WEBVTT

00:00:00.000 --> 00:00:03.138 Funding for Yale Cancer Answers is

NOTE Confidence: 0.928484391818182

00:00:03.138 --> 00:00:06.120 provided by Smilow Cancer Hospital.

NOTE Confidence: 0.928484391818182

00:00:06.120 --> 00:00:08.100 Welcome to Yale Cancer Answers

NOTE Confidence: 0.928484391818182

00:00:08.100 --> 00:00:10.080 with Doctor Anees Chagpar.

NOTE Confidence: 0.928484391818182

00:00:10.080 --> 00:00:11.556 Yale Cancer Answers features

NOTE Confidence: 0.928484391818182

00:00:11.556 --> 00:00:13.401 the latest information on cancer

NOTE Confidence: 0.928484391818182

00:00:13.401 --> 00:00:15.281 care by welcoming oncologists and

NOTE Confidence: 0.928484391818182

00:00:15.281 --> 00:00:17.459 specialists who are on the forefront

NOTE Confidence: 0.928484391818182

00:00:17.521 --> 00:00:19.195 of the battle to fight cancer.

NOTE Confidence: 0.928484391818182

00:00:19.200 --> 00:00:21.126 This week it's a conversation about

NOTE Confidence: 0.928484391818182

00:00:21.126 --> 00:00:22.808 Ewing Sarcoma with Doctor Hari

NOTE Confidence: 0.928484391818182

00:00:22.808 --> 00:00:24.550 Deshpande and his patient, Julia.

NOTE Confidence: 0.928484391818182

00:00:24.550 --> 00:00:26.500 Doctor Deshpande is an associate

NOTE Confidence: 0.928484391818182

00:00:26.500 --> 00:00:28.488 professor of medicine and medical

NOTE Confidence: 0.928484391818182

00:00:28.488 --> 00:00:30.648 oncology at the Yale School of

NOTE Confidence: 0.928484391818182

00:00:30.648 --> 00:00:32.549 Medicine where Doctor Chagpar is

NOTE Confidence: 0.928484391818182

00:00:32.549 --> 00:00:34.434 a professor of surgical oncology.

NOTE Confidence: 0.917423431818182

00:00:35.560 --> 00:00:38.272 Julia, maybe we can start off by you

NOTE Confidence: 0.917423431818182

00:00:38.272 --> 00:00:40.718 telling us a little bit about yourself

NOTE Confidence: 0.917423431818182

00:00:40.718 --> 00:00:43.720 and your story.

NOTE Confidence: 0.850447647142857

00:00:43.720 --> 00:00:46.835 Absolutely. I feel honored to be here.

NOTE Confidence: 0.850447647142857

00:00:46.840 --> 00:00:49.624 So thank you so much.

NOTE Confidence: 0.850447647142857

00:00:49.624 --> 00:00:52.552 I'm a 30 year old woman.

NOTE Confidence: 0.850447647142857

00:00:52.560 --> 00:00:57.448 I was diagnosed with Ewing Sarcoma in 2015,

NOTE Confidence: 0.850447647142857

00:00:57.448 --> 00:01:03.168 so quite a while ago and

NOTE Confidence: 0.850447647142857

00:01:03.168 --> 00:01:08.675 it was to my surprise, I was in

NOTE Confidence: 0.850447647142857

00:01:08.675 --> 00:01:10.800 PA school, physician assistant school,

NOTE Confidence: 0.850447647142857

00:01:10.800 --> 00:01:15.360 I was in my graduate year and had

NOTE Confidence: 0.850447647142857

00:01:15.360 --> 00:01:19.200 been having some pain for a while and

NOTE Confidence: 0.850447647142857

00:01:19.200 --> 00:01:24.472 I got a work up and got the

NOTE Confidence: 0.850447647142857

00:01:24.472 --> 00:01:26.951 diagnosis, had to take off about a year

NOTE Confidence: 0.850447647142857

00:01:26.951 --> 00:01:31.240 and a half of school to do upfront

NOTE Confidence: 0.850447647142857

00:01:31.240 --> 00:01:35.320 therapy and that was very difficult

NOTE Confidence: 0.850447647142857

00:01:35.320 --> 00:01:40.480 you know, being 22, starting my career

NOTE Confidence: 0.850447647142857

00:01:40.480 --> 00:01:43.387 to be a PA and I was so excited and

NOTE Confidence: 0.850447647142857

00:01:43.387 --> 00:01:46.631 and this threw a big

NOTE Confidence: 0.850447647142857

00:01:46.631 --> 00:01:50.824 wrench in my life

NOTE Confidence: 0.850447647142857

00:01:50.824 --> 00:01:53.752 plans as a cancer diagnosis often does.

NOTE Confidence: 0.929461477

00:01:56.000 --> 00:02:00.416 So at that point I started my therapy

NOTE Confidence: 0.929461477

00:02:00.416 --> 00:02:03.728 at Yale in the pediatric

NOTE Confidence: 0.929461477

00:02:03.728 --> 00:02:06.008 world because it's a pediatric

NOTE Confidence: 0.929461477

00:02:06.008 --> 00:02:08.600 cancer and a young adult cancer

NOTE Confidence: 0.929461477

00:02:08.683 --> 00:02:10.998 but often in younger children.

NOTE Confidence: 0.929461477

00:02:11.000 --> 00:02:15.304 So I did that therapy and

NOTE Confidence: 0.929461477

00:02:15.304 --> 00:02:17.730 then there were

NOTE Confidence: 0.929461477

00:02:17.730 --> 00:02:19.480 more bumps along the road.

NOTE Confidence: 0.929461477

00:02:19.480 --> 00:02:24.342 There were multiple relapses and while

NOTE Confidence: 0.929461477

00:02:24.342 --> 00:02:27.779 I was having these relapses I decided

NOTE Confidence: 0.929461477

00:02:27.779 --> 00:02:31.272 to go back to school and get my degree.

NOTE Confidence: 0.929461477

00:02:31.272 --> 00:02:34.460 So I finish and

NOTE Confidence: 0.929461477

00:02:34.460 --> 00:02:36.720 became a physician assistant.

NOTE Confidence: 0.929461477

00:02:36.720 --> 00:02:40.950 So that was really a very proud part

NOTE Confidence: 0.929461477

00:02:40.950 --> 00:02:45.205 of my journey and then as things

NOTE Confidence: 0.929461477

00:02:45.205 --> 00:02:48.280 progressed I started to incorporate

NOTE Confidence: 0.929461477

00:02:48.280 --> 00:02:51.744 my cancer as part of my life

NOTE Confidence: 0.929461477

00:02:51.744 --> 00:02:53.666 instead of something that hindered

NOTE Confidence: 0.929461477

00:02:53.666 --> 00:02:56.736 my life. And so I decided that I

NOTE Confidence: 0.929461477

00:02:56.736 --> 00:02:58.440 really wanted to work in oncology.

NOTE Confidence: 0.929461477

00:02:58.440 --> 00:03:01.568 So I got

NOTE Confidence: 0.929461477

00:03:01.568 --> 00:03:04.396 my first job at Mass General

NOTE Confidence: 0.929461477

00:03:04.400 --> 00:03:08.320 in pediatric radiation oncology.

NOTE Confidence: 0.929461477

00:03:08.320 --> 00:03:10.400 and I've worked there for several years at

00:03:10.400 --> 00:03:13.040 the beginning of my career while

00:03:13.040 --> 00:03:16.784 getting my treatment and so as things

00:03:16.784 --> 00:03:19.652 had progressed there were many

00:03:19.652 --> 00:03:22.130 bumps along the road

00:03:22.216 --> 00:03:24.916 as many cancer patients experience

00:03:24.920 --> 00:03:29.192 and many relapses.

00:03:29.192 --> 00:03:33.746 And this was about a year or so

00:03:33.746 --> 00:03:36.284 ago and there was a a pretty big shock to

00:03:36.284 --> 00:03:38.959 everybody and that was when I contacted Dr.

00:03:38.960 --> 00:03:41.907 Deshpande because the

00:03:41.907 --> 00:03:44.783 cancer had spread to my brain and so

00:03:44.783 --> 00:03:47.745 that was a pretty shocking moment in my life.

00:03:47.745 --> 00:03:52.144 Again was was halted pretty severely and Dr.

00:03:52.144 --> 00:03:55.704 Deshpande was there and surprised

00:03:55.704 --> 00:04:00.696 supported me and and he's a

00:04:00.696 --> 00:04:01.440 really special man

NOTE Confidence: 0.721243432

00:04:04.280 --> 00:04:06.960 that's that's fantastic and and

NOTE Confidence: 0.721243432

00:04:06.960 --> 00:04:09.662 Doctor Deshpande Hari I want to bring

NOTE Confidence: 0.721243432

00:04:09.662 --> 00:04:12.054 you into this conversation just to

NOTE Confidence: 0.721243432

00:04:12.054 --> 00:04:15.225 kind of flesh out a little bit more

NOTE Confidence: 0.721243432

00:04:15.225 --> 00:04:17.622 about what exactly is Ewing sarcoma.

NOTE Confidence: 0.721243432

00:04:17.622 --> 00:04:21.836 So can you kind of tell us what it is

NOTE Confidence: 0.721243432

00:04:21.836 --> 00:04:24.720 and a bit about the demographic that

NOTE Confidence: 0.721243432

00:04:24.720 --> 00:04:27.920 is affected by it and how it presents

NOTE Confidence: 0.717994452

00:04:29.160 --> 00:04:30.720 Yes. So thank you, Anise.

NOTE Confidence: 0.717994452

00:04:30.720 --> 00:04:33.471 It's, it's nice to see you again

NOTE Confidence: 0.717994452

00:04:33.471 --> 00:04:36.239 and it's great to see Julia here.

NOTE Confidence: 0.717994452

00:04:36.240 --> 00:04:37.448 It's a rare disease.

NOTE Confidence: 0.717994452

00:04:37.448 --> 00:04:39.999 So it's not quite one in a million,

NOTE Confidence: 0.717994452

00:04:40.000 --> 00:04:42.799 but it's probably two or three in a million.

NOTE Confidence: 0.717994452

00:04:42.800 --> 00:04:47.000 So it's not surprising that

NOTE Confidence: 0.717994452

00:04:47.000 --> 00:04:48.520 people haven't heard of it.

NOTE Confidence: 0.717994452

00:04:48.520 --> 00:04:50.760 And even when you're at PA school,

NOTE Confidence: 0.717994452

00:04:50.760 --> 00:04:52.895 it's probably not high on your list

NOTE Confidence: 0.717994452

00:04:52.895 --> 00:04:55.160 of lectures that you hear about.

NOTE Confidence: 0.717994452

00:04:55.160 --> 00:04:57.240 But Julia's absolutely correct.

NOTE Confidence: 0.717994452

00:04:57.240 --> 00:04:59.840 It's mainly a disease of

NOTE Confidence: 0.717994452

00:04:59.840 --> 00:05:01.799 children and young adults.

NOTE Confidence: 0.717994452

00:05:01.800 --> 00:05:02.888 In children,

NOTE Confidence: 0.717994452

00:05:02.888 --> 00:05:07.240 it's almost always a disease of the bone.

NOTE Confidence: 0.717994452

00:05:07.240 --> 00:05:08.152 In other words,

NOTE Confidence: 0.717994452

00:05:08.152 --> 00:05:10.280 it starts in one of the bones.

NOTE Confidence: 0.717994452

00:05:10.280 --> 00:05:12.812 In adults, it can be either,

NOTE Confidence: 0.717994452

00:05:12.812 --> 00:05:15.148 it can start either in the bone or

NOTE Confidence: 0.717994452

00:05:15.148 --> 00:05:17.397 in what we call the soft tissue.

NOTE Confidence: 0.717994452

00:05:17.400 --> 00:05:20.634 So that's other areas of the body.

NOTE Confidence: 0.717994452

00:05:20.640 --> 00:05:23.640 And if it does occur in the bone,

NOTE Confidence: 0.717994452

00:05:23.640 --> 00:05:25.992 and you may remember this from your

NOTE Confidence: 0.717994452

00:05:25.992 --> 00:05:27.465 medical school lectures, Anesic,

NOTE Confidence: 0.717994452

00:05:27.465 --> 00:05:30.720 it can have a very characteristic appearance.

NOTE Confidence: 0.717994452

00:05:30.720 --> 00:05:32.688 We call it an onion skinning

NOTE Confidence: 0.717994452

00:05:32.688 --> 00:05:34.000 appearance in the shaft.

NOTE Confidence: 0.717994452

00:05:34.000 --> 00:05:37.289 So, but it really,

NOTE Confidence: 0.717994452

00:05:37.289 --> 00:05:40.104 it's difficult to predict where

NOTE Confidence: 0.717994452

00:05:40.104 --> 00:05:43.262 it's going to occur and who it's

NOTE Confidence: 0.717994452

00:05:43.262 --> 00:05:45.488 going to occur and it doesn't

NOTE Confidence: 0.717994452

00:05:45.488 --> 00:05:47.690 seem to have a specific cause,

NOTE Confidence: 0.717994452

00:05:47.690 --> 00:05:49.915 some cancers that we see.

NOTE Confidence: 0.717994452

00:05:49.920 --> 00:05:51.028 We can say oh,

NOTE Confidence: 0.717994452

00:05:51.028 --> 00:05:53.496 this runs in your family or you got

NOTE Confidence: 0.717994452

00:05:53.496 --> 00:05:55.710 this because you work around nuclear

NOTE Confidence: 0.717994452

00:05:55.710 --> 00:05:57.840 material or something like that.

NOTE Confidence: 0.717994452

00:05:57.840 --> 00:05:59.760 But that's not really the case with Ewings.

NOTE Confidence: 0.938704706666667

00:06:00.080 --> 00:06:02.516 And. And so Julia, you know,

NOTE Confidence: 0.938704706666667

00:06:02.520 --> 00:06:04.116 when you were telling your story,

NOTE Confidence: 0.938704706666667

00:06:04.120 --> 00:06:05.660 you had mentioned that

NOTE Confidence: 0.938704706666667

00:06:05.660 --> 00:06:07.200 this started with pain.

NOTE Confidence: 0.938704706666667

00:06:07.200 --> 00:06:09.120 Can you tell us a little bit more?

NOTE Confidence: 0.938704706666667

00:06:09.120 --> 00:06:12.280 I mean, certainly when you're 30 years old,

NOTE Confidence: 0.938704706666667

00:06:12.280 --> 00:06:15.880 you know, you're, you're APA student,

NOTE Confidence: 0.938704706666667

00:06:15.880 --> 00:06:18.239 I can't imagine that you were thinking,

NOTE Confidence: 0.938704706666667

00:06:18.240 --> 00:06:21.237 you know, if I have some sort of pain,

NOTE Confidence: 0.938704706666667

00:06:21.240 --> 00:06:23.160 this is going to be a Ewing sarcoma.

NOTE Confidence: 0.938704706666667

00:06:23.160 --> 00:06:25.088 So can you tell us a little bit

NOTE Confidence: 0.938704706666667

00:06:25.088 --> 00:06:26.717 more about what was this pain,

NOTE Confidence: 0.938704706666667

00:06:26.720 --> 00:06:28.911 where was this pain and and what

NOTE Confidence: 0.938704706666667

00:06:28.911 --> 00:06:30.692 actually brought you to the doctor

NOTE Confidence: 0.938704706666667

00:06:30.692 --> 00:06:32.512 cause many of us I would think

NOTE Confidence: 0.938704706666667

00:06:32.571 --> 00:06:34.636 would shrug that kind of stuff off.

NOTE Confidence: 0.795902123

00:06:35.360 --> 00:06:39.196 Absolutely. I I I second what doctor

NOTE Confidence: 0.795902123

00:06:39.196 --> 00:06:41.490 Deshpande says about not learning

NOTE Confidence: 0.795902123

00:06:41.490 --> 00:06:43.440 much about ewings in PA school.

NOTE Confidence: 0.795902123

00:06:43.440 --> 00:06:45.012 I don't, I don't even know

NOTE Confidence: 0.795902123

00:06:45.012 --> 00:06:46.680 if we learned of about it.

NOTE Confidence: 0.795902123

00:06:46.680 --> 00:06:49.038 So it wasn't on my mind.

NOTE Confidence: 0.795902123

00:06:49.040 --> 00:06:53.676 But I so at at 22 I I was not it

NOTE Confidence: 0.795902123

00:06:53.676 --> 00:06:55.710 was definitely not on my mind

NOTE Confidence: 0.795902123

00:06:55.794 --> 00:06:58.068 when I was having some pretty

NOTE Confidence: 0.795902123

00:06:58.068 --> 00:07:00.480 severe pain in my right hip.

NOTE Confidence: 0.795902123

00:07:00.480 --> 00:07:03.408 But it presented as a sciatica

NOTE Confidence: 0.795902123

00:07:03.408 --> 00:07:04.872 type of presentation.

NOTE Confidence: 0.795902123

00:07:04.880 --> 00:07:07.148 So some numbness kind of down

NOTE Confidence: 0.795902123

00:07:07.148 --> 00:07:10.159 my leg and in my glute muscle.

00:07:10.160 --> 00:07:12.720 And so that that it started kind of

00:07:12.720 --> 00:07:15.078 vague and it would be on and off.

00:07:15.080 --> 00:07:16.958 And so I started physical therapy,

00:07:16.960 --> 00:07:20.320 which is often the the case.

00:07:20.320 --> 00:07:23.023 This kind of typical course of,

00:07:23.023 --> 00:07:25.081 I think, I'm sure Doctor Spondee

00:07:25.081 --> 00:07:26.759 would agree that you know,

00:07:26.760 --> 00:07:28.280 usually they see, you know,

00:07:28.280 --> 00:07:30.352 you go to physical therapy and you kind

00:07:30.352 --> 00:07:33.000 of do exercises and see if it gets better.

00:07:33.000 --> 00:07:35.385 And it did get better for a bit and

00:07:35.385 --> 00:07:37.519 then it got worse again and then

00:07:37.519 --> 00:07:40.083 it got better and it got worse and

00:07:40.083 --> 00:07:42.033 that that was about nine months.

00:07:42.040 --> 00:07:45.982 And they saw orthopedic an orthopedist

00:07:45.982 --> 00:07:50.760 who had diagnosed piriformis syndrome

NOTE Confidence: 0.795902123

00:07:50.760 --> 00:07:54.768 like which is again you know something

NOTE Confidence: 0.795902123

00:07:54.768 --> 00:07:57.268 that would would be relieved with

NOTE Confidence: 0.795902123

00:07:57.268 --> 00:07:59.353 with stretching and and exercises.

NOTE Confidence: 0.795902123

00:07:59.360 --> 00:08:00.878 So I would start to do

NOTE Confidence: 0.795902123

00:08:00.878 --> 00:08:02.440 those and it didn't improve.

NOTE Confidence: 0.795902123

00:08:02.440 --> 00:08:07.126 So actually a rheumatologist he he

NOTE Confidence: 0.795902123

00:08:07.126 --> 00:08:10.378 was the one who had done a a very

NOTE Confidence: 0.795902123

00:08:10.378 --> 00:08:12.772 thorough exam and ordered the the

NOTE Confidence: 0.795902123

00:08:12.772 --> 00:08:15.051 first image and that was nine months

NOTE Confidence: 0.795902123

00:08:15.051 --> 00:08:17.396 after the the beginning of my pain.

NOTE Confidence: 0.795902123

00:08:17.400 --> 00:08:19.680 So I finally got an image,

NOTE Confidence: 0.795902123

00:08:19.680 --> 00:08:22.392 and the image showed the tumor

NOTE Confidence: 0.795902123

00:08:22.392 --> 00:08:25.780 in my right pelvis and at the I

NOTE Confidence: 0.795902123

00:08:25.780 --> 00:08:27.360 was metastatic A diagnosis.

NOTE Confidence: 0.795902123

00:08:27.360 --> 00:08:31.959 So it had spread to my lungs at that time,

NOTE Confidence: 0.795902123

00:08:31.959 --> 00:08:34.197 likely because of the length of

NOTE Confidence: 0.795902123

00:08:34.197 --> 00:08:38.320 time it took to to to to find it.

NOTE Confidence: 0.795902123

00:08:38.320 --> 00:08:39.648 So again,

NOTE Confidence: 0.795902123

00:08:39.648 --> 00:08:43.520 you know that vague type of pain

NOTE Confidence: 0.795902123

00:08:43.520 --> 00:08:45.704 could be many things, right?

NOTE Confidence: 0.795902123

00:08:45.704 --> 00:08:48.190 We think of a we don't think of the

NOTE Confidence: 0.795902123

00:08:48.190 --> 00:08:50.160 zebra you know all the time And so

NOTE Confidence: 0.814433103846154

00:08:52.440 --> 00:08:55.950 I I think that there's it's I look back

NOTE Confidence: 0.814433103846154

00:08:55.950 --> 00:09:00.178 on that time and and I I have of course

NOTE Confidence: 0.814433103846154

00:09:00.178 --> 00:09:02.776 feelings about wishing I had pushed

NOTE Confidence: 0.814433103846154

00:09:02.776 --> 00:09:05.888 for an image but it it wasn't really

NOTE Confidence: 0.814433103846154

00:09:05.888 --> 00:09:08.520 standard of care to do that. Yeah.

NOTE Confidence: 0.90784579

00:09:09.040 --> 00:09:11.440 So, Hari, can we pick up on this

NOTE Confidence: 0.90784579

00:09:11.440 --> 00:09:13.852 conversation in, in the sense that,

NOTE Confidence: 0.90784579

00:09:13.852 --> 00:09:15.496 you know, understandably, right.

NOTE Confidence: 0.90784579

00:09:15.496 --> 00:09:18.072 You would think common things being common,

NOTE Confidence: 0.90784579

00:09:18.080 --> 00:09:19.784 this is going to be, you know,

NOTE Confidence: 0.90784579

00:09:19.784 --> 00:09:21.176 a muscle pull is going to

NOTE Confidence: 0.90784579

00:09:21.176 --> 00:09:22.120 be piriformis syndrome,

NOTE Confidence: 0.90784579

00:09:22.120 --> 00:09:23.720 it may even be sciatica.

NOTE Confidence: 0.90784579

00:09:23.720 --> 00:09:26.760 You should do physical therapy.

NOTE Confidence: 0.90784579

00:09:26.760 --> 00:09:30.288 Is there often a delay in that diagnosis

NOTE Confidence: 0.90784579

00:09:30.288 --> 00:09:34.118 and how is the diagnosis actually made?

NOTE Confidence: 0.942968595

00:09:35.320 --> 00:09:37.582 Yeah. No, I think both you

NOTE Confidence: 0.942968595

00:09:37.582 --> 00:09:39.639 and Julia just picked up on,

NOTE Confidence: 0.942968595

00:09:39.640 --> 00:09:41.548 on the main problem with this

NOTE Confidence: 0.942968595

00:09:41.548 --> 00:09:43.480 presentation is that it is a very,

NOTE Confidence: 0.942968595

00:09:43.480 --> 00:09:44.683 very rare disease.

NOTE Confidence: 0.942968595

00:09:44.683 --> 00:09:48.300 And so when you see people who don't see

NOTE Confidence: 0.942968595

00:09:48.300 --> 00:09:51.680 this every day or may not ever see this,

NOTE Confidence: 0.942968595

00:09:51.680 --> 00:09:54.515 then it's not something they're thinking of.

NOTE Confidence: 0.942968595

00:09:54.520 --> 00:09:59.925 And that's why I it's important really

NOTE Confidence: 0.942968595

00:09:59.925 --> 00:10:01.920 in in all of medicine if something

NOTE Confidence: 0.942968595

00:10:01.920 --> 00:10:03.726 doesn't get better in a time frame

NOTE Confidence: 0.942968595

00:10:03.726 --> 00:10:05.560 that you expect it to get better,

NOTE Confidence: 0.942968595

00:10:05.560 --> 00:10:08.912 it is worth taking a look to see

NOTE Confidence: 0.942968595

00:10:08.912 --> 00:10:11.239 whether it's something else.

NOTE Confidence: 0.942968595

00:10:11.240 --> 00:10:13.682 But that's a very general statement

NOTE Confidence: 0.942968595

00:10:13.682 --> 00:10:16.828 and that time frame is it can be

NOTE Confidence: 0.942968595

00:10:16.828 --> 00:10:18.633 a very long time unfortunately.

NOTE Confidence: 0.942968595

00:10:18.640 --> 00:10:22.608 But if you are thinking about either

NOTE Confidence: 0.942968595

00:10:22.608 --> 00:10:25.536 Ewing sarcoma or another what we

NOTE Confidence: 0.942968595

00:10:25.536 --> 00:10:28.654 call a primary cancer of the bone

NOTE Confidence: 0.942968595

00:10:28.654 --> 00:10:31.800 or even any abnormality in the bone,

NOTE Confidence: 0.942968595

00:10:31.800 --> 00:10:34.560 the first thing that we really want to

NOTE Confidence: 0.942968595

00:10:34.560 --> 00:10:38.157 do to make a diagnosis is to get a biopsy.

NOTE Confidence: 0.942968595

00:10:38.160 --> 00:10:40.120 So, and this can be done in

NOTE Confidence: 0.942968595

00:10:40.120 --> 00:10:40.960 many different ways,

NOTE Confidence: 0.942968595

00:10:40.960 --> 00:10:44.936 but the most common is to somehow get

NOTE Confidence: 0.942968595

00:10:44.936 --> 00:10:48.016 a needle into the area of concern,

NOTE Confidence: 0.942968595

00:10:48.016 --> 00:10:50.800 get a small piece of tissue which

NOTE Confidence: 0.942968595

00:10:50.800 --> 00:10:53.386 our pathologists can then look over

NOTE Confidence: 0.942968595

00:10:53.386 --> 00:10:55.960 and hopefully make a diagnosis.

NOTE Confidence: 0.942968595

00:10:55.960 --> 00:11:01.150 The the problem with sarcomas in general

NOTE Confidence: 0.942968595

00:11:01.150 --> 00:11:04.360 is sometimes the if any surgery is

NOTE Confidence: 0.942968595

00:11:04.360 --> 00:11:07.400 going to be done after the biopsy,

NOTE Confidence: 0.942968595

00:11:07.400 --> 00:11:09.920 then they have to not just

NOTE Confidence: 0.942968595

00:11:09.920 --> 00:11:11.600 remove the lesion itself,

NOTE Confidence: 0.942968595

00:11:11.600 --> 00:11:15.440 but remove the entire biopsy tract.

NOTE Confidence: 0.942968595

00:11:15.440 --> 00:11:16.580 So in other words,

NOTE Confidence: 0.942968595

00:11:16.580 --> 00:11:18.966 if the needle goes into the skin and

NOTE Confidence: 0.942968595

00:11:18.966 --> 00:11:21.398 then through the muscle and to the bone,

NOTE Confidence: 0.942968595

00:11:21.400 --> 00:11:23.560 they have to reset that whole

NOTE Confidence: 0.942968595

00:11:23.560 --> 00:11:25.864 area that the needle went through

NOTE Confidence: 0.942968595

00:11:25.864 --> 00:11:28.240 if they're going to do surgery.

NOTE Confidence: 0.942968595

00:11:28.240 --> 00:11:32.076 And so we have a special radiology

NOTE Confidence: 0.942968595

00:11:32.076 --> 00:11:34.558 service which many tertiary centres

NOTE Confidence: 0.942968595

00:11:34.558 --> 00:11:36.653 have who are very experienced

NOTE Confidence: 0.942968595

00:11:36.653 --> 00:11:38.600 in doing these biopsies.

NOTE Confidence: 0.942968595

00:11:38.600 --> 00:11:41.314 And and that's what they will do to

NOTE Confidence: 0.942968595

00:11:41.314 --> 00:11:43.850 make sure they do it in the safest

NOTE Confidence: 0.942968595

00:11:43.937 --> 00:11:46.319 but also the best possible way

NOTE Confidence: 0.724269604285714

00:11:46.760 --> 00:11:48.302 presumably a,

NOTE Confidence: 0.724269604285714

00:11:48.302 --> 00:11:52.157 a bone biopsy doesn't tickle.

NOTE Confidence: 0.724269604285714

00:11:52.160 --> 00:11:54.600 Is that done under anaesthesia?

NOTE Confidence: 0.724269604285714

00:11:54.600 --> 00:11:56.735 I mean it, it sounds like it's

NOTE Confidence: 0.724269604285714

00:11:56.735 --> 00:11:57.968 certainly not something that

NOTE Confidence: 0.724269604285714

17

00:11:57.968 --> 00:11:59.516 you would do in the office.

NOTE Confidence: 0.724269604285714

00:11:59.520 --> 00:12:00.520 It depends what kind

NOTE Confidence: 0.818250453333333

00:12:00.520 --> 00:12:03.381 of bone biopsy. So in my earlier

NOTE Confidence: 0.818250453333333

00:12:03.381 --> 00:12:06.429 days I I used to see some hematology

NOTE Confidence: 0.818250453333333

00:12:06.429 --> 00:12:08.124 patients and a bone marrow

NOTE Confidence: 0.818250453333333

00:12:08.124 --> 00:12:10.560 biopsy can be done in the office.

NOTE Confidence: 0.818250453333333

00:12:10.560 --> 00:12:12.534 And I would say most of our

NOTE Confidence: 0.818250453333333

00:12:12.534 --> 00:12:14.519 biopsies are done as an outpatient.

NOTE Confidence: 0.818250453333333

00:12:14.520 --> 00:12:17.358 For someone like Julia who we're

NOTE Confidence: 0.818250453333333

00:12:17.358 --> 00:12:19.760 looking at a particular area,

NOTE Confidence: 0.818250453333333

00:12:19.760 --> 00:12:23.144 then you do have to use a type of

NOTE Confidence: 0.818250453333333

00:12:23.144 --> 00:12:24.964 guided biopsy, in other words,

NOTE Confidence: 0.818250453333333

00:12:24.964 --> 00:12:27.552 some kind of imaging to guide the

NOTE Confidence: 0.818250453333333

00:12:27.552 --> 00:12:29.995 biopsy needle where it's going to go.

NOTE Confidence: 0.818250453333333

00:12:30.000 --> 00:12:31.356 And and I can't remember Julia,

NOTE Confidence: 0.818250453333333

00:12:31.360 --> 00:12:32.840 what they used with you.

NOTE Confidence: 0.818250453333333

00:12:32.840 --> 00:12:33.716 Do you remember,

NOTE Confidence: 0.818250453333333

00:12:33.716 --> 00:12:36.640 was it a CAT scan or an ultrasound?

NOTE Confidence: 0.818250453333333

00:12:36.640 --> 00:12:37.680 But that's usually the,

NOTE Confidence: 0.789538743333333

00:12:38.520 --> 00:12:40.716 I think it was on ultrasound.

NOTE Confidence: 0.933337298571429

00:12:40.800 --> 00:12:42.837 Yeah, that's typically how we do it.

NOTE Confidence: 0.918126430909091

00:12:43.440 --> 00:12:47.507 Julia had mentioned that her cancer was

NOTE Confidence: 0.918126430909091

00:12:47.507 --> 00:12:50.918 metastatic at the time of her diagnosis.

NOTE Confidence: 0.918126430909091

00:12:50.918 --> 00:12:53.234 So Julia where had it spread

NOTE Confidence: 0.918126430909091

00:12:53.234 --> 00:12:55.757 by the time it was diagnosed?

NOTE Confidence: 0.869567610769231

00:12:56.960 --> 00:12:59.042 At the time of diagnosis it

NOTE Confidence: 0.869567610769231

00:12:59.042 --> 00:13:01.440 had spread to my lungs.

NOTE Confidence: 0.869567610769231

00:13:01.440 --> 00:13:04.797 I had a couple lung nodules which

NOTE Confidence: 0.643971541666667

00:13:07.840 --> 00:13:09.556 doctor Deshpande will comment on,

NOTE Confidence: 0.643971541666667

00:13:09.560 --> 00:13:12.440 but I think is very commonplace

NOTE Confidence: 0.643971541666667

00:13:12.440 --> 00:13:14.960 that the sarcoma will spread to.

NOTE Confidence: 0.643971541666667

00:13:14.960 --> 00:13:17.452 So there weren't any other organs and

00:13:17.452 --> 00:13:20.620 I did have a bone marrow biopsy that

00:13:20.620 --> 00:13:22.984 he had mentioned which was negative.

00:13:22.984 --> 00:13:25.588 So the primary tumor had spread

00:13:25.588 --> 00:13:28.076 to the lungs only at that time.

00:13:28.520 --> 00:13:30.431 Well, we need to take a short

00:13:30.431 --> 00:13:32.320 break for a medical minute,

00:13:32.320 --> 00:13:34.210 but please stay tuned to learn

00:13:34.210 --> 00:13:35.986 more about Julia's story and

00:13:35.986 --> 00:13:38.278 Ewing Sarcoma with my guests Dr.

00:13:38.280 --> 00:13:40.040 Hari, Deshpande and Julia.

00:13:40.760 --> 00:13:43.058 Support for Yale Cancer Answers comes

00:13:43.058 --> 00:13:45.048 from Smilow Cancer Hospital where

00:13:45.048 --> 00:13:47.023 their Prostate and Urologic cancers

00:13:47.023 --> 00:13:49.538 program provides a multi specialty team

00:13:49.538 --> 00:13:51.718 dedicated to managing the diagnosis,

NOTE Confidence: 0.888534523333333

00:13:51.720 --> 00:13:54.720 evaluation and treatment of bladder cancer.

NOTE Confidence: 0.888534523333333

00:13:54.720 --> 00:13:59.786 Smilowcancerhospital.org. There are many

NOTE Confidence: 0.888534523333333

00:13:59.786 --> 00:14:02.180 obstacles to face when quitting smoking as

NOTE Confidence: 0.888534523333333

00:14:02.240 --> 00:14:04.760 smoking involves the potent drug nicotine.

NOTE Confidence: 0.888534523333333

00:14:04.760 --> 00:14:06.510 Quitting smoking is a very

NOTE Confidence: 0.888534523333333

00:14:06.510 --> 00:14:07.560 important lifestyle change,

NOTE Confidence: 0.888534523333333

00:14:07.560 --> 00:14:09.212 especially for patients undergoing

NOTE Confidence: 0.888534523333333

00:14:09.212 --> 00:14:12.191 cancer treatment as it's been shown to

NOTE Confidence: 0.888534523333333

00:14:12.191 --> 00:14:14.356 positively impact response to treatments,

NOTE Confidence: 0.888534523333333

00:14:14.360 --> 00:14:16.550 decrease the likelihood that patients

NOTE Confidence: 0.888534523333333

00:14:16.550 --> 00:14:18.302 will develop second malignancies

NOTE Confidence: 0.888534523333333

00:14:18.302 --> 00:14:20.397 and increase rates of survival.

NOTE Confidence: 0.888534523333333

00:14:20.400 --> 00:14:22.276 Tobacco treatment programs are

NOTE Confidence: 0.888534523333333

00:14:22.276 --> 00:14:24.621 currently being offered at federally

NOTE Confidence: 0.888534523333333

00:14:24.621 --> 00:14:25.917 designated comprehensive cancer

NOTE Confidence: 0.888534523333333

00:14:25.917 --> 00:14:28.191 centers such as Yale Cancer Center

NOTE Confidence: 0.888534523333333

00:14:28.191 --> 00:14:30.278 and Smilow Cancer Hospital.

NOTE Confidence: 0.888534523333333

00:14:30.280 --> 00:14:32.360 All treatment components are evidence

NOTE Confidence: 0.888534523333333

00:14:32.360 --> 00:14:35.229 based and patients are treated with FDA

NOTE Confidence: 0.888534523333333

00:14:35.229 --> 00:14:37.395 approved first line medications as well

NOTE Confidence: 0.888534523333333

00:14:37.395 --> 00:14:39.782 as smoking cessation counseling that

NOTE Confidence: 0.888534523333333

00:14:39.782 --> 00:14:41.914 stresses appropriate coping skills.

NOTE Confidence: 0.888534523333333

00:14:41.920 --> 00:14:44.288 More information is available

NOTE Confidence: 0.888534523333333

00:14:44.288 --> 00:14:45.525 at yalecancercenter.org.

NOTE Confidence: 0.888534523333333

00:14:45.525 --> 00:14:49.395 You're listening to Connecticut Public Radio.

NOTE Confidence: 0.888534523333333

00:14:49.400 --> 00:14:49.840 Welcome

NOTE Confidence: 0.92122326

00:14:49.840 --> 00:14:52.240 back to Yale Cancer Answers.

NOTE Confidence: 0.92122326

00:14:52.240 --> 00:14:53.880 This is Doctor Anees Chagpar,

NOTE Confidence: 0.92122326

00:14:53.880 --> 00:14:56.260 and I'm joined tonight by my guests

NOTE Confidence: 0.92122326

00:14:56.260 --> 00:14:58.240 Doctor Hari Deshpande and Julia.

NOTE Confidence: 0.92122326

00:14:58.240 --> 00:15:00.553 Now we're talking about Julia's

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NOTE Confidence: 0.92122326

00:15:00.553 --> 00:15:02.518 cancer journey with Ewing Sarcoma.

NOTE Confidence: 0.92122326

00:15:02.520 --> 00:15:04.320 And right before the break,

NOTE Confidence: 0.92122326

00:15:04.320 --> 00:15:05.968 Julia was mentioning that

NOTE Confidence: 0.92122326

00:15:05.968 --> 00:15:08.440 her pain was in her hip.

NOTE Confidence: 0.92122326

00:15:08.440 --> 00:15:10.558 They thought it might be sciatica,

NOTE Confidence: 0.92122326

00:15:10.560 --> 00:15:12.864 might be piriformis syndrome.

NOTE Confidence: 0.92122326

00:15:12.864 --> 00:15:14.262 Ultimately, A rheumatologist

NOTE Confidence: 0.92122326

00:15:14.262 --> 00:15:16.317 sent her for some imaging.

NOTE Confidence: 0.92122326

00:15:16.320 --> 00:15:18.672 She had a biopsy and ultimately

NOTE Confidence: 0.92122326

00:15:18.672 --> 00:15:20.880 was diagnosed with Ewing sarcoma.

NOTE Confidence: 0.92122326

00:15:20.880 --> 00:15:23.554 But by the time she was diagnosed,

NOTE Confidence: 0.92122326

00:15:23.560 --> 00:15:26.038 it had already spread to her lungs.

NOTE Confidence: 0.92122326

00:15:26.040 --> 00:15:28.674 So Hari, is that common that

NOTE Confidence: 0.92122326

00:15:28.674 --> 00:15:32.096 at the time of diagnosis most

NOTE Confidence: 0.92122326

00:15:32.096 --> 00:15:34.959 patients are already metastatic?

NOTE Confidence: 0.910442766666667

00:15:36.640 --> 00:15:37.798 You know that's a good question.

NOTE Confidence: 0.910442766666667

00:15:37.800 --> 00:15:40.236 I don't know the exact numbers.

NOTE Confidence: 0.910442766666667

00:15:40.240 --> 00:15:43.416 We do see patients who it's

NOTE Confidence: 0.910442766666667

00:15:43.416 --> 00:15:44.600 what we call localised.

NOTE Confidence: 0.910442766666667

00:15:44.600 --> 00:15:46.640 So it hasn't spread anywhere.

NOTE Confidence: 0.910442766666667

00:15:46.640 --> 00:15:48.474 But if it is going to spread,

NOTE Confidence: 0.910442766666667

00:15:48.480 --> 00:15:51.196 then the first place it usually spreads

NOTE Confidence: 0.910442766666667

00:15:51.196 --> 00:15:55.272 to is the lung, just as Julia says.

NOTE Confidence: 0.910442766666667

00:15:55.272 --> 00:15:57.512 And with bone sarcomas,

NOTE Confidence: 0.910442766666667

00:15:57.512 --> 00:16:00.232 we actually have different stages

NOTE Confidence: 0.910442766666667

00:16:00.232 --> 00:16:02.451 that you people listening have

NOTE Confidence: 0.910442766666667

00:16:02.451 --> 00:16:04.713 probably heard of stages of cancer.

NOTE Confidence: 0.910442766666667

00:16:04.720 --> 00:16:09.970 And with sarcomas, we have a stage

NOTE Confidence: 0.910442766666667

00:16:09.970 --> 00:16:11.956 4 if it's spread to the lungs,

NOTE Confidence: 0.910442766666667

00:16:11.960 --> 00:16:14.354 but it's 4A if it's spread to the lungs,

NOTE Confidence: 0.910442766666667

00:16:14.360 --> 00:16:17.920 whereas it's 4B if it spreads somewhere else.

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NOTE Confidence: 0.910442766666667

00:16:17.920 --> 00:16:19.565 And the reason we do that is

NOTE Confidence: 0.910442766666667

00:16:19.565 --> 00:16:21.480 even if it's spread to the lungs,

NOTE Confidence: 0.910442766666667

00:16:21.480 --> 00:16:24.558 we still treat very, very aggressively.

NOTE Confidence: 0.910442766666667

00:16:24.560 --> 00:16:25.835 As Julia said,

NOTE Confidence: 0.910442766666667

00:16:25.835 --> 00:16:28.810 she got over a year of chemotherapy

NOTE Confidence: 0.910442766666667

00:16:28.895 --> 00:16:31.360 and other treatments as well.

NOTE Confidence: 0.910442766666667

00:16:31.360 --> 00:16:34.600 And that's because we know that people like

NOTE Confidence: 0.910442766666667

00:16:34.600 --> 00:16:37.919 her can get treatment and do well for years.

NOTE Confidence: 0.910442766666667

00:16:37.920 --> 00:16:40.194 So that's it's not like other

NOTE Confidence: 0.910442766666667

00:16:40.194 --> 00:16:42.644 cancers where if it has spread

NOTE Confidence: 0.910442766666667

00:16:42.644 --> 00:16:45.200 to the lungs from somewhere else,

NOTE Confidence: 0.910442766666667

00:16:45.200 --> 00:16:48.693 then we may be scaling back on

NOTE Confidence: 0.910442766666667

00:16:48.693 --> 00:16:50.560 treatments because we're not

NOTE Confidence: 0.910442766666667

00:16:50.560 --> 00:16:52.666 sure how well they'll do with

NOTE Confidence: 0.910442766666667

00:16:52.666 --> 00:16:53.719 very aggressive treatments.

NOTE Confidence: 0.92065238375

00:16:54.080 --> 00:16:55.920 Yeah. And so, Julia,

NOTE Confidence: 0.92065238375

00:16:55.920 --> 00:16:59.691 I can only imagine what it must have

NOTE Confidence: 0.92065238375

00:16:59.691 --> 00:17:03.965 felt like being 22 in PA school and being

NOTE Confidence: 0.92065238375

00:17:03.965 --> 00:17:07.280 told that you had metastatic sarcoma.

NOTE Confidence: 0.92065238375

00:17:07.280 --> 00:17:09.457 Can you talk a little bit about

NOTE Confidence: 0.92065238375

00:17:09.457 --> 00:17:12.199 kind of how you felt at that moment?

NOTE Confidence: 0.92065238375

00:17:12.200 --> 00:17:15.360 I mean, was this despondent?

NOTE Confidence: 0.92065238375

00:17:15.360 --> 00:17:16.680 Was it optimistic?

NOTE Confidence: 0.92065238375

00:17:16.680 --> 00:17:18.880 And I'm going to fight.

NOTE Confidence: 0.92065238375

00:17:18.880 --> 00:17:20.752 What was your emotional

NOTE Confidence: 0.92065238375

00:17:20.752 --> 00:17:23.000 response to this diagnosis?

NOTE Confidence: 0.8010929075

00:17:23.720 --> 00:17:25.120 Yeah, I, you know,

NOTE Confidence: 0.8010929075

00:17:25.120 --> 00:17:28.632 I I think I I oscillated back and

NOTE Confidence: 0.8010929075

00:17:28.632 --> 00:17:31.272 forth between many different emotions.

NOTE Confidence: 0.8010929075

00:17:31.280 --> 00:17:34.246 Anger is not a very common or

NOTE Confidence: 0.8010929075

00:17:34.246 --> 00:17:36.276 a familiar emotion for me.

NOTE Confidence: 0.8010929075

00:17:36.280 --> 00:17:40.800 So I would say probably sadness and fear.

NOTE Confidence: 0.8010929075

00:17:40.800 --> 00:17:45.679 And I have a close friend who's

NOTE Confidence: 0.8010929075

00:17:45.680 --> 00:17:49.080 a childhood cancer survivor who

NOTE Confidence: 0.8010929075

00:17:49.080 --> 00:17:52.080 really stepped up for me and

NOTE Confidence: 0.8010929075

00:17:52.080 --> 00:17:54.720 was kind of my main support.

NOTE Confidence: 0.8010929075

00:17:54.720 --> 00:17:57.720 And it was enormously helpful.

NOTE Confidence: 0.8010929075

00:17:57.720 --> 00:18:01.190 I had, I had a a tribe, you know,

NOTE Confidence: 0.8010929075

00:18:01.190 --> 00:18:02.840 for lack of a better word.

NOTE Confidence: 0.8010929075

00:18:02.840 --> 00:18:04.720 And these and people, they,

NOTE Confidence: 0.8010929075

00:18:04.720 --> 00:18:07.944 my girlfriends came together and when my

NOTE Confidence: 0.8010929075

00:18:07.944 --> 00:18:11.256 blood counts were OK and safe to go places,

NOTE Confidence: 0.8010929075

00:18:11.256 --> 00:18:14.280 they would throw a head wrap on like me.

NOTE Confidence: 0.8010929075

00:18:14.280 --> 00:18:16.555 And we would all go somewhere safe,

NOTE Confidence: 0.8010929075

00:18:16.560 --> 00:18:16.940 you know,

NOTE Confidence: 0.8010929075

00:18:16.940 --> 00:18:18.080 go to a restaurant or something.

NOTE Confidence: 0.8010929075

00:18:18.080 --> 00:18:20.519 And we all would would have had wraps on.

NOTE Confidence: 0.8010929075

00:18:20.520 --> 00:18:23.236 So I didn't have to feel different.

NOTE Confidence: 0.8010929075

00:18:23.240 --> 00:18:25.850 And it was those little things

NOTE Confidence: 0.8010929075

00:18:25.850 --> 00:18:28.770 that made an enormous difference in

NOTE Confidence: 0.8010929075

00:18:28.770 --> 00:18:30.520 that year and a half of treatment.

NOTE Confidence: 0.8010929075

00:18:30.520 --> 00:18:35.344 And I had to relocate for some

NOTE Confidence: 0.8010929075

00:18:35.344 --> 00:18:37.840 radiation up to Boston.

NOTE Confidence: 0.8010929075

00:18:37.840 --> 00:18:40.306 And that was a difficult part of

NOTE Confidence: 0.8010929075

00:18:40.306 --> 00:18:41.558 the journey for me,

NOTE Confidence: 0.8010929075

00:18:41.560 --> 00:18:45.640 knowing that I was leaving my support system,

NOTE Confidence: 0.8010929075

00:18:45.640 --> 00:18:48.228 my family and my friends and they

NOTE Confidence: 0.8010929075

00:18:48.228 --> 00:18:50.664 travelled at least twice a month up

NOTE Confidence: 0.8010929075

00:18:50.664 --> 00:18:52.914 there to do the same thing and you know,

NOTE Confidence: 0.8010929075

00:18:52.920 --> 00:18:55.200 bring bring my spirits up.

NOTE Confidence: 0.8010929075

00:18:55.200 --> 00:18:59.358 And and I do remember specifically just

NOTE Confidence: 0.8010929075

00:18:59.360 --> 00:19:05.160 feeling that love kind of, it didn't make,

NOTE Confidence: 0.8010929075

00:19:05.160 --> 00:19:06.558 didn't make the fear go away,

NOTE Confidence: 0.8010929075

00:19:06.560 --> 00:19:10.120 but it felt a whole lot less lonely.

NOTE Confidence: 0.8010929075

00:19:10.120 --> 00:19:13.599 And so I'm forever grateful for the

NOTE Confidence: 0.8010929075

00:19:13.599 --> 00:19:17.040 time and effort that that my tribe,

NOTE Confidence: 0.8010929075

00:19:17.040 --> 00:19:17.816 you know,

NOTE Confidence: 0.8010929075

00:19:17.816 --> 00:19:20.372 put in for me and I wouldn't be

NOTE Confidence: 0.8010929075

00:19:20.372 --> 00:19:21.596 where I am today without them.

NOTE Confidence: 0.8010929075

00:19:21.600 --> 00:19:23.040 So yeah,

NOTE Confidence: 0.946267241666667

00:19:23.040 --> 00:19:24.876 I think, I think we all,

NOTE Confidence: 0.946267241666667

00:19:24.880 --> 00:19:26.440 we all need a tribe,

NOTE Confidence: 0.946267241666667

00:19:26.440 --> 00:19:28.265 whether we're going through cancer

NOTE Confidence: 0.946267241666667

00:19:28.265 --> 00:19:30.799 or or anything else in our lives.

NOTE Confidence: 0.946267241666667

00:19:30.800 --> 00:19:32.352 But particularly when you're

NOTE Confidence: 0.946267241666667

00:19:32.352 --> 00:19:34.680 facing that kind of a diagnosis,

NOTE Confidence: 0.946267241666667

00:19:34.680 --> 00:19:38.320 that's scary. And you know,

NOTE Confidence: 0.946267241666667

00:19:38.320 --> 00:19:40.600 just knowing that you've got people

NOTE Confidence: 0.946267241666667

00:19:40.600 --> 00:19:43.428 around you who love you and care for you

NOTE Confidence: 0.946267241666667

00:19:43.428 --> 00:19:46.227 and we'll go through that with you or at

NOTE Confidence: 0.946267241666667

00:19:46.227 --> 00:19:49.400 least stand by you as you go through it,

NOTE Confidence: 0.946267241666667

00:19:49.400 --> 00:19:52.123 so that you're not alone is so important.

NOTE Confidence: 0.946267241666667

00:19:52.123 --> 00:19:54.289 Hari, can you talk a little

NOTE Confidence: 0.946267241666667

00:19:54.289 --> 00:19:56.760 bit about the treatment itself?

NOTE Confidence: 0.946267241666667

00:19:56.760 --> 00:19:59.120 I mean, on this show we talk a lot about

NOTE Confidence: 0.946267241666667

00:19:59.187 --> 00:20:01.199 different modalities of treatment,

NOTE Confidence: 0.946267241666667

00:20:01.200 --> 00:20:02.808 whether it's surgery,

NOTE Confidence: 0.946267241666667

00:20:02.808 --> 00:20:03.880 radiation, chemotherapy,

NOTE Confidence: 0.946267241666667

00:20:03.880 --> 00:20:08.840 immunotherapy and we talk about

NOTE Confidence: 0.946267241666667

00:20:08.840 --> 00:20:10.700 this multidisciplinary kind

NOTE Confidence: 0.946267241666667

00:20:10.700 --> 00:20:13.120 of approach to to cancers.

NOTE Confidence: 0.946267241666667

00:20:13.120 --> 00:20:16.411 Can you can you talk a little

NOTE Confidence: 0.946267241666667

00:20:16.411 --> 00:20:19.818 bit about how sarcomas and Ewing

NOTE Confidence: 0.946267241666667

00:20:19.818 --> 00:20:22.480 sarcoma in particular are treated?

NOTE Confidence: 0.812541674444444

00:20:23.480 --> 00:20:26.384 Yes. So I'm glad you mentioned

NOTE Confidence: 0.812541674444444

00:20:26.384 --> 00:20:27.836 the multidisciplinary approach.

NOTE Confidence: 0.812541674444444

00:20:27.840 --> 00:20:32.406 We have a tumour board which meets

NOTE Confidence: 0.812541674444444

00:20:32.406 --> 00:20:37.920 once a week and any patients who we see

NOTE Confidence: 0.812541674444444

00:20:37.920 --> 00:20:40.664 either if they're seen by the surgeon

NOTE Confidence: 0.812541674444444

00:20:40.664 --> 00:20:44.112 or by myself or by one of the radiation

NOTE Confidence: 0.812541674444444

00:20:44.112 --> 00:20:46.352 doctors presented at that meeting.

NOTE Confidence: 0.812541674444444

00:20:46.360 --> 00:20:49.045 And we come up with a treatment plan and

NOTE Confidence: 0.812541674444444

00:20:49.045 --> 00:20:50.760 that can involve just like you said,

NOTE Confidence: 0.812541674444444

00:20:50.760 --> 00:20:53.022 either surgery, radiation or some kind

NOTE Confidence: 0.812541674444444

00:20:53.022 --> 00:20:55.959 of what I call systemic treatment.

NOTE Confidence: 0.812541674444444

00:20:55.960 --> 00:20:59.590 So that could be chemotherapy or

NOTE Confidence: 0.812541674444444

00:20:59.590 --> 00:21:01.316 immunotherapy or a combination

NOTE Confidence: 0.812541674444444

00:21:01.316 --> 00:21:03.920 of two or even three of them.

NOTE Confidence: 0.812541674444444

00:21:03.920 --> 00:21:05.620 And for Ewing Sarcoma,

NOTE Confidence: 0.812541674444444

00:21:05.620 --> 00:21:09.076 I think you have to go back to

NOTE Confidence: 0.812541674444444

00:21:09.076 --> 00:21:12.840 the early 1900s when it was first

NOTE Confidence: 0.812541674444444

00:21:12.840 --> 00:21:15.900 first discovered and named.

NOTE Confidence: 0.812541674444444

00:21:15.900 --> 00:21:20.288 And at that time there were very little

NOTE Confidence: 0.812541674444444

00:21:20.288 --> 00:21:22.280 treatments for it and most people,

NOTE Confidence: 0.812541674444444

00:21:22.280 --> 00:21:24.800 even if it was localized in one area,

NOTE Confidence: 0.812541674444444

00:21:24.800 --> 00:21:27.516 did very, very badly with the disease.

NOTE Confidence: 0.812541674444444

00:21:27.520 --> 00:21:30.784 But then in the 1960s and 70s when

NOTE Confidence: 0.812541674444444

00:21:30.784 --> 00:21:32.960 chemotherapy was being developed,

NOTE Confidence: 0.812541674444444

00:21:32.960 --> 00:21:35.672 they started using it on children

NOTE Confidence: 0.812541674444444

00:21:35.672 --> 00:21:38.200 with different kinds of cancers.

NOTE Confidence: 0.812541674444444

00:21:38.200 --> 00:21:42.698 And Ewing's sarcoma had an A really

NOTE Confidence: 0.812541674444444

00:21:42.698 --> 00:21:45.752 very good response to the initial

NOTE Confidence: 0.812541674444444

00:21:45.752 --> 00:21:47.710 chemotherapy regimens and eventually

NOTE Confidence: 0.812541674444444

00:21:47.710 --> 00:21:50.652 they came up with a treatment that

NOTE Confidence: 0.812541674444444

00:21:50.652 --> 00:21:53.130 was a combination of three different

NOTE Confidence: 0.812541674444444

00:21:53.206 --> 00:21:55.058 chemotherapies all given together

NOTE Confidence: 0.812541674444444

00:21:55.058 --> 00:21:57.836 given every two or three weeks.

NOTE Confidence: 0.812541674444444

00:21:57.840 --> 00:21:59.360 And for the first time,

NOTE Confidence: 0.812541674444444

00:21:59.360 --> 00:22:01.838 people were surviving with Ewing sarcoma.

NOTE Confidence: 0.812541674444444

00:22:01.840 --> 00:22:04.000 It was not seen before.

NOTE Confidence: 0.812541674444444

00:22:04.000 --> 00:22:07.048 And even the people who had a relapse

NOTE Confidence: 0.812541674444444

00:22:07.048 --> 00:22:09.064 after that had a good response

NOTE Confidence: 0.812541674444444

00:22:09.064 --> 00:22:11.200 to a second line treatment.

NOTE Confidence: 0.812541674444444

00:22:11.200 --> 00:22:14.301 And so many people make fun of

NOTE Confidence: 0.812541674444444

00:22:14.301 --> 00:22:16.393 oncologists because they say, well,

NOTE Confidence: 0.812541674444444

00:22:16.393 --> 00:22:18.158 if one medicine doesn't work,

NOTE Confidence: 0.812541674444444

00:22:18.160 --> 00:22:19.720 how about we add another one to it?

NOTE Confidence: 0.812541674444444

00:22:19.720 --> 00:22:21.478 And that's exactly what they did.

NOTE Confidence: 0.812541674444444

00:22:21.480 --> 00:22:23.676 So they gave the first regimen,

NOTE Confidence: 0.812541674444444

00:22:23.680 --> 00:22:25.885 waited 3 weeks and then gave the

NOTE Confidence: 0.812541674444444

00:22:25.885 --> 00:22:27.804 second round treatment and then went

NOTE Confidence: 0.812541674444444

00:22:27.804 --> 00:22:29.634 back to the first round treatment.

NOTE Confidence: 0.812541674444444

00:22:29.640 --> 00:22:32.754 So it's an alternating chemotherapy of

NOTE Confidence: 0.812541674444444

00:22:32.754 --> 00:22:36.200 really very high doses of medications.

NOTE Confidence: 0.812541674444444

00:22:36.200 --> 00:22:37.832 But as a result,

NOTE Confidence: 0.812541674444444

00:22:37.832 --> 00:22:41.239 the survival rates went way up from very,

NOTE Confidence: 0.812541674444444

00:22:41.240 --> 00:22:44.120 very low numbers to many people

NOTE Confidence: 0.812541674444444

00:22:44.120 --> 00:22:46.520 with localised disease doing very,

NOTE Confidence: 0.812541674444444

00:22:46.520 --> 00:22:49.796 very well with the with the condition.

NOTE Confidence: 0.812541674444444

00:22:49.800 --> 00:22:52.558 The downside is it's a long treatment,

NOTE Confidence: 0.812541674444444

00:22:52.560 --> 00:22:55.465 so 48 weeks of chemotherapy is very

NOTE Confidence: 0.812541674444444

00:22:55.465 --> 00:22:58.200 daunting when you're talking to someone,

NOTE Confidence: 0.812541674444444

00:22:58.200 --> 00:22:59.439 especially young people,

NOTE Confidence: 0.812541674444444

00:22:59.439 --> 00:23:01.917 about what they have to face.

NOTE Confidence: 0.812541674444444

00:23:01.920 --> 00:23:07.197 But after that, we often in in between,

34

NOTE Confidence: 0.812541674444444

00:23:07.200 --> 00:23:09.360 I should say in the middle of that treatment,

NOTE Confidence: 0.812541674444444

00:23:09.360 --> 00:23:11.796 we often do either surgery or

NOTE Confidence: 0.812541674444444

00:23:11.796 --> 00:23:14.813 radiation or both to try and control

NOTE Confidence: 0.812541674444444

00:23:14.813 --> 00:23:16.993 the place where it started.

NOTE Confidence: 0.812541674444444

00:23:17.000 --> 00:23:19.410 And that's typically the treatment

NOTE Confidence: 0.812541674444444

00:23:19.410 --> 00:23:21.820 definitely for localized disease and

NOTE Confidence: 0.812541674444444

00:23:21.888 --> 00:23:24.396 often for metastatic disease as well.

NOTE Confidence: 0.954618995

00:23:24.880 --> 00:23:27.856 And so, Julia, it sounds like you started

NOTE Confidence: 0.954618995

00:23:27.856 --> 00:23:30.877 on this long journey of chemotherapy.

NOTE Confidence: 0.954618995

00:23:30.880 --> 00:23:32.596 I mean 48 weeks, my goodness,

NOTE Confidence: 0.954618995

00:23:32.600 --> 00:23:34.188 that's almost a year.

NOTE Confidence: 0.954618995

00:23:34.188 --> 00:23:37.138 And and you mentioned that you had

NOTE Confidence: 0.954618995

00:23:37.138 --> 00:23:39.558 to relocate for radiation therapy.

NOTE Confidence: 0.954618995

00:23:39.560 --> 00:23:41.456 Why? Why was that?

NOTE Confidence: 0.954618995

00:23:41.456 --> 00:23:44.278 Was it because the radiation that

NOTE Confidence: 0.954618995

00:23:44.278 --> 00:23:46.608 you required wasn't available where

NOTE Confidence: 0.954618995

00:23:46.608 --> 00:23:49.745 you were being treated or or is was

NOTE Confidence: 0.954618995

00:23:49.745 --> 00:23:51.635 it for a particular clinical trial?

NOTE Confidence: 0.954618995

00:23:51.640 --> 00:23:54.120 Can you tell us a little bit more about that?

NOTE Confidence: 0.954618995

00:23:54.120 --> 00:23:55.160 Yeah, absolutely.

NOTE Confidence: 0.847108545833333

00:23:55.160 --> 00:23:57.455 So surgery and radiation were

NOTE Confidence: 0.847108545833333

00:23:57.455 --> 00:24:00.479 both on the the table for me.

NOTE Confidence: 0.847108545833333

00:24:00.480 --> 00:24:03.875 However the surgery would be pretty morbid.

NOTE Confidence: 0.847108545833333

00:24:03.880 --> 00:24:07.569 So radiation was was was the the

NOTE Confidence: 0.847108545833333

00:24:07.569 --> 00:24:11.244 choice that we made and I relocated

NOTE Confidence: 0.847108545833333

00:24:11.244 --> 00:24:15.038 because of the location of the tumor.

NOTE Confidence: 0.847108545833333

00:24:15.040 --> 00:24:18.840 And they Boston has something

NOTE Confidence: 0.847108545833333

00:24:18.840 --> 00:24:21.880 called proton beam radiation,

NOTE Confidence: 0.847108545833333

00:24:21.880 --> 00:24:25.240 which is a certain type of radiation that

NOTE Confidence: 0.847108545833333

00:24:25.240 --> 00:24:28.484 can spare surrounding tissues of radiation.

NOTE Confidence: 0.847108545833333

00:24:28.484 --> 00:24:33.240 And given that it was in my pelvis,

NOTE Confidence: 0.847108545833333

00:24:33.240 --> 00:24:35.105 my ovaries are there and

NOTE Confidence: 0.847108545833333

00:24:35.105 --> 00:24:36.597 many other important organs.

NOTE Confidence: 0.847108545833333

00:24:36.600 --> 00:24:38.955 And so the radiation oncologist

NOTE Confidence: 0.847108545833333

00:24:38.955 --> 00:24:41.462 here at Yale had had said,

NOTE Confidence: 0.847108545833333

00:24:41.462 --> 00:24:43.639 you know, I think that this is,

NOTE Confidence: 0.847108545833333

00:24:43.640 --> 00:24:46.808 this is the best type of radiation for

NOTE Confidence: 0.847108545833333

00:24:46.808 --> 00:24:50.240 you and and referred me up to Boston.

NOTE Confidence: 0.847108545833333

00:24:50.240 --> 00:24:50.640 Yeah.

NOTE Confidence: 0.930507835555556

00:24:51.720 --> 00:24:54.018 And Hari, you know Julia had

NOTE Confidence: 0.930507835555556

00:24:54.018 --> 00:24:56.516 mentioned as she was telling her

NOTE Confidence: 0.930507835555556

00:24:56.516 --> 00:24:59.156 story that she had many relapses.

NOTE Confidence: 0.930507835555556

00:24:59.160 --> 00:25:03.152 Is that kind of classic for Ewing sarcoma

NOTE Confidence: 0.930507835555556

00:25:03.152 --> 00:25:06.460 that people will relapse and what are

NOTE Confidence: 0.930507835555556

00:25:06.460 --> 00:25:08.910 their options at that point are are

NOTE Confidence: 0.930507835555556

00:25:08.910 --> 00:25:11.640 there clinical trials that are ongoing?

NOTE Confidence: 0.903114341818182

00:25:12.880 --> 00:25:16.486 Unfortunately, the relapse rate is quite

NOTE Confidence: 0.903114341818182

00:25:16.486 --> 00:25:19.720 high for metastatic Ewing sarcoma.

NOTE Confidence: 0.903114341818182

00:25:19.720 --> 00:25:24.235 We do have other what we call

NOTE Confidence: 0.903114341818182

00:25:24.235 --> 00:25:26.640 salvage treatment options and

NOTE Confidence: 0.903114341818182

00:25:26.640 --> 00:25:29.436 Julia's had some of those already.

NOTE Confidence: 0.903114341818182

00:25:29.440 --> 00:25:30.960 As far as clinical trials,

NOTE Confidence: 0.903114341818182

00:25:30.960 --> 00:25:34.992 I know Julia was on one up in Boston.

NOTE Confidence: 0.903114341818182

00:25:35.000 --> 00:25:38.801 We did have one specifically for Ewing

NOTE Confidence: 0.903114341818182

00:25:38.801 --> 00:25:41.680 sarcoma probably about 10 years ago.

NOTE Confidence: 0.903114341818182

00:25:41.680 --> 00:25:45.199 It did not do very well in terms of

NOTE Confidence: 0.903114341818182

00:25:45.199 --> 00:25:48.796 the results were not very promising

NOTE Confidence: 0.903114341818182

00:25:48.800 --> 00:25:53.048 and I like to keep in touch with my

NOTE Confidence: 0.903114341818182

00:25:53.048 --> 00:25:55.240 colleagues from paediatric oncology.

NOTE Confidence: 0.903114341818182

00:25:55.240 --> 00:25:58.240 As Julia also said earlier,

NOTE Confidence: 0.903114341818182

00:25:58.240 --> 00:26:00.151 this is a disease that affects children

NOTE Confidence: 0.903114341818182

00:26:00.151 --> 00:26:01.920 a little bit more than adults.

00:26:01.920 --> 00:26:04.818 So most of the trials will include

00:26:04.818 --> 00:26:06.853 very young children and they'll

00:26:06.853 --> 00:26:09.352 have an upper age group of 30,

00:26:09.360 --> 00:26:12.288 sometimes up to 50 and I will be

00:26:12.288 --> 00:26:15.360 involved in some of the older patients.

00:26:15.360 --> 00:26:19.717 So at the time that Julie was diagnosed,

00:26:19.720 --> 00:26:22.198 we didn't have an available trial,

00:26:22.200 --> 00:26:26.200 but definitely when one opens,

00:26:26.200 --> 00:26:28.076 Julia will be first on my list.

00:26:30.720 --> 00:26:32.904 So, so Julia, it sounds like you went

00:26:32.904 --> 00:26:36.020 up to Boston, you had your radiation,

00:26:36.020 --> 00:26:39.286 you had more chemotherapy and and then

00:26:39.286 --> 00:26:42.030 it sounds like life was going along well

00:26:42.100 --> 00:26:44.760 and then you relapsed again and again.

00:26:44.760 --> 00:26:47.994 Tell us about what that was like,

00:26:48.000 --> 00:26:50.418 how those relapses were were found

NOTE Confidence: 0.879027789090909

00:26:50.418 --> 00:26:53.400 and and how you were treated and

NOTE Confidence: 0.879027789090909

00:26:53.400 --> 00:26:55.120 if at any point you kind of went,

NOTE Confidence: 0.879027789090909

00:26:55.120 --> 00:26:57.360 Oh my goodness, like here we go again,

NOTE Confidence: 0.879027789090909

00:26:57.360 --> 00:26:59.800 How much more is this going to be?

NOTE Confidence: 0.685712601428571

00:27:00.440 --> 00:27:03.180 Yeah, those thoughts definitely cross

NOTE Confidence: 0.685712601428571

00:27:03.180 --> 00:27:06.800 my mind here and there for sure.

NOTE Confidence: 0.685712601428571

00:27:06.800 --> 00:27:10.020 But yeah, so I I enrolled on

NOTE Confidence: 0.685712601428571

00:27:10.020 --> 00:27:12.506 a clinical trial in Boston.

NOTE Confidence: 0.685712601428571

00:27:12.506 --> 00:27:14.718 And at that time,

NOTE Confidence: 0.685712601428571

00:27:14.720 --> 00:27:17.078 I had passed my physician assistant

NOTE Confidence: 0.685712601428571

00:27:17.078 --> 00:27:19.240 boards and said to myself,

NOTE Confidence: 0.685712601428571

00:27:19.240 --> 00:27:23.728 I'm going to continue my life and try to

NOTE Confidence: 0.685712601428571

00:27:23.728 --> 00:27:26.640 incorporate they don't cancer into my life.

NOTE Confidence: 0.685712601428571

00:27:26.640 --> 00:27:29.718 So I was on this clinical trial for about

NOTE Confidence: 0.685712601428571

00:27:29.720 --> 00:27:34.370 5 1/2 years while I was working in Boston.

00:27:34.370 --> 00:27:36.395 So that was an interesting,

00:27:36.400 --> 00:27:39.975 beautiful, challenging all all of

00:27:39.975 --> 00:27:43.584 the above experience and during that

00:27:43.584 --> 00:27:46.510 time had relapses multiple times,

00:27:46.510 --> 00:27:50.862 about three or four times And you

00:27:50.862 --> 00:27:54.719 know we would locally treat the area

00:27:54.720 --> 00:27:57.120 and I'd continue on the clinical

00:27:57.120 --> 00:28:00.880 trial and I was be monitored very

00:28:00.880 --> 00:28:04.950 closely And then and and that was

00:28:04.950 --> 00:28:08.304 that was feasible with living and

00:28:08.304 --> 00:28:11.016 working because I had pretty minimal

00:28:11.016 --> 00:28:13.036 side effects from that systemic

00:28:13.036 --> 00:28:15.908 treatment and those local treatments.

00:28:15.908 --> 00:28:19.064 And then when when it spread to

00:28:19.064 --> 00:28:22.200 the brain that was really kind of

00:28:22.200 --> 00:28:24.576 the decision maker that you know

NOTE Confidence: 0.685712601428571

00:28:24.576 --> 00:28:27.285 this clinical trial is not not the

NOTE Confidence: 0.685712601428571

00:28:27.285 --> 00:28:29.248 the best course anymore and it's

NOTE Confidence: 0.685712601428571

00:28:29.248 --> 00:28:30.912 time to take a pause and and really

NOTE Confidence: 0.685712601428571

00:28:30.912 --> 00:28:32.399 think about where I'm going next.

NOTE Confidence: 0.8287728725

00:28:33.120 --> 00:28:35.760 Julia is a patient of doctor Harry Desponday,

NOTE Confidence: 0.8287728725

00:28:35.760 --> 00:28:37.216 an Associate Professor of

NOTE Confidence: 0.8287728725

00:28:37.216 --> 00:28:38.672 Medicine and Medical Oncology

NOTE Confidence: 0.8287728725

00:28:38.672 --> 00:28:40.880 at the Yale School of Medicine.

NOTE Confidence: 0.8287728725

00:28:40.880 --> 00:28:42.844 If you have questions,

NOTE Confidence: 0.8287728725

00:28:42.844 --> 00:28:44.774 the address is canceranswers@yale.edu,

NOTE Confidence: 0.8287728725

00:28:44.774 --> 00:28:47.498 and past editions of the program

NOTE Confidence: 0.8287728725

00:28:47.498 --> 00:28:49.857 are available in audio and written

NOTE Confidence: 0.8287728725

00:28:49.857 --> 00:28:50.772 form at yalecancercenter.org.

NOTE Confidence: 0.8287728725

00:28:50.772 --> 00:28:53.400 We hope you'll join us next time to learn

NOTE Confidence: 0.8287728725

00:28:53.450 --> 00:28:55.118 more about the fight against cancer.

NOTE Confidence: 0.8287728725

00:28:55.120 --> 00:28:57.622 Funding for Yale Cancer Answers is

NOTE Confidence: 0.8287728725

00:28:57.622 --> 00:29:00.000 provided by Smilow Cancer Hospital.