House of Commons
CANADA

Subcommittee on Neurological Disease of the Standing Committee on Health

SMND • NUMBER 006 • 3rd SESSION • 40th PARLIAMENT

EVIDENCE

Tuesday, June 1, 2010

Chair

Mrs. Joy Smith

Subcommittee on Neurological Disease of the Standing Committee on Health

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● (1110)

[*English*]

The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)): Good morning, ladies and gentleman. We're so pleased to have you here today.

I'm sorry we had to change rooms from one level to the other, and it took a little while for everybody to get here and get settled this morning, but we certainly do welcome you on this very important study today.

We have some very astute guests on this particular topic.

Dr. Duncan.

Ms. Kirsty Duncan (Etobicoke North, Lib.): We have the opportunity of hearing from Dr. Zamboni and Dr. Simka on June 15. They're not available—

The Chair: We'll do business at the end and the committee will decide that.

Ms. Kirsty Duncan: Okay, and could I have seven minutes at the end?

The Chair: I'll try to see what the time is. Our witnesses are very important. We will have business time, and you will have time to do that. I'll try to give seven to ten minutes, depending.

Our witnesses today are very important to hear from, Dr. Duncan.

Pursuant to Standing Order 108(2), this is a study on neurological disorders.

We have, from Detroit, Ewart Mark Haacke, director of the MRI Institute for Biomedical Research, McMaster University.

Dr. Haacke, is it?

Dr. Ewart Mark Haacke (Director, MRI Institute for Biomedical Research, McMaster University): Yes, it's Dr. Haacke. I am here. Can you hear me okay?

The Chair: We can hear you very well. Welcome to our committee.

We also have, as an individual, Dr. Sandy McDonald.

Dr. McDonald, welcome back. I'm so glad you could come. I understand you have a powerpoint presentation for us today.

Dr. Sandy McDonald (Medical Doctor, As an Individual): Yes, I have.

The Chair: Very nice, thank you.

Dr. McDonald is a medical doctor in this field.

We have Lianne Webb, and we have Steve Garvie as well. Welcome.

We will begin with five-minute presentations first of all, and I'll extend that a bit to make sure you get everything in that you need to say.

We'll start with Dr. Haacke, please.

Dr. Ewart Mark Haacke: Good morning, and thank you very much for the opportunity to speak with the committee today.

I'm speaking to you today not just as an MR scientist, but also as the founding president of the International Society of Neurovascular Disease, which is in the formation process at the moment. The goal of this society is to promote the research and treatment of chronic cerebro-spinal venous insufficiency.

For the last four years I have been proposing that MS is related to the small veins in the brain, and I was invited by Paolo Zamboni to present my independent work at his workshop in Bologna last September. Since Zamboni first presented the CCSVI hypothesis, more than 1,000 people have been imaged and more than 500 MS patients have been operated on.

Many of these people show no obvious effects from the surgery, but many people do. Some of them recover their energy, their continence, and their motor capabilities. These are by themselves impressive. The question is how many cases are enough to draw the attention of this issue to the professional societies, such as the neurologists, the Canadian government, and other places?

The wait-and-see attitude of the neurological community, in my opinion, is simply wrong. The evidence for venous vascular abnormalities in MS patients is now overwhelming. The main goal at this time is not whether we should get funding to continue to pursue investigation of this point, but rather that we need funding to sub-categorize the different sources of CCSVI, as shown in part on the five slides I sent to Dr. McDonald. I hope he has received those.

To design a double-blinded study, we need to know how to classify these lesions before we can understand why some people might recover better from surgery than others. To get this information we must collect data in hundreds, if not thousands, of cases. Patients need to know the lesion content, iron content, and the vascular status in their brain, neck, and spine before they have their surgery in order to monitor how things change after their surgery.

The questions of the highest import are whether the patient stabilizes or not, whether the patient gets better, and whether the lesions and abnormalities tend to subside.

If it's possible to show the few slides I have, this would be an appropriate moment to do so. If that's not possible, I will just continue.

Is Sandy McDonald able to show those slides?

The Chair: Yes. Dr. McDonald is going to show the slides. Just continue.

Dr. Ewart Mark Haacke: All right, so I will leave that for him to show later.

So again, the question is how many is enough? The answer depends critically on the question. If there are ten sources—

The Chair: Excuse me, Doctor, can I just say something for a moment? Sorry.

I've just been informed that the text is not bilingual, so you're going to have to read all of it into the record. Okay?

Dr. Ewart Mark Haacke: That's okay. I am reading it verbatim here, directly from the text.

The Chair: Thank you. I just wanted to make sure you had everything on record.

Excuse me, Doctor. I have to interrupt you, because one of the committee members is raising his hand. I know it's hard when you're on video conference. If you'll just bear with me, I have to recognize Mr. Malo.

[*Translation*]

Mr. Luc Malo (Verchères—Les Patriotes, BQ): Madam Chair, I am very sorry for the witness. But the rules of procedure are clear. The documents presented to the committee must be in French and English. If that's not the case, I ask that you do not present them at all, as per the routine motions adopted by the committee.

[*English*]

The Chair: Unfortunately, Doctor, because of the rules of procedure in committee, everything does have to be bilingually presented. That's why at the beginning I asked you to read everything into the record. Mr. Malo, one of our committee members, has voiced an objection to the presentation being visually in front of us without the French translation.

Is there a way you could show the pictures as you read everything without showing the text, Doctor?

Dr. Ewart Mark Haacke: Yes.

The Chair: That is bilingual, so that's okay. As long as it's bilingual, we can see it.

So continue.

[*Translation*]

Mr. Luc Malo: No, I am sorry, it is not bilingual.

[*English*]

The Chair: Mr. Malo, are you happy with that?

[*Translation*]

Mr. Luc Malo: Madam Chair, I am just telling you that it is not bilingual. I would like to remind you that some colleagues from your party have already filed a number of complaints when some of my colleagues accepted this type of presentation in English only. I would just like it to be clear that witnesses must present bilingual documents.

● (1115)

[*English*]

The Chair: All right.

Go ahead, Doctor.

Dr. Ewart Mark Haacke: Thank you.

I'm sorry. If my French were a little better I would try to read this in French for you.

[*Translation*]

Mr. Luc Malo: That's not what I am asking. You can speak in the language of your choice. Routine motions simply state that all documents that are presented to the committee must be in both official languages. I am very sorry about this complication. Given that the clerk does a very professional job, she certainly advised you of the procedure when the committee contacted you. I am sorry about that, but these are the routine motions adopted by the committee.

[*English*]

Dr. Ewart Mark Haacke: I understand.

Am I allowed to continue to finish reading this?

The Chair: Yes, you are. You're going to speak in English, which is just fine. If you have pictures that we could see without text, that would be helpful. I don't know whether you have that or not, Doctor.

Dr. Ewart Mark Haacke: I do have some images to demonstrate a few of the points. I think it might be more appropriate at this point to finish the text and then go to the pictures, if that's allowed.

The Chair: Mr. Malo?

Yes, Mr. Malo is fine with that.

Dr. Ewart Mark Haacke: In terms of making a commitment toward this concept of collecting as much data as possible, I would recommend that Canada consider creating some centres of excellence in multiple sclerosis. If you had a single centre of excellence dedicated to this, you could collect 4,000 MS cases a year. If you had five of these centres across Canada, you could collect 20,000 such cases a year. That would still take you three years to cover the total population in Canada, but it would be a significant progress.

This could fit within the centres of excellence program in the federal government. Within a month of starting such a program, you would have more than 300 cases for each of these sites, or 1,500 cases from across the country. Conventional funding for such a project takes a year to get started from inception to the beginning of the scanning, and no site that I know of in Canada or the United States would be prepared to collect the numbers that I have just mentioned to you. Their research will be ten times more expensive and ten times less the number of people that I have just quoted to you here, using conventional funding mechanisms. The approach I have proposed for you would be 100 times more efficient and cost-effective.

The current wait-and-see attitude to treat people is really something that is coming about by treating people as numbers and not as suffering individuals. This is not just a scientific issue; it is a moral issue. It is akin to watching someone drown while you are testing a new flotation device, while all previous ones only sink several hours later. Perhaps this device will not work perfectly at the beginning either, but if it helps keep people afloat rather than watch them drown, then this testing should be done to save someone's life.

Are double-blinded studies, then, the testing that should be done, as claimed by many people, to save someone's life? These double-blinded studies in fact have their own weaknesses associated with them. I will give you an example of this. There is an operation called vertebroplasty that's performed on 200,000 people a year throughout the world. There are two recent studies that have done 100 cases per study and have claimed they did not find an effect. However, according to the surgeons who performed this operation, they did not use the same criteria we would use when choosing a patient for surgery. Still, the vertebroplasty surgery continues today on a daily basis.

I think that demonstrates to you that if the scientists cannot carefully design the double-blinded study with the right criteria after years of following this process, who is to say that the naysayers today will design the right study for the MS population? We don't need to wait to get strong data to show, first, what types of abnormalities are present, and second, to begin following patients immediately. I would say that we should allow patients to have their data retrospectively reviewed, even if they follow a clinical route where data is not usually used for research. In fact, a retrospective analysis of clinical data is allowed when appropriately presented to human studies approval committees.

To date, I have reviewed, coincidentally, 65 cases—the same number as in Zamboni's pioneering study. I have seen a wide variety of venous abnormalities. Questions arise about the total cardiac input to the brain, about the arterial and venous flow patterns, about the structural changes in the veins, and about other issues related to valves and septums and other abnormalities. The imaging methods that we use today are ultrasound, MR imaging, and the gold standard is angiography itself, where the clinician, such as Sandy McDonald, goes in and actually evaluates what is present in the person's vessels.

All these need to be used as an important—

● (1120)

The Chair: Doctor, I'm sorry, can you wrap up? Your time is way over right now. Thank you.

Dr. Ewart Mark Haacke: I'm sorry. I am almost done.

We're at a crossroads today, where I think we need to combine the clinical and research components associated with the research that is going on. In order to overcome the current inertia and move forward in this direction, I think it is extremely important that the Canadian government look at what has been acquired today and consider imaging MS patients and treating MS patients on a compassionate basis.

Thank you very much.

The Chair: Thank you so much.

We'll now go to Dr. Sandy McDonald. Five minutes please, Dr. McDonald.

Dr. Sandy McDonald: Madam Chair, members of the committee, thank you very much for having me back. I really appreciate the opportunity.

I would like to point out that Rebecca Cooney is back with us today, and this time she walked in without a wheelchair. She had her venoplasty done in Albany, in the United States, a little over a week ago, and she's doing just great.

[*Applause*]

Dr. Sandy McDonald: My goal today is to actually show you images of jugular veins in people who have CCSVI. The abnormalities that we see are real. You don't need to be a physician to see them. Correction sometimes makes a difference in the lifestyle of these people. I believe the problem they have is easily treatable, safely treatable, treatable at low cost and at low risk to the patient. I don't believe that people should be forced, as Rebecca Cooney was, to travel to the United States, Poland, or anywhere else in the world to have it done at significant expense, when they can have it done at home at much less cost.

I'd like to show you some images we made in Barrie of two patients who have waived their rights to patient confidentiality. They are Lianne and Steven. We're going to show you the images. This takes a minute to load, and I apologize for that. The other ones have a little bit of English on them, and these have nothing on them.

This was the venogram that was done in Barrie on Lianne's left neck vein. As soon as it's loaded, I'll show you. I also have images of Steve Garvie, and these images are equally as dramatic. This is dye being injected into the left internal jugular vein. At the bottom portion, where the catheter takes critical angle from going up in the chest in this direction, the left internal jugular vein meets the brachiocephalic vein. At that point, flow is abnormal compared to what one normally sees. At that point we put a balloon inside the vessel, and we stretch up the vessel with the balloon. Once we've done that you get a different image, and it looks a bit like this.

The net effect is we can change the function of the vein. This is going to be the appearance of the azygos vein, which is a different vein inside the chest. What it does is it functionally returns the vein from being a very abnormal structure to being a normal structure.

This is the actual procedure being done. It's a balloon inside the junction of where the vessel is abnormal. This balloon is dilated to 10 millimetres. We subsequently dilated the vein to 14 millimetres.

What you need to understand is the volume of blood going through the vein. This looks like it's a little bit bigger than it was before. Before, if you assume the vein was measured at 2 millimetres, then if we dilate it to 10 millimetres, we have 25 times as much flow in a 10-millimetre vein as we do in a 2-millimetre vein. That's simply math. The net effect is, this was done, and she'll speak to her results herself.

We're just going to put up Mr. Garvie's as well, and it will take a second to load. I must apologize for that, because the other one has some English on it, and we don't want to offend anyone.

● (1125)

The results are actually going to speak for themselves. I think Lianne's results will certainly speak for themselves.

Some people have actually expressed some angst or some fear about having the procedure done. I think if the question were asked of me, if I would have the procedure done and if I have significant confidence in it being done, I would defer that to my interventional radiologist, Chris Guest, who spoke on *W5*. On *W5* he was asked that very specific question. His answer was in essence that the procedure is done at very low risk, and he would have no qualms himself about having the procedure done. That comes from the guy who actually does the procedure. I don't do the procedure; it's done by an interventional radiologist.

I'd really like to take time to show you the images of Mr. Garvie, because the images of Mr. Garvie are even more dramatic than the images of Lianne.

The Chair: As long as the committee understands that your questioning time will be cut down. I just want to make sure. We really want to see the images, so I'm going to say show the images and I will have to watch the time with the questions. It's very interesting. Thank you, Doctor.

Dr. Sandy McDonald: Would it be possible to move and let Lianne give her testimony while I pull up the images on Steven? That would save some time.

The Chair: Absolutely.

Ms. Lianne Webb (As an Individual): Thank you.

My name is Lianne Webb. I'm 48 years old and I live in Hillsdale, Ontario.

In my mid-twenties I began experiencing severe migraine headaches, and by August 1991 I began having very unusual symptoms. I basically lost all control of my right arm and leg. This was accompanied by great fatigue, and after several tests and months of wondering what was happening to me, I was diagnosed with MS in May 1992. That was18 years ago.

MS affects a patient's life and the lives of our family and friends in so many ways, so many profound ways. By 2009, after 18 years of living with this disease, the daily episodes and fatigue, I was naturally intrigued by the news coming from Dr. Zamboni in Italy. I wanted to know if I had a venous insufficiency.

Dr. McDonald diagnosed that I did, and you have seen the images of my jugulars. Unquestionably I did. Naturally I wanted to have the blockage flow corrected, and I wanted this correction even though Dr. McDonald clearly told me that he would be treating my vascular problem and not my MS. Dr. McDonald treated my CCSVI with balloon angioplasty on February 11 of this year. It was such a simple, painless procedure and it was only a few hours—and that included recovery time.

You've seen from Dr. McDonald's images that my unquestionable venous abnormality has been corrected. Dr. McDonald warned that me that this treatment or procedure could have no effect on my MS.

The fact is my MS is much easier to handle now. I have lived through a marked improvement. Some of this improvement I felt right away. The fatigue is gone. I have not had an attack or episode since the treatment, and so far that's four and a half months of true bliss.

Before the procedure I was taking my medication but I was still having attacks and episodes. Since the treatment I have not taken any medication. I stopped this on my own, since I was having no further symptoms. No one recommended that I stop.

I'm able to stay awake in the evenings past 7 p.m. I am living again.

In addition to working full-time, I go golfing two to three times a week, and I walk the course; I don't take a cart. I am enjoying one of my lifetime passions, horseback riding, at least twice a week, and I'm actually looking to buy my own horse. I'm able to go for bike rides and walks with my family after work now that I have the energy to do so. It's hard just to sit and relax. I want to do and try so many things now, whereas before I was just way too exhausted to even think about it.

I can't imagine asking anyone to simply put up with the blockage I had. I ask that this committee do everything possible to remove all possible obstacles for all Canadian patients diagnosed with CCSVI to receive this treatment.

Thank you.

[*Applause*]

● (1130)

The Chair: Now we'll hear from Mr. Garvie.

Mr. Steven Garvie (As an Individual): My name is Steve Garvie. I'm 53 years old. I was diagnosed by Dr. Paul O'Connor, head of the MS Clinic in Toronto, at St. Mike's Hospital. He diagnosed me with secondary progressive MS. This was approximately ten years ago.

Before the procedure on January 29, 2010, I was in SCAPD housing. That's government-funded housing where the caregivers come in three times a day. They help me shower. At four o'clock in the afternoon I was so fatigued that I sat in a lift chair. I couldn't move. They came in and cooked my supper. They fed me. They did my dishes. Came back in. They washed me.

People have pride. I had none. My life was taken away from me. These people gave it back. I don't know how you can put a wait on that. I'm a human being.

They helped me shop for groceries. They cleaned my apartment. I'm a self-motivated person. Having these things done for me is worse than a jail sentence. I was unable to walk without the use of an aid, a rollator or an electric wheelchair. As a man, that part of me was no more. I couldn't share my love with the person I loved. That was taken away from me by MS. It made me totally dysfunctional.

I took anti-depressants. That helped me get through my life. I don't have this thought written down, but I'll tell you right now I tried to commit suicide twice in the early stages. It wasn't selfish—I was trying to make sure my girls, my three daughters, didn't have to go through this. Pride does that to people, and a lot of people die every year because of this. The time is so important.

I've been six months fixed. In that six months I'd like to know how many people have died needlessly, how many people have had more disability because of what happened with the MS. More disabled, more disabled, more disabled. There's no need. None.

I saw the *W5* program online. I didn't see it originally. Someone told me about it. I printed off the protocols. I went to my family doctor, Dr. Kiss, out of Barrie, Ontario. We discussed the blocked Doppler that they were talking about. I wanted to find out if I had that venous insufficiency. She was good enough to book me immediately to Dr. McDonald's clinic, where they did the Doppler scan. There's no pain involved with that. A little goop on your neck and they can show you what's what along the way. And they know exactly what they're doing.

They were good enough to book me an appointment with Dr. McDonald. I went and saw him. My jugulars were unquestionably blocked. I'm sorry for calling it an operation; it's not. It's a 45-minute procedure. Painless. Life-giving. It gave me back what I lost, and I can't thank them enough for that. I really can't. They're my heroes. I think you should let them be heroes for everybody else.

My CCSVI was treated with a balloon angioplasty, a procedure that's done every day of the week. No tests necessary.

● (1135)

My left hand came back to me on the OR table. It was numb; I couldn't use it. I shook the nurse's hand. My head was turned when they did this. I said, “What have you done to me? You've done something.”

Dr. Kiss said, “Why?”

I said, “My hand works. I can lift my left leg.”

I couldn't believe it. I went into this procedure with the thought of stopping progression. I'd learned to deal with the other things. I got my mind straight on the suicide. I didn't feel that I was worth a whole lot, not with what I was going through. I was getting worse every day, every month, every minute. Secondary progressive MS does that to you, and so does primary. You don't get better, you get worse, and that's all you have to look forward to.

They say that this does not help people with secondary progressive MS. I beg to differ. Please look at the evidence. I'm right here.

I have no need for the care any more. I left that apartment three months ago. I wash myself. I cook my own dinner. I can live my life. The housing is gone. I'll leave that apartment at the end of July. I left it three months ago, and I haven't been there except to move stuff.

Dr. McDonald called me and asked me to come here, along with you—

The Chair: Mr. Garvie, I'm not trying to be rude, but I've given you two extra minutes. What I'm trying to do is get presentations that are so important, and yours is very compelling. Could you please be so kind as to wrap it up now?

Mr. Steven Garvie: I sure can.

Please take the obstacles out of the way. Everybody deserves to have a life, and with a simple angioplasty, that can be done.

I thank you very much for hearing me.

[*Applause*]

The Chair: If there are other things you'd like to say, when we go into the rounds of questions, please do it. Even though you're asked a question, if there's another thought that you have, please include it in that question.

We're just thrilled to have you here today. It is a subcommittee. We've added it on. Every person on this committee is your friend. This is why we're studying neurological disorders and learning more about them.

I will begin with a very strict five-minute round, starting with Dr. Duncan. Dr. Duncan, please.

● (1140)

Ms. Kirsty Duncan: Thank you, Madam Chair.

Thank you for your science, for your courage for doing this work.

To Lianne and Steve Garvie, thank you so much for having the courage to come and share your stories. They are overwhelming.

Before I ask my questions, I want to read a letter I got last night. It reads:

> I am a Canadian medical doctor who's been practising since 1969. I also have had MS since 1990 and just got back from Poland, where I had balloon angioplasty to a stenotic right internal jugular vein. I have noticed improvements in several areas... I also met many Canadians in Ketowice who had been treated with positive results. They were ecstatic and so grateful for an improvement to their quality of life. Two-thirds of all the people treated there are Canadians. ... There are 2,000 people on their waiting list. The argument in Canada by neurologists is that we need more studies before we can do this in Canada. The only way you do a study is by treating people and a follow-up. Neurologists should have no input into this aspect of treating MS. They are not vascular surgeons.

He goes on to talk about what it costs per month. He says:

> Improvement of quality of life has no price tag. We will only know if the positive changes resulting from this endovascular surgery will last after months and years of follow-up. There is no problem for paying for angioplasty for coronary artery stenosis or surgery for carotid artery stenosis. Why the discrimination to venous stenosis?

His last line is:

> I hope you fight for the rights of Canadians to get treatment in Canada.

Dr. McDonald, how easy is it to correct these anomalies?

Dr. Sandy McDonald: In most cases the procedure itself is fairly easy. To say it's easy for the inexperienced hand would be foolish. For a very experienced intervention radiologist the angioplasty, as I showed on Mr. Garvie, was done very simply, very quickly, and very safely, with very low risk to the patient.

Ms. Kirsty Duncan: Thank you.

How dangerous is the diagnosis? Does the imaging present any risk?

Dr. Sandy McDonald: To the best of my knowledge, the imaging presents no risk whatsoever. It's done with ultrasound technique, and if it's done by a well-trained technician the results are significantly better than if it's done by someone who hasn't been trained in Zamboni's actual technique.

We started doing them without being trained by Zamboni, and some people with MS had negative studies. We thought that not everybody with MS was going to have CCSVI. I don't know if everybody with MS has CCSVI or not, but when we restudied the patients we had initially done prior to our Zamboni training, they all came back with criteria that met Zamboni's diagnosis of CCSVI after we had been properly trained by Zamboni.

Ms. Kirsty Duncan: Thank you.

Do you have any ethical dilemma in deciding to treat MS patients with CCSVI?

Dr. Sandy McDonald: I would answer that in a different way. I think I have an ethical dilemma as a physician not to treat people with CCSVI. I think there is good anecdotal evidence to suggest that people with CCSVI do well with treatment. Again, as a vascular surgeon I do not treat MS; I treat CCSVI.

Ms. Kirsty Duncan: To Lianne and Steve, thank you.

I know you had your angioplasty done in Barrie. Is that hospital still doing this? I'd like to ask both of you for your answers. Do you know why or why not?

Ms. Lianne Webb: I can't even imagine why not. It's criminal that we're not still doing it. I don't know why we're not doing it.

Ms. Kirsty Duncan: Steve.

Mr. Steven Garvie: I have the same answer. I have no idea why not. It's a simple, painless way of getting on with your life.

● (1145)

Ms. Kirsty Duncan: Thank you all.

I'm going to finish again with the line from the doctor who had the treatment: “I hope you fight for the rights of Canadians to get treatment in Canada”.

Thank you all.

The Chair: Thank you, Dr. Duncan.

We'll now go to Mr. Malo.

[*Translation*]

Mr. Luc Malo: Thank you, Madam Chair.

I would like to thank all witnesses for coming to meet with us this morning. Mr. Garvie and Ms. Webb, I especially thank you for your very personal testimony. I know it is not easy to testify like that. Your lives are actually being discussed before us, before a parliamentary committee. I sincerely thank you for doing that. It is always very enlightening.

I will speak to you, Dr. Haacke...

[*English*]

Dr. Ewart Mark Haacke: Yes.

[*Translation*]

Mr. Luc Malo: During your presentation, you told us that, in your opinion, the only thing left to do was to sub-categorize the CCSVI patients. Could you expand a little more on that? In your view, what needs to be done and how long could a surgery like that take? Finally, why is it important to sub-categorize the patients?

[*English*]

Dr. Ewart Mark Haacke: Thank you.

I think you need to do the ultrasound imaging that Sandy has talked about, but you need to do the MR imagining as well. We have discovered that there are many different sources for CCSVI, and not just narrowed vessels. Sometimes there are bad valves, and sometimes extra material called septum inside the vessels causes a problem. In other cases bones have grown too big and have compressed the vessels. There are many things that can cause CCSVI, so to understand why this treatment might work for some people and not for others one needs to know what the problem is. In order to do that you have to get experience in imaging people.

This can be accomplished at almost any MR site or ultrasound site in Canada. My recommendation is to always do both. It gives you more information. Sometimes we see things better on MR than ultrasound, and sometimes it's the other way around. That can be done in Canada today. There are protocols out from Zamboni for ultrasound and from our group for MR that make this possible. So in order to really follow the surgical results and do a good double-blind study, you need to have an understanding of what the source itself is.

[*Translation*]

Mr. Luc Malo: Have you already done studies to that effect? I know you did a presentation. Was that based on a study you already did?

[*English*]

Dr. Ewart Mark Haacke: That's an interesting point. Unfortunately, since most places have been stopped—that's true in both Canada and the United States—the experience we have is related to reviewing data that has been sent to us from around the world: from Australia, Germany, China, and many places in Canada. So this does come from direct experience of reviewing patients' data. In some cases these patients have been operated on by people such as Dr. McDonald and others. We do find that what we see in imaging is often corroborated by the surgical results.

I think the critical issue for Canada right now is to wrap your arms around how you're going to implement this in your system so that a conventional hospital, whether it's a community hospital or a research hospital, is allowed to collect the extra scans that are done on most MS patients anyway. Almost all MS patients get an MR scan. By adding an extra 30 or 40 minutes to that, you can get the necessary information to tell if that patient has a problem. So why wouldn't you do that when you have the opportunity? I think the technology is there for you to assess this very shortly.

[*Translation*]

Mr. Luc Malo: What is the next step in your efforts to shed light on that?

[*English*]

Dr. Ewart Mark Haacke: One thing we're trying to do at the moment, since it's tough for one site to collect a lot of data, is collaborate with sites across Canada—for example, with Saskatoon. I'm meeting with Quebec City people a week from now, and hopefully with other groups. We'll combine all of their data, so instead of having 50 patients from each site in a few months, we can do 1,000 patients in a few months by bringing this data together. Otherwise, the current rate of research, in both the U.S. and Canada, is so slow under conventional granting circumstances that it would be years before this data could be collected. But with a simple collaborative effort we can do in months what would otherwise take years to create a database.

● (1150)

The Chair: Thank you.

We'll now go to Ms. Hughes.

[*Translation*]

Mrs. Carol Hughes (Algoma—Manitoulin—Kapuskasing, NDP): Thank you very much for your presentations. I would like to thank Mr. McDonald. After suggesting to have witnesses who have undergone that surgery, I am very proud and happy that arrangements could be made to make it happen.

[*English*]

I actually spoke to a doctor about why there would be a need for more research on this. Maybe you can comment on this. The doctor from Manitoulin Island basically indicated that years ago there was a procedure for strokes called carotid endarterectomy. I'm assuming you know what the procedure is.

Dr. Sandy McDonald: Yes.

Mrs. Carol Hughes: It used to be done automatically as soon as someone had a stroke. But stats eventually showed that there were worse outcomes than if they had taken an aspirin a day. Basically it was considered to be a bread-and-butter operation at the time. It is now only done when there is greater than 70% narrowing.

The other procedure she mentioned with regard to the research was on the tonsils. The perceived wisdom years ago was that half of those who came through the doctor's office would need to have their tonsils out. A study was done where if a group was sent to see a pediatrician, 50% would need to get them out. Then they would send the other 50% to another doctor, or the same 50%, and there would be second and third opinions. They would select different groups saying they needed them out.

I'm just wondering if you can put some perspective on this procedure and the fact that you don't feel there needs to be as much research, or we need to go into the procedure right away, given the fact that these procedures were thought to be safe, and then as they followed up they realized that people were having more strokes or were dying earlier because of the procedures.

Dr. Sandy McDonald: If I could go back to the studies that were done, in the early 1990s carotid endarterectomy was a common procedure in Canada. When we got into the mid-1990s, the neurology group thought the carotid did not need to be fixed surgically and it could be controlled by giving drugs. They subsequently did a trial called the NASCE trial—the North American symptomatic carotid endarterectomy trial—and they looked at several thousand patients.They were looking at the outcome of patients treated with carotid endarterectomy versus the outcome of patients treated with drugs. The trial was abandoned after it had gone on for several months because the patients who had carotid endarterectomy did significantly better statistically than patients who were treated with drugs.

You're right, the trial looked at a 70% stenosis, but more studies have been done since then, specifically the ACAS trial—asymptomatic carotid atherosclerosis study—and it suggested that there is significant benefit, though not as significant as the other study, in doing carotid endarterectomy on patients who are asymptomatic. More studies have been done, and there is good data now that supports doing a carotid endarterectomy on patients with greater than a 50% stenosis. That's current data.

To answer your other question, as to where we should go at this point, I agree with Mark Haacke totally. The amount of time it's going to take to get the answers to the question with each individual centre doing 40 or 50 studies a year will take a very long time, and will be done at the significant cost of patient lives. If we collaborate and put all the data together, the question will be answered fairly quickly.

Part of the problem is the cost of doing the studies. Patients need to be treated now because patients are dying. You can gain a lot of information by treating people now, putting them in a registry, having them as part of an ongoing, open-ended study in collecting the data. If you do that, you achieve two goals. You achieve the scientific goal, which is actually generating the science on it, determining who should be treated, and so on, as you collect the data. At the same time, you can treat people with significant disease now. If they have significant CCSVIs demonstrated on an MRV and on a duplex scan, then they should be treated.

[*Applause*]

● (1155)

The Chair: We'll now go to Mr. Brown.

Mr. Patrick Brown (Barrie, CPC): Thank you, Madam Chair.

Let me say at the outset that it is with enormous pleasure that we have Sandy McDonald here again today. I take great pride, coming from the city of Barrie, that we have such a renowned vascular surgeon. Many people in our community refer to you as a local saint. As people around Canada are hearing about what you're doing, more and more people are coming to that conclusion.

I wanted to touch on a few of the things that have been mentioned today, one of them being obstacles to this treatment. I think it's important that we dissect them, so that it's very clear when this committee does a report that we can highlight what those obstacles are and what needs to be rectified.

The first obstacle that is mentioned is hospitals. The hospital you're at no longer permits you to provide this treatment. What is the status of other hospitals in Canada?

Dr. Sandy McDonald: I'm not aware of any hospital in Canada doing the procedure at this time.

Mr. Patrick Brown: And initially they were allowing it—turning a blind eye?

Dr. Sandy McDonald: I wouldn't say a blind eye. I think there has been an incredible amount of pressure generated within the system that says you have to do a controlled double-blind study to see if it's effective, just as you would for a new drug coming out.

The difference is it's not a new drug. It's not a new procedure. It's not new anything. Hundreds of thousands of angioplasties have been done since Gruentzig introduced the procedure in 1984.

Mr. Patrick Brown: Hospitals are administered provincially. Do you think there's been a directive from the provincial Ministry of Health not to allow this? Or are these locally based decisions? Is it a coincidence that every hospital in Ontario or around Canada—

Dr. Sandy McDonald: Your guess is as good as mine.

Mr. Patrick Brown: My guess is that there has probably been a directive to not allow it, which is obviously disconcerting for those who want to have this treatment.

As for the other thing mentioned, I imagine OHIP plays a role in this here in Ontario. Do we know what OHIP's position is on this treatment?

Dr. Sandy McDonald: No, we do not.

Mr. Patrick Brown: Have there been any inquiries to find out, or are we just not getting a response yet?

Dr. Sandy McDonald: I spent a morning, I think it was a week ago, at the Ministry of Health trying to get some of the information you've requested, and we're working on getting the answers to the question. I don't have the answers yet.

Mr. Patrick Brown: Those answers are going to be critical as we look at how to sort this out. Obviously it's very important that we have federal action on the research component, but in terms of allowing this treatment, obviously we need to make sure that the appropriate provincial bodies act quickly to allow work such as yours.

The other thing I wanted to get your feedback on is the Multiple Sclerosis Society of Canada. When we had them on the Hill before, I think they had more of a wait-and-see approach toward this treatment. Why do you think that is, to play devil's advocate? Why do you think there's more caution coming from the MS Society?

Dr. Sandy McDonald: Again, that's purely speculative. I'm a vascular surgeon. I'm trained to treat venous and arterial anomalies. When I see a venous or arterial anomaly that I think I can treat with relative ease at very low risk, at very low cost, I think I should probably be allowed to treat it.

It comes down to what I said before. It's a bit like waiting for the electrical permit to fix a plumbing problem. It makes no sense to me.

Mr. Patrick Brown: I know we sort of left out Dr. Haacke. Do you have any comments on what obstacles you believe need to be removed within the health system in Canada?

Dr. Ewart Mark Haacke: Thank you.

Yes, I think the problem espoused by Dr. McDonald, the comparison between drug studies to treat the stroke versus a direct correction and arterectomy, is a very good analogy to what is happening today.

Double-blinded studies are critical, but there is a very nice paper that was just published on when randomized trials are necessary. Once you have enough evidence to proceed with this, you don't need tens of thousands of cases in order to get started.

So I think the problem here is that someone has to step up to the plate with OHIP and with the other provincial governments to create a province-wide, if not Canadian-wide, plan on how to collect the data that goes with the surgery, because you're going to get constant resistance by the neurologists in this if you don't have some form of research plan associated with it.

I think that having two arms of this, a clinical arm and a research arm running in parallel, is the way you need to do this within the provinces. I don't think the provinces should be stopping the surgery, but they should have some form of monitoring of the surgery that allows the data to be retrospectively analyzed, so that you can follow it on a month-by-month basis and then you can make better determinations as you move forward with this surgery.

But I do agree with Dr. McDonald. This is a very experienced area, so there's really no reason not to be doing that surgery on severe cases.

● (1200)

The Chair: We've run out of time.

Do you have one more comment, Mr. Brown?

Mr. Patrick Brown: Just briefly, before you adjourn, I think what Kirsty Duncan mentioned at the beginning of the meeting is very important. If Dr. Zamboni is available to see us on June 15, I think it's important to switch the dates. We could easily have ALS come on June 8. I just don't want to miss that.

The Chair: I've already taken care of that. We found out he's available on the 15th. So if that's agreeable, we'll bring him in on the 15th. He's not available on the eighth, so we'll bring him in on the 15th.

Does the committee agree to that? Yes.

Thank you so much for meeting with us today. We're very, very pleased that you could be here. I'm so sorry that we have run out of time. Our time is up. We have other things to go to right now.

Hon. Carolyn Bennett (St. Paul's, Lib.): Dr. Duncan has a comment.

The Chair: Very briefly, Dr. Duncan, one minute.

Ms. Kirsty Duncan: Thank you, Madam Chair.

I would like to say to the committee that I will put motions forward on June 15. I had hoped to do it today, but we have run out of time.

The Chair: We've run out of time.

Thank you very much.

The committee is dismissed.

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