Episode 647: Cancer: One Child's Story, and Lessons Learned

Guest: Roger McCaffrey

WOODS: Hard to know really where to begin with this story. I suppose we should begin with — and you know, I know the basic story, because you and I were friends at the time, and I was working for your magazines at the time, so I know basically what happened, but I don't know a lot of the details. So you got a diagnosis for your — was he at that time 8 years old, your son? How old was he?

MCCAFFREY: John was 4 1/2 at that point.

WOODS: Okay, so he was very, very young at the beginning. Wow, so this was quite a struggle.

MCCAFFREY: Yeah, and we had three other children, so we had ages 2, 4, 6, and 8. And this came out of nowhere. As John said to one reporter — because even John was interviewed at the time, eventually was interviewed — you know, one day I felt fine, and the next day I woke up and I had pain in my legs. Well, that was the leukemia, which is really a misnomer for his disease. He had stem cell cancer. It's a form of leukemia, but every leukemia is as different from another leukemia as pancreatic cancer is from lung cancer. So he had a stem cell cancer, and it was always fatal. It took five years; it was chronic, rather than acute, so it took about on average five years to kill its victims, and they were almost always adults. I mean, there were 50 children a year under the age of 16 who got this cancer, so it was utterly rare. I mean, all childhood cancer is rare, but this is almost unheard of. I mean, there probably were 10 other children under the age of 6 who had this disease.

WOODS: So you get that news, and of course your mind races in a million directions, but you think, look, I'll do whatever they tell me to do. Is that what it was like?

MCCAFFREY: Yeah, exactly, exactly what it was like. For the first 10 months, we did — you know, there were two options. One, you treat him with conventional chemo and Interferon, which is not exactly — it's a metachemo; it's not really a chemo. It revs up your immune system. It's a hormone of some sort, I guess. Or you do a stem cell transplant, also known as a bone marrow transplant. So we opted for the latter, because it was, as they say in the profession, curative, which is one of their terms. And so yeah, we did that. We did a bone marrow transplant. The 10 months were

filled with much pain and anxiety for John — more anxiety for us, but much pain for John. So that was phase one.

There were three stages to the cancer, but there's also three elements to this story. It went on for three and a half years. So in any event, we did what we were told, and we treated him at two major places in Connecticut; we'll leave it at that for now. And that was a total failure, in the end. Then we discovered an experimental drug, but that's a story in itself, and I'd like to save it for 5 or 10 minutes down the road, because we pursued it against all odds and got it. That was a miracle in itself.

But so we did what we were told. The protocol that was applied to John was two different kinds of chemo, to oversimplify it, and a lot of bed rest. I mean, the protocol was ancient, of course. Protocols tend to be ancient. That's why they're protocols. So that nearly killed him, you'll be shocked to hear, Tom.

WOODS: Okay, so at some point the parents in these situations presumably assert themselves against the doctor. Is that something that happened here?

MCCAFFREY: Fair enough, that's what happened. That's what happened. But it took us 10 months to get up to speed, both on the disease, on the so-called treatment options, and thirdly on the fact that, like all professions, you have average docs, whether they're hematologists or not, and very below average. You have lots of deception; you have honest people. So that ran the gamut, because we dealt in that first 10 months with 4 major hematologists, pediatric people, regularly, more than most anyone will ever deal with doctors. And then we saw 4 or 5 others, as well, in the transplant unit where John was for 7 weeks. It's a sterile unit, so you can imagine what that was like.

Anyhow, once we figured out that the bone marrow transplant, aka stem cell transplant, because that's what it really was, failed, we expressed our, let's say, disappointment, because we were actually deceived. They knew it had failed, undoubtedly, four months before that was confirmed. And you lose four months with a cancer, the cancer tends to grow, not shrink. So we lost a lot of time being obedient servants to the docs, who really didn't spend a hell of a lot of time worrying about John, let's face it. I mean, they have other patients; they have families themselves. You, the patient, especially the parent of a pediatric patient, have to do your homework and be on high alert. That's the first thing we learned. But the second thing we learned is that we needed to find other institutions that might be better than the ones that we had.

WOODS: All right, before we go there, why would they keep something like that from you for that length of time?

MCCAFFREY: Well, you know, who wants to tell the parents of a beautiful little boy that they botched it? And you know, of course there was a chance this would fail. We all knew that. But there was a particular reason that we felt that they botched it, which had to do with the quantity of stem cells that were actually infused into John. After they blew out his own bone marrow, which is part of the protocol — you blow

out completely the bone marrow in order to replace it with new stem cells, which become bone marrow, and you know, they're blood stem cells, so they become what you want them to be if everything works out.

So anyway, they botched the job, and so they didn't want to tell us. And they never tested for engraftment. We got the chart, which was huge — the chart being the documentation of treatment. We got that. We had the complete chart. I still have it, of course. And it showed no test for engraftment of the new stem cells, which means either they tested and threw out the results because they were disappointing, or they didn't bother to test. I mean, it's that dramatic, that shocking.

WOODS: Well, is this the sort of thing that if you hadn't had a life-threatening emergency on your hands, you might have had legal recourse?

MCCAFFREY: Yeah, you know, of course, but when you're dealing with an officially dying boy —

WOODS: Right, of course.

MCCAFFREY: But yes, certainly there's that. In American medicine, for heaven's sake, you can sue for a hangnail, and these days especially, with this new crop of federal judges. They were no great shakes 20 years ago. Today, man. Yeah, sure, there was legal recourse, which has not been taken.

WOODS: All right, so then you start looking elsewhere. Where are you looking?

MCCAFFREY: Well, we got the news in December of 1998, and so of course immediately I started looking at the best bone marrow transplant places, because in the cancer business, the cancer industry, you just do over again what just failed. I mean, the concepts are almost laughable, you know? So everybody wanted to try another transplant, which had, as I said, just failed. And we were skeptical, so I figured we might have to do this. So I went to Dana Farber, which is a bone marrow transplant, one of the better cancer centers in America. I went to Sloan Kettering; I went to the Fred Hutchinson Institute, all of this with John. I took care of John day to day a lot of the time, because Priscilla had the other children. And I went to — gee, I talked to Mayo Clinic; I talked probably — I forget, I've got to look at my notes — probably to Johns Hopkins bone marrow transplant unit.

But anyway, we went everywhere we could, and I took John everywhere so that I could get the very best second opinions. And I got about five second opinions — all of this, by the way, while fighting off the insurance company, which told me I had to stay in network. We were in an HMO at the time. These days, by the way, almost every insurance plan, in effect, because of the Obama health takeover, is an HMO. Back then you could, and even five years ago, if you had the right plan, you had great flexibility. But now you really don't have the flexibility that you think you might have. You're stuck in networks that are increasingly shrinking. They're not really growing, most of the time.

So okay, we started looking at better places, let's put it that way, to do a bone marrow transplant, but hating the whole idea, because a bone marrow transplant involves blowing out functioning bone marrow, all of it, so that your white blood cell count in this disease goes to zero. *Zero*. So you have no ability to fight infection.

WOODS: Oh my gosh.

MCCAFFREY: That's what a bone marrow transplant typically, to oversimplify it, that's what it typically is, certainly in this disease. So you know, okay. But at the same time, I had been reading for months all kinds of medical journal articles that I had friends would Xerox at the Yale medical center library. I still have everything. I've got eight boxes of files, 1,000 emails and letters and memos and notes of different phone conversations. I still have everything.

But I stumbled on, because a friend of mine who's a journalist saw this tiny little UPI or AP item about a new drug used on lab mice with CML, which was John's disease. CML is a stem cell cancer that has one genetic defect only. Every other cancer has multiple genetic defects. CML has one, called the Philadelphia chromosome. It's a chromosomal defect. In mice in Italy, this drug, which was CGB57148B cured 100% of the mice. So this I found out in January of '99. So you know, almost miraculously, at least in my mind, there was an alternative to stem cell transplant. But it was only in mice.

So I picked up the phone as soon as I read the article, and I called the doctor in Italy, who has since become a good friend, Dr. Carol Gambacorti, who's a clinical oncologist and hematologist, and he's also now a world-renowned, in his field, a world-renowned blood cancer expert. And he said, you know — I said, how do I get this for John. I don't care about the mice bit; how do I get this for John? I mean, this was an unusual phone call, because most people don't do this.

WOODS: Right.

MCCAFFREY: And he said, you know, they're using it in humans in one place, and that was in Oregon, at Oregon Health Science University. And he said you should call Dr. Bryan Drucker. Drucker was the chief investigator, now the most famous oncologist, I would say, probably in the world. Then, you know, just another scientist seeking a cure. But he knew he had something, and he knew it for years. So I called Drucker, and to my shock, first of all, I got through to him. I was accustomed to being elbowed in the face by your standard issue, northeastern, American oncologist. You know, we spent months getting elbowed and misled. Drucker, by contrast, answered the phone, and we spoke. And I said to him, gave him John's situation. Drucker was not a pediatric guy, but I said, look, I'd like to come out and talk to you. And I flew out with John, using a corporate angel network —

WOODS: Yeah, yeah, stop and say something about that. I really, really like — I didn't know about that until you used it.

MCCAFFREY: Yeah, in fact, they fly many hundreds, maybe even into the early thousands of cancer patients per year on empty seats donated by corporations. Almost always it's corporations. I don't think there are too many rock stars sharing their empty seats on their private jets. I only dealt with businesses, and John and I flew, it turned out, dozens of times on these corporate jets, because Drucker eventually took John as a patient, his first pediatric patient. The nonprofit, which is headquartered in White Plains, finds you empty seats on willing corporate jets. So we flew a lot of time with the CEOs or number two guys in companies, and a lot of times the jets were empty. They were being positioned for flights the next day or whatever. And this charity done by these corporations gets them absolutely zero in tax credits or write-offs. This is pure generosity. You know, and they never get credit for this. Only *The Wall Street Journal* has given them any real credit, nationally speaking. Only the *Journal*.

WOODS: But it saved you and many other similar parents a fortune.

MCCAFFREY: Not only does it save people a fortune — you can't fly commercially if your son has a severely immunocompromised system.

WOODS: Oh, yeah, I didn't even think of that. That's the really obvious thing. Yeah.

MCCAFFREY: I mean, that's fundamental, and plus, it was a total hassle to fly, which we occasionally did. But that was, it was almost a nightmare to fly with John, for that reason alone, on commercial airliners. But anyway, the corporations, there's at least a couple hundred corporations, large and small, who share their empty seats. At least. There might, by now, the Corporate Angel Network might have 5 or 600 hundred of these, and they never get credit for this. They just get bashed by everybody from the Pope on over to his friends in the Obama administration and in the Ivy League institutions that dominate our — well, dominate academic life. But the generosity of these people would never cease to amaze me, and a couple times they would divert their planes to pick up John. I mean, it was just very touching to see.

WOODS: Wow, yeah, that's nice.

MCCAFFREY: And I might add that in terms of cancer medicine, Corporate Angel Network cooperators, these companies, actually supply a large number of clinical trial patients, as John was eventually, because they did put him on the drug, although I'm getting ahead of myself in the story. They gave — he was the first child to use this drug, and only because of Corporate Angel Network and these generous companies were we able to do that. But the same was true for many patients, in this clinical trial for this Drucker drug and many other lesser drugs, but still better drugs. So that's a dividend that nobody every talks about, except *The Wall Street Journal* about every eight years when I happen to write an article. I wrote two op-ed pieces for them over a seven or eight-year period. So you know, we got that point across, you know?

WOODS: All right, so you get out to Oregon, you talk to Dr. Drucker.

MCCAFFREY: Yeah, Drucker is now, you know, he's won the Lasker prize for medicine. He's won the Japan prize. This puts him on a track for a potential Nobel Prize. So that's how far he's come, and he's now heading up a billion-dollar cancer research facility at Oregon Health Science University. But we got to just know him as Bryan Drucker, you know? This was pre-famous Bryan. And I still keep in touch with him, because I found him both heroic on our behalf and also I was very impressed by the way he dealt with my son. And you know, he bought John, just by fiat, out of the goodness of his heart, he really gave us, you know, two and half more years with John. And every day is precious, especially in hindsight. That's about as personal as I can get, because this all feels like it happened yesterday, Tom.

WOODS: Yeah, I understand that, sure.

MCCAFFREY: So I'm going to be sounding a little clinical about the case, because I have to some degree separate myself. But you know, it's all been bottled up in me, because aside from the two *Journal* articles, I haven't really talked to anyone about it. You're one of the very few, and it's all still very fresh to me, and I'd like to help other folks who are going through something similar. That goes without saying. But none of my friends ask me about it, and most people kind of assume you don't want to talk about it, after all. And it's not a bad — it's quite rational to think that way. But in this case, what we did was so unusual and so great for John that you're damn right I want to talk about it, and I want other people to know several things about dealing with cancer, either if they're dealing with it themselves or their parents are dealing with it or, God forbid, their children are. Yeah, so I'm writing a book, which is a good year away.

But anyhow, Drucker's a big deal. He was a big deal in John's life, and because of his example and his guts, because he put his career on the line, I assure you, by taking a child as a patient, you know, with the FDA looking down his throat. In fact, one, I won't say who the doctor was, but somebody well known said to me, if John dies when he's on this drug — which became Gleevec, by the way. It's a very well known drug know. If John dies when he's on this drug, they're going to shut the whole program down. By the way, which would be a death sentence for the first 30 or 40 patients who were on the drug. Because at the time John got the drug, there were only 30 — when I spoke to Drucker that first time and took John out to meet him, there were only 31 patients on this drug, all adults, all dead meat if they didn't have this drug. They had failed all the protocol drugs. They were dying, every one of them. Every one of them had his life turned around almost immediately, as did John.

So what we did was we defied the very, very best pediatric and other oncology docs in the country by refusing to do a second stem cell transplant. And Priscilla, my wife, was of course directly involved in influencing that, but we just basically told him, you know, we're not going to do this. And I said to one, and eventually I got John in New York into what one physician refers to as "super duper cancer center." And they were super duper, and they have a super duper PR department, I might add, but they were the very best. And a hematologist said, well, we've got to do a second transplant, and I said, you know, you're so big on this, what are his chances? She said 20%. And I knew

what that meant, Tom. Here's a little hint for your listeners. 20% in that circumstance, that really means 10%.

WOODS: Yeah.

MCCAFFREY: And the suffering that would be engendered in John was unthinkable. I mean, the suffering of — we saw people in the bone marrow unit dying, and people would just turn black. Their organs, when you transplant bone marrow or stem cells, they attack. They see your body as an alien, and they attack; typically they attack your body. They attack the vital organs, and you need anti-rejection drugs for the rest of your life, usually, to deal with that attack. Now, one of the benefits is that those attacking cells from the donor also kill off the leukemia that's in your son. So you know, that's the kind of thing that they were juggling, but you see the mad scientist approach here, don't you?

WOODS: Did Drucker back you in this decision?

MCCAFFREY: Yeah, but we had to make it clear to Bryan that — and you know, we're two fairly intelligent people, and I do write, as you know.

WOODS: Yeah.

MCCAFFREY: So I made it abundantly clear to all concerned that we rejected the option of a second bone marrow transplant. In science, after all, when a concept fails, why the hell do you repeat it? I mean, you know, it was just not logical to roll the dice like that. And mind you, though, we had not completely foreclosed on the option of doing a second transplant, but we argued that since John's leukemia, like everything else, was killed by the transplant process, we had some time. We knew we didn't have a lot of time, but we figured we had some time. But once we discovered the Drucker drug and I went out to meet with Drucker with John and we saw that the thing was really working, we were adamant. By then we were adamant.

But you still need a physician with courage to back you, and we did find them. And Drucker led the way, but by his example there were two or three others who put, to a lesser extent, put themselves on the line for John, again, because in America, you can sue. The minute your son dies, you can file a lawsuit no matter what you promise these people. And we did promise them that we would not hold it against them, and although in the courts our word meant nothing, as you know, to us it meant everything. So you know, Bryan, God bless him, he saw that we meant what we said. We put it in writing. He believed us. In the end, you have to be human, and he took our word. But by taking our word, he risked a lot.

WOODS: Yeah.

MCCAFFREY: So then I got someone on the East Coast to follow John when we were home, because John and I commuted to Portland, Oregon, but you know, we still lived on the East Coast. So we got somebody who's no longer there at Westchester Medical

Center who stuck his neck out for us, and he followed John while we were here. My larger point is you can find men of courage, and of course the nurses tended to be women, and thank God for that, because they made life bearable every step of the way. And in oncology, in pediatric oncology, the nurses are everything. And needless to say, there were a couple female hemoncs who helped us out as well, but most of these guys were men, and most of them showed a lack of courage, but we really appreciated it when we met those who put their careers on the line.

And I can't say it enough: that's exactly what they did in that early stage. That's exactly what they did. But you've got to find those people, and you've got to research — if you have cancer or a loved one has cancer, you have to research. You've got to read. You've got to — it's easy now. It was harder then, because the Web was going, but it wasn't as fertile as it is now. Now you can research almost anything on the Web. Then I had to do a combination of library and Web stuff.

But anyway, we took Bryan — now, there's one thing I haven't said, which is that once the transplant failed and that was documented, as you know, I have a couple friends in Washington, and I'm not ashamed of that — quite (laughing). But I called them. I called every friend I had down there, and I was down there for three years, and you know, our family tentacles go back two generations in politics, conservative politics. But I got a couple of folks to help me who would not be accused of conservatism, like Dick Gephardt. And these guys, what they did was write letters. Nothing was public, and I knew they couldn't convince anyone scientifically. I just wanted them to attest to our sincerity. And so, now, I wasn't a big political wheel asking for anything more than just, you know, contact the drug company. They didn't have to do Drucker; they had to contact the drug company and tell them we're sincere when we say we're not going to sue anybody; we're not going to blame anybody if this doesn't work. But you know, in effect, I know the McCaffreys, and they mean what they say, and couldn't you bend your protocol.

WOODS: Right, okay.

MCCAFFREY: So I did have that help, and that I mentioned in *The Wall Street Journal* article of October 2009, but that wasn't by any means the reason that Drucker did this. When I first met Drucker with John, he didn't know any of this, you know? It was only after he said to me, I think I can help John, that I said to him, well, I think I can help you. And I said I have former President Bush had made a phone call, not about this drug, but to help us get a second opinion in December. So I was able to tell Bryan Drucker that Bush was, at least in theory at least aware of our case. But it was Gephardt and Gingrich and Senator Connie Mack and Congressman Bob Schaffer of Colorado. These were the four who contacted the drug company Novartis and told them, you know, you can trust McCaffrey, in essence. I don't know how much you want me to talk about the political aspect of this, but of course cynics are going to say, well, McCaffrey had money and McCaffrey had connections. The hell I had connections. I mean, yeah, of course I worked down there, so I know people, but —

WOODS: Well, and plus you're asking for something that if the crazy government courts weren't so crazy, you wouldn't even have to ask for. I mean, you would be able to have your word count for something.

MCCAFFREY: Exactly. Imagine you sign a document, and that's the one thing that's useless in a case.

WOODS: Yeah.

MCCAFFREY: I mean, only in America, man. No other country would invent that kind of dipsy doodle and —

WOODS: Yeah, the one thing we're not interested in is your written statement on the subject at the time.

MCCAFFREY: Right.

WOODS: What else you got?

MCCAFFREY: Right. It's just — but you know, this was a major stumbling block in the lives, not only of John, but a lot of people, and still is, because it makes drug companies double talk you whenever you want a good new drug. And there are many good new drugs out there. Nothing like Gleevec, the Drucker drug. Nothing. There isn't a cancer drug like this. It's totally unique, and it remains unique, in that it essentially eradicates on all but a molecular level the cancer that killed everybody and that ultimately killed my son. And you know, many patients are totally molecularly cancer-free on this drug.

In any event, yeah, so we used some friends to write letters. But I didn't know they were going to write these letters. You know, Bush made a call for us in Texas. Thank God, God bless him for that. And politicians, no matter what you think of them, when there's a child's life on the line, they showed me a lot, because all but one that I contacted came through for us with flying colors.

WOODS: Now this is H.W. Bush that you're talking about.

MCCAFFREY: H.W., yeah, this was Bush the First, as we call him. George the First (laughing).

WOODS: Yeah.

MCCAFFREY: But you know, okay — and by the way, not a dime. Needless to say, you know, not a dime changed — that's just unthinkable. Absolutely unthinkable. And in fact, in the one case where somebody didn't come through for me, I went down there, always with John, I took him to Washington, and I look back on those trips with great affection, by the way. There are so many people down there on the staffs, and you know a couple yourself —

WOODS: Yeah.

MCCAFFREY: — on the staffs of these guys who bent over backwards. But there was one guy, I won't use his name, because I just — but he was a major figure in the Republican Party at the time, and I had dinner with his press secretary, I guess. And I said to him, you know Gephardt's in our corner, and Gephardt's really extending himself for John. And I said, would your guy be willing to do something for us. The reason I did this, Tom, is because it turned out in my mind that one heavy hitter wasn't enough. That shows you the power of the FDA, in my book, that even a Gephardt by himself couldn't persuade to let John try the drug, let this dying boy try the drug.

WOODS: Yeah. Yeah.

MCCAFFREY: Gephardt not only called the CEO; he wrote to him and so forth and so on. And so I said to this press secretary for a major Republican power broker — I mean, top guy. He said, well, you know, he'll do it if you can get a joint press conference with Gephardt. You know, and that was the only cynicism that injected itself with regard to John's case among these politicians that I dealt with. I was flabbergasted, and then of course I said, well, first of all, we're not going public with this. This is a situation where I don't want anything said publicly. I just want the drug for John.

WOODS: Yeah. Right.

MCCAFFREY: It would have been a colossal mistake to go public and try to embarrass people and so forth. So anyway, but that's a whole chapter in my book, but it does illustrate how powerful the FDA was. Anyway, so we got the drug, and again, Drucker committed to this privately, and that was all I needed. But before he knew any of this could happen, and I told him I didn't know it could happen, I told him ahead of time I would ask for some help, and I told him by illustration that Bush had helped us, privately. But he didn't know any of this, and he was willing to do it even so. And I contend that the guy who gave him half his billion dollars for his institute probably read the *Wall Street Journal* piece that I did, and I contend that that would have helped, because I can testify to the character of Drucker. I knew him when nobody knew him.

WOODS: Now I want to know, so John gets the drug, and you say that the effects are almost immediate. Well, quantify that. What's "almost immediate"?

MCCAFFREY: Normal blood counts. Now, it took us four months to get him on the drug, four to five months, but Novartis, the drug company, assented after about eight weeks, at least in theory. They said, we're willing to do it. Okay, so once he got the drug — by the way, it was a pill. Here we had been giving him shots and all kinds of horrible — I mean, I was giving him shots personally, because that's what the insurance company insisted upon as a condition for covering John. They said to me, you're going to have to inject him with his chemo. Alternatively I could have driven three times a week to the hematologist's office, which was basically an hour and a half away. So I'd

been giving him — I gave him hundreds of shots over the course of his life, and most of them in that first year. And these were not tiny little flu shots. These were burning injections and —

WOODS: Ugh, horrible. Horrible.

MCCAFFREY: You know, I mean, it was horrible. It was horrible. It was horrible.

WOODS: Ugh.

MCCAFFREY: But, Tom, this was the protocol. This was the protocol that they all, except a couple, wanted to try all over again. You can imagine. I haven't portrayed the sheer horror of that first year. But okay, we were injecting him with two forms of chemo and occasionally — more than occasionally, very occasionally — Epogen, which is a red blood cell-stimulating hormone, and Neupogen, which is a white blood cell-stimulating hormone. All of these are subcutaneous injections, usually in the leg. And in place of that, the Drucker drug was two pills, and it eradicated in John's peripheral blood the leukemia that was going to kill him and was going to kill him within a year or two.

So it was — and the reason it eradicated it was because it was a protein inhibitor. It was an enzyme inhibitor. It kills the errant stem cell, which is the Philadelphia chromosome defect that I mentioned earlier. It inhibits the protein that feeds that cancer cell, and because it's a stem cell cancer and there's only one defect, it just wiped it out. Within two weeks on two pills a day, his blood counts had totally normalized, and then we did a bone marrow biopsy where they drill the hip; anesthetizing the patient, the boy, you know, they drill the hip and pull out a sample. And on the molecular level, it was, as his pediatric guy told me, he looked at the slide, and he came out and pulled me into the lab and said, look at this; this is totally normal bone marrow. If I didn't know he had CML, I would just tell you to go home.

WOODS: That's insane.

MCCAFFREY: And so that — and we sort of knew this would happen. I mean, by then, Drucker knew it would happen. He all but knew that that would happen.

WOODS: Yeah, but until that moment that you get those words, you know?

MCCAFFREY: It was stunning. It was stunning, and at the same time, we were constantly on our guard, both because we had to do hand-to-hand combat with Novartis, which is a Swiss pharmaceutical. And you know, until they gave us the drug, we didn't really know wed get it, and we saw that even with heavy hitting, solid names down in Washington, they were reluctant to do it. So that whole year, that's the second part of this three-part story. That whole year when John was on that drug was heaven-sent, I'll tell you.

WOODS: Now, how did it come about that *20/20* found out about this? I remember watching you, seeing you on *20/20*, talking about — and I saw John on TV, the whole thing.

MCCAFFREY: Yeah, I still have that, of course. I'm going to pop it in and play it one of these days. But they — well, Tim Johnson, Dr. Tim Johnson, who did their medical reporting and all of ABC's medical reporting — he was a pathologist. So in cancer now, pathology reports are everything. He probably read about Gleevec around the time that we did, back when it was CGB57148B. And he called Drucker and followed the progress, because alone among medical reporters of national note, Tim Johnson knew what this meant. So eventually, once Dr. Drucker saw this was working in John, and they asked, you know, do you have anyone young, so he referred Tim Johnson to us. And then they did the big story.

But there's so much to this that I can't — I have to put into a book, because I can't talk about it easily, or there's so much to tell. But one of the dramatic elements to this was that John got pneumonia right after the *20/20* episode ran. So his blood counts, for whatever reason — I mean, he had weak bone marrow forever because of the transplant that failed. But he dropped so low in his white blood cell count — that is to say, the Gleevec drug was killing all his white blood cells, because most of them molecularly had this genetic defect.

So they took him off the drug, because that's what Novartis required. Drucker did not control the drug. He controlled limited supplies of the drug. Novartis owned the drug, not Bryan Drucker. They took us off, and you know, then John recovered, and we went back on. But that four to six-week period ultimately was his downfall, because once he got off the drug, the cancer gathered steam, and then three months after that, he began to accelerate. So that's the real tragedy. And again, the drug companies worry primarily about — I mean, they could easily argue they were worried about killing the patient. The patient was dying anyway, Tom.

WOODS: Yeah.

MCCAFFREY: You know, officially. Officially, John was terminal with a failed bone marrow transplant. But Novartis was also worried about the FDA. And that, that really — I mean, everything you hear about the FDA, in a way, is true. There's more to it than that sometimes, because of course, you know, they're scientists too, and they have something to say that's useful. But of course they're just this colossus, this centralized colossus that has everybody spooked permanently. But secondly, lawyers have everybody spooked.

WOODS: Yeah, yeah, sure.

MCCAFFREY: Let's face it; let's face it: even without the FDA and for better or worse, lawyers would be enough of a force nationally, collectively to scare a lot of drug companies. We had to — I mean, engineering the quiet campaign to get John his drug, that's the greatest thing I've ever done. Period.

WOODS: Yeah.

MCCAFFREY: And I didn't use the press at all. And nobody knows this. Nobody wants to talk about it. I don't even think my family yet knows the details of this. Some of them do sort of, you know.

WOODS: Yeah, that's — because of course there would have been a temptation, if you wanted to carry on some campaign to get this drug, to go to the press, to make a lot of noise, to get a petition, to get some signatures. And it turns out that's actually the very last thing you want to do.

MCCAFFREY: The very last thing. And I knew that much. I mean, my instincts are not bad. By contrast, a couple years later when we needed a second drug because John had — John was really deteriorating. I did go to the press, but that was because I had to do something quick, and it took — I mean, I was doing battle with a second drug company — I call it a battle, because that's what it felt like — for four months, and I wasn't really getting anywhere, and I had four new guys from Washington helping on that. We were getting somewhere, but it wasn't quick enough, so finally I wrote a piece for *The Washington Times*, and you know, I immediately got action after that. But we had prepared the groundwork.

But I'm getting ahead of myself. We're with Drucker in the great year. And by the way, Drucker, he followed John, but John was his only pediatric patient ever. So you know, that was unprecedented, and it's only because of Bryan that we got to see John, the little boy. I mean, John lived for three and a half years, but the last two years were much — the last actually three years, almost, were much less nightmarish because of Dr. Drucker's drug. And for a year there it was fabulous. It was just fabulous. And most patients on the drug enjoy that fabulous year that we saw permanently. I mean, there's tens and tens of thousands of patients on Gleevec now.

WOODS: That's amazing. That really is amazing.

MCCAFFREY: And they're making — you know, they've made several many billion dollars in net profit on that drug, I might add. The drug company, Novartis. It just went off patent, so now they've got — there's an Indian company that does a generic version of the drug. But in any event, it's a gigantic story, but nobody knows the John part, except Bryan Drucker knows it, and a couple people at Novartis know it. I'm not in touch with anybody, except once a year, maybe twice a year with Dr. Drucker. But nobody really knows the story, and it's probably, there are so many elements to it that might need to wait still another few years, so I don't know what all my book is going to say, but that's the guts of the Drucker part of the story.

So what else do I have to tell you about the FDA? Well, the second drug — I'll jump ahead, because this is instructive, again, for people who need — and I think, for example, and there was a mother, for example, who she had five or six kids, she wrote a piece in the *Journal* a couple years after my first one in 2002 ran, and she needed a drug for cancer, and the FDA wouldn't let her take it. And it was not as

dramatic as Gleevec, but it was clearly a giant advance. So you know, there's a lot of people out there who need to know how to deal with protocol-driven drug companies, and to some extent protocol-driven oncologists — and the FDA.

WOODS: So what else do we need to hit on this that finishes this out and that tells people the stuff that you want to make sure they know after you've gone through this?

MCCAFFREY: Well, the third element is John reaccelerated. The second experimental drug, which we took in combination with Gleevec, didn't really do the job and acted like a chemo, so it really killed a lot of good cells. And in the end, he contracted pneumonia, and we had to watch him die over six weeks.

WOODS: Oh, oh my.

MCCAFFREY: But the FDA part of that story is that what the drug companies do, and the bigger they are the more they do it, is that when they have to, they hide behind the FDA, and they'll throw you off, they'll stiff-arm you when you contact them by blaming the FDA for — in effect, they anticipate FDA rejection, so they say we can't do it, or they'll say the FDA is making us file a protocol. One of the funniest things I heard from one of the drug companies was, oh, we don't have — one of the experimental drugs, the second one — well, we don't have a protocol for this drug, they would say deadpan. Well, of course they don't have a protocol for the drug. By definition, a protocol is a tested formula. But they would do that, and always the FDA was an element to that.

But when I went down to Washington with John — and I won't use a name, but again, it was a very big name in politics and staff member assigned to the medical detail in that office — said, I think we can do this, we deal with them all the time. And by the way, this was in an opposite political party, so again, I have to say this office was not looking for a donation. They weren't going to get one out of me. They did it because this was one of their good days, let's put it that way. But I just found it very interesting that if you're on the right committee or subcommittee, you can get your phone calls answered more easily.

WOODS: Yeah, there's something — I mean, you've got to do what you've got to do. There's something weirdly Soviet about the whole procedure, right? You know?

MCCAFFREY: Well, you know —

WOODS: I mean, you've got to talk to — like in other words, everybody involved knows that the requirements are unreasonable. Like everybody. People on the — everybody knows they're unreasonable. And so therefore, nobody is saying to you, well, sir, it would be dangerous if we went ahead and — they all know it's just stupid. It's just a stupid bureaucratic regulation, and so we're going to pick up the phone and get them to override it.

MCCAFFREY: Right. It wasn't that simple, but in one case it was made to sound that simple to me; I'll say that. But no, you're right, and I've said this to another reporter, that the whole FDA colossus puts me in mind of the Soviet Union in the 1980s, when it was known that nobody in the Soviet Union at the top in the Kremlin was really a communist. You know, I mean, everyone knew this had to collapse, but nobody was willing to make it collapse. But it did happen. It did happen. And not to get political here, but that's what fascinates me a little bit about Trump, because he's the very type who could find himself in the White House and wipe out the FDA monopoly or whatever we're going to call it instantly. Because it's going to take somebody like that to wipe the slate clean. Everybody knows the FDA is a problem.

WOODS: Yeah, well, I mean, certainly anybody who listens to this show knows it, and I think when average people have an encounter with it other than what they read about in the newspaper, that it's just there to help us out, they join our ranks on this issue. Let's finish up with, you know, you're talking to people who — there could be people in my audience who know somebody with cancer, they're suffering from it now, they, heaven forbid, know a child with cancer. Or you know, anybody could potentially be diagnosed with cancer at some point. What do they need to know, and what is it that you didn't know before but that you now know because of your experience?

MCCAFFREY: The single most important thing is to read as much as you can about the disease that you have and to be skeptical of the protocol that the oncologist or hematologist almost certainly is using on you or your son or daughter or parent. You've got to read. You've got to go — there are studies that will tell you the truth about the drug, the truth about your chances, and now you can find clinical trials of newer drugs that very often, even if they don't kill the cancer, might be much less damaging to your system. So you've got to be skeptical, and you've got to read.

Otherwise, give up, man. And most people do. Most people just do what they're told. They find a reason to like their oncologist. I've been through that psychology with the first four that we dealt with every day, practically, with John. And that's just a loser psychology, because these folks, as I said, like everyone in every profession, you've got good ones and you've got average ones and you've got poor ones. And it's disturbing to have seen so many poor and average hematologists and oncologists out there. Very disturbing. But it took me at least 10 months to get up to speed on that and to even be able to judge, because the first six or seven months I really didn't read as much as I should have, and I trusted these folks.

Now, I also will say that in the northeast, I found the most arrogance, the most rudeness, and that can really impact your care. It's not just rudeness. If you're not able to talk to your doctor, especially when you're taking care of somebody with cancer, you're not going to get the best information, and somebody's going to suffer as result. More often than not, somebody's going to suffer what they didn't have to suffer. So you just have to do that. And by the way, anyone who wants to talk to me, they can send me an email. Give them my email address, and they can shoot me a note. I will respond, and quickly.

WOODS: Well here's what I'll say, because I don't want to put your email address out there, because heaven knows what will happen, but if people contact me, I'll forward it to you. Contact me, not through email; contact me through the website through TomWoods.com on the contact page, and I will send that right over to Roger.

MCCAFFREY: Yeah, my pleasure, really. And anyway, in evaluating doctors, you first of all have to evaluate them. I don't care where they are. We had one at a major, major place — we'll put it that way — and she actually attempted to stop our use of this drug in a very direct way, and she had no business doing it, but she did. And we found out about it, and we had to fire them. So you cannot put total trust in any physician until they've earned it, and then, by all means, trust them, because in the end you're in God's hands more than anyone's. And all you can do is evaluate and make the best of your situation. But by all means, do that. Don't assume anything just because they're at a good place or have a good record. I mean, God knows how many surgeries, for example, that have been done needlessly by good guys at good places, or how many lousy economists come from Harvard, to switch the image up a bit.

WOODS: Yeah, exactly. Yeah, so it shouldn't be so hard for people to accept this idea. We see it all the time.

MCCAFFREY: Yep. And yet, you know that when you're vulnerable is when this psychology kicks in where you absolutely want to trust the one in whose hands —

WOODS: Yeah, sure.

MCCAFFREY: So it's not that I advocate an ignorant and crude approach to all docs and all medicine. I believe in synthetic drugs. I've seen what they can do. I mean, Gleevec itself comes form the soil in Africa. Ultimately that's where the molecule was found that is now Gleevec. So you have to synthesize and mass produce a lot of these drugs. I'm not that type at all. I don't believe dried blueberries are going to kill your lung cancer. They might help, okay, but you're going to need something, and you're going to need the profession, but you have to evaluate them and you cannot do too much reading. And read the footnotes, too. So I mean, I have so much to say, and it'd probably bore the average listener, but anyone who needs a specific question answered, I'll try to answer it via your — you know, through you, Tom.

WOODS: Yeah, definitely. Write to me.

MCCAFFREY: I'll personally answer them. No problem.

WOODS: Well, Roger, all I can is, I mean, I know you already know this, but go ahead and write that book. Write that book.

MCCAFFREY: It's coming. It's a year away, and I'll call you when it's ready.

WOODS: Yeah, exactly. Do that, because we'll bring you back on. We'll talk some more. I don't know how to thank you for this particular conversation, other than to say

we're all grateful, and I have a feeling you will hear from some people. And thanks a lot for today.

MCCAFFREY: Thanks, Tom. Much obliged. It's the first time I've really — well, first time I've done any kind of public discussion on it.

WOODS: That's really amazing. Well, I'm glad to have been the conduit for that. Thanks again.