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Will you ACCELERATE Patient Outcomes?

Announcer:

Welcome to CME on ReachMD. This episode is part of our MinuteCME curriculum.

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Dr. Casper:

This is CME on ReachMD, and I'm Dr. Corey Casper. Here with me today is Dr. Sudipto Mukherjee and Jovanna, a patient that's been diagnosed with Castleman's disease.

So today, we're going to talk about patient advocacy networks. And these can be a huge asset in facilitating collaboration between patients and clinicians. So I'd like for both of you to share your perspectives on these patient advocacy networks and how they've helped you. So starting with Dr. Mukherjee, could you tell us a little bit about the overall benefits of these networks and your own personal experience with them?

Dr. Mukherjee:

Thank you, Dr. Casper. And I cannot emphasize enough how important it is to have a patient advocacy network, especially for rare diseases like Castleman disease. It's a rare disease, and to be able to advance the field, it is almost critical to establish a network of physicians and researchers across different institutions all over the world. And a shining example is the Castleman Disease Collaborative Network [CDCN], which was launched and is currently a global initiative that is dedicated to accelerating research and treatment for Castleman's disease with the ultimate goal to improve survival. And it's possible only because this collaboration allows connection of the global research community, mobilizing resources, both scientific, laboratory, and financial resources, and then strategizing to invest in high-impact research, while at the same time supporting the patients and their loved ones through their clinical journey.

It also is of tremendous benefit because through these collaborative networks we can establish registries to understand the natural history of these diseases. It allows for collection of tissue and other biospecimens to advance research, and it is critically important in ensuring a faster and quicker accrual in clinical trials, which otherwise might take years or even decades if done by a single institution.

Finally, this provides a sounding board for other groups to join in and including the caregivers and patients' families who can now be involved in shared decision-making on these patients.

From a personal standpoint, I have benefited enormously from being a part of CDCN, which is the patient advocacy group for Castleman's disease. I have been able to contribute patients to the natural history registry, I've been able to contribute biospecimens to the registry for advanced research, and importantly, it has been instrumental in helping me manage several of my complicated patients, because I could get feedback and consultation through a wide variety of my colleagues spread all over the world who are a part of this network.

I would now ask Jovanna to share her personal experience with patient advocacy networks.

Jovanna:

Thanks, Doctor. Yeah, so after my diagnosis, my doctors reached out to the CDCN, and that network has been a huge blessing in my journey with Castleman's disease. I had answers to so many of the questions that had been bouncing around my head, and I finally felt heard and understood. I knew there was someone out there that was doing the work to make my life better and the lives of other Castleman disease patients better. And having a rare disease can make you feel very alone, but having the CDCN makes you feel like you have a whole community out there of people that are just like you. And it's given me lifelong friends who truly understand me and are doing great work. And I can't describe how much that network means to me.

Dr. Casper:

Thanks, Jovanna, and thanks, Dr. Mukherjee. I think we heard very clearly from both of you that having these patient advocacy networks really allows for a sense of community and a true community to be built. And of course, we can do many great things together, much more than we can do alone.

So from Dr. Mukherjee, we heard that participating in these patient advocacy networks provides access to other clinicians with whom stories can be shared and solutions to difficult treatment options can be arrived at. Specimens can be shared in ways that can further research. And of course, because of the rareness of a disease like multicentric Castleman's disease, participating in these patient advocacy networks allows for better clinical research to be done with a global community.

From Jovanna, we heard again, very clearly, that these patient advocacy networks provide a sense of community, a support, and resources to navigate what often can be a difficult and frustrating disease.

So that's been a great but brief discussion. Unfortunately, our time is up. Thanks for tuning in.

Announcer:

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