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**Official Report
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Tuesday 6 October 2015

**Journal
des débats
(Hansard)**

Mardi 6 octobre 2015

**Standing Committee on
Government Agencies**

Intended appointments

**Comité permanent des
organismes gouvernementaux**

Nominations prévues

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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

STANDING COMMITTEE ON
GOVERNMENT AGENCIESCOMITÉ PERMANENT DES
ORGANISMES GOUVERNEMENTAUX

Tuesday 6 October 2015

Mardi 6 octobre 2015

The committee met at 0901 in committee room 2.

SUBCOMMITTEE REPORT

The Chair (Mr. John Fraser): Good morning, everyone. Welcome back to our weekly meeting. We have one intended appointee today, but before we begin our intended appointments review, our first order of business is the subcommittee report dated Thursday, October 1. Can I have someone move it, please? Mr. Pettapiece.

Mr. Randy Pettapiece: I move the adoption of the subcommittee report on intended appointments dated Thursday, October 1, 2015.

The Chair (Mr. John Fraser): Thank you very much, Mr. Pettapiece. Any discussion? All those in favour? Opposed? Carried.

INTENDED APPOINTMENTS

MS. MARISA PIATTELLI

Review of intended appointment, selected by official opposition party: Marisa Piattelli, intended appointee as member, Committee to Evaluate Drugs.

The Chair (Mr. John Fraser): As I said, we have one intended appointee this morning. Our first and only intended appointee is Marisa Piattelli, nominated as member of the Committee to Evaluate Drugs. Ms. Piattelli, can you please come forward?

Thank you very much for being here this morning.

Ms. Marisa Piattelli: Thank you.

The Chair (Mr. John Fraser): You will have the opportunity to make a brief opening statement. Any time that you use will be taken from the government's time to ask you questions. Again, thank you very much for being here this morning. The questioning will begin with the government. You may proceed, Ms. Piattelli—10 minutes.

Ms. Marisa Piattelli: Thank you very much. Good morning. My name is Marisa Piattelli. Thank you very much for the opportunity and invitation to appear before you today regarding my potential appointment as the lay or patient member of the Committee to Evaluate Drugs. It's a pleasure to be here and to have the opportunity to talk to you a little bit about my interest and why I put my name forward through the application process for this committee.

You probably have my resumé before you, but to be very brief, I've had the very good fortune to have a varied and successful career in international relations. I spent 22 years in the foreign service as a Canadian diplomat, serving abroad and here on issues related to international relations and trade policy, foreign policy etc.

Most recently, I'm a member of the team at Waterfront Toronto, the organization that's revitalizing the waterfront—one of the largest infrastructure projects in North America. I sit on a number of small and large not-for-profit boards.

While my professional background has helped me to develop a number of important skills and abilities—international trade, investment, infrastructure issues, inter-governmental issues etc.—I really am here today in a personal and volunteer capacity.

The role of the lay member of the committee is to help strengthen the accountability of the work of the committee by providing meaningful public input into the overall drug-funding recommendation process. Because lay members of the committee can't speak to the diverse needs of all Ontario patients, advocacy groups are allowed to submit evidence for new drugs undergoing review. The lay members' responsibility is to present this evidence to the committee when it discusses societal values and patient perspectives.

I feel that I'm uniquely qualified to act as a lay member of this committee for a number of reasons. First of all, not only am I living with a chronic illness, which, by the way, is a requirement of this position, but I have strong knowledge of the health care system. Over the course of the past several years, I have had direct and personal knowledge of the health care system as a user. As a result, I have an acute understanding of the patient perspective, a perspective that I would bring to the committee.

Moreover, as vice-chair of the Women's College Hospital Foundation board of directors, I also understand very well the challenges faced by our health care system and the ever-expanding portion of government expenditures that is represented by health care. I understand the challenge and the need to find innovative, streamlined and more effective solutions to deliver health care. I see that every day at Women's College Hospital.

Just as an aside, one of the reasons I am so proud to be part of that hospital is because of the innovative approach

it takes to delivering health care solutions through research, innovation and education.

It is the first fully ambulatory teaching hospital in Toronto. It's a hospital designed to keep patients out of the hospital. Ambulatory care includes surgeries, treatments and diagnostic procedures that don't require overnight hospitalization. Ambulatory care means greater cost-effectiveness, fewer risks such as infections, and higher patient satisfaction.

I would like to say how very pleased I would be to serve on the Committee to Evaluate Drugs. I believe that I would bring a balanced and value-added element that includes both a patient perspective but also a real understanding of the realities of our health care system.

Moreover, having served on public boards—and I'm accountable currently to a board in my professional life—I believe also that I would bring to the committee some really good experience in good governance, accountability, transparency—all those practices which are absolutely key when you're serving the public and when you're trying to engage the public.

Thank you for the opportunity to speak with you this morning. I'm very happy to take your questions.

The Chair (Mr. John Fraser): Thank you very much, Ms. Piattelli. The government questions: Mr. Rinaldi.

Mr. Lou Rinaldi: Sure. Thank you so much, Ms. Piattelli, and with a good Irish name—

Ms. Marisa Piattelli: I know.

Mr. Lou Rinaldi:—I'm sure we could—anyway, I did go over your resumé, as my colleagues did, and I just want to say that we're grateful that people like you would put your name forward to provide such a function. It has some connections to you personally, which is part of the requirement, but also it touches the lives of so many people in Ontario at their wits' end to find any last hope or any hope there is. So I just want to say that I think you'd make a great member of that group, and we wish you all the best.

Ms. Marisa Piattelli: Thank you very much.

The Chair (Mr. John Fraser): Thank you very much. Now to the official opposition. Mr. Harris.

Mr. Michael Harris: Good morning, Ms. Piattelli. The Committee to Evaluate Drugs obviously has two patient spots, you being the one, and you applied for this position; correct? You did mention your experience as a patient with a chronic disease. I don't know if you want to expand, perhaps, to the committee a bit more on that.

Mr. Lou Rinaldi: Chair, I'm not sure that this committee should dive into personal issues. I think health care issues are really personal. At least to me they are, and I'm not so sure that Ms. Piattelli should be—

The Chair (Mr. John Fraser): Thank you very much, Mr. Rinaldi.

Mr. Michael Harris: The obvious requirement is that that position be a patient, so I think it's appropriate—be it that she qualifies as a patient designate on the Committee to Evaluate Drugs, it's very much apropos.

The Chair (Mr. John Fraser): Mr. Gates has a point of order.

Mr. Wayne Gates: I'm not sure it's a point of order, but I believe—I don't agree with the Liberals very often, but at the end of the day I believe it's not right to ask somebody what their personal medical is. We understand, I believe, as a committee that that's part of the criteria, but we don't have to know what it is. I think we have to take—

Mr. Michael Harris: I think it's important. You don't need to get into the details, but I mean—

The Chair (Mr. John Fraser): Thank you. I'd like to add—you can go forward with your question, but with respect to revealing the personal nature of one's illness, I think we are treading on territory that is personal and private in nature in terms of disclosure. We all know about disclosure of health records, so I would just caution you in that regard.

0910

Mr. Michael Harris: I think it's important, though, for Ontarians, be it that this representative will represent patients across the province, that one of only two spots given to patients on the Committee to Evaluate Drugs has experience dealing with these issues.

The Chair (Mr. John Fraser): I think—

Mr. Lou Rinaldi: Chair, a point of order.

The Chair (Mr. John Fraser): Just one second. Let's just—

Mr. Michael Harris: Let her answer what she's comfortable with, and we'll go from there.

Ms. Marisa Piattelli: Thank you. I will answer by saying that, throughout my illness, I have worked at my current job. It is something that I separate from my professional life, and happily I've been able to do so.

Let me just say the following, because I think I understand where you're coming from: It is personal, but I would like to answer your question in a broader context. That is to say that, over the course of the last three years, any time that you are involved in a potentially life-threatening situation, you really develop an acute awareness of the privilege of living in Toronto and having access to the hospitals that we have here. I think about people in similar situations in rural Ontario or elsewhere that don't have that similar easy access. You become aware of the privilege, of the cost. You become aware of how important it is to try to address the issues of our health care system so that in the future, people—and every day, really—with similar situations continue to have the wonderful access to hospitals that we do have.

But suffice it to say, my medical record is long, and I can assure you that I do fulfill the criteria of living with a chronic illness.

Mr. Michael Harris: You expand on, obviously, the health care system in general. This specifically is a Committee to Evaluate Drugs. So what is your experience, perhaps, or knowledge of, for instance, rare diseases in Ontario?

Ms. Marisa Piattelli: I'm not a medical doctor. This is a lay position. I don't have a wealth of experience in

rare diseases in Ontario. What I can tell you is that I'm conversant in medical technology. Fortunately or unfortunately, you become conversant with doctors in hospitals and drugs. I now follow with much more interest clinical trials and new drugs that come on the market. I understand the phases of clinical trials now, currently being part of one. So I understand phase 1, 2 and 3, and how long it takes to get drugs to market.

I understand intellectual property issues. Way back, 20 years ago, in a foreign affairs bill—

Mr. Michael Harris: Aside from clinical trials and so forth—I mean, again, this is the Committee to Evaluate Drugs. Ontarians are experiencing frustrations when drugs are approved through Health Canada, and they're even covered by OHIP, but they're not having access to these drugs. This is an important committee.

You talk about living in Toronto and accessing health care and the facilities we have, but there's a large amount of Ontarians who suffer from all sorts of chronic diseases who need pharmaceuticals to treat themselves, but the government continues to stand in their way to treat these people. Rare diseases in Ontario—of course, as the science evolves, more and more drugs will come on the market, and more and more people will need access to them.

Overall, again, how do you believe, as a patient, you'll advocate on behalf of those folks who are running into roadblocks accessing the treatments in terms of pharmaceuticals?

Ms. Marisa Piattelli: The mandate of this committee is a very challenging one. My understanding—not being on the committee but having researched it, and having had a long conversation with the chair of the committee, Dr. Grill, who wanted to speak to me in advance of this process—my understanding of the mandate of the committee is that it's a very difficult one. The committee is supposed to evaluate the effectiveness of a drug. It's supposed to review whether it's interchangeable with a generic drug. It's supposed to look at the cost of the drug. It's supposed to keep the patient perspective in mind. And it's supposed to do that through an evidence-based process. That's the mandate of that committee. That is what has interested me about that committee. It's supposed to do exactly what you are suggesting, which is to try to get cost-effective drugs that actually have an impact in changing the quality of life of patients to market, but it also has to keep all those other criteria in mind.

What I'd like to bring to that committee is a filter that makes sure the committee doesn't lose sight of the patient environment. That's what the lay position is responsible for.

The Chair (Mr. John Fraser): Mr. Harris, you have about three minutes left.

Mr. Michael Harris: How do you see, specifically, your role differ from that of the other members on the committee, be it that these two spots are dedicated to patients?

Ms. Marisa Piattelli: The other members of the committee are doctors, they're scientists, they're researchers,

and they're people involved in the pharmaceutical sector. The lay directors are none of those things. They are patients living with chronic disease but also people who are supposed to have a very good knowledge of the health care system.

The lens that I would like to bring is to ensure that as the committee goes through that evidence-based process—technical and scientific and research-based—that the patient perspective is also brought to bear. The more diverse the views, hopefully, the better ultimate decision one gets.

Mr. Michael Harris: Do you know of anyone or have you had any experience with anyone, aside from yourself, who is living with a rare disease, who has had struggles getting the proper treatment in terms of pharmaceuticals covered here in the province?

Ms. Marisa Piattelli: Well, I have followed the life of the drug Avastin because I have colleagues who suffer from diseases—

Mr. Michael Harris: Is it a covered drug under OHIP?

Ms. Marisa Piattelli: I think it is for some uses like bladder and colon cancer; I believe you can use Avastin. I don't believe it's used for other cancers. So I know of that experience. I talk to them, I hear them. As I say, when you're in the system, you just become more sensitive to drugs and clinical trials and all that.

Mr. Michael Harris: I think the final message—

The Chair (Mr. John Fraser): You have about a minute, Mr. Harris.

Mr. Michael Harris: —is the struggle that Ontarians face on a day-to-day basis. We saw young Madi Vanstone come through Queen's Park, who has cystic fibrosis and needed Kalydeco covered—currently, it wasn't. She was having to raise money through bake sales. The government, through a political process, then listed Kalydeco as a drug. We see patients suffering from aHUS come through here—and Soliris; we're seeing Kuvan and PKU. These types of folks are the ones I'm specifically referring to. I ask that you keep the patients who are suffering from those rare diseases in mind when you're on this committee. I think from a patient perspective, that's an important aspect.

Ms. Marisa Piattelli: Thank you.

The Chair (Mr. John Fraser): Mr. Pettapiece, you have 10 seconds.

Mr. Randy Pettapiece: Thanks for coming out today.

The Chair (Mr. John Fraser): Thank you very much, Mr. Pettapiece.

Mr. Gates.

Mr. Wayne Gates: Good morning. How are you?

Ms. Marisa Piattelli: Good morning. Fine.

Mr. Wayne Gates: You mentioned Avastin, and when I took a look at the report, it's probably one of the reasons why we need patients on the committee. In 2009, there was a cap for the funding, where they could only get so many treatments, even though taking the treatments was making them better. Obviously, there was an appeal process that went in, and they came up with that

they're putting the patient at risk. That's why it's important to have patients there. If you can imagine: You're getting better, the drug's working, and it's cut off or it's capped at how much you can use. It doesn't make a lot of sense to me. So to your point on the Avastin, you weren't sure how it worked—that's exactly what transpired on that particular drug.

I think what you bring to the table is what, quite frankly, a lot of us have been talking about for a while. I'm going to give you an example. I don't know if you're aware of Lyme disease or not, but the battle that we're having in my area—although Lyme disease is really going right across the province. But in Niagara, we have a number of cases. They're not finding out—they're saying it's an American Lyme disease, and so we've got some issues around that. I really want you to understand the importance of that particular disease.

0920

We have people in our area who are going to Florida to get treatment. We have three who—surprising to me—are principals in almost the same area who have Lyme disease and who have had their lives turned upside down. They're going to Florida and they're spending hundreds of thousands of dollars. It should be treated right here in Ontario. It's getting worse.

I wanted to raise that issue with you. I wanted to get it on the record. As somebody who understands the system, when they know there's that disease out there, there's got to be a way to get it paid for so it's not financially—having people lose their homes; in some cases now they're losing their families. So I wanted to raise Lyme disease with you.

You also talked about the health care system. When I take a look at my notes—I'd like to thank the research department that helps us out with this kind of stuff—what it looks like to me is, it's really not about patients; it's about cost-effectiveness. It's not about the patient. In a lot of cases, it talks about how much a drug costs, and whether it's going to be covered. I guess what I'm asking you is, what's the price of a person's life when it comes to drugs? I think that's the issue that somebody like yourself, who has gone through—you said you had gone through the system. I guess that's what bothers me the most around drugs. I believe that there's a better way to do it. I think we should expand generic drugs. We don't do that, and I'm not so sure, from what I'm reading on the new trade agreement that we just did, about drugs and what's going to happen there.

I guess I'm asking you, what's your opinion? Do we pay for it, or do we let the person die? That's kind of where we're at on drugs. It's not a nice thing to say, but I believe it's accurate. I know I'm putting you on the spot, but you have to be that voice for us and for those people who have cancer. Somebody has to be a voice for them, to say, "This is wrong."

Ms. Marisa Piattelli: Right. I don't know how to answer that question. I really don't. I suppose every case is different. I suppose a case-by-case approach is probably the way to go. But if you're asking, is there a point

you can identify to tip the scales one way or another, I don't know how to answer that. Anything that I say might seem to be very personal. I would like all patients suffering from acute diseases to have the drug they need to have a wonderful quality of life, period. That would be an ideal situation.

I think this committee is the committee that struggles with the right thing to do, and I can only hope to be a voice—a reasonable voice—for the patient, to advocate for the patient, and to ensure that whatever decision is made keeps the need of that patient right at the centre. I don't know how else to answer that. It's a tough question. I think this is probably what this committee struggles with. I would be so pleased to try to be that voice, because I think it's easy to get caught up in the research and the evidence-based facts. And that's what they're supposed to do, as well. It's that balance.

Mr. Wayne Gates: I guess it is a tough one, but I don't think you can put a price on somebody's life. Unfortunately, we only go this way once, all of us.

Ms. Marisa Piattelli: I agree.

Mr. Wayne Gates: That's kind of where my heart's at. In my job I've seen what some people have gone through on a daily basis, and it's heart-wrenching to watch.

The other point that I want to make is that—you talk about the health care system, and I think one of the things that I'm hoping you can be a voice for too is to get the message out that I'm not so sure that we don't have enough money for health care, but I think that we have to make sure that it's not all going into corporations that are making profits on it at the expense of patients. I think those dollars could be used a lot more, to your point, in research, drugs or patients. So I think, as one of two patients, that's one I'd like you to bring that voice to as well: It shouldn't be all about making money on health care rather than making sure that patients' needs are met. That's kind of why I'm glad they have patients who have gone through it and seen it. You've seen the people in hospital, your friends. You've made new friends in the hospital, obviously, and you've seen the suffering they went through as well.

Ms. Marisa Piattelli: Indeed.

Mr. Wayne Gates: I wish you the best on the committee. You are only one of two people, like my colleague has said. You're going to be very important on the committee, and I wish you nothing but the best. And in the future I wish you nothing but the best of health.

Ms. Marisa Piattelli: Thank you.

Mr. Wayne Gates: Thanks for coming.

Ms. Marisa Piattelli: Thank you very much.

The Chair (Mr. John Fraser): Thank you very much, Ms. Piattelli. We very much appreciate your being here this morning and answering all our questions. You may stand down. We'll consider the concurrence at the end of the meeting, within a few minutes, so you're welcome to stay here while we do that.

Ms. Marisa Piattelli: Okay. So you'd like me to hang around?

The Chair (Mr. John Fraser): Yes, if you want to hang around, please do.

Ms. Marisa Piattelli: Okay, great. Thanks.

The Chair (Mr. John Fraser): Thank you.

We will consider the concurrence for Ms. Piattelli, nominated as member, Committee to Evaluate Drugs. Can I have someone—thank you very much. Mr. Rinaldi.

Mr. Lou Rinaldi: Thank you, Chair. I move concurrence in the intended appointment of Marisa Piattelli, nominated as member, Committee to Evaluate Drugs.

The Chair (Mr. John Fraser): Thank you very much, Mr. Rinaldi. Any discussion? All those in favour? Opposed? The motion is carried. Thank you very much.

Congratulations, Ms. Piattelli. Again, thank you very much for being here this morning and for putting your name forward.

One last order of business: The next meeting is Tuesday, October 20. Everybody, enjoy your break week.

Mr. Randy Pettapiece: I want to thank the Chair for ordering those chainsaws this morning. It did keep us attending to what was being said.

The Chair (Mr. John Fraser): There we go. Yes, for those of us who are hard-of-hearing, it was quite handy.

Thank you very much. Committee adjourned.

The committee adjourned at 0926.

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