



Patient Power

Cindy Chmielewski on Shifting From Being a Patient to a Patient Advocate

Cynthia Chmielewski
Myeloma Patient Advocate

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Andrew Schorr:

Hello from Dallas. It's Andrew Schorr along with my dear friend Cindy. Hi, Cindy. How are you doing?

Cindy Chmielewski:

Hi, Andrew. I'm doing great.

Andrew Schorr:

We are at HealthVoices 19, the fifth annual conference of patient advocates from around the country and some overseas, right?

Cindy Chmielewski:

Exactly.

Andrew Schorr:

Canada, I met somebody from Scotland.

Cindy Chmielewski:

Scotland, yeah, yesterday they were talking about that.

Andrew Schorr:

Great. So these are e-patients, and one of the most famous ones certainly in myeloma, Myeloma Teacher right here, and you've been living with myeloma, is it nine years now?

Cindy Chmielewski:

Ten years, 2008.

Andrew Schorr:

Ten years. Still get treatment?

Cindy Chmielewski:

I'm still on treatment, my maintenance therapy for multiple myeloma.

Andrew Schorr:

Right. And doing...

Cindy Chmielewski:
...doing well.

Andrew Schorr:
Good.

Cindy Chmielewski:
I am in a very good partial remission, so that's very good.

Andrew Schorr:
So what I want to talk to you about is this whole idea of the patient voice, because you've been going to companies, you go to government, and I want to talk to you about shifting from just being a patient about yourself to being a patient engaged with others and ultimately decision-makers, whether they're deciding whether to develop a new medicine for your condition or legislation about how we pay for it or what insurance companies do. So let's talk about that.

Talk about the transition for you and maybe what you'd say to other people, too.

Cindy Chmielewski:
I guess the transition for me started—I had to first learn how to be an advocate for myself, and for me that took some learning. And once I learned how to be an advocate for myself and was on a road, a good trajectory with my myeloma treatment, I know I needed to give back. And when I started giving back, I thought being an advocate for the myeloma community would be a good way to do that.

And I think the difference between being an advocate for yourself and an advocate for the community is when you're an advocate for the community you have to respect—you have to represent everyone's perspective. You can't just represent your own, so you really need to have an understanding of what's gone on across from smoldering myeloma to high-risk myeloma to relapsed/refractory myeloma so that when you're speaking you could represent those points of view.

And to do that requires a lot of education. So I had to educate myself about different conditions, and then I had to network with others so I was put in the position where I could present those opinions to people that could do something about it.

Andrew Schorr:
Okay. So I'm going to jump back in the discussion here. Cindy, why do it? Why do it? What does it give you? And are you making progress? You go to drug companies, you meet with scientists, you meet with government, are they listening?

Cindy Chmielewski:
They're definitely listening. First of all, I do it because I think everyone here needs some type of purpose in life, and for me, my purpose was to educate others, so now I'm still educating. I'm not only educating myeloma patients, but I'm educating people in drug companies, I'm educating people on Capitol Hill. I'm educating people in many places about the myeloma community and the needs and the unmet needs of the myeloma community. So that's why I do it.

And they are listening. It's come a long way. Many of the pharma companies are actively seeking the patient voice. They want to hear what are the unmet needs of our community. What are areas where they can be focusing in? They're also asking for help in developing the protocols for clinical trials, because no one wants to spend millions of dollars on a trial that no one is going to enroll in, something that's not going to accrue, so having the patient perspective, looking at those protocols and trial designs may help increase accrual to those trials in the long run. So, yes, they're listening.

Andrew Schorr:
So there are people watching who are saying, oh, my God, I just want to get well. I have a heavy load with me. But hopefully, and myeloma is a good example, there are a whole range of treatments now, and many people get to the point that you got to at some point, living better and with some confidence you're going to be around for a while.

Cindy Chmielewski:

Yes.

Andrew Schorr:

And then you can get outside yourself.

Cindy Chmielewski:

Exactly. You have to get yourself well first. You're not going to do anything when you're totally overwhelmed and—or even, I could foresee, if I relapsed, there might be a time where my advocacy work gets put on the back burner until I get myself back on that path to wellness. So you come first. But once you are on a good path, then I think it's time where you could give back.

Andrew Schorr:

Now, as we do this program and in the U.S., there's a lot of debate about health policy and the healthcare system, drug costs, insurance costs, co-pays, all this, so we need to weigh in. I mean, this is kind of a critical time, isn't it?

Cindy Chmielewski:

It sure is, and there are lots of ways of weighing in. Even from your own computer, many of the bigger advocacy agencies, the IMF probably has websites, the LLS, ASH, the American Society of Hematology, all have things that they call e-alerts where you can just send an alert that's already prewritten for you...

Andrew Schorr:

Write your congressman.

Cindy Chmielewski:

Write your congressman about this issue, and you could do it right from your computer at home. Sometimes if you're feeling up to it, you can meet with your legislators right in your own district. And if you get involved with a bigger organization, there are mission days on Capitol Hill where you can actually go and share your story, and the impact of the patient's story is ten-fold, maybe a hundred-fold.

Andrew Schorr:

Really?

Cindy Chmielewski:

Yes.

Andrew Schorr:

Really. You meet a congressman or senator, I'm a myeloma patient, this is my story and it has—it hits them.

Cindy Chmielewski:

It hits them. They all can relate. They—usually when you share your story or sometimes the story of someone else and let them know why you're there, what's your purpose, why you're advocating, usually it could relate to someone in their family. Everyone's family is touched with cancer.

Usually when we advocate for issues they're bigger issues, not just for myeloma but affecting all of healthcare, all of cancer. I've been on the Hill several times for the oral chemo parity act where we're helped with our oral medications, and that affects not only cancer patients but some of the other patients, too.

Even for people who are going through some trauma at the time or not in a very good stage, a good way to share their voice is on the online patient communities. I mean, supporting each other.

Andrew Schorr:

Drop a note.

Cindy Chmielewski:

Supporting each other with advocacy, like I went through that, or this is what I did, or ask your doctor about this. So I think you could support each other from the very beginning.

Andrew Schorr:

And people will support you.

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