

EB-CLINET – An International Contact Point for Health Care Professionals working with Epidermolysis Bullosa (EB)

G. Pohla-Gubo¹, I. Bregulla¹, J. Rebhan¹, R. Riedl²

¹EB House Austria, University Clinic of Dermatology, Paracelsus Medical University, Salzburg, Austria; ²DEBRA Austria

EB-CLINET and the EB House Austria

EB-CLINET – the clinical network of EB centres and experts – aims at linking the global community of EB health care professionals (HCPs).

As EB is a rare genetic skin disease (Fig. 1 & 2), HCPs face a scarcity of relevant knowledge and expertise. With a long-standing experience in the treatment of EB patients in Austria, a specialised centre has been established in 2005. The EB House Austria is a unique clinic for patients with EB, encompassing units for patient care, clinical studies, research and an academy (Fig. 3). It is therefore the first institution in Austria designated by the Ministry of Health as “Centre of Expertise for Genodermatoses specialised in EB”. The EB House is also part of the EB sub-thematic group of the ERN-Skin network (Ref. 1).

The purpose of EB-CLINET, founded in 2011 by the Academy of the EB House Austria, is to share supranational competence and knowledge, to strengthen clinical cooperation, and to foster collaboration for upcoming clinical trials.

The EB-CLINET community is continuously growing and currently counts partners in 58 countries. Information about these EB contacts is displayed in directories on the EB-CLINET website (www.eb-clinet.org), thus being freely available (Fig. 4). An EB-CLINET newsletter is published on a regular basis to keep the EB community informed about helpful tools, such as medical devices, training videos or updates on clinical practice guidelines. Recent developments regarding clinical trials, research activities, training possibilities or events are other topics of the newsletter. Furthermore, HCPs can seek clinical advice from colleagues all around the world via this communication channel.

Conferences promote international collaboration

Organised by the EB-Academy and financed by DEBRA Austria, the 4th Conference of EB-CLINET was held together with the 5th World Conference of EB Research in 2017 in Salzburg, Austria. Both established EB conferences were combined for the first time, as the number of clinical trials regarding therapies for EB has been increasing rapidly over the last couple of years, underlining the need of clinicians and researchers to work closely together. Under the slogan ‘from lab bench to bedside’ more than 300 delegates from 36 countries (Fig. 5), including representatives from biopharma and healthcare companies, engaged in lively exchange addressing progression in preclinical therapy development, clinical trials as well as best medical practice (Ref. 2).

Conclusion

International communities for specific rare diseases as well as the exchange among researchers and clinicians are essential to drive clinical trials and therapy development. EB-CLINET, located in Austria, is a well-established platform for networking and sharing information, which provides a basis for this valuable exchange. The emerging international synergies benefit not only the patients in the initiating country, but they contribute to a global rare equity, making information easily accessible and offering support where it is needed.

References

1. Laimer, M., Pohla-Gubo, G., Diem, A., Proding, C., Bauer, J. W., & Hintner, H. (2017). Epidermolysis bullosa House Austria and Epidermolysis bullosa clinical network: Example of a centre of expertise implemented in a European reference network to face the burden of a rare disease. *Wiener Klinische Wochenschrift*, 129(1), 1–7.
2. Uitto, J., Bruckner-Tuderman, L., McGrath, J.A., Riedl, R., Robinson, C. (in press). EB2017 – Progress in Epidermolysis Bullosa Research toward Treatment and Cure. *Journal of Investigative Dermatology*. doi: 10.1016/j.jid.2017.12.016



Fig. 2 EB everyday, © R. Hametner

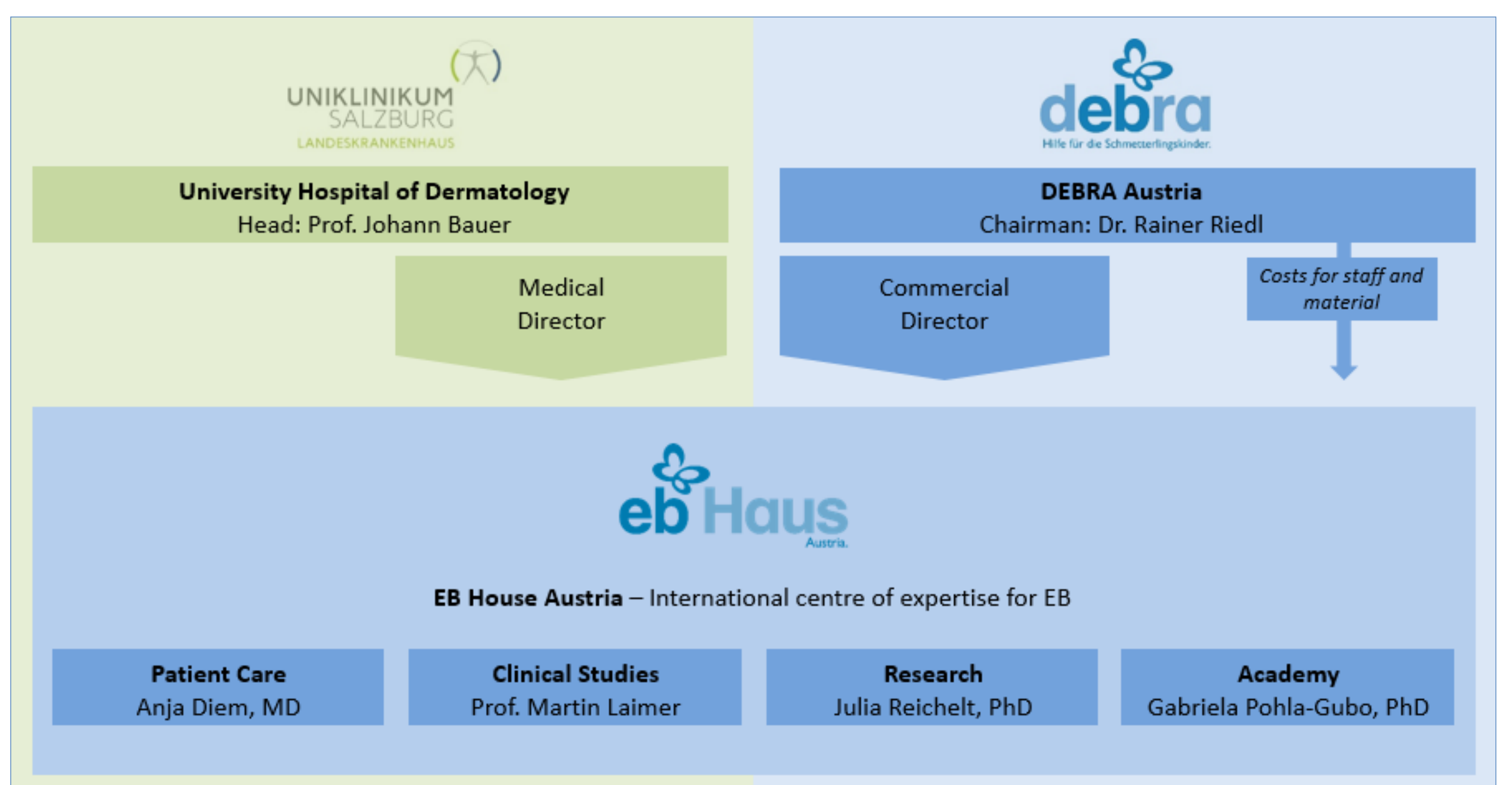


Fig. 3 Organigram of the EB House Austria

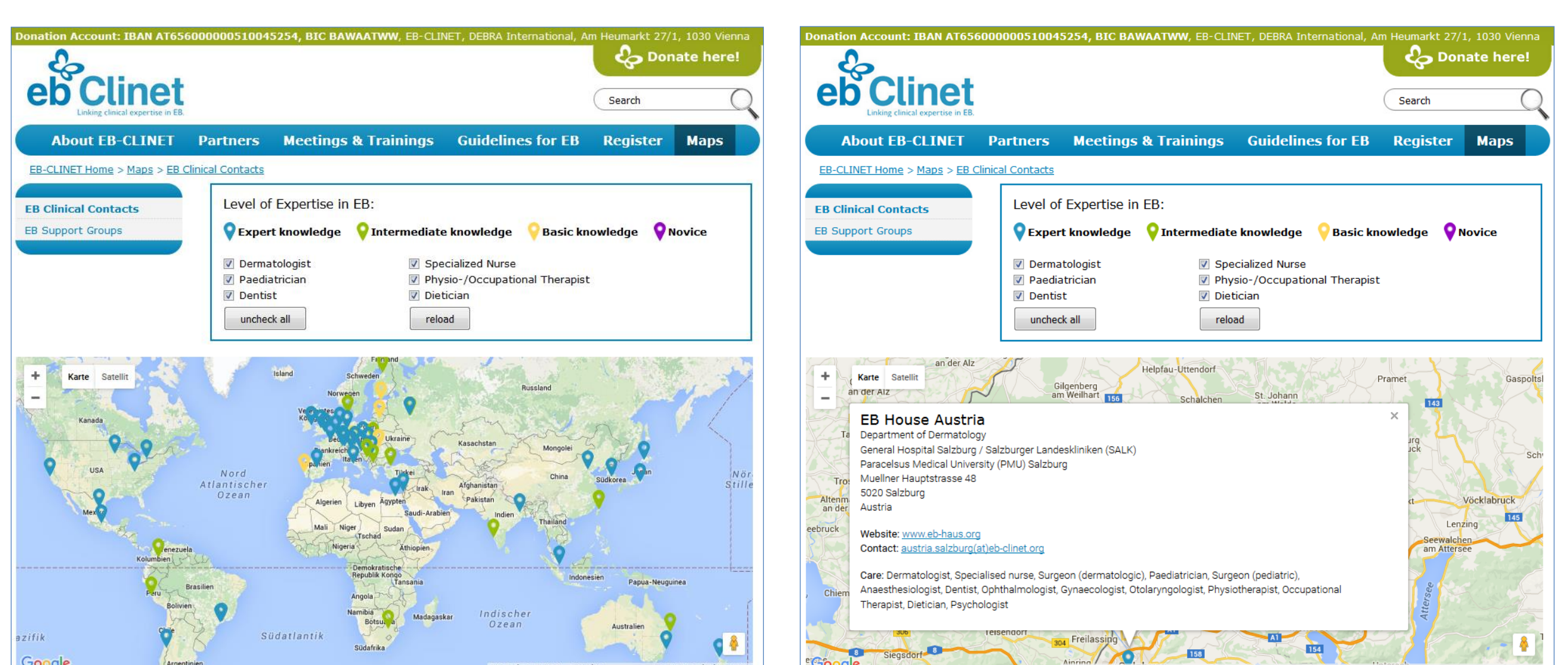


Fig. 4 EB contact directories



Fig. 5 EB2017 and EB-CLINET Conference, Salzburg 2017, © R. Hametner