SCIENCE HISTORY INSTITUTE

JOHN CROWLEY

Life Sciences Foundation

Transcript of a Research Interview
Conducted by

Brian Dick

at

Amicus Therapeutics
Cranbury, New Jersey

on

3 May 2012

(With Subsequent Corrections and Additions)

CHEMICAL HERITAGE FOUNDATION
Center for Oral History
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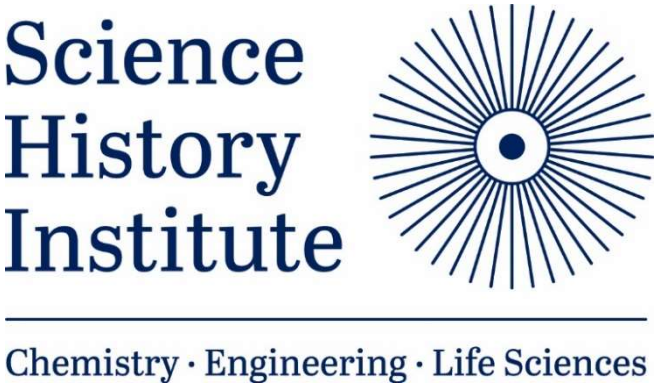

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INTERVIEWEE

John Crowley was born and raised in northern New Jersey. His father was a cop who died on duty when Crowley was seven years old. Later in his life, Crowley attended business school and became a consultant, moving to San Francisco, California. He married his wife Eileen in 1990, and the two had three children. His youngest two children began exhibiting symptoms of a neuromuscular disease and would later be diagnosed with Pompe disease. At the time, Crowley was working as a consultant for Bank of America but moved back to New Jersey with his wife and children to be around his family. He began working for Bristol-Myers and Company in a general management job position. His children's condition worsened and access to treatments for Pompe disease was slow moving, motivating Crowley to leave his job and start a biotech company with Dr. William Canfield called Novazyme. He commuted to Oklahoma City, Oklahoma, from New Jersey every week. Novazyme's research was dedicated entirely to Pompe disease treatment, and after raising twenty-seven million dollars in capital by June of 2001, Novazyme became a subsidiary of Genzyme. Crowley's job entailed evaluating the Pompe programs and determining which would move forward. At the time, Crowley's children did not qualify for Genzyme's treatment program but were eventually accepted as their condition was caused by the same mutation. Crowley resigned as CEO so there would not be any conflicts of interest while his children received treatment. His children's condition started to improve, and Crowley began working for Domain Associates. He later left to work for Amicus Therapeutics, becoming their CEO in January of 2005. In addition to researching therapeutic treatments for Pompe disease, Amicus also researched Fabry disease, Gaucher disease, and other lysosomal storage disorders. When Crowley joined Amicus, the company only had six employees; under his leadership, the staff grew to one hundred and thirty. Crowley's dedication to advancing treatments for Pompe disease for his children was memorialized in Geeta Anand's book *The Cure: How a Father Raised $100 Million – And Bucked the Medical Establishment – In a Quest to Save His Children* and the 2010 film *Extraordinary Measures.*

INTERVIEWER

Brian Dick received his PhD in sociology from the University of California, Davis. Before coming to the Institute he was a research associate at the Life Sciences Foundation. His research interests include the history of agricultural biotechnology, the emergence of the biotech industry, and the Human Genome Project.

ABOUT THIS TRANSCRIPT

Staff of the Life Sciences Foundation conducted this interview, which became a part of our collections upon the merger of the Chemical Heritage Foundation and the Life Sciences Foundation into the Science History Institute in 2018. The Center for Oral History at the Science History Institute edited and formatted this transcript to match our style guide, but, as noted, Science History Institute staff members did not conduct the interview. The Center for Oral History, Science History Institute, is committed both to preserving the recording of each

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INTERVIEWEE: **John Crowley**

INTERVIEWER: **Mark Jones**

LOCATION: **Amicus Therapeutics**
Cranbury, New Jersey

DATE: **3 May 2012**

CROWLEY: Once every semester I'm fortunate to give the last lecture, and then a senior seminar in entrepreneurship at Princeton [University]. Part of what I talk about is innovation and risk-taking and why that's so important for entrepreneurs, and give people kind of a little thumbnail sketch of the history of biotech, which many people in the industry don't know, let alone really bright college seniors. You tell them it's only a thirty-six year old industry, and how it came together, with [Herbert W.] Boyer and [Robert A.] Swanson, and tell the story of [Henri A.] Termeer at Genzyme [Pharmaceutical], and, Sol [J.] Barer at Celgene [Corporation].[1] Those are tremendous examples of—we'll get into—you drive the conversation here, but it's really, really important that people see—that's just eye-opening that people understand that.

JONES: Well, it's an interesting story, and so many dimensions. But let me ask about your bio, going—you got into the pharmaceutical industry, and take me back to growing up and your family and how did you get on this path?

CROWLEY: No, my dad was a cop in Northern New Jersey and my mom's family came from Italy. So, we grew up in a pretty blue-collar family in Northern New Jersey. I was fortunate enough to be able to go to some really good schools in high school and college and beyond. You'd have thought I'd spent a career in the military, or after law school, spent life as a lawyer, and eventually decided that business was interesting, and by my late twenties, early thirties, went off to business school. Out of business school, didn't know what I wanted, so like most MBAs [master of business administration] who don't know what they want to do, you become a consultant.

I did that, and moved to San Francisco, [California]. There's a great old—I think it's an old Yiddish saying that we plan and God laughs. I had my plan in life laid out, and included in

[1] Herbert W. Boyer interview with Arnold Thackray, Sally Hughes Smith, and Mark Jones on 28 March 2000 and 24 April and 21 May 2013 at Michigan Molecular Institute, Midland, Michigan, San Francisco, California, and via telephone (Philadelphia: Chemical Heritage Foundation, Oral History Transcript #0193, in process); Henri Termeer interview by Ted Everson, Arnold Thackray, Pei Koay, and Cassandra Stokes on 23 May and 7 December 2006, 2 August 2007, 18 December 2008, and 30 September 2011 at Genzyme Corporation, Cambridge, Massachsetts (Philadelphia: Chemical Heritage Foundation, Oral History Transcript #0342).

that plan was getting married, which I did, in 1990, and having kids, which we began to do with our son John in 1994, and then Megan in December of '96, when I was a grad student in business school. Then after graduating, Eileen [Crowley] very quickly became pregnant by Patrick. By early 1998, we had three young children. Something was just different with Megan.

That led to her and his—Patrick's diagnosis when Megan was fifteen months old, and Patrick was seven days old, that they had this little-known and devastating neuromuscular disease that I had never heard of. I knew very little about science. But we realized we needed to get pretty smart, pretty quick.

I was working as a consultant on a project for the Bank of America, so nothing to do with biotech or health care. My only experience with biotech was the apartment that we lived in on the campus at Harvard Business School our window in our little patio literally looked out over the Genzyme Allston plant when it was being built. I had no idea what Genzyme did. I knew it was a biotech company, and people would come and go at all hours of the night, and this factory was just very unique, and kind of marvelous-looking.

I remember rocking Megan to bed at night in the spring of 1997 when she was a couple of months old, looking out her window at this plant being built, and the great irony of that, that years later it would be such an important part of our lives, that plant. That we used to kid around, that plant, we used to call it the Willie Wonka plant. We never knew what was going on inside. It looked really cool, really high tech, but pretty secretive. The irony of that becoming such an important part of our lives years later. In terms of career, I never intended to go into biotech. Even in business school, I really didn't know what it was, and certainly not the pharmaceutical industry, even though I grew up in New Jersey. I had no exposure to it.

JONES: What was your age there when you got into consulting, late twenties?

CROWLEY: I graduated business school when I was thirty.

JONES: Thirty. So by that time, you're doing pretty well? A son of a cop and—

CROWLEY: I had a good job, and a ton of student loans, but a good job, and—

JONES: How did your parents feel about your success?

CROWLEY: Well, I think at that point, my mom was hopefully proud, and my dad died when I was real young. He died when I was seven years old on duty as a police officer, and that helped shape part of my perspective in life. I think with any family, where you have a next

generation doing better than the previous, that pride in the child. There's that pride in the family to provide that level of support. I think that was very evidence in our family.

JONES: That must have been really disruptive, at **<T: 05 min>** seven years of age, and then so—

CROWLEY: Oh, that changes your life, too.

JONES: Yeah, what were the circumstances for your family?

CROWLEY: My dad died in a car accident on January 12, 1975, Super Bowl Sunday, early in the morning. It was tragic, and obviously very unexpected. Then it was up to my mom to raise us. I was seven. My brother was four. We lived then with my grandparents. We moved into their, I think, one thousand square foot home. It was two bedrooms, a bath, a little living room, and a kitchen. My grandfather built it after World War II. His family was from Italy before that.

That shapes your perspective. There were two bedroom. It was grandma, grandpa, and my aunt, who was in her twenties at the time, three beds lined up in one bedroom, and the next bedroom was mom, me, and my brother Joe in three beds. One bath. It shapes your perspective on life. You get a lot of responsibility. I think you realize early on that if you want to grow up and have a different and maybe better life materially, in terms of your career, your family, your opportunities, your security, you'd have to work for it. Nothing would be given.

I was just fortunate to be able to have, you know, the family that was so supportive to allow that, and to have those opportunities, and to realize that, you know, the price of success would be hard work with those opportunities. That's all you can really ever ask for. So that laid a great foundation for fast forward to 1997, having gotten, some degree from some wonderful universities, but still not having any money, not having any family with any money, or access, or power. But a network of friends at a business school, who were all very, very young, and early in our careers, most of them as indebted as I was, but being able to realize that I had a certain toolset to be able to maybe shape the field in this area, biotech, at least. But with that, when the kids were diagnosed, we left California. We came to New Jersey.

JONES: What prompted the decision to come back?

CROWLEY: Because right after the kids were diagnosed, we wanted, number one, to be near family. We had no family in California. Family as well out East, primarily still in New Jersey. We wanted to move to New Jersey. We knew we'd need a lot of family support with the kids. I wanted to be closer to the doctors who were experts in the field, who were generally on the East

Coast. There's only a handful of them. I wanted a more stable job that the consulting job was a great experience, but it was a lot of hours. I needed a job where I can have a better balance of time with family.

And [I] took opportunities, and that's where I got the job with Bristol-Myers [and Company]. People have asked, "Boy did you do that, knowing that you'd get a two and half year boot camp in industry at Bristol so you can go start your company?" Absolutely not. I did it because it was—it was in New Jersey. The hours and the life balance was very, very good. The health insurance was good. For me, that was a great opportunity. It was a general management job. I had direct reports, responsibility in marketing and sales. And then—

JONES: Well, let me ask you about—talking to the doctors. At that time, there was no effective therapy, right? Is that right? For—

CROWLEY: No, there was no therapy whatsoever for Pompe disease.

JONES: The doctors—it must have been hard on them, I guess, to have patients and all they can say is, "Well, we can't really help you."

CROWLEY: Like the first doctor who diagnosed the kids in California at Oakland Children's Hospital, wonderful man, very well-trained neurologist with twenty-five years' experience. He had never diagnosed a Pompe case. As he gave us Megan's diagnosis, well, Eileen was just seven days out of the hospital. We had seven-day-old Patrick with us. The doc said, "Your daughter has this disease. This is what it is. It's fatal." At the time, he told us she wouldn't live to be two, and she was fifteen months old. Other than not walking, she seemed perfectly normal. Then he told us Patrick had a 25 percent chance. That changes your life.

The other doctors, when we got to the Pompe experts, they said, "No, actually, they seem to have a hybrid between the infantile and juvenile forms. They could live to be maybe five." Which believe it or not was actually good news, at that point, a couple of months later. But they did say they'd get very weak, very sick, very soon.

On the other hand, they did, especially some doctors at Duke University at the time, told us that **<T: 10 min>** there were medicines being developed, including an enzyme replacement therapy. They could replace the enzyme that was deficient in their body. In animal studies it looked promising, and that it would be in clinical trials within a year. We thought, "Well okay, we've got time, and it looks like we can beat nature. This enzyme looks great in animals. We've just got to get it to the kids." We were told our kids would likely qualify for the first study.

We went home and did two things. We worked with the Muscular Dystrophy Association, and worked with a nonprofit we had started to raise money to build awareness and

to fund some research in Pompe. Then the second thing we did was wait for a phone call to tell us clinical trials are starting, bring your kids down to Duke or wherever. Time kept marching on, and the kids got weaker, and sicker, and eventually, needing wheelchairs, needing ventilators. We were successful raising money for the foundation, and building awareness, and funding some earlier research.

JONES: How much did you raise?

CROWLEY: About a million over a couple of years, so a lot of money, not enough to cure a disease, but enough to have a small impact. But it just wasn't soon enough. Fast forward to the spring of 2000. I'd been at Bristol-Myers about two years. The kids had been diagnosed for two years. They were on ventilators. Their hearts were significantly enlarged. It was the most life-threatening aspect of the disease. They were getting weaker month by month. The treatment that had been promised two years earlier to be any month now still wasn't in patients. We had to think about, "What can we do to drive science towards a treatment, a cure for Pompe?" That's when I made the decision to leave Bristol-Myers, to start the biotech company, and to try to make a difference.

JONES: When you were at Bristol-Myers, and I don't know, you know, what kind of research they were doing there at that time, but were you talking to scientists there?

CROWLEY: Bristol-Myers was actually—I mean, they're an incredible company, and the leaders were so supportive of our family. One of the things I did ask at one point, we had [was] one of the problems was in making the enzyme. The contract manufacturer that Duke had contracted with to make the enzyme was having huge difficulty. The doctor actually told me at one point, he said, "Bristol-Myers has a plant that could make this." We looked at it, and we looked at the opportunity for Bristol-Myers to make it. The timing wasn't right for Bristol, no matter how hard they tried. At that point, Genzyme had begun to get involved in the field. You had a company with a lot of experience and horsepower in the field. But it still wasn't progressing fast enough. And again, we just wanted to do something to catalyst the whole field in Pompe.

JONES: The enzyme at Duke, is that the one that ended up being Myozyme?

CROWLEY: It was the precursor to it. Myozyme was based on that, but it was a separate cell line developed by Genzyme scientists.

JONES: I see. at that point, this is 2000, somewhere in—

CROWLEY: March of 2000 was when I left and with a doctor at the University of Oklahoma, Dr. Bill [William W.] Canfield. He was starting a small company, and I joined him.

JONES: How did you find him?

CROWLEY: I first heard Dr. Canfield in December 1998 speak at an NIH [National Institutes for Health] conference. He was one of a dozen or two dozen speakers. I had never seen him speak before. He seemed very competent, very smart. He was talking about approaching the disease differently than anybody else was talking about. What Dr. Canfield was focused on was manipulating the carbohydrates on the protein, adding a specific targeting market called mannose 6-phosphate that he claimed would greatly enhance the potency and uptake of the enzyme into muscle cells. It was different than anything I'd ever heard before. His experience as a microbiologist seemed very relevant to Pompe. The first area he was applying his technology was in Pompe, because he said it would be most important in that field.

So that's how we began a relationship, beginning with giving him some grant money for some of his research. Then when he wanted to start a company, and did incorporate a business, he was looking for a CEO [chief executive officer]. He was having trouble finding somebody—he had very little seed money in the business, a handful of employees, and it was based in Oklahoma City, [Oklahoma,] so not the most attractive option for qualified CEO candidates.

Finally night in March of 2000, talking about the struggles in building the business, I told him, I said, "Well, hell, Bill, maybe I should just quit my job and come out and run the company."

I was I guess thirty-two years old or so at the time. And there was kind of that awkward silence on the phone.

He said, "What are you doing tomorrow?" A day or two later I flew out. He took me through in depth science, of which I understood very little. I shared with him my **<T: 15 min>** thoughts on how to build a biotech company, again, of which I knew very little. But we knew that there was this huge need. He wanted to build a business, and I really wanted to be involved in working on and thinking about the treatment in Pompe all day, every day. Made the very difficult decision to leave the security of Bristol-Myers. The family never moved. But I commuted every week to Oklahoma City. With that, we started a small little biotech.

Most people told me we were crazy. I was nuts. I kind of looked at them in dismay and said, "What do you mean? I've got an MBA, and of course I can build a business, and I'll learn biotech." Having been in this business now for more than a decade, I understand why they thought I was crazy. In retrospect, I think it was actually necessary that I had that lack of experience, because if I had done things at Novazyme [Pharmaceuticals, Inc.] the traditional

way, and followed kind of the way drugs have been and should be developed, I don't think we would have been as successful or successful at all.

With Dr. Canfield's lack of business experience, but his great science, and my lack of business experience, but great passion in the field, it ended up being a very, very unique combination. That made Novazyme, for the eighteen months it was in existence, going from four to one hundred employees, and building a small plant, and advancing science in just light speed, it made it a very unique piece of history—

JONES: How did you do that?

CROWLEY: —in this industry?

JONES: What did you do wrong that led to, you know, the—

CROWLEY: Well, the first money we raised was angel money. It took us a couple of months. We raised 1.2 million dollars from more than thirty individuals in chunks as small as five thousand dollars. The biggest check was seventy five thousand [dollars]. Then doing some small animal experiments, getting the attention of a small biotech company that doesn't exist anymore, Neos Technologies in Pennsylvania. They were like a biology company, kind of interested in what we were doing. They invested five hundred thousand in the business, dollars. Then eventually some venture capitalists, including, one of the legends in the industry, Dennis [J.] Purcell, who was just founding the Perseus Soros Biopharmaceutical Fund, after his career in banking. We were his first investment, and his first return. So—

JONES: This is a seasoned financial guy, who's looking at how do you sell him on Novazyme?

CROWLEY: He and the guys at HealthCare Ventures, they thought the science was brilliant. They thought they understood the unmet need in the field. They looked at Genzyme and its history, and said, "Boy it would be neat to start another Genzyme." What I've learned in retrospect from Dennis and other investors was they loved my knowledge of the field from a patient perspective, my passion. They didn't ever worry about was he going to work hard or are we going to lose him to an internet startup. They worried a lot about lack of experience, and they worried a lot about objectivity.

What I tried to share with them was never leading with I'm a dad and this is what we're going to do. It's I'm a CEO and we're a company. This is what we're going to do. To support that, later on, would discuss how being a parent can add to that. But at the end of the day, I think I convinced Dennis and others that our interests were pretty perfectly aligned, and that was to

develop the best medicine beginning in Pompe disease, for as many patients as quick as possible. That's a good recipe for success, generally in drug development.

There were lots of times of tension throughout, where my lack of experience, my aggressive nature in trying to develop this medicine, conflicted with their views of the better way to develop a drug, their ways of how best to invest the company resources. At the end of the day, their experience helped temper some of my instincts, and helped make it a better business. I think hopefully my passion, Bill's science, made it a better business. We very quickly attracted the attention of Genzyme, and actually Genentech [Inc.], who had thought of getting into the field. At the end of the day, by June of '01, which to us seemed like a lifetime from when we started the business, was only fifteen months later, we had raised twenty-seven million in capital. We had over hundred employees. We actually built a small pilot GMP [good manufacturing practice] facility. We had animal results. We were looking to be about a year into the clinic. We had two term sheets, one for an acquisition by Genzyme, and one for a very broad strategic collaboration with Genentech in the lysosomal storage disorders.

There was Harvard Business School case study written on it. It's called **<T: 20 min>** "Novazyme: A Father's Love," about that strategic choice for a biotech company to sell or to partner. And for me we agonized over it. I had and have enormous respect for Art [Arthur D.] Levinson and Genentech. I mean, they're the best in the business. Genzyme had such tremendous experience in the rare diseases, and Henri had built such a remarkable company. At the end of the day, the decision for me, and knowing that I would give up control largely, at Novazyme, was driven by knowing that the Pompe program would become the largest program in Genzyme's history, as it did, and it's most expensive R&D effort, as it has been.

It would be the program that for many years would keep Henri and the Genzyme board up at night knowing that it had to succeed. With Genentech, Pompe would be one of twenty really exciting, cool, important programs, but it would not make or break Genentech. So for me, that was the critical factor, knowing that with Genzyme and their experience, they could bring more immediately in value to the program, and it would have to succeed. They would have to invest. That's why we agreed to the sale, and by the fall of 2001 it was completed, and Novazyme was merged as a subsidiary into Genzyme. I became a senior vice president at Genzyme, senior vice president of therapeutics responsible for all of Novazyme, and responsible for their global Pompe development program, which was the largest R&D [research and development] effort at Genzyme at that time.

JONES: Did you move to Boston or did the company stay in Oklahoma City?

CROWLEY: No, the research program stayed in Oklahoma City. It became the Glycobiology Research Institute at Genzyme. We had a presence by that point in New Jersey. We began to wind down that about ten or fifteen, twenty people in New Jersey. We began to wind that down, offering most all of those people positions with Genzyme in Boston. I never moved from Princeton, [New Jersey]. Instead of commuting to Oklahoma every week, I commuted to Boston

every week, and still went to Oklahoma maybe once a month, in the fifteen months I was at Genzyme. My job was to take the multiple different Pompe programs at Genzyme, determine which ones should move forward and which ones should stop, and to get it into patients as quickly as possible.

We did that throughout 2002. The challenge was how do I do that, but by that point, our kids were at doctors in 1998 said they'd live five years. This is 2002. By the summer of '02, doctors had told us they had six or twelve months left. We had about maybe two dozen people, kids with Pompe, on our Pompe enzyme, and many of the children, it was having a terrific impact on reversing the symptoms of disease, saving their life. But the way the protocols were designed at Genzyme, as it was portrayed in *The Cure*, as it was portrayed in *Extraordinary Measures*, in the movie, my kids didn't qualify for the clinical study.[2] That was heartbreaking as a dad, agonizing as an executive. We struggled mightily to figure a way to develop a protocol that could get to Megan and Patrick, to save their lives. Particularly difficult when I'm answering calls from the Ambassador from Spain on behalf of Genzyme for compassionate use of a Spanish patient, or an archbishop in Italy on behalf of the Pope to get a kid in Italy compassionate use, and shipping drug to these dying children around the world. But despite being an executive at Genzyme, unable to treat my own kids. That was the most difficult six months of my life.

JONES: And in the movie, it portrayed a shortage of—that it was very precious, the material.

CROWLEY: Supply was no doubt absolutely very limited. We did have enough to treat dozens of children, not hundreds. In terms of unmet need and sickness, Megan and Patrick were among the small number of most in need children in the world, but they were a little bit bigger. They weren't small infants. To treat them would require more enzyme. But we were also treating adults at the same time. We had inherited a study in Europe. We had an adult in the United States. We had several in Europe, much larger than Megan and Patrick, requiring much more enzyme, who were being treated. It's not as if Megan and Patrick were the outliers. They were one of a small group of children who desperately needed the medicine. I was always careful to make sure that aggressively ramping up our manufacturing at Genzyme was not so we could get medicine just to Megan and Patrick. It was to a lot of other people.

At the end of the day, despite much turmoil **<T: 25 min>** and conflicts personally and professionally, the physicians at Genzyme were able to find a way, and it was a very strong scientific rationale for it. Megan and Patrick were the only two juveniles in that age group identified where they had of course the same mutation causing Pompe. They had different phenotypes, different clinical manifestations. Megan was stronger than Patrick. It would be of enormous benefit to science to understand how they could respond differently potentially to the enzyme, or the same. Having a sibling study that's done in biotech, would be of science benefit,

[2] Geeta Anand, *The Cure: How a Father Raised $100 Million—and Bucked the Medical Establishment-in a Quest to Save His Children* (New York: William Morrow Paperbacks, 2005) and *Extrodinary Measures,* directed by Tom Vaughan (2010; Los Angeles, CA: CBS Films, 2011), DVD.

and it would also help my kids. By the end of '02, that protocol was approved for treatment here in St. Peter's University Hospital in New Jersey, and I resigned the day before the IRB [institutional review board] at St. Peter's met, so there would be no allegation of any conflicts, as we had seen in IRBs before. There wasn't, and they approved it. Two weeks later, the kids were treated, on January 9, 2003. What would have been my dad's sixty-third birthday. That began to change the course of the disease for them. That was a good day.

JONES: Right. The objectivity issues, obviously a key thing. How did your wife respond to—to news that, "Oh we've got these other concerns that we have to balance?"

CROWLEY: Obviously, she wasn't supposed to be objective, and neither were the kids, or our family, or our nurses. Eileen's an amazing lady, and she would never say "John you're not doing enough." And in fact, would often say, "You're doing everything you can." I think that was a good balance for me, so I didn't have that pressure. I only had the pressure of a dad looking at kids every day, and it was different than everybody else. No matter how committed and passionate they were at Genzyme, they didn't have to go home to their two kids every day. Maybe I was away for a week, and would come home, and notice Patrick not holding his head up anymore, or Megan unable to talk as well as she did a week or two before. That was gut-wrenching, to see that.

JONES: Did it affect your on the job. Your demeanor, or just your ability to or maybe maintain objectivity? Maybe that's the only way—

CROWLEY: Tt clearly had an impact within me. I tried as best I could not to have it impact my leadership. I would never in a meeting tell anybody—I don't think in a business meeting at Genzyme I ever mentioned the words Megan and Patrick, except for maybe at the very end. But in the first year, this when we would have manufacturing reviews, clinical reviews, travel the world to visit clinical sites with our medical teams, never said, "Oh and by the way, my two kids need it." It was always about the program. That was where it was generally aligned. If we could make the best medicine to get it to as many people as quickly as possible, my kids would benefit. It was only when they were in that six or twelve months window where it became so critical. For a whole host of reasons wanted to make sure they can get treated. If anything, I think in that last six months or so at Genzyme, I probably didn't push hard enough with people. I probably balanced it too much in favor of being the executive and not the dad.

JONES: Do you feel like the portrayal in the book and the movie are accurate depictions of—

CROWLEY: The book, very accurate. Geeta's an incredible writer and did a remarkable amount of research, so the book is very accurate, the interviews. The movie is a terrific film, and

it captures the spirit of our family. Obviously, it composites characters. It changes locations, condenses timelines. For instance, in the movie, in one scene they had me so desperate at the end as to break into the manufacturing facility and try to about grabbing that vial, and what do I do with it? That didn't happen in real life. I did have that dream, and that's in fact—

JONES: Crossed your mind?

CROWLEY: They originally wrote the screenplay, they wrote that scene as a dream. It just didn't play well in the film as a dream, and they needed to in five or ten minutes capture how desperate we were at that moment, and in a very dramatic fashion, they did that. I think they did it very well in the film, although that event didn't actually occur.

JONES: How involved were you in that production? I know you appeared in the film.

CROWLEY: I did. **<T: 30 min>** Yeah. I got my two minutes of fame there as an actor. That is the start and the end of my acting career. Yeah. Very involved from the moment that Harrison Ford and the producers contacted us after *The Wall Street Journal* story, to their developing the screenplay, to selecting the actors.[3] We were in Oregon, where they filmed it, half a dozen times over twelve weeks. We were very involved. I mean, Harrison came to our company here, worked with our scientists.

JONES: For how long?

CROWLEY: We have a facility in San Diego, [California]. He came to our San Diego facility for a day and a half. On set, we had scientists who were consultants. I mean, all the writing on the wall, the science is accurate. The setup of the labs is accurate. It was very important to them that they get the medicine right, that they get the science right, and that they get the family experience and dynamic right. Those three things they got 100 percent right in the film. They took liberties with the business part of it. My banking friends marvel that I could sell the company in one ten minute meeting, and that, of course, didn't happen. But they needed to. This couldn't be a film about biotech business alone. It had to be from a family-centered view, and that I thought they captured beautifully well. It's the only time Hollywood has ever portrayed clinical trials. The funding of a biotech, the challenges of medicine. They did that in a dramatic, but I think very poignant way.

[3] Geeta Anand, "For His Sick Kids, a Father Struggle to Develop a Cure," *Wall Street Journal*, August 26, 2003, https://www.wsj.com/articles/SB106184568337857300.

JONES: And did you have discussions with the producers going into it about how you wanted to—tell the story?

CROWLEY: Almost daily. It was very important to us, for instance—and to the producers and the studio, that this not be a sad, heavy, "Isn't life awful." We hear references to *Lorenzo's Oil*, and that's a beautiful film, *Lorenzo's Oil*, but it's very different than our journey, and our life story.[4] It's a very heavy film, *Lorenzo's Oil*. *Extraordinary Measures* has some emotional points to it, for sure, but it's not a sad, heavy film. It's got fun music, and it really does capture kind of the tone of our lives, that yes, there are significant challenges, but we're not going to let that get in our way. It's the happiness and the joy in life that's more important to us than the reality of living with a very difficult disease. I think that's what they captured so well. Ending with that Eric Clapton song, the "Change the World," it sets the tone.[5] We didn't change the world. We didn't set out to. We just helped change a very small part of the world that meant an enormous amount of our family and to others.

JONES: Do we have time for you to tell me about Amicus [Therapeutics, Inc.] and—leaving Genzyme, and—what were the circumstances around that? You had success with what—well, how did it proceed at Genzyme? You were deciding, you know, which program to go forward with, right?

CROWLEY: We had picked the programs. The manufacturing was set. The trials were set. By November of '02, it was clear that my kids had a path to be treated. Many of the children did. The manufacturing challenges had been solved. I had felt after that first fourteen, fifteen months that I had done everything I'd set out to do at Genzyme. Quite frankly, years earlier, when I got into the whole field at Novazyme, and it was time to spend more time with family, and time to let the medicine, do what it was intended to do. That's when I made the decision to step aside from Genzyme, and leaving by December of '02.

By January of '03, the kids were being treated. For months, I didn't have a job. I spent time with family. It was different. It was awkward. My wife, after eleven weeks, decided I needed to go get a day job. I started to think about other ideas. By really the summer and the fall of '03, realized that the medicine was having a good effect on the kids.

JONES: How did it change for them?

[4] Lorenzo's Oil, directed by George Miller (1992; Universal City, CA: Universal Pictures, 2010), DVD/
[5] Eric Clapton, *Change the World,* 1996, Reprise Records 9 17621-2 compact disc. Originally released in 1956.

CROWLEY: Yeah, for the first six or nine months were dramatic. Megan in particular responded so well. Both Megan and Patrick's hearts responded, and you can see dramatic changes, that the hearts basically became normal again. From two to three times enlarged to normal size and normal functioning hearts. From a strength perspective, Megan began to sit upright. She could hold her head up. She can talk better. She could smile. You know, it's just remarkable.

JONES: She was the stronger sibling?

CROWLEY: Right.

JONES: The whole time, yeah?

CROWLEY: I mean, she's still very weak. Never able to come off the ventilator, even with the medicine. But even by the fall of '03, we realized that she was plateauing. She wasn't getting any stronger. That was about as good as the medicine was going to be. I had always thought that, God, if we just make this enzyme and get it to the kids, they'd be cured. We realized in time that it was a good start, it was an effective first **<T: 35 min>** treatment, but it wasn't the final answer. That I think is one lesson for me. In biotech, rarely do you have that silver bullet, that magic answer that is a cure. What you typically have are important but incremental advances, and that's what we had in Pompe. By the end of '03 I realized that I needed to start looking for the next best technologies. By that point, was working with Domain Associates in Princeton.

JONES: How did that come about?

CROWLEY: Just through people in the industry, as I was kicking—they were right in Princeton. Through folks, we got to meet.

[END OF AUDIO, FILE 1.1]

CROWLEY: These small molecules, new enzymes. I went on the board of a handful of companies, focused by the summer of '04. The last of six companies that I came onto the board of was Amicus. It was a small company, a handful of employees, early stage seed money, based in incubator space here in New Jersey. They were looking at treating the disease differently. The whole idea was that most people living with these diseases aren't missing an enzyme. They

make it. But because of the mutation, they can't make it right. It doesn't fold properly. You understand protein folding well.

What Amicus was trying to do was to take small molecules that would be developed to selectively target to, bind to, and stabilize a person's own enzyme. They had animal results in February that looked promising. They asked if I'd consider being CEO. I said no, I wasn't ready. I was committed to what I was doing with the guys at Domain. I wanted to stay on other boards. But I'd come on the board and I'd consult. So, I did that in the back half of '04.

By the end of '04, the animal data was looking even better. By that point, I decided that I needed to kind of bet on one horse. They asked again if I'd consider CEO, and I agreed to it. And January of '05, I became CEO of what was then about a six-person company, Amicus, and with one drug in pre-clinical studies for Fabry.

JONES: And where did the technology come from?

CROWLEY: It came out of Mount Sinai School of Medicine [now Icahn School of Medicine at Mount Sinai], from Dr. Bob [Robert J.] Desnick and Dr. Jim [Jian-Qiang] Fan, who were working on it there.

JONES: And did they come to Domain? Is that how—

CROWLEY: No, actually, it wasn't a Domain company. So separate from the work I was doing at Domain. There, I'd helped to start a company called Orexigen Therapeutics [Inc.], that works in the obesity space. Very different than rare diseases, but a company with good promise. Most of the other work I was doing was in the rare diseases, separate from my relationship with Domain.

I stepped aside from Orexigen. I stepped aside from all the other boards I was on, to become chairman and CEO of Amicus, with the notion that we would build this into a very significant company, the next Genzyme. In the field, we would do it with our core technology of pharmacological chaperones in the lysosome storage disorders, beginning in Fabry disease. Fast forward now seven and a half years. That Fabry program is now a late-stage Phase III program. We're also now using the technology not just as a monotherapy for people with Fabry disease, but in Fabry, and now Pompe, and in other diseases. Using it as a combination, because one of the things we've learned is in the limitations of these enzyme replacement therapies. You know what you're doing with the ERTs is actually pretty unnatural. You're taking a bioreactor made enzyme and you're giving it every other week or so, maybe once a week, every other week, infusing it into the blood where these enzymes usually don't live. You're putting it into a very high pH environment in the blood, where these enzymes become very unstable in blood, much

less potent, much less active, and much more immunogenic, which we think is contributing to why they don't always work so well.

JONES: It just brings to mind, I mean, these must be issuing that Genzyme has been considering all along, right? So what's the approach there?

CROWLEY: I mean, we've known of these problems for a long time. We've looked, absolutely, at Genzyme. We looked at different diluents, different stabilizing agents, PEGylation, all of that. Nothing worked very well. PEGylating it, for instance, interfered with the activity in folding and targeting. So yes, we've known these problems. We just haven't had a tool set to address it. It seems that nothing works better than these small molecule chaperones that bind the active site of a protein. As a monotherapy, they bind to a person's own natural enzyme, to enhance its activity and transport it to the lysosome. When used in direct combination with the enzyme replacement therapies, they stabilize the ERT product. They can stabilize it in the infusion bag. They can stabilize it in the blood. By doing that we've seen it now with clinical data in Fabry, it increases by several fold. In Fabry, we've seen 200 to 400 percent increases in plasma activity of Fabrazyme. On biopsy, we've also seen much greater tissue uptake of the enzyme.

We're doing a study now in Pompe. We don't yet have the data. But what we know in animals in Pompe, like we saw in Fabry, is with the addition of the chaperone on board, when the enzyme product is given, you can make these products more stable, more potent, promote the uptake much better in the key tissues of **<T: 05 min>** disease, like muscle in Pompe. We believe you can make them much less immunogenic. By muting the immune response, you can allow more of the enzyme in a more active form to get to tissue.

So, at the end of the day, we think we might have a tool set that can provide for a much better therapeutic outcome with these ERTs. Beginning with an oral co-administration of our chaperone, all the way to we're working on development of next generation enzyme replacement therapies, where a chaperone can be directly co-formulated into this next generation ERT for Fabry, Pompe, any number of these diseases. That's what we think the future may be for the treatment of these diseases, which makes sense. The enzyme replacement therapy technology is a great first-generation approach. The technology is over twenty years old. There's got to be advances, important advances. We think this might be one of them. That's what we do here. We've got about one hundred thirty employees, one hundred twenty here, and a small number in a research lab in San Diego, largely R&D company. Our key partner is GlaxoSmithKline [plc], GSK now, in the rare diseases, which is an incredible advancement. If you had told me five, ten years ago one of the biggest players in the lysosomal storage diseases would be GSK and Pfizer [Inc.], in addition to Shire [plc], BioMarin [Pharmaceutical Inc.], Genzyme, I don't know that I would have believed it. But GSK has been a great partner for us. They own 15 percent of Amicus. They partner with us on our Fabry program. It's been a great relationship.

JONES: And in growing this company, what are the current issues that you're dealing—Sarah was telling me that—it sounds like you had some pretty remarkable success, given the current environment.

CROWLEY: It's biotech. We've been very fortunate. We've been well-capitalized. This is a very new technology. It's an entirely different pharmacology. Any time you've got a new technology, it takes time. For us, the biggest challenge as a monotherapy has been figuring out dosing and dose regimen. That's taken years of Phase II studies in Fabry to get it right. We think—we hope we've got it right now in Fabry. For us the challenge is going to be advancing the science as quickly as we can, getting it into other disease areas, but making sure we do it right, we do it safely, and we have a profound impact.

One thing we're not looking to do at Amicus is have small improvements and changes in disease outcomes. We want to look for where are the areas where we can have the greatest impact, the big changes. That for me is where the lessons or the history of biotech are so important. You tell the story of what Henri Termeer did at Genzyme, and the founders and the scientists there, and getting into Gaucher, and pushing that into a ten to twelve patient pivotal study, an enzyme derived from placental tissue. That's remarkable. If you tried to sell that to people today as a new idea, they'd think you were crazy. That was only twenty twenty-five years ago. That's risk-taking. That's innovation. That's taking huge risks to fundamentally impact people's lives. It doesn't always work. It's taking smart risks. But when you do it makes this the greatest industry in the world. When it works, it makes this the best job you can have, in running these companies.

JONES: And how do you convey that to—you've got hundred and some people out there, and convey that, what we're doing is pretty risky, people.

CROWLEY: Well it's smart risk. So how do we mitigate? We always say in our mission statement—we developed that mission statement six years ago, when it was twenty of us in the company. I'd encourage you to read it. It's on every one of our walls. It starts with the words we believe, and those are the only words I gave them. Then the employees in the company put the rest of it together. It talks about everything in there, our culture and our commitment. But it starts with we—the very first words say we believe that we must constantly build momentum in the fight against human genetic diseases, and we seek to deliver the highest quality therapies for people afflicted with these diseases. But it talks about embracing constant innovation and being passionate, a duty to obsolete our own technologies. We get our first drug approved, we're not going to declare victory and go home. We're going to work on the next best way to treat. We already are, on the next best way to treat the disease. Asking the tough questions, not to be constrained by prior thinking, not because this is the way it's been done before.

We want to build something different, and to give you an example of how we're doing it today, we've got a family in from Florida who have a young girl diagnosed with a lysosomal storage disease. It's not Fabry. It's not Pompe. It's not Gaucher. It's another LSD [lysomal storage disorders]. We've disclosed to the rest of the world in the last few months we are now working with this **<T: 10 min>** combination chaperone plus ERT technology, and the development of next generation ERTs in other lysosomal storage diseases. This is one of those diseases, and it's going to be the first time we've had a family come in and talk about their experience living with this other disease, that our company hasn't been exposed to, except for scientists. We will have our lawyers there, our accountants there, everybody in the company. Our administrative assistants, everybody. They're going to hear a family perspective of living with this particular rare disease. That's part of what—we've done that dozens of times in Fabry, Gaucher, and Pompe. And now we're doing it with the other diseases that we've just started researching a couple of months ago. So, it makes it a very personal journey for everybody in the company.

JONES: I'm sorry. Did you mention the others?

CROWLEY: We haven't disclosed what they are. We haven't disclosed. We have said that they are—

JONES: But they're rare genetic—

CROWLEY: They're rare genetic diseases in the lysosomal storage disorders. Yeah. As we have more data, we'll be discussing what they are. That's kind of who we are. I'm happy to continue and answer any other questions.

JONES: Well, what else should we know about your career? We're going to put together a story for our magazine. What would you like us to say? What do you want people to know about you, about the company, about your career? About the—

CROWLEY: We talked about the objectivity early on. I worked really hard early in my career to either have my company executive hat on or to have my dad hat on. I used to think that they would be in conflict, and I don't think that anymore, and I don't try to wear two separate hats. I'm a dad of two kids with profound special needs. And to not share that with people, whether it's through these articles, through the movie, through our culture here in the company, that would not be telling the full story of who I am and what our family is all about. It means that this becomes a more personal journey for everybody in the company, but that's okay. It's not pulling on the heartstrings. It just is what it is.

I think oftentimes we try to compartmentalize different pieces of our life, and for me, I just don't know how to do that very well. This living now for more than twelve years with our kids with this genetic disorder has certainly shaped who we are as a family. Most all times for the best. Sometimes there's been emotional challenges. We try to balance that. I think one clear—go ahead, Mark.

JONES: Well it occurs to me—I'm sure that, you know, in this business, developing therapies for these diseases, you have families coming to you, and they want to talk to you.

CROWLEY: All the time, every week.

JONES: I mean, is that a challenge to you, to compartmentalize, where you have to say—you have to put on the objective executive hat, and then you have to say—

CROWLEY: I don't have to be conscious about it. So, for instance, this morning, just before you and I met, we just spent two hours with that family, the mom and dad from Florida, and they had their doctor from Florida on the phone. We took them through very detailed science data. They're being very vocal advocates in their disease community. I remember when I was in their shoes twelve years ago. Not a lot of people wanted to talk to me about what they were doing. It was almost like a secretive, hush hush, in companies, and it shouldn't be. I mean, obviously, there's proprietary data that you can't share. But we basically told them everything we know about what we've been doing in these diseases, and in their disease, how we're thinking of tackling the next generation approach.

It's pretty eye-opening on both sides of the table. I learn about their family, their disease, patient needs, family needs. They learn about what we're doing. We figure out are there ways that we can complement each other's work. From a patient advocacy and foundation standpoint to the work that we do. So, I don't know that you need to not be the dad. If I'm in there talking about corporate strategy, financing plans, drug development, manufacturing, it doesn't mean that I'm not a dad, and I have to pretend not to be. Oftentimes I'll mix in my personal experience in Pompe. They asked me, on one of the Pompe slides, "That's great, it's affected these people in this way. How has it affected your Megan and Patrick?" I'll tell them. This is what we've seen personally. I don't think you need to separate it. You just need to be aware of when it's appropriate and not, or when—and most importantly, when it's relevant or not.

JONES: Here you've been very well financed. You've **<T: 15 min>** been able to do. You have the resources to do what—looking ahead, you say, we need to do this, you have resources to be able to do that. That's great. Right now, it's difficult for a lot of companies.

CROWLEY: Extremely difficult.

JONES: Right. As a father of kids with a rare genetic disorder, you started a foundation, raised money. Do you see a role for venture philanthropy?

CROWLEY: I think it's very important. I look what the Cystic Fibrosis Foundation did in getting really what is the first major disease modifying treatment approved, even for a small subset of people living with cystic fibrosis. What Vertex [Inc.] did in partnership with the CF Foundation is a remark—it's a tremendous model.

Not every foundation is the Cystic Fibrosis Foundation, where they can bring that level of resources to it. But it's a good model. I've met with lots and lots of families and foundations, and encouraged them to partner with industry. I used to work for—and still have a good relationship with the Muscular Dystrophy Association [MDA], and in the last few years have been working with the MDA to give research grants not just to academic research, there's—but to industry. We just got a two hundred thousand dollar grant from the MDA to study the immunogenicity of enzyme replacement therapy in Pompe disease. It's going to help us a lot. They've given multi-million dollar grants to companies in Duchenne muscular dystrophy. I think it's a great partnership.

Academic research plays such an important role in discovery, early-stage ideas, research. But drug development is done within companies. That's important to realize, too. A lot of these companies need help financially. They need help with clinical, tools, clinical sites, experience. Those are things that not-for-profits can bring to the table.

What you worry about is we live in a very risk averse environment in the last four years, since the financial crisis in particular. Biotech is by its nature a risky business. You can de-risk it a little bit, but it's always going to involve significant innovation and risk. It should. Because of that, so many early-stage companies have struggled with financing. I don't know today if I can get the Amicus plan from seven years ago financed, if it was at that point. I think it'd be very challenging. That would be a shame. We need a lot more Amicus type companies to be funded, so that companies like ours can grow up to be the next BioMarins, the next Genzymes.

JONES: Well, you've been on both sides of the fence. You were at Domain evaluating, making decisions about, "We can't go there." I mean, that's another sort of—I don't know, maybe can you go back to that? I don't know how looking ahead, how long you will be with this company, see it through, right?

CROWLEY: Yeah, I intend to be here at Amicus a very long time. I would love to, either through Amicus or some other way, much later in my career, to think about how can I help either mentor other CEOs, help drive ideas and capital, basically bring people, innovation, and

capital together. That's what the best venture capitalists do. That's what the Brook Byers of the world did early on, and have fostered for a generation now.

JONES: Yeah, it seems like the model is under some duress here.

CROWLEY: It's under a lot of stress, but I don't know if it's a structural change or a cyclical change. But the very best people in this business the Brook [H.] Byers, the Jim [James C.] Blairs, the Brian [H.] Doveys at Domain, other names, those are the people who—they're still taking the risks. Jim Blair once told me when we were debating an investment idea for an early-stage company a couple of years ago at Domain, and I was really hesitant in recommending against it. I remember Jim standing in my office listening and said, "Yes those were all great points, but we're going to invest, and we're going to put—" I think he was going to put twenty million into the company. He said, "Because at the end of the day, I'm not in the risk mitigation business. I'm in the risk-taking business, so I can create value and build businesses." I think all the VCs [venture capitalists] out there need to keep that perspective.

JONES: Domain is also doing well these days.

CROWLEY: They're among the very best in the business.

JONES: Anything else, John?

CROWLEY: No, I think—

JONES: I think we've got plenty to work with.

CROWLEY: I was going to say, I don't want to give you too big of an article, but you've got *The Cure*, and you've seen the film. I—

JONES: So, I could rely on this?

CROWLEY: I mean, Geeta's —what she wrote is accurate. You know, she interviewed over two hundred people. It was our history a long time ago. A lot's changed. That **<T: 20 min>** basically captures events in our lives from 1998 to 2003. That's more than a decade old. A lot's happened since. One thing we did do when the film came out, Eileen and I—my wife and I had

a chance to reflect on not just the—Geeta wrote very well, very accurately, what happened. Eileen and I tried to capture—we wrote a book called *Chasing Miracles: Our Family's Journey of Strength, Hope, and Joy*.[6] It was really our personal memoir of—

JONES: Is that available? Can I—

CROWLEY: Gosh, I was just looking I don't know that I have a copy here. But I can send you a copy.

JONES: We'll find one. All right.

CROWLEY: Yeah. It was really just our family's perspective of what it's all meant and what we've learned. I do talk in one chapter about innovation and hope in biotechnology in there, but also very personal stories of what we've learned.

JONES: That would be great to have that. I mean, this is the kind of story that we want to tell.

CROWLEY: Even picking a title for it, you know, *Chasing Miracles*, we realized the title has a very special double meaning for us. It's yes, on one hand, chasing the miracles of newer and better treatments for Pompe and other diseases now, but it was also—I guess it took me years to realize this, that Megan and Patrick are our little miracles. We learned more about love and life and living from them than we've ever taught them. We've realized life really is a marathon. It's not a sprint. For us that's been one of the beautiful parts of this journey.

JONES: Pretty inspiring story.

CROWLEY: Well, there it is. [. . .]

[END OF AUDIO, FILE 1.1]

[END OF INTERVIEW]

[6] John F. Crowley, Ken Kurson, and Aileen Crowley, *Chasing Miracle: The Crowley Family Journey of Strength, Hope, and Joy* (New York: William Morrow, 2010)