



Transcription: iwCLL 2017: Deb Sims Discusses her Incredible CLL Journey

Dr. Brian Koffman – Hi, I'm Dr. Brian Koffman, a family doctor and the medical director of the CLL Society here at the last day of IWCLL in Manhattan. And I have a friend with me.

Deborah Sims – Hello. I'm Deborah Sims. I'm a CLL patient on a phase 1 clinical trial of venetoclax and obinutuzumab.

BK – And you live in Melbourne, Australia. So, why are you here in Manhattan, New York as a patient at a researchers' meeting?

DS – Isn't that amazing?

BK – Yeah.

DS – I have 3 monthly appointments in London for my clinical trial. I couldn't get venetoclax in Australia, so I joined a clinical trial eighteen months ago in London. And I'm on my way back to Melbourne. I'm just going the long way around. I'm doing a little bit of work here as a journalist. So, reporting and interviewing doctors, hopefully to be able to share that with other doctors who haven't been able to make the conference.

BK – And I have to ask you, as a patient, and obviously a sophisticated patient, are you getting anything out of this meeting today?

DS – I have to say the hardcore science, my brain shut down. I did not understand. But I'm getting a lot from the summaries. So, when the doctors summarize what they just presented, that's helping enormously. And this session today is very relevant to me. It's about clinical options for relapsed and refractory patients. So, I'm understanding this a lot more than I did... the biology on Saturday about the mutations that lead to CLL.

BK – And you made a huge move, because we met, and I'll just tell a brief background on our story. You were looking for options. You had a very bad disease that was progressing, as a young woman. We met in San Diego. You ended up hooking up with Dr. Gribben in London, and had to fly from Australia to London to get into a trial. And you're still doing that. How long is it now?

DS – Eighteen months now, so it's 2 years since we were in San Diego. And I went to San Diego to see Tom Kipps for a second opinion. I'd relapsed very early after FCR. And 6 months after FCR I was headed to transplant. I was only forty and I had 3 children under the age of 7, and I was scared, very scared of transplant. So, I met you there. Thankfully, there was clinical trials conference, and John Gribben sat next to me at that conference and, yeah, we ended up in London. So, got to... I was declared terminally ill by my doctors, which, from an insurance point of view certainly helped when I got to London. They said that this trial was the only way I was going to get venetoclax, and I needed venetoclax. So, I was very grateful to be on that. I got into remission 3 months, and I'm MRD negative as of December. So, it took about 8 months to get to MRD negative, which is fantastic.



BK – That's wonderful news. Anything that you would advise a fellow patient who was struggling with CLL, especially maybe a younger patient?

DS – Always get a second opinion. Always. And find a doctor you trust. Because, even though I'm an empowered patient, and I've been going and getting all this information, if any one of my doctors had said, "Deb, you have to have this transplant at this point, now it's your best chance at long-term survival." I actually would have done that. So, find a doctor you trust and share the journey, because this is a long journey. Sadly, this weekend has taught me it's not over yet. But there's great people working on this disease. It's a lot of reason to be hopeful. I don't think it's going to kill me, anymore. I don't think it's going to kill you, Brian. And I think in a few years time, CLL will be one of those diseases that they say, 'Oh that used to be terrible'.

BK – Well I look forward to meeting again and again at more of these conferences. Thanks, Deb. Thank you

DS – Thanks, Brian.