



EB-CLINET

Connection | Communication | Collaboration

DEBRA International Congress
24-26 November 2016, Wellington, New Zealand

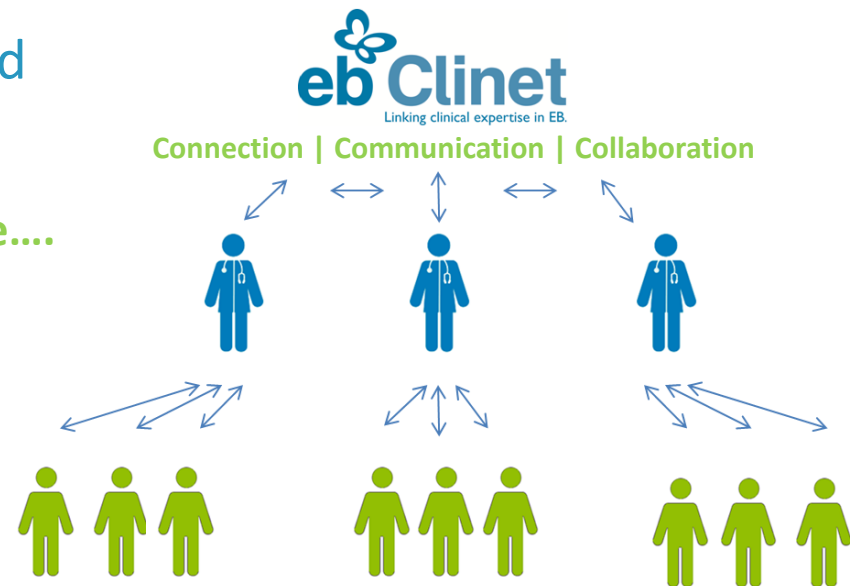
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Why do we need EB-CLINET?

- 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)

- **Group specific mailing lists**

e.g. directed to all nurses or surgeons

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!

EB-CLINET General Questionnaire
(1) General Data

Date: DD / MM / YYYY

Country: _____

City: _____

Languages: _____
Language 1: _____
Language 2: _____
Language 3: _____

Profession/Organization: _____

Please specify in which capacity you have experience with EB:

☐ Clinician/Physician ☐ Researcher

☐ Therapist ☐ Diagnostic Laboratory

☐ Nurse ☐ Patient Representative

Other (please specify): _____

Level of Expertise in EB:

☐ Expert knowledge ☐ Basic knowledge

☐ Intermediate knowledge ☐ Novice / New to EB

Contact:

Person responsible / first contact:

Position: _____

Title: _____

First name: _____

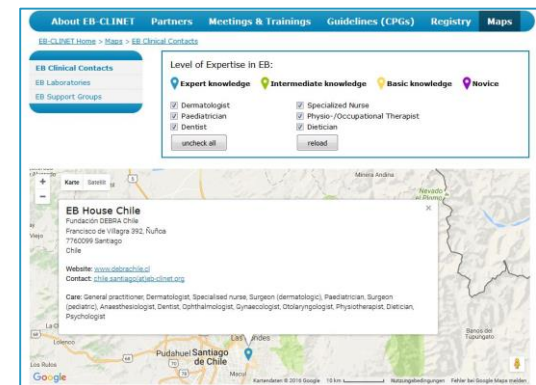
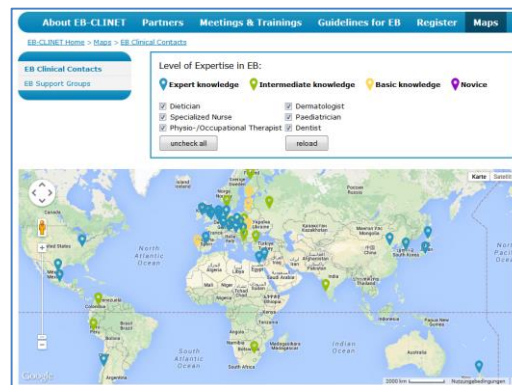
Last name: _____

E-mail: _____

■ Direct contacts

- Interactive maps

→ Anonymised EB-CLINET
E-mail addresses!



EB-CLINET & EB Without Borders (EBWB)

- Requests from different sources
 - Clinicians, patients, family members, DEBRA staff...
- Close cooperation and coordination
 - EB-CLINET, EBWB, DEBRA International

WWW.EB-CLINET.ORG
SUPPORT FOR CLINICAL TRIALS
CLINICAL FOCUS
EB-CLINET
BUILDING CAPACITIES
MEDICAL ADVICE
ON-SITE TRAINING
INFORMATION PLATFORM
EDUCATION
CLINICAL CONTACTS
GUIDANCE IN SETTING UP AN EB CLINIC

SUPPORT IN FINDING LOCAL CONTACTS
PARTNERSHIP BUILDING
PATIENT SUPPORT FOCUS
HELPING IN AREAS WITHOUT DEBRA STRUCTURE
EBWB
BUILDING CAPACITIES
ADVOCACY
EB NETWORKS
GUIDANCE IN SETTING UP A NATIONAL DEBRA CHAPTER
ON-SITE MENTORING
PARTNERSHIP PROGRAM
WWW.DEBRA-INTERNATIONAL.ORG

EB-CLINET – Partners (October 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		



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Thank you for your attention!