

Transcript Details

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IBD: A Journey from Parent to Advocate

Narrator:

Welcome to Crohn's & Colitis Perspectives on ReachMD. This series is produced in collaboration with the Crohn's & Colitis Foundation, providing updates and driving innovation in IBD research, education, and clinical support.

Dr. Caudle:

Those who are affected by inflammatory bowel diseases are all too familiar with the constant, daily struggle to maintain their symptoms. For many young patients and their parents, becoming involved with local advocacy groups provides an excellent support system. But what's important to remember is that there are also opportunities for these patients and families to make a difference on a national level as well.

Coming to you from the ReachMD studios in Fort Washington, Pennsylvania, this is Crohn's & Colitis Perspectives on ReachMD, and I'm Dr. Jennifer Caudle, your host. Sharing his personal, turned professional journey with our audience today is Frank Russomano, President and CEO of ReachMD. Also joining us is Michael Osso, President & CEO of the Crohn's & Colitis Foundation.

Michael and Frank, it's wonderful to have you here. Thank you for joining us.

Mr. Osso:

Thank you for having us.

Mr. Russomano:

Thanks for having us.

Dr. Caudle:

So, Frank, can you share with us a little bit about your personal journey of being a parent of a child with IBD and how you and your family first became involved with the Crohn's & Colitis Foundation?

Mr. Russomano:

Be happy to. Our son Nicholas was diagnosed with Crohn's about 7 or 8 years ago when he was 14 years old, and we knew nothing about the disease. The first time I had connected to the disease is when his GI told him he had Crohn's disease, so the way that the process worked for us was I had to study and learn as much as I could about the disease and try to educate myself and our family so that we could help Nicholas and be partners with his healthcare professionals in learning how to care for him. The first thing I did was go to the website, saw so many great resources, and then we got involved with things like walks and those sorts of things. During that process, we met some people from the foundation, got to know more about the foundation, learned about how great the foundation is in helping patients and healthcare professionals, and so that's how the journey began.

Dr. Caudle:

Right, right. So let's talk a little bit about your relationship with the foundation. How did your engagement with your local chapter really evolve over time?

Mr. Russomano:

So, from going through a number of those walks, I got to meet some people from the Crohn's & Colitis Foundation corporate office and then some people from the local chapter and so had an opportunity to join the chapter board and got to learn more, and those were really educational sessions for me and an opportunity for me to learn about the challenges in providing those resources around the country—so got involved in that, got to meet some really great people, and my first impression was that there was a ton of passion

around the table every time I got to go to a board meeting and participate.

Dr. Caudle:

Sure, sure. My next question, Michael, you might be included in this one as well because I'd love your perspective as well. But what led to expanding your relationship with the foundation to include your business?

Mr. Russomano:

Yes, so I mentioned earlier about the passion around the table. And when Nicholas was diagnosed, he was probably diagnosed a year or a year and a half later than he should have been. And I understand how challenging it is for healthcare professionals to have to learn everything about every condition.

Dr. Caudle:

Sure.

Mr. Russomano:

So as I learned about the organization, I thought that given our strengths in ReachMD and our ability to reach healthcare professionals, that it would be a shame if we didn't offer that resource to the foundation and be able to expand the education around the country.

Dr. Caudle:

Right, absolutely. Michael, anything to add to that?

Mr. Osso:

Only that it was evident to us early on that Frank had a tremendous amount to offer to the organization, not just locally at the local chapter but on the national level as well, so of course we invited him to be on the national board. We are increasingly engaging with professionals and educating them. Frank brings tremendous expertise in that regard. But he's also a marketer, and he's also a technologist. He might not call himself that, but we'll call him that.

Mr. Osso:

Yes, absolutely. And so for all those reasons he adds tremendous value to everything that we are doing.

Dr. Caudle:

That's wonderful. It seems like a mutually beneficial relationship, which is wonderful. And speaking of this relationship—and you kind of answered this a little bit—but I know that you're involved with the foundation on the national level. Perhaps, Michael, it's what you were referring to. But can you talk a little bit more about that?

Mr. Russomano:

Yes, I joined the national board earlier in early—I guess it's this year, and I continue to be amazed at the time commitment that the board members put in and all of the employees at the Crohn's & Colitis Foundation. And there's so much opportunity to help. This is a disease that affects so many people. I didn't realize that when Nicholas was diagnosed, and there's a lot of opportunity to help. I think my desire to commit time and our company resources comes from learning about how these resources are utilized in the foundation, and whether it's in-kind support or financial support, the foundation puts all of those resources to work, and so I'm proud to be part of it. I think that this is a worthwhile organization to invest time and money into, and I'm excited about the opportunity to participate.

Dr. Caudle:

Absolutely. And as we're talking about this, I can only see that there might be audience members listening or watching in who may say, "How can I get my business involved with the foundation?" And what advice would you give to other volunteers who might be interested in sort of collaborating with their business and with the foundation?

Mr. Russomano:

I think my best advice is we all bring certain resources to the table. Some of us have financial resources. Some of us have professional resources or knowledge or relationships. And my advice is, first, this is a great foundation to donate those resources to. This organization is narrowly focused on finding a cure and focused on making lives comfortable for patients on the way to a cure, and so my advice is put whatever resource you have available to help this organization forward, and it will be put to good use.

Dr. Caudle:

That's really nice to hear. From your side, Michael, anything to add to that?

Mr. Osso:

Yes, only that we are an organization that has activities happening in all 50 states around the country. We have 38 chapter offices. You can go on our website, Crohn'sColitisFoundation.org, and find out the activities that are happening near you. And for some corporations,

they want to focus their effort and their giving and their involvement locally. We have those opportunities, as well as to assist the national organization in a variety of ways.

Dr. Caudle:

Right, that's good to know that there's lots of options to become involved.

Mr. Osso:

Yes.

Dr. Caudle:

So, lastly—we'll start with you, Frank—are there any other takeaways that you'd really like to share with our audience today, either regarding your personal story or your professional relationship with the foundation or even the things that you have learned along the way?

Mr. Russomano:

Yes, I think what comes to mind is what I said earlier about how the resources are put to good use. I mean, this organization invests so much in research, and what I've learned from being on the board for a short while is that passion for investing in the right resource and partnering with the right external organizations is truly valuable in helping to find a cure and make lives more comfortable for patients. And this guy is an awesome leader, and I've gotten to work with him and be in a few board meetings with him, and it is no question why this organization is contributing so well to the patients' lives.

Dr. Caudle:

Wow, that's wonderful. It's a wonderful endorsement. And, Michael, anything final that you'd like to add?

Mr. Osso:

Only that we can only do everything that we do, not just through the 280 people that are employed at the Crohn's & Colitis Foundation, but literally the thousands of volunteers that are an enormous workforce and led by the 27 members of the national board, of which Frank is one, so we're thrilled to have that volunteer power.

Dr. Caudle:

Well, it sounds like you both are doing great things to bring more awareness to the prevalence of inflammatory bowel disease. And I want to thank Frank Russomano and Michael Osso for sharing their personal and professional stories with our audience today. Thank you both so much.

Mr. Russomano:

Thank you, Jen.

Mr. Osso:

Thank you.

Narrator:

The preceding episode was brought to you in collaboration with the Crohn's & Colitis Foundation. If you have missed any part of this discussion, or to find others in the series, visit ReachMD.com/foundation.