

FH podcast #4 Managing FH Transcript
American Heart Association & The FH Foundation

Announcer:	00:02	Welcome. You are listening to a series from the American Heart Association and the FH foundation. This series is focused on educating patients, caregivers and health care providers on ways to improve awareness, detection of FH and management of high cholesterol.
Cat Davis Ahmed:	00:24	Hi everyone. My name is Cat Davis Ahmed and I'm the vice president for policy and outreach for the FH Foundation. I myself am diagnosed with familial hypercholesterolemia. Our fourth podcast in this series is all about managing familial hypercholesterolemia or FH. And joining me today, I'm very happy to say, is Dr. Seth Baum the immediate past president of the American Society for Preventive Cardiology and clinical affiliate professor at the Schmidt College of Medicine. His practice includes cardiovascular prevention and treating complex lipid disorders. Dr. Baum is also the FH Foundation Board secretary and treasurer. And thank you, Dr. Baum, for joining us for this discussion on managing familial hypercholesterolemia.
Dr. Seth Baum:	01:12	Well, thank you Cat. It's always great to speak to you about this or other things.
Cat Davis Ahmed:	01:22	Before, an extraordinarily rare disorder and we don't really know much about it." But today so much research has accumulated over the last decade and with the FH Foundation's incredible work over the last five years, we now really understand FH or familial hypercholesterolemia much better than we used to. So, FH is a genetic disorder, typically the result of a mutation, one of

FH podcast #4 Managing FH Transcript
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that he or she has FH, sometimes that patient is not going to be treated as aggressively with risk factor modification. That includes lowering of LDL but other things as well. And then the family members, the children or other members of the family, will lose the opportunity to be treated at a young age. Losing that opportunity means that they have a higher risk of having vascular disease.

So the first thing we have to do is make the diagnosis. Anybody with LDL off the charts, at least raise the question to your doctor, your clinician, raise the question, do I have FH? Do I have familial hypercholesterolemia? You have to actually start that conversation sometimes with your doctor because your doctor may not start it with you. So that's the first thing that I think everybody should come away with.

Once that diagnosis is made, then we have to talk about treatment. So how do you treat somebody? Well, the treatment will often depend upon where you stand in the spectrum of FH. So, Cat, you just mentioned the higher risk of premature vascular disease. If somebody has not yet had a vascular event, a stent, clinical peripheral arterial disease or an ischemic stroke, things like that, then we sometimes will treat them a little

FH podcast #4 Managing FH Transcript
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And then there's also hypertension and diabetes and other what we call comorbidities and these things have to be managed very aggressively because if you start piling on risk factors, especially unmanaged risk factors, the risk goes up exponentially for an individual patient and we don't want that to happen.

Cat Davis Ahmed: 09:17

I think that's such a great point that we all need to do everything in our power to lower our risk no matter where that risk comes from and then to focus also on the FH management. Are you saying, is there like an FH diet? Is there something very specific that people with FH are supposed to do with their diet or is it similar to what the rest of America and the rest of the world should be eating?

Dr. Seth Baum: 09:46

Well, you know, it really depends on what you read with regard

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alone. So that's pretty much the way I would approach the patient who has FH.

Cat Davis Ahmed: 17:22 You start with the ... If you can and many people can take the high intensity statin. There are I think seven different statins available on the market, six of which are generic. Is that correct? So people sometimes do better on one than another and they may have some side effects on one and not on another so the process of finding the right one that might take a little while, is that right?

Dr. Seth Baum: 17:50 It's true. But here's the thing. So most of us will start with the two most effective statins, rosuvastatin or atorvastatin and we'll give those a try. If patients can't tolerate those two drugs and you start moving to the less effective or less intensive statins, you're gonna get less bang for the buck. You're basically gonna get less LDL reduction and at some point you say, Uncle, enough, this is not really worth it.

So usually we'll try two or three and not all seven statins. That's generally the way people practice and that's also what is in statements written by organizations such as the AHA.

Cat Davis Ahmed: 18:38 So, I mean I like what you said, I know from the FH Foundation's research that you're a part of in the cascade FH registry we, before PCSK9 inhibitors were available, only about 25% of people in the registry were able to get their LDL down below 100. So we know that in the FH population when you're starting, you know, you've said, people with LDL's over 200, but of course my own experience and what I hear from many people with FH, were starting much higher than that even at 300 or higher.

Dr. Seth Baum: 19:14 Or 4 or 500 absolutely.

Cat Davis Ahmed: 19:17 Right, sure. So that a 50% lowering is not good enough to get you where you were saying at the beginning, we needed to go and you may need to add, an additional therapy. That some people might get where they need to go on the first statins or the statins. 1.217 Td [(go) Td [(th)10.6onxg5.2 (th)5.8ly ao5.2 (3(e s)12.5t)-3.

FH podcast #4 Managing FH Transcript
American Heart Association & The FH Foundation

- Dr. Seth Baum: 19:58 Yes and yes I can talk about it. We've shown it with the statins and we've shown it with the PCSK9 inhibitors. So both types of lipid lower therapies will decrease risks of heart attack and stroke and death. So this has been documented.
- But why is that? Well it's because of the direct connection between LDL and the formation of plaque. LDL causes plaque formation and multiple genetic studies have proved that. So we have our highest level study which is called an RCT. Those studies have demonstrated uniformly frankly, that lowering LDL lowers risks and when I say risks, it's heart attack, stroke and death.
- But we've also shown genetically that those people who have mutations such as patients with FH that mutations that impact LDL adversely. So you have a higher LDL, have a higher risk of developing heart attack, stroke and death. Whereas those people who have mutations that lower LDL and the classic mutation that does that, it effects PCSK9.
- So those people who don't make ~~the~~ PCSK9, will actually have a much lower risk of heart attack, stroke and death. So those two lines of reasoning and understanding have really proved to us that it's not just lowering a number, it's actually lowering risk and everybody needs to understand ~~that~~. You lower your LDL, that's equal to you lower your risk.
- Cat Davis Ahmed: 21:50 Well that's good news. Just in case this isn't clear for FH or for

FH podcast #4 Managing FH Transcript
American Heart Association & The FH Foundation

- Cat Davis Ahmed: 22:54 I think it's so important with people with FH and for the healthcare professional to treat them and other decision makers to decide what medication is available. It's a genetic condition. You're born with it. You're born with that high LDL. It's not going to go down on its own in spite of your best efforts with diet and exercise, as important as those are. And so, taking our medication every day, or every two weeks, or whatever medication it is it's so important. It's something I try to remind myself of every morning, to take my medication. Some people take them in the evening. Does that matter? Actually a lot of people ask that question. Do you take your statin in the morning, take your statin at night, does that matter?
- Dr. Seth Baum: 23:45 It doesn't matter with some of the statins like Rosuvastatin and Atorvastatin. But Simvastatin, it does matter. Some of the shorter acting drugs, it does. But most people are using, and certainly in patients with FAH, or other patients with very high LDL cholesterol who are at very high risk, we're using the Rosuvastatin and Atorvastatin, and it does not matter.
- Cat Davis Ahmed: 24:09 Whenever you're more likely to take them every day.
- Dr. Seth Baum: 24:10 Whatever, yeah.
- Cat Davis Ahmed: 24:11 Whatever works.
- Dr. Seth Baum: 24:13 Right.
- Cat Davis Ahmed: 24:15 What would you say, what does the future look like for people with FH? I really want to make sure we walk away feeling hopeful and empowered, because we do have these treatment options available to us today.
- Dr. Seth Baum: 24:29 I'd like to answer that with two lines of thinking. The first, I think I should mention the genetics, genetic testing. We had that publication in the Journal of the American College of Cardiology, a consensus statement that was convened by the FH Foundation on the use of genetic testing in familial hypercholesterolemia. I bring that up because I think that's going to be happening much more frequently. The advantage of genetic testing in sum really, in summation, not some people is that genetic testing would be twofold. One is, if you identify mutation in an individual, we know that particular person with FH has an even higher risk than if you didn't identify a mutation in a patient with FH. Two, you can use that mutation to cascade screen, to screen the family members, and it makes it easier to identify other people and lower their risk through identification

FH podcast #4 Managing FH Transcript
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and treatment. It should be understood from the genetic testing standpoint that if you don't identify a mutation that does not exclude FH. That's really important. I'll say it again. If we don't see a mutation on genetic testing that does not mean a patient

