

Transcription- 2016 Post-ASH Patient Forum: Interview with Leila Evangelista of LLS

Brian Koffman, MD- Hi, Dr. Brian Koffman. I'm a family doctor and a CLL patient myself and I'm here at the City of Hope as we're putting on an educational forum, the CLL Society. I'm the founder and Medical Director of that. But we're working with other people: The City of Hope has helped and The Leukemia & Lymphoma Society has helped (LLS). And Leila, tell us a little bit about you and your involvement with LLS.

Leila Evangelista, Patient Access Manager, LLS- Yeah, absolutely. My name's Leila Evangelista, I'm the Patient Access Manager for the Leukemia & Lymphoma Society for Southern California and Hawaii.

BK - Tough!

LE- I know, and you know, it's a great organization. We're working to provide education and support for those who are affected by all blood cancers, but CLL, as well. So, we provide a lot of education. We have information specialists who are available during the weekdays, that can help patients with finding more information about their diseases, their treatments, clinical trials, just really making sure that they are able to navigate where they're going and we can really work together with The CLL Society on that, as well. But we also provide emotional support, in the form of support groups, throughout the country. We have a First Connection program where people can talk to other people who are diagnosed with a blood cancer. So, if a CLL patient came and they said they had this specific diagnosis, and a specific treatment we can try to find a volunteer to really help them understand what they might go through in the future, and what's coming up. Because sometimes, we all know that a lot of the times, the best information is through somebody who's been through it.

BK- Yeah, there's only things that a peer can tell you.

LE- Yeah, absolutely! And the same thing goes for caregivers, for those who are the cosurvivors in this and really knowing what they can do to move forward with somebody who's diagnosed with blood cancer.

BK- And you put on some large regional programs, too, which deal with all blood cancers, but often have a breakout session.

BK- Absolutely.

LE- specifically for each cancer type, including CLL.

LE- Right. So, across the country we have what's called a Blood Cancer Conference. We do have the one coming up on March 4th in Southern California, and they cover all of the blood cancers, with a breakout on each of the blood cancers, so CLL is no different, as well as some quality of life issues. So, for this year, for example, we'll be focusing on side effects and symptoms management, looking at pain, fatigue, neuropathy, and chemo brain, to really help patients to manage those extra things that happen because of, in result to their cancer.



BK- And I've attended several of these and they've all been excellent. So, I want to thank you so much, what you do personally, what your organization does, any final words or thoughts that you wanted to share with the CLL community?

LE- I think, I didn't get to mention we also provide financial assistance.

BK- That's important, yeah.

LE- That is definitely important. It's a big part, oftentimes in addition to all of these things that you need to learn and have to keep up with, there's the logistical part of being diagnosed. And we provide co-pay assistance. Every now and then we'll have, depending on your chapter, they have other financial assistance programs like travel assistance. So, we're there to help support.

BK- And you help people navigate, not just their disease, but the whole insurance issues and how to get coverage and all that kind of stuff, too.

LE- Right, I mean I think what we really provide is the, we can help with the navigation, but also if we don't have the expertise in that, we can definitely steer people in the right direction of who would be the best person to reach out to about a specific situation.

BK- Well, it's a pleasure to work with you and your organization.

LE- It's always been great.

BK- Thanks. - Thanks, thanks so much.

LE- Thank you.