

The diploma Ryan holds is more than a degree. It's a disavowal of the death sentence that once hung over a little boy's head.

"Ryan," said Greg Buchanan of Coppell, raising a glass at Friday night's party, "we wish you the best of luck. And may you fulfill your lifelong dreams."



Ryan Dant, 29, raises his hand during a toast for him by his father, Mark Dant, during a college graduation party for Ryan at a family friend's house in Carrollton. Dant was diagnosed with MPS1, a genetic enzyme-inhibiting disease that kills most kids before they become a teenager. He is a recent graduate of the University of Louisville. (Ben Torres/Special Contributor)

In 1991, a liver issue brought baseball-loving Ryan, 3, to UT Southwestern Medical Center, where doctors found his body wasn't breaking down the proteins that build tendons, bone and tissue.

He was diagnosed with MPS1, a genetic enzyme-inhibiting illness affecting just one in 100,000 children worldwide. Little research had been done to find a cure.

Ryan's parents, Mark and Jeanne Dant, learned what would unfold. Left unchecked, proteins become sludge in the pipes, slowing everything down: Hands and feet curl, spinal columns narrow, organs are severely damaged. Eventually, cognitive abilities decline.

They mourned the prognosis. And then Mark Dant told himself: I'm not going to just give up on my boy.

He began knocking on doors, making calls, seeking funds to help fight the disease. An initial bake sale raised \$342. With the help of seven couples, the Carrollton-based Ryan Foundation grew into a thriving agency, throwing charity golf and fishing tournaments.

The foundation funded the work of then-UCLA researcher Emil Kakkis, who developed a synthetic enzyme called Aldurazyme. Ryan, who'd had to quit baseball when he could no longer hold on to a bat, was one of 10 kids chosen for clinical trials; five years later, his four-hour infusions at Children's Medical Center were working, slowing and turning back the disease's effects.

But the drug had one foil. It couldn't reach the brain through the bloodstream, diverted by the body's inherent defense against infection. And so, the one effect of MPS1 that the drug couldn't fight was cognitive decline.

Though his condition was improving, Ryan knew his mind would soon start to go.





Eventually, researchers devised a way to get the drug into the brain — through the spinal column. The Dants were ecstatic — but learned that because the boy’s spine had become so clogged, he was ineligible for clinical trials.

The news was devastating. By 2011, Ryan’s brain began to forsake him: At 23, he couldn’t read a book to its end, and despite cramming for exams, he couldn’t remember anything.

He went into a funk. College, a future, it all seemed out of reach. His annual cognitive study at the University of Minnesota outlined what he already knew: His mind was failing.

Despondent, he posted on Facebook: “Things happen for a reason. Things you don’t think are possible happen and you’re shocked and upset. I’m going to continue to march in the direction I was. Nothing is going to stop me from fulfilling my dreams.”

Nurse Sarah McNeil, who’d gotten to know Ryan as a 10-year-old while overseeing his early Aldurazyme infusions, saw the post and reached out to learn what was wrong.

By then McNeil was working with neurologist Elizabeth Maher of the O’Donnell Brain Institute at UT Southwestern. Maher, it turned out, also treated patients using spinal drug injections, a rare procedure.

McNeil approached Maher to see if she would take on Ryan’s case pro bono, hesitant because the center focused on brain tumor research.

“I’ll never forget her response,” McNeil said. “She said, ‘Why wouldn’t we do this?’”

In 2012, they began a compassionate-use clinical trial using Kakkis’ drug and protocol.

“We just felt like, this couldn’t be the end,” McNeil said. “He’d come so far. And really, he had nothing to lose.” Though she considers herself ever hopeful, “deep down, I wouldn’t have expected things to unfold as they did. I think it’s a miracle.”

The quarterly injections, which he continues to receive, “essentially Roto-Rootered” through Ryan’s spinal obstruction, not just halting his mind’s decline but reversing it. Ryan could feel himself

getting smarter.



At the University of Louisville, Ryan Dant became the football team's student equipment manager. Here he stands next to No. 8, 2016 Heisman Trophy-winning quarterback Lamar Jackson. (Dant Family)

He achieved his dream of attending a major university and working with the football program, becoming the student equipment manager.

“It was really amazing to be part of a big football program, to see the ups and downs,” Ryan said.

Upbeat and easygoing, the effects of his experience are evident if you look closely: He is stocky, compact as a wrestler, with husky shoulders and hands thick and slightly gnarled.

The future, while brighter, remains uncertain. Annual cognitive tests show his brain function is stable. For now, he looks at it as buying time until better science comes along.

The Dants, including Ryan, have relocated to Louisville but return to Dallas at least once a quarter for Ryan's injections.

Recent months have been emotional for Mark Dant, who retired after 32 years with the Carrollton Police Department and is now president and CEO of the Durham, N.C.-based National MPS Society.

He'd once shelved the idea of seeing his son stride across a college graduation stage. Then it played out, right before his eyes. He and Jeanne couldn't snap enough photos.





Ryan Dant receives his diploma at the University of Louisville graduation ceremony on May 13, 2017. (University of Louisville)

At Ryan's party Friday, his father told the gathered couples that among those at his son's graduation was Kakkis.

"Show them your watch," Mark tells Ryan, who holds his wrist aloft.

Kakkis, Mark explained, handed him a box and said to tell Ryan, "For me, it's always been about giving you time."

Later, privately, he glanced around the room and then at his grown son.

"It happened because of all these people," he said. "But it really happened because he just refused to quit. He had so many opportunities to say, 'I can't.' But he never did."

