

## Press Release

# DEBRA Research and the University Medical Center Groningen Launch Dedicated Clinical Trial Site for Epidermolysis Bullosa

- The new partnership strengthens local and international research infrastructure for Epidermolysis bullosa (EB), improving access to studies and supporting patient-focused research.
- DEBRA Research also funds the international COSEB project, intended to standardize outcome measurements for future EB trials.

**Munich, Germany, and Groningen, the Netherlands, 19 January 2026** - DEBRA Research gGmbH, a global non-profit organization dedicated to advancing research and drug development for Epidermolysis bullosa (EB), and the University Medical Center Groningen (UMCG) in the Netherlands, are pleased to announce the establishment of a dedicated EB clinical trial site at the UMCG. Specialized trial sites are essential for successful therapy development in rare diseases, as they centralize expertise, improve trial efficiency and recruitment, and ensure high-quality, patient-centric approaches. The new collaboration strengthens translational EB research infrastructure and expands clinical trial capacity in a region recognized for its expertise in the diagnosis and care of people living with EB.

EB is a group of rare and painful genetic skin disorders characterized by extremely fragile skin, leading to blisters and chronic wounds from even minor friction or trauma. The UMCG Center of Expertise for Blistering Diseases brings extensive clinical experience and a strong commitment to advancing EB research. Through this partnership with DEBRA Research and under the leadership of Principal Investigator Dr. Marieke C. Bolling, the Groningen site is now equipped to conduct both company-sponsored and investigator-initiated clinical trials. The site will also participate in emerging international EB initiatives, such as the planned EB Registry and the Clinical Trial Network, and contribute to the scientific community through publications and shared data.

DEBRA Research is also supporting the international project “Core Outcome Sets for Epidermolysis Bullosa (COSEB)”, initiated and led by the Groningen team. COSEB aims to harmonize and optimize outcome measurement across EB studies, ensuring that future clinical trials generate robust, comparable, and patient-relevant data.

“This support not only enables us to enhance care and research for the patients in our own center, but also ensures that, through international collaboration, patients in other countries benefit from new insights generated by this process, hopefully leading to a faster and more efficient way of bringing effective therapies to patients,” said **Marieke Bolling, Head of the EB part of the UMCG Center of Expertise for Blistering Diseases.**

“Robust infrastructure is one of the most important enablers of progress in rare diseases,” said **Christoph Coch, Managing Director of DEBRA Research.** “By strengthening trial capacity in Groningen and supporting global initiatives like COSEB, we are helping create the foundation that researchers, clinicians, and industry partners need to deliver meaningful therapeutic progress for the EB community.”

By reinforcing local capacity in Groningen and contributing to the international EB research infrastructure, this collaboration represents a meaningful step toward accelerating therapeutic innovation for people living with EB worldwide.

## **About the University Medical Center Groningen**

The University Medical Center Groningen is home to the Dutch National Expertise Center for Blistering Diseases, which includes EB. The EB Center in Groningen is led by Dr. Marieke Bolling and is responsible for the diagnosis, care and treatment of all people with EB in the Netherlands. It also provides care to patients from neighboring countries, together serving over 500 patients across all age groups.

The Dutch EB Center has been in existence for more than 30 years and has built a detailed and extensive national registry. Over the years, it has contributed significantly to improving diagnosis and care, as well as to the development and investigation of novel therapies for EB worldwide. The goals of the center are to provide every patient with an early and precise diagnosis, deliver the best possible care – preferably in the home setting – and ultimately make socially and financially acceptable, targeted, disease-modifying therapies available to all patients.

## **About DEBRA Research**

DEBRA Research is a non-profit organization dedicated to advancing treatments and cures for EB, a rare life-limiting genetic condition. As the research arm of DEBRA Austria - a patient organization established in 1995 to support individuals living with EB – DEBRA Research collaborates globally with academia, biotech, pharma, patient organizations, and regulatory bodies to drive innovation. DEBRA Research focuses on translational research and clinical development to address the unmet needs of people living with EB. Its goal is to accelerate the discovery and development of treatments improving their quality of life, while striving for a future where EB is curable – a “world without EB.”

For more information, please visit [www.debra-research.org](http://www.debra-research.org) and follow us on [LinkedIn](#).

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