# Providing support and advanced care for children affected by rare dermatological diseases and their families

Grantee: Le Ali di Camilla
Location: Italy, Europe
Grant Cycle: 2024 – 2025
Type of Grant: one-year program support, Human Welfare & Rights
Website: lealidicamilla.org

Le Ali di Camilla is a non-profit organization founded in July 2019 to advance research, treatment, and support for individuals affected by rare skin diseases and epithelial disorders. The organization focuses particularly on conditions treatable with advanced epithelial stem cell therapies, such as Epidermolysis Bullosa (EB) - a rare and life-altering genetic disease for which no definitive cure exists.

Building on decades of research and commitment from its founders in regenerative medicine, Le Ali di Camilla collaborates closely with the renowned Centre for Regenerative Medicine Stefano Ferrari at the University of Modena and Reggio Emilia. Under the leadership of Prof. Michele De Luca, this center pioneered the world's first successful application of gene therapy for EB. Patients from across Italy and abroad travel to Modena for treatment, clinical studies, and research participation, with numbers steadily increasing. Le Ali di Camilla provides comprehensive support, including up-to-date information on research, diagnostics, and treatments, as well as practical assistance. This includes reimbursement of travel expenses, on-site support for extended stays, and accommodation arrangements near the clinical center. To amplify its impact, the organization partners with EB-focused groups such as Debra Südtirol Alto-Adige and Olly Onlus and collaborates with Italian organizations like Telethon and ASEOP.

Epidermolysis Bullosa (EB), often called the "butterfly children's disease", is a rare and severe genetic disorder that makes the skin and internal mucous membranes as fragile as butterfly wings. Children with EB are highly vulnerable to injury: everyday activities such as eating, drinking, sleeping, walking, holding objects, playing, or even receiving affectionate gestures can cause painful wounds. These injuries require different forms, with varying degrees of severity. Tragically, the most severe cases are incompatible with life, and affected newborns rarely survive beyond the first few months. This was the heartbreaking reality for two infants, both named Camilla, born in December 2017 and passing away in 2018. In their memory, Le Ali di Camilla was founded.

Le Ali di Camilla is developing a fully equipped, accessible residence near Modena University Hospital to support patients with rare dermatological conditions and their families. Designed to accommodate both short-term (a few days) and long-term stays (months, particularly for newborns requiring extended care), the facility will provide a much-needed refuge for families facing the immense challenges of EB. This project aims to ease the burden of long-distance medical stays while fostering a sense of community among affected families. Ultimately, this "home for butterfly children" will serve as a model for similar initiatives worldwide, bridging the gap between families and cutting-edge medical research and treatment.

The **Nando and Elsa Peretti Foundation** (NaEPF) has a long-standing commitment to advancing health promotion and medical research, recognizing the profound impact of supporting individuals with rare

diseases. In 2023, the NaEPF awarded a grant to Le Ali di Camilla in memory of Dr. Yvonne Katharina Schmucker, a dermatologist and dear friend of the Foundation. This grant will fund the construction of the new residence, ensuring a vital space where EB-affected children and their families can receive the care and support they need. Through this initiative, NaEPF reaffirms its dedication to dignity, resilience, and the well-being of vulnerable communities.