

A Father's Quest for Answers

When Ryan was born at Princeton Medical Center in Princeton, New Jersey, in 2006, his parents, Robert and Cheryl Lagay, immediately noticed that something was not right with their baby son: His little legs were dark blue, his feet were raised up to his ears, and both femurs were dislocated, which made his kneecaps stick out through the back of his legs. "I never expected him to walk," says his father.

Ryan was born with Larsen syndrome, a rare genetic disorder with an incidence of about one in 100,000 births, whose characteristics are marked joint hypermobility, congenital dislocations, and distinctive facial features. At 5 days old, Ryan's dislocated femurs were set, and his legs were cast at a slight bend. More castings followed—each designed to hold the legs at a greater degree of bend so that the knees would ultimately stay in position and function. At 7 months, Ryan was placed in a spica cast that encased him from stomach to feet—a treatment so severe that Rob Lagay is barely able to describe what it was like for him and Cheryl to watch their infant son endure it. "He is the most beautiful, strong-willed boy with the most infectious laugh," says Rob of Ryan, now 2, "and he is our family's shining light."

That was the beginning of the Lagays' committed journey to give their son the best possible care from the world's top physicians and researchers, leading them to the International Skeletal Dysplasia Registry at Cedars-Sinai Medical Center. Skeletal dysplasia encompasses more than 380 conditions, including Larsen syndrome, caused by genetic mutations that lead to abnormally developed bones and connective tissue. Says Robert emphatically, "It is the best such program

in the world, and for us there simply was no alternative but to go to Cedars-Sinai."

Under the direction of David L. Rimoin, MD, PhD, the Registry is a referral center for diagnostic opinions. It also gathers vast amounts of genetic data into a central repository, the largest one in the world, allowing researchers to develop a set of common characteristics for different disorders. Aided by this general knowledge, doctors can create specific therapy regimes tailored to each patient, and avoid or minimize the many complications associated with these disorders.

Dr. Rimoin and his colleagues, Deborah Krakow, MD, and Daniel H. Cohn, PhD, have been studying Ryan's condition and are now working with his medical team in Philadelphia. Such collaboration ensures that this courageous little boy is given every advantage that medical science can offer him.

It was Rob's colleague at Lazard Capital Markets, C.E.O. William Buchanan, who proposed to create a "charity day" on which all the New York-based investment bank's trading profits would be donated to an organization of their choice. Because the employees at Lazard all knew about the Lagays' connection with Cedars-Sinai for their son's treatment, they chose to make the International Skeletal Dysplasia Registry their 2008 "charity day" beneficiary.

"The motivation really inspired everyone, and we had one of our most profitable trading days ever," Rob says. On a trip to Los Angeles this past May, Ryan's dad was clearly moved and genuinely proud of his colleagues as he presented Dr. Rimoin and his team with a check for \$220,000 on behalf of his company.



Such funding gives the Registry's physician-scientists the opportunity to engage in key research as they pursue the identification of the genetic mutations and metabolic disorders that lead to skeletal dysplasia.

"Certainly the funding will enhance our ability to study skeletal dysplasia," says Dr. Rimoin. "So far we've been able to identify the gene defect that causes Larsen syndrome. Lazard's support will now help us to focus our research on the specific mechanisms by which that gene mutation causes the clinical characteristics of the disease, and how to interfere with these mechanisms."

The Lagays' admiration for the work Dr. Rimoin and his colleagues do at Cedars-Sinai is twofold: "The Registry is a place where we can find answers to our most haunting questions," says Rob. "It also gives us the assurance that our son is receiving the best possible care." And that, from a parent's perspective, is invaluable. ■

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—ROBERT LAGAY (RIGHT), SHOWN WITH DR. DEBORAH KRAKOW