

Saving Lives With Bone Marrow Transplants

Webcast

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Introduction

Andrew Schorr:

Bone marrow transplantation, BMT, has been successfully treating patients diagnosed with leukemia, aplastic anemia, lymphomas such as Hodgkin's disease and many other blood-related cancers and now more recently, experimentally, also autoimmune conditions. In the next hour you'll hear the latest from a renowned expert and real patients who have benefited from BMT. It's all coming your way on Patient Power sponsored by the Seattle Cancer Care Alliance.

Andrew Schorr:

Hello and thank you for joining us this evening or whatever time it is around the world. This is a live webcast. I'm Andrew Schorr, and this is sponsored by the Seattle Cancer Care Alliance as we do every two weeks. Now, the Seattle Cancer Care Alliance is made up of the Seattle Children's Hospital, University of Washington and also the Fred Hutchinson Cancer Research Center. And if you've studied your BMT history you know that Dr. Donnell Thomas and his team really invented bone marrow transplant, and that's what gave rise to the Fred Hutchinson Cancer Research Center. So as we meet an expert from Fred Hutchinson, Seattle Cancer Care Alliance in a couple of minutes we're sort of going to where it all began. Now, certainly there are many major centers around the world that have been helping perfect the approaches for bone marrow transplant and applying it to an expanding list of conditions and age groups, including now experimentally autoimmune conditions like multiple sclerosis and scleroderma and others, and I know you may have questions about that. Hold your questions until a little later on because I want you to meet some inspiring patients.

One of the things that's impressed me being a leukemia patient and not knowing would I need a transplant sometime, but also being a medical journalist, is just the progress that's been made with transplant and also in the mix with a variety of newer drug therapies as well and sometimes radiation and different ways and preparing people for transplant, the expanding ages that people could have for different kinds of transplants and even where cells come from, sometimes from yourself, autologous transplant, sometimes from others, allogeneic transplant, and

now we've even done interviews that are on our websites about the potential of stem cells from the cord blood of babies and being able to expand that and make that useful for an adult. So so much to talk about.

First, I wanted--being a cancer patient people call me, friends, family, sometimes strangers and say, you know, somebody in our sphere has been diagnosed with something serious. So I guess it was back in 2001 I got a call like that from my old friend, Rick Minor, who had lived in Los Angeles as I did, and then he moved to Seattle as I did, and his lovely wife, Joyce, has been diagnosed with ALL, acute lymphocytic or lymphoblastic leukemia, and she was real sick, and they started talking about a transplant. Now, interestingly, Rick and Joyce have lived for years in a houseboat, I think it's about a couple hundred yards from the Seattle Cancer Care Alliance where they have really helped continue to do research in transplant and perfect strategies. Joyce joins us now. You're going to meet some other inspiring patients along the way and of course our medical expert.

Joyce, the transplant for you, you had a lot of family and friends who were tested to see if they were a match, they weren't, and so it ended up being an unrelated donor. Is that right?

Joyce Miner's Story

Joyce:

Hi, Andrew. Yes, that is right.

Andrew Schorr:

And so the transplant ended up being lifesaving, you think?

Joyce:

I know so. I don't even just think so. I know so.

Andrew Schorr:

Now, one of the things we want to mention to people, and there may be people who hear this program live or they go to our replay, or even eventually read a transcript that we add, in the middle of the night, and someone in the family, may be themselves have been told that you might need a bone marrow transplant, and they're terrified. Now, it can be lifesaving, but it's not a walk this the park, is it, Joyce? How long did the whole situation take, the treatment and the recovery?

Joyce:

Well, for me the whole process of just the treatment took four months. Right away after I was diagnosed and they found out that I had ALL leukemia they also found out that I had a Philadelphia chromosome which meant that I couldn't stay in remission with chemo. So I was on the fast track. My only hope was a stem cell transplant. So they put me on the fast track, and I had to complete it three rounds of a chemo recipe which was three months plus another one just to kind of keep me going and keep me in remission until the transplant. So that was four months. And then I was in the hospital for 15 days from the transplant until my cells

engrafted, and then I was a hundred days passed that at the SCCA, the Seattle Cancer Care Alliance, under their care, and then they released me back to my oncologist.

But I would really say that it was probably from the time of diagnosis to a good month or, pardon me, a good year or two, 14, 16 months before I really felt like I was up, not up, healthy, and I could go anywhere and not worry about catching something and that I was kind of on my way.

Andrew Schorr:

Now, we should mention, though, the diagnosis was in late 2001, transplant in 2002, so now we're in 2009, wow. But you are busy in real estate, right, and living a full life.

Joyce:

I'm busy in real estate, feeling incredible. And I am completely off of any kind of my immunosuppressant drugs that I was on.

Andrew Schorr:

And then one other part I think we need to remind ourselves is that if you have a donor, someone else other than your own cells, somebody else has really given you the chance of life, and it was a 37-year-old woman from Wisconsin who you've met, right?

Joyce:

Yes, I have.

Andrew Schorr:

Who you wrote a letter to after a year and it was passed on, and you got in touch with each other and you've met her, and I understand you're going to meet her again this summer.

Joyce:

Yes. She's coming out to Seattle again and we will reconnect. But we've been in contact since then. She's a very special woman.

Andrew Schorr:

I bet you give her a really big hug when you see her.

Joyce:

Yes, I do.

Andrew Schorr:

Okay. Well, we're going to meet a couple of other patients who have had transplants for a variety of reasons as we go along, but I want to introduce our medical expert, and that is Dr. Leona Holmberg, who is a medical oncologist and a

transplant specialist at the Seattle Cancer Care Alliance, very much involved in research, who can help us understand how transplant has matured, if you will, and it certainly has, and how it's expanding.

And, Dr. Holmberg, welcome. I know you've had a busy day in the clinic and it's a very place at the Seattle Cancer Care Alliance, but--I know we're going to talk about studies, but one of the things that I am impressed with transplant is the art of it. So I know you try to do everything evidence-based medicine, but it's also based a lot on the experience of the practitioners, isn't it?

Evidence-Based Transplants

Dr. Holmberg:

It is. Thank you, Andrew, for inviting me. I'm happy to participate in the program. I have to say that medicine in general, though, is evidence-based and scientific driven, but there is a lot of art to medicine for any condition, whether it's a transplant or just treating a general patient in a general medical service. But the majority of our transplants that are standard care are evidence based. They've been proven that they have a benefit to patients. As we learn new things, that's more cutting edge, that's more investigational, that's learning how to applying it into a broader base both for different diseases as well as alternative sources of stem cells, how to do less intense transplants to try to cut down on some of the toxicities like the reduced intensity allotransplants.

Andrew Schorr:

Now, I gave kind of an explanation of some of the different types, like autologous, where someone has their own cells sort of cleaned up and given back to them, and we're going to meet a man in a minute who has had that happen more than once for multiple myeloma. There's Joyce where the hope was in ALL an allogeneic transplant giving her the immune system of a young woman from Wisconsin could restore her totally to health and be curative. Are we still looking toward transplant being curative, or sometimes are we looking at it as a tool to simply knock the disease back just like you'd take a medicine to keep it in check?

Dr. Holmberg:

Well, many of the autologous transplants, unfortunately, still [inaudible] your own stem cells for certain diseases like myeloma, are more to kind of make it a more chronic disease to buy people time while we get smarter and we have more options for them in the future. In other diseases, though, autologous transplants from yourself are really for cure. For example, an aggressive lymphoma, a diffuse large type is an example of an aggressive lymphoma.

When you talk about doing a transplant, though, from another individual, whether it's a brother or sister or a parent or a child, because we do do also half matches now from related family members, or a perfect stranger such as our first participant was talking about, or also core blood, which is an alternative source of alternative donors, you really do allotransplants to try to go for a cure. That's in almost every disease that you go after them because they do have more toxicity with them than

autologous transplant from yourself. They also have the added problem of potential graft-versus-host disease, so they tend to be done for diseases when you're really trying to cure a disease, whereas auto may have a different role in different conditions like autoimmune and myeloma.

Andrew Schorr:

Now let's meet someone who has had one of these allogeneic transplants, so an unrelated donor, but has had some complications but she's here to tell the story as well and is grateful for the transplant, and that's Karen Koltonow, who is a painter and a ceramic artist who joins us from San Francisco. Now, I had--I don't want to say an easy go with chronic lymphocytic leukemia, but I was able to go quite a while, four and a half years, before I had any treatment, combination chemotherapy and monoclonal antibody therapy, and it worked. And it's what a lot of people get worldwide now. But some people, it doesn't work, and they go on to transplant, and that's what happened with Karen.

And Karen, if I've got it right, you had an allogeneic transplant, and then your CLL was knocked back I guess, but you also had complications. It sort of morphed into myelodysplastic syndrome, and you had some graft-versus-host disease, and so you've dealt with the effects of a powerful immunotherapy, if you will, but you're happy to be here, too.

Karen's Story

Karen:

Yes. Actually, let me clarify that a little bit more. I was diagnosed primarily with chronic lymphocytic leukemia, or small lymphocytic lymphoma, which means it presented itself on lymph system. And I had a lot of other blood complications during that time, too, including autoimmune hemolytic anemia, which changed to pure red cell aplasia, so I went from destroying my blood cells to not making them. And then it all morphed to myelodysplastic syndrome, which put me on the road to a transplant.

Andrew Schorr:

I see.

Karen:

So post transplant is the---first it was some skin GVH, and then I developed immune thrombocytopenia purpura, which we were really trying hard and hard to get rid of, and I was platelet dependent. We tried all kinds of things for that, and nothing worked, and then we decided that I should have my spleen taken out, and that worked for about ten days. And then the ITP returned, and it took another year to get rid of that. And then seems like about a year after that then I developed what they call a post-transplant lymphoproliferative disorder, and we hit that with some more chemotherapy, and that seemed to work for a short time. And just recently, just as of November, the PTLD has returned, and I'm back on chemotherapy again.

Andrew Schorr:

Now, you're certainly dealing with different things, but you're gardening and you hope to be teaching ceramics again soon.

Karen:

Mm-hmm.

Andrew Schorr:

Sounds like while we haven't had a perfect answer you're with us.

Karen:

Oh, yes.

Andrew Schorr:

So I think, Dr. Holmberg, I guess the lesson here is everybody's situation is different, and that's part of it too, right, is that first of all what's going to work for them and how well it works for them, that may vary. Certainly have studies and statistics, but everybody is different, right?

Dr. Holmberg:

In terms of just when people talk numbers they're population numbers. You can think when people start talking to you about your disease, your situation, what to anticipate potentially, those are based on hundreds of thousands of patients treated with the underlying condition you have and how you have responded to therapy, what's the status of disease at the time. The population numbers give you a sense to what to expect. They don't mean what's going to happen, but they're like buying a lotto ticket. There's an odds to when you buy it, but it doesn't mean what's going to happen.

Unfortunately some people do have complications with a transplant. Many of them are associated when you get a transplant from somebody else with graft-versus-host disease. That's when the cells from the donor even though we try to type and match them as well as we can with what we know today still can recognize the body that they're placed into as not what they're used to seeing. They can cause complications and attack and cause inflammation.

So again everybody's stories will be a little bit different. Some people will sail through transplant with no complications. Some people unfortunately will get complications of infection, or a combination of all of the therapies that they've had in their lifetime kind of just taking a toll on their heart or their lungs or graft-versus-host disease. And I think when you go in you kind of balance what the risks are with what the benefits are, and that's how you go into therapy. And then if you elect to do it when something happens you just, as the speakers have talked about, the other participants, you take it a step at a time and treat as needed and try to get it controlled. We have more options for things today than we had ten years ago, which is good because that makes it more easy for us to treat some of the side effects that turn up.

Andrew Schorr:

Right. We're going to take a quick break, and we're going to talk about where transplant is headed, helping with the side effects. We're going to meet another gentleman who has had two autologous transplants separated by a number of years for multiple myeloma. And we're also going to talk about a transplant as it relates to autoimmune conditions and opportunities for transplant for people who used to be considered too old.

Now, write down this phone number. And in a bit we'll let you call the studio. You'll be able to ask questions of Dr. Holmberg or our experienced patients too. We'll be right back with our live webcast on bone marrow transplant sponsored by the Seattle Cancer Care Alliance.

Andrew Schorr:

Back live on our worldwide internet broadcast. Andrew Schorr here in Seattle with our program sponsored by the Seattle Cancer Care Alliance. We're going to go back with Dr. Leona Holmberg from the Seattle Cancer Care Alliance, a transplant expert in just a minute. But I was thinking back. I did a video probably 12 or 14 years ago on transplant and interviewed patients before I was diagnosed leukemia, and I had to try to understand it. And so I'm going to try to dumb it down for people. I know we have a lot of people who know this stuff really well, just so everybody understands. And, Dr. Holmberg, tell me if I get it right.

So when one develops a cancer your immune system has let you down, and some abnormal cells have started developing and proliferating and they start doing bad things in the way the body is supposed to operate. And like in leukemia or my leukemia or Karen's, we were packing the bone marrow with white cells, B cells that just couldn't do the job and starting to crowd out the other guys we needed to fight infection. And there are other variations of cancer of course. So that's one situation.

Another situation is where your immune system lets you down or turns on itself and you have autoimmune conditions like multiple sclerosis or scleroderma or rheumatoid arthritis, and again immune system problem. So the idea is can you either give your cells back, cleaned up, take some out, clean them up like this autologous transplant and kind of reboot your immune system, or can you have somebody else's or a mix of somebody else's cells and give you in a sense a new immune system that wins over and starts to take over and give you a healthy life. Now, Dr. Holmberg, how did I do?

Dr. Holmberg:

You did pretty well except for just one other caveat.

Andrew Schorr:

Okay.

Dr. Holmberg:

In autologous transplant, when you're talking about somebody for example who has lymphoma or myeloma, it's really you're doing the autologous transplant. We give back somebody else's previously stored stem cells to rescue them from the high doses of chemo or radiation that you need to try to get rid of their cancer. And it isn't so much to reboot their immune system in that setting. It really is you're using the stem cells as a rescue because they allow you to give the needed therapy to try to treat the cancer, but one of the side effects of that high-dose therapy is it destroys your marrow, your normal cells, and if you couldn't give them back stored stem cells then they would have infection and bleeding problems. So there is another caveat to it.

Andrew Schorr:

Okay. So I have--I give kind of weird analogies, but it's kind of like planting grass seed again in the bone marrow but it's your own that your body is going to accept. There's somebody who has been through that twice, John Rico. John joins us from just outside Detroit where it's real cold tonight, right, John?

John's Story

John:

Oh, absolutely. Like zero degrees.

Andrew Schorr:

Yeah. My kid's a freshman at the University of Michigan and I sent him a really warm coat, so I hope he's got that tonight. John, so you have multiple myeloma, and so you've had two of these transplants where your own cells have been given back to you, correct?

John:

Right. Correct. The first was in 2000, and then last year I relapsed in January and had a second one in June of last year.

Andrew Schorr:

Now, let's talk about multiple myeloma for a minute because it's been really interesting in transplant. Dr. Holmberg, there have even been double transplants, and there's a debate, as I understand it, in multiple myeloma whether newer biologic therapies can supplant the need for transplant, and it sort of depends on who you ask or which study. But what's going on there? It seems like we have this juncture coming now of newer and better medicines and various refined transplant strategies. What's your take on it?

Dr. Holmberg:

Well, in terms of is there still a role for autologous transplants in myeloma, I think there is. I think that the data with the new drugs like the Velcade and Revlimid drugs which are the newer ones in treating myeloma don't have long enough follow-up to say that we should stop doing as we standardly do, which is an

up-front autologous transplant. So you initially get standard therapy. If you have good response you go to a transplant because that prolongs survival. There are ongoing studies in Europe that will address that question.

I think that the new drugs like Velcade and Revlimid open up two possibilities. One is that these newer drugs work better than our old drugs for treating myeloma so you get a patient in a better shape when they go into a transplant. That means they're less likely to need the tandem transplants, two autos back to back, because there's a lot of data that says if you come out of your first one with a very good response you don't need a second one. They also allow us to bring in the whole concept of maintenance therapy where after an auto you can add some low doses of standard therapy to try to make the auto work better. So people go longer before their disease comes back, and maybe that hopefully will translate into our curing more patients with myeloma than we've done in a past.

Andrew Schorr:

Well, John, I know that's what you hope for. So looking at transplant, in some of these cases we want to cure people if we can, but if we can't where we can just kind of keep bopping the disease on the head and maybe using it with chemotherapy and other targeted therapies to keep the disease at bay and give people back quality of life. Is that one of the approaches now?

Dr. Holmberg:

Well, I think that many transplants, like we talked about before, are really done to do a cure. But unfortunately in certain diseases like myeloma a cure with an autologous transplant has eluded us and relapse is a real problem. But one of the things that you can do is try to make a disease a more chronic disease, and it's like for example high blood pressure. You use medicine to control it. It doesn't get rid of it. And so in diseases like myeloma you can use the new drugs in combination with transplant to allow people to live longer, make this a more chronic illness as opposed if you aren't smart enough yet to have a cure and hopefully some day we will in an autologous transplant setting but we aren't to that point or even with our standard therapies in myeloma. So I think again that's a kind of a concept that if you can't cure a disease then you want to buy people more time with the disease, make quality time. You want to make it a chronic illness because the longer people live with a disease the smarter we will be with more options for them in the future.

Andrew Schorr:

Now, John, everybody's situation with myeloma is different, and you've had your own cells given back to you twice and various drug therapy. How are you doing?

John:

I'm doing great. I had a remarkable remission from the first transplant of nearly seven years. As I said, I relapsed last January, and I went through the whole thing. Again at the doctor's point the number of options were much greater this last time than in 2000. The protocol was much less severe. I had no radiation,

also no Cytoxan at one point as I did in 2000. So it was an improved therapy, more choices, and that all got me back in remission again. So I've been in remission now for about, well, six months. And I'm enjoying life.

And I took my first remission as an opportunity to assess where I wanted to be in my life, things I wanted to do. And I wrote a book about *The Ride of Your Life: Fighting Cancer With Attitude*. So from the mental aspect, attitude standpoint, I call it a tool kit of many tools or components that help you attain a positive attitude to carry you forward through the diagnosis, treatment, more importantly your life ahead. So that's where my focus has always been, and this second time was much easier because of the positive attitude I felt worked for me. I've seen it work for others.

Andrew Schorr:

Good for you. We're going to talk more about that. And as we continue our discussion with Dr. Holmberg and all of you we're going to also apply the latest in bone marrow transplant, understand it for older people. Mini transplant. We're going to understand where the research is for these autoimmune conditions I mentioned. Now, this is a live webcast so you can call in with questions. Or sent an e-mail to patientpower@seattlecca.org. We will be right back.

Andrew Schorr:

Thank you for being with us tonight. We've got a lot more ground to cover as we discuss bone marrow transplants, state of the art, as we hear from the perspective of the Seattle Cancer Care Alliance and a transplanter there, Dr. Leona Holmberg, who shared with me in talking last night, she was saying, this is what I went to medical school for. This is what I wanted to do. So she's very devoted to it. I want to say we might go a little over the top of the hour. So just fasten your seat belt. We're going to cover as much as we can.

Also I want to thank two organizations that have really helped us put the program together. Of course the Seattle Cancer Care Alliance and Fred Hutchinson. The National Bone Marrow Transplant Link has helped us, and that's how we met John and Karen as well, and I'll give their phone number in a bit. But they help families cope with the social and emotional challenges of bone marrow and stem cell transplant, so that's a resource to. I'll mention their website, nbmtlink.org, nbmtlink.org. Also our friends at the National Marrow Donor Program, and they have a wide range of services for people if they're considering transplant, all the decisions involved in it, helping connect you with others, case managers. So there's a lot of resources at the Seattle Cancer Care Alliance. They have many people to help. But there are these national organizations as well. And their website is [marrow, m-a-r-r-o-w dot org slash patient](http://marrow.org/patient). That takes you right to the patient website, marrow.org/patient. So two wonderful resources.

Now, we mentioned just a minute ago how transplant is now offered to older people who used to be told, I'm sorry, we can't do that. So help us understand what's

going on there and what illnesses this applies for, Dr. Holmberg, so-called what people call mini transplant. Of course it's still, you know, a therapy, and it's not just like popping a vitamin pill. But tell us about that and who it could be right for.

Dr. Holmberg:

Well, I will say that one of the things that's happened over the last decade is in general just in transplant for allogeneic from somebody else overall survival has improved because we've been better at typing. We get better matches. We're much better with supportive care so that people survive infections now where in the past it used to be that they had a much harder time. So people started saying, well, there are still groups of patients that with the intensive high-dose therapy and getting cells from somebody else that's still not---it's too toxic for them. Either they're too sick because they have other organ problems, liver, kidney, lung, heart, that makes it too hard for them to be able to handle a high-dose chemo or radiation and transplant regimen with somebody else's cells, or that there's a certain limit in terms of age where people just don't handle very well very aggressive therapies. So that was the whole concept of mini or light reduced-intensity regimens, but a lot of names, nonmyeloablative.

The idea was could you be gentler on your regimen, just give enough so that people would accept cells from somebody else and really depend on treating the cancer cells that are bad by using the immune cells from the donor to give them to the patient and they would attack the bad cells. And that's the whole concept behind. And that has really opened up this field to expand the access to transplant to patients in the past in an allogeneic setting where they wouldn't have a curative potential because of the excessive toxicities with high-dose therapy but now they have the potential to be treated with a cure when their disease in such a situation in standard therapy is not working.

Andrew Schorr:

So what age at Seattle Cancer Care Alliance would these mini transplants are you going to now if somebody is in okay health?

Dr. Holmberg:

I must admit we have no age restriction on our protocols.

Andrew Schorr:

Wow. That's good to know.

Dr. Holmberg:

So really it is physiologically what you do and what kind of shape you're in. We have treated people in their 70s with these reduced-intensity regimens, mini allos.

Andrew Schorr:

Okay. I want to mention the phone number again. David has been holding. David, stay with us a minute because I just want to get one other issue on the table. I'll give you the phone number again if other people want to call. Or you can send an e-mail. Patientpower@seattlecca.org.

That one other area is one I've mentioned. It's just fascinating to me, and that is about autoimmune conditions, Dr. Holmberg. So I know there have been transplants now experimentally for people with multiple sclerosis, and maybe there have been some others. I don't know if it's been done with scleroderma or rheumatoid arthritis. Help us understand what's going on there and what you've been learning.

Dr. Holmberg:

For the last ten years the question was could you expand transplant beyond cancer to either problems of the immune system or the bone marrow, and one of the things that was looked at because there were some patients who had an underlying autoimmune disease like lupus or systemic sclerosis, which is scleroderma, or multiple sclerosis, and we saw that when we went to treat their cancer with a transplant we would put their autoimmune disease to make quiet, and they would get a benefit from treating their cancer by treating their autoimmune disease. So people started saying, can we be more aggressive with getting rid of the immune system that causes these autoimmune diseases and then kind of reset the clock and see if we can establish a very kind of more primitive immune system so that they will get a benefit from aggressive immunosuppressive therapy.

And there are in fact national trials in terms of systemic sclerosis where we are randomizing people to do a transplant from themselves to a standard therapy with Cytoxan because the pilot data looks so promising. We have people at four or five years who have had no flare up of their autoimmune disease. It's become quiescent. And so again that's similar to Europe has had with MS as well as the States.

So the problem with autoimmune diseases is we don't really understand what causes them to happen. We don't always know all the cells that are involved in the immune system that causes the problem. But when we give very high doses of immunosuppressive therapy we know we can kind of wipe the slate clean, and people can then just kind of reset the clock like they did when they were a kid, and so that was the concept behind it.

Andrew Schorr:

Wow. All right.

David, welcome to Patient Power. David, where are you calling from?

Caller:

Thank you. Thank you very much. I'm calling from Marin County, just about 15 miles of San Francisco in California.

Andrew Schorr:

I know it well. I used to live across the water in the marina in San Francisco.

Caller:

Yes.

Andrew Schorr:

David, what's your concern about transplant? What's your connection to it?

Caller:

Well, I'm a patient. I received an allogenic bone marrow transplant in May 11, 2007. My sister was my donor, and my disease was actually something that I hope we can address here with a few incidental questions. It's called a biphenotypic, AML, ALL disease. My understanding at the time I was diagnosed and ever since is that it's rather rare and produces some major questions at the time of treatment as to how to go about treatment. But I did receive chemotherapy and full body radiation for a period of roughly three months, and at this point I'm in remission, doing pretty well. There are significant side effects to those two forms of treatment that are still plaguing me, but obviously I'm still here and grateful for that. But I would love to have some questions about biphenotypic disease addressed, especially to see where we've come since I was treated even a year and a half ago.

Andrew Schorr:

All right. Let's find out. Dr. Holmberg, what is this term he's talking about, because it's a new one on me?

Dr. Holmberg:

Well, biphenotypic is really talking about that you have a stem cell in your bone marrow, and dependent on the pressures on it can go to become a myeloid cell or a lymphoid cell. And so as David said it's really a rare disease. It's not common, but it is a really primitive cell that hasn't quite committed itself what it wants to do. And unfortunately you get mutations in it that makes it become a malignancy. And it has both markers of myeloid and lymphoids on it, and that's why you call it a biphenotypic.

It's interesting in that on a national level the cooperative groups for leukemias, like AML, acute myeloid leukemia, and ALL are really talking about trying to do studies with all of us participating where we identify patients from the beginning and we start offering them all of the options they have, both with standard therapies, investigational transplants, and we start presenting people with everything up front. So I think that the thing I see in terms of changes in the last year per se is more that we're going to start really on a national level presenting people with all their options early, both with the new drugs that are out there on a more systematic way as well as transplant options from very early in the course of disease to give them that information that they need and that there really is an effort to do that, which is a brand new effort that's just going to be opening up in the next few months.

Andrew Schorr:

Okay. We're going to take another break. We will go past the top of the hour because I have a few things I want to discuss. Want to have more time for your

questions. And I want to have a discussion with Dr. Holmberg and all of you joining in. All of us want to know our full options, and I think the idea is knowing our options, as you said, early, and that's a whole debate. What trigger, what approach to do when, and do you do it by itself or do you do it in combination with a drug therapy? What's your blueprint? So we have a lot more to talk about. Please send us an e-mail if you like or give us a call. We'll be back with much more of our Seattle Cancer Care Alliance Seattle webcast on bone marrow transplant.

Andrew Schorr:

Welcome back as we continue our discussion on bone marrow transplant with Dr. Leona Holmberg from Seattle Cancer Care Alliance.

Now, as I mentioned during the break we do this every two weeks with sponsorship with the SCCA, and I'm very grateful for that. In two weeks we will have a program on breakthroughs for gynecological cancers, so that particularly is ovarian cancer but others too. And we'll have back a wonderful guest to Patient Power who has been on a number of times before, Dr. Barbara Goff. So Dr. Barbara Goff will be here. Send us your questions on ovarian cancer and other gynecological cancers, and we'll be discussing that in two weeks from tonight.

Remember that all of our programs are featured as audio replays, and then we add the transcripts, and that's online. It's a couple places. So it's in the website, sccapatientpower.org. And then we also put them on our website, patientpower.info. So lots of places to look for it.

Now, let's continue. Dr. Holmberg, so where are we headed with transplant? So we've made it available in some cases to people who are older, and you said you have some protocols where there's no age limit. We're investigating it for some autoimmune conditions. We're seeing how it can make some cancers chronic and be used with drug therapy. And you've also mentioned that there's all this discussion about trying to decide when should transplant be used and in what order related to the other tools that you in oncology have. So where are we headed next? Because there's been a tremendous evolution just during the time I've been watching it.

Dr. Holmberg:

Well, I think the other thing is the expansion of using alternative donors in terms of half matches from family members, children, parents, for a patient. Sometimes a sibling is a half match. Core blood, as you alluded to, is opening up for adults by either double core bloods as well as expansion studies.

I think the other thing that people are doing in an allogeneic transplant setting both in ablative, which is high doses of chemo, chemo radiation, or nonmyeloablative like the reduced, is even bringing in maintenance therapy especially in some of the myelodysplastic syndromes as well as acute leukemias where we still have a high relapse rate in allogeneic transplants. That people are also adding maintenance

therapy as a way to try to give the immune cells from the donor a better chance to be able to attack because there's---any cells that remain by decreasing the amount of bad cells that are there. So I think you'll see more and more of that.

People are getting creative with doing two transplants in an autologous, both for lymphomas, in Europe for Hodgkin's, for example. There are ongoing studies in the United States for two transplants. More they're introducing the whole concept that if you have a transplant like an autologous transplant and, like David was talking about, it works for a period of time but unfortunately it stops working, about the whole role of second transplants, both in myeloma which is more commonly done now, but there is data both in the United States and Europe about doing that in a lymphoma setting too. Using transplants from somebody else in a reduced intensity is also an option if you have had an autologous transplant and unfortunately it fails you. So I think again those are kind of things that are ongoing.

Looking at building a better regimen, taking some of the new targeting antibodies, like Zevlin, Bexxar, for lymphoma for example. There are a number of drugs that are coming out for some of the other leukemias or Hodgkin's disease and finding a way of intermeshing them into the transplant regimens so that we can also make them more effective regimens. I think that's what you'll see in the next few years.

Andrew Schorr:

Okay. Here's what I take away from that. So wherever you are in the sound of my voice, these are powerful approaches around transplant and these drug therapies that can go with them, and so it's really important to get all your options on the table and be talking with one or more experts in this who really have a lot of experience. Now, obviously the Seattle Cancer Care Alliance, where it all started, they have a lot. They have their points of view in these different approaches. You may consult with more than one center. And then these groups that I mentioned can help as well, and I'll mention them again. The National Bone Marrow Transplant Link, and their website is nbmtlink.org. And then also the National Marrow Donor Program, and their website is marrow.org/patient. And they're both very helpful.

And then we've got our friends here, and I want to just go to them for a second. Joyce, when you were diagnosed and I got the call from Rick, your husband, my old friend, you all were terrified. And now you can look back on it. What would you say to somebody who may be listening tonight or listening to the replay in the middle of the night or their family member. They never heard of bone marrow transplant, they don't know what's in store and they feel that somebody's life, their life is on the line. We don't know how it's going to turn out, but what would you say to them in that you've come out the other side?

Joyce:

Well, I would say to someone that life is precious, and it's a decision you have to make whether you want to continue that life. And for me I had no question that I

was not ready to give up, and I was not ready to take anything but living. And so you just kind of have to go for the gusto. And as John said just be as positive as one can.

Andrew Schorr:

Now, you were fortunate to be a stone's throw from the Seattle Cancer Care Alliance. Do you feel you got good care there? Here you are, right?

Joyce:

I had excellent care. They are incredible people, positive. And it's kind of hard not to be positive when you're being treated by them because every person I came in contact with was so positive. I also had this huge group of family and friends around me keeping me positive. But I wanted to make it through this, and I knew that was going to help me.

Andrew Schorr:

Wow. We're glad you're here.

Joyce:

It's a daunting thing to be told that. It is very daunting.

Andrew Schorr:

Yeah, I know. It certainly is. Now, John, you wrote a book about it. What's the name of your book again?

John:

It's called *The Ride of Your Life: Fighting Cancer With Attitude*.

Andrew Schorr:

Okay. So if you were going to sum up what you want people to know about what you were trying to say in that book, and they ought to go buy it of course, but what would you want to leave people with who are listening and probably saying is transplant for me? Where should I go? There are all these choices. What's the blueprints for hopefully a cure for me or long-term remission? But just the emotional side of it or how to proceed, what would you say?

John:

Well, there's a number of factors, components. I call them tools in the tool kit that together collectively help you get to a positive attitude to help you cope with the cancer and your treatment and arrive at this point where you really want to think about where you want to go with your life and the meaning of your life going forward. That's what's more important than the negativity of cancer and the past. And as far as someone facing a transplant I would talk to other bone marrow transplant survivors that have been through it, like through the National Bone

Marrow Transplant Link. Share those stories. I talked to two BMT people before with myeloma before I had mine, and that helped immensely, and I've done a lot of peer patient support that way myself personally through these bone marrow organizations. I think that helps the patient survivor tremendously as well.

Andrew Schorr:

Right. Well, there's a lot of support for the patient and for the spouse and family and friends and the people who have walked in these shoes ahead of you.

Karen, what about you in San Francisco? So you're still dealing with complications of your illnesses and even the treatment, but you're with us and you sound strong tonight. For someone who is facing this not knowing what lies ahead, any words of wisdom you want to leave us with?

Karen:

Well, we never know what's facing us ahead, you know, cancer diagnosis or not cancer diagnosis. And I don't believe that I would still be here without the bone marrow transplant. I have a great support system, and I too spoke to people who had had bone marrow transplants before. I went ahead and had mine, I even had a second opinion in Stanford, and I just knew whatever, you know, whatever it would take I had it. Whatever I, with faith and confidence when I began this adventure, and I had a little bit of time from my diagnosis to my transplant that, you know, it was amazing, the connections and the people and the support that I had. And I still have the belief that whatever I need will be there on my road when I need it.

So I'm still dealing with a lot. I'm in a lot better shape than I was a year ago as I was two years ago in spite of dealing with the lymphoma. I think I'm doing really terrifically. I saw my doctor on Tuesday and I'm doing great, and he said this is the year for health. So no year has been the same, no day has been the same, and whatever it takes to make it to tomorrow I'll be there.

Andrew Schorr:

Okay. Well, let's do a program again in 2010 and you'll tell us how much better you're doing, I hope.

Karen:

I'll there. I'll be here.

Andrew Schorr:

Thank you for joining us. So, Dr. Leona Holmberg, you went to school, if you will, to be a transplanter, and you are one of the people at the Seattle Cancer Care Alliance and part of a club, if you will, of experts around the world who continue to try to push it forward and refine it. You've seen a lot of progress. Are you hopeful that this modality and the mix of what you have in medical oncology can continue to be perfected, if you will, and help more people?

Dr. Holmberg:

Yes. I mean again just over the last ten years there's been a lot of changes. Outcomes are better for patients. We've opened up to make the ability to get the transplants to a broader group of patients. In the ideal world I would say I'm hoping some day transplanters will be obsolete. I'm hoping that we get so much better to treat cancers that nobody ever will need a transplant, to be honest with you. Because that would be the goal. The ultimate goal is that we don't need to do such aggressive therapy. And hopefully some day that really honestly will come, that we get so good at treating cancer earlier in the course of it and not need such big guns, but we're not to that point.

But I do think again people have more choices. We do things better. They are easier for patients to get through them than ten years ago, and I think that the hope will be that things will continue to improve, that we can make it easier for patients to get through, more successful for them to really get rid of their problem. And that's kind of the hope for, until we end up getting so good that we don't even need to transplant anybody with all of the getting rid of cancer from the beginning when people are early diagnosed.

Andrew Schorr:

Well, you know, I hope your dream can come true, but I want to thank you for what you do, Dr. Leona Holmberg. And I want to tell you how cool it's been to be here for many years now in Seattle as we've watched this develop here and talked to other experts around the country but also meet Dr. Thomas, who started it all and won a Nobel Prize deservedly for really leading the team developing bone marrow transplant. And here we've had three people tonight who have benefited, are here with us today and living pretty well, even very well because of it. So I know it's got to make him feel great and people in your field around the world.

Well, this is what we do on Patient Power. We don't do it alone. I want to thank these organizations that have helped tonight besides the Seattle Cancer Care Alliance and Dr. Holmberg being with us. The National Bone Marrow Transplant Link, again their website nbmtlink.org, and they have all sorts of resources for you. And then there's the National Marrow Donor Program, and they have a whole patient advocacy office. I'll give you their website. That's probably easiest. Just go to marrow.org/patient. Their case managers in these organizations as you know can connect you with other people who have been down this road before.

Thank you so much for joining us tonight. We went a few minutes long but we wanted to cover a lot of ground, let you meet some very inspiring people. This is what we do on Patient Power.

Now, we have some other programs that you can listen to on various aspects of transplant if you go to sccapatientpower.org. That includes our interview with Dr. Rainer Storb, who was there at the beginning, more on mini transplant. And also with Colleen Delaney where we're talking about her research in cord blood transplant and using that, expanding those cells to help adults.



Have a great evening. I wish you the best of health. If transplant is in your future hopefully it will go well and you'll lead a full, long life. I'm Andrew Schorr. Remember, knowledge can be the best medicine of all. Good night.

Please remember the opinions expressed on Patient Power are not necessarily the views of Seattle Cancer Care Alliance, its medical staff or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.