



Finding Support: MPN Connections

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Andrew Schorr:

So when people are diagnosed, we feel really alone. David didn't know anybody. I didn't know anybody. We mentioned some of these connections. Do you help people know that they're not alone?

Michelle Woehrle:

Yes. So even though we're research focused, we absolutely have to connect to people when they call us, they email us, and they feel very isolated. And I mentioned our support group program. So don't run support groups, but we connect people to a person—to someone in their area whether for a peer-to-peer consultation or through running an actual support group. And if someone is kind of energized, maybe they have—they want to do something more, we try to encourage them to start their own support group. And we even have a small stipend program to help them to do that.

In addition, we have a Cancer Connect online forum on our website, which is a private group. We decided to partner with Cancer Connect, because some people were enjoying the Facebook comments and various Facebook groups, networks for some people who are okay with talking publically about their disease. But for some people, they wanted a little bit more of a private setting. So it's housed on our website. And there's—there's basically a way for all people to connect with them—with each other one way or another.

Andrew Schorr:

So, David, community, just for a minute, somebody may be watching this program, MPN Awareness Month, and they say, oh, my God, what's happened to me?

And woe is me, I'm all alone. And nobody has ever had this issue before. And I'm hopeless. What do you want to say to them to give them hope and connection?

David Wallace:

What I would tell them, Andrew, is, you know, I felt the same way when I was first diagnosed. I didn't know who to turn to or what to do. I actually made my first call to the MPN Research Foundation myself, and they were very helpful to me. But I'd also like to point out that since I was diagnosed in 2009, research has come forth with new medications, new treatments, and the horizon is really much brighter today than it was six or seven years ago—and that they're not stuck with one or two options. But there are multiple options.

And really, they need to seek out an MPN specialist and get the best care that's available to them. The future looks bright, in my opinion.

Andrew Schorr:

Dr. Verstovsek mentioned a word early on, confidence in coming out of the team dialogue with your doctor, and I would say connection with these resources, Michelle's resource, David's, the others we've mentioned, Patient Power can really lower the anxiety. And I think you've seen this, haven't you, Dr. Verstovsek? But as people get informed and get connected, they can be more of a partner with you and do better.

Dr. Verstovsek:

Absolutely. I agree with your statements here. What I tell the patients, many times, is the best patient is the educated patient that understands what is happening, why is it happening, to understand the biology beyond the disease, the evolution potential of the disease, the therapies that are given, and to actively engage in a discussion about the future and what needs to be done and how. This is the best case scenario. We are talking about chronic diseases. People live with those diseases. Perhaps, the life needs to be adjusted to some extent to cope with the disease problems.

The medications need to be introduced when it's necessary to control the quality of life, to control the signs and symptoms of the disease. We are working toward elimination of the disease. But we don't have medications yet to eliminate the disease. And that concept of making these diseases as chronic as possible, controlled as well as possible, eliminate issues that interfere with quality of life, and make it the normal for people to enjoy life fully with the disease there is the goal at the moment. That's the goal that needs to be understood by the patient. And we need to work together when we are together in the clinic.

Andrew Schorr:

Amen. I want to just bring up a couple of points that I've learned along the way. First of all, we've mentioned these conditions, and you said earlier, Serge, it's very variable. So some people have ET. Some people have PV. Some people have MF. And their journey may be extremely different. I mean, Lindsey, you probably tell people that every day. This is what we know about your situation now. And yes, you may even seek people on the Internet or with other MPNs, but that doesn't mean that's you, right?

Lindsey Lyle:

Correct, yes, absolutely. So even though somebody may have the same exact diagnosis, two PV patients are not necessarily the same. And so I think that getting involved with other patients who have similar disorders is very beneficial to the patients. Also recognizing that, should they have questions about maybe what someone else is experiencing or different therapies that different people are on, there's generally a good reason, from a medical perspective. And so that's when the communication with the provider is really important, you know, especially when patients are talking about their experiences. And each patient is unique. And that's how we try to treat them as well.

Andrew Schorr:

Right. So connect with other people. But if they say you should do this, then maybe see a specialist, get a second opinion. But if they're saying, clinically, this medicine worked for me. I bet it will work for you, that's the discussion with knowledgeable providers with your healthcare team. So please do that. Or I have PV, and it transformed to MF. Well, that

is some people's journey, not everybody's. Some people have ET forever, you know, whatever it may be. So the situation varies. And I think that's why you need a good team.

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