

FH podcast #2 FH and Women Transcript
American Heart Association & The FH Foundation

- Speaker 1: 00:02 Welcome. You're listening to a series of four familial hypercholesterolemia podcasts brought to you by the American Heart Association and the FH Foundation. This series is focused on educating patients, caregivers and healthcare providers on ways to improve awareness, detection of FH, and management of high cholesterol.
- Maria Sophocles: 00:25 Hi, everyone. My name is Dr. Maria Sophocles. I'm a board member of the FH Foundation, a practicing ob-gyn, and the medical director of Women's Healthcare of Princeton in Princeton, New Jersey. I'm also a patient with FH. Joining me today is Dr. Larry Sperling. Larry is the founder and director of preventive cardiology at the Emory Clinic in Atlanta, and an FH expert.
- Larry Sperling: 01:01 Thanks, Maria. Very glad to join you in speaking about this really important topic.
- Maria Sophocles: 02:09 As an ob-gyn, I take care of women. I want to know, to be able to tell our listeners, what do women need to know about familial hypercholesterolemia? How is it different for women?
- Larry Sperling: 02:24 FH in women is an equally powerful risk factor. There's no gender difference. If you have a very high cholesterol from birth, this predisposes you to heart disease, often at an early point in time.
- Maria Sophocles: 02:43 I tell women that the estrogen in their bodies protect them from the onset of heart disease and delays heart disease and atherosclerosis. Do women with FH have that same protection?

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- Larry Sperling: 03:00 Unfortunately, if you have a genetically high cholesterol, you lose the protection of being a woman. Compared to other women, you're at risk of earlier heart disease. Even if you have no other risk factors, if you're otherwise healthy, this single risk factor of a genetically high cholesterol predisposes you to heart and vascular disease. I look at it as losing the protection of being female.
- Maria Sophocles: 03:30 Mm-hmm (affirmative). What kind of studies have been done about women with FH, and what does that data show us?
- Larry Sperling: 03:38 Yeah, so it's important to know that we're learning more about those with FH. At Emory, we're one of the sites for the national CASCADE FH Registry. Here, we're learning about individuals living with FH within the United States. What we know so far is that women do have a delayed onset of heart disease compared to men, but compared to other women, this onset of heart disease is much earlier. We know that women are less likely to reach their goal cholesterol even on medical therapy. They're less likely to be prescribed medications that we know can protect them from heart disease, like statins. We absolutely need to emphasize that women with this disorder need to be treated equally aggressively.
- Maria Sophocles: 04:30 Very important, and they have to advocate for their symptoms. If they're in an emergency room or they go to a doctor, and they have symptoms or they have a family history that is suspicious, with members having cardiac events early, they need to speak up. I'd say this goes not only to their primary care, but to their ob-gyn as well.
- Larry Sperling: 04:52 Yeah, I would agree. I know you're an ob-gyn, and that you have become a champion and advocate for women with FH. What is it that you-
- Maria Sophocles: 05:06 Mostly because it's so underdiagnosed. I think it's shocking to me that something as common as diabetes is 90% underdiagnosed and not diagnosed. I think it behooves all clinicians to try to find it, but it's important for patients to think about it and speak up to their doctors.
- Larry, I have another question for you, though. As far as the treatments, is the efficacy of the treatments the same in men as it is in women? With FH, do the statins, for example, work equally effectively in men and women?

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- Larry Sperling: 05:43 Yeah, the medications we use to lower cholesterol, and protect or hopefully prevent people from developing heart problems or vascular problems in the first place, are equally effective. The statins, which are one of our mainstays, are equally effective in women as they are in men.
- Maria Sophocles: 06:02 That's good to know. What about, should be we advising women with FH just not to have children?
- Larry Sperling: 06:11 No, absolutely not. Women with FH can have children, but as I think I'm going to ask you a little bit, because you're the expert of guiding women through healthy pregnancies. I would not dissuade a woman from embarking upon a pregnancy, but it would be important to be aware of the diagnosis of FH going into the pregnancy.
- Maria Sophocles: 06:38 Mm-hmm (affirmative), yup, I agree 100%. I think a woman needs to know the FH status of the father. The father can easily spit in a vial or have a blood test, and have genetic testing, which will tell the couple whether he has any gene defect, whether he has a single gene or a double, I call it a single dose or a double dose, of the genetic defect. We call this, in medicine, heterozygous or homozygous. Certainly, depending on the status of the father, that can help the couple understand what is the likelihood that they'll have a child with any problem, or a single dose of the problem, or a severe problem. Patients also who are on statins, I ask them to stop the medication about three months before they plan to get pregnant. I don't think they should be on a statin during pregnancy. If they are on a statin and get pregnant, that's okay, but they should stop the statins and get monitored. There have been studies in humans where they look at 100 women on statins, and they actually had no issues, but the party line as of today is that women should stop their statins during pregnancy, and then resume after they finish breast feeding, if they choose to breast feed.
- Larry Sperling: 08:12 Yeah, and I think there are medications that women who have FH can safely take during their pregnancy, in addition to following a healthy diet and keeping up with regular exercise. We have a regimen that we use in terms of planning for a pregnancy, like you said, stopping the statins about three months before they become pregnant. Then we treat with what's called a bile-acid-binding resin or sequestrant during the pregnancy. Then when breast feeding is concluded, we can get women quickly back on the statins, because we know we don't want to leave them unprotected for too long.

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- Maria Sophocles: 08:51 Right. But at least the bile-acid sequestrants, they bind the cholesterol in the gut. They don't even go into the bloodstream, so they really are extremely safe. I've had pregnant women say, "Are you sure? Are you sure I should be taking something?" I think we can safely tell them, in fact we, ob-gyns, use these to treat gallbladder disease in pregnancy, so we're used to using these type of medicines for other issues in pregnancies, so it's absolutely safe.
- Larry Sperling: 09:20 What about, are complications more common in women with FH, because I know you help care for a lot of these women?
- Maria Sophocles: 09:30 Yeah. Happily, I can happily say they're not. The only time we see complications is in a woman with FH who already has significant cardiovascular disease, especially aortic stenosis. This is a patient, if you are an FH patient with significant cardiovascular disease, your pregnancy will be co-managed with the cardiologist and the obstetrician. That's okay. It doesn't mean you can't get pregnant, but it means your cardiovascular function will probably be monitored during pregnancy.
- Otherwise, if you're an FH patient who's been diagnosed, you have heterozygous FH, your cholesterol's high, but you don't really have evidence of substantial atherosclerosis, you probably will have absolutely no complications at all during or after the pregnancy, as long as you just get back on your statins. They've really looked at preterm labor and all kinds of things, and never been consistently shown, so I'm happy to say, it really can be a complication-free pregnancy.
- Larry Sperling: 10:41 Maria, any specific advice you give your patients about contraception? Is there certain things that you help guide them with, if they have FH, regarding contraceptive therapies?
- Maria Sophocles: 10:54 A combination birth control pill, the common good old birth control pill, contains estrogen and progesterone, and there is a very small risk of a progression of cardiovascular disease only because it tends to increase cholesterol. If FH patients ask me about birth control options, they truly could take anything, and if their heart was set on the pill and it was really the only good option, they could take it, but I tend to steer them away from that. There's so many other good, long acting, reversible options out there, like IUDs. There's just no need to be on the pill. So technically, they can take anything, but I tend to try to avoid combination birth control pills, and use anything else.

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- Larry Sperling: 11:43 Alright. Because familial hypercholesterolemia is a family disorder, I always look at this as an opportunity to not only focus on the very best care of the patient that we're caring for, but really extending that care to their family. Because women are caregivers across the board, and that's their general tendency, is there advice you give your patients about how to think about caring for their family? Then what about their children? Do you give advice beyond your patient?
- Maria Sophocles: 12:21 Yeah. That's the amazing opportunity we as clinicians have, is that if we can uncover one patient, we can technically diagnose the whole family. Yes, if I have a patient who comes to see me, and whether she's pregnant or whether she's just getting well woman care, and we ascertain that she has FH, I want to know about her children. How old are they? Have they been checked? Actually about her parents, her siblings, everyone. There are centers around the country, and the FH Foundation does a great job of connecting patients with these centers. But I say the earlier the better. I mean, what do you think, Larry? What age do you like to have the children tested?
- Larry Sperling: 13:04 Yeah, so it is very evident, even at an early age, which children have a genetic cholesterol problem. Even at the age of two, which would be the recommendation for a child of an individual with FH, it's evident that their cholesterol, as a two-year-old compared to other two-year-olds, is on the very tail end of the distribution and the population. Early awareness is the most important thing we can do for patients who have FH, because with early awareness comes being proactive about your care, and with early awareness comes early treatment, and with early treatment comes prevention.
- Maria Sophocles: 13:52 But you said age two. If I want to have a young woman with her two-year-old who's got FH, and I ask her to go get the two-year-old tested, what age can I expect to tell her that you'll be interested in treating that two-year-old? You won't treat a two-year-old, will you?
- Larry Sperling: 14:12 That's a good question. There the answer to that question is I would need to know a lot more about that family and that family's history, because sometimes if there's a very strong history of early heart disease, so I'm talking not in people's 40s, 50s, 60s, but in their 20s, which I do see patients with FH that have heart disease as a teenager or a 20-year-old. These are people that we wouldn't want to wait til they are quote young adults, because at that point we would've missed that window of opportunity to treat over time, because this risk factor exerts

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risk over time. We also can prevent the risk by treating over time.

Maria Sophocles: 15:03 Okay, so certainly the message is early. How early's going to depend on that particular patient's family history, and maybe any other disease processes they have.

I want to just get on my ranting pedestal for a minute and complain that women get underrepresented in scientific research. This is so frustrating to me as a menopause specialist and a gynecologist, but I do think things are changing. I can only hope that there'll be some more attention paid to the study of FH in women. You're closer to this than I am. What can we do to help women with FH get involved in research or promote research studies or something like that. What can we do, Larry?

Larry Sperling: 15:52 Yeah, it is important that we learn more about women with FH, and more about women in general and cardiovascular prevention. There are clinical trials and observational studies like the CASCADE FH Registry that I mentioned, but we don't have enough research on high cholesterol in women, including women with FH. I do think there are opportunities to become involved with research, either through the FH Registry, or through clinical trial opportunities. I know you've been involved also in some of the initiatives related to understanding more about the impact of high cholesterol, not only on the mother, but on the child.

Maria Sophocles: 16:41 Right. There's a long way to go, but I think we both agree that the key is to get more FH patients diagnosed, so we can have more to enroll in these studies.

For ongoing information on clinical trials and FH, you can visit the FH Foundation website. Currently, there are multiple studies on both the effect of high cholesterol, as well as the effect of different therapies during pregnancy. If you're interested, check out the website, mothertobaby.org, for more information. In case you missed any of what we discussed on this podcast, visit the FH Foundation at www.thefhFoundation.org and the American Heart Association at www.heart.org/cholesterolpodcasts.

Thanks for listening, and keep your ears open for our next podcast about FH and children.

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