PHOTOGRAPHED FOR *BIOGRAPHY MAGAZINE* BY JILL JOHNSON

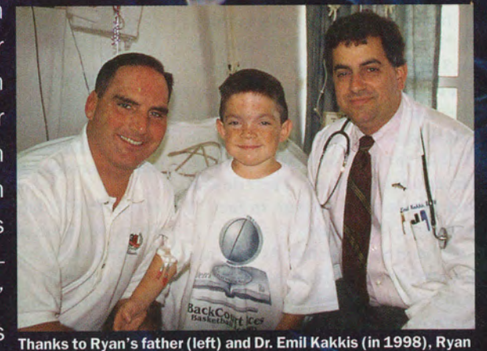
Ryan's Hope

How a Father Refused to Let His Son Die

BY DAVID MARTINDALE

In most ways, Ryan Dant is a typical 15-year-old. He's a die-hard Dallas Mavericks fan. He plays in youth baseball and basketball leagues. He'd like to be a major league baseball umpire. His musical tastes range from Kelly Clarkson and Justin Timberlake to Creed and blink-182. He's hooked on *American Idol*. He knows a lot about cars and can't wait till he's old enough to drive. Ryan is small for his age (just under 5 feet tall and barely more than 100 pounds), but he considers it a triumph that servers in restaurants no longer offer crayons with his menu. He has been fitted with braces to straighten his teeth and wears his hair long like his favorite NBA players, Steve Nash and Dirk Nowitzki. He's eager to start high school in the fall. He's interested in girls and has his eye on one in particular. "Her name is Melissa," Ryan says. "Can you put that in the article?"

He's a teenage boy like any other—and that is a miracle.



Thanks to Ryan's father (left) and Dr. Emil Kakkis (in 1998), Ryan now leads a normal life

Ryan Christopher Dant has mucopolysaccharidosis, a disease also known as Hurler/Scheie syndrome, or simply MPS I. It's a rare genetic disorder in which the body lacks a crucial enzyme for breaking down sugar polymers. Ryan was 3 years old when doctors discovered he had it, and his parents, Mark and Jeanne Dant of Carrollton, Texas, were given the devastating news about their only child: MPS I is a killer. No cure, no treatment, no hope.

"It was the worst day of our lives," Mark says. "Jeanne and I were sitting there, Ryan on her lap, and the doctor was telling us, 'Ryan is going to pass away in your lifetime, more than likely by the time he's 10, most definitely before he's 15. And he will suffer.' It's not the normal progression of life where Mom and Dad have to pick out a casket for their child, but that's what we were hearing would happen."

An estimated 500 U.S. citizens—and about 3,000 people worldwide—suffer from MPS I. The disease enlarges and severely damages the liver, spleen, and heart valves. It stiffens the joints, limiting mobility and creating "claw hands." It stunts growth, restricts breathing, and causes agonizing headaches that can lead to brain damage. Those who have it rarely live beyond their teens.

Yet here is Ryan—12 years after being diagnosed with this horrible disease. He has suffered, just as the doctor forecast. But today he's alive, reasonably healthy, remarkably well-adjusted, and supremely confident that a rewarding future awaits.

It's a testament to the power of faith, family love, tireless fundraising, and a breakthrough medical treatment that ultimately could save hundreds, even thousands, of young lives.

At home in Carrollton, Texas, with his Sheltie mix Patty

With his parents, Jeanne and Mark Dant

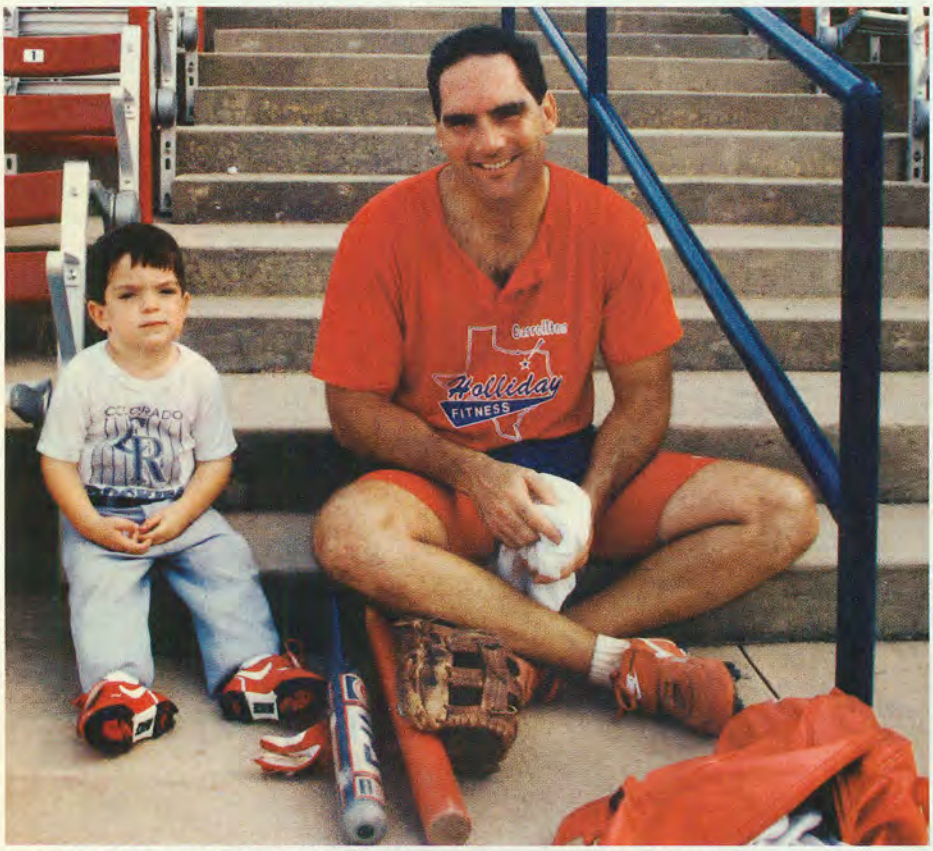
Ryan has heard his parents tell the story many times, but he has no memory of the day his doctor broke the terrible news to them. "I was too young," he points out. "I was just 3 then." As for Mark and Jeanne, they can't remember anything that happened *after* that meeting. "It's like we were numb," Mark says. "We were in such a state of shock that the rest of that day is just blocked from our memories." Their desolation lasted nearly a whole year, in fact. "I cried every night," Mark says.

Ryan had been an active boy. At 4, he was one of the best players on his baseball team. But it wasn't long before he experienced muscle and joint pain. His fingers and toes began to curl and lock. By 5, he had trouble gripping a baseball bat. His dad enabled him to play another season by attaching Velcro to Ryan's bat and batting gloves. But Ryan, who soon needed help putting on his T-shirt because he couldn't extend his arms, eventually quit sports. Because of his bloated spleen and liver, his stomach swelled to two and a half times normal size. He had violent migraines and often vomited himself into unconsciousness.

The disease also beat Ryan up psychologically. "When he was younger," Mark recalls, "he would talk about what kind of car he would want to have and how he wanted to be a major league baseball player. By the time he was 8, he stopped mentioning those things."

"Well, there wasn't much point," Ryan says. "Why should I think about the future if I'm not going to be there?"

What Ryan didn't count on, of course, was that his father is a stubborn man. Mark and Jeanne Dant have lived in suburban Dallas since they married in 1982. He's a lieutenant in the Carrollton Police Department; she's the manager of software programs at a company affiliated with American Airlines. Before his son was diagnosed with MPS I, Mark's driving ambition was to become chief of police,



Ryan's father felt "numb" when this photo was taken, one day after the diagnosis

but career goals suddenly took a back seat to "being the best dad I could possibly be." He had no grasp of genetics and no experience raising money to fund scientific research. He learned quickly.

"I went to the Dallas library to find out as much as I could," Mark says. "Because the disease is so rare, there really wasn't much data out there. This was before the Internet. I read about a doctor who, in the early '90s, invented a drug to treat Gaucher syndrome." Kids with Gaucher are missing an enzyme too, a different one from MPS children, and this drug puts the enzyme into their systems by way of IV infusions. "I thought, 'Well if he can do this for Gaucher, why can't he do it for MPS?'"

Mark was by no means the first person with that idea, as he learned when he met that doctor at a medical symposium in Germany. "I said, 'My son is almost 4. He's got MPS I. You did it with Gaucher. Is it possible to do this with MPS I?' And he was really blunt. He said, 'It's possible, but it'll cost millions. You don't have enough money. The science is not ready. You won't have time.' Meaning there won't be time for Ryan. But the only part I chose to hear was, 'It's possible.'"

In the meantime, the Dants started the nonprofit Ryan Foundation for MPS Children to raise money for MPS I research. Their first fundraising event, a bake sale, netted a mere $342. "It rained on our bake sale," Mark says. "How symbolic is that?" But the Dants and other volunteers who joined the crusade didn't quit. "If there was some way we could make enough money for somebody to make the drug that would help, even if it didn't cure him, even if it just helped, that was the goal," Mark says. Was he counting on raising millions of dollars, $342 at a time? "Believe it or not," Mark says, "that was the plan."

Fortunately, his fundraising skills improved. He is a persistent, persuasive individual. The first Ryan Foundation charity golf tournament in 1993 brought in $27,000. Last year, the organization, which has swelled to include hundreds of participants, raised more than $500,000.

But he still wasn't sure what to do with all that money. Then, in December '94, an expert in genetics told Mark about her former student, Dr. Emil Kakkis, who was developing an enzyme replacement therapy for MPS I. Kakkis was on the verge of a breakthrough, Mark learned, but lack of funding was holding him back. "We were tantalizingly close, scientifically close, but operationally very far," Kakkis says. "I was surviving on minimal research support that was covering the equivalent of one low-paid technician and a few supplies. That's not enough to develop a drug."

Mark decided to pump every dollar into Kakkis' work. "A lot of parents, when their child gets a disease, are devastated and not very functional as far as getting anything done," Kakkis says. "Some parents go out and get some information. But very few parents go out and raise research funds and then find a focus for those funds and *then* get them to the person who can make the drug to treat their child. The thing that's unique about Mark is he turned his grief into solid action."

In early 1997, Kakkis' research got a $5 million shot in the arm from BioMarin Pharmaceutical. And by February '98, eight weeks shy of Ryan's 10th birthday, Ryan and nine other young MPS patients entered the pediatric intensive care unit at Harbor-UCLA Medical Center to receive their first infusions of the new enzyme-rich drug.

The results were immediate and impressive. "One day at the hotel," Ryan recalls, "I had my shirt off and I was looking in the mirror and my stomach had shrunk. My spleen had shrunk. And I yelled for my dad and he came running. I said, 'Dad, my stomach looks more normal!'"

HOW YOU CAN HELP

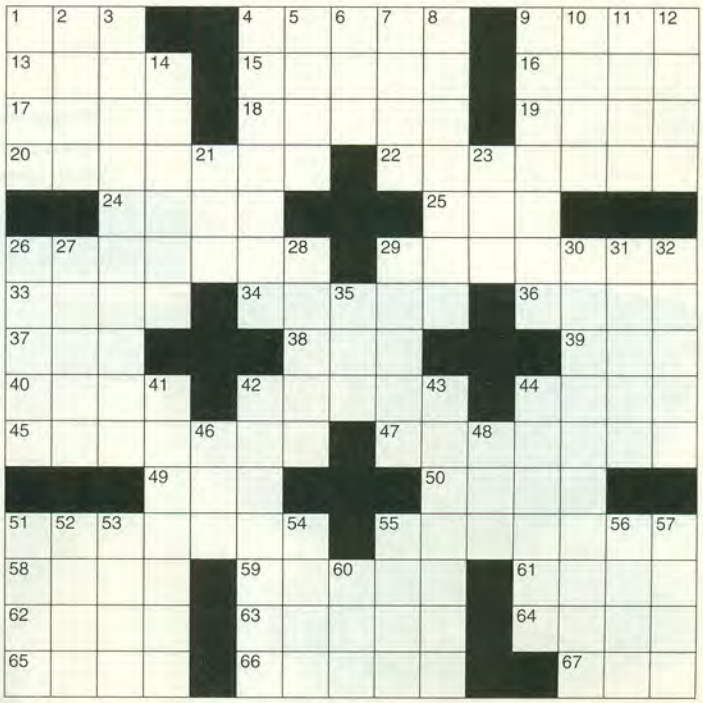
Fortunately, today parents can find extensive support and information about MPS I, and have the opportunity to meet other families dealing with the disorder. Many resources are available through the National MPS Society in Bangor, Maine, at www.mpssociety.org, or by calling 207-947-1445. Information on making a tax-deductible donation to the Ryan Foundation in Carrollton, Texas, can be found at www.ryanfoundation.org or by calling 214-870-RYAN.

That was just the beginning. For the past five years, every Monday afternoon Ryan has received enzyme infusions—and the transformation has been nothing short of glorious. He's growing. His once-misshapen body

(Continued on page 100)

Crossword *by John M. Samson*

The Rat Pack



Across

1 Mahal of Atlantic City
4 Like Heidi
9 Boris Godunov, e.g.
13 Langston Hughes poem
15 "Over the Rainbow" ending
16 "She's Leaving ___": Beatles
17 Coffeehouse reader
18 Williams of *Happy Days*
19 *Night* author Wiesel
20 1996 Leslie Nielsen film
22 *Ocean's Eleven* star
24 Telephone inventor
25 Howard Hughes' airlines
26 MacLaine in *Can-Can*
29 Second American in space
33 *A Fine* ___ (1986)
34 ___ cotta
36 Photojournalist Yamasaki
37 Suffix for sheep
38 Finnish composer Kalevi
39 Efface
40 General ___ chicken
42 Woolf's ___ *of One's Own*
44 Thompson in *Wit*
45 Anthony in *Red Dragon*
47 *Kate & Leopold* star
49 Pachelbel's "Canon ___"
50 Starring role
51 1970 Dean Martin film
55 Palace of Las Vegas
58 "___-Dee-Doo": Como
59 De Valera of Eire
61 Bacchanal cry
62 Youngest Brontë sister
63 Song from *Rent*
64 *Green Mansions* girl
65 Brown U. mascot
66 Playground sight
67 Sun Yat-___

Down

1 Gratuities
2 At the apex
3 *Ocean's Eleven* star
4 *A Study in* ___: Doyle
5 Solti's stick
6 Electees
7 Convertiplane
8 *Ocean's Eleven* star
9 ___ *and the Furious* (2001)
10 Fly like Fossett
11 Prince of Arabia
12 Oliver in *Oliver!*
14 Nicole Kidman film (with *The*)
21 ___ *About the Benjamins* (2002)
23 *The Blue Max* setting
26 *Ali* star
27 "___ Fine": Chiffons hit
28 *The Best* ___ *of Our Lives* (1946)
29 *Forrest Gump* author
30 *Ocean's Eleven* star
31 Suffix for pan
32 Erin of *Happy Days*
35 Greek P
41 *Gilligan's Island* role
42 *Thoroughly Modern Millie* star
43 Griffith in *Crazy in Alabama*
44 Schwarzenegger film
46 She saved Odysseus
48 "Well, I'll be!"
51 Daggoo's captain
52 Skye in *Say Anything*
53 *Oxford Blues* heroine
54 "Blue ___ Fly"
55 *In* ___ *Blood* (1967)
56 *Lady in Cement* sleuth
57 Astin in *Lord of the Rings*
60 Year in Henry III's reign

ANSWERS ON PAGE 104

Ryan Dant *from page 79*

looks normal. His strength and energy have increased exponentially. The headaches have all but disappeared. "And it was probably within six months of his first treatment that he started talking about cars again," Mark says. "I thought that was pretty cool."

It's important to note, though, that Ryan isn't cured. Kakkis' wonder drug, which received FDA approval this year and will be marketed as Aldurazyme, doesn't treat the brain or heart valves. Nor can it completely reverse nine years of punishment that MPS inflicted on Ryan's body. His heart valves were damaged before treatment began and doctors found a bit of leaking, which they'll have to watch. Also, Ryan's hands remained frozen in claw-like positions; he underwent surgery in March to straighten the fingers on his left hand.

Meanwhile, Dr. Kakkis keeps working to develop the elusive cure—and Mark, now in his 19th year with Carrollton P.D., is still raising money, a pursuit he views as his primary mission in life. "This is a way the Dant family can help change the world for the better," he says. "I keep coming back to the picture of Jeanne and me sitting there, with Ryan on us, and the doctor telling us what would happen. Now, when other families are in that position and hear, 'Your child has a terminal disease,' there will be a comma at the end of that sentence—and the doctor will add, 'But there *is* a therapy.'"

As for Ryan, at the moment he says he's not going to follow in his father's crusading footsteps, at least not full time. He has other plans. Such as? "Growing up. Marrying someone. Having kids. Becoming rich. Living in a big house. Having tons of cars."

The same dreams, in other words, that all kids have. •

DAVID MARTINDALE IS A CONTRIBUTING EDITOR OF THIS MAGAZINE.

Paul Rudd *from page 74*

"I had no idea it would turn into such a phenomenon," he recalls. "Everything changed for me after *Clueless*." Though he wasn't overwhelmed with movie offers, Rudd found it easier to meet directors without first running the gauntlet of casting directors and producers. In 1996 he turned up in *William Shakespeare's Romeo & Juliet*, a typically manic outing from Aussie director Baz Luhrmann. Leonardo DiCaprio and Claire Danes played the Bard's star-crossed lovers; Rudd was Dave Paris, Juliet's smarmy rejected suitor. The film was another hit with teens and critics alike.

Rudd appeared to be on the Hollywood fast track, but in 1997 he took a slight detour to Broadway for a major part in Alfred Uhry's Tony Award–winning drama *The Last Night of Ballyhoo*. "I remember getting in some long conversations with my agent at the time," he says with a laugh. " 'Why are you doing this? Why are you in a *play*?' But I was 25, and I had very specific ideas of what I wanted to do." Those ideas did not initially include taking a lead role opposite Jennifer Aniston in the 1998 film *The Object of My Affection*. "I was having such a good time doing *Ballyhoo* that at first I turned the movie down, until the producers worked it out that I could leave and come back."

Object turned out to be one of Rudd's best performances—he's both funny and goodhearted as the gay schoolteacher who develops complex feelings for roommate Aniston. In summer 1998 he worked again for his *Object* director Nicholas Hytner, this time onstage, playing Orsino in the well-received production of Shakespeare's *Twelfth Night* at New York's Lincoln Center Theater.

Over the past few years, Rudd has racked up a broad range of screen credits, including the zany independent comedy *200 Cigarettes* (with Courtney Love), and *Cider House Rules*, where he played a World War II airman who's engaged to Charlize Theron and befriended by Tobey Maguire (*Spider-Man*). He was a horny summer-camp counselor in