



Cancer: Keys to Survivorship – Living With, Through, and Beyond Cancer/Communicating with Health Care Providers

Susan Scherr:

Good morning again and welcome to Cancer: Keys to Survivorship. The National Coalition for Cancer Survivorship, or NCCS as some of you may know us, and *The Leukemia & Lymphoma Society*, have joined together to do a program that you will see this morning, that has been put on around the country and 58 chapters.

The unique thing about the program this morning is that it is going to be web-cast and Robin Kornhaber will tell you a little bit more about it. NCCS was founded in 1986 of, by, and for cancer survivors and really changed the language. When you hear the word "survivor," when you hear the term "survivorship," it really is because NCCS set the groundwork and changed definition, which is – the NCCS definition, which has been adopted by many organizations, many groups, and even people, researchers, and doctors use this now, is from the moment of diagnosis and [for] the balance of life.

We have extended that to include loved ones, caregivers, after a person has died, because the continuum goes on and you survive in the hearts and minds of your loved ones.

This program started out four years ago as sort of a concept with Leukemia & Lymphoma and NCCS, using NCCS materials that were available, talking about communication and empowerment, talking about hope, talking about some of the issues of insurance and employment, and we had developed materials along these lines that we disseminated.

But when we met with *The Leukemia & Lymphoma Society*, there was a core group of four of us, two health professionals and two cancer survivors, one of which was myself. We developed a curriculum. We did a pilot program at, I believe it was four sites? Five sites and then we gradually rolled it out, and over the last two years, it has been held at all 58 chapters of *The Leukemia & Lymphoma Society*.

Ortho Biotech, who is a pharmaceutical company owned by Johnson & Johnson, has been on board from the very beginning and has underwritten it with a generous educational grant and is actually underwriting the webcast today.

We are going back to them for funding and hope that this program will continue for many years to come, and we will modify it and revise it and, based on the evaluations that are on the left-hand side of your packet, we will ask you to suggest, perhaps changes, things that you would like to see, things that you would like to see enhanced, things that you feel perhaps are not necessary. We will benefit and make the program better.



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Susan Scherr:

I just wanted to mention this morning that our president and CEO is in the audience, Ellen Stovall. A number of you may know her. She is very well known in the cancer community and she is with us this morning. Ellen, if you would just like to raise your hand. There she is.

As I say, the program has been rolled out now. It is really institutionalized with NCCS and *The Leukemia & Lymphoma Society* and I just wanted to let you know that there are materials in your packets, specifically dealing with teamwork, communicating with your doctor, also HOPE. It's a wonderful booklet. Feel free to share it with your friends and also an order form for the cancer survival toolbox, which some of you may have taken. They were out at the back table. If not there are additional order forms.

That's material that is totally free of charge. It's a set of audiotapes that deal with a lot of the issues that you will hear about today. But it was done in conjunction with the Oncology Nursing Society and the American Association of Oncology Social Workers, as well as NCCS.

So it incorporates the patients' input along with professional input and there are role plays and a lot of very practical information with an excellent resource book. The beautiful thing about that program is, it's totally free of charge. So if you know of someone that's been newly diagnosed, someone that's dealing with issues of caregiving, someone that is having Medicare or financial problems—a lot of these issues are dealt with in the toolbox and it is available, as I say, as a resource.

I invite you all to move forward if you feel comfortable, or actually the whole program will be televised for our webcast and it will be on both sites for two months. One other housekeeping detail that I wanted to mention is, as you notice, there is coffee and food and fruit out front. It is not permitted in the auditorium.

I just wanted to ask you again to fill out the evaluation so we can improve on the program. One final note: NCCS has a distribution house that answers a lot of our calls and sends our materials around the country, called PMDS. I am happy to mention that several of their representatives are here this morning to learn more about this program and to be able to better serve the public.

So we are delighted to have them and we appreciate their coming. We are very glad to see all of you on a very rainy Saturday morning. I would like to bring up Robin Kornhaber, who is Vice President of Patient Services. She is going to give you some further information about the program and about *The Leukemia & Lymphoma Society*.



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Robin Kornhaber:

Thank you, Susan. It's really a privilege to be here today on this very dewy morning in Washington. Over the past four years, the Cancer: Keys to Survivorship program has touched the lives of 9,000 patients, empowered them to become a partner in their own care and advocate for themselves, through their cancer experience.

As Susan indicated, it was only with the generous support of Ortho Biotech that this program became a reality and continues to serve patients in an ongoing way. We are truly thankful to them for their support. *The Leukemia & Lymphoma Society* wants to provide critical information and support to all patients, families, and caregivers. We believe this can make a difference in your lives.

At a time of great stress and vulnerability, you need rapid access to current, authoritative, understandable information, information on your disease, possible treatments, clinical trials, insurance, financial aid, prognostic indicators, medications, and much, much more.

Today, we have information and choices that did not exist just a few years ago, information and choices that can prolong and even save lives. Our challenge is great. The Society has a goal to reach all people. We are here to serve and to do so early in their illness. We want to be able to provide the information that patients need most, treatment options, asking the right questions, balancing the quality of life with treatment outcomes.

Cancer: Keys to Survivorship, this program, is provided nationwide through the efforts of the National Coalition of Cancer Survivorship and *The Leukemia & Lymphoma Society* chapter staff. The Society has 58 chapters and provides a broad array of services to patients, including family support groups, First Connection, which is our peer program, an information resource center which is staffed by our nurses and social workers to answer your questions, a patient financial aid program, and educational programs like the one you are attending today.

Throughout our four years of implementing this program, we have learned through the evaluations that patients find this information most useful if it is provided very close to the time of their diagnosis. As a result, we have arranged, also through a grant from Ortho Biotech, to have today's segment audio- and videotaped and placed on the websites of our organization as well as the website of CancerEducation.com.

Starting July 10th, patients can then access the information at any time and also come back for a refresher if they choose. In order for us to air this webcast, we would appreciate if you would give us your permission to use anything that we



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Robin Kornhaber: tape today. You should have done this at the time that you registered and if you did not, would you please sign the consent form before you leave?

It's now my pleasure to introduce Carson Jacobi, who is the National Director of Patient Services at *The Leukemia & Lymphoma Society*, and she will be moderating today's program. Thank you.