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00:00:00.076 --> 00:00:21.730 Announcer Funding for Yale Cancer Answers is provided by Smilow Cancer Hospital. Welcome to Yale Cancer answers with the director of the Yale Cancer Center, Doctor Eric Winer. Yale Cancer Answers features conversations with oncologists and specialists who are on the forefront of the battle to fight cancer. Here's Doctor Winer.

00:00:21.807 --> 00:01:02.461 Eric Winer Tonight is a slightly unusual show because we have two guests, and we're going to be talking about the treatment of myelodysplastic syndrome and leukemia. These are two blood cancers. And what's different about tonight is that we have Doctor Amer Zeidan, who is professor of medicine and chief of hematologic malignancies. Accompanying him is his patient, Tom Mix. And we're going to hear from Amer about the treatment of leukemia somewhat briefly.

00:01:02.461 --> 00:01:40.500 Eric Winer And then we're going to talk to both of them in particular Tom about his experience going through treatment, going through a bone marrow transplant and how that has impacted his life. Amer, people know the term leukemia. We've talked about leukemia here on the show before. Maybe you could tell us a little bit about myelodysplastic syndrome, because I think in general that's a bit more of a of a topic that's less familiar to people.

00:01:40.576 --> 00:02:03.538 Amer Zeidan Yeah. And even to physicians, I would say the non oncologist, it can be a very confusing term. And part of this is because it's a heterogeneous condition. So the main features of MDS is what we call bone marrow failure. So the bone marrow similar to the other organs is not. When it fails it does not work well. I usually tell patients it's almost like a factory that shut down.

00:02:03.538 --> 00:02:24.576 Amer Zeidan So it's supposed to make red blood cells, white blood cells and platelets. And when the factor is not working, all these numbers go down. And that lead to the symptoms which are symptoms of anemia, symptoms of low platelets such as bruising and bleeding, and symptoms of low neutrophils, which are infections. However this is also a type of cancer.

00:02:24.576 --> 00:02:48.615 Amer Zeidan This is very important to understand, but the severity of the MDS happens on a spectrum. So some patients have what we call lower risk MDS where they can live for many years and have minimal symptoms and maybe just some mild anemia. While some symptoms have all of their blood counts very low, they have a high number of what we call blasts or the kind of the bad cells.

00:02:48.653 --> 00:03:07.884 Amer Zeidan And they have bad genetic abnormalities. And those patients, they behave almost like acute leukemia. They have a survival without treatment of less than a year. So it really happens on a broad spectrum. And this is why it's very important not only to the knows it, but also to classify it at the right risk stage.

00:03:08.000 --> 00:03:18.038 Eric Winer And Milo dysplasia, if I remember correctly, is something that typically affects people who are on the older side.

00:03:18.076 --> 00:03:43.500 Amer Zeidan Correct. So typically the typical age for MDS, this is I always joke that my clinic is a largely geriatric clinic because most of my patients are in their 70s and 80s, actually have a bunch who are in their 90s. So Tom is certainly on the younger end of MDS. We do see it around 15 to 20% of patients are less than six years old when they are diagnosed.

00:03:43.500 --> 00:04:12.076 Amer Zeidan And I would make also the point that Milo dysplasia is a descriptive term. It means that the cells under the microscope in the bone marrow are not maturing correctly. So this can happen from things like nutritional deficiencies, B12 deficiency, some medication side effects. However, Milo dysplastic syndrome is a cancer condition, so always important to make the difference because if it's related to a reversible condition, the treatment would be to kind of correct that abnormality.

00:04:12.115 --> 00:04:18.730 Eric Winer And it can also happen after someone has been exposed to cancer treatment like chemotherapy.

00:04:18.769 --> 00:04:46.115 Amer Zeidan Correct. And I always joke with my colleagues in medical oncology as part of why we are seeing many more patients now is because of all the success that's being seen in solid oncology, many patients a typical patient used to be for us, around 20% would have prior chemotherapy already generally for use to be primarily for conditions that can be cured, like Hurley, breast cancer, like early prostate cancer, get radiation, chemo.

00:04:46.115 --> 00:05:10.307 Amer Zeidan But now we are seeing patients who are after lung cancer, after ovarian cancer, after things that, to be honest, the patients never used to kind of live long enough to develop those secondary MDS. But we are seeing a number of these also multiple myeloma. We see a large number of patients with MDS from who have multiple myeloma because they because the treatments are just so successful, these patients are living ten years and more.

00:05:10.307 --> 00:05:12.846 Amer Zeidan So we are seeing more of these secondary cases.

00:05:13.000 --> 00:05:22.846 Eric Winer And to be clear, most patients who receive treatment for these cancers do not get Milo dysplasia. It is the the very small minority.

00:05:22.846 --> 00:05:42.461 Amer Zeidan Correct, correct. And this is something also we always emphasize. This actually never comes into the discussion when when you are treating a breast cancer or prostate cancer because it's as you said in my clinic, I see many of them because this is where they come. But the percentages are generally less than 1 to 2% out of the patients who have these conditions.

00:05:42.538 --> 00:05:58.038 Eric Winer Milo dysplasia can be a problem in and of itself. It can. Sometimes it isn't a problem, as you pointed out, and it can just smolder along. Sometimes it can be a problem and sometimes it actually turns into acute leukemia.

00:05:58.076 --> 00:06:22.576 Amer Zeidan Correct. And turning into acute leukemia happens in generally in around one third of patients. But to be honest, many of the patients with the more aggressive forms of MDS would die from MDS, from the bone marrow failure, from complications of infection and bleeding without developing into full acute leukemia. So I think most patients will tell me their biggest fear is to turn into acute myeloid leukemia.

00:06:22.576 --> 00:06:30.538 Amer Zeidan But I always tell them we don't want that to happen. But the MDS by itself can be quite problematic unless you unless you treat it.

00:06:30.576 --> 00:06:50.423 Eric Winer And is it ever thought that the acute leukemia is more treatable than the than the MDS so that although this is a dreaded complication and it makes the situation much more critical, perhaps it's somewhat easier to treat at that point.

00:06:50.500 --> 00:07:19.000 Amer Zeidan Yeah. I mean, depending on the specific genetics and situation. So there are forms of acute myeloid leukemia, as you mentioned, that can be completely cured just with chemotherapy, especially the type of leukemias that happen in younger patients, what we call favorable risk like core binding factor leukemias. However, MDS by nature, because it's so pervasive in the bone marrow, it cannot be cured without a bone marrow transplant, meaning that you have to replace the bone marrow completely.

00:07:19.000 --> 00:07:40.076 Amer Zeidan So that's one of the major differences. Sometimes you have to do that for AML, but in MDS all the cases have to be transplanted. And that's our biggest one of our biggest problems is that most of the patients are older and they are not able to go through transplant. So whenever we have a younger, patient like tone, our top priority goal is to go to transplant.

00:07:40.153 --> 00:07:50.884 Eric Winer So we've been talking about Tom. Let's bring Tom into this conversation. So Tom again welcome. And maybe you can just tell us a little bit about yourself.

00:07:51.000 --> 00:07:52.769 Tom Mix I am 56 years old.

00:07:52.846 --> 00:07:59.653 Eric Winer And so when you were diagnosed with myelodysplastic syndrome you were just over 50.

00:07:59.692 --> 00:08:00.692 Tom Mix Correct.

00:08:00.884 --> 00:08:15.846 Eric Winer So definitely on the young side. And you're originally from New York, you told me. And now you live in, in, in Connecticut. And tell us about the kind of work you do.

00:08:16.000 --> 00:08:22.269 Tom Mix Yeah, I live in Brookfield, Connecticut. Now, for the past 25 years. I'm an executive recruiter.

00:08:22.307 --> 00:08:28.000 Eric Winer And you're married. And happily, you have four children.

00:08:28.076 --> 00:09:01.730 Tom Mix My youngest is 18 years old. I have another daughter. She's currently in college now at Clemson University. I have a daughter that is graduating early from West Virginia, have a son, Jack, who's graduated from UNC Chapel Hill and actually is starting to pursue his physician's assistant degree this coming fall. And my oldest is 29 years old now. She's going to be 30 this coming year, and she lives down in Charleston, South Carolina and works for the Navy.

00:09:01.769 --> 00:09:13.230 Eric Winer So this diagnosis what what what were your thoughts when you first heard that you had this pretty, pretty critical blood cancer?

00:09:13.269 --> 00:10:07.076 Tom Mix Well, I was I was very surprised, obviously took took me and my wife and my family by by surprise. It happened during Covid too. So that brought some some other challenging and mitigating factors into play. Actually got Covid before and as a result not of Covid itself, but as a result of that some blood work was was was done and they saw some issues with my blood and some of my platelets and blood cells and white cells and, and something wasn't right and got a diagnosis, which I then took from the original hospital to Yale to for a second opinion.

00:10:07.153 --> 00:10:12.192 Eric Winer Doctor Zion has been taking care of you for the last several years.

00:10:12.269 --> 00:10:49.692 Tom Mix That's correct. He's, as I call him, he's my head coach, and he saw me through the and continues to see see me through the entire treatment, you know, right through the transplant and then some of the maintenance after that. And we just actually were down there recently for a visit and happy to say it was the visit was been a while, probably close to a year and a half since since I'd last seen him and his team and got great news from him, which he could probably share with you.

00:10:49.769 --> 00:11:06.307 Eric Winer So when you were first diagnosed, your kids were 13 through mid 20s, and I have no doubt that you didn't feel like you were ready to leave this world. Did you think you were going to make it through this?

00:11:06.384 --> 00:11:32.653 Tom Mix I always maintained a very positive personality throughout the entire treatment. That's just part of who I am. And I have a wonderful support system, both personally with my family, with many close friends, and developed that same connection with with my team at Yale.

00:11:32.692 --> 00:11:44.230 Eric Winer And so first, when you were diagnosed,

it was mild dysplasia and then maybe can can comment this this transformed into leukemia.

00:11:44.307 --> 00:12:10.076 Amer Zeidan Yeah. And it transformed actually while he was being treated. So when Tom presented to us he had a subtype of MDS that we call higher risk MDS, meaning that the number of the plus cancer cells was high. But more importantly, he had a very kind of bad type of a mutation called TB 53. Tp53 is a guardian of the genome.

00:12:10.076 --> 00:12:34.076 Amer Zeidan It's a gene that's very commonly mutated in cancer. But in MDS, when this mutation happens, it makes the outcomes of the disease very difficult. So the general statistics that I always like provide it because I think it's very important to kind of be honest with the patients, is that most patients do not make it based on the statistics.

00:12:34.076 --> 00:12:58.153 Amer Zeidan Around 20% of patients who have TB, 53 mutated acute leukemia or MDS survived. But what I always tell our patients is that we have no way of knowing which patients are going to actually be cured out of this and which patients are not. And therefore, I always recommend that we go with that treatment, do the best we can, and then hope, hope for the best.

00:12:58.153 --> 00:13:22.769 Amer Zeidan And this is the approach we we talk with Tom. We gave him, I think, very kind of clear understanding of the disease and then recommended the treatment. He was actually treated on a clinical trial initially, which randomized this patients to receive the standard of care drug, which is as a cytidine plus minus a drug called Veneto class, which is approved for acute leukemia.

00:13:22.769 --> 00:13:50.461 Amer Zeidan So he was seated on that trial, but he didn't respond to the to that treatment. And when we did the bone marrow at the end of the trial, his disease actually has progressed at that point to acute leukemia. And this is when we diagnosed him with acute myeloid leukemia. We gave him additional treatment. And finally we were able to get him into our mission and then subsequently and underwent the bone marrow transplant.

00:13:50.692 --> 00:14:00.153 Eric Winer And we're going to need to take a break in just a few seconds. But I'll just ask. That transplant was from a relative or from an unrelated donor, or.

00:14:00.230 --> 00:14:05.846 Tom Mix It was an unrelated donor. And I'd love to to tell you more about that as well.

00:14:06.153 --> 00:14:14.000 Eric Winer Okay. Well, I'll you'll tell us more in just a minute. When we come back for the second half of Yale Cancer Answers.

00:14:14.230 --> 00:14:34.461 Announcer Funding for Yale Aancer Answers comes from Smilow Cancer Hospital, where experts on the forefront of cancer research and clinical trials advance research, prevention and patient care.

Smilow's Cancer Research provides some patients with access to unique cancer clinical trials. SmilowCancerHospital.org

00:14:34.538 --> 00:15:01.730 Announcer Over 230,000 Americans will be diagnosed with lung cancer this year, and in Connecticut alone, there will be over 2700 new cases. More than 85% of lung cancer diagnoses are related to smoking, and quitting, even after decades of use, can significantly reduce your risk of developing lung cancer each day. Patients with lung cancer are surviving thanks to increased access to advanced therapies and specialized care.

00:15:02.000 --> 00:15:26.423 Announcer New treatment options and surgical techniques are giving lung cancer survivors more hope than they have ever had before. Clinical trials are currently underway at federally designated Comprehensive Cancer Center, such as the battle two trial at Yale Cancer Center and Smilow Cancer Hospital, to learn if a drug or combination of drugs based on personal biomarkers can help to control non-small cell lung cancer.

00:15:26.538 --> 00:15:33.500 Announcer More information is available at YaleCancerCenter.org. You're listening to Connecticut Public Radio.

00:15:33.576 --> 00:16:08.615 Eric Winer Hello again. This is Eric Winer host of Yale Cancer Answers. And I'm joined tonight by Doctor Amer Zeidan, chief of human malignancies at the Yale Cancer Center. And his patient, Tom Mix, who is an executive recruiter and has been talking to us about his experience having Milo dysplasia and acute leukemia. So when we left off, Tom, you were about to tell us the story of the unrelated donor.

00:16:08.653 --> 00:17:05.307 Tom Mix Just backing up for one second. I remember doctors Zidane had shared with me one of the positives or good news about this diagnosis is there is the opportunity for transplant and to be cured. Which always stuck with me during my entire journey. And at some point I was also joined with the transplant team under Doctor Serapion and his transplant team, and registered or used my my numbers and my blood work to register me on what was called Be the Match and be the match matched me up with a with a fine young gentleman young man out of Canada and he was a perfect match for me.

00:17:05.346 --> 00:17:36.692 Tom Mix He was a, at the time, 23 year old athlete and college student up in Canada. They let me know that they had found what they thought was a very strong match for me, which was great news and continued continued to keep me positive and and move me towards transplant, which Doctor Zidane and the oncology team were able to to accomplish.

00:17:36.846 --> 00:17:58.038 Eric Winer I think that it's actually worth making a point here about unrelated transplants and the fact that 30 years ago there were just so few of them because we didn't have a national bone marrow donor program the way we do today. Amara, can you just talk about that a little bit and what an impact that has had?

00:17:58.076 --> 00:18:25.000 Amer Zeidan Yeah. So transplant has seen a

lot of advances in the last two decades in several fronts. One of them is the availability of donors. So as you mentioned in the past, we used to be only able to do transplants from match siblings. So that was in Western countries where people did not have many siblings. Sometimes can be a challenge to find someone who's a full donor.

00:18:25.000 --> 00:18:53.230 Amer Zeidan But then once the unmatched sorry, the match unrelated donors became feasible to do as a source for the draft, we have very large registries now, more than 20 million people are actually signed up in those registries. So our ability to find a match is more than 85%, largely for Caucasians. Now, for minorities, they are not as well represented in these registries.

00:18:53.230 --> 00:19:17.615 Amer Zeidan So it can be a little bit more of a challenge. And this is why we always kind of recommend people to join up for the registry so that they can donate. And, you know, it's a gift of life. Patients with transplant, they call it their second birthday as I'm short term turned us. But since the last ten years, we actually are doing many more what we call happier transplants, which are half matched transplants.

00:19:17.615 --> 00:19:47.769 Amer Zeidan And this is making effectively a donor available for everybody. Because your son could be a donor, your daughter could be a donor. You have matched brother or sister could be a donor. So I think transplant has become a much more feasible option. We are also transplanting older patients now. We can do up to the mid 70s, and we can do a much better job at reducing the complications that Tom was talking about, like graft versus host disease and infections.

00:19:47.769 --> 00:19:52.423 Amer Zeidan So because of all of these reasons, we are able to do many more transplants compared to the past.

00:19:52.461 --> 00:19:58.884 Eric Winer And with a half match donor, do you have a lot more difficulty with graph versus host disease?

00:19:59.153 --> 00:20:21.807 Amer Zeidan No. And this is actually has improved a lot. This was actually a very fascinating time during my training because I trained at Hopkins where they developed this, what they call a post-transplant cytokine. And this is a way in which cytokine is given on day three and four of the transplant, and somehow it reduces the incidence of the graft rejection and the graph versus source disease significantly.

00:20:21.807 --> 00:20:34.038 Amer Zeidan So when I joined Yale, this was starting to become national kind of use. And now it's pretty standard. Like people are doing half matches kind of across the country.

00:20:34.230 --> 00:21:13.615 Eric Winer Wow. Yes, it has really changed things. And although I guess we all hope that there will be easier treatments than bone marrow transplants at some point in the future and even more effective treatments, it's remarkable how much they've improved and the growth in the number of transplants. All right, Tom, so let's get back to you. Tell us a little bit

about the experience being in the transplant unit, and tell us how you manage to maintain such a positive attitude even then.

00:21:13.692 --> 00:21:49.461 Tom Mix Yeah. And I just wanted to mention about the donor program, it was called Be the Match, but it's now called ND, MP National Donor Marrow Program. And one of the things that I learned and that I promoted once I got better with Alex, my my donor was was creating more awareness around being a donor, which is very simple to do and is not a well attended here in the US, more in Europe and Canada where there's much more people registered.

00:21:49.461 --> 00:22:22.423 Tom Mix So I just wanted to mention that as, as you know, creating a little bit more awareness around that. But as far as my once I went to transplant, my rebirth date is 11 2621. And once I went to transplant doctors, Ayden kind of handed me off to that team for some of the complications with graft versus host, and I work with that team probably for a couple of months.

00:22:22.500 --> 00:22:50.653 Tom Mix Once I was discharged from the hospital and my graph versus host lingered for a bed. But for the most part, it was it was manageable and and and done so through medications and checkups. At Yale, it was not hard to maintain a positive attitude. I was grateful at that point to to go down, you know, get my blast all the way down into remission by doctors, Aiden and his team.

00:22:50.653 --> 00:23:21.000 Tom Mix And then from there go to transplant. I spent I think I broke a record doctors I can talk about that in terms of my discharge and how quickly I was able to get discharged from my transplant. And so I was, you know, I was on a high going in working with the transplant team, and nothing was going to deter me, just just as maintain that same attitude throughout.

00:23:21.076 --> 00:23:26.884 Eric Winer It's really remarkable to hear how well you did.

00:23:27.038 --> 00:23:33.730 Eric Winer I'm I'm sure that not everyone does quite this well. Can you comment on that?

00:23:33.884 --> 00:24:16.153 Amer Zeidan Yeah, absolutely. Actually there are several things to comment. And the first thing is that while we were able to get Tom into what we call a remission, he still has evidence of the genetic mutations that TB 53, which generally, as I mentioned, generally predicts a long term cure of around 20%. And the reality, to be very honest, is that many transplant programs in the country, one of the problems, I think, or things that could be improved in how transplant programs are evaluated in the country, is that they are judged by their, what they call 12 month mortality, meaning how many patients die during the first year of the transplant.

00:24:16.153 --> 00:24:40.115 Amer Zeidan And that and this these outcomes are publicly reported. So what that leads to is that some transplant programs

will actually not transplant patients who have high risk disease because they don't want their numbers to kind of not look too good. Then I have to give a lot of credit for our program because, you know, despite knowing the odds not being great, we can never know which patient is going to be good.

00:24:40.153 --> 00:25:05.884 Amer Zeidan And not all the overall patients might not do great. And our approach has been always is that to give the patient the best chance possible. So if the patient is a candidate, he should go under undergo the transplant. So and I think in terms of this worked out very well. But you're right. Like unfortunately sometimes other patients leukemia would come back and it becomes very difficult to treat it at that point.

00:25:05.884 --> 00:25:14.500 Amer Zeidan But it's very important, I think, for the patients to have teams that strongly advocate for, for the best thing for the patient.

00:25:14.576 --> 00:25:48.384 Tom Mix Yeah, this is something that really stood out to me too. And you know, as a patient, you don't necessarily know all the behind the scenes and you know, what's what's taking place. But for me, this is something that me and Doctor Zidane discussed in my last visit there. And the team and himself have always been such advocates, and there have been hurdles that had to be jumped throughout the treatment and the chemotherapy and being, you know, in the hospital.

00:25:48.384 --> 00:26:14.769 Tom Mix And one of the things that I'm grateful for, along with, of course, my family and the donor is, is, you know, that they were always advocating for me. I always felt well represented. And that was not even knowing all the details that, you know, that came to light, you know, as, as time has passed. So that was really important for me.

00:26:14.769 --> 00:26:24.115 Tom Mix That was a big decision in me making the choice, you know, was the team that I met over there, and I'm grateful for that.

00:26:24.115 --> 00:26:41.346 Eric Winer So there's one more little facet of your story, Tom, that I did know about until we were talking before the show. And that's something that happened to your wife. So you're getting better from this transplant. And then what happened?

00:26:41.384 --> 00:27:15.846 Tom Mix I was recovering back at home at that point, just doing maintenance of chemotherapy, which was was weaning over the months. It was probably about a year into my recovery was feeling much better, much stronger. And then unfortunately, I got a call from my wife in a bit of a panic, had a terrible headache. We agreed that she should go immediately to the emergency room, and turns out that she just made it to the emergency room and collapsed and.

00:27:16.000 --> 00:27:20.307 Eric Winer And she drove herself to the emergency room. So thankfully she.

00:27:20.307 --> 00:27:44.115 Tom Mix Got she drove herself, which in and of itself was a miracle that she got there. But she she had to. Aneurysms. Two ruptures in her brain as a result from that was basically in the hospital for about a month and, and had a long recovery that lasted well over a year.

00:27:44.192 --> 00:28:09.000 Eric Winer Well, you know, I think hearing your story, hearing her story, it just reminds us that there's so much that's unpredictable in the world. And many of us have to be very grateful for all the good things that have happened to us, to get us through all sorts of challenging situations. It's been a real pleasure having both of you on the show.

00:28:09.038 --> 00:28:32.769 Eric Winer Amer, thanks for the education about myelin dysplasia and acute leukemia. And Tom, thanks for joining us and being such a positive force, but also just sharing with us all that all that you experienced. Thanks everyone. We'll talk to you next week.

00:28:32.846 --> 00:28:52.038 Announcer If you have questions. The address is CancerAnswers@Yale.edu and past editions of the program are available in audio and written form at YaleCancerCenter.org. We hope you'll join us next time to learn more about the fight against cancer. Funding for Yale Cancer Answers is provided by Smilow Cancer Hospital.