Episode: ‘Stopped Treatment, Started a Family’

Description:

Twenty-three years old and living in New York City, Glamour magazine Editor Erin Zammett Ruddy finds herself writing her biggest story yet when she is diagnosed with chronic myelogenous leukemia. Upon diagnosis, this writer, author, blogger and survivor, along with her husband Nick, make the brave decision to stop treatment three times in hopes of expanding their family. Listen in as Alicia and Lizette from The Leukemia & Lymphoma Society (LLS) speak with Erin and Dr. Michael Mauro, hematologist at Memorial Sloan Kettering Cancer Center. Dr. Mauro has treated Erin since her diagnosis, going on 16+ years, and is a strong advocate for women and fertility within the cancer realm. You’ll hear about Erin’s journey, fertility preservation, questions patients can ask their healthcare team when considering fertility, and how patients are not only ‘patients’ but people seeking to live the life they’ve always envisioned for themselves.

Transcript:

Alicia: Welcome to the Bloodline with LLS. I am Alicia.

Lizette: And I am Lizette. Thank you so much for joining us on this episode.

Alicia: Today, we will be joined by hematologist, Dr. Michael Mauro, from Memorial Sloan Kettering Cancer Center, and Erin Zammett Ruddy, who is a writer, author, blogger and survivor. We know that chemotherapy and radiation can have late effects that may manifest months or years after treatment has ended and one possible late effect is infertility, which is the inability to conceive a child naturally. Dr. Mauro, how can treatment for blood cancers affect fertility?

Dr. Mauro: Sure. Thanks, by the way Alicia and Lizette, for having me on. This is a very important topic. It is often underdiscussed. In the intensity and the urgency of a cancer diagnosis, we sometimes forget to talk about fertility, fertility preservation and what it means for the future, but in simple terms, many of the treatments of cancer can significantly affect fertility. Some can render someone infertile so it is that serious. It really depends on the diagnosis and the treatment. We often do have time to discuss, can we preserve fertility; can we do something to plan for the future. We may do something in the short-term, which allows for fertility to be preserved in the long-term, even though treatment or side effects may render someone infertile or less capable of being fertile whether it is a man or a woman. We have definitely better treatments for cancer and, even though we have now targeted therapy, oral agents with lower toxicity profiles and, thank goodness, probably less effects on fertility, it is still a very important question. It is still the possibility that it needs to be discussed in the same context, that the future may be uncertain. There may be a period of time, sometimes short, sometimes long, when fertility is not possible, but we certainly want to keep the door open for men, women, couples, families at all points. Overall, it is a major topic that needs to be discussed as quickly as possible to plan for the future. It may be unavoidable, but there are many things that can be done and, fortunately, there are
many good treatments now, which are making cancer treatments better and less likely to be a black and white story for fertility.

Alicia: On episodes, we have more than one speaker, they know each other or they don’t know each other and we have to introduce them. Erin, how do you know Dr. Mauro?

Erin: Oh, goodness. I have known Dr. Mauro for almost 16 years. We met when I was 23 and had just been diagnosed with chronic myelogenous leukemia. I was living in New York City at the time, but Dr. Mauro was working at Oregon Health and Sciences University in Portland, Oregon and I decided to fly out there to meet Dr. Mauro and Dr. Druker, who were doing some exciting things with a drug called Gleevec, which I ultimately was able to get on. Dr. Mauro became my doctor and 16 years later, we are still here and doing exciting things. We have known each other for a long time. We have been through a lot, right Dr. Mauro?

Dr. Mauro: Absolutely. I had the pleasure of meeting Erin when she was just diagnosed and, as you said, we were just into an era where we had an approved medication, Gleevec, for her type of leukemia. She actually was a participant in a clinical trial using an additional medication with Gleevec. Right away that is a perfect example where I have a young woman who, at that point, was not married and her whole life was in front of her and Erin was one of the most amazing patients I have ever had the way she embraced what she was facing—her diagnosis, her battle with bravery and public faith, and openness, and honesty. We probably did not talk a lot about fertility in the very beginning, Erin, as I recall, I think it rarely came up, but I think again we were into this era where we knew we were able to access treatment which probably wasn’t going to be black and white. Clearly, as we got into the treatment and as her life moved forward, and she got married and that became a very relevant issue, as it naturally does, we tackled this topic a few times.

Lizette: Do you guys remember who brought up the topic? Was it you, Doctor, or was it Erin?

Erin: I remember my very first cancer appointment when I was in the City still at Sloan-Kettering before Dr. Mauro was there. It was my first appointment. I had just been diagnosed with cancer. My Mom and Dad were in the room with me and my Mom said (we were asking 4 million questions; we were all very upset and anxious) and she said, “what about having children” and I shot her daggers and I was, like, “Mom, ahh, you know”. I was 23; I was living in the City. I was not even thinking that, but she was right to ask that question. In retrospect, it is very important that cancer patients do ask that question because there are things that cancer patients can do to preserve fertility and it is certainly a valid question to ask. I was lucky because I knew that with Gleevec, which was the treatment option I chose, I was able to—I knew that down the road—all my doctors kind of assured me that it wasn’t going to take away my fertility, this drug. Whether I could go off the drug or not and have children down the road was another hurdle that we would cross when the time came, but it wasn’t that I had to do anything immediately before starting treatment if that makes sense. Then, when did we talk about it? Goodness, Dr. Mauro was at my wedding. I hope I didn’t bring it up that night.

Lizette: Wow!

Erin: I hope I didn’t bring it up that night, but I think it is was always on the back burner. It was something that we discussed. I would come visit him and we would talk about it,
but I really wanted to be married and enjoy that time for a little bit before we had to talk about it because I knew that, for me, it wasn’t going to be very simple. I would have to do a lot of research, a lot of discussion, a lot of soul searching, a lot of should we/shouldn’t we, but I am sure that it just came up naturally. Like everything that he and I discussed over the years, there is lots of lead up to it. Nothing was sprung on either of us.

**Dr. Mauro:** I knew Erin needed to get on with her treatment, but I also knew that we probably could pass on some of the things other patients need to talk about, which might be harvesting embryos or eggs if you are a woman, or for men, sperm preservation in talking to a couple. Erin was not married yet and I didn’t think we had that circumstance where we had to talk about that. It did kind of naturally come, but I am a pretty strong advocate for women in this base, so I knew it was coming, and I didn’t know it, but the research was pointing us in a direction where that door was going to open more readily. It kind of just evolved naturally with the great results she had and her life evolving.

**Alicia:** You mentioned being diagnosed at 23, Erin. Dr. Mauro said you had so much of your life ahead of you. What were you doing at that point of your life when you were diagnosed?

**Erin:** I was living in New York City. I was working at Glamour magazine. I was basically living the life that I had always hoped to live. I was super excited. I was hanging out with friends. I felt like my life was really just getting started in the City. I had a ton of dreams. I was super ambitious and I didn’t really ever—no one expects to be diagnosed with cancer, but certainly at 23 that came as a huge shock. What was almost equally shocking is that it didn’t really slow me down. Because of this drug, Gleevec, because of Dr. Mauro’s care, I was able to continue to do all the things that I had wanted to do. I still worked at Glamour. I still wrote. Actually, I wrote more. As you know, I was still able to have children as well. That was pretty remarkable, I think, for a cancer diagnosis because, I think, when I was first diagnosed, those first few days, my family and I were certainly not thinking that I would be continuing my normal life.

**Alicia:** Dr. Mauro, can you walk us through Erin coming to your office, you letting them know what the diagnosis was, fast forwarding to the conversations about fertility? To her and for others in similar situations, how do you then begin that journey or that route of working with your patient who then wants to consider having children?

**Dr. Mauro:** Sure. It’s a little more black and white, I think, for other patients who probably face some predictable risk of maybe losing their fertility or diminishing their fertility before they get treatment or from their treatment. They then go through cancer treatment and, hopefully, it’s successful. Hopefully, then, they are in remission. One can then assess, where are we now? Is fertility impaired? Is it absent? What can we do based on some actions that might have been taken earlier in the diagnosis? That sounds like the formula that should have been, but Erin’s diagnosis and her treatment were quite different. The type of leukemia that Erin had, chronic myeloid leukemia, has really set an example for a different kind of treatment where people take a lower risk, but yet still chemotherapy and targeted drug for an extended period of time. At the time when Erin was in a fantastic deep remission and was very keen to start a family, as she naturally should have been asking about, we didn’t have final answers about how that looked. We were in a bit of unchartered waters. I could tell you in 2017, this story with this diagnosis, a good number of patients can get into a good enough remission where they can follow that same pattern, where they may be done with their treatment and
safe enough to do whatever they wish, whether its conceive, carry a child if it's the mother or be a father if it is a man. We had to go on best available knowledge which was, would it be safe for her to stop her treatment? Probably the most important thing about cancer therapy and pregnancy is not only what it can do to a woman or man and impair their fertility, it is what might be the effect be on an unborn child if there is exposure. Some exposure is unavoidable. If a woman has had treatment, the elements of conception for a woman, the ovaries contain all the eggs for life so, for the woman, any chemotherapy exposure; in turn the potential effects on fertility are there. For men, it is different. Spermatogenesis or sperm production is an ongoing process. It recycles every 6 weeks so that is a different issue. When Erin wanted to conceive, we knew that she had had exposure to treatment including an older medication called Cytarabine, in addition to Gleevec, which is used in leukemia, we faced a bigger question, which was, is it safe for her to stop her treatment and would she stay in the excellent remission she was in off treatment? At the time, that was a research question, for people not embracing that question for the purpose of getting pregnant, just for the purpose of, is it possible? We were in a much different situation. The common situation is what happened in the beginning; was fertility preserved; how did treatment effect my fertility; I am in remission; my doctors had told me I have a green light; it is safe. I think, Erin, you probably would acknowledge we had maybe a yellow light. We had no idea what the future held.

Erin: Yes; yellow light. That sounds about right. I think that my parents and everyone else—Dr. Mauro and I were pretty gung-ho about it. Gung-ho is the wrong word, I would say. I was gung-ho about it, but I think that everyone else who was keeping score at home, if you will, was really nervous and I was really nervous, too, but I knew that, for me, having been part of the clinical trial—that original clinical trial—then having the care that I got from Dr. Mauro and knowing that I had such constant care and people there for me and I was so closely monitored. I went and saw fertility specialists in the City. I went through all of these tests. I made sure that my husband, that his sperm was healthy, that my body was healthy, that we actually could conceive because we didn’t want to go through all this trouble to find out if we could do it cancer-wise and then find out, like many other women and men, that we had an issue otherwise. There are people at the time, there are people now who still can’t believe that I would have taken that risk and I know a lot of other patients, cancer patients, CML patients, who chose surrogacy or chose adoption because they just didn’t want to take this chance. I try to remind them that this wasn’t just, “oh, let’s do it”. We put in months and months of homework and research and really had all our ducks in a row so that we could minimize the risk. That said, we had a blood test every month and every month, I remember being incredibly nervous thinking, “is this the month that it is going to come back?” Dr. Mauro, correct me if I am wrong, but I think we had several back up plans. Worse case, I could go on Interferon because I could do that while pregnant or Leukapheresis if we had to. We had some back-up plans. They weren’t ideal.

Dr. Mauro: Exactly. I think you raise some issues that face really everyone, which is, is it safe to do that? I mean, I think any person, maybe not the man because I think his (not to be flippant) but the man’s role in fertility is relatively limited whereas a woman has a long commitment to carrying a child and delivering. Of course, both parents take care of the child and support them. I am not trying to trivialize that. It’s the fear of what happens if something goes wrong during the pregnancy if I need treatment or my cancer comes back. That question was literally front and center staring us in the face with this kind of leukemia because we didn’t know that answer. It was a gamble. I probably said this is a 50/50 chance that the leukemia would remain in remission during the pregnancy. That was based on best available information. We weren’t operating
completely in the dark and, as you said, we knew we had things we could do, not resume your treatment you were on, but other treatments. Patient have those same options today. The CML patient faces the double challenge of is this what I want to do, do I want to be off treatment and see if I can stay in remission and, in turn, make that my opportunity to achieve pregnancy and carry a baby to term. It is complicated. It is complicated for any patient with cancer, of course. The two are completely overlapping. Am I going to stay in remission and am I going to be able to conceive and successfully complete a pregnancy?

Lizette: Erin, you were probably one of the first people that actually wanted to go through this journey and actually successfully went through this journey. I feel like people are looking at you and they are looking at your journey and feel like there is hope there. I think there is more knowledge now, Doctor?

Dr. Mauro: I think what you said is definitely true. People probably view Erin’s story and many know her story because she has been very public and open about it. She is one of the pioneers and women probably feel braver knowing that someone like Erin was able to do what she did and has come out on the other end in good condition and well. I think, ironically, we don’t know about the way we manage in this specific case. We still have about a 50/50 chance of retaining remission if someone stops treatment. We know a lot more about how to choose the person who may be best suited to think about stopping treatment. If you are able to stop your treatment, if your doctor thinks you are a reasonable person to stop your treatment and be very carefully monitored (which is still relatively new, just basically past the experimental stage and just out and ready for prime time), if you are eligible for that, then you might be eligible to be able to consider pregnancy, especially if you are a woman. That is really the more focused population. But the trouble is your reaction to it—the 50/50 chance goes the wrong way and your leukemia returns. If you are pregnant, you can’t exactly resume treatment right away. The knowledge we do have now is if this type of leukemia returns, it is generally within the first 6 months and babies take 9 months, not 6 months. We have a little bit of a conflict there. I talk to women all the time and I am proud to say I am going to be, hopefully, part of a group of physicians who are going to write some guidelines for other doctors to say, how do you manage someone who has this type of leukemia and wants to become pregnant? What do we know? What has the outcome been of folks, who like Erin, (she will be part of that research) stopped their medication to achieve pregnancy and was successfully able to deliver and the leukemia did not return during pregnancy. Erin has an even more complicated story she can share with you about her CML journey when she ultimately would try to stop treatment just for the sake of stopping treatment, which unfortunately was not successful, which is why she is still on Gleevec. One never knows, but when it comes to the pregnancy, we were able to manage through quite successfully 3 times.

Lizette: 3 times. Wow!

Dr. Mauro: I might have stolen your thunder there.

Erin: No; you never steal my thunder. Well; no, 3 times, but to go back to is it—I was one of the first, I think, who did this. I am certainly very public about it. I mean I don’t know how many people I refer to Dr. Mauro (a ton) so I am so glad to hear that you are writing these guidelines because people often e-mail me, Facebook me, whatever, and ask me questions and I am very open, but I always do obviously tell them to talk to their own doctors. None everyone is as lucky as I am that I have Dr. Mauro as my main doctor. Some doctors don’t are a little nervous about saying, “sure, go off your drug and
have your baby”. That is definitely something you have to really think about. I am certainly not giving advice, but I am happy to be a beacon of hope for people who still want to have the families that they had hoped for before they were diagnosed so I do share a lot of my story and I am always happy to refer people to Dr. Mauro.

Alicia: Depending on the time of diagnosis, Doctor, we know that there may be steps before treatment that can begin to help preserve fertility. What are those options for males and females?

Dr. Mauro: For men, I think the things we need to think about in this area, when facing cancer or even extending to if my partner has cancer; for men, it is quite simple. You can try to preserve sperm, which can then be used for in vitro fertilization. It can also be used for other procedures where you can have intrauterine implantation, meaning that something that has been preserved can be placed where it should be after conception to allow for a pregnancy to happen. For men, again, that is a very low risk, very easy process. It has to be spoken about and done and can be done rather quickly. Under certain circumstances, it could be a challenge, but it can even be done surgically, meaning a urologist, a physician can actually harvest from a man the sperm that is needed to conceive a child. It doesn’t have to be produced by the man. That is what men need to think about. For women, I think it is an area that continues to evolve. We know that if a woman is married and time is of the essence, there can be a woman’s ovum or eggs, can be harvested from the ovary. She can be stimulated to produce as if she was cycling and was fertile. They can be removed surgically. They can be removed endoscopically by a gentler procedure and in vitro fertilization can happen. It can be carried by another person, a surrogate. If the woman is facing cancer, that may be the reason why this is all happening and she may not be able to carry the pregnancy. I think fertility specialists have “a very high success rate” with being able to essentially make a baby from the products of conception and make sure it has got a home, all with technology, meaning either the products are harvested in some way or another or obtained. It is done in the laboratory and then as long as it is put in the right place and it is supported, it will thrive and you can have a successful pregnancy. What is a little bit less certain is if a woman is not married, does not have a partner and we just want to think about a future conception, meaning harvesting unfertilized eggs, that is a little bit of a harder procedure. I think it is highly successful, but I think it has improved dramatically. I am a hematologist; not a fertility specialist, but I need to be familiar with these options. That is immediately why I would refer someone to a fertility specialist to say, “I am a woman and I have just been diagnosed with cancer; maybe I am married; maybe I’m not; maybe I have a partner or not; or I have ideas about how I would like to preserve my fertility. What are my options?” There are definitely many options. Again, for a man it is much more simple. For a woman, there are a number of different ways it can happen, it is just something we have to talk about and pursue.

Lizette: For women, do you have to start the conversation a little bit earlier just because I know there are some treatments that can cause premature menopause.

Dr. Mauro: Yes; any complications could change fertility or infertility, it could be by that simple fact of bringing on menopause early. That is a common result, unfortunately, of many treatments. That would just run the clock down rather than change the biology, physiology or harm potential products of conception so; yes. The other point just to make, it often takes a little more time for a woman to preserve her fertility than a man so there is sometimes time needed, for example, to take medication to harvest the eggs, the ovum, or to successfully accomplish an in vitro fertilization, if a woman is married, or find a surrogate, if it needs to be through a surrogate, or sort all that all out. That can
take a little bit of time. Often, in a cancer diagnosis, you are diagnosed today and you are starting treatment tomorrow; especially when it comes to blood cancers. We have a particular challenge there or with more other serious cancers.

Alicia: Erin, earlier you mentioned making a decision with your husband, how important was it to have the support at that time and for anyone listening who is making the decision with their husband, what advice would you give to them?

Erin: I think you definitely have to be on the same page. I think having kids is a challenge without cancer and certainly doing this with cancer, it’s challenging and it is important that you both agree on the timing of it all. I am assuming if you are listening to this Podcast, this is a topic that you are interested in and you want to have kids, right, so you can check that box. My husband, Nick, and I both definitely wanted to have kids. We both knew that this was a risk we were willing to take. We talked about it a lot, but then we also, at a certain point, you have to stop talking about it and obsessing about it and just watch some bad TV on BRAVO, some reality TV, something to take your mind off of things because you can really, really talk yourself into a tizzy if you let yourself. You have to just try to find people that you can talk to who are supportive, who maybe challenge you and ask questions that you should be asking, but I think it is important to surround yourself with positive people and people who want this for you as much as you want it for yourself. That should include obviously your doctors, but definitely family members and your partner and all that. It’s huge. It’s huge to have that support. It is necessary.

Alicia: When you began chronicling your journey, were you surprised at the responses of others who read and kind of either couldn’t relate or were just intrigued by the entire thing? What feedback were you

Erin: In general, I received a lot of incredible feedback. I think, again, this is almost 16 years ago that I was writing about it in Glamour magazine. This was pre-blog days so there was not as much content out there as there is now. There certainly weren’t many cancer patients who were 23 and still living in the City and working and having a good life. I felt that was a message that I really wanted to get out there because I think that, hopefully, that is why we all work so hard and donate money and fundraise for LLS. Hopefully, we are going to get to a point where more and more people can have cancer and can be treated that way; take a pill and continue to live their life. I felt like that was a story that needed to be out there. The having children component, it’s huge. I am going to be 40 next year and I can’t believe it. I was diagnosed with cancer at 23 and I didn’t know if I was going to live 5 years. I certainly did not know if I was going to be able to have children and here I am turning 40. I don’t run marathons like Dr. Mauro, but I probably could if I forced myself to. I did run a half marathon. I feel great. I have these 3 kids. I think people appreciate that because I think there are a lot of negative stories out there or sad stories and I want to be able to give people hope so I do get some really great feedback. One person, in particular, that I just got a Facebook message from—it’s a 15-year-old girl who had just been diagnosed with CML. She reached out to me and she said that she—I guess she must follow me on Instagram or whatever—I had taken a photo of myself getting a blood test. I still cringe getting a blood test. I don’t mind it, but I can’t look. She said, “That made me feel so good to see that. Here you are all these years later and you still don’t like it because I don’t like it.” She said that she read all my stuff and it made her feel so hopeful. I am obviously not 15. I could probably be her mother at this point, but she felt like I was a young person with cancer. Getting those messages definitely keeps me going and reminds me that it is important to share this stuff. My husband thinks I share too much sometimes.
Alicia: On your blog, you tell everyone you overshare. It is an interesting thing.

Erin: I am a big over-sharer. Yes; absolutely. I think it is important because I remember when I was diagnosed, there was nobody. I didn’t know any other young cancer patients that were talking about it. Certainly, in the time that I have been diagnosed, the young cancer movement has happened and there are so many great things out there for young cancer patients and for fertility and all of that. It really wasn’t a thing 16 years ago. I feel very lucky that I have been able to do it and will continue to do it—to share my story and to help in any way I can so that people like that 15-year-old girl or people that e-mail me all the time saying I want to go off my drug to have a baby, what was it like; how did you feel; all the questions that they ask me. I feel very lucky that I can be here to help those people.

Lizette: And you decided to do this 3 times. That is what Dr. Mauro said, right? 3 children.

Erin: I did it 3 times. I remember when I was thinking about having the second, Dr. Mauro said it really wasn’t a matter of how many, he said--what did you say? It was very funny, but you were—the question was if we were going to do it, not how many times. It worked once and he was “okay, if we did it once, I guess we can do it again”. The big dilemma was deciding do we or do we not do this. Once we did, it was like “ahh” we will just keep having kids. After 3 (we certainly weren’t that flip about it), but after 3, that was plenty, but I will tell you the second time around was so much more relaxing, right Dr. Mauro? It was not as nerve wracking at all. Then, with the third, I don’t even think we worried. It was really nice. You probably worried, Dr. Mauro. I didn’t worry as much. My Mom worried. You and my Mom worried.

Dr. Mauro: I think that is my job. My worry level didn’t really change. It might have actually gone up. I might have been trying to keep you optimistic about it and say things like, “well, the third one’s a charmer.” My part is obviously a bit more serious. Back to I’ll answer your first question about her husband. I sort of have a tough job of being open and honest with couples as they are talking about what happens if something goes wrong, especially when there is this dual challenge of stopping treatment and seeing if we can become pregnant. It can put us in a corner where we have a pregnancy that is moving along and a mother whose health is at risk, then what do we do? Sometimes people make different decisions so we have to iron out those decisions. How are we going to handle the worst case scenarios even to the point to talk to the partner to say that this could mean trouble for your spouse. It’s generally in the direction of this can mean trouble for your wife and you need to be prepared to take care of her and the baby if something horrible happens. I need to be open and honest with people and ask them those kinds of questions. I probably put you guys through that, Erin, didn’t I?

Erin: Oh yeah!

Dr. Mauro: On the other hand, there is tremendous optimism, I think. I think this whole question about can patients stop treatment in this type of leukemia and how this is setting the examples for other cancers, where we have better treatments that aren’t so hard on patients that can cure their cancer and allow them to move on with life and preserve their fertility. I think it was probably stemming from the fact of a pregnancy. It is such a natural extension of life and it should be the thing you want to preserve the most and make sure you don't forget about it.
Alicia: I think it is so great, Dr. Mauro, that you are such a strong advocate for this because—Erin, when you heard the cancer diagnosis, your reaction was very much like, “where did this come from”? Out of nowhere. You are 23. You work at Glamour. You are doing your own thing and then this comes up and you are thrown into a whole different world that you never could have imagined. You forget the details of life. I think fertility is one of those things that a lot of the people that we speak to, a lot of patients that we speak to, they kind of push it off to the side as a “not for me” type of thing because of everything they now have to go through with themselves and their families. I think having such a strong advocate, being a doctor and having such a strong voice, Erin, allows people to see that it could be a possibility depending on where they stand in their diagnosis.

Erin: Absolutely. I think to have to give that up is, in many cases, really not necessary. I think Dr. Mauro is so great about that because he is not just there to treat the cancer. I think a lot of doctors—their job is to cure you or get you well and the rest of it is really not their problem, but I think that there are a lot of great doctors like Dr. Mauro out there who understand that we are not just cancer patients. We want the lives that we had hoped for ourselves and that can still be possible in many ways. It may not always be the way you thought it would be. You may have to explore other ways to become a parent and it may be harder work; and you may have to go see different specialists and do all these crazy things, but in the end, I think that Dr. Mauro always, he understands. He is a big family guy and he understands why someone would want to have a family and he helps so many people do that. I think that if I could say anything to patients it would be if you are hitting a dead end with the doctors that you have, I think it is worth finding people who might be able to help you or certainly refer you to even Dr. Mauro’s literature that he is going to be writing about this because there are people out there who are doing these things. It is hard with a disease like CML because it is still so relatively new, right Dr. Mauro? With this 16 years ago, this wasn’t something people were doing and now it is very common for people to say, “hey, I want to have kids”. I think we have to remember that. We are still kind of writing the script as we go along.

Dr. Mauro: The research that we base our comfort increasingly now about stopping treatment potentially for pregnancy has stemmed from stopping treatment, in general. That is just February of this year that that has become incorporated as a standard approach. Before that, it was considered experimental. I think I am encouraged by my colleagues in the field of oncology, hematology/oncology both that people are increasingly recognizing it. My group here at Sloan Kettering just the other day met with our fertility nurse specialist just to say how can we do better? Can we ask more? Can we ask earlier? How can we educate better? It is an active topic of conversation. As Erin said, if you are not getting the answers that you are needing, you got to push.

Alicia: In regards to questions, what questions would you suggest listeners ask if they are considering fertility and want to explore that with their healthcare team?

Dr. Mauro: I think just raising the topic as a general discussion. Say, “I understand all that you are saying and I know it might not be what’s on your mind, but I would like to have a family someday.” Whether you are a man or woman of any age, say “What do I need to do now? What do I need to know now?” I think there are many good specialists that that is their expertise; not that the primary treating physician can’t manage those questions with their team, but to seek another specialist in that same area or your own other doctor, if you are a woman, talk to your gynecologist, obstetrician/gynecologist. I am sure that is something they will know more about or will
be able to. It just has to be discussed. The basic questions are: What do I need to do right now before I receive any treatment or what can I do right now? What might happen during my treatment? What are your expectations at the end of treatment? Quite pointed questions—will I be able to father a child, carry a pregnancy, have children some day?

Alicia: Erin, in addition to what Dr. Mauro just mentioned, are there any additional questions you think patients should ask?

Erin: I think it is important, if you can do this, to start the conversation before you are ready to become a parent because there is going to be a lot of things you have to do leading up to that. Don’t go in and say, “Okay, I’m ready to have a baby. Can we talk about it” because it might come as a surprise to your doctor. I think laying that groundwork—laying that groundwork with yourself, with your spouse, with your doctor, with your family—just talking about it. “This is something that I am interested in and is something I want to start doing the leg work to get there” is important. Then, just yeah, asking if they have other patients, asking if there is people they can talk to. Dr. Mauro has always been very good with connecting some of his patients with me if they want to. I think that, something I have found, people who have done things like having children after having cancer, or while having cancer, were pretty excited about it, were pretty happy to be here and were willing to talk to other patients because we know how lucky we are. I think if you can find someone who has gone through it, you should try to do that. Asking your doctor about that is a good place to start.

Lizette: Erin, how did you feel when you heard you were pregnant the first time?

Erin: Well, it was very—it wasn’t like I’ll just pee on a stick and say, “oh, I’m pregnant”. It wasn’t like that the first time because I was seeing a fancy fertility specialist because we had to time my going off Gleevec with—what we had to do was off the second I found out I was pregnant basically because, at that time, we didn’t know that I could go off Gleevec for an extra 2 weeks, 3 weeks, 3 months. You don’t know how long it is going to take to get pregnant. It could be a very long time. We waited until the second I got pregnant. In order to find that out early on, I had some special tests done with this fertility specialist. I found out basically the day after we conceived. It was definitely slightly medical. I was sitting in my office at Glamour editing probably a story on sex and dating and my doctor called me and told me that I was pregnant. I was definitely excited, but I came to really, really love and rely on my drug because it kept me healthy and alive for so long. To know, at that moment, that I would not be taking it for the next 9 months was a little like “whoa”, but of course I was super excited. I was definitely excited. That was the moment. It wasn’t really like some movie scene. It was a little bit more medical, but it was very, very exciting.

Lizette: And you said that your Mom is actually the first person that brought up fertility. Did she want to speak with him during this process just to get more information to see possibly how you might do? I know that they were very concerned about you going off your medication.

Erin: It is interesting you say that because Dr. Mauro in all of the things that I have done, like having my children and going off for the clinical trial when I just stopped taking my Gleevec for that trial without having kids, he has always said he will talk to Nick. He’ll talk to my parents. He’ll talk to anyone who wants to be talked through it. I don’t know, probably, I mean my mother and I flew to Oregon for years to see Dr. Mauro so we have logged a lot of time together (the 3 of us). Yes; I am sure there were many times in your office in Oregon where my Mom would ask you all sorts of questions, who knows. She
felt—she knew, at this point in my treatment, if Dr. Mauro said it was going to be okay (and he didn’t say it’s going to be okay; he is not going to say that), but mostly, he thinks, hopefully, pretty sure it should be fine. But, anyway, his word really means a lot in my family. I don’t know. Did my Mom secretly call you? Were you guys e-mailing you crazy questions, Dr. Mauro? I would not put it past her at all.

**Dr. Mauro:** No; I don’t think that is actually looked upon favorably.

**Erin:** Oh HIPPA.

**Dr. Mauro:** No. I think we had a really good open dialogue between your family. To be honest with you, I kind of knew that it was going to raise some anxiety with your husband and your family, your sisters. That is natural. That is expected. Much like it raises that question in someone who thinks about stopping treatment not to get pregnant, or a woman or a man to think about getting pregnant after they have had cancer, like maybe I am damaged in some way. Even though the doctors have given me green lights, something bad is going to happen. It is going to make my cancer come back. The baby is not going to be right. The baby will have the same cancer. I get a lot of questions that are really easy to answer, but they are just natural questions that people are going to have. Of course, the family is going to say, “wait a second. We just want to have you. We would love to have you with a small person next to you, but . . .”. We handled this quite well. Much like a baby, we had a long gestation of your treatment, your remission. We had a lot of time to think about it, to talk about it. We had time on our side because your life changed over the years.

**Alicia:** Erin, you said that you trusted—that you and your family ended up trusting Dr. Mauro and the advice that he gave you. How important is open and effective communication between a patient and a physician or a healthcare team?

**Erin:** I think it is the most important thing. I think that I talked to a lot of newly diagnosed patients, including friends, recently, and I always tell them, and it may be awkward for a while, but you have to find a physician that you click with. You have to find somebody who you really feel you can talk to and can lean on. It is not just a one and done situation. This person is going to be a part of your life. I do think that communication is key, especially when you are talking about fertility and pregnancy. It is a long time. You are pregnant forever. You are going to be going through hormones and all this other stuff. You are going to want someone there who can reassure you and who you know is looking out for you. I think that is incredibly important. If you don’t have it in your current doctor, you should find a new doctor who you feel like you have some kind of rapport with and can talk openly with.

**Alicia:** Absolutely. Erin, before you mentioned a young woman who messaged you who was 15-years-old and diagnosed with CML. Dr. Mauro, what conversations do you have with those looking to preserve fertility in children and teens with cancer?

**Dr. Mauro:** That is a great question. I think the case of this leukemia in children is not one we face a lot because it is not that common, but, of course, there are many different conditions children have to face. It could be much more profound, I think, the impact on a developing—one who is in their developing years—pre-teen, teen years when fertility is actually being established can be pretty devastating. I think it is so important for a child. I wouldn’t expect a 12-year-old girl to say, “what about getting pregnant”. Her parents would probably fall down if she asked that, but the parents need to ask, too. They need to be thinking about their child’s future. I would be open and honest there,
too, because I think children that face cancer are beyond their years; not of course the very young, but anyone who has knowledge about this and who has reason to talk about it; not that you talk in isolation, but as a family, they need to talk about that. You want your life to be as normal as possible. There are things we should be talking about; we should be able to do. It is probably not an issue like we talk about in adults, but there is a right context to do it there. For a 15-year-old girl, if I were treating her for CML, I would speak to her with her, probably with her parents, about where she is at in her development and what I think might happen with her cancer treatment and make sure all those issues are on the table. They can be addressed and then tucked away to say, “you know what, that is not something that we are ready for or that we are ready to talk about”. That is okay, but if it is not talked about, it is a missed opportunity. The effects can be more profound when we treat the younger patients, especially before they have gone through puberty and developed.

Lizette: What made you so comfortable with sharing your journey? I look at myself and I think I may not be able to share as much as you do through your blogs, through your writing. Your sharing has really helped a lot of people and I do commend you for that? I just want to know how you feel so comfortable and you do it so well.

Erin: Thank you. I remember when I was first diagnosed and I do remember a moment where I was thinking a lot of people would not say anything. I know people who have CML who don’t share their story because you don’t have to because you are not going to lose your hair. You could definitely keep this disease to yourself. I just felt that I am already an open book. It wasn’t like cancer changed that in me. I definitely already was somebody who wanted to talk about whatever I was feeling, but I think my editor, Cindy Levy, at Glamour was the one who first came over to my desk at Glamour just a few weeks after I was diagnosed and said, “would you ever be interested in writing about your experience because I think our young female readers would be really intensely interested to know what’s it is like, what you are going through”. I said, “wow, of course”. I was already writing about the experience. I had a million things to say about it. Then, I think once I opened up a little bit and got that feedback, I realized that not only was I helping other people, but I definitely was helping myself because I am somebody who has to talk about the things that are going on in my life; otherwise, like most people, they could fester. For me, it has always been the way I live and it makes me more comfortable to talk about it. I like people who tell me things about themselves, too. I think that is just part of being a human is relating to other people and normalizing the things that we are going through. You start talking and you find out that somebody else is going through it, or they had a cousin, or an aunt. You would be very surprised that the things people tell me once I tell them I had cancer. They open up to me about all sorts of things. For me, it was never a matter of “if”. I came right back to the office when I was diagnosed and told my boss and we sat in her office and we shared a box of tissues and we cried. I haven’t looked back. That was almost 16 years ago and I haven’t looked back. Like I said, my husband, Nick, is not as open as I am about stuff, but I feel like this is not something to be ashamed of in any way. This is not something that—again, it only normalizes it if we can talk about it. Certainly, fertility is a universal issue. It is not just something that cancer patients face so I feel like (I don’t know) why not talk about it. It is more interesting than talking about the weather, right? You should see me on the soccer sidelines when people ask me a question. Sometime new people will say, “Oh, you have cancer. I am so sorry. Do you mind—can I ask you about it?” I was like, “Oh, you don’t know. I have written a book, yeah, I’ve written a book; I’ve written a blog. You can ask me anything.” There is nothing inappropriate here. You can ask me whatever you want.
Lizette: I think that is good because that is bringing it to the forefront, like you said. Now, for Dr. Mauro to be writing information about it so doctors who may not feel comfortable, and even the whole topic, now they will have a guideline so it will be so much easier to bring this topic up and to talk about it.

Dr. Mauro: I am really proud to say that we have come so far in cancer treatment and this diagnosis is an example where we can sit people down and say, “you know, this is a highly treatable and probably a functionally curable cancer.” When it comes to fertility, we are going to move from forget about it, go adopt a puppy to let’s talk about the fact that you may want to have children some day and let’s see how that might fit in with our bigger plan that you may be able to get treated for a number of years and then, potentially, be off your treatment and be cured of your leukemia or whatever your cancer is. Life can go on the way it is supposed to.

Alicia: Here, at LLS, we have a free publication called, “Fertility Facts” that people can download or order. Dr. Mauro and Erin, are there other resources that you think others would find helpful as they consider fertility?

Dr. Mauro: I think people ought to, for sure, look at the LLS for their cancer information. There are other advocacy groups. There has been information about clinical trials, which sometimes include fertility, on clinical trials.gov. Of course, no matter what your diagnosis is, there is probably is a specific advocacy group or website that is going to get you patient information. You know with Erin’s diagnosis, CML, there is a national CML Society, a Canadian CML Society. There is an international CML Foundation. There is a number of different organizations. The internet is a powerful tool. Now, it gives a lot of information and sometimes it is hard to filter. Of course, some of the best are the ones we mentioned first like the LLS, like other advocacy groups, like the net, like the government with regards to clinical studies and, of course, your doctor and other specific scenarios. Erin, you might know some secrets, as well.

Erin: I think that you have to tread lightly with social media, but there are a lot of groups on Facebook that I am a part of where you can just link with different people who are going through different things. There certainly are CML patients out there who are having babies and chat rooms and things like that. There are definitely some social medial groups. There are some Facebook groups that you can find patients in real time going through this and you can connect with them. I think this is a good source and just talking to, like I said earlier, asking your doctor if there are any patients that you can talk to.

Alicia: Absolutely. One of our podcast guest speakers—she is a young adult and she was diagnosed with Hodgins lymphoma. She just started You Tubing her entire journey from Day 1 and now it has gotten to a point where she is getting married and all of her bridesmaids are survivors that she met alongside this journey.

Erin: Oh my gosh! That is awesome.

Alicia: Yes; it speaks for the power of using social medial or using the internet in the right way and not going on there just absorbing everything that you read or see, but definitely in a way that connects with others. One of the resources that we have here is LLS Community, which is an online platform that allows patients to log on, create a profile, and speak with other patients and ask questions and share information. That is so important when you can find tools like that.
Alicia: For anyone who would like to learn more about Erin’s story, you can visit www.erinzammettruddy.com; that is e-r-i-n-z-a-m-m-e-t-t-r-u-d-d-y.com. To download or order the Leukemia & Lymphoma Society’s fertility fact sheet or any other support resource, you can visit www.lls.org/booklets or you can call our information specialists at 1-800-955-4572.

Thank you both so much for joining us today. Dr. Mauro, thanks for all you do for blood cancer patients and for being such a strong advocate for women and fertility. Erin, thank you so much for being so honest and transparent and letting the world in, not only on your life, but on your journey. It has been great speaking with both of you and we hope that others will learn as much as we did on this episode.

Erin: Thank you both so much. This was great.

Dr. Mauro: Thank you for having me.