

Survivor Stories: Kayleigh and Cassidy

Learn how CTOAM helped Kayleigh move from Stage IV Lymphoma to Remission

Cassidy: And so I've been on the phone, you know, quite frequently over the past few weeks by people that want to know a little bit more about how, you know, we handled it because we have a success story, that we could plan on continuing to be a success story. And they want to know what we did differently or if we did something differently and where to go if treatment's not working. And so I have to do the full sales pitch for CTOAM with a grain of salt that says, so you asked what do we tell people, you ask, you know, would we refer them and what would we tell 'em about and what to, what to think or what to expect or what I've kind of come around to after my last month, I've literally trying to push people for a consultation with CTOAM, just to learn about, whether there's an opportunity for their situation, because every cancer is, is different.

Cassidy: No two cancers are the same. and that's something that I never knew. You know, the diagnosis will typically be, oh, this is where we found it in your body. The cells look like they're from this part of your body. This is the type of cancer we think it is. And in our experience, this type of chemo works fairly well more often than not on that type of cancer based on where we found it. Right. And so that's why people get so scared of chemo and they say chemo doesn't work, right? You got 40%, 30% success rates in a lot of different types of cancer. And it's basically them saying, here's the odds game, here's the treatment that seems to work more often than not for that type of cancer. But what they don't tell you is that you can have two totally different types of cancer in the same tissue.

Cassidy: You can have, you know, a, a lung cancer that is moved into a different part of the body, and if they find it there first, they're gonna call it that type of cancer. and so you don't know until you look at the genes driving these things of what's going on. And so I'll tell them that to start with and get their mindset in, the, well, get them in the mindset that, hey, it's a possibility you've got the wrong diagnosis. It's not that uncommon once you start looking into it, treatments that fail and people that have have been through several treatments learn the hard way that, oh, they've been misdiagnosed or they never find that out, and it goes, it goes bad. So I say if anything else, if you wanna be sure of the diagnosis and make sure that you're getting the right, type of medication or treatment, you have to look at the genetics.

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Cassidy: I mean, some cancers confidence is relatively high. Other types of cancers, confidence can be all over the map on, on whether their diagnosis is on point. so that's number one. And then I tell 'em, you have to be prepared to spend some money. I'm like, you gotta look at, you know, you gotta have \$10,000 to \$30,000 to answer the question, have we got the diagnosis right and have we identified the best treatment or all treatments out there. So I tell them, you know, the genetic profiling, the next generation sequencing costs are coming down, but they're still in the thousands. I think, you know, Foundation One ranges from like the \$7,000 to \$15,000 range depending on what types of panels you want to do. I'm like, what it will give you is peace of mind that you've identified all possible treatable things and you may come back with these mutations, that are unknown from your existing treatment plan.

Cassidy: But there's no guarantee that there's any treatments out there for them. Like this is an emerging field. We're adding new mutations and, you know, drugs that treat, that target those mutations all the time. And the list is growing every single day. So, you know, be prepared for the fact that you're spending this money just to learn that there is something, but we don't have a treatment for it yet, but that doesn't mean we won't have one in a few years. So that's where your money is going to. It's that understanding that, you know, you've identified every treatable component of your disease. even if it means that there's nothing on the table now, but if there is, these guys will help you find it and help you get access to it and help you navigate the implementation of it and the cost aspect of it. That's what you're paying for with CTOAM. It's not a cure. It 's the approach you need to take if you want to be sure that you've done everything you can to cure the position you're in.

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Kayleigh: Yeah. And just to build on that, from more of the, the perspective of if I was talking to the cancer patient and not the cancer patient support system, I would say it's also the feeling of, I guess security and control and the possibilities that, you know, it can get better. I think one major aspect of getting through cancer and surviving and thriving is actually your attitude. And before I had CTOAM's kind of responses, and here's what we'll do if this treatment fails, we're gonna move to this, this, and this, and here's why. Before I had that, I would go to bed at night not knowing if I was going to live. It's a black box. Yeah. So it's, you can put on a smile and you can do everything that you're supposed to, but you're not always thinking positive. And then once you have that, it was like once I saw, and ours took a little bit longer to be fair, because of covid.

Kayleigh: It was just like the timing, but it was still pretty quick turnaround to get it . And when I saw all the science behind their recommendations, I had a sense of, "okay, I'm gonna get through this because I'm not alone". It's not, "hey, let's just hope these chemicals we're pumping into your body do something." It's " if those chemicals don't work, don't worry. We've got a whole other thing that we're gonna try and it's completely different and it won't have the same side effects that you are currently experiencing on your chemo". And I was able to change my whole outlook on being a cancer patient because I saw that my future had a roadmap to resolve this issue instead of sitting around with hope. And I've said this so many times when I was going through treatment, I hated the word "hope" because hope means that there's nothing to be done, but just sit there and think about it. Whereas, yeah, fingers crossed. Yeah. Control and options gave me possibilities, which helped my mindset so much more than just hoping.