



CLL Patient Café: Tools for Facing a Mid-Life CLL Diagnosis

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Esther Schorr:

Hi there. Thank you for joining our Patient Cafe today sponsored by the Patient Empowerment Network. I'm Esther Schorr, and today I'm meeting virtually with a group of CLL patients, chronic lymphocytic leukemia, who are all facing this diagnosis during their middle years. So, of course, there's no really good time to be diagnosed with something serious or diagnosed at all, and it's never easy and it's never welcome, but in our middle years the career ball, your personal life direction, the people that you indirect with, the relationships you have are already pretty well in progress, and a diagnosis can feel as though personal and professional life kind of had a monkey wrench thrown into it and that your plans for life could be derailed.

Our guests today are going to share their stories and advice about how they've been able to deal with a mid-life diagnosis. So just before we start I want you to know that this conversation is never, would not be a replacement for medical care, medical advice. Each patient's situation is unique, so I really encourage you to consult your own doctor, your own medical team for the treatment that's right for you.

So first of all, I just wanted to tell you a little bit of where I fit into this conversation. My husband, Andrew, who you're going to meet in a second, was diagnosed with CLL in his mid-40s, and at the time we had two small children.

Also, we were in the middle of growing a fledgling business that then became what we do now in educating patients. And we were devastated. It was scary. We didn't know what the complications long-term were, we even wanted to have a third child at the time, and certainly, like most people, we didn't know anything about CLL. We didn't know. And the word "leukemia" was very frightening. We were very lucky at the time. We had supportive family and friends, and we found great medical care through networking with other people on the internet, through online support groups, etcetera. And ultimately Andrew got through a clinical trial, went into it, went through the trial and had a long remission, and we're very, very thankful for that.

As a care partner, I will tell you it's taken years of ups and downs for me emotionally to come to terms with the fact that we can't really live our life based on what-ifs.

And we've gone on together with our friends, our family, and we just live our life. We now live in Southern California near the beach with our dog, and we have three grown kids who are very supportive, and—but we've learned a lot along the way. And so I'm hoping that this discussion will help those of you that may be in similar circumstance to kind of come to a place where you can move on with your life and feel empowered. Is that's my story. I want to have each of our guests introduce themselves. So why don't start. Jeff, Jeff Folloder, why don't you start.

Jeff Folloder:

Hi. I'm Jeff Folloder from Katy, Texas, which is just outside of Houston. I am a CLL patient, and I am also a Patient Power advocate, champion, evangelist, pick one of the terms, whichever one you're comfortable with. I was diagnosed at 46 years of age.

I absolutely, positively was not expecting to hear my doctor say something's wrong and you need to go see a specialist. Walked into the specialist's office, saw a bunch of old, sick people in there, said this isn't me, and the next day I was told, yes, it is. So my diagnosis did absolutely come as something of a huge shock. It was like a sucker punch in the gut, and it took me a bit of time to figure out has comes next.

I was very fortunate to get connected with some folks here in Houston who got me enrolled in a clinical trial after two, two and a half years of watch and wait. I got six and a half years of rock solid remission out of my clinical trial. This past July I have recently relapsed, and I'm looking at it right now quite frankly as no big deal.

I'll get treated when it's time to get treated. In the meantime, I'm driving all over the country, I'm doing all kinds of things. I'm living life to the fullest, and it's actually okay to take a nap.

Esther Schorr:

Thanks, Jeff, that's perfect, and we'll talk more about that journey for you in a minute.

Jeff Folloder:

Absolutely.

Esther Schorr:

Let's try the other person, Andrew, and then we'll hit Michelle and Jeff.

Andrew Schorr:

Esther, thank you for hosting this program. So you recall vividly I had a routine blood test at age 45, and the doctor initially said when he tested my blood, oh, you're probably fine because I had been getting some nosebleeds, and then he called me, and he said you're not fine. What is it? Leukemia. What is leukemia? I wasn't even sure it was a cancer. And I also didn't understand the difference between acute leukemia and chronic leukemia.

And so what knowing I'd heard somewhat about acute leukemia then, Esther, you and I, remember, we walked in the park in a sunny spring afternoon near Seattle, and I thought I was dead. And I was saying at 45, we have two kids, hopefully you'll be well provided for, and I had life insurance. Is that it?

Well, fortunately, it hasn't worked out that way, and I got a long remission, pretty long, Jeff, 17 years, actually and then needed CLL treatment again many months ago, and that's worked well. So just like what Jeff said, knocking it back, going on with my life. We had a third child, but when I was first diagnosed I thought it was over, but now looking back I know it was really just the beginning, but maybe seeing life a little differently but living.

Esther Schorr:

You thank you. Thank you for that, Andrew. Michelle, tell us a little bit about you.

Michele Nadeem-Baker:

Hi. I'm Michele Nadeem-Baker, and I'm a Patient Power advocate as well and a Patient Power patient reporter. And I have to say, as Jeff had mentioned, I was in shock, absolute shock, no awe, but in shock when I was told that I had CLL. My PCP like everyone else's had said that my white blood counts were a bit off, told me to see a hematologist, and I was very naive not realizing hematologists generally went along with oncology.

Went to the local medical center when I lived in Miami and was not told I had CLL, and then I was called back in for when some other test results came in, the flow cytometry came in, which I now know but at the time had no clue what that meant, had no clue what the doctor was talking about. He didn't even—he said I had the C word. He didn't even say cancer. And then he said CLL. I had to ask what that meant.

And that's why I've been such an advocate for communicating better for patients, because I was a bit dumbfounded as well as in shock. He had no information to give me, and I have since tried to learn a lot and become an advocate for other patients. Patient Power has helped immensely as I've—you know, Andrew is the first person I met with CLL. I reached right out to him, but it was very tough.

I had been married at that point for only two years to my now husband, and it was a real, real shock. My career went into a tumble, a turmoil, and it got put on hold for a while. So I was in watch and wait for about three years. In that time I moved back to Boston, so I could be seen at Dana-Farber. And as both Jeff and Andrew said, life does go on. You just—you have to get into kind of a new step and a new rhythm, but life does go on thankfully and thanks to all the research that's been going on.

And I'm still on a clinical trial. Still in remission. Fingers crossed that will continue. And I'm happy to chat about anything that will help.

Esther Schorr:

Right. We'll have a lot to talk about, I think. Thank you, Michelle. And the other Jeff, tell us a little bit about where you're from and where you're at now.

Jeff Brochstein:

Will do, Esther. Thanks again for having me. Really, my story follows much of the same path. Diagnosed at a fairly young age, 38 years old. I discovered a small lymph node in my neck while I was washing up one Sunday night back in late 2012 and got it checked out and couple months later high white blood cell count, and another high white blood cell count when I was tested again, and I was diagnosed. And really from there I just buried myself in just doing all the research and all the data gathering that I could.

Maybe about three, four months after diagnosis I discovered Patient Power. I found Andrew. I gradually started corresponding with him. From that point on, the next four and a half years I was in watch and wait until probably late 2016, early 2017. Reached out to Andrew again at that point. We had a conversation about FCR, which my doctors here in Atlanta had been talking to me about. Decided to go to MD Anderson after seeing some of the videos on Patient Power of Dr. Keating, Dr. Thompson. Went there to see actually Dr. Thompson who had mentioned ibrutinib and some of the other targeted therapies that had been just approved for frontline. And came back to Atlanta and my doctor and I kind of came to the conclusion that maybe starting with one of the targeted therapies was probably best me being unmutated.

And started ibrutinib (Imbruvica) March 2017 and lymph nodes went away after a week and kind of been in remission pretty much ever since and everything's going well.

Esther Schorr:

Thank you, Jeff. And all of you, there are some recurrent themes here that we'll talk about, but obviously this whole idea of coming into the middle of your life when a lot of things were already in play was something that you had to pretty quickly say, okay, what am I dealing with and then figure out how do you continue with what you were already doing and how does it fit in.

So I want to dig into that a little bit more, and I'd like to start with you, Michelle. And tell me if I'm wrong, but my understanding is that when you were first diagnosed you were really in a pretty high-level executive position in PR and communications, and how did you cope with the diagnosis in the middle of a very busy professional life?

Michele Nadeem-Baker:

It was—it was not easy, and that part still isn't easy. I've been trying to still come to terms years later with that. I was at a height of my career in a dream job, and I knew that I could no longer stay in that job because it meant staying in Florida, and I needed to move back home where my family was and my husband was. We had a long-distance marriage because of career. It made me realize what's really important in life, and that's to be with family, but I was able to then continue using parts of my career in other ways and to help, as Andrew did. You're doing very similar things yet now you're doing it to help patients, and that's what I've been trying to do. You're a great mentor, Andrew. And so it, yes, it was very difficult when it comes in terms of that and as well as income and being used to being a high income earner and then not having that.

Esther Schorr:

So how did you make—so can you share how you made that transition? It sounds like you moved closer to family.

Michele Nadeem-Baker:

I did.

Esther Schorr:

And career-wise what helped you make that transition?

Michele Nadeem-Baker:

I had to give up my job and my career. And I was well-known in Florida, and I moved back up to Boston. I needed to remake connections from when I lived and worked here. And I've been consulting ever since versus within a company and a full-time job. So trying to use what I do best, just communicate and go and help others. And what's been happening is I found that it's been mostly in life sciences and related fields.

Esther Schorr:

Okay. Thank you. You know, you mentioned Andrew. Andrew, did you want to speak a little bit about that transition

that you had to make because we were at the time sort of building—well, sort of. We were building a business and a family at the same time.

Can you share a little bit about what it took for you to make the change that you did?

Andrew Schorr:

Sure. Well, I think—we were fortunate. We were already working in health communications. Michelle has sort of made that transition, and Jeff too actually is spending a lot of time doing that. So you kind of—for us, you know, Esther, you and I I think accelerated in what we were doing. I think for Jeff and Michelle they've sort of joined in where you can leverage what you're learning as a patient to help others, and that's very satisfying. And fortunately now with the internet we can to some degree do it on our schedule.

So sometime we're tired. Sometime we're distracted—not distracted, that's not fair, but we have doctor visits. We have bone marrow biopsies. We have other things. I get IVIG, monthly infusions. So how do you juggle all that?

And I think we learned to do that. At least that's what I've done, and I think it's been satisfying that we can communicate with others, and it's part of who we are. Never wanted the diagnosis of CLL, no, no, no, but if you have it how can you go forward and do that? And I know both Jeffs are involved in helping other patients as Michelle is too, so that's part of it.

Esther Schorr:

Thank you. So, Jeffs, any additional comments or points you want to make about this?

Jeff Brochstein:

As someone who is probably I think out of everybody here who is maybe less in a patient advocacy role, I mean, I've done it a few times, I'm always open to who, you know, Andrew sends me in terms of young people who are diagnosed who want to speak to someone with whom they can share experiences with, you know. I'm an IT projects manager. It's not necessarily boiler room type work but it's still, it's pretty fast-paced.

It's pretty intense at the times. One thing that I've really experienced in terms of just first firsthand trying to deal with having CLL and making all the appointments, the bone marrow biopsies, the routine blood work, you know, I tend to—I don't openly communicate my condition to everyone at work, but I've been lucky and I've been blessed to have pretty decent managers who I directly reported to ever since diagnosis, and they've been just very accommodating and understanding. And in some regard they have to be, but I've been lucky enough to find that in the workplace, and that's been really, really great.

Esther Schorr:

Okay. And actually that's a great segue, because the next thing I was going to ask about was how each you have handled communication with family and friends about the diagnosis. That's a very personal thing. There are some people who are way out there and, gee, we don't know anybody like that, but it's a really personal thing. So maybe Jeff, Jeff Folloder, how did you handle that initially, and has that changed over time?

Jeff Folloder:

Well, I never hid my cancer diagnosis from anyone. I believe in the very first Patient Power event that I did I talked about the mistake that I made with my cancer diagnosis. I told my family. I told my wife. I told my daughters. I told my friends. But I kind of sort of forgot to tell my daughters that my CLL wasn't considered hereditary, and my daughters kind of sort of flipped out for a significant period of time until I learned, wow, I should probably let them know what exactly is going on so that they can stop worrying a little bit.

And I did. And so now I make sure that people understand what it is that I think they need to hear. I don't tell everyone the gory details of my CLL experience. Some people I tell, yes, I've got cancer. I'm a survivor, or I'm in remission, or I've relapsed. And the people I care about, I make sure they understand what's really going on and how it affects me.

And at this point some almost nine years after diagnosis, and I know this is going to sound very counterintuitive, cancer gave me an awful lot of opportunity. I would have not had the ability to pull the hand break up on my life and reprioritize everything without a cancer diagnosis. I was moving too fast. Concentrating on the wrong things. Spending my energy on the wrong things. Now I focus on the right things.

And as Andrew is fond of saying, I've learned how to live well, and that's because I've learned from everyone involved with Patient Power.

Esther Schorr:

Wow. Well, thank you. Michelle, Jeff B, Andrew, other commentary about how you communicated or chose not to communicate?

Michele Nadeem-Baker:

I did the opposite. Because—probably because my career included crisis communications I was afraid if once I let out the info it would be career suicide, which is a very sad thought when you think of society. But instead now I'm trying to change that, that thought has that's out there, that you still can be viable when you have a cancer diagnosis, which everyone here is proof of. But I was very afraid of that, that that would ruin my career.

As a matter of fact, I did not come, you know, out until I started in the infusion room and reported for Patient Power from it each time.

I was in infusion with the FCR part of my trial. So it dawned on me that in the past I had worked with the American Cancer Society and convinced people to come out about their cancer and explain to other patients. And I felt somewhat like a hypocrite that I did not, and I realized it was time. It was really time to do that. And it wasn't only about me. It was about others as well. And that really helped empower me a lot.

And also as Jeff has said and I was saying before, it really does help you prioritize what is right, the right things to be spending your time on, because I was on the hamster wheel of career and never sleeping, and this forced me, I had to. And as you said, naps aren't a bad thing. I had to learn that, too. So it does help in certain ways, although it's not a great way to have to learn the lesson. It is what we have, so you have to make lemonade out of lemons, and I think that's what all of us here have been doing.

Esther Schorr:

Thank you. And Jeff B?

Jeff Brochstein:

When I was first diagnosed, there were a handful of people, friends and family, who I told. And I can honestly say and somewhat brutally say this, there were some people that swept it under the rug because it's a chronic condition. I didn't need treatment right away. Many of them didn't understand that, it being cancer, because they're used to acute cancers, tumor-based cancers that you have to attack immediately.

You know, I had other people who kind of buried me already because I told them cancer, and they stopped reaching out to me. And even up until today I still get a rare text message from some of these folks asking me, not in these words, but they pretty much ask me if I'm still alive. And I've kind of put them out of my life.

And there were some who were understanding, who actually read up on the things that I had sent them about CLL and how it's chronic and how there's all these emerging therapies on it.

So really for about a couple years after that, to kind of going to what Michelle was saying I was kind of in the closet about it. And then when my lymph nodes in my neck became a little more apparent and I really couldn't explain it away all that easy, I came out a little bit more about it. And, you know, like I said, there have been people who have been very understanding. There have been people who have told me, well, it's chronic and you're taking a pill for it now so it can't be that bad. And there's been other people who have been like, oh, my God, cancer, you're still alive. And, you know.

Esther Schorr:

I'm going to go a little bit out on a limb, Jeff. If I understood correctly you were diagnosed—weren't you diagnosed when you were still dating your wife? Is that?

Jeff Brochstein:

Her and I had just gotten engaged. We got married last year. She's actually expecting, by the way, late February.

Jeff Folloder:

Congratulations.

Esther Schorr:

Congratulations.

Jeff Brochstein:

We're having a boy.

Esther Schorr:

Oh, that's so exciting.

Jeff Brochstein:

Thank you.

Esther Schorr:

And I bring that up because the other question I kind of wanted to explore with all of you is how did your diagnosis, if you're willing to share, impact your relationship with your significant other or your spouse, you know, the person that's closest to you? Was that different than dealing with other people? Anybody want to...

Jeff Brochstein:

I can start that off. You guys met Olga at ASH last year. If anything it's solidified us. She's a fire brand about it. She's my rock. I really couldn't make it through this without her. She's been vital in terms of just my survival and us just having a happy life together. And we've been challenged by a lot of things. This is probably one of the biggest challenges, and it's just made us better. So even under those circumstances, so.

Andrew Schorr:

Esther, I think I should jump in.

Esther Schorr:

Go ahead.

Andrew Schorr:

And you can tell us. So, you know, I was sort of more clinical. What do I have? What do we do, etc.? And as I said earlier, I thought my life was over, was relieved to find out it wasn't. But all this was coming down on you too, and I don't know to what extent you really shared how you were feeling because it definitely affects. We were—you were a young woman. Esther's seven years younger than I am, so you were younger. We had the idea—we had two little kids, and we had the dream of having a third, so you might share what you were thinking.

Esther Schorr:

Sure. There was never—I think the hardest person to share your diagnosis with was you, and my feelings about your diagnosis, the hardest one was to share that with you. And what was most helpful to me because I had loads of fears was to share it with other people who loved you as much, loved you in their own way as much as I loved you as my spouse.

So, you know, I think if anything it just solidified my dedication to our relationship and to figuring out the best way to support you emotionally and physically and professionally. So, yeah, you know, all of you have been talking about sort of there's this weird silver lining of having a diagnosis of something. The silver lining is you look at what you're really grateful for. And that's really what it did for me as a care partner to you, Andrew. To say, okay, this ain't good, but what's the good stuff that we can do if we work together, and that's really what's happened.

Andrew Schorr:

We should mention that we began couples therapy.

Esther Schorr:

That's right. We did.

We did, and that was very, very helpful so that I was able to communicate with you openly and you weren't afraid to tell me when you had feelings, whether they were of fear or trepidation or not knowing how I was going to react. It took a long time for us to figure that out. I think we have.

Jeff Folloder:

One of the interesting things that happened in my particular journey, I got the diagnosis and of course everyone's freaking out in the house. My wife is freaking out in the house, and she was being somewhat stoic about it and really didn't know quite how to deal with things.

When the first doctor that I had seen that had given me the diagnosis described the treatment plan he wanted to do, I did a typical type A personality thing and said stop, went and talked with Dr. Google for an awful long time and decided that I needed a second opinion right then and there.

And one of the watershed moments of my treatment journey was when we were sitting in that clinic room at MD Anderson when my doctor, not me, but to my wife walked over, picked her up out of the chair and gave her a bear hug to let her know that she's a part of this process as well. It's not just about me. And that was sort of a little bit of a release from the pressure valve because this is very much a team journey. I can't even begin to imagine someone with CLL going through it by themselves, so I am extremely grateful to my beautiful bride of 31 years, and I could not have gotten to this day without her, period.

Esther Schorr:

Thank you. Michelle, did you have something you wanted to add on this?

Michele Nadeem-Baker:

Yes. A few things in that we waited until recently for couples therapy. I would suggest that it be started sooner, as you and Andrew did, because it would have been very, very helpful.

In the beginning I tried to protect my husband from things, and as I was living in Florida and he was in Massachusetts I considered not even telling him. In the first 24 hours, you know, your mind does crazy things. He was not with me because I didn't even know there was anything wrong with me when I was told, and I even considered for him ending the marriage, because it wasn't fair to him. This all went through—crazy things go through your mind. So I didn't think it was fair to him, and his first wife had cancer. So the mind goes to crazy places.

Thankfully I did not. I shared, and he has been—he has been by my side every step of the way probably much to his own physical health detriment, which is on track now. But he sacrificed a lot. He has been with me for every appointment. Every treatment he was by my side, every bone marrow biopsy. And thanks to him they redid some of mi tests which showed my genetic markers which they were not aware of as to how serious my CLL was.

He had read about that things could mutate or that tests only test a certain percentage of your blood and that perhaps it was different, and my symptoms were becoming more apparent that I was getting closer to treatment even though other things, other numbers did not show that through my FISH tests, my flow cytometry test. So he pushed them to redo the tests, and lo and behold, I was 11q, and they didn't realize that. And IGHV they had known unmutated, but they didn't realize the 11q. So I do suggest that people if they start seeing certain symptoms they do push for certain things, but my husband did that. I didn't. I would not have pushed for that myself, so thank goodness I had a partner along the way, and I don't think I could have done everything I did to be here today.

Esther Schorr:

If I'm reading all of you correctly, the relationship with someone else, a care partner, a caregiver, was additive for you.

Jeff Folloder:

Absolutely.

Jeff Brochstein:

Absolutely.

Esther Schorr:

And open communication.

Michele Nadeem-Baker:

Absolutely.

Esther Schorr:

Yeah. Because I know that we, Andrew and I, have spoken with patients where they really were reticent to share with the people closest to them for fear of scaring them, scaring them away, not knowing how they were going to react, so that's a really important point.

The other thing I wanted to ask you all about was a few of you referenced having a wonderful medical team and finding a specialist and educating yourself. So finding the right doctor, educating yourself about the disease, what did that do for you? I mean, did it help you with just the emotional part of it? Did it help you feel more in control? Why was that a good thing?

Andrew Schorr:
Could I start, Esther?

Esther Schorr:
Yes.

Andrew Schorr:
So, first of all, Jeff Folloder mentioned about the doctor giving a hug and maybe it was probably Dr. Keating, but other doctors, Dr. Kipps down in San Diego gives hugs too.

I was—put my hand out, and he said, no, I want to give you a hug, and he's done that with you too, as Dr. Keating has. What it did by getting the right doctor is I think gave me, and I think you too, confidence. And this ties in to Jeff Brochstein as well. Confidence to go on with your life and at that age, earlier age, said go ahead and father a child, which is a big deal, right? That's not just a short-term thing. And I'd be interested in what Jeff Brochstein says, but I know you and I, Dr. Keating gave a hug and said, go have your baby, which here we were in a major cancer center. Go have your baby.

Esther Schorr:
And he's 21 now.

Andrew Schorr:
Yeah, he's 21 and he drives us crazy and we love him, but he's our thirties, he's our miracle baby. And, Jeff, you and Olga having the confidence to do that.

Jeff Brochstein:
Well, Andrew, a couple, I mean, we'd been trying for a while, and a couple of years ago a doctor told Olga and I that we had a better, almost a better shot of hitting the Powerball than we did of conceiving, and it kind of happened on its own a few months ago.

Esther Schorr:
That's great.

Jeff Brochstein:
So it's really a miracle. You know, I think what really found a comfortable place for me is I found a community oncologist who did have a specialty in hematology though he wasn't a research specialist who has a great bedside manner, and he was also very cool with me going to MD Anderson and talking to Dr. Thompson and talking to a research specialist, and that gave me a good counterbalance. That gave me that second opinion. I could weigh that with what Dr. Stephen Szabo here at Emory was recommending, and I came up with what was best for me.

And Olga—and us getting pregnant was just all the more of a present on top of that, so life is good in that regard.

Esther Schorr:
Any other comments on that? Jeff?

Jeff Folloder:
I'd like to chime in just a little bit. Andrew had mentioned Dr. Keating and his bear hugs and all that wonderful you stuff. One of our very first appointments with Dr. Keating, I felt the need, as many new patients do, to sort of like unload the guilt, all the things that I was doing that may or may not be exactly healthy, so it was sort of like a confessional.

And I can remember telling Dr. Keating, okay, you need to know that I smoke an occasional cigar, maybe an occasional briar pipe. And he asked me, well, how often do you smoke, and I said, ah, three or four times a month. And he said, okay. And I didn't quite understand what okay meant. And then I kind of confessed, okay, you need to understand that most evenings I have a whiskey or two.

And he asked me what type of whiskey I drank, and he complimented me on my taste. And he actually stopped me and said, I am here to help you live a good life, not make you miserable. That's where we were focused on. My first doctor just wanted to start treatment. Dr. Keating wanted me to live well, so instead of just getting a, quote/unquote, gold standard of treatment, Dr. Keating was focused on getting me the best treatment. So that was sort of my start to living well.

Esther Schorr:

Yeah. That's how we felt about finding the right team for you, Andrew, was that. It's what's the quality of life and what are your priorities in your life and will your medical team—is that what they're focused on.

Andrew Schorr:

Right. You know, I make one comment about that, Esther, and I want to hear what Michelle says too.

So we're blessed now with a range of—a whole array of treatments, Jeff, you recently, Jeff Folloder led a town meeting in Jeff Brochstein's home town recently where you spoke about that, that there are more treatments either approved or in research than ever before. So part of it is what's your situation, and Michelle talked about unmutated and 11q, what treatment lines up with that clinically, but also what are your goals? Somebody who has FCR might be able to stop treatment after six months if it's right for them and if it works for them. Some people may—there's some idea with venetoclax (Venclexta) combined with obintuzumab (Gazyva), maybe you'll be able to stop after two years. With ibrutinib you're taking it long term.

So what's right for you? And I think all of us need to take a look at our lives, have a conversation with a knowledgeable doctor and state our goals. What are our personal goals for what works for us. Michelle, I mean, you may have things you want to add too.

Michele Nadeem-Baker:

Certainly. So when I went on the clinical trial I'm on, which some people know as IFCR, ibrutinib and FCR, I did not know at the time nor do I think they knew long-term what would happen, but here it is. I can't believe it. It's three years this month I've been on it. I've been on ibrutinib for three years now, and I will be indefinitely until either it stops working or something better comes along, and I am able to live life. I am looking of course, as we all are, for a cure someday, and I'm still not MRD negative. That would be wonderful. That would be great. But right now I'm holding steady, and that's a good thing. So my goal is to be able to live life as healthy as I can, and that's what this is doing right now.

Esther Schorr:

Great. Well, so, I'm going to switch gears a little bit, and I want to ask you all a question.

Have any of you dealt with a situation where you tell somebody what's going on for you and they say, well, you don't look sick. What do you say? What do you do when somebody says that to you?

Jeff Folloder:

A lot of smiling and nodding. It is a very common response. I think the two most common responses that we as CLL patients hear is, one, you don't look sick, or two, oh, you've got the good cancer. Neither of these are acceptable. Yeah, I look good, because I work at it. The whole concept of you don't look sick, well, there's a difference between

looking sick and feeling sick, and as a CLL patient I take as much charge of my physical well-being as possible. Before I was diagnosed with cancer, I was a couch potato. I never exercised.

I didn't need to. I was pretty lethargic and sedentary. Now I'm an avid power walker knocking out between 30 and 35 miles every week. I do it pretty fast, too. I'm trying to maintain my weight, and I'm trying to maintain my energy level. So, no, I don't look sick. Sometimes I feel sick. I just did a week and a half on the road. I missed a bunch of naps. I'm a little tired. Actually, I'm a lot tired, and I'm looking forward to a nap this afternoon. And I'm going to take one, and it's okay.

But this is part of my new normal. My new normal is the way I feel doesn't necessarily show. And my wife understands that. My family understands that. The people close to me understand that. My doctors understand that. So if people don't get it, that's their problem, not mine.

Esther Schorr:

Any other commentary on that? I think that's a great, very positive way of looking at it.

Michele Nadeem-Baker:

I have to say that I'm trying to look at the positives about people saying you don't look like you have cancer. In other words, I feel like they're trying to convince me I don't have it, because I don't look it, but I guess I'd rather not look it than look it. That's what I keep trying to tell myself. And as Jeff just said, I do smile a lot, it's like, oh, yeah, you really don't know what you're talking about, but thank you. I know you mean it to be good and be nice. I also know people don't know what to say. So I try to put the little sarcastic bubble aside and just try to think of that.

But as Jeff said you do have to—you have to take charge. And I continue to, as Jeff was saying, I continue to work out in the way I do throughout even infusion. Continue to go to the gym and use weights and do cardio. And when the weather's good enough up here, which it's now turning to not be, do whatever I can outside as well as in the gym because you feel better.

And that is one way I felt I could take control when everything else was out of control health-wise. So it also helped me in that way, in that respect as well as to be healthier physically. So it's very important, I'd say.

Esther Schorr:

And really what you guys are all talking about is how do you stay empowered and positive. And for you, Jeff, it's everything from power walking to taking naps, and for you, Michelle, it's going to the gym and being an advocate. And Jeff, Jeff other Jeff, you've talked about some of the things that you do. And you're going to be a lot busier with a baby in the house.

Jeff Brochstein:

That's right.

Esther Schorr:

Anything else that helps you to stay positive in all of this?

Jeff Brochstein:

You know, I was always active for I don't know 20 years before I was diagnosed. I've always lifted weights, done Cross Fit in recent years. So I spoke about this earlier, and this really kind of repeats some of the stuff that Michelle and Jeff were saying.

I've never appeared sick. I've always been physically fit. There was a time for about two years since I was diagnosed that I had some lymph nodes that went away once I started the ibrutinib. People never associated me with some sort of chronic or acute illness. And when I've told them what I have and I've told them about the condition, you know, I've also followed up with just trying to create awareness around this, send them some links, sending them some videos. Maybe sending them the original video I did at ASH last year, just to really create awareness around it. And it's really up to them if they want to absorb it, on Jeff's point.

Esther Schorr:

So, you know, I think to kind of wrap up all the things we've talked about, what advice do each of you have that might help someone who is facing a diagnosis of CLL in mid-life? What lessons have you learned along the way that helped you face it?

You know, just kind of giving somebody advice, what would that advice be? And maybe, Andrew, do you want to start?

Andrew Schorr:

Yeah. I will say first given what we know about CLL and the range of things going on how, your life is not over. I thought my life was over. Here we are. I was diagnosed in 1996, or 22 years. I mean, I had no idea that I'd make it 22 months, right? And if you read some of the old articles and stuff you'd say, oh, life expectancy is not very long. So first of all, you're going to live a long life and thank god for the medical research and the array of things that are available.

And I think Michelle said it too, right now, she's been in a trial, she continues to take the ibrutinib, maybe there'll be something else that she'll need at some time and we're confident that there will be. So, Esther, you remember that there was a guiding light, a patient advocate in CLL years ago when I was diagnosed, and she gave us two words as advice.

Chill out. And so that's what I'd say. I'd say chill out. I don't mean to be harsh. There's a lot of grieving that goes with a diagnosis. I've probably said it to my friend Jeff Brochstein when we met in Atlanta last year, to you and Olga, but I would say that, and that's based on evidence. That I'm living longer and people living a long time. And we get an eye into the research going on, and there's a lot. So I think—it's not perfect. There are side effects, there are expenses, and there are course corrections in your head as well as in your life, but you're going to live a long time. Believe me.

Esther Schorr:

Nice. Jeff B, any advice you would give to someone?

Jeff Brochstein:

Really along the same lines that Andrew just spoke and what Jeff had mentioned when he gave his intro.

When you get CLL, when you get a diagnosis of this kind, god forbid, but when it happens during these years just take the what-ifs out of your life. Take the projection out of your life because that will just make you grow worrisome and grow older and grow grayer. You really have to—just to take things by the day. Just do your best early on to do as much research as you can about it. Try to see a specialist early on. I think that would helped me out my first couple of years if I would have gone to see a specialist as well as have somebody local and community-based where I lived.

Reach out to people like Andrew, to groups like Patient Power. It's a different world now than it was 10 years ago in terms of technology and information that's out there. And I think most of all just keep tabs on the treatment landscape that's changing every month it seems like or every six months something is approved, something new, something better, something not chemo-related. Really, just pay attention to those things and you'll be okay.

Esther Schorr:
Thank you. Jeff?

Jeff Folloder:

I would tell everyone that is recently diagnosed with CLL to do a couple of things. First, take a deep breath. I guess during pregnancy they would call that the cleansing breath, but you're going to need to do a couple of them. So remember, that, Jeff, cleansing breaths.

Second, everyone has said it again and again and again. See a CLL specialist. You don't have to see the specialist regularly, but you need to get a CLL specialist as part of your team. The landscape of medicine is changing not just monthly. It's changing weekly, daily and hourly. One of the things my doctors keep on telling me the longer we wait the more likely we come up with something even better to treat you with. When I was first diagnosed we never heard the word "cure."

Now we're hearing the word "cure" for some forms of CLL, and it's getting better for lots of people very, very fast.

Make a few goals. I want to do this. I want to do that. Esther, you guys just saw Bruno Mars. Well, you saw him in a coffee shop. I'm going to go see him in concert this weekend. Why not? This is not a death sentence. This is just a part of my life. So I'm going to go do the things that I want to do, and that's what I tell every single patient. At several of our town meetings, I have made the point to remind people that statistics only look backwards. When you start looking at Dr. Google you're going to see that the average life expectancy of a CLL patient is about six years. Well, that's only looking backwards. I'm now nine years into it, so some people would say that I'm past my expiration date. I don't look at that way. I'm living a great life. Every minute that I'm kicking, I'm kicking it for real.

Esther Schorr:
Thank you, Jeff. And, Michelle, any parting advice in this discussion?

Michele Nadeem-Baker:
That's a tough act to follow.

Jeff Folloder:
Sorry.

Michele Nadeem-Baker:
You just said kicking it.

Andrew Schorr:
You should have a shelf life of 25 years, you know, I mean.

Michele Nadeem-Baker:
So I would say the number one thing is to educate yourself and not just with as Jeff calls it, Dr. Google. Because if so you will get frightened by what it says because it does look backwards. But I would say to educate yourself as much as you can through credible sources, through current information versus past. Otherwise, you'll get really frightened.

And the other thing is for those of you watching this, Patient Power generally has the leading doctors around the world for CLL on it. If you can get to one of those doctors that you see or one of the institutes, then that is a great source to go to to find out what is best for you to match you up.

If you do need treatment yet or not, projected time to treatment. And then if you can either go to whichever doctor that is, or in conjunction to what Jeff of Atlanta as opposed to Jeff of Texas is doing, pair that with your community doctor if at all possible so that you don't have to travel. But that way you can be confident that you're getting either in a clinical trial tomorrow's treatment today or the best in treatment there is today. And there are so many out there.

The other advice I'd give, and someone gave this to me in my first week of diagnosis. Stay as healthy as you can today because there will be something to treat you tomorrow. And we're all proof of that, all of us here right now.

Jeff Folloder:

Excellent advice.

Esther Schorr:

Yeah. Those are all such great advice, and you all are a delight and an inspiration to talk to. I feel very honored to be sort of in the middle of this circle of empowerment.

I want to thank all of you, Michelle, the two Jeffs and Andrew, for sharing your personal experiences as positive and very empowered CLL patients. It's always inspiring to talk with each of you, and you provided some great perspectives and suggestions. And I want to thank our CLL community for joining us today and I hope that this conversation has been helpful to you. I'm Esther Schorr. Thanks again.

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