Welcome to Yale Cancer Answers with Doctor Anees Chagpar.

Yale Cancer Answers features the latest information on cancer care by welcoming oncologists and specialists who are on the forefront of the battle to fight cancer.

This week it's a conversation about Ewing Sarcoma with Doctor Hari Deshpande and his patient, Julia.

Doctor Deshpande is an associate professor of medicine and medical oncology at the Yale School of Medicine.
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
and a half of school to do upfront

therapy and that was very difficult

you know, being 22, starting my career

this threw a big

wrench in my life

plans as a cancer diagnosis often does.

So at that point I started my therapy

at Yale in the pediatric

world because it’s a pediatric

cancer and a young adult cancer

but often in younger children.

So I did that therapy and

then there were

more bumps along the road.
There were multiple relapses and while I was having these relapses I decided to go back to school and get my degree. So I finish and became a physician assistant. So that was really a very proud part of my journey and then as things progressed I started to incorporate my cancer as part of my life. And so I decided that I really wanted to work in oncology. So I got my first job at Mass General in pediatric radiation oncology. and I’ve worked there for several years at
the beginning of my career while getting my treatment and so as things had progressed there were many bumps along the road as many cancer patients experience and many relapses. And this was about a year or so ago and there was a pretty big shock to everybody and that was when I contacted Dr. Deshpande because the cancer had spread to my brain and so that was a pretty shocking moment in my life. Again was halted pretty severely and Dr. Deshpande was there and surprised supported me 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
people haven’t heard of it. And even when you’re at PA school, it’s probably not high on your list of lectures that you hear about. But Julia’s absolutely correct. It’s mainly a disease of children and young adults. In children, it’s almost always a disease of the bone. In other words, it starts in one of the bones. In adults, it can be either, it can start either in the bone or in what we call the soft tissue. So that’s other areas of the body.
And if it does occur in the bone, and you may remember this from your medical school lectures, Anesic, it can have a very characteristic appearance. We call it an onion skinning appearance in the shaft. So, but it really, it's difficult to predict where it's going to occur and who it's going to occur and it doesn't seem to have a specific cause, some cancers that we see. We can say oh, this runs in your family or you got this because you work around nuclear material or something like that.
00:05:57.840 --> 00:05:59.760 But that’s not really the case with Ewings.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

NOTE Confidence: 0.938704706666667
cause many of us I would think

Absolutely. I I I second what doctor

Deshpande says about not learning

much about ewings in PA school.

I don’t, I don’t even know

if we learned of about it.

So it wasn’t on my mind.

But I so at at 22 I I was not it

was definitely not on my mind

when I was having some pretty

severe pain in my right hip.

But it presented as a sciatica

type of presentation.

So some numbness kind of down

my leg and in my glute muscle.
And so that that it started kind of vague and it would be on and off. And so I started physical therapy, which is often the the case. This kind of typical course of, I think, I’m sure Doctor Spondee would agree that you know, usually they see, you know, you go to physical therapy and you kind of do exercises and see if it gets better. And it did get better for a bit and then it got worse again and then it got better and it got worse and that was about nine months. And they saw orthopedic an orthopedist.
who had diagnosed piriformis syndrome

like which is again you know something

that would be relieved with

stretching and and exercises.

So I would start to do

those and it didn’t improve.

So actually a rheumatologist he he

was the one who had done a a very

thorough exam and ordered the the

first image and that was nine months

after the the beginning of my pain.

So I finally got an image,

and the image showed the tumor

in my right pelvis and at the I

was metastatic A diagnosis.

So it had spread to my lungs at that time,
likely because of the length of time it took to find it. So again, you know that vague type of pain could be many things, right? We think of a zebra you know all the time And so I think that there’s I look back on that time and and I have of course feelings about wishing I had pushed for an image but it wasn’t really standard of care to do that. Yeah. So, Hari, can we pick up on this conversation in, in the sense that, you know, understandably, right.
You would think common things being common, a muscle pull is going to be piriformis syndrome, it may even be sciatica. You should do physical therapy.

Is there often a delay in that diagnosis and how is the diagnosis actually made? Yeah. No, I think both you and Julia just picked up on, on the main problem with this presentation is that it is a very, very rare disease. And so when you see people who don’t see this every day or may not ever see this, then it’s not something they’re thinking of.
And that’s why it’s important really in all of medicine if something doesn’t get better in a time frame that you expect it to get better, it is worth taking a look to see whether it’s something else. But that’s a very general statement and that time frame is it can be a very long time unfortunately.

But if you are thinking about either Ewing sarcoma or another what we call a primary cancer of the bone or even any abnormality in the bone, the first thing that we really want to do to make a diagnosis is to get a biopsy.
So, and this can be done in many different ways, but the most common is to somehow get a needle into the area of concern, get a small piece of tissue which our pathologists can then look over and hopefully make a diagnosis. The problem with sarcomas in general is sometimes if any surgery is going to be done after the biopsy, then they have to not just remove the lesion itself, but remove the entire biopsy tract. So in other words, if the needle goes into the skin and then through the muscle and to the bone,
they have to reset that whole area that the needle went through if they’re going to do surgery. And so we have a special radiology service which many tertiary centres have who are very experienced in doing these biopsies. And that’s what they will do to make sure they do it in the safest but also the best possible way presumably a bone biopsy doesn’t tickle. Is that done under anaesthesia? I mean it, it sounds like it’s certainly not something that
you would do in the office.

It depends what kind of bone biopsy. So in my earlier days I used to see some hematology patients and a bone marrow biopsy can be done in the office. And I would say most of our biopsies are done as an outpatient. For someone like Julia who we’re looking at a particular area, then you do have to use a type of guided biopsy, in other words, some kind of imaging to guide the biopsy needle where it’s going to go. And I can’t remember Julia, what they used with you.
00:12:32.840 --> 00:12:33.716 Do you remember,
00:12:33.716 --> 00:12:36.640 was it a CAT scan or an ultrasound?
00:12:36.640 --> 00:12:37.680 But that's usually the,
00:12:38.520 --> 00:12:40.716 I think it was on ultrasound.
00:12:40.800 --> 00:12:42.837 Yeah, that's typically how we do it.
00:12:43.440 --> 00:12:47.507 Julia had mentioned that her cancer was
00:12:47.507 --> 00:12:50.918 metastatic at the time of her diagnosis.
00:12:50.918 --> 00:12:53.234 So Julia where had it spread
00:12:53.234 --> 00:12:55.757 by the time it was diagnosed?
00:12:56.960 --> 00:12:59.042 At the time of diagnosis it
00:12:59.042 --> 00:13:01.440 had spread to my lungs.
00:13:01.440 --> 00:13:04.797 I had a couple lung nodules which
00:13:07.840 --> 00:13:09.556 doctor Deshpande will comment on,
00:13:09.560 --> 00:13:12.440 but I think is very commonplace
00:13:12.440 --> 00:13:14.960 that the sarcoma will spread to.
So there weren’t any other organs and I did have a bone marrow biopsy that he had mentioned which was negative. So the primary tumor had spread to the lungs only at that time. Well, we need to take a short break for a medical minute, but please stay tuned to learn more about Julia’s story and Ewing Sarcoma with my guests Dr. Hari, Deshpande and Julia. Support for Yale Cancer Answers comes from Smilow Cancer Hospital where their Prostate and Urologic cancers program provides a multi specialty team dedicated to managing the diagnosis.
evaluation and treatment of bladder cancer. There are many obstacles to face when quitting smoking as smoking involves the potent drug nicotine. Quitting smoking is a very important lifestyle change, especially for patients undergoing cancer treatment as it’s been shown to positively impact response to treatments, decrease the likelihood that patients will develop second malignancies and increase rates of survival. Tobacco treatment programs are currently being offered at federally designated comprehensive cancer.
centers such as Yale Cancer Center
and Smilow Cancer Hospital. All treatment components are evidence based and patients are treated with FDA approved first line medications as well as smoking cessation counseling that stresses appropriate coping skills. More information is available at yalecancercenter.org.

You're listening to Connecticut Public Radio. Welcome back to Yale Cancer Answers. This is Doctor Anees Chagpar, and I’m joined tonight by my guests Doctor Hari Deshpande and Julia.
cancer journey with Ewing Sarcoma.

And right before the break, Julia was mentioning that her pain was in her hip.

They thought it might be sciatica, or piriformis syndrome. Ultimately, a rheumatologist sent her for some imaging. She had a biopsy and ultimately was diagnosed with Ewing sarcoma. But by the time she was diagnosed, it had already spread to her lungs.

So Hari, is that common that at the time of diagnosis most patients are already metastatic?
You know that’s a good question.

I don’t know the exact numbers.

We do see patients who it’s what we call localised.

So it hasn’t spread anywhere.

But if it is going to spread, then the first place it usually spreads to is the lung, just as Julia says.

And with bone sarcomas, we actually have different stages that you people listening have.

probably heard of stages of cancer.

And with sarcomas, we have a stage if it’s spread to the lungs,

but it’s 4A if it’s spread to the lungs,

whereas it’s 4B if it spreads somewhere else.
And the reason we do that is even if it’s spread to the lungs, we still treat very, very aggressively. As Julia said, she got over a year of chemotherapy and other treatments as well. And that’s because we know that people like her can get treatment and do well for years.

So that’s it’s not like other cancers where if it has spread to the lungs from somewhere else, then we may be scaling back on treatments because we’re not sure how well they’ll do with very aggressive treatments.
Yeah. And so, Julia, I can only imagine what it must have felt like being 22 in PA school and being told that you had metastatic sarcoma. Can you talk a little bit about kind of how you felt at that moment? I mean, was this despondent? I think I oscillated back and forth between many different emotions. Anger is not a very common or familiar emotion for me.
So I would say probably sadness and fear. And I have a close friend who's a childhood cancer survivor who really stepped up for me and was kind of my main support. It was enormously helpful. I had, I had a tribe, for lack of a better word. And these people, my girlfriends came together and when my blood counts were OK and safe to go places, they would throw a head wrap on like me. And we would all go somewhere safe, you know.
And we all would have had wraps on. So I didn’t have to feel different. And it was those little things that made an enormous difference in that year and a half of treatment. And I had to relocate for some radiation up to Boston. And that was a difficult part of the journey for me, knowing that I was leaving my support system, my family and my friends and they travelled at least twice a month up there to do the same thing and you know, bringing my spirits up. And and I do remember specifically just feeling that love kind of, it didn’t make,
didn’t make the fear go away, but it felt a whole lot less lonely. And so I’m forever grateful for the time and effort that my tribe, you know, put in for me and I wouldn’t be where I am today without them. So yeah, I think we all need a tribe, whether we’re going through cancer or anything else in our lives. But particularly when you’re facing that kind of a diagnosis, that’s scary. And you know,
just knowing that you’ve got people around you who love you and care for you and we’ll go through that with you or at least stand by you as you go through it, so that you’re not alone is so important.

Hari, can you talk a little bit about the treatment itself? I mean, on this show we talk a lot about different modalities of treatment, whether it’s surgery, radiation, chemotherapy, immunotherapy and we talk about this multidisciplinary kind of approach to cancers.

Can you talk a little bit about how sarcomas and Ewing sarcomas are treated differently?
sarcoma in particular are treated?

Yes. So I’m glad you mentioned the multidisciplinary approach. We have a tumour board which meets once a week and any patients who we see either if they’re seen by the surgeon or by myself or by one of the radiation doctors presented at that meeting. And we come up with a treatment plan and that can involve just like you said, either surgery, radiation or some kind of what I call systemic treatment. So that could be chemotherapy or immunotherapy or a combination of two or even three of them.
And for Ewing Sarcoma, I think you have to go back to the early 1900s when it was first discovered and named. And at that time there were very little treatments for it and most people, even if it was localized in one area, did very, very badly with the disease. But then in the 1960s and 70s when chemotherapy was being developed, they started using it on children with different kinds of cancers. And Ewing’s sarcoma had an A really very good response to the initial chemotherapy regimens and eventually they came up with a treatment that...
was a combination of three different chemotherapies all given together given every two or three weeks.

And for the first time, people were surviving with Ewing sarcoma. It was not seen before.

And even the people who had a relapse after that had a good response to a second line treatment.

And so many people make fun of oncologists because they say, well, if one medicine doesn’t work, how about we add another one to it?

And that’s exactly what they did. So they gave the first regimen,
waited 3 weeks and then gave the second round treatment and then went back to the first round treatment. So it’s an alternating chemotherapy of really very high doses of medications. But as a result, the survival rates went way up from very, very low numbers to many people with localised disease doing very well with the condition. The downside is it’s a long treatment, so 48 weeks of chemotherapy is very daunting when you’re talking to someone, especially young people. But after that, we often in in between,
I should say in the middle of that treatment, we often do either surgery or radiation or both to try and control the place where it started. And that’s typically the treatment definitely for localized disease and often for metastatic disease as well. And so, Julia, it sounds like you started on this long journey of chemotherapy. I mean 48 weeks, my goodness, that’s almost a year. And and you mentioned that you had to relocate for radiation therapy. Why? Why was that? Was it because the radiation that
you required wasn’t available where you were being treated or was it for a particular clinical trial?

Can you tell us a little bit more about that?

Yeah, absolutely.

So surgery and radiation were both on the table for me. However the surgery would be pretty morbid. However the surgery would be pretty morbid.

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And they Boston has something called proton beam radiation, which is a certain type of radiation that can spare surrounding tissues of radiation. And given that it was in my pelvis,
00:24:33.240 --> 00:24:35.105 my ovaries are there and
00:24:35.105 --> 00:24:36.597 many other important organs.
00:24:36.600 --> 00:24:38.955 And so the radiation oncologist
00:24:38.955 --> 00:24:41.462 here at Yale had had said,
00:24:41.462 --> 00:24:43.639 you know, I think that this is,
00:24:43.640 --> 00:24:46.808 this is the best type of radiation for
00:24:46.808 --> 00:24:50.240 you and and referred me up to Boston.
00:24:50.240 --> 00:24:50.640 Yeah.
00:24:51.720 --> 00:24:54.018 And Hari, you know Julia had
00:24:54.018 --> 00:24:56.516 mentioned as she was telling her
00:24:56.516 --> 00:25:03.152 Is that kind of classic for Ewing sarcoma
00:25:03.152 --> 00:25:06.460 that people will relapse and what are
00:25:06.460 --> 00:25:08.910 their options at that point are are
00:25:08.910 --> 00:25:11.640 there clinical trials that are ongoing?
Unfortunately, the relapse rate is quite high for metastatic Ewing sarcoma.

We do have other what we call salvage treatment options and Julia’s had some of those already.

As far as clinical trials, I know Julia was on one up in Boston.

We did have one specifically for Ewing sarcoma probably about 10 years ago.

It did not do very well in terms of the results were not very promising and I like to keep in touch with my colleagues from paediatric oncology.

As Julia also said earlier, this is a disease that affects children a little bit more than adults.
So most of the trials will include very young children and they’ll have an upper age group of 30, sometimes up to 50 and I will be involved in some of the older patients. So at the time that Julie was diagnosed, we didn’t have an available trial, but definitely when one opens, Julia will be first on my list. So, so Julia, it sounds like you went up to Boston, you had your radiation, up to Boston, you had your radiation, you had more chemotherapy and then it sounds like life was going along well and then you relapsed again and again. Tell us about what that was like,
how those relapses were found and how you were treated and if at any point you kind of went. Oh my goodness, like here we go again, How much more is this going to be? Yeah, those thoughts definitely cross my mind here and there for sure. But yeah, so I enrolled on a clinical trial in Boston. And at that time, I had passed my physician assistant boards and said to myself, I’m going to continue my life and try to incorporate they don’t cancer into my life. So I was on this clinical trial for about 5 1/2 years while I was working in Boston.
So that was an interesting, beautiful, challenging all of the above experience and during that time had relapses multiple times, about three or four times And you know we would locally treat the area and I’d continue on the clinical trial and I was be monitored very closely And then and that was feasible with living and working because I had pretty minimal side effects from that systemic treatment and those local treatments. And then when it spread to the brain that was really kind of
the decision maker that you know

this clinical trial is not not the

the best course anymore and it’s

time to take a pause and really

think about where I’m going next.

Julia is a patient of doctor Harry Desponday,

an Associate Professor of

Medicine and Medical Oncology

at the Yale School of Medicine.

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.
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