

Experience in setting up integrated care

EB House Austria
(member of ERN Skin)

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Epidermolysis bullosa (EB)



RARE

1 : 17,000

One in seventeen thousand live births affected.

GENETIC



Hereditary, but parents may not know they are carriers.

ANYONE



Equally affects Both Genders and Every Ethnic Group.

NOT CONTAGIOUS



Being genetic, there is no risk of 'catching' EB.

NO CURE



yet ! But Research is hopeful. Current treatment is based on Wound Care and Pain Management.

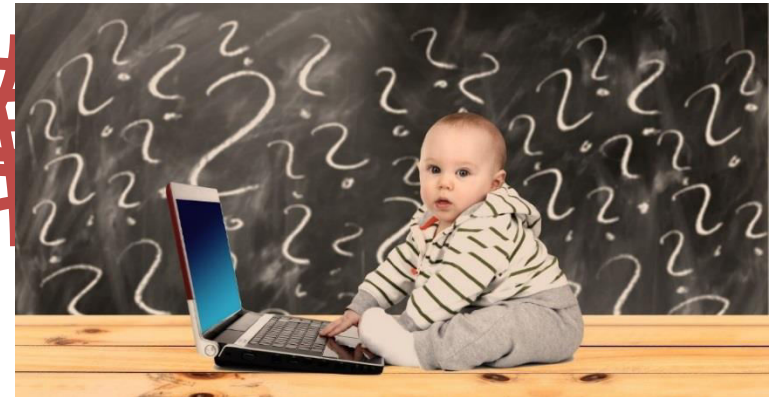
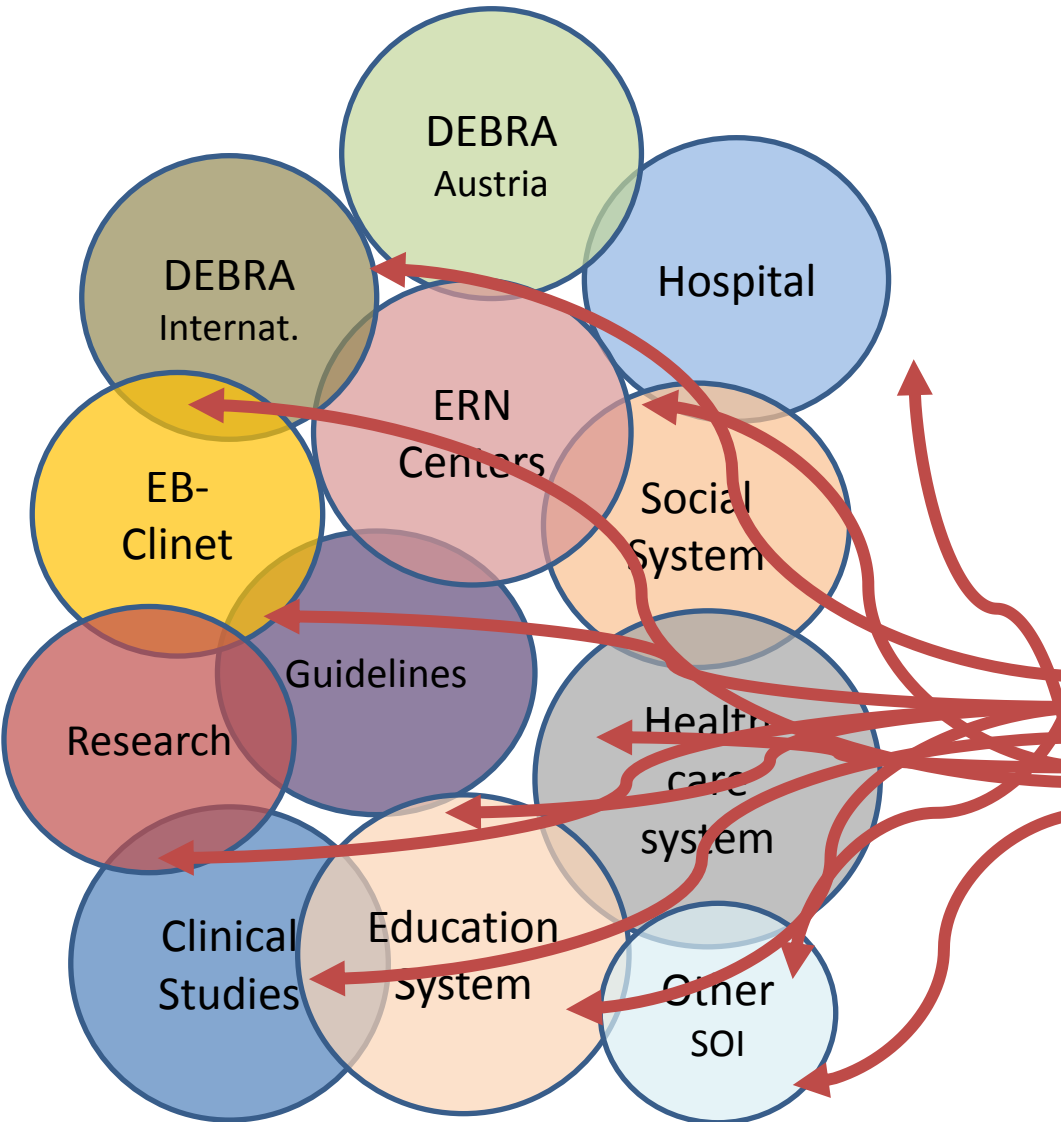
- ❖ ~37 subtypes
- ❖ huge variety of symptoms
- ❖ multi-systemic disease
- ❖ different levels of severity
- ❖ life expectancy widely varying

- long list of problems and needs
 - medical, social, psychological, nutritional, every day life, financial,
- profound changes during lifetime

EB-Patients and Families

- **exhausting**
- **frustrating**
- **time consuming**
- **confusing**
- **insufficient**

for everyone!

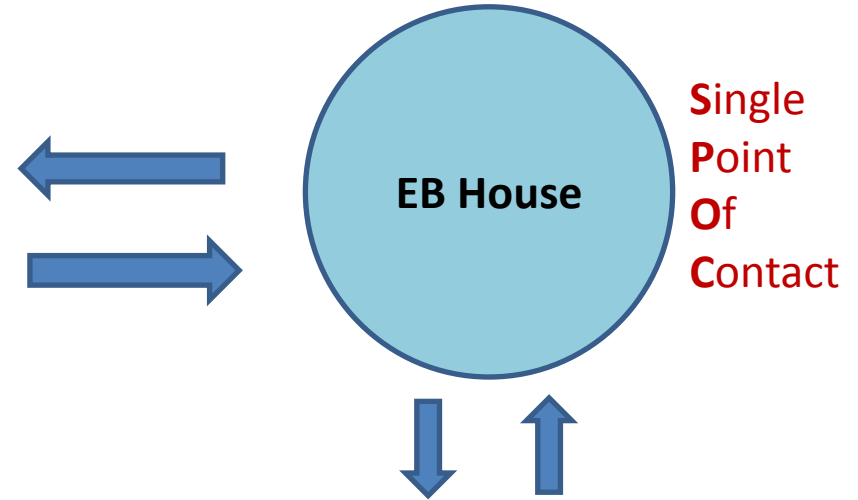
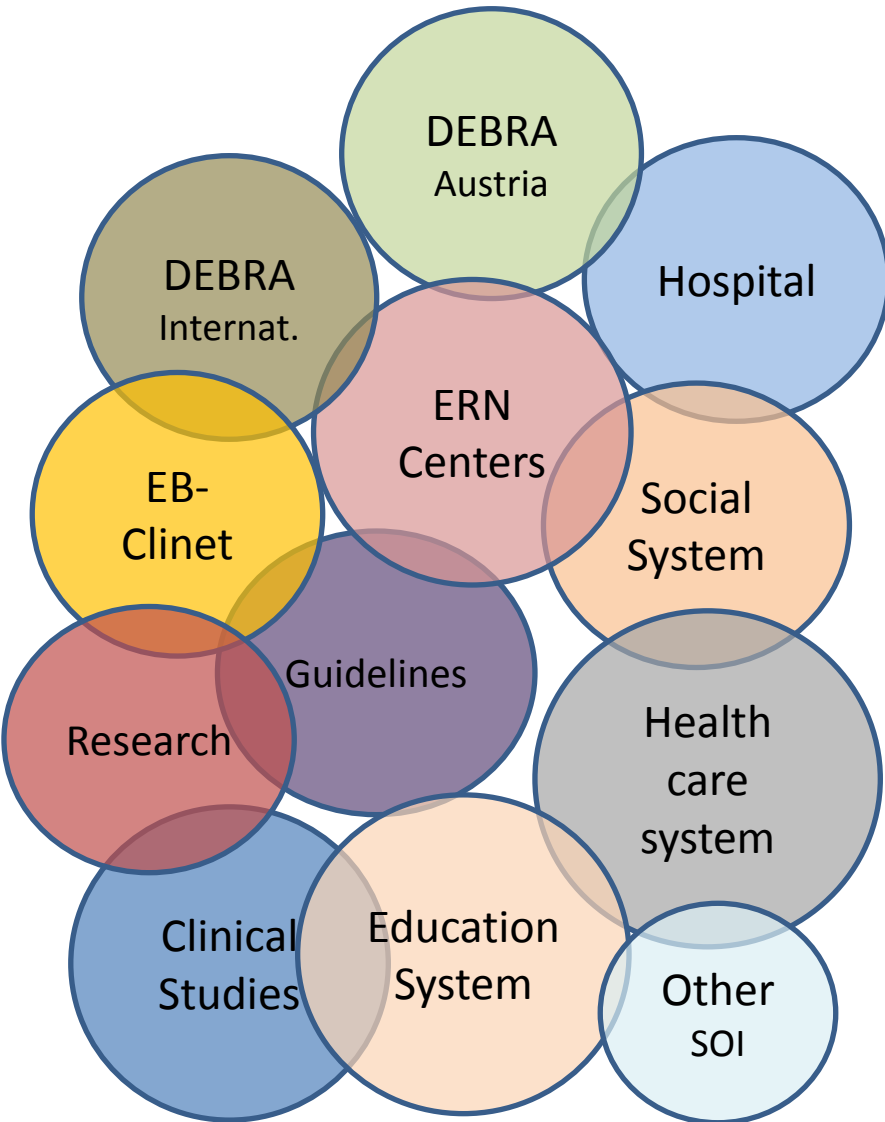


What do we want to achieve?

we = patients, families and health care professionals

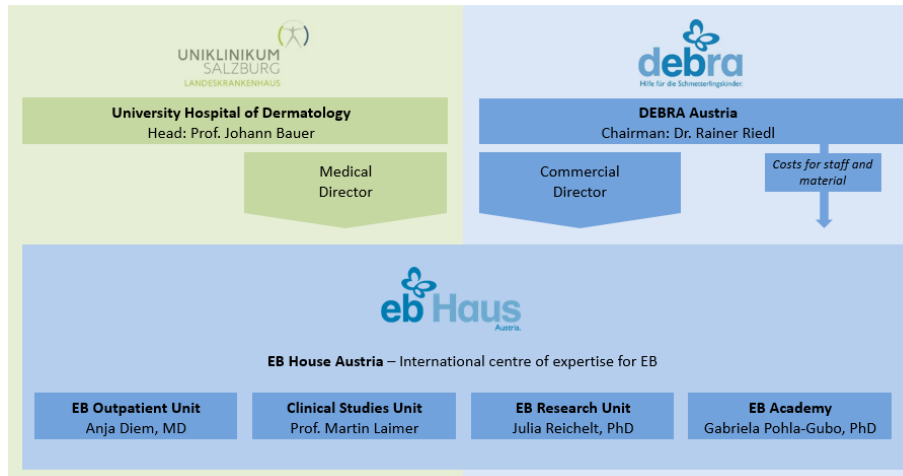
- Goal 1: To improve quality of life of each individual living with EB
 - ... „quality of life“- very individual ideas about what this means exactly!
- Goal 2: To enable „clinical best practice“ care for each individual living with EB

EB-Patients and Families



EB House

- ❖ cooperation of DEBRA Austria and Department of the University Clinic of Dermatology, Salzburg
- ❖ opening November 2005
- ❖ costs mainly funded by DEBRA Austria



Univ. Clinic of Dermatology

EB House Austria

EB Patient Care

Core Team EB House

2 MDs (1,2 FTE)
3 nurses (2 FTE)
1 office manager (0,75 FTE)
1 assistant (0,5 FTE)



Extended Team (DEBRA)

social worker (0,75 FTE)
2 psychologists (0,25 FTE and on demand)



„Back-Up“

- other EB House Units (Academy, Research, Clinical Studies)
- University Clinic of Dermatology SALK (pediatric surgery, physiotherapy, nutrition, ophthalmologist, ENT, radiology,)
- **local health care providers**



What do we offer?

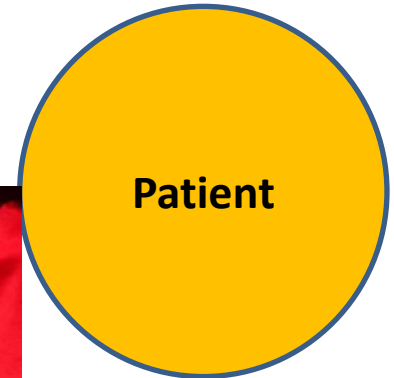
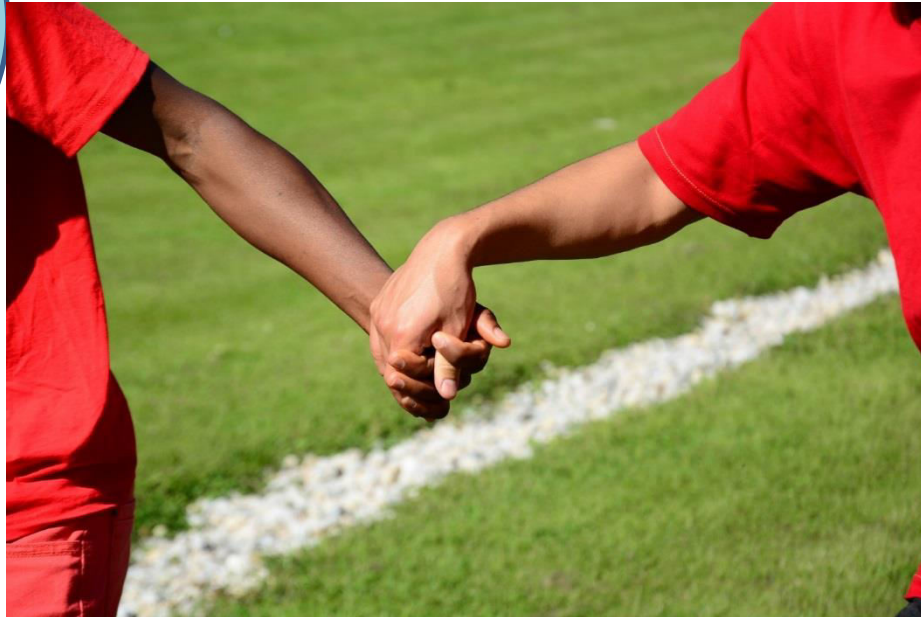
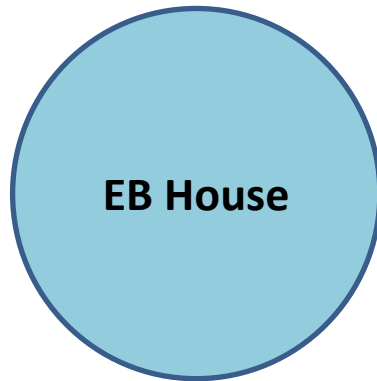
- therapeutic advice („best clinical practice“)
 - multidisciplinary team
 - local, national and international network
 - including all aspects of EB (wound-care, nutrition, pain, physiotherapy, dental care, operations,.....)
 - complementary medicine
 - children and adult services
 - cooperation with local services (near patients home)
 - psychological care
 - social counselling
 - guidance through bureaucracy
 - participation in clinical studies
 - counselling regarding nursery, school, work, sports,...
 - connection with patient organisation
-
- time (!)

Remaining Challenges

- still too many questions with no or disappointing answers
- long distances between patients home and EB house
- admission to hospital
- no 24/7 service
- growing patient number from other countries
 - we are set up in a public hospital with limited possibilities to include patients from abroad
- we are still depending on donations
- Austrian health care system undergoes profound changes
 - increasing shortage of medical doctors and nurses
 - growing gap between public and private medical system
 - difficult to build solid, long-term interdisciplinary teams
- bureaucracy...

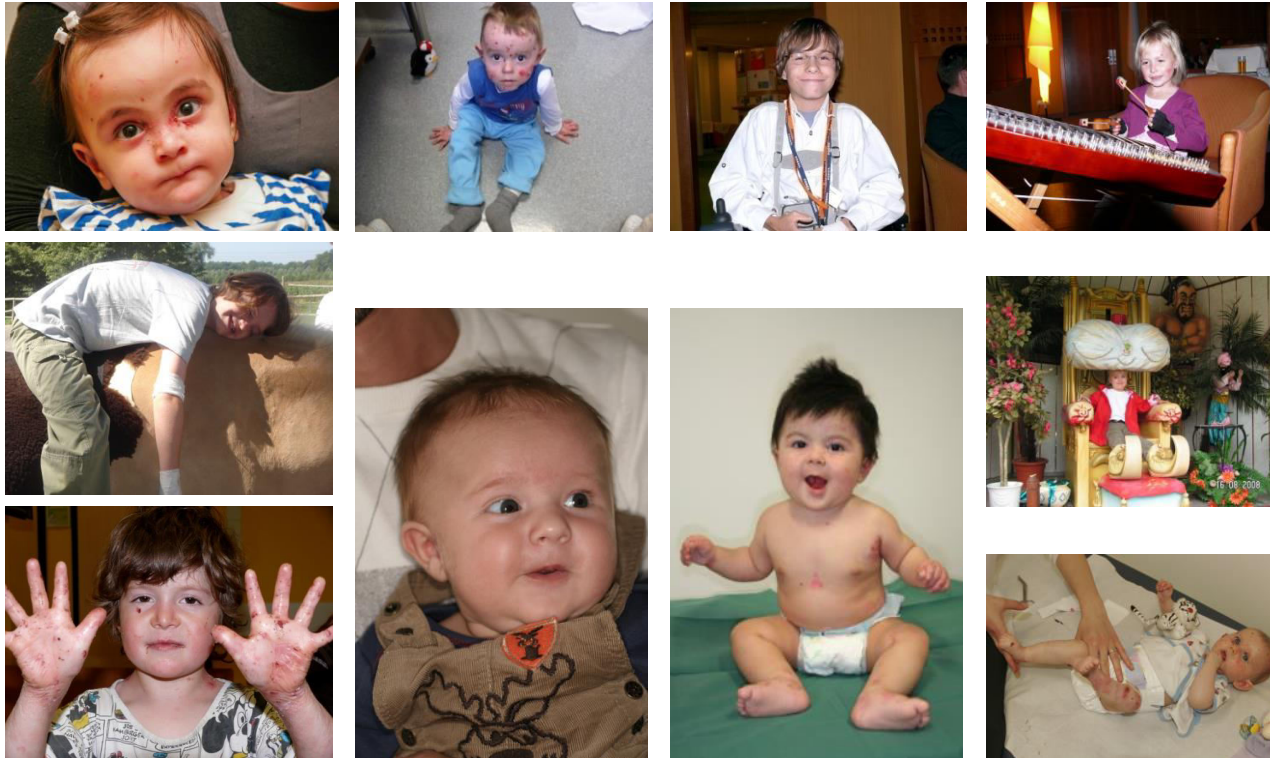
Single Point of Contact

„What is the suitable therapy for this special person with this special life in these special circumstances?“



- ✿ **2017 designated Centre of Expertise for EB and Genodermatoses (Ministry of Health, Austria) and member of the ERN-Skin (EC)**

Thank you!



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