

- **EB-CLINET Partners:** 88
- **EB-CLINET Countries:** 58

**Partners coming from:**

- Argentina
- Australia
- Austria
- Belgium
- Bosnia
- Brazil
- Bulgaria
- Canada
- Chile
- China
- Colombia
- Croatia
- Cyprus
- Czech Republic
- Denmark
- Egypt
- Estonia
- Finland
- France
- Germany
- Greece
- Hungary
- India
- Indonesia
- Ireland
- Israel
- Italy
- Japan
- Kuwait
- Lithuania
- Luxembourg
- Macedonia
- Mexico
- Montenegro
- Netherlands
- New Zealand
- Norway
- Palestine
- Peru
- Poland
- Portugal
- Romania
- Russia
- Serbia
- Singapore
- Slovakia
- Slovenia
- South Africa
- South Korea
- Spain
- Sweden
- Switzerland
- Taiwan
- Turkey
- Ukraine
- UAE
- United Kingdom
- USA
EB-CLINET Conferences

4th EB-CLINET Conference
26-27 September 2017, Salzburg, AT

5th EB-CLINET Conference
2019, London, UK

Please find all information on our website: www.eb-clinet.org