Ryan Dant had an early talent for baseball. By the time he was 3-years old, he could hit an overhand pitch from his dad and throw with enough force that his mother had to send him outside every time he picked up a ball. His parents imagined future stardom. But during a routine doctor visit, the pediatrician noticed something worrying. Ryan's liver and spleen were enlarged. Soon after, a geneticist diagnosed him with MPS 1, a rare disease with no treatment and no cure.

The doctor told the stunned parents that their seemingly thriving child would not live past the age of 10 or 12. He said: Take your son home and love him for as much time as you have left.

Like millions of other parents faced with a rare disease diagnosis, the Dants found themselves without hope. Only about 5 percent of rare diseases currently have any FDA-approved treatments, and 30 percent of children diagnosed with a rare disease die before they turn 5. The Dants began a journey that day, nearly three decades ago, that would not just create hope for their own son but for every person affected by a rare disease.

"For the first year, my wife and I slept on the floor next to my son's bed," Dant said. They listened to Ryan breathe and feared the inevitable hastening of the disease, the stiffening of limbs, stunted growth and cognitive decline.

After a year, they got up. Mark, a police lieutenant in Carrollton, Texas, began spending afterhours at the library, learning everything he could about the disease. Children with Mucopolysaccharidosis (MPS) I lack an essential enzyme that breaks down chemical byproducts in their cells.

His research led him to an international conference in Germany where he learned about a nascent enzyme replacement therapy that was being used successfully to treat a different rare disease. "It's possible," he began to think.

The newly determined father found more hope in Dr. Emil Kakkis, a medical geneticist and fellow at UCLA who was researching a therapeutic use for a newly cloned gene that could potentially replace missing or damaged enzymes in humans. For Kakkis, the research began as an intellectual exercise. But when he met Mark and Ryan, he recalled that his work took on a new sense of urgency.

"It was not just an experiment; It was life and death," he said. "You can have all the science in the world, but if you don't help anyone, what have you done?"

Despite strong scientific underpinnings and successful treatment in canines, he could not find an industry partner to fund his research—too much investment for too few potential customers. Colleagues warned he was ruining his academic career by pursuing something unachievable.

Mark and Jeanne Dant did what they could to help. They started The Ryan Foundation and held a bake sale, their first official fundraiser, netting $342. Through auctions and charity golf tournaments they raised $40,000 more that year. The funds paid for a part-time technician and helped Kakkis stock his lab with second-hand lab equipment. In subsequent years they brought in $100,000, then $200,000.

In the meantime, Ryan's disease was progressing. By the time he was 7, his joints were so stiff he could no longer play on a playground or grasp a baseball bat.

Finally in 1997 a biotech startup called Biomarin took a risk on the new therapy. A clinical trial was approved in 1998, and Ryan became one of the first patients. The response was dramatic. Ryan regained motion in his joints and the swelling in his liver and spleen subsided. Despite positive results for all the patients, the FDA required a second trial, adding more years and tens of millions of dollars of added investment before Aldurazyme was approved in 2003.

With treatment, a weekly four-hour IV drip and, later, a quarterly spinal tap to bring the enzyme fluid to his brain, Ryan was able to go to school and play sports and pursue a future that included college and a career. He learned to drive and bought his dream car, a Mustang.

Dr. Kakkis went on to found a company, Ultragenyx focused on developing therapies for rare disease. And in 2008 he started the EveryLife Foundation for Rare Diseases, a nonprofit dedicated to accelerating biotech innovation and influencing policies to speed treatment.

Last year, Mark Dant retired as assistant chief of police and became chairman of the Everylife Foundation board. To date, the Ryan Foundation he and his wife started has raised in excess of $3 million to further research for MPS.

In May 2017, Ryan graduated from the University of Louisville, where he worked as a manager for the football team. He moved to San Francisco to intern with the 49ers.

Mark said he is proud that today other parents who receive a diagnosis of MPS 1 do not have to relive the same conversation that he and his wife had nearly 30 years ago. “Now doctors can say, ‘Your son has MPS 1, and soon we will start treatment.’”