

Graduating Louisville football manager Ryan Dant 'changed the world'

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(Photo: Alton Strupp/CJ)

Mark Dant has been reflecting a lot lately on the journey his son, Ryan, has taken to become an improbable graduate of the University of Louisville on Saturday.

He has thought about the shocking diagnosis Ryan received when he was 3 years old of a rare disease that would likely kill him by 10.

And Mark has thought about the fight his family and Ryan's doctors undertook in trying to save his life.

Thanks to the Dants' efforts, a disease that had no treatment now has one. And nearly two decades after he was expected to die, 29-year-old Ryan is set to fulfill a lifelong dream by graduating from U of L, where he also served on the football team's equipment staff.

All that "is what I see when I see Ryan walk across the stage," Mark Dant said.

Ryan has mucopolysaccharidosis type No. 1, or MPS 1, a genetic disease in which the cells fail to produce an enzyme required to break down protein buildups in the bones, organs and central nervous system.

At the time of the diagnosis in 1991, there was no treatment for MPS 1 – which is among 12 types of MPS and which occurs in about one in every 100,000 births - and hardly any ongoing research.

When Mark Dant, who was a police officer in Carrollton, Texas, went to a conference in Denver to learn more about MPS, he saw young children who, like his son at the time, had shown no or few ill effects of the disease.

But he also saw 6-year-olds who were suffering at a more advanced stage. And, he noticed, there were no kids older than 12 there, because kids with MPS 1 didn't live to that age.

Many times that first year, fearing the worst, Mark or his wife, Jeanne, would sleep on the floor next to Ryan's bed so that they could listen to him breathe while he slept and confirm he was still alive.

"We were just so scared he would die in the night and that would be the end of it," Mark said. "We wanted to be there. ... I just had this fear, 'What if he dies in his sleep, and he's alone?'"

The Dants were determined they would not accept letting their son die without having exhausted or unearthed every means to keep him alive.

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"We had to get off the floor," Mark said.

Mark traveled to Germany and around the United States looking for doctors with expertise.

The Dants located one doctor, Emil Kakkis at UCLA, who was pursuing research for a treatment method of synthetically replacing the cellular enzyme lacking in MPS 1 patients, but Kakkis lacked the money to move forward.

The Dants started the Ryan Foundation, and Mark began diligently seeking funds to go toward Kakkis' research. It began with a bake sale that raised \$342. They held boxing tournaments, raffles, silent auctions and golf outings, and word started to spread. Dant raised \$40,000 to present to Kakkis.

Ryan needed help because his condition was worsening.

By age 7, he was experiencing severe headaches and had difficulty breathing, and his fingers curled up so severely that he had to quit playing baseball, which is his favorite sports.

By 1998, when Ryan was 9, Kakkis had developed a drug that was ready for a clinical trial with the support of the Dants' continued fundraising.

Over the years, Mark Dant has raised more than \$1 million for MPS research.

"I'm graduating to show him thank-you," Ryan said of his dad. "Without him, I wouldn't be able to do this. ... I can't imagine what life would be like if he hadn't done any of this. I wouldn't be here today."

More: [Internet falls in love with Tahj Rice's college commitment video \(http://www.courier-journal.com/story/sports/preps/kentucky/2017/03/14/internet-falls-love-tahj-rices-college-commitment-video/99178410/\)](http://www.courier-journal.com/story/sports/preps/kentucky/2017/03/14/internet-falls-love-tahj-rices-college-commitment-video/99178410/)

Ryan was born and raised in Texas but comes from a family of Cardinal fans who are from Louisville. From the earliest age, he followed suit and loved the Cards and always wanted to attend U of L.

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U of L football equipment manager Ryan Dant was diagnosed at age three with mucopolysaccharidosis, or MPS. It's a deadly disorder that disease that stiffens limbs, attacks the heart, and destroys the brain. Dant's family immediately set out to find options to save his life. Today, thanks to a compassionate-use clinical trial at UT Southwestern Medical Center, the 29-year-old Dant has restored brain function and has nearly accomplished his dream of obtaining a college degree. May 11, 2017 (Photo: Alton Strupp/CJ)

His mother, the former Jeanne Roberts, and Mark Dant attended Seneca High School, and Jeanne attended U of L for three years before she moved to Texas to be with Mark.

While the Dants were temporarily living in Southern California for Ryan's treatment, Ryan even got to meet the Louisville basketball team, which happened to be playing at UCLA, and coach Denny Crum invited Ryan to sit on the Cards' bench.

But as Ryan got older, his dream of attending U of L began to feel more and more unreachable.

Though the new enzyme treatments to his organs were working and had improved his health and extended his life, the effects of the MPS 1 were still taking hold on his brain and cognitive function.

The membrane barrier of the brain was preventing the medicine that had been intravenously injected into his blood stream from reaching his central nervous system. So the protein buildups were still occurring in his brain and spinal cord.

It most glaringly affected his short-term memory. Ryan would study all night for a test, then forget it all the next day when it was time for class.

Also: [Waggener swimmers with Down syndrome find empowerment in the pool \(http://www.courier-journal.com/story/news/education/2017/02/07/down-syndrome-swimmers-waggener-find-empowerment-pool/97371262/\)](http://www.courier-journal.com/story/news/education/2017/02/07/down-syndrome-swimmers-waggener-find-empowerment-pool/97371262/)

After graduating from high school, he enrolled at Brookhaven Community College in Dallas. He needed five years to earn his associate's degree because he could handle only one course each semester.

It was obvious that Ryan's enzyme treatment would require a special delivery method that would get the medicine to his brain. There was great hope when UCLA started a study on just such a method, but the Dants were devastated to learn Ryan had failed an initial test to qualify as a candidate.

"He told me, 'Dad, I'll never get to U of L now,'" Mark recalled, and Ryan posted on Facebook that a door had closed on his life.

But a nurse who'd treated Ryan as a boy at Dallas' University of Texas Southwestern Medical Center saw the Facebook post and asked him to explain what had happened. Ryan told the nurse, who then approached Dr. Elizabeth Maher, a neurologist with the O'Donnell Brain Institute at UT Southwestern, for her input on the case.

Maher, whose specialty is working with brain cancer patients, received the backing to pursue a compassionate-use trial focused on injecting the enzyme into Ryan's spinal fluid.

He began the treatment in 2012, and it worked remarkably well. Within a month, Ryan's vocabulary and reading score improved 120 percent, according to tests performed by the University of Minnesota.

Ryan has been thriving academically. Determined to graduate this spring, he loaded up with 23 credit hours this semester and earned a 3.55 grade-point average. He has a 3.5 for his U of L career with a major in sports administration.

"The idea that he could even apply and think about even going to the University of Louisville is unbelievable," Maher said. "Now, here he is. ... He had an incredible will to live."

Maher was stunned and thrilled that the treatment not only halted the damage being done to the brain but that the brain actually recovered – a development that she said could be a hopeful example for other degenerative genetic brain diseases such as Alzheimer's.

Treatment methods similar to the ones pioneered on Ryan are now in use in 75 countries, according to Mark Dant. Ryan has been on the treatments longer than any other MPS 1 patient in the world at this point, his dad said.

"A graduation message from this story is: A simple person can change the world," Maher said. "... What he and his dad did, they changed the world. These are devastating, genetic, rare, terrible diseases, and now they've got life-saving treatments."

Mark Dant's work continues. After retiring from the police force last year, he was hired as the president of the National MPS Society in Durham, North Carolina, and commutes back and forth from Louisville. He and his wife moved back home last year and were able to go to every U of L football game in 2016.

Without the brain treatments from Maher, Ryan likely never would have ended up at U of L or a member of the Cardinals' football program. With them, he got to live out a dream.

"He did it," Mark said, his voice breaking up. "It still chokes me up."

While Ryan was in junior college, he became a non-student equipment staffer for the Southern Methodist University football team.

A member of the SMU equipment staff was friends with U of L football equipment director Mike Kurowski, and he asked if Kurowski would meet with Ryan.

As it turned out, Kurowski used to work on the Dallas Cowboys' staff and had actually attended one of Mark's many fundraisers when Ryan was a kid. Kurowski had gotten former Cowboys player Roy Williams to sign a jersey to put in a charity auction.

Kurowski was happy to reconnect with Ryan and put him on scholarship as a student manager. Kurowski said he's been inspired by Ryan's perseverance.

"He's definitely one who will always be remembered back here, without a doubt," Kurowski said. "For anyone to ever tell me they can't do something, that's ridiculous, because everything that kid has gone through and put his mind through - coming here, graduating, working in football, getting a career in athletics - he fought for it."

For the past three seasons, Ryan participated fully in all aspects of the job, helping do laundry for 100-plus players and prepping their apparel for practices and games. Combined with his class schedule, it was a 40- to 50-hour commitment per week, Kurowski estimated.

But unlike the other 15 student managers, Ryan was also spending his one off day each week hooked up to an IV through his chest for 4 1/2 hours in his apartment at Cardinal Towne, receiving the full-body enzyme treatments.

Every three months, he would fly to Dallas for a day to see Dr. Maher and get the spinal-tap injections, lying upside down on a declining bed for 12 hours.

The next day, he'd be back at practice.

Ryan, who's had 14 surgeries in his life, guessed - and Kurowski agreed - that probably only a couple of coaches and players on the team know the full story of Ryan's life. During his time at U of L, Ryan said he has never wanted anyone to treat him differently, so he's kept it mostly secret.

"A lot of people might use it as a crutch every day that, 'Well, I can't do this and this and this,'" Kurowski said. "He never did use it as a crutch."

Ryan said working with the football team was a grind but also a thrill. He'll fondly remember the excitement of being on the sideline for trips to Notre Dame, Florida State and Clemson and the opportunity of working with Heisman Trophy winner Lamar Jackson.

"It was a great ride," Ryan said.

Saturday's commencement ceremony will cap Ryan's U of L journey.

He expects to have his parents, grandparents, aunts and uncles, girlfriend and best friend in attendance. Kakkis, the California doctor who has remained a Dant family confidant, will be there, too.

"I know it's going to be difficult not to cry," Mark Dant said. "I just want to be able to watch the moment and feel it for him because I know how much work he's put into it and how long he's wanted it."

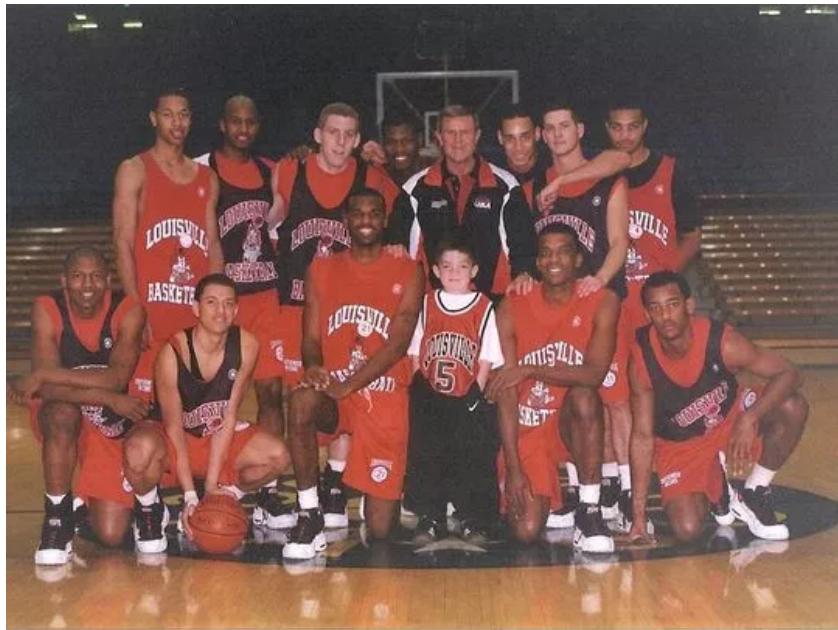
For more information, visit [RyanFoundation.net](http://ryanfoundation.net) (<http://ryanfoundation.net/home>) and [MPSSociety.org](http://mpssociety.org) (<http://mpssociety.org>).



Ryan Dant and his father Mark return to UT Southwestern Medical Center for Ryan's quarterly spinal injections, which keep his brain functioning properly. Ryan will graduate May 13, 2017 from the University of Louisville with a bachelor's degree in sports administration. (Photo: David Gresham, UT Southwestern Medical Center)



Ryan Dant with Dr. Elizabeth Maher, of UT Southwestern Medical Center in Dallas. (Photo: Courtesy of Mark Dant)



Young Ryan Dant got to meet the Louisville basketball team during the Cardinals' trip to UCLA in 1998. (Photo: Courtesy of Mark Dant)