

Bill Lundgren - DTRF 2022 Patient Meeting Webinar #1

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Jeanne Whiting: Okay. All right. We'll go to our next speaker now, who is a patient a caregiver of a patient, father of a patient, Bill Lundgren, and so many of us as we learn down the road in our journey, we learn things that we wish we'd known when we were first visiting our doctor or deciding on a treatment plan. And we just asked Bill if he could give a patient's perspective on what would I do differently, starting the journey with his beautiful young daughter.

Bill, go ahead and please, and I love the slides you have because they show his beautiful daughter but really describes a difficult journey that he's learned from and I hope we can all learn from.

Bill Lundgren: So my name is Bill Lundgren. And I'm father and caregiver to my daughter along with her mom. So meet Suzy. So, Suzy's a wonderful young girl. I'm biased, but I think she's super awesome.

Suzy, when Suzy was born, Suzy was born with her left calf was slightly larger than the other. So at the time, this was in 2006, so at the time the doctors here in Dallas were like, Oh, that's a sign of an abdominal tumor. Like, okay. So we had her scanned and prodded until she's five or six years old, and based on everything that came back they said, Well, it's just an asymmetry. You know, there was no symptoms. It was asymptomatic. Her one calf was slightly larger than the other. Well, in middle school when Suzy hit puberty, her left heel started to raise off the ground. And at that time we had the unfortunate diagnosis that in fact, Suzy had a desmoid tumor.

So, we were, you know, we reached out and we were recommended to we were given a quote unquote surgeon, that knew all about desmoid tumors. And so it says, Yeah, I have experience with tumors and we can, you know, as Dr. Pollack had mentioned, we can remove it with clear margins. And since she's had it in her whole life and it hasn't moved, hasn't done anything, there's a high probability that it won't come back.

Try to gather myself. So three months later it came back larger, more aggressive. It quickly began to wrap around the rest of her calf muscle and continued to pull her heel into a locking position, much like a ballerina point. Her foot cannot be extended any further than it is today. So, okay, so now we're in it, right?

So we've tried multiple medications. We've tried multiple treatments. We started with chemo. We've tried with different, you know, forms of pill forms of medication, you know, sorafenib we've done nirogacestat. We've done high frequency ultrasound. We've been in several clinical trials and on top of the medications, and it's the side effects that go along with the medications, right?

So then it's this constant juggling act. It's now we're trying this new treatment, so that then introduces a plethora of side effects that then you have to take additional medication to counter those side effects. So Suzy's now 16 and her backpack looks like a pharmacy. So Suzy has been in a wheelchair for almost four years now.

The last medication dropped her bone density to an all time low. And just a simple act of trying aquatherapy, of moving a cone underwater that had fractured her fibula at the point of where the tumor was pushing on it. So, you know, game on times 10. Pain unable to put any weight on the foot whatsoever.

And so, that's where we are. And why are we here? Right? Cause 40% of all desmoid tumors are misdiagnosed, and you can or cannot quote me on this one. This is kind of the terminology. I know there's some research that might, that will back some of this up. But you know, when you are diagnosed with a quote unquote tumor the chances of actually being diagnosed correctly are not extremely high.

So what would we ask our oncologist if we could do it all over again? Right. So before I ask my oncologist anything, I think there's a checklist that we all have to go through. First of all, this is so rare that the odds are that your oncologist has never heard of it are kind of high. So you need to educate yourself.

Cause no, it is not fun being the smartest person in a room full of doctors. And how do we do that? And I say that it's no discredit to our medical community, but it is a rare disease and the chances that your family doctor knows about desmoid tumors are very low. So what can you do? You're, the best thing you can do is educate yourself.

So obviously the Desmoid Tumor Research Foundation, DTRF.org is probably your best and main place to get as much information as possible. SpringWorks has also launched their new site with desmoidtumors.com. And you know, you don't have to be a scientist or a doctor to truly understand what you're dealing with.

But you do have to familiarize yourself with the terminology because in your conversation with anybody who's gonna offer some kind of treatments, there's questions that you can ask and there's things that they're gonna say to you that you at least need to have some familiarity with because you don't want to be, you know, cross-eyed in a meeting like, I have no idea what you're talking about. You really have to do your homework.

And so what are our options? Obviously, you know, Dr. Pollack just went through quite a bit of great information on on your options, but can you wait and see, Right. Whereas it now Suzy's case it was an extra abdominal tumor, so it was becoming active and it was starting to impede, you know, mobility, so we had to do something. Right.

There are also obviously a ton of chemo options, Right. And I can't even pronounce most of 'em. And then there's new, obviously there's oral medications that are coming out and they're coming out all the time. And also alternative procedures. You know, obviously we mentioned cryoablation, there's TACE, there's HiFU, trans partial radiation, etcetera.

And if you don't know what these are that's another reason to at least educate yourself. Right. And then what clinical trials are available to you? And are there surgical options? Should you do surgical options? So there's this diagram that I show here on the screen that I think is just key. I wish we had this from the get go.

This is on the global consensus paper from 2018. It's listed on the DTRF.org site. Really it's kind of a flow chart. Flow chart. So you're diagnosed, okay, so what do we do? Is it abdominal? Is it intra-abdominal? Is it an extremity? Where is it head and neck? And so what are your different options based on that?

So you have to have at least know what your options are. And then you need to formulate a team. Odds are that your oncologist is gonna have all the information for you are also a little rare. So you need to find the accredited sarcoma specialist that truly has experience in desmoid tumors and ask them how are you experienced? Right.

Not just, Well, I know about it. It's probably the worst answer you want to hear. And also just because your oncologist is local doesn't mean that no discredit to them doesn't mean that they're the appropriate oncologist for you. You really have to do your homework and you find a multidisciplinary approach. Right?

You need a team that's gonna try all aspects of of treatment, Right. And ask other patients for referrals and advice. Because it truly, I hate to pull this quote, but it does take a village to diagnose and plan to treat a desmoid tumor. So what does a team look like? Right? So at, in our particular case we have an oncologist I think we're very lucky that we have an oncologist is connected to the greater community and is connected to the desmoid tumor community.

Obviously a radiologist, and in Suzy's case, we need an orthopedic surgeon to understand, you know, what we're looking at structurally palliative care for pain management. Obviously there's nerve damage. I could be pushing. It could cause other type of or pain, nerve pain. So how are you gonna manage that?

Physical therapy, something you know, specifically for Suzy, how are we gonna lower her heel? How do we do that? How do we maintain range of motion? A dermatologist, some of the medications she's been on has been just, you know, very hard on a young girl and she's become a skincare professional at this point.

A dietician, you know, what kind of food should we stay away from? What kind of food should we eat? And psychologist, that's been very key for Suzy as well. And physical medicine and rehabilitation specialists, right? So we made a mistake of just, let's just get a wheelchair and then by the time we've already been in it for a year and a half, then we, you know, found we could get a better one. And they're like, I wouldn't put anybody I know in that wheelchair. I'm like, Oh, sorry. So, you know, we resurrected that part.

But so what's a game plan? You have to make a game plan. And when I say that everybody has to be on board, you have to make it together with your oncologist, with your team of doctors, and with your patient, with the caregivers. And you know, what is your plan? If your option don't go by the options, if it's just locally available to you, it is worth taking a drive or a flight if

something's really gonna be a game changer for you. And what's your timeline? And so this is a balancing act. How long can I endure a particular medication?

Because we know some of them, the side effects are very rough, but at the same time, how far can I go? How soon can we tap out, don't stop too soon. Right? It's almost like the bell curve, like a lot of the side effects are kind of ramping up and getting used to, and then you kind of, you know, get used to some of the symptoms and then you kind of get over the curve and maybe it's a little bit more manageable.

You have to take that balancing act. And then what is the risk versus reward? So we don't, you know, you have to look at what your treatment options are and how risky is the treatment, You know, what's the reward? And most importantly, you can't go it alone. And I know that's probably one of the hardest things for this disease, because people feel like they're on an island. This is so rare. They really don't have anybody in their local circle to talk to. So one of the game changers for us is finding the Desmoidian Facebook group. We found so many great people and just being able to get advice and people just want to vent and people just need you know, just hear somebody just say, Hey, I hear you. I'm in your corner.

And connecting with other patients that have a similar situation as you. Right? Cause desmoid tumors are also very different. There's some people on Instagram you know, that are having some that post their journey. You know, we found some great people that, you know, are close to us with, you know, finding somebody on social media.

There's also testimonials and videos on YouTube, you know, you know, there's a wide range on YouTube. So that, you know, that's the wild west there. But I highly recommend, you know, reaching out and getting connected. And don't give up. Stay connected. Keep focused, stay present. Try not to think too far.

Sometimes the light at the end of the tunnel is really hard to see. Excuse me, Volunteer. Fundraise, you know, go outside of yourself and try to help others. That'll help you. And then you need to center, find yourself, whether that's prayer, whether that's meditation whether that's exercise, whatever it is you need to find a release.

One of the silver linings here is that you knows, been Suzy's been somewhat mobile, immobile, I should say. She's become a great movie buff, and she knows more about different film movements and directors and, you know,

actors. And you know, I think in the silver lining here is that, you know, when she's looking at college, we're looking, you know, something along film degree.

So, there are some silver linings here to take away from it. So also, I also wanna say that in the four years we've been in this, you know, two drugs have come online since we've been here, there's clinical trials still coming up, There's new treatments that are available all the time. I really feel that we're at a great point in time where medical advancements are happening all the time, that I truly feel confident that we're going to find a cure soon in our lifetime and then and in the coming future. And we can't lose sight of that. So, thank you so much. You're all warriors and I appreciate your support. Thank you.

Jeanne Whiting: Bill, thank you so much. We don't have any specific questions for you in the q and a, but just comments. Thank you for being so brave to speak openly about, you know, this vulnerable situation that we all deal with, the emotions of this, and I think you had some great suggestions on things that can help us along our journey. So thanks so much for your presentation.