

Giving Matters

THE GIFT OF HEALING: ONE FAMILY'S GIFT DELIVERS HOPE TO EB RESEARCHERS AND PATIENTS

Imagine being unable to hold your child to comfort her. With every touch, not only does she experience excruciating pain, but her skin also blisters and tears off.

Then imagine, in an attempt to thwart infection, regularly placing your child—with open skin wounds that never properly heal—into a bath filled with bleach solution and meticulously bandaging her, a painful process taking hours.

Epidermolysis bullosa (EB) is a rare and debilitating disorder that leads to agonizing pain, disfigurement, and wounds that never heal. Children with recessive dystrophic epidermolysis bullosa (RDEB)—the most severe, chronic type of EB—often develop deformities caused by the recurrent scarring and fusing of the fingers and toes, called pseudosyndactyly. These individuals also often suffer from contractures, where the hands and arms become fixed in stiff positions. It is also painfully difficult, if not impossible, for a child with RDEB to ingest food due to the internal blistering that occurs in the mouth, esophagus, and gastrointestinal tract.



THE DESHE FAMILY

Ari Deshe, the founder and chairman of Safe Auto Insurance Co. of Columbus, Ohio, was diagnosed with a mild form of EB, as were three of his children. Ari and his family, including his wife, Ann, and their children Elie, David, and Daniel, together with daughter Dara and her husband Zachary Segal, made the decision to give \$3 million to the EB Research Partnership, the largest non-profit organization dedicated to treating and curing EB.

A good portion of their substantial gift will be used to fund EB research initiatives at Stanford Medicine, with the goal of not only treating but curing this devastating disease.

When asked about the motivation for their gift, the Deshe family shared, “We would love to see this disease gone, and we want to be a part of helping eradicate it—forever.”

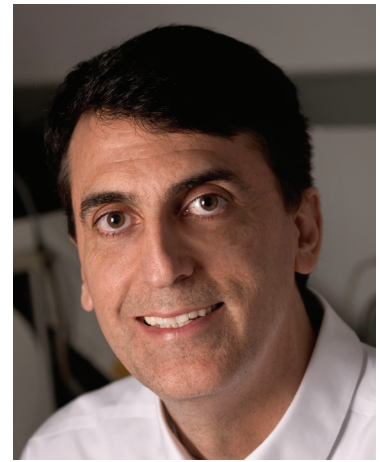
Stanford’s Department of Dermatology, the recognized leader in skin disease research, has specialized clinical programs for EB and other severe skin disorders. These programs attract patients and their families from around the world. The department’s combination of leadership in clinical care and in research is vital for making progress in treating such a vexing disorder like EB.

Department Chair Paul Khavari, MD, PhD, and his team wholeheartedly share the Dashes' goal.

“Even as a physician who understands this disease and has treated many patients with this disease, I cannot imagine what it takes as a parent to go through the steps involved with caring for a child with EB on a daily basis. I have the utmost respect for parents who care for EB children. They are true heroes,” expressed Dr. Khavari, the Carl J. Herzog Professor of Dermatology in the School of Medicine.

“And when you have a family step forward to make a difference, committing themselves to changing the future for people affected with this disease, it’s an enormous source of hope—not just for the community of physicians and scientists dedicated to curing EB, but also for all the families and patients who wonder if there will ever be a chance to live more of a healthy and normal life. A gift like this is an injection of hope into our entire physician, researcher, and patient community,” says Dr. Khavari.

“The only way we can hope to change the future for patients with these diseases is through research, innovation, and discovery. I am extremely confident that with dedicated effort and resources, we will change the future for patients with EB and other disorders like EB. I have not the slightest doubt in my mind that we will do it.”



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