



## Jeanette Wright: How a Couple Won't Let Myelofibrosis Hold Them Back

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### Jeanette and Stephen Wright

Power Patient Team

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#### Andrew Schorr:

Hello. I'm Andrew Schorr. As we continue to meet people affected by myelofibrosis we want to introduce you to a couple because certainly the other person in the couple is affected too.

And so I want to introduce you to Steve and Jan Wright from Houston, Texas. We asked Jan how her journey with myelofibrosis began.

#### Jan Wright:

1994 I was diagnosed with essential thrombocytosis, and I think I got on hydroxyurea (Hydrea, Droxia) right away. And then that led to a blood clot, too many platelets in my liver in 1998, and that wrecked my liver, and then I waited 18 months to get a liver transplant.

#### Andrew Schorr:

We spoke with Steve about being on this journey with Jan through transplant and so many medications, and he told us his perspective.

#### Steve Wright:

One interesting feature of that was when tropical storm Allison came through Houston in 2001, Jan was in a medically induced coma. She was recovering from her transplant, and the hospital lost all of its electricity. And we got a call and said could we come help, and we carried her down nine flights of stairs to a helicopter, and she was evacuated to Memorial Hermann Katy Hospital where she recovered.

#### Andrew Schorr:

I asked Jan about what symptoms she had.

**Jan Wright:**

In 2005 I was more tired, and I think I needed a couple of transfusions, and so the bone marrow biopsy showed it was myelofibrosis. I came over to MD Anderson and met Dr. Verstovsek, and he said there was nothing they could do.

And then in 2008 I became extremely tired and ended up needing three units of blood, and I came over here again, and he said, Would you like to join my study, and I said yes.

**Andrew Schorr:**

I want to know from Jan how has it now worked out?

**Jan Wright:**

When I had my transplant I did lose a lot of weight, and I was in the process of gaining it, and when I got on this drug I gained 25 more pounds, so that was a little disconcerting to me. But he said it was good to be a little chunky, so I continued at this weight, and immediately my spleen went down, and I stopped the night sweats and all the itching, which was very bad. Ever since then I've had to get one transfusion a month, so I have had 50 transfusions of two units each, but I've been living a full life, so I'm very happy.

**Andrew Schorr:**

I asked Steve about Jan taking the new medication Jakafi (ruxolitinib). What has it meant for them as a couple?

**Steve Wright:**

Oh, it's extended our life together. I think without this medicine, if Jan were even still alive, she would probably be in a wheelchair, and we would have very limited chance to do things. We're retired, and we really enjoy our grandchildren and our children, and we travel as a hobby, and we've been able to travel in the United States and abroad. And I'm pretty well convinced that we would be able to do none of that without this medicine.

We travel in a couple different ways. We fly on airliners like a lot of people do, but we also have a hobby of private flying. We have our own airplane, and we fly all over the United States. Just a week ago we were in South Dakota and Colorado. Next week we will be in New York and Michigan. We use it to visit family and to see our great country, and so it's something we both enjoy. Jan is my co-pilot, and we've had thousands of happy hours together in our airplane.

**Andrew Schorr:**

I wondered with Jan, what it's meant to have a new, powerful medicine available when she's really needed it.

**Jan Wright:**

I felt very lucky to have been in this study because otherwise I don't think I would be here.

**Andrew Schorr:**

I wonder with Steve, his perspective of seeing all this come together, Jan doing better and then being able to enjoy life together.

**Steve Wright:**

It's a blessing. It's extended our married life together, and it's allowed us to see the birth of our grandchildren, and it's just been a gift, and we're very appreciative of this gift.

**Andrew Schorr:**

So from the caregiver's perspective, from the spouse's perspective, I asked Steve what he would say to someone else, where their loved one is affected by myelofibrosis.

**Steve Wright:**

My first comment to them would be don't lose hope. There is research developing in medicines. The medicine that Jan is on has worked very well for her. We are aware that MD Anderson is conducting other trials on other advanced medicines, and my message would be get as much information as you can, put yourself into competent medical care such as MD Anderson, and the future may be brighter than you think and don't lose hope.

**Andrew Schorr:**

I asked Jan what she would say to someone going through this.

**Jan Wright:**

Well, this drug may help you and it may extend your life and make your life much more enjoyable. You'll have quality of life on this drug, and there is nothing else around. Like when I came here in 2005 he just sent me home, and I was very disappointed.

**Steve Wright:**

Nobody wants to have myelofibrosis, but if you are going to have it this is a good time to have it because now there are medicines that can treat it. I think that people who are being diagnosed with it today can be thankful that they weren't being diagnosed with it 10 years ago when there

was little if anything that people could do. Now there are things that people can do, and so as I said a moment ago, there's reason for hope.

**Andrew Schorr:**

I have this ongoing image of Steve and Jan getting in the plane, flying around wherever they want and feeling pretty good about things right now, and that certainly, as Steve says, is a blessing.

I'm Andrew Schorr. Remember, knowledge can be the best medicine of all.

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