

# Questions to Ask to Make Informed Treatment Decisions

March 12, 2014

**Speaker:** Gail J. Roboz, MD

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## Slide 1 - Welcome & Introductions

### **OPERATOR:**

Hello, everyone, and welcome to *Questions to Ask to Make Informed Treatment Decisions*. It is my pleasure to introduce your moderator, Lauren Berger, of The Leukemia & Lymphoma Society.

### **LAUREN BERGER:**

Thank you and hello, everyone. On behalf of The Leukemia & Lymphoma Society, a warm welcome to all of you. Special thanks to Dr. Gail Roboz for sharing her time and expertise with us today.

We have over 1500 people participating from across the United States and several countries around the world.

For more than 60 years, LLS has helped pioneer innovations such as targeted therapies and immunotherapies that have improved survival rates and quality of life for many blood cancer patients. To date, we have invested nearly \$1 billion in research to advance therapies and save lives. Until there is a cure, LLS will continue to fund promising research, from bench to bedside.

We would like to acknowledge and thank Millennium, the Takeda Oncology Company for their support of this program.

You should have received or downloaded program materials, including a biography for Dr. Roboz and slides for her presentation. If you have not already accessed the slides, you can view or print them from our website at [www.LLS.org/programs](http://www.LLS.org/programs). Following the presentation, we will take questions from the audience.

We are audiotaping and transcribing this program for future posting on our website at [www.LLS.org/pastprograms](http://www.LLS.org/pastprograms). This provides an opportunity to read or listen again to the program.

I am now pleased to introduce Dr. Gail Roboz, Director of The Leukemia Program and Associate Professor of Medicine at Weill Medical College of Cornell University at New York Presbyterian Hospital in New York City. On behalf of The Leukemia & Lymphoma Society, thank you for volunteering your time and expertise. Dr. Roboz, I am now privileged to turn the program over to you.

## Slide 2 – Questions to Ask to Make Informed Treatment Decisions

### **DR. GAIL ROBOZ:**

Thank you very much and welcome to everybody on the call. I am very happy to be here and I appreciate the invitation to try to address a difficult topic of how do you as family members, as patients, how do you figure out what questions to ask your doctors, your medical care teams, to make the best treatment decisions for yourselves, for your loved one. How do you make informed treatment decisions?

And the objective of my presentation is going to be to give some concrete suggestions as how to navigate what is often an exceptionally complicated and frightening world. I think that many patients and family members have no idea what a hematologist or an oncologist is. And when they find out, they're not very happy with the news because words like cancer and tumor and malignancy and neoplasm start

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creeping into the conversation and, frankly, it becomes very difficult to hear even the rest of the sentence at that point.

And I think that what I'm going to try to do today is to step back a little bit and to give some guidelines to try to deconstruct the overwhelming information that is given to patients dealing with these types of diagnoses and to try to form a plan of how you can really know what you're talking about and advocate correctly for yourself.

## **Slide 3 – First, know what you're talking about**

So you can see in the first slide, I actually started out by saying something which seems obvious, but I have to tell you it really isn't. Know what you're talking about. And what exactly is the diagnosis. I can't tell you how many times patients are told a bunch of letters rather than a name or a word or if they're told a name or a word, it might come out something like myeloproliferative neoplasm or myelodysplastic syndrome or some unpronounceable long thing that comes out like what? And I think that because the doctor may have used the term 10,000 times, it's not unfamiliar to the doctor, but it's very unfamiliar to the patient. And I can say that stopping for a moment and actually writing down and perhaps even spelling correctly, to make it easy for yourself to look it up later, what is the diagnosis.

The other thing is that especially with blood cancers it's important to know that sometimes there is actually a little bit of confusion on the part of the doctor as to what the exact diagnosis is. And there are, in fact, areas in the blood cancers especially, where the diagnosis may overlap between one or two different categories. And these are the ones that are particularly difficult to explain to patients because they want to be able to look up something and read about it. And actually what the patient is dealing with may in fact fall between two categories. So for this reason it's very, very important to make sure that the initial terminology that's being used is extremely clear.

One of the important things about blood cancers or hematological malignancies is that the bone marrow is frequently involved. And the bone marrow is the part of the body that is the factory for making blood cells, but I can't tell you how many times that gets turned into, well, I have bone cancer. And bone cancer is a completely, completely different thing from a tumor that is involving the bone marrow. So even right there you can see from sort of step one of the conversation, how challenging it is to figure out exactly what you're talking about. So try to write it down, try if possible to get an explanation of any terms that are included in the diagnosis that may be unfamiliar to you.

Now then usually the next question that people is alright, well, I've got this, what do I do about it? And I think that it's very important to understand is there a standard treatment for what I've got, is there something that's considered the routine gold standard pretty much anywhere in the world, this would be plus or minus what I would get for this disease?

And if there is, how well does standard treatment work? And I think this is a very important point, that just because the therapy is standard, does not necessarily mean it is effective. There are many areas within the hematologic malignancies where the standard of care gives exceptionally excellent outcomes, high cure rates, and one can be very comfortable receiving what is called standard of care. But unfortunately, there are also quite a few areas where even though the treatment is standard and routinely given, it

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doesn't work very well. So I think it's quite important right from the beginning to get the questions out about okay, what is the standard, but what are the chances that it will cure me? And if it doesn't cure me, what exactly will it do? Is this a treatment that might keep me stable for many, many years? What exactly does stable mean? Do I feel good, do I run around, do I go to work, but I have this in the background? That might not be so bad. Or is this something that would kind of hang around for a long time and also have an impact on my quality of life?

Because these are the questions that lead to, okay, what does treatment do for me and what happens if I don't get treatment? And sometimes, even in the initial conversations of a new diagnosis, it's very helpful to understand pretty clearly what is out there to treat this, how good is the treatment, am I getting rid of this disease or am I going to hang out with this disease for a long time?

Now one of the hard parts of this, and there are many, is that often there is a very quick launch into treatment and treatment can include lots of long complicated sounding names also, and people immediately get into concerns, understandably, about the risks and the side effects associated with the treatments. And what I often say to patients is look, if you read the package insert on a Tylenol, you're not going to want to take one of those either because there are 9,000 things that could happen that are nasty side effects. And I think it is very, very important that before you start getting into discussions of therapies and their possible risks and side effects, you have to really understand what is the risk of the disease. So don't turn the treatment into the enemy early in the discussion. The disease is the enemy. Let's figure out how bad is this, what can this disease do to me if it's not treated correctly, and then one can have a much better understanding of why anybody in their right mind would take any risk with therapy, let alone chemotherapy, which often has a very long laundry list of potential side effects.

So I think getting the name of the diagnosis, figuring out if there is a standard treatment for the diagnosis, how bad is this diagnosis, and does treatment work, once you understand those first three bullet-points, then you can start really processing alright, let's talk about these treatments that are being offered to me, let me put the potential risks and side effects in perspective, so that I really understand what also are the benefits.

Now might there be more than one accepted standard for the disease and how am I going to pick between them? I don't even understand anything you're talking about so far and now I'm getting a Chinese menu of several different treatment options with names and things that I don't understand. And I hear this very frequently and patients will come with pages and pages of, well, I could do this, I could do this. It's not easy to make decisions about things that are completely unfamiliar.

But again, take it back to the simple. If there's more than one treatment that is considered a good choice for what you have, in general there are specific aspects of one treatment plan versus another that can be a little bit more individualized to a particular patient. It does happen, especially in the hematologic malignancies, that there are a couple of different, for example, chemotherapy combinations that could be effective. But there might be specific things about you or your medical history or your other medications that you take for other things, that may help you choose between one regimen and another. And once again, don't let anybody get you completely overwhelmed with lists of unfamiliar names. You try to get a sense of, well, how come I have several options here? Is it because they all work really well or is it

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because none of them work that well? That will immediately frame your discussion.

If you have several different options which work very well, then you're going to start micro-managing a little bit, which option might be tailored for you, to match up with your personal history and to match up with your other medications.

If it looks like there are several different options and none of the options are actually that great and they lead to cure rates that seem low to you or to success rates that seem low, then we get into the rest of my slide, which is in a nice way are you the right doctor for my disease? Not necessarily in an aggressive or a confrontational manner. The doctor may be doing the best that he or she can. But if we're talking about something that's unusual or that is more rare or that is something in which a lot of clinical trials might be available, I think that is the time, when you start hearing about success rates that don't sound like they're that great, or standard therapies that don't sound convincingly like they're getting you where you need to go, then the question is well, if I got myself into either an academic center or a cancer center where there might be more experience with this particular disease, might my list of options look a little bit different?

## **Slide 4 – Success stories in cancer medicine**

Now I think that it is important to take note of some of the spectacular success stories in cancer medicine. Diseases like chronic myeloid leukemia, acute promyelocytic leukemia, Hodgkin disease, and then let's not leave solid tumors out completely, breast cancer, testicular cancer, prostate cancer, there are areas of cancer medicine and certainly areas in the hematologic or blood cancers, where there have been spectacular successes, taking diseases from ones in which almost everybody died, like acute promyelocytic leukemia, and turning that into something where almost everybody is cured. All of that happened because of clinical trials.

## **Slide 5 – Clinical trials have many objectives**

So whereas a lot of people are immediately worried about the concept of a clinical trial, I urge you to think about these spectacular successes. And when you're hearing about what you've got, to ask the question, is it possible that there's something new on the horizon or that there's something being developed right now, which is a great story that I'm not hearing about, because maybe it's something that I would need to be on a clinical trial to get.

## **Slide 6 – In 2011, few cancers can be cured**

So we know that there are success stories. We also know that very few cancers overall can be cured. But how come the participation is so poor, so few patients in the United States actually participate in clinical trials? Why, why is this?

## **Slide 7 – IMPORTANT: Clinical trials give patients the answers they want and need**

Well, we actually think that it's because of information. And part of the entire reason for webinars and for seminars and for programs like what the LLS offers is to actually correct some of the misinformation that's out there and to allow patients and family members and caregivers to ask all of the right questions, so that they're led comfortably and confidently potentially into a path of clinical trials, instead of feeling worried about it.

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### **Slide 8 – Information**

And both on this slide and also elsewhere in your materials, we have lots of websites and references that help you to navigate the incredible amount of information that may be relevant for your particular disease.

### **Slide 9 – But, people have many concerns about clinical trials**

So people have very many concerns about clinical trials. I hear all the time, well, I don't want to be a guinea pig. So that's a very, very common one. I think that that's something which kind of comes from a long, long time ago, and I think that currently you should be very much reassured that the explaining and the consenting process that is involved in clinical trials really, really is very, very thorough. So you really do know what you're getting into. And you also may not be being treated with something that is a brand new drug at all. There are many clinical trials that involve either agents or procedures or other types of actions that are not brand new at all. You might be getting into something where you are the many thousandth patient who is being treated. So don't necessarily assume that just because it's a clinical trial, it's something brand new.

The new two I hear all the time. Oh, I'm too old, they're not going to take me. Or I'm too young. Don't make any assumptions like that. There are often age restriction criteria on trials, but they're not what you think. So don't make assumptions based on your age.

The next bullet-point gets to what I was saying before, that the clinical trials involve an experiment or an experimental drug. That's not necessarily true at all. Sometimes we know that we have combinations of drugs that work pretty well, but maybe they could work better if we changed the schedule around or if we shifted which day we give what drug. So it is very possible that the clinical trial that might be of benefit to you does not in fact involve an experimental agent.

And I'll tell you that one of the biggest success stories in all of cancer medicine has been curing pediatric ALL, or acute lymphoblastic leukemia, for kids. And those cures came using actually very, very old standby chemotherapy drugs, but mixing them up in the exactly right proportions and combinations, and giving them in the right order. So those cure rates came from working with drugs that we have on the shelf. Very important to think about.

Another thing that people say is that oh, my God, if I'm being considered for a clinical trial, that must mean that nothing works for me. That must mean that I have no treatment options. Also completely not true. We may just want to be doing even better than what you would be standardly offered, or there might be an opportunity, for example, to minimize side effects from a standard therapy, or to optimize quality of life with a standard therapy. So the implication, if you're discussing a clinical trial, is not at all necessarily that your situation is dire and that's why you're being offered a trial. So please don't make that assumption.

Patients often worry that they have to pay to get onto a clinical trial or they're hopeful that they will get paid to be on a clinical trial. In general, neither of those is the case. You don't have to pay to get onto a trial and you don't generally get paid to be on them. But again, there are specifics that are related to individual trials and the finances that may be involved for you either getting to the location of the trial or other aspects of the financial commitment to being on a clinical trial, that you really should be discussing

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on a very individual basis. Don't make any assumptions, though, about the money or about the insurance that may be involved because my guess is that you're going to come to the wrong conclusion if you don't actually ask the question.

### **Slide 10 – More concerns**

Other concerns. My doctor will be mad at me if I participate. I hear this a lot and it's actually, in a way, it's very sweet. Because somebody might have a very close relationship with a doctor and may not want to hurt the doctor's feelings by saying well, are you sure I shouldn't go here or there or talk to this other doctor about a clinical trial. That they worry that they're going to be hurting somebody's feelings. Never mind. This is your life, these are your medical decisions. Presumably this doctor that you care deeply about hopefully cares about you, too, and it should be an absolutely open conversation. You're not being mean, you're not expressing a loss of confidence, you're just saying that, well, you know, this is a rare disease and I need to maybe be somewhere where they see a lot more of it. So I would say that that type of a conversation can almost always happen very successfully. And I can certainly tell you that I and many other investigators who do a lot of clinical trials, we try very hard to work very closely with patients' original doctors and to try to have as many things as possible happen, with local doctors who might have a longstanding relationship with patients. So that need not be a messed up story at all.

My doctor will be mad at me if I don't participate. Well, that also shouldn't happen. And a clinical trial is a discussion and a possibility and part of your search for answers of what to do for yourself, but it's not jail and it's not mandatory and it does happen that sometimes the circumstances of a trial just are not right for a particular patient or family and nobody should be mad at anybody, whether you do or you don't participate.

Now this next one is a big one. I don't want to get a placebo. So first of all, actually relatively few clinical trials involve a placebo. So just because you're on a clinical trial does not at all mean that a placebo or a sugar pill, as they may be known as, or a fake treatment, would be involved. Sometimes, it is true, that there is a placebo component to the trial, but that doesn't at all mean that it's not a worthwhile trial to participate in. And there may be situations – you know, I think it's natural to assume that just because something is new, that it's better. It may not be. And sometimes when a trial is offering, for example, a standard treatment versus a standard treatment plus an investigational drug, we don't know whether the addition of the investigational drug necessarily makes anything better. It might make things worse. So don't assume that just because a trial includes a placebo, that it's something that you wouldn't want to do. I would absolutely listen to the circumstances of the trial and think about it. Because again, don't fall into the trap that just because a drug is new, it's necessarily better. We have, unfortunately, tossed many, many new drugs in the garbage because they didn't turn out to be better than what was standard.

Now a lot of people worry, I don't want to stop my other medications. We don't want you to stop your other medications either. There are circumstances in which changes have to be made because of potential interactions with something that might be on the clinical trial, but there are also plenty – in fact, the majority of situations – where your other medications can continue along just fine. So that's something that would be, again, discussed on an individual basis and medication by medication.

Now here's an important one, I think. Clinical trials won't help me, just other patients. You know, I think that many of us would like to help the universe, but you also want to help yourself. And it is absolutely

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not the case that a clinical trial is just helping mankind. There are scores and scores and scores of patients who are directly benefitting from their participation in a trial and you can certainly look at all of the chronic myeloid leukemia patients who were able to get drugs like imatinib, which is known as Gleevec®, and other of the pills that have made it to the front page of the New York Times and beyond. These were drugs that were offered on clinical trials. So you are in it for mankind, yeah, but mostly for you. And you must look selfishly, that what is the benefit to me, and many clinical trials do in fact have a potential benefit directly to you.

Doctors can never guarantee that a drug is going to work for you or that a trial is going to be of benefit to you, but that is certainly the hope.

Now a final point to make is about privacy, that I don't want other people to know details about me. I think privacy issues in medicine are exceptionally important and they are certainly complicated. There are aspects to the consenting process in clinical trials, that are very specific about what information would or would not be available to anybody else. And I think that again don't assume that, well, everybody'll know everything about me, because that's rarely the case. But you'll see in the consent forms that you're given, what specifically might be able to be known about you, and there are often opportunities for you to restrict that type of information. So I would look carefully at those forms. And you can be very hopeful that your privacy will be safeguarded, just like the rest of your medical record.

## **Slide 11 – Whatever your concerns...**

So whatever your concerns, do ask your doctor about clinical trials and if you are at the point of this last slide, my hope is that you've understood what your diagnosis is, you have a working relationship with your doctor and your team about what are the treatments that are out there and how are they likely to work for me, and then if it seems that the standard treatments are not giving you the results that you feel that you should be having or that you'd like to be having, what could we do to make that better? Might there be a clinical trial that would be suitable for you?

And I'm going to end my comments there, so that I leave some time for questions.

## **Slide 12 – LLS Resources**

### **LAUREN BERGER:**

Thank you, Dr. Roboz, for your very clear explanation. And you provided us with so much information that I think will be helpful for patients to go back to their healthcare team.

## **Slide 13 – Question and Answer Session**

### **LAUREN BERGER:**

We'll take the first question from the web audience and this question is from Patty. "Are there services where I can find an advocate to help me find clinical trials? We have gotten lists of trials to go through, but it is so overwhelming. I can't speak for others, but I'm a nurse and a caregiver for my husband with stage IV lymphoma, and we have been left to our own devices."

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### **DR. GAIL ROBOZ:**

Well, I think that this question definitely, I'm sure, that there are many heads nodding throughout the entire audience because I certainly appreciate exactly where this person is coming from. It is absolutely overwhelming to go through lists and lists of trials and nobody on the patient or caregiver side should be expected to do that.

But to answer your question, there absolutely are resources. So first of all, I do think that your physician should be helping you go through those lists and figure out what's good for you. And if your doctor doesn't feel comfortable doing that, then I think that that is an indication that possibly somebody with a little bit more expertise in the particular area of lymphoma that you're dealing with, could help you. Because I can tell you that most of us who are experienced in clinical trials know pretty much all of the clinical trials that are out there, or can certainly make calls on your behalf and figure out details of them. And we should be the ones who are guiding you.

In addition to that, I have to say that LLS is absolutely phenomenal at helping people navigate these types of lists. And I think that if you make contact with LLS they can often be extremely instructive about letting you know who or which institution might be able to break down that long list for you and figure out which ones are the most relevant.

### **LAUREN BERGER:**

Absolutely. And after the call I suggest that you call an Information Specialist at The Leukemia & Lymphoma Society. They certainly can help you with what Dr. Roboz was just explaining. And the telephone number is 800-955-4572. And there's a flyer in your packet explaining about clinical trial searches and how we can be helpful.

We'll take the next question from the telephone audience, please.

### **OPERATOR:**

The next question comes from Paul in Ohio. Your line is now open.

### **PAUL:**

Dr. Roboz, if you fail to ask a doctor about the risks associated with a treatment and whether there is a standard of care, is that doctor still obligated to tell you anyway?

### **DR. GAIL ROBOZ:**

Well, I think that in general most doctors, when they're offering a treatment plan, it is expected that the treatment plan would be within the realm of accepted standards of care. So in general, if you're not signing a document that you are specifically participating in something that is investigational, in general what's being offered would be considered part of standard of care. Now there are certainly areas of treatment where there's room for interpretation in terms of what's considered standard. And I don't want to imply that there's necessarily an exact number of milligrams or an exact recipe that qualifies as standard and that any deviation from that would be not standard. There are definitely gray areas that are included in what is basically the standard.



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### **DR. GAIL ROBOZ:**

But I think that you certainly should be having the treatment discussions that you're having, are expected to reflect what would be within the common practice among hematologists/oncologists around the country, who would be treating you in such a way that you would be likely to hear the same type of information from multiple different hematologists/oncologists. That's what really defines standard. And that is something that you should be expecting to hear from your doctor.

### **LAUREN BERGER:**

Thank you for your question, Paul. We'll take the next question from the web audience and this is from Matt. "I have been very reluctant to talk with my doctor about complementary and alternative options. Are doctors generally open to talking about natural and complementary therapies? And is there some validity to any of these therapies?"

### **DR. GAIL ROBOZ:**

This is a great question and a challenging one. I think that it is definitely the case that most, quote-unquote, standard hematologists/oncologists do not have an extensive depth of experience with various complementary or holistic or so-called natural approaches.

That said, I do think that there are situations in which these types of approaches can be of benefit. I think in general mixing and matching pretty much anything with investigational agents is something that we don't recommend because we have enough trouble figuring out how to predict the behavior of an investigational agent, let alone adding things to it.

And I think it's very, very important to know that just because something is quote-unquote natural, doesn't mean that it's good for you. And I want to underline that 8,000 times. Natural things can be very powerful, they can be very strong, they can absolutely have side effects and they can interact with other medications. And I can tell you that lots of medications – digoxin, Taxol®, which is a chemotherapy, these are plant-based medications that are very powerful, and as many of you know, even things like having too much grapefruit can interact with other medications. So my general thinking is that if it's shaped like a pill, it's medicine. Whether or not it comes from the drugstore or the natural foods store. And I'm going to assume that anything that I'm taking into me has potential side effects. And I'm going to assume that if nobody can tell me what the specific benefits of something is and if nobody really understands what it is in my healthcare team, I'm a little bit worried about taking it.

That said, for desperately ill patients for whom doctors are saying that really none of the standard therapies are working, patients do often try a whole bunch of different approaches in that situation. And I certainly understand that, if standard approaches aren't working.

And the other thing is that often oncologists will make the call and work with the prescriber or complementary medicine doctor, who is trying to add in additional pharmaceuticals to the patient's regimen, and try to figure out that, well, even if I don't know what these supplements might do, maybe somebody could explain it to me and then I could figure out whether it's a good idea or not.

So I think you're right that most doctors don't know a lot about it. I think it is generally the case that if there is something that is of proven benefit, most of us know about it and are happy to incorporate it into

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the treatment. And I think that you should definitely never assume that just because something is natural, that it's okay for you to take.

**LAUREN BERGER:**

Thank you for your question, Matt. We'll take the next question from the telephone audience, please.

**OPERATOR:**

Our next question comes from Shirley in Washington. Your line is now open.

**SHIRLEY:**

Yes, I was diagnosed with MDS back in 2007 and I was on transfusions for a year and the Dacogen® for two and a half years. And since 2011 I was recommended to take what they call Liquid Life and liquid antioxidant. I showed it to my hematology doctor and they said keep taking it. Well, I was just in the other day and he calls me the miracle. I said does that mean I'm cured because my blood isn't low enough to get treatment, but not high enough to be normal. So am I cured then from MDS?

**DR. GAIL ROBOZ:**

Well, I'm always happy to hear about people who are doing well, but I definitely can't tell you anything about whether or not you're cured. Most patients aren't cured from MDS, outside of having a bone marrow transplant. So I certainly can't comment at all about specifically how you're doing, but I'm happy to hear that your numbers looked good at your last visit.

**LAUREN BERGER:**

Thank you for your question, Shirley.

We'll take the next question from the web audience and this is from Linda. "What criteria and timeframe help determine remission? And what is the difference between remission and undetectable disease?"

**DR. GAIL ROBOZ:**

So unfortunately this is a question that is not directly answerable because it actually depends, the answer depends on what the underlying disease is. So depending on whether we are talking about a leukemia or a lymphoma or a myeloma or a solid tumor, all of the different disease entities have slightly different definitions of responses. And I think the best way to answer your question is to be clear with your doctor, what am I looking for exactly to be called in remission?

What you'll find is that for your specific disease, there is a specific definition of remission and then there are sometimes even more specific categories of remission. So you may have a hematologic remission, a molecular remission, a bone marrow remission. So all of these different terms have specific meaning and you must ask your doctor, with respect to your specific diagnosis, that what is the definition of remission that we're looking for for my disease, and am I meeting criteria for that or not?

**LAUREN BERGER:**

Thank you for your question, Linda. We'll take the next question from the telephone audience, please.

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### **OPERATOR:**

Our next question comes from Ron in Arizona. Your line is now open.

### **RON:**

Hi, thank you, Lymphoma Society, for hosting this today. I had non-Hodgkin's follicular lymphoma. It was only found in a lymph node in my left thigh, never got in the bone marrow. I went through six chemo treatments and at the present state my doctor put me on two years, on Rituxan®, every two months. My question for the doctor, is this standard care? And you know, the actual tumor in my leg is gone, which is great, and my other part of the question, I'm only supposed to ask one, is treatment like CT scans – I've had four and he's scheduling – actually scheduling my fourth. And I got your point about the Tylenol. I mean everything on TV, there's side effects in everything you do. And the main thing is to try to stay alive and stay with your family. I just wonder what the doctor would say about the Rituxan treatment over a two year span, is my main question. And thank you so much for what you're doing today.

### **DR. GAIL ROBOZ:**

So I think that your questions are excellent questions. I'm going to again answer generally because any doctor who takes care of you over the phone is a dopey doctor. But I think the way to really understand whether that is the standard of care for you, and there are lots of different details within the non-Hodgkin's lymphomas that are very, very important. And the reason that I can't answer your question without the rest of those details is because those details help to determine the extent and the duration of additional therapy, above and beyond what is considered the main treatment. So usually there's a main treatment and then there might be a maintenance phase.

It's not atypical to give prolonged courses of Rituxan for patients who have the type of disease that you're describing, but I would just ask your doctor the question that hey, how'd you come up with the number two years? And usually they can actually point to a specific study that said, well, there was a study of a bunch of patients with similar disease to what you have and the ones who got two years of therapy did better than the ones who got less than that. So there might actually be a study or some data that the doctor can point to, to reassure you about where that number came from. Because some of the time we have to take our best guess as to what's the right duration and extent of therapy, but sometimes we actually have data from other clinical trials to guide us.

With respect to monitoring and CAT scans, there is certainly concern about limiting exposure to radiation when possible. I think again within the lymphomas, there are pretty well worked out schedules of what's the balance between not missing something, so doing so few scans that you miss something, that wouldn't be a good idea, but you also don't want to do too many of them. And these numbers are usually obtained from prior clinical trials, which give us a baseline of what we think is kind of the lowest number of CAT scans that we can get away with and still feel like we're monitoring you adequately.

### **LAUREN BERGER:**

Thank you for your question, Ron.

We'll take the next question from the web audience and this question is from Rod, "Should I get a second opinion regarding treatment changes or is that overkill?"

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### **DR. GAIL ROBOZ:**

So I think that there are different types of treatment changes and it's never wrong to get a second opinion if you're unsure about what's going on. But there are treatment changes that are relatively minor ones and then there are treatment changes that are very, very different from what you started out with. And I think the best way to answer your question is for you to ask yourself the question that is this a big change or a little one, from what I was doing before? In other words, are we doing the same medicine, but just changing the dose and schedule a little bit, or are we doing a completely different approach?

And secondly, do I understand why the change is being made? And if you're not clear why a change is being made and if it seems like it could be a pretty significant one, then I'd certainly advocate getting a second opinion, so that you could at least understand why the change is being proposed.

### **LAUREN BERGER:**

Thanks for your question, Rod. We'll take the next question from the telephone audience, please.

### **OPERATOR:**

Our next question comes from Claire in New York. Your line is now open.

### **CLAIRE:**

I just wanted to know what the range of survival is for non-Hodgkin's lymphoma. I've had it 14 years, no treatment.

### **DR. GAIL ROBOZ:**

So there was a lot of interference on that line, but I think that I was being asked about survival statistics. So I would encourage you to go over those statistics on an individual basis rather than me just float a number out, especially since I'm not sure that I understood what cancer it was for.

### **LAUREN BERGER:**

Thanks for your question, Claire.

We'll take the next question from the web audience and this one's from Janet. "How does cytogenetic testing affect a patient's treatment protocol?"

### **DR. GAIL ROBOZ:**

So cytogenetic testing is looking at chromosomes, not necessarily the chromosomes that make you a boy or a girl, but the chromosomes that are within the tumor or the malignant cells. And there are, within the hematologic malignancies, different chromosomal abnormalities can predict different clinical behavior. So within MDS or leukemia or CLL or multiple myeloma, there are specific chromosomal abnormalities which suggest whether or not the disease is going to be on the easier side or on the more difficult side to get into remission. And often those specific chromosomal abnormalities will indicate A, whether a specific medication might be of benefit, or B, whether something like a bone marrow or stem cell transplant may be in order.

So in general, chromosome abnormalities usually fall loosely into so-called better prognosis ones, medium prognosis ones, or worse prognosis. And again the nature of the specific chromosomal

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### **DR. GAIL ROBOZ:**

abnormality is different, depending on which disease you're talking about. So the chromosome abnormalities for somebody with MDS are going to be a different discussion, different chromosomes, from somebody with CLL.

But your doctor may tell you that hey, you have this or that chromosome abnormality, that's usually associated with a disease that is a slow-moving one, so we don't have to do anything right now. Or in MDS, if you have a particular chromosome abnormality involving the fifth chromosome, there might be an oral medication that could be of benefit to you. So there are specific data points related to chromosome abnormalities that may guide your treatment.

Just because a chromosome is abnormal does not mean that there is bad news, first of all. And secondly, just because a chromosome is thought to be a better one or a worse one, there aren't guarantees with that either. What it does is it gives a little bit of a basis to try to decide on the nature of the initial intervention, based on whether we think the chromosomes are looking like they're suggesting a more aggressive disease or a less aggressive disease.

### **LAUREN BERGER:**

Thank you for your question, Janet. We'll take the next question from the telephone audience, please.

### **OPERATOR:**

Our next question comes from Stacy in New York. Your line is now open.

### **STACY:**

Hey, I'm Stacy Hayes. Dr. Roboz, I'm a patient of Dr. Feldman, seen you many times, thank you for your time and your wisdom, you are a wonderful woman. Besides that, I have myelofibrosis. I currently take hydroxyurea. My counts have been falling. I'm JAK2-negative. Want to talk fast so you get it and other people get a chance. JAK2-negative. My question is, do you think – and I go to Dr. Feldman and I'm aware of all the clinical trials and we're discussing it now because my counts have dropped, the medicine's no longer working – question is they've come up with this new CALR and they're finding out whether or not you're JAK-negative, you may have a better chance of living longer, or if you're JAK-positive, there's different JAK inhibitors that are coming out. And my question to you is, do you think I should get tested, blood work, when I come I to see Dr. Feldman and find out whether or not how I test with all these new findings they're coming out with, with the CALR, and whether or not where I'm at with this disease, am I progressing? I mean I've had it, started with ET in '01, now it's 2013 and my counts have plummeted. I can't eat, I've lost a lot of weight. My question is, do you think I should get tested or it doesn't really make a difference?

### **DR. GAIL ROBOZ:**

So I think that Stacy can inspire the rest of the audience to be a well-educated consumer about talking about lots of specifics related to her disease. So I think part of the conversation that we've had, all of this afternoon, is to learn the details, so that you can ask lots of questions. And the specific nature of calreticulin and the myeloproliferative disorders is definitely beyond the scope of this type of a webinar. But the good news is, since this particular person is actually a patient in our office, that we can actually continue this conversation on an individual basis.

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### **LAUREN BERGER:**

Thank you for your question, Stacy.

We'll take the next question from the web audience. The question's from Laura. "What is the accuracy of bone marrow biopsies versus molecular blood studies?"

### **DR. GAIL ROBOZ:**

So it depends on the disease that is under discussion. So I'm going to have to guess a little bit, where this question is coming from, but there are diseases such as chronic myeloid leukemia, in which there is a molecular marker of the disease that can actually be followed in the blood. And we are quite successful for certain diseases, like CML, that have a molecular marker that can be picked up in very sensitive testing. Those types of diseases, once they are in remission, can often be followed with blood testing versus bone marrow.

However, in general, the information that is obtained from a bone marrow biopsy is very, very different from the information that is obtained from a blood test.

So for the rest of the listeners on the call, I think the important thing to keep in mind is that there are certain hematologic malignancies that have a molecular fingerprint that can be followed in blood tests, once the disease is already in remission. But most of the time, in general, the information that is obtained from a bone marrow biopsy is again very different and cannot be gotten from the blood. So I just want to be careful that it doesn't in any way sound like I'm saying in general it's okay to use blood instead of bone marrow. There are certain specific situations in which it's okay. And we know that bone marrow tests aren't anybody's most fun procedure, so we certainly would try to limit them to situations where we really have to get the information from the bone marrow and could not get equivalent results from the blood.

### **LAUREN BERGER:**

Thank you for your question, Laura. We'll take the next question from the telephone audience, please.

### **OPERATOR:**

Our next question comes from Janice in Connecticut. Your line is now open.

### **JANICE:**

Yes, hi. I'm calling about the term marginal zone. Doctor, I was diagnosed 13 months ago with marginal zone non-Hodgkin's lymphoma, and I know that my lymphoma is an indolent type. My doctor has told me that there are actually patients who go without any treatment ever. And I have searched all over the web, trying to figure out what is the percentage of folks who never end up having to be treated. It just doesn't make sense to me that I have a blood cancer and it doesn't need treatment. And there could be no treatment.

### **DR. GAIL ROBOZ:**

So I definitely appreciate where you're coming from, that one worries about having been given a diagnosis and not doing anything about it. So I think that that's a very important concern. While I can't tell

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### **DR. GAIL ROBOZ:**

you anything about your specific situation, of course, I can tell you that there are definitely patients with marginal zone lymphoma and with other types of indolent non-Hodgkin's lymphomas, who in fact don't get treated for the disease. And some of these patients, 30 years later, are still not getting treated from the disease. So it is true that some of the patients with non-Hodgkin's lymphoma in fact do carry the diagnosis, but never require treatment for their disease.

That said, it sounds like you're doing the right thing and seeing somebody periodically and monitoring it. And you know, future telling and fortune telling we're not so good at, so it becomes very difficult for doctors to say for sure that, well, don't worry, you're never going to need treatment, that's a very hard thing to say. But to say that, well, it looks like right now everything is quiet and you don't need treatment, is definitely a reasonable possibility.

### **LAUREN BERGER:**

Thank you for your question, Janice.

We'll take the next question from the web audience and this question is from Steve. "Is there a single source recognized by the medical industry that contains the standard treatment recognized worldwide for a specific diagnosis?"

### **DR. GAIL ROBOZ:**

The answer to that question is no, there is not.

### **LAUREN BERGER:**

Thank you, Steve, for your question. We'll take the next question from the telephone audience, please.

### **OPERATOR:**

Our next question comes from Monica in California. Your line is now open.

### **MONICA:**

Thank you for taking my call. I have been diagnosed 17 months ago with AML. I have been in treatment now with decitabine and just had today my 67th dose. My question is, is this all I can do? I know that there are clinical trials, but I'm already 74 years old. How long can I live this way? My quality of life is not too great because with no immune system, I kind of have to be more or less in quarantine. And I would like to find maybe another solution.

### **DR. GAIL ROBOZ:**

So I definitely appreciate your question very much. And I have, as you may know, many, many patients with AML who I think would feel very, very much the way that you do. I think that while decitabine works for many patients with AML, I think it's quite important to go over with your doctor what exactly is your current situation on the decitabine. Are you in fact in remission, are they expecting you to go into remission, and there might actually be quite a number of different options for you. And there are certainly multiple places in California where there are trials available. So I do think it's quite important for you to review with the doctor are you in remission, are they expecting you to go into remission, and if you're not

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### **DR. GAIL ROBOZ:**

in remission, to ask the question of what could be given next. I would say that at 74 years old you are a young patient with AML and you are not excluded by age from anything, including bone marrow transplantation. So I would say that you should certainly push hard on asking the question.

### **LAUREN BERGER:**

Thank you for your question, Monica.

We'll take the next question from the web audience. And Valerie asks, "I have been involved in a clinical trial and would like to know what the results were. Is there a site that I can go on to get the results?"

### **DR. GAIL ROBOZ:**

So there isn't a specific site that you could go to get results. The results from clinical trials really depend on what the status of the overall trial is in terms of where it is in the process and what type of results you're talking about. So in general, where you've been treated, your doctor must be a treating investigator on the trial and can answer that question for you, because there are different results that are available at different times to patients and that's not something that you would be able to get access to without knowing from your treating investigator, you know, what exactly you can have access to and when.

### **LAUREN BERGER:**

Thank you for your question, Valerie.

We'll take the next question from the telephone audience, please.

### **OPERATOR:**

Our next question comes from Diane in Massachusetts. Your line is now open.

### **DIANE:**

Hi, good afternoon. Thank you, Doctor. Fifteen months ago I was diagnosed with APML and you know, I was given 100 chemotherapy of arsenic. And now include in the ATRA. Now I'm on two weeks of ATRA and off for three months. My question is, I was never told or given any information about a clinical trial. Is this the only standard treatment for the APML? And currently I am in remission, so thank God for that. So I just wanted to know. Thank you.

### **DR. GAIL ROBOZ:**

You're very welcome, congratulations on being in remission. And you have so – the therapy that you've had is actually gold standard therapy for APML, so the combination of arsenic and ATRA is perhaps the most powerful and excellent combination of treatment for this. And while there may be out there clinical trials in APML, there are actually, because it's such a rare disease and because the standard therapies are actually doing so well in that disease, it's more common that the clinical trials are either for patients with relapse or that they are making sort of tweaking changes to what's already the standard. So in your specific situation you should be comforted very much by the fact that you've had the gold standard drugs for your disease and that you're currently in remission and you must continue to follow closely with your doctor because things are going well.



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### **OPERATOR:**

Okay, we'll actually take another question from the phone. Our next question comes from Christine from California. Your line is now open.

### **CHRISTINE:**

I don't really have any question to ask, but I really appreciate all of the information that I've been given. Actually I do have MDS, but I guess it isn't a very severe type of situation in my case and I'm just wondering is there any particular advice that I should follow.

### **DR. GAIL ROBOZ:**

Well, I think that you can definitely be in touch with your doctor to get all the details that you can about the specific type of MDS you have and what the doctor's plans are for you.

### **CHRISTINE:**

He doesn't seem to be very communicative. But then maybe I have not been asking the right questions.

### **DR. GAIL ROBOZ:**

Yeah, maybe try an approach of some more direct questions and see how that goes.

### **CHRISTINE:**

Okay, thank you.

### **OPERATOR:**

Thank you. Okay, we do have time for another phone question from Pat from California, your line is now open.

### **PAT:**

Thank you. I was diagnosed with CML about a year ago and tried various chemo pills, which made me very, very sick. I'm currently taking Sprycel<sup>®</sup>, like one every other week. But my question is, I lost red blood cells and my doctor thought it may have been the chemotherapy and I had to get a transfusion every month. This started about nine months ago. Have you ever heard of anybody with CML losing red blood cells and what happened? I've had three bone marrow biopsies and they said yeah, there's nothing there. And so he said you can't keep getting transfusions forever, you know. And I thought oh, my God. So that's my question. Have you ever heard of something like this?

### **DR. GAIL ROBOZ:**

So it's not actually unusual for CML patients who are on dasatinib or Sprycel or some of the other tyrosine kinase inhibitors to go through periods of significant anemia. And in general there can be modifications both to – either to the doses or the medication itself can be changed or there are other reasons that can be found for having these increased transfusion requirements. But the answer to your question is I have absolutely not only heard of, but encountered this situation. And in general there is an

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### **DR. GAIL ROBOZ:**

answer that can be found that relates either to something else that's going on in you or to something specific about the medication or the dose that could be manipulated.

### **LAUREN BERGER:**

Thank you for your question and thank you all for your questions. We hope this information will assist you and your family in your next steps.

### **Slide 14 – Questions to Ask to Make Informed Treatment Decisions**

The Leukemia & Lymphoma Society also offers online chats for patients with lymphoma, CML, myeloma, young adults, and chats for caregivers. And these chats are moderated by oncology social workers and they provide forums for patients and caregivers to share your experiences and to support each other. So for information on how to participate in a chat, please review the flyer in your packet, or you can go to [lls.org/chat](http://lls.org/chat).

If we were not able to get to your question today, please call The Leukemia & Lymphoma Society's Information Specialists at 800-955-4572. Information Specialists are available to speak with you from 9 AM to 9 PM Eastern Time. These are new expanded hours, so please call an Information Specialist with your questions, or you can reach us by email at [infocenter@lls.org](mailto:infocenter@lls.org) and we can provide information about treatment, clinical trials, or answer other questions that you have, including questions about financial assistance for treatment.

Please help me thank Dr. Roboz for volunteering her time with us today.

On behalf of The Leukemia & Lymphoma Society, thank you all for sharing your time with us. Goodbye and we wish you well.

**END**