

ATTR-CM Podcast, part 3 of 3

- Patty Clemmons, Announcer
- Dr. Amrut Ambardekar
- Dr. Michelle Kittleson
- Patient Richard Hawkins

- Patty Clemmons: [00:00](#) Hello, I'm Patty [Clemmons 00:00:01] with the Communications Team at the American Heart Association. Today we're concluding our three part conversation with Dr. Amrut Ambardekar, Medical Director, Cardiac Transplant Program, Associate Professor of Medicine, University of Colorado.
- Patty Clemmons: [00:14](#) And Dr. Michelle Kittleson, Director of Heart Failure Research as well as Postgraduate Education, and Heart Failure and Transplantation, and Associate Professor of Medicine, Smidt Heart Institute, Cedar Sinai.
- Patty Clemmons: [00:25](#) And ATTRCM patient, Richard Hawkins, is helping us to understand the patients needs. In parts one and two, we defined ATTRCM and we looked at its causes and its symptoms. To wrap up, we're going to discuss diagnosis and treatment options. Dr. Ambardekar, let me begin with you. How is ATTRCM diagnosed?
- Dr. Ambardekar: [00:46](#) The diagnosis may be suspected because of typical symptoms and the result of routine cardiac tests, including an electrocardiogram or echocardiogram. Once suspected, more specialized tests are needed to confirm the diagnosis. These can include imaging studies of the heart, most commonly a cardiac MRI, and/or a nuclear medicine scan of the heart. Also, a tissue biopsy of an affected organ, or genetic testing.
- Patty Clemmons: [01:14](#) Dr. Kittleson, how is ATTRCM treated?
- Dr. Kittleson: [01:18](#) There are several promising new therapies for ATTRCM on the horizon. Medications are approved for hereditary transthyretin amyloidosis affecting the nerves, causing a condition called neuropathy. With ATTRCM affecting the heart, doctors focus on easing the heart failure symptoms and slowing or stopping the formation and deposition of [inaudible 00:01:47]. Recently, a medication was also approved for treatment of ATTRCM. In the cases of advanced heart failure, heart transplantation may be an option. In some patients, both heart and liver transplantation is required as the abnormal transthyretin protein is produced by

the liver. Given the important new therapies now available, patients should talk to their physicians about treatment options.

Patty Clemmons: [02:15](#) That's certainly good news. Any last thoughts for our audience? What should patients know about seeking treatment, seeking help?

Dr. Ambardekar: [02:21](#) We encourage patients to talk with you. Know that awareness of the disease among clinicians is low. In fact, it is often misdiagnosed as hypertensive heart failure or hypertrophic cardiomyopathy. Because of the many different and subtle ways in which patients present, ATTRCM may already be advanced by the time the patients receive a diagnosis. It is important that providers take the time to talk with their patients and start the patient education piece. Starting that conversation could be a lifesaver.

Patty Clemmons: [02:52](#) Turning back to the diagnosis, ATTRCM is a complicated disease as you've noted. What's been your biggest challenge in understanding what's going on?

Richard Hawkins: [03:06](#) When you learn to let go, you just sort of take things as they come. I mean, my body is really not my body anymore. It really belongs to the doctors. I just learned to let go. One day, I had six different tests, several that were invasive. I just said, "Whatever. Whatever, Lord." I was very content with wherever they're going to lead me, because I trusted implicitly in everything they were doing for me. I did not struggle from a practitioner's perspective, or any procedure that they were recommending. The only thing I struggled with was my breathing and my depleted energy level.

Patty Clemmons: [03:51](#) If you had to share your top tips in breather recovery, or daily management of the condition, what would you tell others?

Richard Hawkins: [04:01](#) It begins with my faith, first and foremost. Let go and let God. God can't be God unless you let go of control of all things. Once you do that, then you have a totally different perspective in life. With regard to managing the disease, do what you're told to do. Get out there and exercise. Walk, because it makes you stronger and you heal better. I have great joy in exercising. I just had to lay back because I had a back injury. I just had that repaired. Aside from that, be diligent in doing what the doctors tell you. Take your meds on time, and exercise. Exercise is a joy, and without it your heart's going to weaken. My encouragement is be diligent in your meds and your exercise.

Patty Clemmons: [05:02](#) So, if you wanted to tell other healthcare providers who are dealing with this condition and treating their patients with this, what would you tell them that they need to know?

Richard Hawkins: [05:11](#) The problem I had was practitioners outside of Cedars Sinai, because they were totally unfamiliar with amyloid. As one doctor told me, "Amyloid, nobody has that. It's only a question you have on your bar," or Medical Board, excuse me. I was the first patient with amyloid post-transplant and pre-transplant that any local doctor had ever seen, including cardiologists. Their difficulty is dealing with something that is totally foreign to them. Fortunately, I had one cardiologist, two actually in Riverside, who said, "You need to go beyond these walls and go to Cedars where they have the capability of dealing with whatever it is you have."

Patty Clemmons: [06:01](#) How are you feeling now? Let's get to the important stuff.

Richard Hawkins: [06:04](#) I love my work. I'll be 69 years old in a couple of days, and I'm working as hard as I ever have. I don't have the same endurance, same energy that I did before my heart disease. The fact is, I have enough to do a full-time job. My joy is not doing what I do. My joy is in sharing my joy, if that make sense. And, touching other people's lives with what has been given to me.

Patty Clemmons: [06:33](#) As we arrive at the end of this podcast series, I want to thank you all for your participation in this podcast. Thanks to Dr. Amrut Ambardekar, and Dr. Michelle Kittleson for your time. And, Richard, your participation and insights as a patient have been key to all of us understanding this process as well. So, thank you. Please visit us at heart.org/ATTRCM for additional information. The American Heart Association would like thank Pfizer for funding these educational resources through a grant. Thank you all for your time today.