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IMPROVING THE LIVES OF THE “BUTTERFLY CHILDREN.”

Tecan Journal Article.



“Seeing the patients every day visiting our outpatient clinic is a strong motivation for our research” reflects Dr. Roland Zauner, TechOps and Scientific Lead at the EB Research Institute in Salzburg, Austria. “This is what drives the team.”

Epidermolysis bullosa or “EB” is a cruel inherited rare disease, affecting approximately 1 in 17,000 children. Fundamentally a dermatological disease, the inherited mutations affect structural proteins including various collagens and keratins, resulting in a catastrophic disintegration of the different layers of the skin and severe blistering over the entire body. The skin becomes ultra-sensitive to touch or abrasion; its fragility being likened to that of a butterfly’s wing. This has led to the common name of “butterfly children” for the affected individuals.

Although the impact on the skin is the most well-known symptom, EB more widely affects the internal mucosa and can cause impairment of lung and intestinal function, problems with tooth enamel decay and difficulty swallowing, to name just a few.

Within the patient population, different levels of severity are observed. Around 70% of patients are affected by EB Simplex, the subtype including some of the milder forms of EB. Although these patients can expect a normal lifespan, life-long management of the symptoms is still required. Dystrophic EB, the most severe form, accounts for around 20% of cases. These patients also have a high risk of developing aggressive skin cancers and the outcome is often rapidly fatal.

Although frequently referred to as a rare disease, it is estimated that there are currently as many as 1 million patients worldwide. With such a devastating impact on those affected and their families, the need for ongoing research is extremely high to look for new therapies to improve the quality of life and to pursue the hope for an eventual cure.



Headquartered in Vienna, DEBRA Austria is one of several international patient organizations dedicated to supporting the local and global EB community. In 2005 it established the EB house within the University Hospital of Salzburg (SALK).

“EB House has a unique set-up and we are delighted to celebrate our 20th anniversary in 2025” says Dr. Zauner.

EB House consists of three units, an outpatient clinic, an academy for training physicians and for international communication and a clinical trial center. A research team, originally incorporated into the EB House organization, has recently been reorganized into the EB Research Institute (EB RI), a non-profit organization funded from charitable donations to DEBRA Austria and SALK. It is fully dedicated to developing therapies and a cure for this devastating disease.

“Being physically close to the outpatient clinic brings the importance of our work home to us every day” continues Dr. Zauner. “Furthermore, there are additional benefits in that clinical trials are run on site and we have been able to build up an extensive biobank of tissue samples and establish cell lines which are a highly valuable resource enabling our research.”

“Research into EB therapy can be split into causal therapy and symptomatic therapy. Encouraging signs of progress can be seen in the first regulatory approvals for therapies that started coming online in 2022. These include gene-replacement therapies as well as a drug that supports wound healing, so both causation and the symptoms are being addressed”

Dr. Zauner stresses however that further progress is needed: “So far all of the therapies that have been approved for the European market are for topical use, so we still need treatments for internal manifestations, such as impairments of the digestive tract .”

The mission of the EB Research Institute is to develop treatments for EB also by bridging the existing molecular understanding of the mechanisms of the disease with therapeutic innovation and this is where Tecan comes in.

The relationship between Tecan and EB House goes back almost a decade. Originally a Spark® M10 multi-mode reader with an additional imaging module was installed and the positive impact the team saw on their workflows led them to add a Spark® Cyto. “The Spark® Cyto has opened more doors for us” continues Dr. Zauner. “The ability to mix assays simultaneously, for example viability with visualization and actual cell counting was something we could not do before. Spark® Cyto allows us to count dead cells using simple fluorescent stainings plus the latest software that utilizes AI deep learning has algorithms that even allow bright field counting. This allows us to run certain assays stain-free, eliminating the risk of a staining agent interfering with our experiment and allowing continuous kinetic measurements over a long time period compared to endpoint assays. Finally running screening assays in 96 well plates is obviously much faster!”

The team also appreciate the collaborative partnership with Tecan. “Tecan listens and reacts. The role of Tecan’s application specialists is crucial here. We are able to give our input to enable, for example, the improvement of algorithms and we always appreciate Tecan’s help to build robustness into our assays”.

Tecan’s purpose to scale healthcare innovation from research to the clinic is well reflected in the collaboration with the EB Research Institute. Looking to the future, Dr. Zauner says the fundamental goal of improving the lives of butterfly children will not change. “This is a big challenge and needs a concerted effort, however it is a very optimistic time.”

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