

State-of-the-art treatments for childhood leukemia

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Webcast

Blythe Thomson, M.D.

Jan Keller

Ricky Keller

Hosted By Andrew Schorr

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INTRODUCTION

Andrew:

Hello and welcome once again to one of our Seattle Cancer Care Alliance Patient Power programs. We do this every two weeks. Tonight is a live webcast, and we're going to be discussing leukemia in children, and fortunately state-of-the-art treatments that over the years have made a difference where, quite frankly, when you think back just a few years ago if a kid was diagnosed with leukemia most of the time it was fatal, and then over the last years most of the kids are living and living well. So we invite your calls today as we talk about leukemia in children with an expert from Seattle's Children's Hospital and Regional Medical Center and the Seattle Cancer Care Alliance. We'll be meeting Dr. Blythe Thomson, who is both a researcher and a clinician, a hematologist, oncologist for children in just a minute.

And we invite your calls any time along the way, 877-711-5611. You can also send us an e-mail at Patient Power at seattlecca.org.

First I want you to meet a young man, ten years old, a fourth grader from Federal Way, Washington, south of Seattle, Ricky Keller. And Ricky came home from school, he had a normal day at school, he's got homework waiting for him after this broadcast. He is an incredible young man because if you go back to May of 2004 he had a really bad visit to the pediatrician. He went one day, he wasn't feeling well, they couldn't find anything. Then he went back ten days later and before he knew it he was weak. He was feeling terrible. Before he knew it, he was in the emergency room. He went at 11 in the morning to the doctor. At eleven o'clock at night in the hospital his family was told that he had ALL, acute lymphocytic or lymphoblastic, sometimes called that, leukemia, a common leukemia when a child does have leukemia. Fortunately leukemia is not a common ailment for children, but when it happens, typically it is ALL.

Ricky, the good news is how are you doing today? How are you feeling right now, Ricky?

RICKY SHARES HIS STORY

Ricky:

Pretty good. Pretty good.

Andrew:

Speak up there, buddy. So you had a pretty normal day at school?

Ricky:

Great day.

Andrew:

Oh, there you did go. I can hear you. But going back four years ago you were a pretty sick guy, weren't you?

Ricky:

Yeah. Yeah.

Andrew:

And so now you're getting ready to do your homework. Do you feel like a pretty healthy guy now?

Ricky:

Yeah, really healthy.

Andrew:

Now, what are some of the things you do? I know there are some sports you like.

Ricky:

Yeah, I like football. I like fencing. I do Cub Scouts and fencing. I can't do football, basketball or soccer, though, because I have a medical port inside of me and--yeah. But I still like to do football, basketball at school, yeah.

Andrew:

Okay. Well, good for you. And I know at some point you'll get that port where they put that medicine and you'll get that out, and you'll be a busy guy. And I wanted to tell folks that I have a young friend, Aaron, who lives where I do, and he was diagnosed when he

was four with ALL, and he was treated for three years or so, as Ricky was, and then and he's 14 now and he's a very active 14-year-old boy and you'd never know what he had gone through. And that's the good news.

Ricky, we're going to let you go, buddy, and when we come back later on we're going to hear what you'd say to other kids. But we want to spend a little time with your mom, Jan.

Jan Keller, you have four kids, and I know your fourth child was born six weeks before Ricky's diagnosis. You have four kids, Ricky is in kindergarten and you go to the doctor, the first time, the pediatrician, and they can't find anything, and then he gets real sick and then you go back. That must have been the worst day of your life.

JAN KELLER SHARES HOW SHE FELT AFTER RICKY'S DIAGNOSIS

Ms. Keller:

It really was, and I've talked to other parents who have had children diagnosed with cancer, and one of the things we've all agreed on is you have a life before and then there is this horrible event and then you have a life after. It becomes one of the defining moments of your life.

Andrew:

You were worried, of course, once you heard about cancer and leukemia and Ricky, and I know you had told me on the phone that you had had a schoolmate many years ago who died of leukemia as a kid.

Ms. Keller:

Right.

Andrew:

You knew how terrifying it was, but then you started to get information, and that's what many of our listeners are doing tonight. And did that give you hope?

Ms. Keller:

Oh, most definitely. I think like most people when I heard "cancer," you know, it's terrifying, but the most hopeful thing was when the following day I began to speak with the doctors and find the materials that are out there for patients and their families, I realized that cancer is not the automatic death sentence that it was when I was a child. There is so much out there, information, treatments, protocols, wonderful physicians, and those things are critical, especially in the first days following a diagnosis.

Andrew:

Now, Ricky was in the hospital for a long time. How long was he in the hospital for receiving treatment?

Ms. Keller:

63 days, initially.

Andrew:

Wow.

Ms. Keller:

And that's an unusually long treatment for an initial diagnosis. He had a few unusual complications, mainly his white counts were not strong enough for him to go home. But

I've heard of children who respond a little more quickly, who are out within ten days to two weeks on a first visit.

Andrew:

Well, we'll find out more about that. And then his treatment went on for just over three years?

Ms. Keller:

Just over three years. It went from the middle of May in 2004 to just this past July. July 30th was the last day of chemo.

Andrew:

And how would you say Ricky's doing now?

Ms. Keller:

Oh, he's wonderful. He feels so good, of course, that I now find myself, you know, Ricky, that's enough, where for three years I would have been delighted if he had had that much energy. So he's a normal, happy, healthy ten-year-old. And it's wonderful to see that.

Andrew:

Yeah, I have a ten-year-old boy now, and you can love them and they can drive you crazy. But I guess after he was so sick you're kind of delighted to have him driving you crazy.

Ms. Keller:

Yes.

Andrew:

I want to also make one other comment about your family before we meet Dr. Thomson, begin to learn more about leukemia and treatments.

Ms. Keller:

Sure.

Andrew:

And that is what is so neat is as people--families who have been touched by leukemia sort

of come out the other side of it. They're very dedicated to helping others, which is why Jan and Ricky are with us today. But you've also been raising money and a lot of that through the leukemia and lymphoma society. Ricky kind of picked them and he's been raising money, and how much has he raised with the help of friends and family?

Ms. Keller:

To date it's almost right at \$20,000, and it's very exciting. I'll tell you, when Ricky was first diagnosed of course it's crushing, not just emotionally but it can be financially as well. And I had some wonderful family members who just picked up and helped. And the one

who really served as a father figure to me at that time because my own father was gone, he told me at the time he would do anything to help me. He never wanted me to pay him back. He just wanted me to pass it on. And I really think that that's one of the things that mentally Ricky picked up on and has run with it. So we're trying to with the fund-raising we're trying to pass it on to the others. We had help and we want other people to know that help is out there.

Andrew:

We'll come back to you with sort of how your family coped with this, but now let's get to more of the medical side of it.

Joining us today is Dr. Blythe Thomson and she is a pediatric hematologist–oncologist at Seattle's Children's Hospital and Regional Medical Center, which is part of the Seattle Cancer Care Alliance with the Fred Hutchinson Cancer Research Center and the University of Washington.

So, Dr. Thomson, help us understand. We may have some people where they're listening to this, and their kid was just diagnosed or friend or family member. They're trying to understand. What is leukemia in children? What's gone wrong?

DR. THOMSON DEFINES LEUKEMIA

Dr. Thomson:

First I wanted to thank the very gracious family who has joined us tonight and also thank them for all their hard work in raising money for the Leukemia and Lymphoma Society. They've done an amazing job.

To answer your question What is leukemia, leukemia is cancer of the white blood cells. And we don't know what causes it in children. There are some thoughts in adult leukemias that there might be some reason why people get it, but in children we have not figured out the cause of it. Cancer of the white blood cells is divided into a variety of different types. The most common, as you said, is acute lymphoblastic leukemia. The second most common in children would be acute myelogenous leukemia. And what that basically tells you is that for some reason something has gone wrong in the bone marrow. The bone marrow is where white blood cells are made, so that would be sort of the spongy stuff inside people's bones. If you ever broke open a chicken bone you saw that kind of squishy stuff in the middle. That's the marrow.

So, in the big bones of your body, your marrow makes these cells, the white blood cells, red blood cells that keep you from being anemic, and you make little tiny cells called platelets that keep you from bleeding if you cut yourself. Well, something happens when you have leukemia, we don't know what. For some reason one white blood cell will just start making more and more and more of itself, never dies and eventually take over the bone marrow then cause the normal blood cells to be essentially sort of pushed aside. You become anemic. You start having bruises because you're not making those healthy little platelets, and you get a very low white blood cell count, and you're at risk for infections.

You start having pain, you can have fevers, and you just feel terrible. And the doctor will find that you're very anemic or have a low blood platelet count and then will start seeing these abnormal blood cells when we take a blood sample. So that's where leukemia comes from.

JAN KELLER DESCRIBES RICKY'S DIAGNOSIS

Andrew:

Okay. Jan, does that sound like the way Ricky showed up at the pediatrician that second time?

Ms. Keller:

That was exactly what happened with us. He had had some intermittent fever at night and had some pain in his chest. It was his breast bone, of course, what I know now, right before diagnosis, some pain in his lower back and his pelvis as well. So that was exactly what happened with us.

Andrew:

Now, Dr. Thomson, leukemia is kind of really serious in kids, but it's not something most pediatricians see often or maybe just a few times in their career. But I guess it's pretty dramatic. Once you check the blood it becomes pretty clear what's going on.

Dr. Thomson:

Majority of time, I mean yes, cancer is rare in children. To give you some sort of frame of reference: Each year approximately 250,000 women are diagnosed with breast cancer of some sort. Comparing it to children though, with ALL, there's only 2,000, a little bit over 2,200 patients who are diagnosed with pediatric ALL every year. So 250,000 versus 2,000. It's a rare disease, but when a pediatrician sees it in their office it's dramatic. It's frightening. The good thing is that there's a large group of consortiums across the country who have invested a lot of significant resources and time to take care of these kids.

UNDERSTANDING HOW FAR WE HAVE COME IN RESEARCH

Andrew:

Dr. Thomson, so I mention that we'd made tremendous progress. So help us understand

how far we've come and how Ricky situation now--and I mentioned that other young man who's 14 years old, chasing girls around my neighborhood, that they're more typical now.

How have we come so far and how far have we come?

Dr. Thomson:

I think the reason why we've come so far is through a cooperative group effort. So the majority of children who are treated for cancer in the United States at present are

participants in research studies, clinical research studies, and the majority are run through the Children's Oncology Group. The Children's Oncology Group is a group of over 250 institutions in the United States, Australia, Canada and Europe where we recognized that if we work together we will have a better chance of eventually curing pediatric leukemia.

And to give you an example, if you looked at a child who was diagnosed with ALL in the 1970s the survival at five years would be around 20 percent. Today with the current therapies, for standard risk ALL, some of those children who have some favorable prognosis have a 95 percent survival. So that through cooperative group studies but most importantly through the participation of families and children and being willing to participate in clinical research. Overall children with ALL have upwards of 85 percent and approaching 95 percent of event-free survival. That means they get their chemotherapy, they are doing great, they're running around having a normal active life and chasing girls

Andrew:

There you go. Or the girls chasing boys.

Dr. Thomson:

Or the girls are chasing them.

Andrew:

There you go. We're going to take a break on our live Seattle Cancer Care Alliance Patient Power webcast. We invite your calls if you have questions for Dr. Blythe Thomson or for Jan Keller, a parent who has been through it. The number again is 877-711-5611. 877-711-5611. Or you can send us an e-mail, as some people already have, to Patient Power at seattlecca.org. We'll be back with much more Patient Power sponsored by the Seattle Cancer Care Alliance.

HOW IS TREATMENT DETERMINED?

Andrew:

Welcome back to our live Seattle Cancer Care Alliance webcast. Andrew Schorr here. So I'm an 11-year adult leukemia patient, and I'm proud to say that I'm on the board of the Washington Alaska Chapter Leukemia and Lymphoma Society. And thanks to them for connecting us with Ricky and Jan Keller from Federal Way, Washington. They've been very devoted to fund-raising and turning Ricky's diagnosis of leukemia and his successful fight so far against it into something where they can do a lot of good for others. So thanks to them. And I know researchers like Dr. Blythe Thomson at Seattle Children's are very grateful for their dedication, as she said earlier.

Dr. Thomson, so when somebody like Ricky is diagnosed, they find themselves in the hospital, it's acute, what are the treatments that are typically brought to bear? Is it combinations of medicines to kill those aberrant, if you will, white cells? What are you trying to do? And how do you go from knocking it back to knocking it out?

Dr. Thomson:

So chemotherapy is the backbone of therapy for ALL and the majority of other leukemias.

Pediatric ALL is treated essentially is in blocks of chemotherapy. The first month is called induction, and the intent of induction is to reduce the tumor burden, obviously to also take care of the child, get their pain under control. And the pain that Ricky felt is actually from the marrow space being literally almost stretched, and it causes actual bone pain from the marrow being packed with leukemia cells.

So the first month, induction. Essentially the first month we give a combination of typically four chemotherapies. We also give chemotherapy into the spinal fluid to either treat or prevent leukemia cells coming back into the spinal fluid. It has a tendency to hide there. And we give a combination of medicines either by mouth, through IV, through a port, a more permanent line that's put in in the child, and sometimes we have to give shots.

We do a bone marrow test at diagnosis, then after one week of therapy, sometimes after two and then at the end of the month. What we want to see at the end of that first month is a nice, healthy bone marrow, all those normal, healthy cells that have been pushed to the side have recovered and that we see very few leukemia cells. The current research studies are better defining what is a deep remission and how to best divide up the patients or give them risk adaptive therapy where we're treating patients based on their response, on their unique features, their age, their white count, the chromosomes of the leukemia. That will be the first month. We do a lot of work to basically define the leukemia and define their good response to that.

The second month, the second block is consolidation. And the intent is to consolidate therapy, keep them in a good remission and additionally give a little bit extra chemotherapy into the spinal fluid. Some patients do get radiation, radiation to their brain and their spinal fluid if they have leukemia there.

And then we go on and give them a break called interim maintenance. And then we essentially repeat the first two months. That's delayed intensification. We've recognized that that has really added to the overall good outcome for these kids. And then they go into what's called maintenance where they are getting a combination of chemotherapies, a majority of them are by mouth, and they're only coming to visit us once a month for IV chemotherapy.

But if you add it all up it's a lot of chemotherapy. We use a lot of different kind of medicines. We use a lot of different agents to basically target that leukemia cell every way we can so that it will go away and stay away.

Andrew:

Now, the way I think of it with combination therapy now, and I had this for my adult leukemia, was one drug is kind of hitting it in the mouth and another is in chopping it at the knees and one is in the abdomen, and you're just trying to make that wily cancer cell just be knocked down and knocked out and hitting it from different directions, and it looks like with different intensities over time too.

Dr. Thomson:

Absolutely.

Andrew:

You mentioned that care, it sounds like, is becoming increasingly individualized. So you're looking almost at the biologic level at what's going on for that particular kid. And so it sounds like you have different strategies depending upon what you get back from the lab, I guess.

Dr. Thomson:

Absolutely. What we have, through a lot of cooperative group studies and a lot of patients what we have learned is how to better define leukemia. Initially we take the patient's age at diagnosis. So an infant is treated one particular way because we recognize that infants are actually a more challenging group of patients to get in remission and keep in remission. Then we take an older adolescent, also we find that they need a little bit more intensive therapy. So kids over the age of ten get a little different therapy, more intensive.

Then we take a look at their white count, white blood cell count. Is it high? Is it low. Then we divide the patients up into what we consider standard risk, so that would be over one year of age and less than ten and a white blood cell count at diagnosis of 50,000 or less. High risk, that would be an adolescent or a high white blood cell count at diagnosis. And then infants are treated differently.

Then we take a look at the type of leukemia. Essentially there's two types, and that's going back to the original cell that led to the leukemia. There's B cell and there's T cell. We recognize that T cell needs a little bit different therapy and there are research studies that actually have drugs that have been engineered specifically for T cell disease. Then we take a look at how the patient responds that first week, two weeks, end of the first month.

Then we take a look at their leukemia chromosomes. So we look at the chromosomes that are within the leukemia cells. We also see what the DNA content of the leukemia cells. Do they have chromosomes that we've learned from prior studies make it a better leukemia, or do they have chromosomes such as the Philadelphia chromosome that we've recognized need different individual therapy. Imatinib that had been used for CML, we do use that for ALL. Or do we need to consider a transplant? Is this a very high risk leukemia where their very best chance of cure would be to go to some type of bone marrow transplant?

So each patient in that first month, we collect as much information as we can, sit down with the family and say, This is what we've learned about your child's leukemia. This is the path that we think we should go on and essentially try to individualize it to each individual patient and their leukemia.

JAN KELLER DISCUSSES THE IMPORTANCE OF BEING A PRO-ACTIVE PARENT

Andrew:

Now, that brings me to a question for Jan as a parent. So, Jan, you were doing your information gathering, and then you were having conversations with your doctor. So it seems like you really have to be very involved as a parent, and you have these discussions to try to get at what's right for your kid's situation.

Ms. Keller:

That's right. And of course the doctor is going to give you any information that they can, and we also pursued information from the American Cancer Society and the Leukemia and Lymphoma Society. And my husband's background made him able to sift through quite a bit of medical information as well. But Ricky didn't respond, quote/unquote, typically. We did have to make some adjustments for what he in particular needed. And as a parent, I think the more proactive you are in determining what will benefit this individual child, then the better the outcome.

Andrew:

Here's a question we've gotten in via e-mail for you, Dr. Thomson. John from Seattle writes in, "Are there studies showing that acute lymphoblastic leukemia, ALL, is a different disease in a 15-year-old versus an adult or a child?" Because you were talking about different approaches at different ages as well.

WHAT HAVE WE LEARNED ABOUT CHILDHOOD LEUKEMIA?

Dr. Thomson:

I think absolutely pediatric leukemia is a different disease, and we're learning more and more about it. The best example would be to look at the chromosomes that are abnormal in the leukemia cells and the difference in children and then the abnormal chromosomes we find in adult leukemia. I had mentioned Philadelphia chromosome, the positive leukemia which is a portion of chromosome 9 has moved to chromosome 22. That's much more common in adults. It's a much harder leukemia to treat. It's more unusual in children.

And then on the flip side there are some abnormal chromosomes that you find very commonly in children, portion of chromosome 12 being a link to chromosome 21, or extra copies of several chromosomes, much more common in children. They do better. They have much better outcome. Very unusual in adults. You just don't see that very often in adults. So, yes, pediatric leukemia is different than adult leukemia.

The one group of patients, though, that is current research focus here and at other institutions is the young adult population and where they are best treated. Do they have a leukemia that's like a child, or do they have a leukemia that's more like an adult? And that goes back to sort of individual therapy. Do they have features that make it more of a pediatric leukemia, or do they have features that make it more of an adult leukemia? But there is a lot of push right now for the adult oncologists and the pediatric oncologists to work together. And the adult oncologists are adopting some pediatric ideas, and we are always looking at the adult studies and research protocols to see, how we can advance this even further, especially for the young adult population.

Andrew:

Now, you talk about advancing it even further. So there have been tremendous advances, but we're not at a hundred percent.

Dr. Thomson:

Yeah, we want to get to a hundred percent.

Andrew:

Yeah. What are some of the natty challenges?

Dr. Thomson:

I'm sorry?

Andrew:

What are some of the natty challenges where--that 10 percent, where are the road blocks where you're just so frustrated because you look at it from a science point of view and you say, We just can't quite figure this out. We haven't found the right drug combination when this situation or that situation comes up. Where is the challenge?

Dr. Thomson:

I think the challenging populations are the children who are not going into a quick response, the patients who are what we would call an induction failure, where when we looked at their bone marrow at the end of the first month we're still seeing leukemia cells. The adolescents and young adult population, they have overall survival, event--free survival in the high 70s to mid 80s, so they're a challenging population. And that may be a unique feature of the leukemia or something that we just don't understand.

And then the T cell patients, patients with T cell ALL. I mentioned previously there was a drug that's been engineered, Nelarabine, specifically for T cell leukemia that is currently in trials through the Children's Oncology Group.

And then the other big challenging group is the infant leukemia who relapse very quickly and are very difficult to take care of. They don't handle chemotherapy very well. These are babies with leukemia and are a very difficult patient population to take care. They have a lot of side effects. They have infections. They have toxicity. So there are many groups that we really have a long way to go. And I haven't even touched upon?

Andrew:

We're going to take a break

Dr. Thomson:

Ok.

Andrew:

And we'll come back with much more. We have to put this in perspective, though, that tremendous progress has been made. Also starting this next weekend there's a big meeting in your field of hematologists and oncologists and studies presented again to show how research is moving forward in the leukemias. As part of the discussion we'll love to know what you think will be discussed there and a little preview of what news may come out.

We'll be back with more Patient Power as we discuss leukemia in children. Give us a call. 877-711-5611. Several people have sent e-mails and you can too at patientpower@seattlecca.org, patientpower@seattlecca.org.

We'll be right back with more Patient Power sponsored by the Seattle Cancer Care Alliance.

STUDIES IN LEUKEMIA THAT HAVE YET TO BE EXAMINED

Andrew:

Thanks for joining us tonight for our live Seattle Cancer Care Alliance webcast. We're talking with Dr. Blythe Thomson who is a pediatric hematologist-oncologist with the Seattle Cancer Care Alliance and Seattle Children's Hospital and Regional Medical Center.

And she was just describing the challenges we still face. We are talking about leukemia, we are talking about cancer, and while tremendous progress has been made with pretty aggressive care there are people who don't respond the way we would like and lots of need for more research.

Now, you were saying that there was an area we haven't touched on yet, Dr. Thomson. What's that?

Dr. Thomson:

Comes back. In your bone marrow, your spinal fluid, wherever.

Andrew:

Yeah, that's terrifying. So do you call that relapsed leukemia?

Dr. Thomson:

Yes.

Andrew:

And tell me, how does that show up? So there are kids gone through all this treatment and you think you're doing well, and then what typically happens?

Dr. Thomson:

It's unpredictable, and often they come with, unfortunately, moms know before anybody because they were there with their child when the leukemia was first diagnosed. Obviously, when a patient is on therapy or even after they've finished their therapy they're always a patient at a cancer center, and we always want to see them back if there's any concern. They may have the resurgence of their bone pain that they may have had a diagnosis, more bruising, fevers that won't go away or could come in and we'd find an abnormal blood count. Or they could have headaches, a new lump or bump, and we would find the recurrence of their original leukemia.

Also in the back of everybody's mind there's always the risk of a secondary cancer. It's not related to the leukemia, more related to the medicines and the chemotherapy that they've gotten, that they've received. That's always a risk, but the bigger risk to any patient who has leukemia is their leukemia coming back.

Unfortunately, relapse leukemia is the number one cause of cancer-related death in children, and relapse leukemia is actually the fourth most common cancer in the United States. Number one is leukemia, number two would be brain tumors, and relapse is actually the fourth most common disease.

Andrew:

Oh, my. Now, when might this happen? Is it like a week later?

Dr. Thomson:

No. Typically, it would be unusual in the first week. It would be any time after you're in remission. The first three to five years is the time where we're watching very closely. When a patient finishes their chemotherapy, that maintenance chemotherapy where they're taking it at home, they finish that, they're doing great. We have them come in once a month just to make sure everything is still doing well for that first year. Then we start spacing it out. But we all want to see a mom and a child if there's a worry. The most dangerous time is the first five years.

Andrew:

Right. So, Jan, you hear this so your heart probably starts beating a little faster. So you go in all this, though, with your eyes open. And I'm sure you're very grateful that from that day back in May of 2004 you worried about your kid being at death's door, he's gone through a lot but you have him like playing video games now, and I guess we can celebrate that even though there's always this holding your breath a little bit too.

Ms. Keller:

Well, of course. And I think as far as that goes not only do I know and my husband knows what to look for, and we would be extremely proactive if there was a hint of a problem, but

Ricky, as an older child, he's ten now and he's aware of what he needs to be aware of as far as how he feels and what's going on with his treatment. So, yes, it's very scary, but on the other hand he's tough. He's a tough little guy, and we're more educated and we understand more about not only what we're facing but what we might face.

HOW ABOUT SIDE-EFFECTS?

Andrew:

Well, good for you for being so aware of it.

Here's an e-mail question we got in from Molly from Seattle. Dr. Blythe, she writes, "Kids treated with chemotherapy and radiation therapy often develop long-term side effects." And maybe you can put that into perspective for us. "Has a method of tracking been developed to monitor long-term side effects, and are you doing anything special at the Seattle Cancer Care Alliance?"

Dr. Thomson:

It's a great question and it's becoming an increasing problem. There is some estimates that one out of 250 people in the year 2010 will be an adult survivor of a pediatric malignancy of some sort. They may have had a surgery only or they may have had a bone marrow transplant.

The SCCA has built an amazing survivorship program that's headed by Dr. Friedman and Dr. Lee and funded by the Lance Armstrong Foundation where they are doing research studies on late effects. Specifically, are the kids growing? Are they having neurocognitive? Are they having troubles in school? Are they having cardiac effects of chemotherapy? Or are they growing into normal, healthy teenagers and young adults who are having children of their own?

So there is a definite push here and at other institutions across the nation to recognize that there is this unique population who has had a lot of therapy and radiation where we actually have unique challenges. And honestly we need to know a lot more about it, and the SCCA has built an amazing program to answer those specific questions. We don't know a lot of the questions. We don't know what the 20-year effect of something for a one-year-old would be because, honestly, kids 20, 30 years ago were not living and they were dying of their disease. Now we have the rare and wonderful opportunity actually to take care of people who are really long-term survivors of a pediatric cancer.

Andrew:

Right. And this is of course an issue, the late effects of treatment throughout cancer whether you're a kid or an adult..

Dr. Thomson:

Absolutely.

CURRENT TREATMENTS FOR CHILDHOOD LEUKEMIA

Andrew:

But kids with a whole life in front of them. So let me ask you this then as far as drug development. So you're using very powerful chemotherapy agents and radiation and trying to do it in as targeted a way as you can. Are there some new agents that are coming in that can target the cancer but have less risk of either short-term or hopefully long-term side effects?

Dr. Thomson:

Well, probably the best example of that would be imatinib, or Gleevec, as it's commercially known. Imatinib is used most commonly for chronic myelogenous leukemia, and where a lot of patients including children are being treated with imatinib only and with close observation to make sure the leukemia remains gone. And they are getting imatinib only which is an oral medicine where before they would have gone to bone marrow transplant. So certainly imatinib would be a very good example where we've swung from a very aggressive therapy, bone marrow transplant--which some patients who have CML absolutely need if they have developed new clones or they're not responding to their imatinib or their leukemia comes back--where we're swinging a little bit more towards the imatinib alone, which is just a by-mouth chemotherapy.

A great question would be if you have a five-year-old who has CML how long can they stay on imatinib and should we be considering transplants for them when the best donor is available. So that would be a best example where we've really got a targeted agent, and that's really where oncology research is going, to targeted agents that will basically attack a specific portion of the cell cycle or a unique mutation or something specific about that leukemia cell and protect the rest of the body as best you can.

Andrew:

So we have this big hematology-oncology meeting coming up in just a matter of days. So will that be a focus of some of the discussion when it comes to pediatric cancer is how you can have less toxic agents?

Dr. Thomson:

Certainly, the American Society of Hematology meeting is in Atlanta this weekend and, yes, pediatric oncology is going to be discussed there. In pediatric research we have not gone really very far away from multiagent, rather intensive chemotherapy, though what we are doing is taking those backbones of chemotherapy that have given the very good event-free survivals that we've discussed and adding in these very specific targeted agents.

Best example would be the plenary session that one of the physicians, Dr. Schultz will be presenting from British Columbia Children's where he discusses the addition of imatinib to a backbone of ALL therapy for the patients who have the Philadelphia chromosome positive ALL, and it has some very promising early results. We'll have to see if it pans out, but the one-year event-free survival was 20 percent improvement over previous results. We'll

have to see if that continues over three to five years, but certainly that is one of the topics that will be discussed at ASH this year.

Andrew:

We've been discussing leukemia in kids with our expert, Dr. Blythe Thomson from the Seattle Cancer Care Alliance. We also have with us Jan Keller, a mom who's been through it, a mom with four kids with her oldest child, Ricky who was diagnosed when he was in kindergarten age six and a half. Now he's ten, playing video games right now. We're going to get Ricky back on in just a second. He went through over three years of treatment.

Just help us understand how treatment is delivered, Dr. Thomson. So Ricky had to stay in the hospital for a long time because he had some complications, but typically more often can someone have some treatment in the hospital and then be an outpatient and then go home?

Dr. Thomson:

The majority of ALL therapy is as an outpatient. There are a few times where I patient would come into the hospital for a chemotherapy infusion. More commonly though the reason to come in the hospital is you have a fever or an infection because of the low white blood cell count. I think Ricky's mom commented that he had a low white blood cell count that kept him in the hospital for many days. When we give leukemia therapy we're trying to kill bad white blood cells, cancerous white blood cells. But we have normal white blood cells, and so those normal white blood cells, the number gets quite low, you're at risk for infections, and that's probably the more common reason to come in the hospital. But the majority of chemotherapy for pediatric ALL is done as an outpatient.

Andrew:

Now, where are we, we talked about the drugs you're working or have to treat the cancer, but these are heavy-duty therapies. Where are you in helping with the side effects? For instance, like nausea, can you help just make it a little easier there?

Dr. Thomson:

We have, if you look back maybe even to ten years we've made some amazing strides.

I'm kind of dating myself, but when I was a resident learning how to be a pediatrician everyone was nauseous and we had very few medicines that would help, and everybody was throwing up and it was awful. But in the past ten or 15 years there have been great serotonin agents, ondansetron and granisetron that really have significantly impacted upon the quality of life for all these children and for adults.

So the norm is to feel okay. We are very proactive if anybody is feeling nauseous and feeling awful. Our goal is for you to be feeling well enough to go to school.

HELPING YOUR CHILD RETURN TO SCHOOL AFTER A LEUKEMIA DIAGNOSIS

Andrew:

Now, let's talk about going to school because we had a question about that. Karen wrote in from where I'm from, Mercer Island, Washington, and she has a ten-year-old who's just gone back to school after successful treatment for leukemia. And the concern was, well, how do you reenter? Now, at the SCCA are there some folks or social workers or even you as a physician who help the kid and the school understand what's going on and the needs of this child going forward?

Dr. Thomson:

Absolutely. And I think it's not only for that child to reintegrate into the school but also to help the other kids and other families understand what leukemia is, that it's not

contagious, how to treat the child and when to let the school nurse, you know, or not to send your other child to school with chickenpox because there's a child there who's undergoing therapy for leukemia.

We are more than thrilled to come to the school. We have great nurse practitioners, and they have slides and demonstrations. We have child life people and we have a great team of social workers who are more than happy to go to the school, meet with the kids. I've gone to schools and met with families and had parent night where there was a real worry.

She should approach her doctors and her nurse practitioners and the hospital and ask if they can come to our school and answer some questions. We are more than happy to come, and it really makes getting back into school and being a normal kid again a lot easier.

Andrew:

Let's underscore this: Leukemia is not contagious.

Dr. Thomson:

No, not at all.

Andrew:

It's not contagious.

So Ricky, in your school as you came back were the kids pretty helpful and pretty friendly? It sounds like you've also had kids who also helped you raise money, right?

Ricky:

Yeah. Yeah, the kids were nice, and they helped me raise money. Yeah

Andrew:

Well, that's neat. And they understand that you were sick but that you're well now, right?

Ricky:

Right, they were nice. Right. They knew I was sick and then I got better.

Andrew:

There you go. You got better.

So, Jan, what would you say to other parents? You have to be proactive with the healthcare team, and you have to represent your kid and your family. It sounds like it's helpful to be proactive with the schools too, and maybe there are other parents or the PTA. I know in your case they really responded, didn't they?

JAN KELLER SPEAKS ABOUT HOW THE SCHOOL SYSTEM EMBRACED THEIR FAMILY

Ms. Keller:

We had a wonderful school system, and when Ricky was first diagnosed the school came to me and said, How can we help. And from the beginning they worked with us to set up an at-home tutoring program for Ricky that when he felt like going to school he could go and when he didn't it wasn't an issue. But, yes, there are quite a few details. Most schools will arrange for an individual learning plan for the student, and that allows for tutoring or for extended absences if needed. But each school district is different, and parents do need to research from the beginning how to keep their child on track

Andrew:

Now, you had moved to your home town of Federal Way, Washington just two years before, and I know your husband, Rick's, parents nearby.

Ms. Keller:

Right.

Andrew:

You had other family like 3,000 miles away in North Carolina and Tennessee. They came running, didn't they? You were able to get a lot of family support.

Ms. Keller:

Yes, they did. My mother-in-law, of course, was already here. She was actually keeping the other children the day I took Ricky to the doctor where we ended up staying for nearly two months. So she stayed and simply just didn't go home that day and was here for I think ten days. And then my mother got here, and mom stayed for four months. And then my first cousin Julie, godsend, she would pick up. And my family took turns being here so that my other children were cared for while Rick and I were at the hospital with Ricky. It was wonderful. They were amazing. And I don't think I would have made it without them.

ENCOURAGEMENTS ABOUT HOW FAR WE HAVE COME

Andrew:

No, I can understand.

And I'm sure you see that, Dr. Thomson, and also the SCCA, you mentioned social workers, you mentioned child life specialists. There's a whole team to draw on, both at the medical center and also the families need to know to speak up too. And of course one other group I'll bring into play here is the Leukemia and Lymphoma Society, and they have loads of information. You are not alone. Leukemia is not common anywhere, and it's not common in kids, but certainly there are other people who've been down this road, and there are people to talk to, whether they're around the corner or across the country.

So all you have to do is call the Leukemia and Lymphoma Society. It's not just about fund-raising, which is what Ricky has helped and he's been mentoring other people, and you have too, Jan, and your whole family. But there are services, and I know you drew on those too, right, Jan?

Ms. Keller:

Oh, definitely. As a matter of fact the child life specialist with us, one of the first things she did was recommend that we contact the Leukemia and Lymphoma Society, and that was where I started my own research on what leukemia was and what we were going to be facing for the next few years. So that was a jumping off place for us.

Andrew:

Now, when there's contributions like what you and Ricky have worked so hard on, it helps doctors like Dr. Thomson.

Dr. Thomson, are you encouraged? You've got some challenges yet with leukemia in children, but are you encouraged? You look back at where you've come just since you were a resident and now there's these conferences like the one next week. Are you encouraged that we can move forward even more?

Dr. Thomson:

Absolutely. And I think all of the pediatric oncologists here are very encouraged by how far we've come and are challenged by where we need to go and then also to take care of the children that we've given chemotherapy to, not just now but well into the future. So we have a lot. We've come a long way but by no means are we there yet, but we're very encouraged by how well we've done.

And I just wanted to thank all the families who have participated in clinical trials. We truly could not have done this without those children and their families.

Andrew:

That's so true.

So, Ricky, I want you give you a chance to talk to other kids who may hear this program and maybe they've been diagnosed with what you were four years ago. They're not feeling well at all. They're scared. What would you say so them to maybe help them feel a little better about the future?

Ricky:

Well, I'd probably say that just maybe they can see if they can beat it. Just let them get into the habit of saying, I can beat it, I can beat it, I can beat it.

Andrew:

And you have, Ricky, and we wish you all the best. I know you told me on the phone earlier you had this image of your blood cells fighting the bad guys, right, and winning?

Ricky:

Right.

Andrew:

Okay. Kind of like a video game inside your body. I bet you're good at video games. Ricky, we wish you all the best.

And, Jan, what would you say to parents who, you know, have that terrible day that they'll never forget like you had, May 11th in 2004. What would you say to them?

Ms. Keller:

I think one thing that parents hear over and over is, I don't see how you do it. And I heard that hundreds of times when people learned that Ricky had been diagnosed. And my response was, Well, you do it. You just do it. It's your child, and you will get through it. No matter how overwhelming it seems or how devastating it feels you will come to the end of the treatment and you'll make it through. And you'll make it through. You do it because it's your child.

Andrew:

Well said. Well, Jan, we wish you all the best. I know Ricky will have monitoring and you'll go forward and work with your cancer doctors. But all the best to you, your three other kids, your husband, Rick, and Ricky, and may he soon be playing football and basketball to go along with his fencing. All the best to you. Thank you for being with us. Thanks to your dedication in helping others both in numerous ways and through the Leukemia and Lymphoma Society too.

Ms. Keller:

Oh, I hope eventually we'll be able to pay back even a fraction of what other people have done for us. But it's our pleasure and our honor to help.

Andrew:

Well, thank you so much for being with us today. And Dr. Blythe Thomson, hematologist-oncologist at Seattle Children's and the Seattle Cancer Care Alliance, thanks for all you do in being with us to do. We wish you continued progress with your colleagues so that we can say that we can just always cure this cancer and help kids live a long and healthy life. Thanks so much for being with us.

Dr. Thomson:

Thank you and thanks for this wonderful program.

Andrew:

Oh, sure, yes, ma'am.

And on Wednesday December 19th we'll be back with another program, and that will be with my friend Dr. David Maloney, who is an expert in adult leukemias. And we'll be talking about promising treatments for lymphomas--lymphoma, leukemia, of course, very related. It's been increasing in its incidence, but fortunately they have lots of tools to fight it. So we'll be hearing about that. All the best to you. Thank you for being with us. As always knowledge can be the best medicine of all. This has been Patient Power sponsored by the Seattle Cancer Care Alliance. I'm Andrew Schorr in Seattle. Good night.

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