



Patient Power

Young Adult With ALL: Why I Chose IV Therapy

Annmarie Uliano
ALL Patient and Advocate

Amy Uliano
ALL Care Partner

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Theresa (Clementi) Doan:

Hi and welcome to Patient Power. I'm Theresa, one of your community managers, and I'm joined today by an ALL patient, Annmarie Uliano, and her mom, Amy. Amy and Annmarie, welcome to Patient Power. Thanks for being here with us.

Annmarie Uliano and Amy Uliano:

Thanks for having us.

Theresa (Clementi) Doan:

So, Annmarie, can you walk me through your ALL diagnosis and then some of your treatments?

Annmarie Uliano:

Sure. I was originally diagnosed with ALL in November of 2012, and I had sort of the traditional chemotherapy and radiation protocol that they give to young adult leukemia patients. In 2017, I found out I had relapsed, and I was presented with an option to take an amino therapy drug, and then get in remission from that in order to be able to get a stem cell transplant.

Theresa (Clementi) Doan:

Okay. Got it. What were some of your treatments before 2017?

Annmarie Uliano:

I had gone through two years of chemotherapy with one month induction inpatient, about six months of consolidation which was still relatively high-dose chemo, kept me out of school. And then I had about another year and a half of maintenance treatment where I was able to go back to school with a limited course load and be able to travel to the chemotherapy clinic once a week to finish with maintenance.

Theresa (Clementi) Doan:

Right. Right. And then you relapsed. How did that feel? Amy, how did it feel to hear that your daughter like relapsed, too?

Amy Uliano:

When she called and told me that she had a relapse it was right before the holiday, and I honestly thought she was joking, because there had been no indication of any relapse. I mean, she was leading a normal, healthy life. She was active in school. She had a job offer.

Theresa (Clementi) Doan:

Yeah, just a regular 20-something-year-old.

Amy Uliano:

A regular 27-year-old hanging out with her friends, family. I honestly—I was at work, and she called me up, and I just couldn't believe it.

Theresa (Clementi) Doan:

Yeah. Annmarie, were you...

Annmarie Uliano:

...I thought it was a joke too when my oncologist entered the room. I was—I really went into that five-year appointment with a list of accomplishments and how well I was doing, and he walked in and he told me that they had seen blasts, and he's kind of a funny guy, but why would he joke about that. Quickly realized that he wasn't joking.

Theresa (Clementi) Doan:

And then he presented you the option of an immunotherapy, so a continuous IV. Can you explain what that is for people that may not know about that?

Annmarie Uliano:

Sure. So the treatment was 28-day cycles where the medication needs to be administered continuously over that 28 days. So with the first cycle that I did I spent about three of the four weeks inpatient. You often have a reaction in which you get a fever, which is an indication that it's working for your body, but they do want to monitor you especially during that first time on the drug.

Theresa (Clementi) Doan:

How did you prepare during that—for that inpatient treatment? You just kind of braced yourself to be in the hospital? Was there anything, Amy, that you did?

Amy Uliano:

I was very apprehensive, because we had had five years of not having really any setbacks, and I had just put my mindset as to how it was the years before and the rigor and the, really, just the change in our lifestyle, and I really felt really bad for Annmarie because she was really taking off with her career and it was very, very hard. I knew that my life was going to be changing again, and, you know, you have to prepare for that both mentally, financially, spiritually, and so it was a change.

But I knew we were in really great hands. I knew that the treatment plan that was presented to us was going to be the best option for Annmarie and I knew that we would come through it. So we went in with the belief that she was going to get back into remission and that we would head for a stem cell transplant, and this was just a little blip on the radar and we would be back to our same pattern in a year or two.

Annmarie Uliano:

For me, I prepared for the inpatient stay by going home and spending Christmas with my family.

Theresa (Clementi) Doan:

I love that.

Annmarie Uliano:

Luckily, I think the first time that I got sick there was no time. As soon as they discovered that I had abnormal blood work I was sent to the hospital and stayed there for a month.

Theresa (Clementi) Doan:

Wow.

Annmarie Uliano:

Whereas this time my condition was not at the severity that it was the first time, and so being so close to the holidays my doctor kindly let me spend time at home with my family and really get some quality time. I think otherwise it kind of— inpatient stays have—I was just talking with somebody recently, another fellow cancer survivor who had a different form of cancer, and she was so surprised about how casually I talk about inpatient stays.

You know, I think it's just kind of run-of-the-mill with ALL or other types of leukemia where an inpatient stay for an extended period of time isn't really a big shock. So I think that previous experience had helped me mentally prepare for what another couple of inpatient stays would look like.

Theresa (Clementi) Doan:

Got it.

Amy Uliano:

We take over when we get there. We decorate her room.

Theresa (Clementi) Doan:

Oh, I love that.

Amy Uliano:

We play games. We somehow snag the big screen TV. So, you know, you do have to also, you know, make it a time where, yes, it's going to be difficult but we're going to get through this and still maintain family time.

Theresa (Clementi) Doan:

Right. Right. It sounds like you really try to make it as homey and as comfortable as possible, and I think that's great advice for other people that may be in your shoes, Annmarie.

Annmarie Uliano:

Yeah.

Theresa (Clementi) Doan:

So the continuous IV, how big is it? It's kind of like almost like a little fanny pack or a small purse, right?

Annmarie Uliano:

Yeah. So it's about that big, long, and be about this tall, but within the bag one side has the actual pump, and then the other side you can actually see the bag of medication going in. It looks just like how a regular IV would be, it's just that it's a little bit smaller and you're carrying it around. And mine was connected through a pick line in my arm, and, you know, I'd have to get the dressings changed, but the bag, you know, you just wore it. Some people wore it as a fanny pack. I've seen people at the clinic wearing it as a fanny pack.

I tended to wear it just on my shoulder. When I wore it on my shoulder I could also hide it in a big purse, so that was really convenient for me because I could still do a number of activities and not carry around this clunky thing that everybody's going to ask you a question about.

Theresa (Clementi) Doan:

Yeah. So you could kind of lead some kind of normalcy, a new normal, if you will, for that period of time.

Annmarie Uliano:

Yeah, absolutely.

Theresa (Clementi) Doan:

You were inpatient for a little bit, a month, you said?

Annmarie Uliano:

Yes.

Theresa (Clementi) Doan:

And then how long were you hooked up to the IV but you could go about your normal day?

Annmarie Uliano:

So the second and third cycles I got to do outpatient mostly where I would have to go into the infusion clinic every 48 hours and get is new bag, attach the pump and the pump reset. So I always went at the same time every two days, and it was sort of a unique experience because you really get to develop deeper relationships with your nurses because you're seeing them so frequently.

And I also got to meet a lot of other nurses as well. You'd have to go one day on the weekend with it being every 48 hours. And so the weekend nurses rotate. It's always a different representative from your floor that would be taking care of you on the weekends and it may not be someone you are used to seeing, and so I definitely got to meet and make relationships with almost every nurse in the clinic.

Theresa (Clementi) Doan:

That's really cool.

Annmarie Uliano:

Yeah.

Theresa (Clementi) Doan:

You were able to develop personal relationships, and because you came back every two days we should mention to our audience that it's important that you're nearby the clinic when you're doing it. So if you're from a small rural area it's worth moving there for a short time to be able to get that transfusion. You are in Boston, right, so at Dana-Farber you were getting care?

Annmarie Uliano:

Yeah. And I live right around the corner too, so during the warmer spring-summer months I actually walked a couple of times.

Theresa (Clementi) Doan:

Oh, nice.

Annmarie Uliano:

So that's how well I was doing. I was well enough, I was feeling well enough, and I wasn't in pain or having nausea and all the typical chemotherapy side effects, so I could walk over there, and it was really convenient.

I have heard of other patients, though. I know that people come from all out of state, around the world, to come to Dana-Farber, and they've had to relocate for a short term. But many cancer institutes do have short-term accommodations programs, so there's lots of...

Theresa (Clementi) Doan:

Assistance.

Annmarie Uliano:

...options and opportunities for out-of-staters, out-of-country people to be able to take advantage of a continuous infusion drug like that.

Theresa (Clementi) Doan:

Nice. And, Amy, you were able to kind of pop in and help Annmarie out. What was that like for you being able to see her kind of have the freedom while still being treated?

Amy Uliano:

That's was one of the things that I really liked about the treatment is that it was very--there was a lot of normalcy.

Theresa (Clementi) Doan:

Right.

Amy Uliano:

She could go out, we could go out, we could go shopping, we could go out to dinner. We could do--you know, we could walk together. It was very easy to disguise. We also with it being a continuous pump, you know, bathing was sometimes an issue, and so we would treat each other or treat her to have her hair done at an salon.

Theresa (Clementi) Doan:

Oh, nice. That's always my favorite part of getting a haircut.

Amy Uliano:

Yeah. And it was great, because obviously it accommodates for that type of thing. You don't get wet. But I just thought it was great for her in terms of not being in a bed for that period of time. She could go out and just do normal things, go to work, do whatever she needed to do. And also it gave her freedom in the sense that I didn't have to go to every appointment with her.

She could go on her own, and I thought that was important for her, for her mental health just to be able to do something independently, meet with the nurses. The time was very, you know, not long, and she could just do it on her own and just be a normal, regular 27-year-old going on with her life. And I thought that was really great.

Annamarie Uliano:

I think one piece that I struggled with was that the immunotherapy was presented to me as a bridge to transplant. And there was no other real option than going to transplant after it. Especially with immunotherapies being so new they haven't been able to study long-term successes with it. And so that was sort of an uncomfortable note to sit with, that I'm going to have to have this treatment but then I also must go to transplant.

Theresa (Clementi) Doan:

Right.

Annamarie Uliano:

And two things I want to say about that. The first is trust your doctors. They really know. They're making a recommendation not because they want to put you through more treatment but because they know that that's the right course of treatment for your disease.

And the second thing is I want to tell leukemia and lymphoma patients to not be so afraid of transplant. I was super afraid. In fact the first time around when it was presented to me as a potential option after the initial chemo I said I didn't want it.

Theresa (Clementi) Doan:

Yeah.

Annamarie Uliano:

And I still felt some of those sentiments with the relapse, but given the relapse I knew that transplant was the best option. And so I know everybody's different with transplant, but for me it was not as terrible as what I painted a picture of it being in my mind.

Theresa (Clementi) Doan:

Okay. Good. Yeah. That's nice to hear. So you did three cycles of the IV and then you did a stem cell transplant. How are you doing now?

Annmarie Uliano:

I'm in remission, and I'm 99 percent of my donor, my mom was my donor.

Theresa (Clementi) Doan:

Oh. How is that, mom, being her donor and going through the stem cell transplant?

Amy Uliano:

It was—it was—it was great. It was really, you know, I would do it in a heartbeat, and I did it in a heartbeat. And if somebody else needed my stem cells I would do it again. But it was just a few shots and just basically almost like if you were giving blood, and it was just—I wasn't anything difficult. It wasn't painful. It was just something that I did, and I'm happy that I was able to do it for her.

Theresa (Clementi) Doan:

Yeah. Yeah. That must be reassuring for our audience to hear as well. So, Amy, do you have any other tips for other care partners seeing their children go through this and all the different treatment options.

Amy Uliano:

I have to agree with what Annmarie said. Really listen to your health team, your medical team. They are there, they are the ones, they are the experts. As Annmarie said originally that she, you know, when she was originally diagnosed that she was--should have had a stem cell transplant and maybe we should have looked into that more seriously back then. But really depend on them.

Also really stay involved too. Be at every appointment. Get to know the nurses. Get to know the medical staff. Get to know the teams. Because they are your allies, and you really spend a lot of time with them especially if you're--whoever, if you're a patient or your child or your husband or spouse is going through this because they do need an extra set of eyes and an extra set of ears, and sometimes you have to digest that.

Also, meet with whatever resources are available. Ask a lot of questions, whether it be pastoral, whether it be social work, whether it be finance. Don't be afraid to ask questions and ask for help. It's out there. It's hard to find it if you try to do it on your own, but if you really ask and talk to people you will find it. And don't be afraid to talk to other people about what's going on, and you'll find the support that you need.

Theresa (Clementi) Doan:

Wow. Wow. What great advice, both of you. When I think about your story, Annmarie, it's really a story of hope and new-found freedom, so you went through your treatments beforehand. You had five years, you're told you've relapsed. Here's an option, a continuous IV option before you go to transplant. You have some freedom from your continuous IV, and then you overcame your fear of stem cell transplant, and now you're doing well, you're back to work.

Annmarie Uliano:

Yes.

Theresa (Clementi) Doan:

Living your normal life. You said that you talk to other cancer survivors and keep in touch that way.

Annmarie Uliano:

Yeah. I love connecting especially with the young adult cancer survivor community. I've participated in First Descents and more local sort of piggy-back onto First Descents called Clean an Orchard, and through that I have made a number of really great friends. I've also been connected with the young adult group, support group, and they have a program at my clinic, and I will randomly end up meeting people from it at various points.

I've also been doing—my clinic offers, they have like a wellness center, and there's exercise classes throughout the daytime, and so I've made connections with many people through that as well. Not so many young adults come to that, but it's great to have the connection, listen to other people's experiences and give them advice. Maybe we don't have the same type of cancer but we have had the same type of struggle, and so it's always great to do that knowledge sharing with others.

Theresa (Clementi) Doan:

Wonderful. Wonderful. I want to thank you for your time, Annmarie and Amy. We really appreciate you sharing your story, and we wish you all the best in continued health and happiness.

From Patient Power, I'm Theresa. Remember, knowledge can be the best medicine of all.

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