BY KIM RIBBINK

A Journey of the HEART

When presented with shocking news concerning the health of his two youngest children, John Crowley responded by embarking on a mission to help uncover a novel therapeutic option for treating Pompe disease, a lysosomal storage disease (LSD) that, like other LSDs, interferes with the body's ability to break down molecules inside the lysosomes, compartments inside the cell.

This determination has carried over to his leadership role of three companies, and it is what is steering Amicus Therapeutics' development programs, which are centered around the discovery, development, and commercialization of a new class of small-molecule, orally administered drugs to treat a range of human genetic diseases. These innovative therapies apply to conditions in which crucial proteins are defective as a result of improper folding.

Founding a company in any industry, but particularly in the the life sciences, takes confidence, knowledge, and a leap of faith, and often only after several years or decades of service in the industry or in academia. But just two years after starting his first job in the pharmaceutical industry, John Crowley helped to found Novazyme Pharmaceuticals, a specialty biopharmaceutical company focused on finding a treatment for Pompe disease. What is even more remarkable is that Mr. Crowley is not a research scientist, and until joining Bristol-Myers Squibb in 1998, he worked as a business strategy consultant for Marakon Associates after starting his professional career as a litigation associate in the healthcare practice group of the law firm of Bingham Summers Welsh & Spilman.

His quest — to save his children — is what drives him, inspires him, and attracts others to his extraordinary story. But it is the man behind the story that makes all he has achieved even more impressive.

Armed with a personal commitment to find a treatment for Pompe disease, **JOHN CROWLEY** started one company, led two others, and is now steering Amicus Therapeutics' innovative pharmacological chaperone technology to address this and other diseases caused by defective crucial proteins.

THE FATHER OF NECESSITY

Mr. Crowley's story has been told in a variety of formats — from newspaper and magazine articles, to a book, to a forthcoming movie — and each time his story is told, his audience, those who speak with him, write about him, read about him, or watch his family's story unfold are moved and inspired.

In March 1998 his daughter Megan was diagnosed with Pompe disease. Then four months later, Mr. Crowley and his wife Aileen learned their youngest son Patrick also had the disease.

Rather than wallow in despair, Mr. Crowley did what he does best: he took action. After visiting dozens of doctors and specialists, Mr. Crowley learned about LSDs, which led to meetings with scientists working in the LSD field, and specifically with Pompe disease. He then began to look for ways to help them progress their research, and, ultimately help his children. The quest culminated in him cofounding and leading Novazyme in 2000.

Along the way, he discovered a lot more about himself, not only as a father but also as a business leader.

"I started with Bristol-Myers Squibb when I was 30 years old, and at the time I envisioned staying with a big pharmaceutical company for my whole career," he says. "But after starting Novazyme and comparing the two experiences, I think I'm much better suited for the entrepreneurial environment."

Since then, Mr. Crowley has used his business strengths to the benefit of several companies. Within a year and a half of its inception, Novazyme had achieved significant milestones and was sold to the specialty company Genzyme. And after spending just more than a year with Genzyme, Mr. Crowley cofounded an emerging biopharmaceutical company called Orexigen Therapeutics that is focused on the metabolic and neuroscience areas. He ran Orexigen for 18 months before taking the helm at Amicus Therapeutics, where he is currently CEO and president. His leadership skills have inspired many, including former colleagues at BMS, to join him in his various ventures.

"The most important roles for a leader are to set a vision and inspire others," he says. "By articulating a clear vision, hiring the best people possible, and encouraging them to do everything they can to achieve a common mission, the inspiration part falls into place."

THE MAKING OF A LEADER

Mr. Crowley's parents — his father was an Englewood, N.J., police officer who died on duty when he was 7, and his mother, a waitress — instilled in him commitment and a strong work drive. When deciding what to study after finishing high school, Mr. Crowley says he relied on his grandfather's advice.

"Being the first in my family to attend college meant I didn't have a script to follow," he says. "My grandfather told me: 'Go to the best schools you can and education will be what allows you to do whatever you want to or need to do.' "

His grandfather had been a carpenter who had only completed the seventh grade.

This advice led him to Georgetown, where he studied at the School of Foreign Service, focusing on international economics. Then, continuing with his grandfather's advice, he earned a law degree at Notre Dame.

"Law School at Notre Dame was a terrific experience," Mr. Crowley says. "I learned the disciplines of how to think rationally and to communicate persuasively. These skills have come into play in a number of different forums, whether negotiating a deal, obtaining financing, communicating with regulatory authorities, or developing a business strategy."

Though he took immense satisfaction in learning to become an attorney, Mr. Crowley says he didn't expect to practice law forever, and in fact he only practiced for four years. He found that business was a bigger draw, and he went back to school to continue his education, with an MBA at Harvard.

"If law school taught me how to think, then business school taught me how to act," he says. "There's no magic playbook in business school, but one can develop a set of skills and behaviors to apply in different situations, particularly as a CEO running a company."

Mr. Crowley was on the path to business success, having joined a strategic consulting firm, Marakon Associates in San Francisco, when he found out about his daughter's illness. Not long after, his younger son also was diagnosed with Pompe disease. Over the next several months, with his wife, Aileen, and children returning to stay with her family in New Jersey to be closer to doctors, the stresses of time on the job and being away from the family became too much, and Mr. Crowley decided a change was needed. In the summer of 1998, he joined Bristol-Myers Squibb in Princeton, N.J., as director of U.S. area marketing for the Neuroscience and Infectious Disease Division.

"I'd never been in a pharmaceutical company in my life," he says "But the kids had just been diagnosed, and I went in for the interview because we wanted to be closer to family and the kids' doctors. I wanted to work for a company that was stable, had reasonable work hours, and good health insurance."

> "Good business is about balancing innovation, having an entrepreneurial spirit, and doing drug development in a smart, disciplined fashion, without being overly reliant on the paradigms of the past.

For Mr. Crowley BMS offered a lot more; he was inspired by its mission: to extend and enhance human life by providing the highest-quality biopharmaceutical products.

"The BMS credo fit with what my wife and I cared about right then, and it was reassuring to be part of a company where the focus on patients was so significant," he says.

The experience turned out to be invaluable when Mr. Crowley took the giant step to found Novazyme. Among other things, working for BMS gave him insights into the language and culture of the industry, such as how

> I envisioned staying with a big pharmaceutical company for my whole career, but after starting Novazyme and comparing the two experiences, I think I'm much better suited for the entrepreneurial environment.

deals are developed, how drugs are developed and marketed, and how to build a network.

BUILDING A DREAM

The Novazyme journey began in late 1998 when Mr. Crowley met William Canfield, Ph.D., a physician and biochemist from the University of Oklahoma. Dr. Canfield had some novel ideas on how to treat Pompe disease. Over time, Mr. Crowley became more intrigued by the work Dr. Canfield was doing and its potential to ultimately uncover a viable treatment for Pompe. Mr. Crowley provided Dr. Canfield, who was looking to start a company to pursue his work, with funds from a charitable foundation, which he and his wife founded in 1998. He also agreed to help him find a CEO. But finding a leader for a startup company in Oklahoma City proved difficult, and determined to help the company get off the ground, Mr. Crowley became that leader at 32, a step he had not planned on taking.

"We never set out to found a company; it came about almost by default," he says. "We met a brilliant scientist with some terrific ideas. I was helping him find a CEO and a management team. Quite frankly, I was the best he could do for a CEO at the time. We were so desperate to take control of the situation, we were willing do almost anything to drive toward a treatment for our kids."

Taking this leap was far from an easy decision. Although Mr. Crowley was eager to help get the company going, there was a need to balance practical considerations, such as money and healthcare insurance afforded by BMS, with wanting to step up and make a difference.

"Finally my wife said one night, 'This is what you care most about in life, just do it,'" Mr. Crowley says.

There was another important consideration to weigh — the amount of time the couple would have with their children. Early onset, or infantile Pompe disease, is the worst form of the disease. According to the National Institute of Neurological Disorders and Stroke, most babies with Pompe disease die from cardiac or respiratory complications before their first birthday.

"We knew our time with our kids might have been very short, and so we came to a decision that balanced my time and that of Aileen," Mr. Crowley says. "I knew I was going to be away for long stretches of time building the company and traveling around the world, and I might miss most of their days. But we made the choice where Aileen would spend that time with them and I would go out to see what I could do to make them better. This choice was the ultimate trade-off."

The couple wanted to ensure they had done all they could with no regrets in the future. That soul-wrenching decision has most certainly paid off.

On April 28, 2006, the FDA granted marketing approval for Myozyme. The compound, alglucosidase alfa, which had been researched by Novazyme and later became part of the Genzyme pipeline as a result of the acquisition, literally saved the lives of Megan and Patrick.

"We took some big risks and made some bold decisions at Novazyme, and ultimately they paid off but not without an emotional toll along the way," he says.

The company, in a sense, was a victim of its own success. Having quickly reached proof of concept — the stage of development Novazyme was best equipped to handle — the management team was forced to take stock of their options. After quite a bit of debate about whether they could take the product to the next stage of development in humans, Mr. Crowley and his team realized they needed the help of a more established company.

"We needed the horsepower of a big company to get to the next plateau," he says. "The question we asked ourselves was, can we develop the drugs better and faster by ourselves, with a partner, or with an acquirer? And the answer became clear."

So began the task of selecting a buyer. The choice was between a purchase by Genzyme or a joint venture with biotech giant Genentech.

"Each deal had its pros and cons," he says. "A deal with Genentech would have meant a partnership with one of the biggest and most innovative biotech companies in the world. But

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at the end of the day, I realized that the Pompe program would become the largest development effort in Genzyme history. At Genentech, the Pompe program would have been a very exciting new program, but one of about 20 programs at the company, and for me that was the difference."

Another advantage of the Genzyme deal was the direct experience the company had in the lysosomal disease field, which would help move the Pompe program forward.

"And much to its credit, Genzyme has had a passionate commitment to the rare disease field," he says.

A NEW PATH

His time at Genzyme as a senior VP working on the Pompe disease enzyme was a seminal chapter in Mr. Crowley's life, but it took its toll emotionally.

"I had spent four years, night and day, thinking about nothing

John and Aileen Crowley and their three children: Megan (12), John (14), and Patrick (10).

FINDING THE INSPIRATION

It is not unusual for a leader to derive inspiration from a parent, teacher, or mentor who provides guidance. It's less common to have one's children provide that catalyst. For John Crowley, president and CEO of Amicus Therapeutics, his children are both the drive — leading him to cofound a company to find a treatment for Pompe disease — and the inspiration — they keep him going when he's weary.

"We all have tough days at work," he says. "As entrepreneurs we all struggle to advance programs, hire people, and make payroll — it can be very discouraging."

Long, tiring weeks and frustrations can leave their mark on all leaders, leading to disgruntlement and lack of purpose.

"At times, I would be traveling for days around the world, getting home late on Friday nights with the thought that I don't want to do this anymore," he says. "But then I'd go upstairs and talk to the kids for five minutes or just watch them sleeping and think, this is so important. Aileen and I have learned more about life and love from Megan and Patrick than we've ever taught them, and they're only 12 and 10; they have helped to really ground me in the fundamentals of life."

It's the love of his children and the passion to make a difference that has led Mr. Crowley to tell his family's story and share their ups and downs as a way to bring greater attention to Pompe disease.

"About nine years ago, even before I started Novazyme, a newspaper reporter called and said he heard that we had kids with a rare disease and that we were raising some money to help further research," he says. "To see ourselves on the front page of a newspaper was a little odd. Since then we've talked selectively, but to a fair amount of the press over the last decade, and for a number of reasons."

One of the motivations to speak openly, Mr. Crowley says, was so people could get a better understanding about rare diseases, and the gifts of raising special-needs children, and how important it is to overcome adversity and to cherish every day.

Despite their significant physical handicaps, Mr. Crowley says Megan and Patrick are both extremely bright children who love going to school, the same school as their older brother, John. But the difficulty of preparing for that school day is enough to give most people pause.

"They only go four hours a day, and it takes them two hours every morning to get up and get ready," Mr. Crowley says. "They want to go and they're sad when they miss school. When I'm a little tired and don't want to get up and go to a tough board meeting or investor meeting, I just look down the hall and realize how much the kids value life. One of the lessons my wife and I have learned is that it's not the quantity of the years, it's the quality of the life."

In 2006, a book titled "The Cure" by *Wall Street Journal* reporter Geeta Anand was published. Subtitled, "How a Father Raised $100 Million — And Bucked the Medical Establishment — In a Quest to Save His Children," the book tells the story of the Crowleys and their struggle with coping with their children's disease and keeping them alive and healthy. That book has inspired an upcoming film called "Crowley" starring Harrison Ford, tentatively scheduled for release in early 2010.

"This film will be, as far as we know, the only movie really focused on the biotech and pharmaceutical industries, and it will be an incredibly positive movie about how a lot of good people came together with some great science and a little bit of luck and a lot of determination to make a difference and treat people who have a severe disease," Mr. Crowley says. "In the movie, people are going to see a biologic bioreactor, they're going to get an understanding around animal studies, and they're going to see what a Phase II clinical study is. It will tell the pharma industry story in a very human way."

Highlighting Pompe disease and helping to increase awareness about neuromuscular disorders are major reasons why the Crowleys decided to cooperate with the film's producers.

"It will be great, and if we can use the film as a forum to drive even more research and focus on rare disorders with unmet medical needs, it will be well worth it," Mr. Crowley says.

Another motivation was the fact that the film highlights how inspirational people with special needs are to their families and to the broader community.

"These individuals are not a burden, they're a gift," he says.

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but rare genetic diseases, particularly Pompe disease," he says.

In January 2003, Megan and Patrick joined a clinical trial. Shortly before, in December 2002, Mr. Crowley left Genzyme to avoid the appearance of a conflict of interest over having his children in a study for a Genzyme drug.

He took some time off, since the kids were in a treatment program, and began to evaluate how he could next use his healthcare knowledge and network and do something else.

While working with venture capitalists at Domain Associates in Princeton, he came across Orexigen.

"Orexigen had some great ideas about how to address obesity and metabolic disorders through CNS pathways," he says. "This was a chance to apply my skills to a different therapeutic area and work with some different people. Orexigen has turned into a terrifically successful company."

But his children's condition and his passion and determination to continue to fuel research into the Pompe disease field meant he was constantly keeping an eye out for possible therapies.

He was on the boards of several startup companies, and in 2004, one of those companies, Amicus, asked him step into the CEO role. The result has been a perfect fit for both the company and Mr. Crowley.

Amicus' approach to the treatment of human genetic diseases consists of using a new type of drug, which the company refers to as a pharmacological chaperone, that selectively binds to the target protein increasing the stability of the protein and helping it fold into the correct 3-D shape. This restores appropriate trafficking of the protein, thereby increasing protein activity, improving cellular function, and reducing stress on cells. This has broad applicability, since many human genetic diseases or diseases with genetic components involve unstable or misfolded proteins, Mr. Crowley explains.

"For instance, in Pompe disease, rather than using a biologic to replace a defective protein in the patient, we use a small molecule to target the deficient enzyme, stabilize it, and then harness the power of the patient's own enzyme to repair it at the cellular level," he says.

In the four years since Amicus began operating, the company has made huge strides. Today it has three drugs in the clinic for Fabry, Gaucher, and Pompe diseases, respectively. The first of those drugs, Amigal, is set to enter Phase III trials in the first half of 2009, while the other two drugs for Gaucher and Pompe are in Phase II. In addition, Amicus has an advanced preclinical program in Parkinson's disease and a pipeline of activities that it hasn't yet publicly disclosed in programs targeting other disorders of misfolded and unstable proteins.

"If all Amicus ever grows up to be is a company with one or two marketed small-molecule products for lysosomal storage diseases, it will be an incredibly successful business," Mr. Crowley says. "But our vision is much broader. We believe Amicus can grow up to be one of the leaders in the industry. The challenge is to execute our lead clinical programs by continuing to drive data and build value, while aggressively investing in the pipeline and exploring new applications of the technology."

Mr. Crowley is committed to innovative thinking, and he challenges the industry as a whole to ensure there is a sound balance between the need to innovate and the discipline to develop drugs.

The small biotechs must remain the industry innovators, Mr. Crowley believes. He points to companies such as Celgene, which has taken some bold risks and has delivered tremendous benefits to patients and investors.

"Good business is about balancing innovation, having an entrepreneurial spirit, and doing drug development in a smart, disciplined fashion, without being overly reliant on the paradigms of the past," he says. "If you get that balance right, you can have an enormous impact on people's lives." ✦

LIFE MEETS WORK

JOHN CROWLEY – RESUME

2005 – PRESENT. President and CEO, Amicus Therapeutics Inc.
2003 – 2005. President and CEO, Orexigen Therapeutics Inc.
2001 – 2003. Senior VP, Human Therapeutics, Genzyme Therapeutics Inc.
2000 – 2001. Cofounder, President, and CEO, Novazyme Pharmaceuticals Inc.
1998 – 2000. Director, Business Strategy, U.S. Pharmaceuticals, Bristol-Myers Squibb Co.
1997 – 1998. Associate Consultant, Marakon Associates
1992 – 1995. Litigation Attorney, Bingham Summers Welsh & Spilman

EDUCATION
1997. MBA, Harvard Business School
1992. Juris Doctor, University of Notre Dame Law School
1989. B.S. in Foreign Service, Georgetown University

AWARDS
OCTOBER 2008. Recipient, "Professor Edward Murphy Award" for outstanding service to community and commitment to faith, Notre Dame Law School
FEBRUARY 2008. Recipient, "The Ambassador's Award" from His Excellency Michael Collins, Irish Ambassador to the United States
MAY 2007. Recipient, New Jersey Ernst & Young Entrepreneur of the Year Award

MILITARY EXPERIENCE
COMMISSIONED OFFICER, U.S. Navy Reserve United States Special Operations Command

PERSONAL
MARRIED FOR 18 YEARS TO AILEEN ANN CROWLEY. Three children: John (14), Megan (12), and Patrick (10)

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A BIG-PICTURE PERSPECTIVE

The industry at large is slowly starting to recognize the role patients play in their own health, but for many years the ultimate consumer has been kept at arm's length. Even today, few companies consider the patient perspective early on in development.

Having been on the other side of the lab as a father of two sick kids, John Crowley understands all too well the sense of alienation patients often experience.

"When I was just a dad of two kids living with a disease and I wanted to talk to big or little biotech companies, they weren't very open to having a conversation," he says. "I was amazed; I couldn't believe they didn't want to have that perspective."

When he started up Novazyme in 2000, he put the patient perspective at the heart of the

PUMPING UP THE PIPELINE

AMICUS THERAPEUTICS IS A CLINICAL-STAGE BIOPHARMACEUTICAL COMPANY focused on the discovery, development, and commercialization of a new class of small-molecule, orally administered drugs to treat a range of human genetic diseases.

Amicus' innovative therapies apply to conditions in which crucial proteins are defective as a result of improper folding.

Instead of trying to replace these complex proteins, Amicus' approach uses pharmacological chaperones to selectively bind to the misfolded target protein, increase stability, and help the protein fold into its proper three-dimensional shape. This allows the protein to be trafficked to the specific location in the cell, where it performs its intended biological function. Pharmacological chaperone technology represents a novel, next-generation approach to the management of human genetic diseases and offers the potential to improve treatment options for patients.

Amicus' most advanced product candidate, Amigal, for the treatment of Fabry disease, completed Phase II clinical trials in December 2007. Based on these results, Amicus plans to initiate a Phase III clinical trial in the first half of 2009. For more information, click here.

The company's second most advanced clinical product candidate, AT2010 for the treatment of Gaucher disease is in Phase II clinical trials.. One study was completed in March 2008 ,and additional studies are ongoing and planned. For information about the positive results of the first trial, click here.

Amicus' third most advanced product candidate, AT2220 for the treatment of Pompe disease, completed Phase I clinical trials in October 2007. For information about the positive results from these trials, click here. Based on these results, Amicus has initiated a Phase II clinical trial of AT2220.

Additionally, Amicus' biologists and medicinal chemists are leveraging the company's breakthrough scientific platform to conduct targeted drug development, allowing for the rapid identification and optimization of lead compounds across a variety of disease areas, including Parkinson's disease.

The scale of the platform became apparent when the company examined preliminary data four years ago in some animal models in Fabry and Gaucher disease.

"We realized that this is a new, novel platform technology, and if we developed it right, it could lead to potentially dozens of treatments for many dozens of human genetic diseases or diseases with genetic components, such as Parkinson's," says John Crowley, president and CEO of Amicus. "So not only do we have the potential to make a difference in the lysosomal storage diseases area, but we could also do so with some diseases that reach into the many, many millions of people with incredible unmet needs. That's very exciting. It's the stuff that 20 years ago used to inspire the dreams in biotech; it's the stuff that got people excited about Genzyme and Amgen 25 years ago."

company's operations. It's an approach he has continued at Amicus Therapeutics, where he is president and CEO. Not only does the company have a scientific advisory board, as is standard at most life-sciences companies, but it also has a patient advisory board.

"We bring patients in at least every couple of weeks who are living with Pompe, Fabry, and Gaucher diseases, as well as their families, and they talk about what it's like to live with the diseases and the different challenges they have in life and medicine," he says. "It's important for our people to hear their stories. It's important to humanize these disorders. This helps our employees understand the importance of what they are doing. At the same time, we believe it's important that patient groups understand that Amicus isn't a cold, monolithic entity that is making medicines in a vacuum."

To that end, Mr. Crowley says Amicus won't design a clinical study until employees hear from patient focus groups about the basics of living with a disease, how they take medicines, at what frequency, how far they can travel to a clinical practice, how long they can participate in a study, what their prior experiences have been, and so on.

For a company that doesn't have marketed products, this level of interaction with patients is extremely rare, Mr. Crowley says.

Beyond insights gleaned from these patient interactions, Mr. Crowley derives a great deal of inspiration, and he is encouraged about the progress of the company's goals.

This connection with patients extends into his broader world view, and he encourages his employees to embrace a philanthropic outlook. Volunteerism is encouraged at the company; employees are given three paid days a year for voluntary activities. In addition, Amicus has given more than $1.5 million to various charities, hospitals, and organizations.

"We all have obligations in life to our families and to each other, but I believe it's important to be well-rounded," Mr. Crowley says. "We spend so much time at work that it's important to use our businesses as centers for enhancing the quality of life of our employees and giving them opportunities to serve."

In addition, Mr. Crowley finds time in his busy work and home life to serve his country as an officer in the U.S. Navy Reserve and even for tough physical activities, including triathlons and mountain biking.

"I tell Aileen it's cheaper than therapy," he quips. ✦

FAMILY IS PRIORITY NO. 1 FOR JOHN CROWLEY