Interview

Living with CML: Solveig's Story

Mendus is expanding clinical development of vididencel into chronic myeloid leukemia (CML) – an area where patient experience highlights significant unmet need.CML is often described as a manageable cancer, thanks to major advances in treatment of the disease with a class of drugs called tyrosine kinase inhibitors (TKIs). But behind that progress are individual patient experiences that are rarely fully understood. While many people live long lives with CML, the day-to-day reality associated with life-long daily medication can carry a significant physical and emotional burden. Vididencel immunotherapy may allow more patients to safely stop their TKI treatment and experience durable treatment-free remissions.

Solveig was diagnosed with CML at the age of 25. In this conversation, she shares her personal experience—from the moment of diagnosis to living with long-term treatment. Her story highlights both the progress that has been made, and why continued innovation in blood cancer treatment remains important.

When were you first diagnosed with CML, and what was going through your mind?

I was diagnosed in September 2020. I was 25 years old. I had never heard of CML before. I had heard of leukemia, but I thought there was just one kind, and it sounded like a death sentence. My doctor explained that it was not a death sentence and that people can live with it and take medication, but the only thing I heard was leukemia.

I went to the doctor because I thought I had irritable bowel syndrome. I thought it was something small that you adjust your life around. And I came out of the office thinking, "I'm going to die soon." I had to hear what the doctor said many times after that, because as soon as he said leukemia, it was like my ears became deaf.

How did your family react?

It was during COVID, so I couldn't tell my family in person. I had to call them, and those were some of the hardest conversations I've ever had. Everyone reacted very differently.

My father went straight into damage control—looking into bone marrow donation, contacting organizations, trying to find solutions. My mother was devastated, and I felt like I had to lift her up, even though I was the one who was sick. My brother was very angry and kept asking why it had to be me. And for me, I was just numb, trying to tell everyone the same information while not fully understanding it myself.

My boyfriend was also thrown into it all with me and had to care for me while also processing his own emotions. He and his family were the ones closest to me at that time, they all live where I do. I've since felt like their own child, they were the biggest support in the early days and through the years of treatment.

How did it impact your life early on?

Everything changed very quickly. I was studying at the time and going to school every day because I loved it. Then suddenly I was in the hospital every day, going through tests and starting treatment.

It also felt very urgent because I was in blast phase, so there was a risk it could develop into something more severe. I didn't really know how to explain it to people. I would just say I was sick, but in reality I was in the hospital every day, going through tests, and I didn't know if I was going to survive.

What has your experience with treatment been like?
I'm still on treatment, and I am of course grateful that it exists. But I think we can do a lot better. If something else could help, I would be the first one in queue.

For me, the side effects are very real. I have a lot of fatigue –I sleep most days around 12 hours, and if I push myself, it can be much more. I have pain every day, but I have limited access to stronger pain medication, so I manage with what I can. I also have concentration problems and memory loss. Before, I could read something once and remember it. Now I feel like I've lost the key to my own library.

What is the impact on your daily life?

This life I have on TKIs—it has a price. I don't think it is a long-term solution, at least not for young people who cannot continue life the way they did before.

Even small things come with trade-offs. If I do something like meeting people or doing a hobby, that can be everything I do that day. I used to be very active and had many hobbies, and now I feel like I've lost a lot of that. Sometimes I feel like I'm not even half a person anymore.

What gives you hope?

What gives me hope is that people are still working on this. That there are companies and researchers trying to find something better. It feels like a light at the end of the tunnel.

I don't think we have looked at every possibility yet. There are still things to discover, and I believe there will be progress. Even if it takes time, knowing that something better could come makes a big difference.

What would you say to someone who has just been diagnosed with CML?

I think the most important thing is to ask for help. You cannot do this alone. At least i could not have done this without my partner and his family's support. It's really hard, especially in the beginning, and having someone with you—at appointments or just in general—can make a big difference. When you're sitting there hearing everything for the first time, it's easy for things to get lost or feel more negative than they actually are.

I also think it's important to connect with other people and to speak about it. Even though CML can sometimes feel like it's treated differently because there are good medications, you are still going through something very real, and your experience matters. And I would love to say it will get better—that's what I tell myself every day. I believe there will be progress, and that there are still many possibilities we haven't explored yet. So even if it's difficult, it's important to hold on to that hope.