What Happens After Cancer? Childhood Cancer Survivorship

Webcast
August 20, 2008
Kelly Anderson, N.P.
Cole Connealy

Please remember the opinions expressed on Patient Power are not necessarily the views of Oregon Health & Science University, its staff, our sponsors, partners or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. Please have this discussion you’re your own doctor, that’s how you’ll get care that’s most appropriate for you.

Introduction

Andrew Schorr:
Hello and thank you for joining us once again for our Ask the Experts program. We do this every two weeks, and we connect you with leading Oregon Health and Science University and often Doernbecher Children’s Hospital experts and always inspiring patients.

Now I want you to think about this. We have made a lot of progress in medicine, and in one area we’ve made tremendous progress is in treating cancer in children. There are about 12,000 children across America who are diagnosed each year. It used to be, it’s always a bad diagnosis, but it used to be often years ago a death sentence, but happily now it most of the time is not. Children go through very aggressive treatment whether they are a little infant or a young person in their single digits or even in adolescence, and they usually come out the other side, but they’ve received very aggressive care. You can imagine that their childhood may well have been ripped away from them. They have to grow up very fast, and they were treated with very powerful medicines.

So now we begin to look at what does it mean to be a survivor of cancer when you were a child? What are the effects of the medicines that may show up many years or even decades later? How do we keep a look out for cancer coming back, either the one you had or another? What are all the emotional issues, career issues, education issues?

Well as you would expect, Doernbecher Children’s Hospital being one of the leading centers of its kind certainly in the Northwest but in the country has now started a year ago a Childhood Cancer Survivor Program, and it’s designed to help children as they grow up and come through the other side of cancer, support them with all those issues I just described, and it’s actually available to anyone who was diagnosed with cancer and not just treated at OHSU but anywhere, and was diagnosed with cancer before the age of 21, and then it carries them through all the way up almost to age 30, and then it sort of does a handoff to other providers with all the things that OHSU knows about helping these people as they go on with their life.
**Cole’s Story**

**Andrew Schorr:**
Let’s meet a real person who’s lived this and is benefiting from their program, and that’s Cole Connealy. Cole joins us from Portland. He’s in sales now and works out three times a week and is a very busy, very bright young man as you’ll hear, but when you were 16, Cole, you were dead tired, and when you went to the doctor, what happened?

**Cole:**
Well, like you said, I was really tired. I was sleeping 18 or 19 hours a day. Luckily I actually had a different physician than my regular one that kind of was a little more patient-oriented. He did a whole battery of tests. He knocked off mono, TB test, they all came back negative, so as kind of a one last chance he took an x-ray of my lungs, and you could see a big flurry of tumors. So after another more narrowed-down test they figured out it was testicular cancer.

**Andrew Schorr:**
Now let me describe what’s happened. So many people are familiar with Lance Armstrong, of course, the famous Tour de France cyclist and of course with his wonderful organization “LIVESTRONG” the Lance Armstrong Foundation that has helped so many people and of course is often dedicated to young adults with cancer. He had testicular cancer and was treated. Now in Cole’s case it was really advanced, metastatic, so it had spread. They saw it on the chest x-ray. They saw it in your brain too. Is that right Cole?

**Cole:**
That is correct. They didn’t find the brain tumor immediately, but it had eventually spread to my head about six to eight months later.

**Andrew Schorr:**
So now we’re talking about being in the hospital, and you were almost rushed to OHSU. Two days later you’re hospitalized. I think you had your first surgery the same day, is that right?

**Cole:**
The same day. I got in, I met my nurse, and literally hours later I was being wheeled into the surgery room. They weren’t kidding around. They really were pretty serious so they wanted to get a hand up on it.

**Andrew Schorr:**
Now Cole had two years of treatment, and during that time 13 surgeries, and he’s had the full boat of cancer treatment; not only the 13 surgeries but also Cole had radiation and chemotherapy. Now you’ve heard where he is today physically working out three times a week, a successful job, and overall you feel healthy. Is that right, Cole?
Cole:
Oh absolutely. I couldn’t feel better. You know I have the scars to remind me, but it’s almost like it never happened physically. I’m active. I play sports. I work out. I hang out with my friends. I’m doing very well.

Andrew Schorr:
So that’s terrific news and a tribute I think to your courage and a wonderful medical team and I’m sure a wonderful family, and I’m sure there were people praying for you and tremendous support, and what a wonderful result, but now life goes on for Cole as it is for thousands of young people who were treated for cancer where the result has been good.

So now let’s meet Kelly Anderson who is a nurse practitioner at this one-year-old now Childhood Cancer Survivor Program at OHSU, the Doernbecher Childhood Cancer Survivor Program. Kelly, so it must do your heart good, you’ve been in oncology for about eight years, to know Cole and hear his story and know probably many other children. It’s not always the result, but now more often it is where they can be returned to a full life and that must make you feel, and all the folks who work in cancer, just tremendously well.

Ms. Anderson:
It does, and first of all thanks so much for having me. It really is a wonderful way to get health information into the community, but yes definitely Cole’s story is inspirational.

Andrew Schorr:
Let’s go on then and take it from there. So then what, and what we’ve been calling this program is what happens after cancer and learn more about the Childhood Cancer Survivor Program at Doernbecher at OHSU as an exemplary program.

So I mentioned about I think what you call “late effects” of medicines. So the patients are given powerful medicines, but there’s no free lunch is there? It can cure the cancer, but what can be effects that show up much later from the powerful medicines that fought the cancer in the first place?

Ms. Anderson:
You know, that varies depending on the treatment that you get, but really the late effects can be anything from head to toe. So it could be problems with vision or problems with hearing or problems with teeth or heart or lung or fertility problems or joint or bone problems, and even some psychosocial kinds of things that actually we see more often than the physical problems. Things like insurance issues and education problems or career barriers or needing to change vocations, sometimes depression and anxiety or some posttraumatic stress sorts of things.
Andrew Schorr:
Now is it often the case where someone has been treated for cancer in their early years when they wanted to be out playing ball or visiting with friends or going to the mall or whatever might be age appropriate, and that is taken away from them, and so they have to grow up very fast, and they’re changed because of it. I don’t know if there’s anger that comes out of it; we’ll ask Cole in a second; but from where you sit, Kelly, what’s going on for them? Is it just that maybe there were some lost years?

Ms. Anderson:
That’s true. There are definitely losses associated with treatment even when you have a good outcome and when you have a cure, and the funny thing is that these losses really have to be reprocessed at each developmental level. So something that affected you a certain way in junior high affects you in a very different way in college, and so we often see these kids needing to revisit and sort of reprocess some of these things as they get older.

Andrew Schorr:
Who’s on the team in your Childhood Survivor Program? So there’s yourself as a nurse practitioner. What other members of the team are there to help support someone who comes to see you?

Ms. Anderson:
We have a core team of a physician, a nurse practitioner, nurse and social worker, and then we have access to all kinds of other specialists that may be needed depending on the problems we encounter.

Andrew Schorr:
Okay, Cole, what about you? So I know it’s going to vary, and I would get a different response depending on the young person I ask, but do you have anger about what you went through now that you look back on it, and how do you feel about life today?

Cole:
When I was going through my treatment obviously there is a lot of anger and there’s a lot of mixed emotions, but during my treatment yes I was mad and upset and frustrated. As I look back today, like where I’m at right now, I have zero anger towards what happened to me. I wouldn’t have traded it for anything. I know that sounds really bizarre to say that, but I wouldn’t be involved with this telephone call, the nurses and doctors up there that are just incredible people I would never have teen to know them or be where I’m at today. So to answer your question, no I don’t feel any anger or resentment at what happened.

Andrew Schorr:
As a leukemia survivor I go in for checkups, and fortunately my cancer seems to be in deep remission. There are some people who have been through cancer, and they
don’t want to be around an oncologist. They don’t want to be around an oncology nurse practitioner or social worker, the works. They want to go a thousand miles away. If you’re feeling good, is it difficult for you to go to a survivor program where some of these; you know, they’re looking to see has the cancer recurred, how are you doing, what’s your attitude, is there any late effects of medicine; or do you welcome that as getting quality care?

Cole:
I see both sides of the spectrum. I know when I go in for my checkups I get really nervous and scared. I don’t sleep the night or maybe even the week before just because you have those thoughts; oh is my cancer going to come back? I guess I’m feeling like this; uh oh is that cancer? So in that aspect I can see going back to an oncology survivor program and having that same anxiety, but I can also see how it’s such a huge help and such a huge benefit that speaking personally I would definitely go to that program so I could get further knowledge and empower myself to recognize certain symptoms and recognize certain things.

The Doernbecher Childhood Cancer Survivor Program

Andrew Schorr:
Kelly help us understand from your perspective why the need for this program? Why couldn’t the Coles of the world just, you know, they say thank you very much OHSU and particularly if I’m not near Portland, Oregon, and that I go back to my little community clinic and doctors who see a wide variety of patients, and that will be sufficient because I’ve been cured. Why isn’t that enough?

Ms. Anderson:
Well, 30 years ago we weren’t really able to cure very many kids, and so it’s sort of a brand new body of knowledge that’s coming to us in the last 10 or 15 years about what happens to kids 10 and 20 and 30 years out, so we want to take that knowledge and pass it on to the patients and the families and be able to connect that to a screening plan and some health maintenance sorts of things that make sense for each individual.

Andrew Schorr:
What we’re going to do is we’re going to take a short break. When we come back, I’d like you Kelly to take us through the process if somebody comes to the survivor program. How do you start? If they weren’t treated, where they have a medical record at OHSU, how do you gather the information and as you were alluding to there really have an individualized plan both for when they’re part of your program and then when they graduate, if you will, as they approach 30 and go on further out into the world so that really hopefully they live to be 100 and they have the right care. We’re going to learn that as we go on in our webcast.
Now, this is a live webcast, and I think we have people listening all around the country, and thanks to our young adult groups who are cancer survivors for being interested. We’ll be right back. You’re listening to Ask the Experts brought to you by Patient Power and sponsored by OHSU.

Welcome back. I’m Andrew Schorr and you are listening to Ask the Experts brought to you by Patient Power and sponsored by Oregon Health and Science University, and today a wonderful expert from the Doernbecher Children’s Hospital up there on the hill in Portland. It’s a beautiful setting if you haven’t’ been there. It really is, and now there’s this really neat, I guess you’d call it, cable car that goes down the mountainside, if you will, and connects right down there in Portland with up there on the hill. It’s quite neat.

Anyway, what’s important of course is they give great medical care there, and it’s not just when you’re sick but it’s when you’re well, and in the case of children who have come out the other side of cancer, as many more children do, and we’re happy to report that, and then support you so that you have long-term health.

Let’s go back to Kelly Anderson who is the nurse practitioner in the now one-year-old Childhood Cancer Survivor Program. Kelly, take us through it. So where do you start? So somebody becomes part of the program. What’s the starting point to see what is personalized for them?

Ms. Anderson:
The first important thing is that we need to review records and find out what really did happen to this young body, what ages were they when it happened be it surgery or radiation or chemotherapy, or were there problems with the cancer itself before it was removed affecting normal tissues. Once we have that treatment summary done, everything else sort of falls out from there. We translate that into a health screening plan individualized for that person whether they need heart tests are lung tests or lab tests or what sorts of things, and we will recommend a screening plan based on that.

That’s all done before the clinic visit ever happens, and once the person comes to clinic we have a detailed discussion about how they’re doing in all kinds of ways including those psychosocial things that we talked about before. Then together with the patient and the healthcare team we can sort of pinpoint where we need to focus our time and energy on that visit. Are there resources we should be connecting them to? Do they need help navigating the emotional journey? Are there specialists that we ought to be referring to look for specific problems or just manage specific problems? And then at the end we sort of give them a summary of all that written down so if they do visit another healthcare provider for an urgent care visit or they’re off to college and being seen in the student health center or anything like that they’ve got everything written down that they can share with someone else to sort of help in their future healthcare.
Andrew Schorr:
Wow, that sounds like a tremendous starting point. Now of course some people though come back to you periodically. Tell us about that.

Ms. Anderson:
Right, we would like folks to be seen yearly, and they can either come back to our survivor program yearly or they can share that with either their oncologist or their primary care provider, but as we’re learning more and more about these late effects, we want to be able to share that with people. So it isn’t just a one-time visit. It’s generally ongoing care that needs to take place.

Andrew Schorr:
Let’s understand these “late effects” a little bit, and maybe it takes a little cancer education. So my understanding is, and for being a leukemia survivor too, when someone has cancer as I always recall one doctor saying at a seminar, it’s your own cells gone haywire, but there are many, many different cancer types, and I know as we get into more personalized medicine what was just called one diagnosis is really many sub-diseases even. So you’re continuing to develop targeted medicines for exactly the cancer cells that you have, but they each have different, I guess, side effect profiles that may be immediate or delayed. So if somebody had one kind of drug you’re maybe watching because there are known effects on the heart or maybe it leads to a higher risk of skin cancer or whatever. Is that, am I getting this correctly?

Ms. Anderson:
Exactly right. We sort of know some things we should be watching for based on the therapy they got. So was the primary disease in their brain, and did they have brain surgery that we should be watching for effects there? Did they have radiation to a certain part of their body that puts that part of the body at risk for certain things? Then there are many, many different types of chemotherapy agents and biotherapy agents that we know quite a bit about in terms of the effects.

Also sometimes very young kids have had a life-threatening complication of their cancer and maybe they had an infection or needed to be in the ICU for a period of time or on a ventilator for a period of time, so all of those things can sort of add to the possibility of late effects as they grow.

Psychosocial Challenges of Surviving Cancer

Andrew Schorr:
Now there’s a flip side of this, and this relates to kind of the psychological side of it, and you touched on it Cole, and I’m the same way. So I now go to my oncologist for blood tests, because I’ve had leukemia, every six months. I can sleep okay the night before, but I definitely get, as I say, twitchy when I’m having the blood draw and waiting for the result and waiting to see what the doctor’s face is when he walks into the exam room with the blood test result, but I also sometimes get a
little nervous when I have symptoms that I don’t know if they’re connected at all. You know, if I was a little tired or if I felt a little lump or bump, oh my god, is that the cancer I’ve had coming back or another?

So what about you, Cole? Do you worry about little aches and pains and other things that come up and say, ‘oh my god it’s the cancer again?’

**Cole:**
You hit the nail on the head with that exact analogy. I mean any kind of pain or if I’m sleeping too much, that’s the first thing that I think of is, oh my gosh, is that cancer back? What am I gonna do? And I start panicking, and I often call my mom because she’s a nurse, and she has to settle me down. You know it’s been five or six years since this happened, but every ache and pain, if I start sleeping too much, automatically with the snap of the finger I start thinking about cancer.

**Andrew Schorr:**
I just have to share a story, and I’m sure it applies to young people as well. My favorite conversation with my oncologist as we went down the road and there continued to be no sign of leukemia was when he said, because I’m you know in my late 50s and still very vibrant in my late 50s, and he was saying, ‘Well maybe you should start taking a baby aspirin.’ Now I always thought the oncologist would just talk to me about cancer medicine or something like that, and I said, ‘Well a baby aspirin, what’s that about?’ And he said, ‘Well just for your heart you know to lower your risk of a heart attack, etc.,’ and I said, ‘You’re talking about my heart but you’re a cancer doctor.’ And he said, ‘Well, cancer survivors have heart problems too even unrelated to any medicine. You’re just growing older, Andrew.’

So Kelly, how do you help younger people know, I don’t want to say when to worry, but also when not to worry and to just relax or know they got the flu, they got a cold, and things like that?

**Ms. Anderson:**
Right. That’s a very difficult question, and I think another thing that’s very important is to have a good primary healthcare provider who knows your history and who we’ve been able to communicate with and given this treatment summary to and given our screening plan to so that they can help sort of sort some of that stuff out because you won’t be able to run into your oncologist’s for everything, but a good primary healthcare provider can really be helpful in helping with some of that.

**Andrew Schorr:**
We’re visiting with Kelly Anderson from the Childhood Cancer Survivor Program at Doernbecher Children’s Hospital at OHSU and also Cole Connealy who is with us, 24-years now strong, healthy, motivated in sales and in relationships too. Cole, I’m looking for a date for you tonight too, okay?
Cole:
I hope you do. Please do.

Andrew Schorr:
There you go, this is “Match.com” on Ask the Experts, all right.

Cole:
I love it.

Andrew Schorr:
But he’s really a neat guy, and we’ll be posting his photographs too. Kelly as we go on then, you talked about kind of the psychological part of it and related to work and also education. So how do you help people related to the educational issues and work issues? Give us an example of that.

Ms. Anderson:
I think communication is the number one thing. School reentry can be quite a difficult thing whether they’re entering school at the time that they’re still on treatment or whether they’re waiting until they’re finished. There are lots of things to think about ahead of time to preplan and to make sure that good communication happens among all the team members. They may have some physical stamina issues. They may have some emotional problems with fitting in or having anxieties or different things like that. They may look different than they looked before be it their hair has not grown back or another effect to an arm or leg. Their immune system may not be as strong as it was, and maybe they have some late effects that are already affecting school like hearing or some cognitive function changes. So all of those things need to be considered and looked at and planned for ahead of time and then really good communication between families and health teams and education teams.

Andrew Schorr:
Okay Cole, here comes an e-mail from your date; no, I’m joking, but we do have an e-mail from Megan in Portland, and she has a question for you, and she wants to know does cancer run in your family, and did the doctors ever figure out why the cancer spread so rapidly?

Cole:
Well, that is actually a really good question. The answer is it does not run in my family. The women do have breast cancer, or are at least very prone to getting breast cancer, but there have been no men in my family to ever have cancer, so I am the first unfortunately.

Andrew Schorr:
Now I want to talk about you’ve been treated for testicular cancer, and I don’t know the details, maybe someone else does, about what I’m going to talk about, fertility related to Lance Armstrong, but in your case Cole, there you were 16. Obviously, I
don’t believe, you’d fathered a child at that point, but you may want to have children at some point, and here you were having a testicle removed and lots of other surgeries and heavy duty chemotherapy and radiation. What did they do to protect your fertility, and what’s your hope for being a dad down the road?

**Cole:**
During my, I had just gotten into the hospital, and I was approached by one of the doctors about storing some semen in an andrology lab so that in case something were to happen; the chemotherapy might affect my fertility, surgeries, just all that kind of stuff. They recommended that I store some in an andrology lab to protect me for later on down the road if I do want to have kids, which I do. I unfortunately haven’t gotten tested since then, but that is on my list of things to do this week, so hopefully everyone cross your fingers that I’m good to go.

**Andrew Schorr:**
We’re with you. Let’s talk about Kelly now. Now Kelly, this fertility discussion is probably one that comes up a lot at the clinic doesn’t it?

**Ms. Anderson:**
It does, and it’s so important that that’s thought of right at diagnosis because especially for boys we can bank sperm, which is a great way to preserve their fertility later on. For girls there aren’t as good of options, but if a woman already has a partner and has two or three weeks before treatment needs to start, then some fertilized eggs can be stored, but there’s a lot of great research happening in this area, so hopefully down the road we will have better options.

**Talking to Others About Your Condition**

**Andrew Schorr:**
Now one of the things that comes up all the time is as you start relationships, so these are children, so they go on and they’re single young adults or teenagers, do they talk about it? Do they volunteer the information? Now I know that you’ve had some scars from your surgery, Cole, so maybe in your case people say what happened, and you’ve told me you choose to speak about it, but maybe it’s not so obvious with someone else that there was anything, and I know a young man here in our own community who’s got a twin brother. One was treated for leukemia, and they look the same. They look identical and healthy and strong, and they’re about 15 years old now. So how do you handle that Kelly, and what does the social worker work through with these young people as far as whether they even talk about it?

**Ms. Anderson:**
You know, we just talk to them about if that’s an issue for them, and sometimes it is. Sometimes those intimate relationships are very difficult to form after cancer
and after body image issues, so it’s just something we want to bring up and get the conversation started so that if that is an issue for them we can refer them to people who would help if that’s a continuing problem.

Andrew Schorr:
Okay, and Cole we’re going to talk to you when we come back, and maybe you’ll give some advice for people how you discuss it when it does come up for you, and I know that’s the kind of thing that gets discussed in support groups online and in person. I’d love to hear your point of view. We are having our live Ask the Experts webcast, and it’s brought to you by Patient Power, and it’s sponsored by Oregon Health and Science University, and we’re discussing cancer in children and life after that and the wonderful Childhood Cancer Survivor Program at the Doernbecher Children’s Hospital at OHSU. We will be right back.

Thank you for joining us this evening for our live webcast. You know, there really aren’t discussions enough around the country like this, so I’m delighted that I get to do this. It’s such an important issue, and isn’t it great that while there are 12,000 children diagnosed with cancer each year in the U.S. that many can go on to full lives, but there needs to be a vigilance and an acknowledgement of what they’ve been through for the people around them and for themselves too, and that’s why we’re talking about it today. We have Kelly Anderson with us who is the nurse practitioner with the Childhood Survivor Program at Doernbecher Children’s Hospital at Oregon Health and Science University in Portland, Oregon, and also Cole Connealy who’s been through the “full meal deal” if you will, as far as 13 surgeries and radiation and chemotherapy to treat his testicular cancer that had spread at age 16 with two years of treatment but now doing well.

Andrew Schorr:
So Cole I promised before the break maybe you could give us some guidance. So how does the conversation go? So people see some scars. You had 13 surgeries, and certainly you can have some scars from that. How do you talk about it and then make it positive and build a relationship?

Cole:
I really encourage people to ask about them instead of just stare and point and then kind of talk to whoever they’re with. It’s always better when you approach the person straight on to say, hey, I noticed some scars on the back of your head. Tell me about it. I like that when people do that because it just means they want to know and have empowered themselves. So if someone does ever ask about them; and you always get the one guy who is like, “whoa man, what happened there?” but then you also get more compassionate people who will just come up and say, “Hey I noticed those, can you tell me about them?”
So if people do ask I just tell them straight up, “Hey I had testicular cancer and had some things go a little wrong. I had some infections and complications and it spread to my head, and this is what happened. It’s been this long since I’ve had the surgeries. I’m doing awesome now.” I use it as a tool. I mean it’s an everyday reminder of how valuable life is and how you shouldn’t really worry about the small things in life. You know, you don’t have to yell when you’re in traffic. I use that one a lot because I find myself yelling in traffic a lot. I’m sorry.

**Andrew Schorr:**

<Laughing> We should mention...

**Cole:**

So, and things like that kind of in a positive ways like that, and people kind of reevaluate the way they look at their lives and their overall demeanor.

**Andrew Schorr:**

I talk to my wife about that all the time. Now we should mention that you have been a counsellor now at Camp UKANDU that is for kids dealing with cancer either currently or they have had it and their siblings. So as a counselor, what’s kind of the message that you tell the campers there who are going through it and a little younger than you are. Now obviously there’s the name of the camp, Camp UKANDU, but what do you say to them?

**Cole:**

I say you’re no different than any other kid. You don’t have to explain anything to me just because you have no hair. You are still normal, and you are still awesome, and you are unique. It’s kind of different the way that little kids approach cancer. They’re young. They’re memories are short, so that’s reality to them, and so they just need encouragement that they are normal and they don’t have to explain. People aren’t staring at them and you don’t have to say what is that, what is this, why do you look like this? It’s a place where people can go and be themselves and not have to worry about people asking questions because they’re normal.

**Questions from Listeners**

**Andrew Schorr:**

Kelly I’ve got some other questions for you now. Here are some that came in via e-mail that were sent to experts@ohsu.edu. Here’s one that came in from Benjamin in Portland, and he writes, What is the likelihood of childhood cancers recurring in adulthood, and is it always necessary to have long-term followups?’ Now I know it’s going to vary, but help us through that.

**Ms. Anderson:**

It does vary based on the disease. Most of the childhood cancer diseases within about seven or eight years of being off treatment will not recur. Now there are a few exceptions to that but the thing we worry about later in life and in adult life is a
second cancer of another type, and we know that kids who have had a first cancer and gone through chemotherapy treatment have an increased lifetime risk of having a second cancer, and so we’re always counseling our patients about that risk to keep healthy.

**Andrew Schorr:**
Now one of the things, for instance, and I know for me with leukemia treatment would be to wear sunscreen because you’re at higher risk of skin cancer. What are some of the typical things you’re on the lookout for?

**Ms. Anderson:**
We want them to definitely avoid tobacco smoke. We want them to do self breast exams and/or self testicular exams, and definitely sunscreen is very important because skin cancer is a young person’s cancer, and it’s been shown that the fewer sunburns you’ve had in your life the better off you are in terms of skin cancer later on. We want them to have immunizations as they should, and there’s a great cervical cancer vaccine out now that we’re really encouraging our young women to look into, those sorts of things. If they notice anything going wrong or a new lump or bump we want them to get that checked out sooner rather than later.

**Andrew Schorr:**
Here’s a question we got e-mailed in from Selina, also in Portland, and she writes, ‘Have researchers been able to point out similarities between childhood cancers, and do these young patients who are diagnosed with cancer share any commonality?’

**Ms. Anderson:**
You know I think that varies based on the disease, so I don’t know the answer to that for a specific disease.

**Andrew Schorr:**
Okay, that’s fair. You know I was doing a program on bladder cancer, and of course that’s in people like 50 years and older, and of course many of those people were smokers, but in the childhood cancers where hopefully we didn’t have that going on, you’re not able to find a commonality I guess at this point.

**Ms. Anderson:**
There are definitely more similarities in childhood cancers, all comers, versus adult cancers. We note some of those differences and why childhood cancers are easier to treat than adults, but specific diseases I’m not quite sure about the differences.

**Life After Cancer Treatment**

**Andrew Schorr:**
Okay. Cole, let’s go back to you. So here you are. You’re in sales so you’ve got to feel really positive to be successful at that, and you went through college too. So
how difficult was it for you to leave cancer in the review mirror, if you will? Not forget it but just be propelled to be successful?

Cole:
It was a little more difficult because memory, actually mainly memory is kind of hard for me. I had radiation to my head so I find for myself that index cards and Post-it notes are absolutely my best friends in the world. So in that aspect it was really difficult. I had to do extra studying, just extra effort all around for college, but once I got out of college sales was kind of; I love meeting new people, so, I mean that’s just, you kind of take it on head on. You know, you can just look at a cancer and just say well, look at me now. I’m being successful. I’ve got a great job, and I’m doing well, and I kind of use that for my motivation as well.

Andrew Schorr:
Now I have to touch on something you just said. So as I said, I’m 57 and went through chemotherapy like you did, and so there’s this idea of “chemo-brain” and so when I can’t remember things I say well is it the chemo-brain or is it just Andrew getting older? But it sounds like you in your early 20s have validated that there is chemo-brain, huh?

Cole:
Absolutely, absolutely, and it’s definitely an issue. I was originally going to school to be a pharmacist but was advised against it by one of my favorite doctors in the world just because memory is not my strong point, and pharmacy and pharmacists need a sharp memory for all the drugs, chemotherapies, and medicines, so I was actually advised differently just because of that exact purpose, having that memory loss.

Andrew Schorr:
Let’s ask Kelly. So Kelly, am I right? There really is chemo-brain?

Ms. Anderson:
Definitely. There is a lot of research to support that. We call it neurocognitive deficit, and the kids who are most at risk for that are the kids who were very young when they were treated, the kids who get a lot of what we call intrathecal therapy for the leukemia and the lymphoma where we do a spinal tap and push medicine in that space that goes up around the brain and spinal cord. Kids who have had radiation to their brain are at higher risk, and kids who have had brain tumors or brain surgery are at higher risk of that effect.

Andrew Schorr:
Now what about then counseling, and Cole just touched on it as far as maybe changing his career goals just acknowledging there are certain strengths he has post cancer and some things he’s not as strong in. Do you help kids as they grow older work through that as far as a positive direction for the rest of their life?
Ms. Anderson: We do. We have a neuropsychologist here, Dr. Robert Butler, who does in-depth neurocognitive testing of learning abilities and can do some of that counseling regarding effects and what to expect and are there any therapies that may help them.

Andrew Schorr: Okay, we’ve got a lot more to talk about as we continue. We invite your questions, and we’ve got some more. We’re going to find out where research is headed too in understanding children who have been treated for cancer and growing older and understand with the Childhood Survivor Program how people who participate can help advance the knowledge as fortunately kids are growing older and they’re cancer survivors. All that coming up as we continue our Ask the Experts webcast brought to you by Patient Power and sponsored by Oregon Health and Science University.

Andrew Schorr: Welcome back to our live webcast. I want to get into a major issue, and Kelly you mentioned it earlier, and that is insurance. Cole, so you’re working for a corporation, right, and you have insurance through that?

Cole: That is correct.

Andrew Schorr: Was there any difficulty at all? Did somebody see you coming and say, ‘Oh my goodness, what do we have with this guy and what costs are involved?’ Or no problem at all?

Cole: I did actually have someone call me from our corporate office in Cincinnati to talk to me about it, but everything eventually went through. So I didn’t really have any pushback. They just wanted to call and ask me about it and try to get some general information about what happened and that kind of stuff.

Andrew Schorr: I’m happy to hear that, but I know that’s not always the case. Kelly, you mentioned it early in the program about the things that the cancer survivor program helps people work through. So we mentioned education, relationships, late effects of earlier treatment they received, surveillance for other cancers. What about insurance because now these are young adults often who now their time at home and under their parents’ insurance, if their parent had insurance, that may be ending. So what about moving forward from there?
Ms. Anderson:
That’s true. That is a major issue at times and particularly kids whose college plans have been derailed because many insurance companies will let you stay on your parent’s insurance through college, but if you are not attending college and you’re 18 or 19 you may have to work on this sooner than you had planned. Also the idea of preexisting condition and there are some companies that discriminate a bit against folks with a preexisting condition, so we have a social worker who will really work carefully with families and kids to try to do what she can and help this issue to go smoothly.

Andrew Schorr:
Now I want to mention there is a lot of support. There’s this wonderful program, the Childhood Cancer Survivor Program, at Oregon Health and Science University and Doernbecher Children’s Hospital. Here’s the phone number by the say that you can call to get connected with it: (503) 418-5150, and just tell them you want to learn more about the Childhood Cancer Survivor Program, and then beyond that is there is support, there are various support groups, and I know you’re developing a new one Kelly there in Portland, and there’s a lot on the web too. You don’t have to feel like you’re alone Cole do you? As terrifying as it is for a child or as you get through it and grow older, you’re not alone are you? Not just in the cancer care but in the survivorship, so what advice would you give people to get connected with others?

Cole:
I think it’s absolutely necessary to get involved with others. This program here at Doernbecher is absolutely amazing and they give you some much knowledge and they give you a crowd of people that have commonalities. I mean I really, really encourage people to get involved in whatever program. If you can talk with other people that have gone through similar things I think you’re 100% better off than if you hadn’t because it’s always nice to talk to someone who’s been through the same thing that you have and be around the people who are knowledgeable about what you’ve gone through.

Andrew Schorr:
That’s so neat. Hey, while we’ve been here, Tamara our producer just e-mailed me a picture of you Cole, a big, tall, strapping guy, in a Superman outfit. So there you are Superman. So tell me about the Superman outfit, and what’s the story behind that, and you have two smiling ladies with you too.

Cole:
I was lucky enough to have really, really good friends that came up and saw me all the time, and those are just some of my friends that came up one day, and my mom bought me that Superman shirt just to kind of encourage me because I was in the hospital. I wasn’t too mobile when I was in the hospital. I kind of just laid around and didn’t really do anything, so I think that was kind of her way to
encourage me to get up and bebop around the floor and meet new people, and I think it worked, but like I said I was blessed to have really good friends that came up and saw me and didn’t treat me any different than if I hadn’t had cancer.

**Andrew Schorr:**
And those people are still your friends I hope for a long, long life.

**Cole:**
They absolutely are.

**Benefits of the Survivor Care Program**

**Andrew Schorr:**
That’s such great news. So Kelly, there are people who listen to this, and hopefully if they’re close by or even at some distance they can have a relationship with you at Doernbecher or another program if they’re far, far away as more of these programs are being developed. How should someone carry on with their sort of neighborhood doctor, if you will? One might be if they’re in a program I guess to try to connect you all at a special center with that other provider and help educate them. The other might be just to kind of have an open dialogue? What would you recommend?

**Ms. Anderson:**
Yes, both things. I think as you said getting very good survivorship care, and then there are always letters and things that go out to your primary care provider, and they’re much more comfortable calling and talking to us about things, and also that serves as some education about the things that we’re talking with patients about and the things that we’re counseling them about, and so I think that’s a very good way to connect us with the primary care provider.

**Andrew Schorr:**
Now, as I’ve done programs on pediatric cancer, many of the pediatric cancer experts have said you know you go to the local pediatrician, and there are certain types of cancer they may never have seen before in their entire career or they’ve seen maybe very few cases of pediatric cancer. Fortunately it’s rare, but if you take the whole country, we’re talking about 12,000 cases. So do you find that those pediatricians or even then internists or family doctors later welcome your expertise and sharing it with them?

**Ms. Anderson:**
They do, yes, and they’re generally pretty invested in their patients because they’ve already been there with them through their childhood, and so they’re generally very willing to do whatever it takes to participate in their healthcare.
Andrew Schorr:
So Cole, you are participating in this one-year program now, so for people in the Oregon/southern Washington State area who can drive over or take the train or take the bus, however, what would you say to them about getting involved? What would you say the advantages have been for you?

Cole:
Just knowing, I guess, having more knowledge about what happened and being able to transfer that knowledge to like you said you primary physician so they have more knowledge or can speak to other people about it who can speak knowledgeable about it, and also it’s just encouraging to be a part of that and giving back to others that were in your same situation. So I definitely encourage anyone, I know Portland has great mass transportation, so anybody in the Portland area definitely get involved.

Andrew Schorr:
And you can ride that cable car at OHSU.

Cole:
Exactly, you can ride the cable car, you can ride a bus, the MAX, the trolley.

Andrew Schorr:
There you go. So Kelly Anderson, we talked about we know that OHSU and Doernbecher are research institutions too. By participating in the program, I know so many young people have come through cancer want to give back. Can they work with you and your team too with research that may help other young people who are or have been treated for cancer?

Ms. Anderson:
Absolutely. There’s always ongoing research on not only specific late effects but how often they’re occurring. The most exciting research lately is coming out about prevention; what can we do to make some of these things go away altogether, and some exciting research happening in fertility is can we take ovarian tissue and/or testicular tissue of kids who haven’t reached puberty yet and can we freeze those and then have those work later on when the child grows up. There’s also a lot of research going on in genetics. Could we do a blood test and tell whether you will or will not tolerate certain drugs or whether you have a much higher incidence of say heart problems with something or other lay effects based on your genetic profile. So those things are pretty exciting and hopefully it will yield a lot of good information over the next years.

Andrew Schorr:
So Cole, how does that sound to you because you have to wonder when you come out the other side, whether you’re religious or not, is what’s it all about? What’s life about? And so I imagine this participating in research sounds like a good opportunity. What do you think?
Cole:
Oh I absolutely agree. The more research and development that we do and more that me personally that I want to get involved as much as possible, and all these new breakthroughs and technology and everything is breaking through all these great things, and I couldn’t agree more, and I would love to get involved in all this.

Andrew Schorr:
Well, Cole, I want to give you an opportunity to do one more thing. So you know that had you been diagnosed with advanced testicular cancer 10 or 15 or 20 years ago or maybe even two or three years earlier, you might not be talking to us today. What do you say to the people whether they’re at Doernbecher or researchers who helped develop medicines, when you think about it what do you say to them so that you can be here with us today?

Cole:
I guess I don’t really understand the question. I’m sorry.

Andrew Schorr:
I guess I’m asking about are you grateful?

Cole:
Oh absolutely. I try to make it back up to Doernbecher as much as I can. I know I definitely hang out. I go eat and hang out with a lot of the doctors and nurses that are up here right now. I definitely keep in contact with all of them, and I definitely relay the appreciation and gratitude that I have for them. There’s only so much you can say to someone who really saved your life. I try to do as much as I can, but yes, I absolutely love every person that was ever involved in cancer research and in my recovery.

Andrew Schorr:
Well, you’re a big handsome guy there with that Superman outfit on, so I’m sure the ladies will appreciate hugs, and I want to wish you all the best Cole Connealy.

Cole:
Thank you so much.

Andrew Schorr:
And if you’ve got something to sell that I can use, give me a call, and I’ll try to increase your sales commission, all right?

Cole:
Wonderful.
Andrew Schorr:
Yes, thank you, and I hope we can get together and have a conversation like this like 50 years from now; I’d like to be around.

Cole:
I think you will. You’re prime time right now.

Andrew Schorr:
Yes, thank you buddy, and I look forward to you having the relationships you dream about, the children you dream about, and a long, happy, successful life. All the best to you and Kelly Anderson at the Doernbecher Childhood Cancer Survivor Program, all the best to you because isn’t it great that we can talk about survivors and also that you’re there for them for so many years with your team. Thank you for what you do, and I appreciate you being with us today.

Ms. Anderson:
You’re welcome. Survivors are a wonderful group to work with.

Andrew Schorr:
Yes it sounds like it. Cole’s a great example. Here’s the phone number again by the way: (503) 418-5150. Also as I said, we do this program every two weeks, and we’re going to have a wonderful program two weeks from tonight, and that’s with Dr. Fay Horack, and she is at OHSU, and she is a neuroscientist or neurophysiologist helping people with Parkinson’s Disease and movement disorders as they use exercise to limit the effects of the symptoms and disability of Parkinson’s. It’s fascinating stuff that’s two weeks from tonight on our Ask the Experts program.

Thank you for joining us tonight. I look forward to a lot more discussions with young people and have the numbers of cancer survivors grow of course in any age group, but wouldn’t it be great if we could prevent it? Some cancers are preventable, and we’ll talk about that on other programs and also limit the effects and catch it early so you can live a long, full life and then have the support of wonderful people like the folks at Doernbecher and at OHSU and other centers like it.

Knowledge can be the best medicine of all. Have a great night. Thank you for joining us tonight. I’m Andrew Schorr. You’ve been listening to Ask the Experts brought to you by Patient Power and sponsored by Oregon Health and Science University. Goodnight.

Please remember the opinions expressed on Patient Power are not necessarily the views of Oregon Health & Science University, its staff, our sponsors, partners or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. Please have this discussion you’re your own doctor, that’s how you’ll get care that’s most appropriate for you.