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Canadian Perspectives on Managing Lipid Disorders in Children

Dr. Brown:

You're listening to ReachMD and this is **Lipid Luminations**, sponsored by the National Lipid Association. I'm your host, Dr. Alan Brown, and with me today is Dr. Julie St. Pierre, who is professor of pediatrics at Sherbrooke University in Canada, fellow and chairman of the Healthy Living's Communication Committee at the American Heart Association, as well as a fellow and member of the Cardiovascular Disease of the Young and Obesity committees.

So, today we're going to be discussing the Canadian perspective of pediatric lipid disorders. Having had an uncle in Canada, he did have a few different perspectives than I had; he was a judge in Toronto many years ago. But I think it's an interesting topic. What would be different about the Canadian perspective versus our perspective and, as usual, you're probably far advanced over what we're doing here.

Dr. St. Pierre

Actually, in Canada, what is very different, I think, is the high prevalency of certain dyslipidemias, especially familial hypercholesterolemia and other triglycerides rarer disease. So, in certain regions, especially where I do practice, there is up to 1 out of 50 as a frequency of hypercholesterolemia, the familial disease. So, that brings up to 6000 people around my area that are affected by the genetic disease, and it is so prevalent that the costs also that are associated with the complications, as you know, myocardial infarction or cerebrovascular disease, are very high, so we are trying as much as possible to prevent by finding those people in the population and we do not have a population screening program; we do have to inform our GP's and educate them to find those patients and to prevent.

Dr. Brown:

So it's really the French-Canadian population, the so-called founder effect, right?

Dr. St. Pierre:

Exactly. Exactly.

Dr. Brown:

Yeah, I think it's something we talk about a lot, but it's fascinating because in the US we think we have 1 in 250 to 1 in 300 patients with familial hypercholesterolemia, which to me, still sounds like a lot of patients.

Dr. St. Pierre:

It is.

Dr. Brown:

And yet, we haven't focused on it to the point where our primary care doctors know the diagnosis and even a lot of our cardiologists still haven't had the uptake. So I'm very interested in hearing how you tackle such a problem and...

Dr. St. Pierre:

Well, the battle right now is more with the pediatricians and the GP's that are receiving, in first line, the kids. We are trying to have them as informed as they can so they can screen as young as 2 years old to find those patients, because we have very nice data from

Europe that says that if you detect early and you treat them early, and this is the work of John Kastelein, very worldwide known, that if you treat them as young as possible, you're going to reach a normal survival rate of life.

Dr. Brown:

Right. So, I'm very interested, then, when you have that kind of a high prevalence, how do you get the word out to the pediatricians? In this country, I think sometimes the pediatricians are just so uncomfortable with thinking about statins, even though we...

Dr. St. Pierre:

Yeah.

Dr. Brown:

We start at 8 or 9 years old.

Dr. St. Pierre:

Yeah. And that is a myth. You know, we have great data now that support that statins are very safe in kids. And you know, a lot of people kept in mind, probably when he did med school, that there was some concern about bone maturation and, finally, the group that was treated in a very high number of patients, actually they were taller. So, maybe it's a matter of inflammation that is less present in the kids, but there are some hypotheses that support that. But it's a myth and we need to reverse the education that was made 15 years ago about that.

Dr. Brown:

So, my guess is if you have a 1 in 50 incidence as opposed to our 1 in 250, as embarrassing as it is for us, in Canada you've probably got better methods to get the word out. So, can you tell us a little bit about what you're doing to make sure the pediatricians, and even the internists and cardiologists, are aware of the disorder?

Dr. St. Pierre:

We have a nice tribune at the National Meeting of Pediatricians, so they are aware, and you know of the consequences that we have in the adult population. So, I think it's the best way to do it is to be present in those meetings and have workshops and answer the physicians' questions about statins and screening and insurance and all that. So we do that in different provinces also, and what is very nice is you have the FH Foundation in the US, but in Canada what we did, it's a little bit different, it's the Canadian FH Networks and it's a huge, also database that we are trying to build with Health Canada and to learn from that. So I think the physicians feel it is very safe because we have such a great organization, and that is the work of Jacques Genest from Montreal. So with this huge network that is present on different social medias also, it gives some credibility, I think, to our physicians, and they see that there all a whole bunch of lipidologists, pediatricians that are a part of it and that make sure that what we are saying, it's very safe and away from any commercial BS.

Dr. Brown:

Right. So, let me ask you, then, has there been any thought, considering the high prevalence, to screen children in school, for example?

Dr. St. Pierre:

We would love to do that, because I think, as you may be aware of, it's difficult just with a cutoff of LDL to find everyone. Sometime recently at the ACC, we saw that we are missing people that are at very high risk and that they have mutation in their DNA. So, we would love to do it, but right now we do not have enough data to support universal screening. So we did cascade screening instead. But the families are very well-educated in the lipid clinics, so they are a very good screener in their families. So they have the responsibility to bring the information in their family and to ask them to come to the clinic. So it's free. They can have a blood shot and have a fasting lipid profile that is seen by a lipidologist.

Dr. Brown:

Let me ask you, since you got on the topic of genetic mutations, we struggle here in the States with insurance coverage for genetic testing; Dr. Kastelein doesn't have that problem. How about in Canada; if you decide that you should be doing genetic testing on a patient, is it paid for, number one, and number two, how often are you ordering, actually, genetic testing?

Dr. St. Pierre:

Well, we have a free healthcare system, so the genetic testing is free. It's paid by Canada and every province is. So the mutations, as a matter of insurers, sometimes what I've seen is that the rise of the price of insurance. But you know, every time—and my colleagues are doing the same thing—we are calling back, writing to them, and showing that the patient is compliant to the medication, has a healthy living, and that his risk, being very well-managed, is the same as the other population.

Dr. Brown:

Yeah, that's such an important point for the listeners is that if you inherit FH, the risk is from not treating 20, 22 times the risk. But, if you treat the patient your numbers are well-controlled, especially if you catch them in childhood, right?

Dr. St. Pierre:

Yeah. The problem is that our physicians, you know, sometimes it's a lack of medical education. They don't know that in Canada we have up to 60% of our patients that do not reach the goals. So, I think in the US it's about the same thing, so we really need to reach those goals, especially for the patients that may have an insurance rising price.

Dr. Brown:

Yeah. So, I mean, this is one of those things where these are the hardest patients to treat; you're starting out with LDLs 190, 200, 230, and sometimes maximum statin plus ezetimibe you still don't get there, and now we're adding PCSK9's, and in this country it's a little bit of an adventure to try and get those approved, even for the FH patients.

Dr. St. Pierre:

It's the same thing. I mean, it's always a matter of how much time you will spend on the phone, you know? Because with my experience so far with PCSK9 inhibitors, I have a whole bunch of patients that are using this medication because I see also adults. So those patients they are reimbursed if you spend some time over the phone to explain the **importancy(sic)** of reaching the goals for those patients.

Dr. Brown:

If you're just tuning in, you're listening to ReachMD, I'm Dr. Alan Brown and I'm speaking with Dr. Julie St. Pierre who's a professor of pediatrics at Sherbrooke University in Canada and has a special interest in lipid disorders, particularly familial hypercholesterolemia.

So, let's talk a little bit about if you had your druthers, I see that you're working with the Heart Association and other organizations, we kind of brought up the statin safety issue and you pointed out that there's been several studies over 8 years old that showed that the kids do well. In your wildest dreams, with such a high population of FH, what would be your approach to the pediatric population? And you pointed out the same issue that we have, that trying to teach doctors, how do you reach them all? And sometimes the patients drive the screening because they come to you and they're worried about their family. Should we be going through healthcare professionals, or should we be on a public campaign?

Dr. St. Pierre:

I think we should be on a public campaign, and I think that universal screening should be done before entering school because since 2 years old, you can make a difference. You can reduce fat from milk that parents are giving to their children, and also work on the diet. So I think, in my wildest dreams, I would love to have universal screening before entering school. And the other thing is that we are entering, with social medias, a new area of how to reach our doctors and keep them informed and, actually, also the patients are getting more educated on the disease because of that phenomena. So I think we need to have campaigns over Twitter, over LinkedIn, over also Facebook, to reach all our doctors and to educate them on how to at least identify those patients and know the cutoff values of LDL cholesterol that they should suspect a genetic disease under this value.

Dr. Brown:

So, you did mention that, of course, we have the FH Foundation, which is a patient-driven organization and once I see a patient with FH, I encourage them to join the FH Foundation. Is there something similar in Canada once you see a patient that you can steer them to that's sort of a patient focus?

Dr. St. Pierre:

Not yet, and I think you are very lucky to have this foundation in the US. And if we compare with other disease, cystic fibrosis has a similar approach in the US and it's very interesting because the foundation in cystic fibrosis is working very close to doctors and researchers; actually, they are invited to the annual meeting. So, I think that would be interesting to develop, especially at the AHRD

NLA, a special activity with the FH Foundation to bring this collaboration more, and I think that seeing those patients and the passion that they have to raise funds and to support each other, it gives also a lot of inspiration to doctors to find those patients and to do some prevention.

Dr. Brown:

I think that's a great idea. I can tell you, the NLA would probably be very interested and I have no doubts the FH Foundation would be thrilled to expand to the Canadian population.

Dr. St. Pierre:

I'm sure.

Dr. Brown:

We could certainly reach a lot more patients in need, so that's something that I would challenge you through your associations...

Dr. St. Pierre:

Actually, the president, she came 2 years ago in Canada. Just before we published our Canadian guidelines, we asked her point of view and it was important for us, as a panel of authors, to know exactly what they were experiencing with this foundation and in the US. So, one of our recommendations in the guidelines is to be closer to our patients and to bring such an association in Canada.

Dr. Brown:

Well, thank you so much. I wish we had more time, but I really appreciate your insights.

Dr. St. Pierre:

It was my great pleasure.

Dr. Brown:

And I appreciate your involvement in the NLA, I think we can learn a lot from you because we have the same issues. We don't quite have the same incidence here, but it's still an unbelievably high incidence and despite being the most common inherited metabolic disorder, it's one of the least diagnosed.

Dr. St. Pierre:

Yeah.

Dr. Brown:

And that's a source of frustration even on this side of the border.

I'm Dr. Alan Brown and you've been listening to Lipid Luminations, sponsored by the National Lipid Association on ReachMD. Please visit ReachMD.com/lipids where you can listen to this podcast, as well as many others in this series, and please make sure to leave your comments when you do so and share those comments with others. We certainly welcome your feedback. Thanks again for listening, and I'm your host, Dr. Alan Brown.