A. Diem*, K. Ude-Schoder, B. Sailer

General Hospital Salzburg (SALK), Paracelsus Medical University (PMU), Salzburg, Austria

Epidermolysis Bullosa (EB)

- EB is a rare genetic skin disease which affects approximately 30,000 patients in the EU.
- EB is the term for a heterogeneous group of rare genetic skin disorders characterized by fragility of skin and mucous membranes following even minor trauma. Severe extracutaneous complications like nail and tooth decay, fusion of fingers and toes, malnutrition, or even skin cancer, can also occur.
- Currently a causative EB treatment is still lacking.

EB House Austria

- In 2005 the EB House Austria (EB-Haus Austria) was established as a cooperation between the patient support organisation DEBRA Austria and the General Hospital Salzburg/Paracelsus Private Medical University.
- As a special clinic for the multi-disciplinary care of EB patients, supplemented by relevant EB research and continuous EB-related education and training, the EB House Austria meets all relevant criteria for a European Centre of Expertise for the treatment of this severe disease.

Life with EB

Living with EB means to live with a severe disease. Blisters, wounds, pain and the necessity for time consuming treatments are daily routines for everyone living with this challenging condition. At the same time families affected by EB try to live a normal life with its highs and lows, successes and failures, wishes and dreams, strengths and weaknesses. Every form of EB has its own special problems. Experiences with the disease will differ from one patient to another. Therefore, individualized care for patients is necessary. To face everyday life, patients should be prepared for possible problems and pitfalls, but also for the opportunities that are given to them.

EB Handbook

The main purpose of the “EB Handbook” is to provide all needed information about EB to get a better idea of this disease and all its various forms and consequences. Furthermore it provides recommendations and options for possible treatment of this disease.

Conclusion

- The main purpose of this online “EB Handbook” is to provide all needed information about EB to get a better idea of this disease and its various forms and consequences. It is intended to serve as a base to help overcome the various challenges of living with EB.
- We strongly believe that this can contribute to a better quality of life for people with this challenging disease.