



EB-CLINET

Connection | Communication | Collaboration

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

Gabriela Pohla-Gubo, PhD
University Hospital of Dermatology | EB House Austria | EB Academy

EB-CLINET – Clinical Network of EB Centres and Experts

■ EB House Austria (Centre of Expertise)



University Hospital of Dermatology



EB Clinical Unit

Dr. Anja Diem



- Counselling
- Treatment
- Clinical projects

EB Research Unit

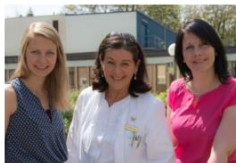
Dr. habil Julia Reichelt



- Diagnostics
- Basic research
- Specific research fields and groups

EB Academy Unit

Dr. Gabriela Pohla-Gubo



- Training & education
- Networking
- Fundraising & public relations

■ EB Academy

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

■ EB-CLINET

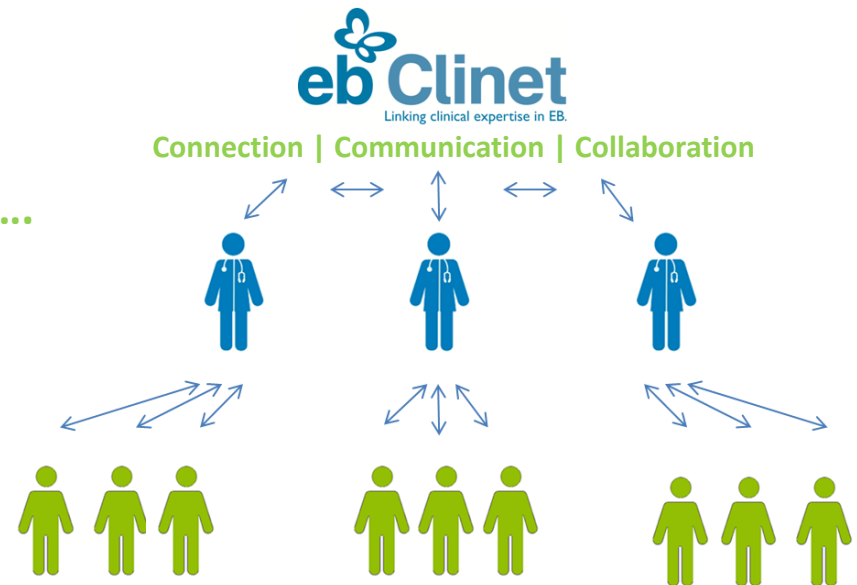
- Project of the EB Academy (since 2011)
- **Platform for connection, communication and collaboration**

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

EB-CLINET to serve....

- 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



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)

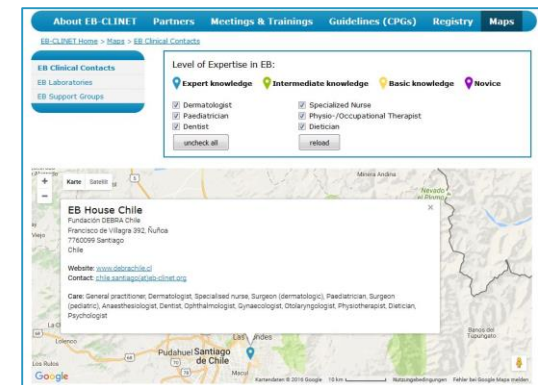
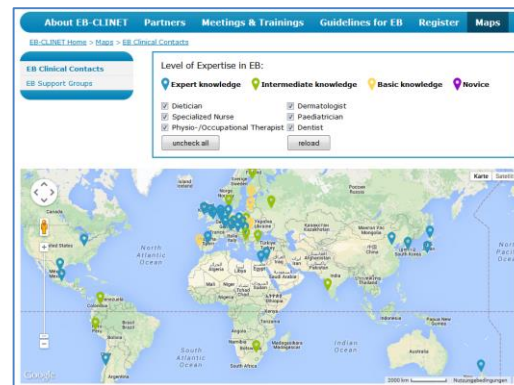
- General Questionnaire
(mailto:office@eb-clinet.org)

→ Annual update!

- Direct contacts

- Interactive maps

→ 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)

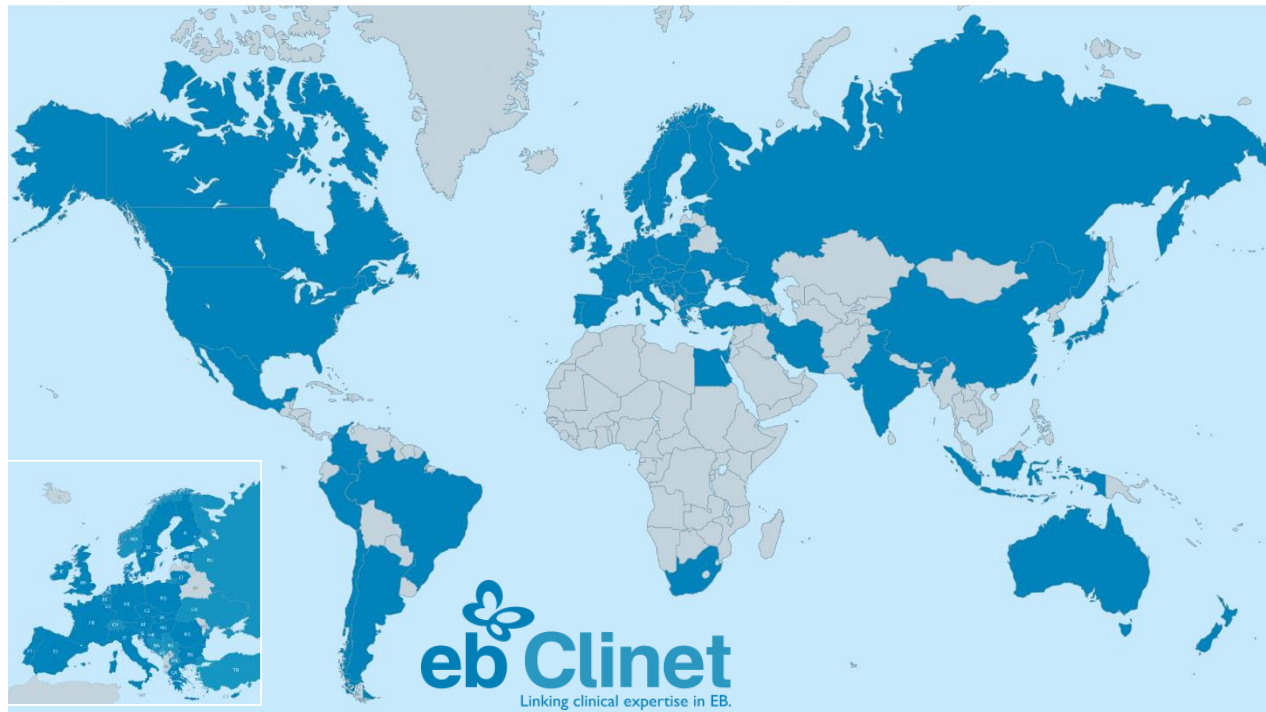
EB-CLINET – Partners (September 2017)

- 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

Goodbye
Au revoir
Adiós
Merci beaucoup
Dank
Tot ziens
Thank you
Grazie
Dank u wel
Auf Wiedersehen
Arrivederci
Gracias