



# Living with an MPN: The Perspective of a Patient and a Caregiver

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**Andrew Schorr:**

Hello, I'm Andrew Schorr. Welcome to Patient Power. Being diagnosed with a rare cancer is certainly scary—not only for the patient for all the people that care about him or her. We are joined now by Brian Lopez and his wife Sharon. They faced this. Brian, tell us about your diagnosis.

**Brian Lopez:**

My diagnosis is essential thrombocythemia. And it's thick platelets or overproducing of platelet count. Anyway, I'm feeling good. It's slowed me down a little bit, just with fatigue, nauseousness, cold, flu-like symptoms, thinking impaired, a little spacey at times, and not as physical as I once was.

**Andrew Schorr:**

Sharon, what did you see in Brian as he was going through all this? How did it affect him emotionally?

**Sharon Lopez:**

It takes a toll because you—he didn't feel well with the medication that he was taking and so it was hard to, he was working and ill at the same time, so trying to manage both was difficult. And I think when you first have a diagnosis of a cancer or leukemia, and you get so frightened and you're kind of thrown out into the middle of the ocean.

Just you're—it kind of rips you from your normal life that you think. And then you're trying to get back on a boat or get back to land, and navigating those waters is a little difficult. But you just keep going, and just the whole process of it, coming to terms with a chronic illness and just balancing work and illness at the same time is difficult.

**Andrew Schorr:**

Brian, how did you come to terms with your diagnosis, and what advice would you give others?

**Brian Lopez:**

I came to terms with it with a medication that I was on, the help here at City of Hope and with Dr. Snyder. My wife's a big support, a big supporter of what's going on with me, and she's my biggest advocate. I'm comfortable with doing things in life. You know, sports, and with kids and stuff it's, became a lot easier, and we're moving on.

And as far as advice for anyone else out there with the same diagnosis, always research and second opinions and go with what you feel is best—not because someone says you need to be taking this. I mean, you have to be in charge of yourself—your own advocate.

**Andrew Schorr:**

Sharon, you've been a big support to Brian. So at one point, you stepped in more aggressively than Brian had been. Why did you do that, and how has it worked out?

**Sharon Lopez:**

Well, he was, he was never ill before the diagnosis, and even after the diagnosis he didn't have any symptoms of illness. And then when the medication started, he started to go downhill so quickly. It was night and day. And it was difficult because it's such a rare disease. And it's not, he was not taking chemotherapy, but he was as a chemo patient.

So it was very difficult because if I knew what we were dealing with, I can say, okay, he has leukemia, and this is the treatment. Well, he didn't have leukemia per se that, you know, you understand. It's a chronic blood disorder, so, and it's a cancer but not really a cancer. So navigating those waters is difficult.

**Andrew Schorr:**

So what did you do about it?

**Sharon Lopez:**

I got online and started reading, and watching videos, and educating myself about the disease, getting second opinions. And then we came to the City of Hope and found Dr. Snyder. And when we first went to see him, he had read his medical records.

And what was kind of shocking, he said, you really should not be on any medication at all except a baby aspirin. And Brian could see me levitating off the chair, like, okay, I knew there was something wrong. He just kind of validated what I felt in my gut, that there was, you know, it wasn't right. So we needed to find an answer.

So you just don't ever give up. There's always something out there. So, I kind of look at it as even though he suffered for that year on the medication, it kind of led us to Dr. Snyder. So in the long run, you know, I guess the mistakes or the not feeling really good, helped us. Because it got us to the City of Hope sooner rather than later.

**Andrew Schorr:**

Sounds like you stepped in and when Brian really needed it. Brian, so you've worked through all this. It seems like you've got it sorted it. How do you feel now about the future?

**Brian Lopez:**

Busy. My future is real bright. I'm looking forward to living a long life. I feel healthy, I feel strong. I got a lot of support from my wife, family, friends, and it's great. I don't feel like I'm living with this chronic disease. I feel okay. I feel fine. It's something that happens once a month when I get treatment.

That's when it reminds me, hey, I'm sick, or I'm ill, or I'm carrying this disease. Other than that, I'm living life as normal.

**Andrew Schorr:**

So, Sharon, your husband is living with a chronic condition. How do you think about the future now, together?

**Sharon Lopez:**

Very hopeful. I know we're aware of it. So and then we're aware of it before something, it progressed to something more serious, and so I feel very fortunate with that. The advances in the medication that we've seen here at the City of Hope are so exciting—just not only for us, but for so many other patients, that it's miraculous.

I just feel very hopeful and exciting that, I feel hopeful that they will find a cure sometime in the future, and so that makes me excited about us, and then our children, and what lies ahead for other patients that are suffering with it. We just, we live life as we want to live our life, nothing's changed.

We have a vision. We have a plan. We have how we want to raise our children with certain values and teaching them how to deal with, you know, the ups and downs of life and to persevere and not give up. And so, you know, you live life to the fullest, I think, when you don't, you don't know, you never really know what tomorrow is going to hold.

But it makes you appreciate what you have right now, so we live day to day. But we still think about, you know, planning what lies ahead. But then, planning on, you know, what if it goes the other way? Well, I think we're more prepared to handle that and find answers or finding answers to whatever challenges may show up in the future.

**Andrew Schorr:**

Sharon, how have you talked to your children about Brian's condition, and have they stepped up?

**Sharon Lopez:**

Honesty's so important. I think it gives them skills to be able to deal with their challenges in life when they're adults. Because they're young, I don't think it's right to shelter them so much. It just teaches them, you know, life's not always easy, and just, you have to communicate, and you have to be honest, and you have to work towards your future.

And I think it's a good lesson for them to understand what's going on in the house, and it teaches them responsibility because my sons had to, you know, mow the lawn a little more often and do things like that. So we pitch in and work together, and you have to be a unit. And they'll be better adults because of it I think.

**Andrew Schorr:**

Brian, of course, you want to dance at the weddings of your children and celebrate with grandchildren someday. How have you talked to your children about the highs and lows of this, and what you're dealing with?

**Brian Lopez:**

Right. I've explained it to them, you know, I have thick blood, and that's pretty much the easiest way I can explain it to them is Dad has thick blood, and it slows me down sometimes. I actually got the kids involved. I brought two of the three to doctor visits with me, and they met Dr. Snyder.

And they kind of see the routine that I go through, coming to get my infusion. They were there at my bedside during the infusion, and it's a two-hour infusion, and they were okay with it. They were comfortable with it. And they understand that that medication is actually helping me. You know, I'm down for a few days.

But after that, they see the results, Dad's fine again, you know. So it's like having a cold. You're down and out for about three to four days. Then you're back to normal. So they really understand the concept of going to the doctor, getting the medication, feeling better, and giving me a hard time.

**Andrew Schorr:**

Thanks to Brian and Sharon Lopez for sharing their story and remember we have many inspiring stories for you. So be sure to be signed up for alerts on our website, so we can let you know whenever we posting something new. I'm Andrew Schorr. Remember, knowledge can be the best medicine of all.

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