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Therapeutic Challenges in NTM/MAC Lung Disease: One Patient's Journey from Diagnosis to Treatment

Announcer:

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Your host is Dr. Ashwin Basavaraj, Assistant Professor of Medicine at NYU Grossman School of Medicine.

Dr. Basavaraj:

Welcome to *Deep Breaths: Updates from CHEST* on ReachMD. I'm Dr. Ashwin Basavaraj, and our special guest is Mary. Mary is a patient of mine at NYU with bronchiectasis and NTM, who I have been treating with here for the last few years. Mary is here to share with us her journey from diagnosis to treatment. Mary, welcome to the program.

Mary:

Thank you. I'm very happy to be here.

Dr. Basavaraj:

Mary, I think it would be so helpful to the listening audience for you describe your journey and persistence in searching for the correct diagnosis involving bronchiectasis and NTM. Can you talk a little bit about that?

Mary:

Oh, yes, happily. So, I think like most patients who have bronchiectasis and an NTM lung infection, my road was long and a little bit winding. I experienced multiple yearly lung infections over about six or seven years, and I searched sort of high and low, although each infection obviously was treated, I was looking for a way to get a handle on what was going on in the bigger picture and how to manage that. So, it involved, seeking out specialists, pulmonologists, immunologists, infectious disease physicians, gastroenterologist. I had more tests done than I could count almost. But finally, a bronchoscopy at about the 7th year period uncovered the fact that I had bronchiectasis. And what followed from there were a couple of sputum samples that it finally returned positive. I think those AFB sputum tests were really key.

So, at that point, we knew what the culprit behind everything. And I received a referral to you, Dr. Basavaraj. It was a long journey, and it took a fair amount of determination on my part to just get to the bottom of things. But I remember feeling just incredibly relieved when I discovered indeed that there are people that know what this is and what to do with it.

Dr. Basavaraj:

Thank you for sharing that, Mary. And we know that there's a number of specialists that are involved in the care of bronchiectasis and NTM. We have pulmonologists, infectious disease experts, chest physiotherapists. And it can be a challenge in fact to find the right team.

Mary, how did you find your right team? And what members were a part of it for you?

Mary:

Yeah, that's pretty critical. I think I'm lucky that I live near a large metropolitan area with a university teaching hospital. And certainly, lucky that at that location there was a group of physicians who have specialized in bronchiectasis and NTM. So, I had the benefit of being able to go to one organization and get kind of everybody that would support me. That included you, of course, as a pulmonologist, but also nurse practitioners, respiration therapists. I wrestle a little bit with gastric reflux, although it's under control, but I can well

imagine in the future that I will be calling on a gastroenterologist as well. So, it seems to be quite an interdisciplinary team that has to pull together. But really, really a critical factor is finding a physician with some experience and knowledge about nontuberculous mycobacteria.

Dr. Basavaraj:

Now, communication is important. It's very important that patients reach out to their providers when they have questions that they have and can ask those questions readily. How important was communication with your medical team, Mary?

Mary:

Oh, frankly, for me, it was a make-or-break deal. I had spent a lot of time getting to the place where I found the right people. But I really wanted to be confident that they were communicating with one another. This isn't necessarily a straightforward path through treatment. And I also wanted to be sure that we were developing a relationship that was a real partnership. I'm very pleased to be able to say that I always felt that you welcomed questions, in fact. And throughout the process, we had discussions, and we talked about pros and cons. And that gave me a level of confidence that, for me, was critical in making decisions and taking the right path. So, I can't stress it enough the importance of communication and the development of a partnership with the medical team.

Dr. Basavaraj:

Yeah, I agree, Mary. And, from a provider standpoint, it's so important to keep the open lines of communication with your patients, not just in the medical decision-making but also in education. Right? And just communicating with your patients on what bronchiectasis is, what NTM is, what the expectations are, in terms of management of this disease, I think are so crucial to the overall care of the condition.

Mary:

Yeah, I think you're completely right there. It's interesting that this is still considered a rare disease. And for me, that meant I had no idea what I was getting into once the diagnosis was made. So, the fact that you offered documents that I could read, articles that explain what was going on, numerous websites that helped me understand what was happening to me and how the road ahead might go. That was really, really important, really critical.

Dr. Basavaraj:

If you're just tuning in, you're listening to ReachMD. I'm your host, Dr. Ashwin Basavaraj, and I'm speaking with Mary, who is sharing her patient journey with NTM MAC lung disease.

Mary, let's, shift gears a little bit. With your diagnosis of NTM MAC lung disease, you know, there could be a number of lifestyle changes that patients are faced with. What specific lifestyle changes were you faced within your overall condition?

Mary:

Right, right, good question. I really see sort of three areas that are related to one another, but I kind of see them in three buckets, three ways in which, my lifestyle had to make adjustments. The most significant one is that I really had to learn how to do airway clearance, which are various routines that might use a nebulizer and saline solution, or devices that allow you to loosen and clear the sputum in your lungs. Learning that that even existed and how to do it, and what kind of time it was going to take was a pretty big learning curve for me. I definitely got the support of a lot of videos that you provided, as well as the hands-on training from the respiration therapist. But it became clear that that was now going to be a twice-a-day event throughout the rest of my life. So, I began it before I actually went on medication and used airway clearance twice a day throughout the treatment period. And I know that I will be continuing that. That first element of lifestyle change is a pretty big one.

The other two are kind of related to that. NTM is everywhere apparently. It's in the air, it's in the water, it's in soil. And so, I have had to become knowledgeable in how to avoid environmental risks that will either reinfect me or if I could have known this, maybe avoiding the initial infection. So, on a concrete level, that means I've had to adjust how I approach drinking water. I drink only water that's been boiled for 10 minutes or water that has been filtered through a pitcher that uses a 0.2 micrometer pour size. I have put a filter on my shower as well to make sure that I am not inhaling a whole bunch of NTM in an aerosolized form. I've raised the temperature of my heater - my hot water heater. I never go in a hot tub or a spa or indoor swimming pools. So, learning about the sort of day-to-day environmental risks has it's been a plus and a minus. It's a minus insofar as perhaps I have to make adjustments, but it is a plus because it gives me the knowledge and confidence that I do have some control over exposure for reinfection.

And then the third area is really sort of socializing and traveling. I do still travel, and I certainly do still socialize. But because I'm making adjustments for the airway clearance twice a day and because I now have a little bit more medical equipment, I'm no longer quite the person with a single suitcase on the airplane. I've got a bunch of things that I'm lugging around. So, I have to be aware when I'm traveling of how I'm going to be cleaning my equipment. I've got to be able to plan for daily water consumption, when I'm in a place that's

not my own home. And I've found that my friends need to understand what's going on so that they and I can find a way to socialize. All these things are a big adjustment, I think at first, but the recognition that they really matter to my health has in an odd way, given me a sense of kind of control over this. So, I try to look at it through that lens.

Dr. Basavaraj:

As we come to the end of our discussion, Mary, we want to talk a little bit about your treatment course. With your NTM, we talked about a lot of options. And we decided to choose a clinical trial that's underway right now. And that's the two antibiotics for MAC versus the three antibiotics for MAC. We opted to enroll you in the study, and you were randomized into the two-antibiotic arm, which we continued. And just wanted to hand it over to you about talking about any sort of side effects that you may have had with that course and how your treatment course was looking afterwards after starting that treatment.

Mary:

Sure. Yes, as you said, I got in the group that was receiving just two of the oral antibiotics. So, I was taking azithromycin and ethambutol. And for the most part no major side effects, some intestinal distress, which was fairly easy to take care of with probiotics. Unfortunately, though after about eight months, my sputum was still showing positive for NTM.

Mary:

Right, right. And so, you and I had additional discussions about this, and discussed alternative approaches that would allow me to continue treatment. And we went forward after that. And I began to receive negative sputum cultures, which was fantastic. And ended up receiving 12 months more of proof that the sputum was converting. And I very recently graduated from the antibiotic world. So, I'm very grateful that it took that turn. And I'm grateful also for the opportunity to have worked with you throughout that.

Dr. Basavaraj:

Yeah, Mary. You know, I think you bring up an important point is that it's not only important to monitor patients while on treatment, but it's also important to monitor patients after the end of their antibiotics. And, you know, with you, it's been great because the cultures have remained negative, and we're going to continue to monitor moving forward. So that's great. And there's a lot of resources I know, Mary, you and I talked about. And I just wanted to know if you can talk about some of those resources that were most helpful to you.

Mary:

Sure, they were really, really important in my journey to help me understand where I was and where I was going. You gave me a number of written documents to read, and you referred me to several websites that had very comprehensive information. The ones that come to mind are the NTM Info Information and Research website. The COPD Foundation and an organization in Australia that has the Bronchiectasis Toolbox. Those were really very, very helpful in helping me understand what I was facing and what I needed to do. So, I would recommend those to anyone in my position.

I also think of members of support communities as part of the resources that have helped me out. That NTMIR organization has a global forum, which is a place where individuals like myself can ask or answer questions, where we share experiences, encourage one another, and that along with organizations that meet either on Zoom or in person that's gone a long way to help me take the proper steps to get myself healthy and keep myself healthy. So, all those resources, I think of as very much important on my journey.

Dr. Basavaraj:

Yeah, thank you so much for providing those excellent resources. And Mary, thank you for being with us so much today and sharing your journey. I know our listening audience will benefit from the education and the experience that you provide with us today. Mary, it was great speaking with you today.

Mary:

Thank you. Happy to be here. Thank you.

Dr. Basavaraj:

I'm Dr. Ashwin Basavaraj, and on behalf of CHEST and ReachMD, thanks for listening.

Announcer:

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