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ReachMD

www.reachmd.com
info@reachmd.com
(866) 423-7849

The CLL Patient Journey: From Diagnosis to Initial Treatment

Announcer:

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Dr. Koffman and Dr. Danilov have received compensation from the US Medical Affairs Department of AbbVie Inc. to prepare and present the following information and are speaking on behalf of themselves with input from AbbVie.

And now here’s your host, Dr. Matt Birnholz.

Dr. Birnholz:

This is ReachMD, and I’m Dr. Matt Birnholz. In this first episode of the two-part program, we’ll be hearing the journey of a survivor of chronic lymphocytic leukemia, or CLL for short, from initial diagnosis and active surveillance to initial treatment considerations. Joining me for this discussion today are Dr. Brian Koffman and Dr. Alexey Danilov.

Dr. Koffman is a retired family medicine physician and Clinical Professor at USC. He’s also a CLL survivor who co-founded and serves as the Chief Medical Officer and Executive Vice President of the CLL Society, which is a non-profit dedicated to the unmet needs of the CLL community. Dr. Koffman, thanks for being here today.

Dr. Koffman:

Thank you. I’m looking forward to it.

Dr. Birnholz:

Me as well.

Dr. Birnholz:

And Dr. Danilov is the Marianne and Gerhard Pinkus Professor in Early Clinical Therapeutics and Director of the Early Phase Therapeutics Program at City of Hope in Duarte, California. Dr. Danilov, it’s great to have you with us as well.

Dr. Danilov:

Thanks for having me

Dr. Birnholz:

So let’s start our discussion with you, Dr. Koffman, and focus on your perspective as a patient. When you received the CLL diagnosis, what were your initial thoughts and emotions?

Dr. Koffman:

When I was diagnosed with CLL in 2005, it was a shock. I remember I just received some good news about my cholesterol and was feeling pretty happy about that, but my white blood cell count was unusually high. A few weeks later, I received the diagnosis, and that I had several very poor prognostic markers. It was particularly tough for my family, especially since my daughter was about to get married. At the time of my diagnosis, there weren’t the targeted therapies that have subsequently revolutionized CLL care. The only

treatment option was chemotherapy, and my particular type of CLL was predicted to be refractory to it.¹ Being told that you have cancer and that it's incurable, it didn't matter that I was a doctor – I was still in shock. It was that feeling of a 'deer in the headlights.'

Dr. Birnholz:

Well, the story that you shared offers such valuable insight, Dr. Koffman. Thanks so much. But, based on your research and advocacy within the CLL community, can you just share what patients typically experience at diagnosis and how that may influence their treatment considerations?

Dr. Koffman:

Yes, so keep in mind that when a patient is first diagnosed with CLL, it's often an incidental finding, meaning they were asymptomatic at the time of diagnosis like I was.² So it's important that even prior to treatment, health care providers take the extra time to not only understand the impact of the disease, but the impact of the emotional aspects of the diagnosis on the patient and their family members.³ Then, when the time comes for selecting the initial therapies, patients have multiple treatment options to consider. And making treatment selections is a little bit like a game of chess in which you usually have to think two to three moves ahead.² With CLL, some initial treatment choices can prohibit a future treatment option.⁴ For example, a stem cell transplant can exclude participation in a future clinical trial.⁵

It's also crucial for patients to think carefully about the timing of their treatments: Most therapies in CLL are palliative, not curative,⁶ so the goal is to stay healthy long enough to take advantage of new therapies. Optimally, this includes extending the time before a patient needs the next treatment.⁷ The last thing I'd like to point out is that the presence or lack of presence of caregiver support can be a deciding factor in treatment selection.

Dr. Birnholz:

You know Dr. Koffman, it's obvious that the journey from diagnosis to treatment based on your experience involves a lot of careful considerations. Now can you just share a little bit more about how mental health factors into this experience?

Dr. Koffman:

You bet. When patients go from their life before diagnosis, the new normal patients call it, one of the most significant symptoms is anxiety.^{8,9} And a particularly challenging period for patients is before the treatment begins. What's traditionally been called 'watch and wait' or what patients call 'watch and worry.'⁹ I much prefer the term 'active surveillance' as it conveys a more positive proactive approach.

Dr. Birnholz:

That makes a lot of sense, and I appreciate you sharing all of that with us, Dr. Koffman.

So Dr. Danilov, I want to turn to you then. How have you talked with your patients at the time of initial diagnosis and active surveillance that Dr. Koffman is speaking to?

Dr. Danilov:

The diagnosis of CLL majorly increases anxiety. From my experience, one of the most effective ways, if not the most effective way to help patients is to provide them with as much information as possible concerning their diagnosis, concerning their prognosis, and the natural history of the disease. For many patients, it's reassuring to learn that the majority may not need treatment for several years. Sometimes, even several decades, and that depends on the genetic characteristics of their disease.⁹

In terms of practical strategies, I find it important to maintain open communication throughout this period of active surveillance. Reassure patients that just because we aren't treating the leukemia immediately, it doesn't mean we aren't monitoring it closely.

Dr. Birnholz:

Now, Dr. Koffman, coming back to you, when moving out of active surveillance and into initial CLL treatment selection, how do patient and caregiver preferences contribute to the decision?

Dr. Koffman:

What's important to remember is if even in the same patient at the start of treatment, there can be very different preferences, goals, and needs during and after treatment. We need to be flexible and consider the long-term journey. In CLL, we have the option to start with either continuous or fixed-duration therapies. Some patients may prioritize a fixed-duration treatment because they like the idea of completing therapy and moving on, while others may be more comfortable with taking a medication daily in a continuous treatment option.¹⁰ Patient preference should be a key factor in the decision-making process. While overall survival is always the primary goal for

both patient and healthcare provider, we can weigh some other considerations like long-term side effects and the quality of life.^{4,9}

Dr. Birnholz:

Yeah. That's a great point, Dr. Koffman, thank you. And Dr. Danilov, I want to come back to you on this one. Given that you're a physician, you're treating patients with CLL, what are some of the considerations that you make when selecting an initial treatment?

Dr. Danilov:

When deciding on the initial treatment for patients with CLL, we have several important factors to consider. Efficacy and safety are always our primary considerations, of course, because we want to optimize survival outcomes throughout the patient's treatment journey. But we also may want to individualize the decision based on each patient's circumstances and goals. So patient preferences play a significant role here.^{4,9} Some of the things I'll consider include the genetic characteristics of the disease, comorbidities, and concurrent medications. Quality of life and the psychological impact of ongoing treatment are other major considerations. I also factor in logistical considerations—such as patients who live far from treatment centers—in addition we look at duration of therapy, drug exposure, and of course, cost.^{11–14}

Dr. Birnholz:

Interesting. Well as our program nears its close, Dr. Koffman, I'm going to turn to you again, anything that you want to share, any final thoughts with our audience today from the patient lens?

Dr. Koffman:

Yes. Absolutely. Shared decision-making needs to start before the patient processes the diagnosis and extend through every stage of therapy. Providers need to consistently consider what's important to their patients whether it's about the quality of their life, the potential side effects, long-term/short-term, or the impact on family and caregivers.

Dr. Birnholz:

Thank you, Dr. Koffman. Excellent insights there. They're going to resonate with our audience for sure.

And Dr. Danilov, let's give you the final word.

Dr. Danilov:

It's very important to reassure our patients that we have a range of therapies available for them. And by planning ahead, we can ensure they receive the best possible care throughout their CLL journey. The conversation needs to be ongoing, with an understanding that CLL is a dynamic disease and that our treatment strategies need to be flexible to meet the patient's evolving needs.

Dr. Birnholz:

Wonderful. Thank you, Dr. Danilov. Those are fantastic takeaways from our discussion. I very much want to thank my guests, Dr. Brian Koffman, Dr. Alexey Danilov, for sharing their perspectives on treatment selection and shared decision making with CLL patients and their caregivers.

Dr. Birnholz:

Dr. Koffman, Dr. Danilov, it was great speaking with you both today. Thanks so much.

Dr. Koffman:

Thank you for this opportunity to present the patient's perspective.

Dr. Danilov:

Thank you for this opportunity.

Dr. Birnholz:

For ReachMD, I'm Dr. Matt Birnholz. For even more insights on the treatment of CLL, be sure to check out the second episode of this two-part program, which will explore key data on patient and caregiver preferences as well as strategies for discussing them.

Announcer:

This medical industry feature was sponsored by AbbVie U.S. Medical Affairs. If you missed any part of this discussion or to find others in this series, visit *Project Oncology* on ReachMD.com, where you can Be Part of the Knowledge.

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