

# The Record

## THE CEO OF HOPE

With two children stricken by a rare disease, John Crowley dedicates his career to raising money for lifesaving research

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STAFF WRITER

He arrives at his Cranbury office just a few minutes late, offering coffee, water, an apology and an explanation. All four are unnecessary, but John Crowley politely reveals this: There was an issue with Megan.

It is 8:35 a.m. on a frigid January morning. The parking lot outside his biopharmaceutical firm is still filling with cars.

Crowley has been up for hours. A few miles down the road, at his Princeton home, the 42-year-old CEO of Amicus Therapeutics was helping his teenage daughter. She had trouble with one of the life-sustaining tubes connected to her body.

So Crowley – the father – stayed home a few extra minutes, attending to his daughter. When the crisis passed, Crowley – the CEO – went to work, back to the first-floor office where he raises capital to develop drugs that will save patients like his daughter.

His two youngest children, 13-year-old Megan and 11-year-old Patrick, are both battling Pompe disease, a rare neuromuscular disorder. Twelve years after their initial diagnosis, they are still breathing, fighting and joking. Their survival is in many ways a tribute to their father, an Englewood native who has spent the last decade raising money to

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fund research for lifesaving drugs.

Their story will get the Hollywood treatment Friday, when “Extraordinary Measures” hits theaters nationwide. The film, which stars Harrison Ford, Keri Russell as Crowley’s wife, Aileen (pronounced EYE-leen), and Brendan Fraser as John Crowley, is an inspired-by-real-events document of Crowley’s quest to save his children.

“For us it’s been a very special

time in life,” Crowley said. “It’s been a time to reflect on the last decade or so with the kids. It’s a particularly neat experience for Megan and Patrick and our older son, John. You think of all the things Megan and Patrick can’t do in life. But then you think about them having a movie made about them. That’s a pretty neat deal.”

It is a story that would not surprise anyone who knows Crowley, a Bergen Catholic graduate who was weaned on faith and hard work when he was an altar boy at Immaculate Conception in Norwood.

“He was very dedicated,” said James Puliatte, a former deacon at Immaculate Conception. “He was dressed to the nines all the time. He always came dressed up with shined shoes and tie. He was very meticulous about his serving. He never missed [a week].”

But Crowley’s faith would be tested in 1998, when Megan was first diagnosed. Months later, his newborn son, Patrick, was given the same grim forecast.

In the movie, Crowley learns through research that most Pompe victims do not live past the age of 9. One of the first scenes in the movie chronicles Megan’s eighth birthday party.

In real life, Crowley left a secure job at Bristol-Myers Squibb – a job that included medical insurance – to co-found Novazyme, a biotech start-up that he hoped would find answers for his sick children.

Plenty of people, from doctors to colleagues to friends, recognized the conflict of interest and tried to steer Crowley away.

“I must admit that I was hesitant to encourage John to get into it,” said Dr. Alfred Slonim, a professor of clinical pediatrics at Columbia University who treated Crowley’s kids, “because it’s very difficult to be objective as a parent,

to be working on such a project and knowing that two of your children are dependent on everything he’s going to do. But he was very determined to do that.”

On Jan. 9, 2003, Megan and Patrick participated in the start of a clinical trial that would save their lives. In his soon-to-be-released memoir “Chasing Miracles: The Crowley Family Journey of Strength, Hope, and Joy” (Newmarket Press, 2010), Crowley writes that he joked with the nurse, “Be careful with that treatment. It cost \$200 million.”

Inside his kids’ hospital room, Crowley pushed a button, sending the much-needed enzyme dripping into their bodies. It repaired some of the damage the disease did to their hearts. Megan, according to Crowley’s book, was able to lift two-pound dumbbells for a short period of time.

Progress slowed, but Crowley has no doubt the enzyme replacement saved their lives.

“Megan and Patrick are still profoundly affected by their Pompe disease,” Crowley writes in the introduction of the memoir. “They will never walk and they remain on ventilators. But their hearts are fixed. They are alive, smart and happy.”

Their story, first told in the pages of The Record back in March of 1999, took on new life when Pulitzer Prize-winning journalist Geeta Anand filed a piece on the family in The Wall Street Journal in 2003. Harrison Ford read the article. He wanted to turn the story into a feature film.

In the movie, Ford plays Dr. Robert Stonehill, a scientist who is a composite of several real-life characters. There is a touching scene where Ford tells Fraser he can’t cure his kids, “but I can save their lives.”

“I think the way they drama-

tized it is very appropriate," Crowley said. "And I think it's a way that reflects the passion in our lives, the determination and ultimately the love and hope that we, and many, many other people who struggle with adversity face."

Crowley got his first look at the film in December. The studio rented a theater on Route 1 and screened the movie for friends and family members.

"We were most concerned about Patrick, because he's very private and much more reserved than his very outgoing sister Megan," Crowley said. "We went up to him literally as the credits were rolling, before family even came up to us, and I just said with Aileen standing there, 'So, little buddy, what do you think?'"

"He kind of looked up at me from his wheelchair, paused for a few seconds, and said, 'I like it, Dad. I really like it. Can we see it again?'"

The family spent some time on the movie's set in Oregon (Crowley has a one-line cameo as "Renzler Venture Capitalist No. 2). His kids got to know the actors. He said that Megan hit it off with Meredith Droeger, the young actress who plays her in the film.

"I was telling my daughter, Megan, that in a lot of ways she and Patrick are going to be proxies for many other little kids in wheelchairs," Crowley said. "And they understand that. Although Megan still says, 'That's great, but when do I get to meet the Jonas Brothers?'"

But there were heartbreaking moments on set too. Crowley said it was jarring the first time he saw Droeger get up out of her wheelchair to walk off set.

"It's just transference," Crowley said. "You think, 'Wow, that girl, everybody calls her Megan. Her trailer says Megan Crowley. And she looks like Megan and she acts like Megan.' But she got up and walked out of that wheelchair whenever she wants."

"And our Megan can't."

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## About Pompe

### Q. What is Pompe?

According to pompe.com, it's a neuromuscular genetic disease. Victims have trouble breaking down glycogen. The buildup of glycogen damages muscle cells. Breathing and mobility are most often affected.

### Q. Can I get Pompe?

It is a genetic disease. You would need to inherit a recessive gene from both of your parents. Even if both parents are carriers of the gene, the odds are only 1 in 4 that you would have Pompe disease. The disease affects between 5,000 and 10,000 people worldwide, according to unitedpompe.com.

### Q. Is there a way to treat Pompe?

One method of treatment is enzyme replacement therapy. In his book "Chasing Miracles," John Crowley writes that his children are not producing as much of a critical enzyme as other children. "Their bodies produce that one enzyme," Crowley writes, "but about 99 percent of it is discarded by the quality-control mechanisms in their cells, which have evolved to allow only perfectly made enzymes and proteins to do their jobs."

### Q. How much time does it add to a patient's day?

From Crowley's book: "The daily ritual of waking [my children] Megs and Patrick, cleaning them, giving them an array of medicines and breathing treatments, dressing them, and getting them settled in their wheelchairs takes about two hours."

### Q. What is the life expectancy for a patient with Pompe disease?

Life expectancy can vary greatly. In the foreword of

"Chasing Miracles," Crowley's wife, Aileen, writes that her two youngest children "weren't supposed to see their mom turn 30, let alone 40." Dr. Alfred Slonim said that the outlook is "still very guarded" for infantile patients.

## John Crowley file

Age: 42

Hometown: Englewood

Current residence: Princeton

Job: CEO of Amicus Therapeutics, a Cranbury-based biopharmaceutical company.

Family: Married to Aileen Crowley. They have three children: 15-year-old John, 13-year-old Megan and 11-year-old Patrick. Megan and Patrick are battling Pompe disease.

### Quote:

"We don't think about how long are the kids going to live or, 'God, I wish we could do this,' or 'I wish they could do that.'"

You're thankful for everything that they can do, everything they want to be. You celebrate events. You look forward to the kids going to high school in a couple years, which years ago was unfathomable."





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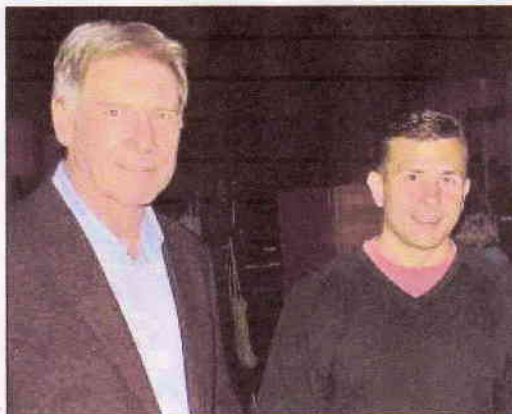


In a family photograph, John and Aileen Crowley with Megan, John and Patrick. Megan and Patrick were diagnosed with Pompe disease 12 years ago.

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Megan Crowley with her mother, Aileen. In the movie "Extraordinary Measures," Megan is portrayed by Meredith Droeger.



John Crowley with Dr. Hung Do, a colleague who acted as a technical adviser on the film. At right, Crowley with Harrison Ford, whose character is a composite of several colleagues.