



CML Patient Story: A 20-Year Survivor Shares His Clinical Trial Experience

Mel Mann, MBA, M.Ed

Patient Advocate, Longest Living #Gleevec survivor

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Andrew Schorr:

So Mel, in the late '90s you were dying, right, of chronic myeloid leukemia, correct?

Mel Mann:

Yes, I was.

Andrew Schorr:

Losing weight and being told that there wasn't much to do, right?

Mel Mann:

Correct, yes.

Andrew Schorr:

Maybe a transplant. But you were in Atlanta and you went from doctor to doctor, but somehow you got to MD Anderson, a major research center in Houston. What did they offer you there?

Mel Mann:

When I first went out to MD Anderson, they said they were going to put me on a clinical trial after clinical trial. And the first thing they did was increase my dose of interferon, and that was the medication, the standard therapy at the time, and then they tried different combinations of drugs, and eventually I started on different clinical trials.

Andrew Schorr:

Okay. And, Cecelia, you were there in Atlanta and he was scooting over to Houston, it's not exactly around the corner. Why were you supportive of that?

Cecelia Mann:

I was supportive of that because that was the last chance that he had to a cure and for survival. So from the very beginning, whatever type of treatment he needed when he was flying around, whether he was going looking for bone marrow transplants, doing bone marrow drives, and therefore I was supportive of. We had a 5-year-old daughter at the time, and so anything that Mel needed I was there to support him.

Andrew Schorr:

So, Mel, this is a happy story because here we are in 2018 as we do this program and you are with us when many people with CML at the time were not with us that long. Hopefully, a transplant could be curative, but a lot of people passed away. You were lucky enough to come back as they were rolling through different trials and there was a new one that opened up for a drug called imatinib (Gleevec), a pill.

Mel Mann:

Yes.

Andrew Schorr:

What happened?

Mel Mann:

Okay. So in the summer of '98 the Phase I Gleevec study opened up, and I went out to MD Anderson, and I was patient number two, and I started taking it at a low dose, and it was effective for me. And eventually they increased the dose and it started changing my leukemia around to eventually I reached what they call a major molecular response. And that was 20 years ago. This summer I went over 20 years.

Andrew Schorr:

Wow. Well, Dr. Schilsky, is that an example of a patient getting, if you will, tomorrow's medicine today, what we hope for?

Dr. Schilsky:

Absolutely. And, first of all, it's such a wonderful story, Mel. It's great to hear you tell it, and it's exactly why we do research, exactly why we do clinical trials, to try to discover the new therapies that people need that will give them the kind of long-term survival and quality of life that you've been experiencing. It's just—it's wonderful.

Andrew Schorr:

Mel, so for you, you went around to some doctors who were not aware of anything new to do for you, right? And that's still true in so many areas of cancer. Now, what do you say to patients about speaking up because Dr. Schilsky just referred to it, people are terrified. They really just want the doctor to have the answer. What do you tell people so that they maybe advocate for themselves?

Mel Mann:

Okay. So if you're looking for a clinical trial and I'm out at, like you say, a health fair, we have a—The Leukemia & Lymphoma Society has something called the clinical trial support center, and they have nurses who work early in the morning till late at night. And you call them up and you tell them about your illness, and they check the availability for what clinical trials are out there, and then they narrow it down to what you actually qualify for, and then they take into consideration your finances and other issues.

And then you're left with a number of possible clinical trials that you have, and you can take that back to the doctor and you can discuss that with him. So that's one of the things I talk with them about.

Andrew Schorr:

I could mention, now this is really more broadly across cancer, too. So there are breast cancer groups, there are lung cancer groups, and I would just make a pitch to find out, is there a local chapter or national number for you, for the cancer you or a loved one been diagnosed with, and that's the question.

Mel Mann:

Yes.

Andrew Schorr:

Say, look, A, I don't want to feel I'm alone, and, B, how do I get—how do I get connected with what could be lifesaving or life-extending treatments for me and that I could discuss with my doctor. And understanding—and then, boy, if there are obstacles like financial issues, logistical issues, travel issue, is there support for that.

Mel Mann:

Yes.

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