

Alumni News
To the Heroes Among Us
Curated by Jennifer Garr, '75

In eighth-grade gym class, did you ever consider you might be playing dodgeball with a hero? Or as a senior, did you ever think the guy who sat behind you in homeroom for four years might step up and do something so special it would be featured on “60 Minutes”?

I didn't.

Sure, I was aware that the teenagers who graduated before, after and alongside me would go on to be good parents, build things, run companies, maybe even save lives, but as I scanned the faces in my yearbook, it never entered my mind that one of us would be the driving force behind finding the cure for a life-threatening, previously incurable disease – not because that person was a doctor or scientist, but because he was a loving father determined to not let his young son die.

In the spring of 1991, Mark Dant, a 1977 graduate of Seneca, was faced with horrific news when his 3-year-old son, Ryan, was diagnosed with Mucopolysaccharidosis (MPS I), a rare disease affecting only a few thousand children around the world. At the time of Ryan's diagnosis, MPS I meant that he would most likely not see his tenth birthday. It also meant that all of his days between that moment and his death would be filled with pain and physical devastation. Very simply, children born with MPS I are missing an important enzyme that helps the body break down cellular waste.

As most of us can only imagine, after the diagnosis, Mark and his wife, Jeanne (also a Seneca grad, our very own Jeanne Roberts, 1978), set out to learn everything they could about this threat to Ryan's life. The more they learned, the more obsessed they became with finding a cure. Even after attending a conference of the National MPS Society, an organization for families in the same situation, Mark didn't know from where the cure might come, but he knew they would need money – for you see, this is one of those stories where pharmaceutical companies weren't actively seeking a cure as there was little chance to recoup their investment.

The first of the eventual millions of dollars Mark raised began with a local bake sale that netted \$342. But it was a start. As the 2001 “60 Minutes” story explained, Mark walked his beat as a policeman in Carrollton (a large suburb of Dallas), then he changed and walked another beat – shaking hands, telling Ryan's story, and asking for donations. He was tireless in his commitment and even in the face of 99 “nos” to every one “yes,” he just kept walking, determined to raise money for the newly created Ryan Foundation – the financial support he knew would be needed when he found the hope of a cure.

That hope eventually came in the form of Dr. Emil Kakkis, a young scientist in Torrance, California, who had committed himself to creating the missing enzyme and developing a treatment for MPS I. Sadly, his biggest challenge wasn't the science but finding the funding to take his work to the next level. In 1994, just as Dr. Kakkis had reached the realization that without more money, his work couldn't go any further, he was introduced to Mark and Jeanne.

Due to a heroic decision on the Dant's part, Dr. Kakkis' research was kept afloat for three years by the hundreds of thousands of dollars being donated to the Ryan Foundation, or as Mark describes it, "wonderful friends who cared enough to make a difference." This funding and an unflinching commitment on the part of Dr. Kakkis led to the realization of his vision for a synthetic enzyme designed for the treatment of MPS I. Further support by a biotechnology startup called BioMarin Pharmaceutical ensured that the treatment got to market.

Selected as one of the ten children to receive the experimental treatment, Ryan was soon returned "his potential to be a great person," as Mark said during the "60 Minutes" interview.

From my view, Mark knows a lot about being a great person. Where does someone find the kind of courage and perseverance Mark displayed as he raised money for the cure? Given the stakes, you could say he had no choice; he had to do everything in his power to save his son. I would agree. But not many of us could do what he did when faced with devastating news such as this. Scour the world for scientists. Raise millions of dollars. Find a cure. Did his parents instill this ferocious determination? When did he begin to believe that even one man, walking alone, could make a profound difference? Or was he alone? Was it his faith? His friends? I don't know if it matters. What I do know is that Mark Dant is a hero.

But this story can't close with Mark. How's Ryan? Well, I was able to find a 2010 account of Ryan (at age 22) and his Dad headed to a Rangers game – still sharing their love of baseball. And in a recent email exchange, Mark was proud to tell me that in addition to attending college part-time, Ryan works year-round with the equipment staff for the football team at SMU. If you look closely you can sometimes see him running the sidelines during ESPN televised games.

Mark being Mark couldn't just revel in his son being able to live life to the fullest, he was also simply ebullient over all of the other good things that has happened since the "60 Minutes" segment: The drug is now sold in 89 countries around the world. The Ryan Foundation has continued funding science for MPS, which has now translated to therapies for over half a dozen other diseases. In addition, they continue to fund UCLA and numerous other university labs around the U.S. to treat brain disease and orphan diseases. To date, they have funded over \$2 million in brain therapy alone, which is now translating to several medical trials not only in the U.S., but also now in Europe.

So, to the heroes among us like Mark and Jeanne Dant, you have our respect and eternal thanks.