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Standing Committee on Social Policy

Heart Valve Disease Awareness
Act, 2024

Planning for Your Silver Years
Awareness Week Act, 2024

1st Session
43rd Parliament

Monday 8 April 2024

Comité permanent de la politique sociale

Loi de 2024 sur la sensibilisation
à la cardiopathie valvulaire

Loi de 2024
sur la Semaine de sensibilisation
à la planification de l'âge d'or

1^{re} session
43^e législature

Lundi 8 avril 2024

Chair: Steve Clark
Clerk: Lesley Flores

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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

**STANDING COMMITTEE ON
SOCIAL POLICY**

**COMITÉ PERMANENT DE
LA POLITIQUE SOCIALE**

Monday 8 April 2024

Lundi 8 avril 2024

The committee met at 0900 in committee room 2.

HEART VALVE DISEASE AWARENESS
ACT, 2024

LOI DE 2024 SUR LA SENSIBILISATION
À LA CARDIOPATHIE VALVULAIRE

PLANNING FOR YOUR SILVER YEARS
AWARENESS WEEK ACT, 2024

LOI DE 2024

SUR LA SEMAINE DE SENSIBILISATION
À LA PLANIFICATION DE L'ÂGE D'OR

Consideration of the following bills:

Bill 66, An Act to proclaim Heart Valve Disease Awareness Day and Heart Valve Disease Awareness Week / Projet de loi 66, Loi proclamant la Journée de sensibilisation à la cardiopathie valvulaire et la Semaine de sensibilisation à la cardiopathie valvulaire;

Bill 137, An Act to proclaim Planning for Your Silver Years Awareness Week / Projet de loi 137, Loi proclamant la Semaine de sensibilisation à la planification de l'âge d'or.

The Chair (Mr. Steve Clark): Good morning, everyone. The Standing Committee on Social Policy will now come to order.

This morning, we're here to conduct hearings on Bill 66, An Act to proclaim Heart Valve Disease Awareness Day and Heart Valve Disease Awareness Week.

I'm glad to see that our first presenter is here, MPP Rudy Cuzzetto. MPP Cuzzetto, you'll have 15 minutes as the sponsor of Bill 66 to make an opening statement, followed by 15 minutes of question and answers, and it's divided as follows: The first round is five and a half minutes with government members, then followed by a five-and-a-half-minute round of the official opposition, followed by one round of four minutes for the independent members as a group.

As always, to members, please wait to be recognized by myself before asking questions. And as all of us know, all questions and comments should go through the Chair. Any questions?

Okay, MPP Cuzzetto, you now have 15 minutes for your presentation. Welcome to the committee.

Mr. Rudy Cuzzetto: I'm proud to be here with you this morning to speak about Bill 66, the Heart Valve Disease Awareness Act.

In heart valve disease, one or more of the four heart valves aren't opening or closing properly, and the heart has to work harder to provide less oxygen. In my case, I was born with a bicuspid aortic valve, in which the heart's main artery—the aorta—had only two leaflets instead of three.

Arnold Schwarzenegger had the same condition. He had an aorta valve replaced in 1997. As well, if you remember Three's Company and John Ritter, John Ritter died because his aorta exploded due to a leaky heart valve. I had mine replaced 15 years ago, in 2009.

When it's not treated early, heart valve disease can lead to heart failure or death. The one-year survival rate for the most severe forms of heart valve disease is as low as 50%. Over a million Canadians are living with heart valve disease. That includes at least one in 40 Ontarians and at least one in eight seniors over the age of 75.

With Ontario's aging population, the number of people living with heart valve disease is expected to double by 2040, or triple by 2060. Cardiologists have described this as "the next epidemic of heart disease." Fortunately, heart valve disease is a very treatable condition, especially when it's detected early, with a simple stethoscope check. And family doctors can use a stethoscope to listen to your heart murmur and other sounds that can indicate heart valve disease. If they hear anything unusual, you can be referred to a cardiologist for more tests and to a surgeon for a repair or replacement that can save your life.

Regular scanning is critical for Ontarians at high risk, including those over the age of 60, those with family history of heart disease and those with high blood pressure, high cholesterol, diabetes or other risk factors for heart disease. Unfortunately, patients with heart valve disease are too often undiagnosed or under-diagnosed, and untreated or under-treated. This means that more patients are hospitalized for heart problems that are completely preventable.

Chair, that brings us to the purpose of Bill 66. Heart valve disease isn't well known and isn't well understood by the public. Based on a recent survey, only about 3% of Canadians over 60 are aware of or concerned about the most common types of heart valve disease. They're concerned about cancer, strokes and many other conditions, but not heart valve disease.

The symptoms are hard to detect, and it is easy to dismiss them as normal signs of aging. Even more troubling, only about a quarter of adult Canadians over 25 had a stethoscope check in the past year, and this fell to only about

19% in Ontario during the COVID-19 pandemic, the lowest in Canada.

About half of Canadians say their family doctor rarely or never checks their heart with a stethoscope, and Canadian women are much less likely to get a stethoscope check than Canadian men. Considering the risks of valve disease and the burden it causes on our hospitals, we can and we should do much better.

In France today, over three quarters of visits to their family doctor include a stethoscope check. That's why, recently, the Canadian Cardiovascular Society set up a heart valve disease working group to help raise awareness of heart valve disease and to encourage everyone to get regular stethoscope checks, led by friends like Dr. David Messika-Zeitoun, an expert in heart valve disease from the University of Ottawa Heart Institute. He joined us here at Queen's Park for our reception on February 22 last year, which was Heart Valve Disease Awareness Day, along with Dr. Janine Eckstein, who flew in from Saskatoon to give stethoscope checks to MPPs and staff here at Queen's Park.

Dr. Michelle Graham, a professor of medicine at the University of Alberta and president of the Canadian Cardiovascular Society, said, "I applaud Bill 66, and I hope all provinces and territories do the same. I see patients every day who live with this condition. How will an awareness day help them get better? It won't, really. But there are things that we can do that can be life-changing and reduce some of the pressure on the health system. Raising awareness of heart valve disease, promoting detection through regular and simple stethoscope checks, and identifying problems through regular check-ups are things we can do."

And that's what Bill 66 will do. It would support doctors, patients and non-profits as we all work together to spread the word about heart valve disease and about the importance of regular stethoscope checks, especially for those at great risk.

Chair, I would like to take a few moments to speak about my own experience. My family doctor, Dr. Eric Farkas, diagnosed me with a heart murmur when I was 18. He had come to Canada after the Hungarian revolution in 1956, and his office is now my constit office in Port Credit today. He recommended a follow-up test, but I was young and I felt healthy. My father died of lung cancer and asbestosis soon after, on December 12, 1985. So, now I'm aging myself here.

So I went on with my own life, without the test. I went to work for Ford Motor Co. in Oakville, but I never had any energy. At the time, I thought it was because of the shift work; I was working 10 to 12 hours a day. But my wife, Marie, knew it was something else. When I had another physical by Dr. Sabetti, she listened to my heart with a stethoscope, and she heard a murmur. A cardiologist in Toronto, Dr. Peter Fountas, confirmed that I had a bicuspid aortic valve and it had to be replaced.

Next, I had to choose between a pig valve, which would have been replaced every 10 to 15 years, and a mechanical valve, which lasts a lifetime but requires that you take blood thinners or Coumadin every day for the rest of your life to reduce the risk of blood clotting. I was fortunate that one

of my neighbours worked as a sales representative for St. Jude mechanical valves, so he was able to answer all my questions and I chose a mechanical valve.

I had the surgery just across the street, 15 years ago, in 2009, at the Peter Munk Cardiac Centre. I was fortunate to have Dr. Christopher Feindel, one of the top cardiac surgeons in the world, nicknamed "God" by hospital staff. When I went into surgery, all I can remember saying to Dr. Feindel was, "Remember, I have two young sons."

Again, I want to thank Dr. Feindel and give him all the very best on his retirements, because today, I'm living a normal and healthy life because of him. I see another cardiologist every year and I have an angiogram to check that my mechanical valve is in good working order.

0910

Chair, since I've had my surgery, there has been significant progress on new treatment options. Today heart valves can be replaced or repaired with minimally invasive surgery. New valves can be inserted through your artery, with just a small incision in your groin area. Some new mechanical valve designs can reduce or eliminate the need of blood thinners.

But again, in order to take advantage of this incredible new technology, it is absolutely critical to detect heart valve disease early. That's another reason why raising awareness about heart valve disease is so important.

Chair, I also want to take a moment to thank Ellen Ross, the managing director of Heart Valve Voice Canada, for all her support with our reception and the draft of Bill 66. I know she will be here this afternoon, but I'd like to read a short statement from her: "Bill 66 will bolster Heart Valve Voice Canada's mission to raise awareness about heart valve disease. With Ontario's population growing older, the burden of heart valve disease is on the rise and early detection can save lives."

I'd like to take a moment to talk about the burden, because we know that low awareness of heart valve disease comes with significant risk and costs not just to the patients and our families but for our health care system. For example, we know that between 2007 and 2017 there was a 68% increase in the number of Canadians hospitalized for heart valve disease. A paper published in 2020 by several authors concluded that Canadian hospital costs for patients with aortic stenosis, just one kind of heart valve disease, were \$393 million in 2014. A paper in 2019 concluded that the health care expenses related to heart valve disease in the US are \$77 billion each year. Again, much of this can be avoided with a simple and cost-effective stethoscope check.

Chair, in closing, again, I want to thank you for the time this morning to speak with you about Bill 66. I look forward to answering the questions here today regarding this bill.

And again I want to encourage everyone—committee members, staff and anyone watching—to have a regular stethoscope check. And please encourage your constituents to get a regular stethoscope check.

Listen to your heart. It saved my life. It could save yours.

The Chair (Mr. Steve Clark): Thank you, MPP Cuzzetto. I appreciate your presentation.

We'll now move to the government members. As I said earlier, you will have five and a half minutes for the government members. MPP Martin.

Mrs. Robin Martin: Thank you, MPP Cuzzetto, for sharing your experiences, and thank you for organizing the Heart Valve Disease Awareness Day last year, which we were just saying—I also had my heart checked. I think I was born with an arrhythmia, so I'm always nervous about what's going on in my heart, but it seems to be working so far. But you never know. We don't know these things, and as you pointed out, the symptoms of heart valve disease are very subtle and might look like other things, and so it is sometimes hard to tell whether somebody is suffering from heart valve disease.

Is the best way through stethoscope checks—that's what you're saying—and is that the only way that people will find out?

Mr. Rudy Cuzzetto: Thank you, MPP Martin, for that question. It is the most effective way, because right away they can hear a heart murmur. Once they figure out it is a heart murmur, then they can proceed to send you to a cardiologist.

At the time in 2009, I had an issue: I could not find a cardiologist at the time. I was lucky to find Dr. Fountas, and he was in Toronto East. I had to find my own cardiologist because the health care system was in terrible condition at that time.

I recommend that you do get a cardiologist as quick as possible, because as soon as they can diagnose that it is a heart valve issue, you can have it repaired or replaced, and today's surgeries are much easier than in 2009. They don't have to have open-heart surgery anymore. You can go through the groin area, and they just drop a valve right in there. You can be back up in—I think I heard in six hours, you can be back up and functioning normally instead of being there for a week.

Mrs. Robin Martin: Well, that's very interesting, that point, as well, you mentioned in your testimony. I was born with a heart murmur, so I think people know that they have heart murmurs at different times in their lives. I don't know if that is significant, but the doctor who checked me at your event said I was okay, so I'm counting on that.

You did say that this valve can be inserted through this small opening. I wrote down—here's a stupid question—what exactly is a valve? And how could they insert it through such a small opening?

Mr. Rudy Cuzzetto: Well, today's technology—they can insert a camera through your groin area, through your artery, which goes up to your heart.

I'll tell you the truth: When Dr. Fountas did the test on me at Toronto East General, my valve was leaking so badly that he was scared to take more than two pictures, so he pulled the camera out. He was worried that he would puncture my aorta at the time. If you puncture your aorta, it's sudden death, like John Ritter. So he was only able to take two pictures, and he pulled the camera out. At that time, they put you in a room after that, and they clamp your leg down for about four hours because they have to stop the artery from bleeding.

But right now, with the technology they have, the same camera—instead of a camera on the end of the wire, they put the valve on the end of the wire. They just go up your artery and just drop that valve where the existing valve is, so they don't have to remove the existing valve with a new valve.

Mrs. Robin Martin: So that's what opens and closes?

Mr. Rudy Cuzzetto: Correct. And I'll tell you, my valve—I was born with this. I didn't know until—a normal valve has three leaflets. Mine had two, and one was there which was very tiny. It was not developed at birth, but it was there. At 18, when they heard a heart murmur, I said, "Whatever." I just kept on going with my regular life. But they older you got, the less energy you had. I blamed it on my work, like I said, because I thought working 10, 12 hours at Ford Motor Co. shift work—I thought that's why I was tired. But it wasn't due to that fact; it was due to the leaking valve. Once it was replaced, after two months, I had so much energy, I couldn't believe.

Mrs. Robin Martin: You said you had a bicuspid aortic valve. Is that the two leaves? Is that what's meant?

Mr. Rudy Cuzzetto: Yes.

Mrs. Robin Martin: Okay. I was wondering about—

Mr. Rudy Cuzzetto: Instead of three.

Mrs. Robin Martin: Okay. So otherwise, it would be tricuspid or whatever the word is.

The Chair (Mr. Steve Clark): You've got about a minute, MPP Martin.

Mrs. Robin Martin: You also mentioned that aortic stenosis is only one kind of heart valve disease. Can you tell us what the other ones are? Do you know?

Mr. Rudy Cuzzetto: Offhand, I can't explain the other ones, because the other ones are—the aorta is the main—

Mrs. Robin Martin: Right. So this is the main kind?

Mr. Rudy Cuzzetto: That's the main one, but there are other valves inside your heart.

Today, the procedure is very normal and pretty well—I remember Dr. Fountas would do two surgeries a day. That's unbelievable, two surgeries a day for a doctor. The success rate is over 99%, unless you have any underlying issues.

Mrs. Robin Martin: Excellent.

Am I hogging all the time? Does anyone else have a question?

The Chair (Mr. Steve Clark): You've got about 22 seconds. Yes, MPP Wai.

Mrs. Daisy Wai: I'll just ask the question first and then you can answer it later. It's really touching information that you have shared with us. It is important. I thank you for doing this for the general public. We just had our—

The Chair (Mr. Steve Clark): Thanks, MPP Wai. Sorry, the time for government questions is up. I apologize.

We'll move now to the opposition. MPP Gélinas.

Mme France Gélinas: The same: I would like to thank you for sharing your story. You have become very knowledgeable and a powerful voice to effect change, and I want to thank you for this. You have 100% our support. We will do whatever we can to bring you to third reading and royal assent.

In your bill, you select a day and you select a week. Have we thought this out? Is this good to have two recognitions? Should we focus on one?

Mr. Rudy Cuzzetto: The day is really more for the North American market, and the week—we're going to have to change that week as well. Because right now in the bill, we said the—we probably need to change the week beginning the second Monday of September to the third Monday in September, because that's how they do it in Europe.

I think it's good to have more awareness about heart valves because it's very unknown. You know if you go to a hospital or you have a heart issue, but you don't know it's a heart valve issue, and I think it's very important that we know more about the heart valve issue. We've heard of major people who have had this surgery: Arnold Schwarzenegger; John Ritter, who died from it. This could have been prevented if it was detected much earlier.

0920

M^{me} France Gélinas: So the one day is selected based on the day where it is recognized in the States. Is that it?

Mr. Rudy Cuzzetto: Yes, correct.

M^{me} France Gélinas: Okay. And the one week is selected based on the week where it is recognized in Europe.

Mr. Rudy Cuzzetto: That's correct.

M^{me} France Gélinas: Funny we cannot all get along.

Laughter.

Mr. Rudy Cuzzetto: It's politics.

M^{me} France Gélinas: But I'm not going to go there. I agree with you that the more people know about those things, the more they will make the right decision.

You did mention that you had a tough time finding a cardiologist; 40,000 people in my riding do not have access to primary care, so to get a stethoscope check is very difficult. It's not the kind of stuff you can get done if you go to emerg, and it's not the kind of stuff that is easy to get. It's the same thing with finding a cardiologist. So how did you go about finding your own cardiologist? Like, how did that work out?

Mr. Rudy Cuzzetto: Well, I went in first to my doctor. They heard a heart murmur, and I was waiting for my family doctor to call me back with a cardiologist. It was already a month that I had not received any phone calls from my family doctor, so I decided to call her up and she said, "Well, we're still looking for a cardiologist." So I said, "Do you mind if I am able to find my own cardiologist?", and she said, "Yes, go right ahead."

I had a few friends who started asking around if they knew any cardiologists, which they did. I called the cardiologist up myself, personally, and he said, "The only thing I need is a requisition from your family doctor, and you can come and see me at any time." That's what I did. I let my family doctor know, and I was referred to Dr. Fountas in Toronto East—you must know Dr. Fountas.

Mr. Adil Shamji: Very well.

Mr. Rudy Cuzzetto: Yes. Dr. Fountas—I'll be honest; the first day I went to see him, he knew what it was, so he said, "Tomorrow morning, I want to see you at Toronto East." So I went in to Toronto East and I said, "Dr. Fountas

is coming." The nurse there said, "No, he never comes for these types of things." Luckily, he did. He showed up that morning.

Some people know how the test is done. They put a probe down your throat, which is a black, thick pipe, which is one of the worst experiences that you can have. He went down and he knew right away what it was, then he rushed me—well, I'll tell you the truth. Then the next day, I did the other test through the groin area, and I said to him, "Well, I'm going to Florida." He goes, "You're not going anywhere. You're going to Toronto General."

The Chair (Mr. Steve Clark): You've got about a minute left.

Mr. Rudy Cuzzetto: And he goes, "I have two great doctors: Dr. Feindel or Dr. Tirone David." A lot of people know Tirone David, because he's another world-renowned heart valve specialist. He was probably the best in the world at the time. So he called both of them up, and Dr. Tirone David said, "Oh, this is not complicated. I don't want to do it," because he only likes complicated cases. So Dr. Feindel ended up taking me and he ended up doing the surgery.

But the funny thing is, everybody called Dr. Feindel "God." Now, I don't know if it was before or after, because my mother was there—my mother was in her eighties at the time, and she said when Dr. Feindel came out of the surgery, he goes to my mother, "Everything went well." My mother touched his hands, an old Italian woman, and she goes, "Mani di Dio." It means, "hands of God." I'm not sure if he got that name before or after, but it was just a coincidence—

The Chair (Mr. Steve Clark): Thanks, Mr. Cuzzetto.

Now we'll move to the final four minutes of questioning from the independents. MPP Brady.

Ms. Bobbi Ann Brady: Thank you, MPP Cuzzetto, for your passion on this issue. Education and awareness are always a good thing, and I'm so happy that you are feeling well. You did say you're living a normal life, and I'm not sure any of us in political life can say that, but good for you.

I fully support this bill, because it hits very close to home for me. Both sides of my family are saddled with severe heart disease, and much like you, I was diagnosed when I was 16 with a heart murmur. So far, a little intervention and I live a healthy—I won't say normal life, but I live a healthy life. Unfortunately, I did pass it down to my firstborn, and I do worry about her. She's going on 23. But she will be a front-line health care worker very soon, so she has her own stethoscope. I should remind her to use it on herself and perhaps on me as well.

I do have a few questions. You mentioned that this is becoming a bit of an epidemic, and there's an easy fix: a stethoscope check. Three of us have already said that we have a condition, and there may be more in the room who do. If a stethoscope check is really the answer, should we not be making it mandatory every time a physician looks at someone that they do the quick stethoscope check?

Mr. Rudy Cuzzetto: I think that a physician should be doing that anyway for any type of thing, just even to listen

to your lungs at the same time as they're listening to your heart. Should we make it mandatory? We could look at that in the near future. I think it would be a great idea to do that. I just hope that most doctors do a stethoscope check, but here in Canada—compared to France—we do not do a stethoscope check every time you enter a doctor's office, unfortunately. I think it would probably be a great idea to do that.

Ms. Bobbi Ann Brady: Yes, you're right, because I do have this heart murmur and my daughter has the heart murmur, and the stethoscope check isn't done on us. I can't remember the last time I had one. It's really up to the patient oftentimes to advocate to have that continuous monitoring or those checks done once in a while. Every few years I go through that.

One of the other questions that I have—and MPP Martin alluded to this as well—is that the indicators are really hard to pick up on as an individual. What could we tell people to look for? When should they visit their doctor? What kind of alarm bells are ringing?

Mr. Rudy Cuzzetto: Well I'll tell you, with mine, I never had any energy. I even had sometimes blurry vision.

The Chair (Mr. Steve Clark): You've got about a minute left.

Mr. Rudy Cuzzetto: I never had any pain in the chest area, but when I would go out in the winter for a walk, I felt it was very hard to breathe. Those were all symptoms that were contributing to the heart valve leaking.

But like I said, I grew up with it, so for me it was a normal life. I didn't realize. If it happened to me at the age of 40 or the age of 50, that would be one thing, but I've had it since I was 18. I was born with it, so for me it was just the normal everyday life. Unless you have a stethoscope check, you will never know.

Ms. Bobbi Ann Brady: And quickly: Who will you be partnering with on this week? What kind of organizations will be helping you spread awareness?

Mr. Rudy Cuzzetto: The heart valve awareness—Ellen Ross; she will be here this afternoon to speak about it.

Ms. Bobbi Ann Brady: Excellent.

Mr. Adil Shamji: Thanks for sharing your story. As you may have surmised, I know Dr. Fountas pretty well, and he is as great as—

The Chair (Mr. Steve Clark): Sorry, MPP Shamji. That's the time we have for questions.

Mr. Adil Shamji: At least I got that on the record.

The Chair (Mr. Steve Clark): I apologize.

MPP Cuzzetto, I want to thank you for your presentation today and your advocacy and really appreciate it.

Mr. Rudy Cuzzetto: Thank you.

The Chair (Mr. Steve Clark): Thank you so much.

The next item of business—we're almost at 9:30—is the public hearings for Bill 137, which is to proclaim Planning for Your Silver Years Awareness Week. The first witness is the sponsor for the bill, MPP Daisy Wai.

MPP Wai, thanks for being here today. As the sponsor—very similar format to what we just experienced with MPP Cuzzetto—you're going to have 15 minutes to make your opening statement. There's going to be 15 minutes of ques-

tions, going first to the official opposition for five and a half minutes, and then the government for five and a half, and the independents for four minutes.

MPP Wai, whenever you're ready, we certainly would love to hear from you about Bill 137. Welcome.

Mrs. Daisy Wai: It is exciting to share with you this Bill 137 that I have presented in front of you. Thank you, everyone, for being here today as I introduce Bill 137 to draw awareness to the importance of planning for the silver years. I am thankful I have this opportunity to introduce this private member's bill and get the unanimous support in the second reading.

0930

Seniors are always dear to my heart, which is why, before I became an MPP, I served on the board for Mackenzie Health, Markham Stouffville Hospital, as well as the CCAC. I also served as a volunteer for Yee Hong and Mon Sheong. I am thankful that I am serving as the PA for the Ministry for Seniors and Accessibility because that is an area that I really want to serve in.

I trust that Bill 137 will enhance the lives of seniors. I would like to dedicate a week to bring the awareness for us to properly prepare for our silver years. While we are too busy with our daily lives, the silver threads are growing among the gold and, in my case, black. Making plans in our early sixties on how we want to live the rest of our lives can help to steer our path in the direction we prefer—most importantly, when we discuss our preference with our family members and especially our children, so that they will know what kind of support they can give and how they can help you to leave a very good life in your golden years.

As the projections from the Ministry of Finance indicate, Ontario's senior population numbers are set to increase significantly, and I'm sure we all know it very clearly because of the baby boomer era. We will be reaching about 20.3% by 2046.

Our senior adults deserve to live a life that they should treasure because they are the “silver years,” and they should lead it comfortably, with the dignity and respect that they have earned. However, too often, necessary conversations about future arrangements are delayed until a crisis arises, leading to undue stress and challenges for both seniors and their families. This is a reality we must change.

The Planning for Your Silver Years Awareness Week Act aims to encourage proactive conversations among Ontarians—families, friends and caregivers—about planning for the senior years well before retirement. This bill proclaims the week beginning on the first Monday in November in each year as Planning for Your Silver Years Awareness Week. It recognizes that determining the most suitable living environment for seniors requires early engagement, thoughtful preparation and careful consideration of their psychological, physical and financial needs.

As we navigate this demographic shift and the rapid growth in the number of seniors, it is our responsibility to support them in living fulfilling lives within their communities. This bill is an opportunity to empower seniors and their family members to explore a multitude of options

that will enable them to remain engaged and active members of our society.

I was stimulated by a speaker at one of the conferences for seniors. He encourages seniors that they are to pursue their new dreams after they're retired. We, after all, are not retired at all. We are still very active in our early sixties. If people retired at 65, they are still very early. A lot of us still live another 30 years or more of life. How can we make the best use of this kind of timing? We need to plan ahead of time and also with the support of our family members.

I am encouraging all of you to do this in the early sixties because I have experienced that. I am very fortunate that my daughter asked me almost 10 years ago if I would want to be aging at home or living in long-term care, because she has to be prepared. If I want to be aging at home, it can impact her life as well. She worked as an IT specialist supporting long-term care, and she has seen a lot of things happening in different long-term-care agencies and facilities. She wants me to realize the comfort I can face and also the challenges that might come with it. That opens a lot of scenarios for me. If I choose aging at home, who would take care of me? I have four children, but each one of them may have their own family. They may be too busy for me. I have to be careful about them as well. My daughter was not married at the time. But when she gets married, will she still have the time, the energy and the finances to take care of me?

If I want to live in a luxurious retirement home—I was introduced to one; it's almost like living in a hotel—can I afford it? How much will that be? What can I do? What options do I have? What will I have to do now in order to live a life of a luxurious hotel with people helping me all around? How can my family members help me to achieve my dream after I retire? Because I may want to do a lot of other things. I want to be a painter. I want to be sitting by the lakeside, really just painting and doing, luxuriously, the work I want to do. Can I afford that? Will my family member, will my caregivers support me on this? Will my husband be able to be strong enough to do that together with me?

There are many questions, of course—I'm sure you all share the feelings I am having—and also so many unknowns. But at least, we share a goal. If I share ahead of time what I want or even think about thoroughly what I really want when I am at that stage, then my family members, my children, if they know, would know how to support me, to help me to lead me to the goals that I want to have by promoting meaningful and positive conversation.

Thank you, Chair, for allowing me to share this, my heartfelt urge with everyone here, because this is something that I have had even before I became an MPP, which is why I have been serving on different boards in the hospital to really see how I can help the seniors. I'm happy that I'm allowed this time to help—having a bill to help people to plan for their silver years. It's used as an awareness week. Having that as an awareness week, they can start thinking about that. A lot of times, people don't even want to think that they are getting old.

I still remember just recently—my mother-in-law passed away two years ago. When she was reaching her nineties, we wouldn't dare say one word of death, couldn't even plan anything for her. It took a long time for us to put her into long-term care. She didn't even know that that was long-term care. But this is something that, if I know what I will be doing down the road, I will be thankful for all my family members.

So I really hope that this bill is an opportunity to empower seniors and their families to explore a multitude of options that will enable them to remain engaged and active members of our society. Thank you very much, Chair, for this time that I'm given.

The Chair (Mr. Steve Clark): Thank you, MPP Wai, for your presentation. I appreciate the opportunity to hear your story.

We're going to move to the question portion. I'll start with the official opposition. You'll have five and a half minutes.

MPP Lise Vaugeois: Thank you. So I think we've spoken about this before. Generally, I'm in favour of it, and I think that we will be supporting it. An awareness week is never wasted.

But when I think about this, I often think of people who have a lot of privilege who are able to actually make plans, knowing that they've got the money to do it. So I'm thinking a lot about my own mother. She's 96. We've been through this—

The Chair (Mr. Steve Clark): Wow.

MPP Lise Vaugeois: Yes. She wanted to stay in her home, but we couldn't get the help to do that. Then, she moved in, actually, with us; that didn't work out very well. It was too much upheaval. Then she moved into a Revera, which was lovely. It took a lot of adjustment, but she was there. But then the rent kept going up. Within two years, it went from \$5,000 to \$6,000 a month. So we thought, "Well, she's going to be out of money very soon." She's moved to another place now, but we're seeing now 200 seniors being turfed out of their Chartwell home. Those are seniors who planned; I mean, you've got to have money to live in a Chartwell in the first place. They've planned, and now they're going to be homeless. These are very, very serious issues that we need to take up together as a government.

0940

I know that home care is on the agenda, that we're trying to make that better. We really are going to have to do something about what's happening with the Chartwells. That cannot be allowed to happen. Where are they going to go?

I'm also thinking about the people on WSIB, people on ODSP. But just to go a minute on WSIB, people probably don't realize that someone with a permanent injury will get 85% of their wage. They're no longer able to contribute to CPP. It used to be 10% money put aside; now it's only 5%. When they hit 65, actually, they're entering a new period of poverty, so they're going to have even less than they had before. So they don't have a lot of options for planning ahead.

Of course, people with disabilities who are trying to survive on ODSP are really going to have a lot of trouble,

again, planning ahead where they're going to live. But another thing that we're seeing right now in my community is the affordable apartments—people are being moved out and they're being turned into Airbnbs or VRBOs, whatever that's called. So that affordable housing isn't going to be there for them. It doesn't matter how old they are; they actually don't have the means to plan, even for tomorrow, right now.

I just want to make sure that those things—that we're all aware that those choices aren't there for many, many people. And even when they are there, in the case of the people in Mississauga who have been living in the Chartwell, where you'd think, "Okay, I can spend \$6,000 a month. I've got that money put away. I'm safe. I'm going to stay here for my senior years, until maybe I have to go into long-term care"—that choice has been taken away from them.

I don't think I need to belabour it anymore. I agree. When I look at this for myself, I think, "Well, I have passed the 65 mark. I better make sure I've taken care of business." But I also want to make sure that people realize that the choices are quite constrained for quite a few people in our society.

Mrs. Daisy Wai: Thank you very much, MPP, and thank you very much, Chair, for allowing me to respond to this.

You are totally correct. Yes, there are a lot of unknowns, and we have different levels of people that will need different kinds of choices. That's why this is an awareness week, for us to start thinking about that and plan about that.

What I would envision to do is, there are different kinds of options for different levels of people so that they can come out and see what options there are, or if there is an option—in my case, I want to be in a luxurious retirement home. Can I ever reach that? Maybe not for sure—

The Chair (Mr. Steve Clark): There's about a minute left in this round of questions.

Mrs. Daisy Wai: Thank you. But at least I know that I need to know what is there and what else really fits with what my family members can afford, and let's work on that.

As I said, there are a lot of unknown factors. Things keep on changing. So let's plan on it and work together. The most important part for this bill is to let our family members be aware of what is out there for what I want and what is out there for us. What options are there? There are different kinds of ways. And if we do, maybe they will say, "We'll have to take care of you at home," but how can they do that? There are a lot of things that they will have to work and discuss among the siblings, in my case, or, in other cases, different family members.

This bill is really for awareness, and really for people to see and also bring to them what options are out there.

The Chair (Mr. Steve Clark): Thanks, MPP Wai.

We'll move to the independent members for four minutes. MPP Shamji.

Mr. Adil Shamji: Thank you, MPP Wai, for raising this really important issue.

When I reflect upon my own clinical career, I can't tell you the number of times I've been working in the emergency department and we find a family that comes in with

their senior, or a senior comes in alone, in extremis, with some sort of critical illness, and, though well-intentioned, there has been no planning that's taken place—anything from what could possibly happen if they don't return to their normal state of health to how to manage disability to what their advanced directives might be around whether they will be resuscitated or not. And unfortunately, we don't get to make the most informed decision within the spirit of what that person would have wanted, had we had the time to have a very fulsome conversation. I do sincerely appreciate your effort to bring this forward so we can have this conversation.

When I reflect a little bit around what these planning conversations should entail, I think about everything from planning how to age with dignity at home to what advanced care directives should be and resuscitation conversations—all of those sorts of things. And those simply don't happen enough because people are uncomfortable having those conversations. They don't know how; they don't know what to speak about in the first place.

As I review the bill, one thing I notice: Planning for Your Silver Years Awareness Week. If I were, for example, my parents, who are reasonably well-educated, that title, or having that week, may not actually prompt them to think about all of those things. They might make the connection, "Okay, this is planning for aging and having those conversations," but it wouldn't prompt them to think, "Okay, those conversations should be X, Y and Z."

How does your bill get us there, or how can we get there?

Mrs. Daisy Wai: Thank you very much, MPP Shamji, for asking me that question. This is something that I've planned for, and that's why I'm so anxious to have this bill pass and start doing active action.

For November coming up, I would just be doing the awareness week and getting through different kinds of mediums to let people understand. But in the following years, I'm expecting to have different kinds of options displayed in front of them, to have people doing different kinds of conferences, and I would let them know what they are. They can include, what are they planning for after their retirement years? It doesn't have to be just talking about when you go into hospital or whether going into long-term care. There are a lot of exciting things that they can do, even what cruises are available for seniors out there, you know?

The Chair (Mr. Steve Clark): There's about a minute remaining.

Mrs. Daisy Wai: Letting them think about that seniors are exciting years. And also giving them the option, as I was just explaining earlier, what are the different levels of long-term care and retirement homes? What is out there, and how long does it take to get them into a retirement home? They will have all that kind of research done ahead of time. This will all be listed out for them. We will have brochures. Maybe if this bill gets passed and if I get something done in time for November, we'll start doing that and inform them so that they would know what this is all about.

It is a lot of education. It is a lot of communication with them. And, as we know that our seniors are growing, this

is really necessary, and I thank you for bringing that up. I share with you that I have this, really, urge for doing it because when I was on the board, the—

The Chair (Mr. Steve Clark): Thank you, MPP Wai. That concludes the independent questions.

We'll now move to the last five and a half minutes for the government. MPP Jordan.

Mr. John Jordan: Thank you, MPP Wai, for the presentation. I was thinking about when we toured your home in Richmond Hill and there was a woman—I think it was your home—there sitting by the window, the sun coming in as she was painting, and there was a flowerbed outside. I don't know if that's where you got that thought, but that was a perfect picture for long-term care.

One of the committees that I used to sit on in my previous career was the Lanark county hospice and palliative care, and they had a program in advanced care planning. They had kits and they had presentations and they tried to get as many people as they could to come in—so, early on, as you have described.

I'm wondering if you could just tell us how you think this bill will assist in promoting programs like that going forward.

Mrs. Daisy Wai: Thank you very much, MPP Jordan, for that question. Definitely, as I was mentioning earlier, I will be doing different kinds of programs during the awareness week. In fact, I would have to say thank you to MPP Dawn Gallagher Murphy. She has already organized a kind of trade show, almost, to display what is out there. But I want to do something even more positive. It doesn't have to be just about retirement homes, about long-term care. It can be very positive. It can be different, kind of saying, okay, what kind of career can you still start—maybe not to make money—or how can you use your experience to help the next generation?

We share a lot of great experience in our work. We have to find a way to let them share it to the next generation without leaving them by dying. They've thought that, "Oh, I'm now retired"—and I have seen a lot of people, after they're retired, they get themselves into different kinds of sickness, and some of them, sadly, pass away very quickly. We can do a lot better for them. They have done too much for the family and for our society. Let's work together and make their life really something that they find exciting and worth living.

When we thought about silver years, we only think about the time that maybe we are in long-term care and other parts—as you say, in the hospice support. But there are a lot more years before that. How can we make the best use of what the energy will have? This is the kind of awareness I want to bring to them, share with them what options they have.

Going on a cruise is also a very, very good thing, and I know there are a lot of seniors going on a cruise. In fact, seniors will down the road be the economic driver around the world, because they have the money, and a lot of them, the next generation, do not need the money. They can use that in a very positive way. Let's engage them soon and earlier.

The Chair (Mr. Steve Clark): MPP Gallagher Murphy.

M^{me} Dawn Gallagher Murphy: Thank you, MPP Wai, for bringing this bill forward. I think it's so important. When I think about it, people are living longer, and I think people need to be really thinking about this even in grade school, quite honestly, because if we think about it, as the MPP opposite noted, the cost of living is just going sky-high. I think about people who are 55, 58, retiring on a good pension through the OPS or something. And you know what? How good is that pension? Because at the end of the day cost of living is going crazy.

So my question to you would be, thinking about these things—we're living longer. Cost of living is crazy, and we've got young people dealing with older parents. I'm an older mom. I have a 17-year-old, and I'm already, let's say, getting up there. When I think about these things, it's important to engage our young people very young. So my question to you is looking at planning for your silver years.

The Chair (Mr. Steve Clark): There's about a minute remaining.

M^{me} Dawn Gallagher Murphy: How do you think that would affect the plans, taking those things into contraction?

Mrs. Daisy Wai: I agree with you. Thank you, MPP Gallagher Murphy, for your question. I totally agree with you. There are a lot of things, as I say, beyond this, and there are a lot of unknowns. Honestly, the cost of living is not only faced by seniors but by everyone, and when the things evolve and things change, we will work together and get us through the problem. But planning is actually a lot better than no planning at all. That's why I want to have the awareness week: to help them to do the planning and face the challenges as they go. And at least they have the objectives. They know what the senior wants, and encouraging them to work as a family—as a family member, that is the key. Of course, we will have to face different—

The Chair (Mr. Steve Clark): MPP Wai, that concludes the time. I want to thank you so much for your presentation and your engagement with members.

We will now recess the committee until 1 p.m., when we will continue the public hearings.

The committee recessed from 0954 to 1300.

HEART VALVE VOICE CANADA ALZHEIMER SOCIETY OF ONTARIO

The Chair (Mr. Steve Clark): Good afternoon, everyone. Welcome back. We're going to resume public hearings for both Bill 66 and Bill 137.

This afternoon, we have presenters from Heart Valve Voice Canada for Bill 66 and a presenter from the Alzheimer Society of Ontario for Bill 137. Each organization has been allotted seven minutes for their opening statement, followed by 39 minutes of questioning of the witnesses, divided in two rounds of seven and a half minutes for the government, two rounds of seven and a half minutes for the official opposition and two rounds of four and a half minutes for the independent members as a group.

I'll provide, as normal, to the presenters a one-minute warning near the end of your time. And I just want to say to please continue speaking. The warning is only for your reference for time. At the start, please state your name for Hansard. Please wait to be recognized by me.

I know the members know this, but the comments and the questions you have should be directed through the Chair. Any questions from anybody?

Okay, we've got Heart Valve Voice Canada. You have seven minutes. You can start and your colleague can share your time.

Mr. Len Crispino: Mr. Chair, we're splitting remotely, so I'll go second.

The Chair (Mr. Steve Clark): Okay, sounds good. Ellen Ross, I think you're going to start. You can start speaking, Ellen. I think you're connected to us. So do you want to start your presentation?

Can either of the two presenters on Zoom or Teams—can you hear me, either one of you? I take that as a no. I can say lots of glowing things about them, and they won't hear it.

Interjections.

Mr. Len Crispino: Mr. Chair, if you prefer, I can start, and then Ellen can join.

The Chair (Mr. Steve Clark): Okay, sure. Okay, Len. That would be great. Just introduce in the mike for the purpose of Hansard, and you can start.

Oh, Ellen, you can hear me now?

Ms. Ellen Ross: Yes.

The Chair (Mr. Steve Clark): Beautiful. Okay, we'll go back to—there we go. Technology is wonderful. Thanks, everybody, for doing that.

Ellen, you can start. Just introduce yourself, and then Len will take over and then we'll go to Kyle after.

Ms. Ellen Ross: Super. Thank you.

Thank you to the committee for having me here today. I'm Ellen Ross, and I'm the managing director of Heart Valve Voice Canada, as well as the chair of the Global Heart Hub's heart valve disease council.

Heart Valve Voice Canada is the only national, patient-led heart valve disease organization. We're a not-for-profit that raises public awareness on heart valve disease by engaging patients and care partners to educate, support and advocate for Canadians with heart valve disease.

I'm pleased to be here today in favour of MPP Rudy Cuzzetto's Bill 66, the Heart Valve Disease Awareness Act. I sincerely thank MPP Cuzzetto for his leadership with this bill. MPP Cuzzetto, who has lived experience with heart valve disease, has been a tireless advocate for raising awareness. We're forever grateful for his support.

Bill 66 has the power to improve the outcomes of people living with heart valve disease by increasing awareness of the signs and symptoms, therefore improving early detection. Heart valve disease is common, serious but treatable. It affects over one million Canadians and can be fatal if left untreated.

As Ontario's population is aging, heart valve disease is on the rise, contributing to increasing hospital admissions. But while this burden is increasing, awareness remains

low. Only 3% of Canadians over 60 are aware of aortic stenosis, which is the most common type of heart valve disease. The signs and symptoms, such as fatigue and heart palpitations and chest pain, are often dismissed as a normal sign of aging. Yet, between 2007 and 2017, there was a 68% increase in the number of hospitalizations for heart valve disease in Canada.

While there are effective treatments for heart valve disease that can improve quality of life and reduce mortality, in too many cases, the condition is undetected, untreated or treated too late. This results in avoidable deaths, high health care costs and significant compromises to the patient's quality of life. So much of this burden could be alleviated by improving awareness, particularly in older adults, so Bill 66 will really help.

I want to thank MPP Cuzzetto again for his leadership and the advocacy in bringing this bill forward. On behalf of Heart Valve Voice Canada, I want to express our full support for this bill and thank the committee for your time and advocacy.

At this point, I'd like to turn it over to my esteemed colleague Len Crispino, who will speak about his lived experience with valve disease and the power that greater awareness will bring.

Mr. Len Crispino: Good afternoon. My name is Len Crispino. I'm an active volunteer and board member of Heart Valve Voice Canada. For some 28 years, I held senior roles in the Ontario public service and subsequently with the Ontario Chamber of Commerce.

I am here today to support the efforts of Heart Valve Voice Canada, a not-for-profit organization whose role, just explained by Ellen, is there to improve the quality of life for people living with heart valve disease. But more than that, Heart Valve Voice is there to help prevent the devastating effects if not detected or treated early.

I am also a proud patient advocate, someone who, like thousands of others across Canada, experienced and lived the debilitating effects of heart valve disease. Years ago, as a 15-year-old at St. Michael's College high school in Toronto here, I was casually told that I had a heart murmur when trying to join the football team. But life, like everything else, moved on with the unspoken note that there wasn't much to worry about.

Years later, as things began to deteriorate with a plethora of complications, it was determined that I would urgently need an aortic valve replacement. Had I been more aware at that time of valve disease, earlier in that journey, perhaps it may have better impacted my outcome.

My story is just one story, but I quickly realized that my story resembled other patients' stories, underlined with powerful emotional roller coasters, whether around potential loss, disruption to work, social interactions and family life. I say family life because this disease is not just a patient's disease; this disease is one that envelops the entire fabric of family, friends and community.

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I stand in partnership with the thousands facing heart valve disease and countless others walking among us undetected or untreated.

The Chair (Mr. Steve Clark): You've got about a minute left.

Mr. Len Crispino: Passage of this act will serve as an inspiring agent for community-building and collective action. I know at times you must feel, "What is the value of what I'm doing?" I can tell you that your support of this act is very, very important.

One last comment I would make—I know my time is limited to about 30 seconds. One of the leading and internationally recognized heart surgeons in Ontario, Tirone David—some of you may know him—coined the term "circle of bravery." The circle of bravery is the recognition of the need for all of us to work together. This circle brings together patients, medical professionals, government, communities and families in a circle of bravery, of hope and the expressed will to make a difference together.

So I thank all members of this committee for the vital work that you do, day in, day out. We at Heart Valve Canada look forward to working with all of you.

The Chair (Mr. Steve Clark): Thank you.

I'll ask now the Alzheimer Society of Ontario, if you could begin your presentation.

Mr. Kyle Fitzgerald: Good afternoon, Chair Clark and committee members. Thank you for the opportunity to speak with you today. My name is Kyle Fitzgerald. I'm the director of policy and government relations with the Alzheimer Society of Ontario, and I'm happy to appear on behalf of the Alzheimer Society in support of Bill 137, the Planning for Your Silver Years Awareness Week Act, brought forward by MPP Daisy Wai.

The Alzheimer Society of Ontario represents 26 local Alzheimer Societies active in communities across Ontario. Last year, we supported over 70,000 Ontarians living with dementia and their care partners, helping to support our clients in their desire to remain at home as they age. Today, approximately 60% of all Ontarians with dementia live at home, and the overwhelming majority—nearly everyone in Ontario—say they want to age in their own home if at all possible.

Dementia is not a normal part of aging; however, age is the number one risk factor associated with developing dementia. Half of all adults in Ontario know someone concerned about the risk of developing dementia, and a third of Ontarians have a close family member who is living with dementia. There are over 315,000 Ontarians living with dementia today, a number that will increase by 100,000 by the end of this decade and will triple within the next 30 years.

In around 40% of cases, your risk of developing dementia is modifiable, meaning you have the power to delay, avoid or reduce the severity of dementia symptoms by addressing 12 major risk factors starting earlier in life and continuing into older age. What's good for your heart is good for your brain. Quitting smoking, reducing alcohol intake and maintaining a safe level of physical exercise all help to lower your risk of developing dementia as you age. Less obvious factors such as education, hearing loss and air pollution have also been shown to directly impact the risk of developing dementia.

Greater awareness of diseases, including Alzheimer disease and other forms of dementia that can reduce the quality of life of Ontarians as they age, as well as of lifestyle choices we can all make to reduce our risk of developing dementia and other neurodegenerative conditions, is a crucial part of planning for older age. We welcome any and all opportunities, including the awareness week being proposed in Bill 137, to educate Ontarians about common risk factors associated with developing dementia.

Prevention is an important aspect of planning, but it cannot replace advance care planning conversations. All Ontarians, especially those at greater risk of developing dementia, should think about how they wish to be cared for under different scenarios. This should include obtaining information about available medical procedures and treatment options, and what trade-offs you're willing to make to receive these treatments. If you are comfortable doing so, talk about your wishes with family, friends and care providers, and record these wishes so they are clear in times of great stress.

Ontarians may also wish to nominate one or more powers of attorney and a substitute decision-maker you trust to act on your wishes. These are all important conversations that Ontarians, including those affected by dementia, should have to ensure they are planning for their silver years. Your local Alzheimer Society can help you navigate advanced care planning decisions, and I encourage all Ontarians to learn more at alzheimer.ca.

We applaud this bill for encouraging Ontarians to discuss their advanced care wishes; however, the best laid plans will fall apart if the care options Ontarians want are not available to them. Wait-lists for long-term-care beds; underfunding of home and community care leading to a lack of access to in-home care options; and growing wait times to access routine medical procedures, including those used for prevention and screening, all undermine the right of older Ontarians to live out their silver years in accordance with their wishes. We hope that Bill 137 forms part of a broader initiative to expand access to the care options older Ontarians need to age as and where they wish.

We also draw attention to Bill 121, the Improving Dementia Care in Ontario Act, which has been referred to this committee. We urge the committee members to call this bill for consideration at the earliest opportunity as a means to further support older Ontarians, including those living with dementia, in their desire to age with dignity at home.

We thank the committee for considering Bill 137. We are proud to express our support for this legislation and thank you for your time. We would welcome any questions committee members may have.

The Chair (Mr. Steve Clark): Thanks to all of you for your presentations.

We'll now move into the questions and comments section. We're going to start the first rotation with the independent members. You have four and a half minutes for your questions. MPP Shamji.

Mr. Adil Shamji: Great. Thank you very much. My first question is for the Alzheimer Society of Ontario. Thank

you very much for your presentation. I also want to thank MPP Wai for introducing this legislation as well. Earlier, she said that this legislation could be a first step towards increasing awareness around planning issues, and then, in a second step, there could be awareness and education programs and that kind of thing. Could you speak a little bit to what those kinds of programs could look like?

Mr. Kyle Fitzgerald: Yes. Thank you, Dr. Shamji, for that question and for that point. Ultimately, individuals who are living with dementia will have different care needs as they progress through their dementia journey, and that's an important part of advanced care consideration as well, checking in at those various progression and transition points and planning ahead as well. For example, Ontarians may wish to avail themselves of home renovation tax credits if they're planning to have live-in support, live-in PSW or nursing support. They may wish to move closer to a long-term-care home that has a shorter wait-list, or indeed, may have to make lifestyle decisions based on where they can access care options.

We know that Ontarians living in rural and northern communities and those on Indigenous reserves have chronically lower access to home and community care options and, unfortunately, that does limit the care planning decisions of some Ontarians—all considerations that folks will have to make as they plan for a deterioration of their health and for aging as and where they wish.

Mr. Adil Shamji: Would it be helpful or would you be supportive of additional language in the bill that would outline some of the steps or some of the commitments that the government would make in order to increase the education and awareness after declaring this awareness week?

Mr. Kyle Fitzgerald: Certainly, we wouldn't want to derail a positive step in favour of two positive steps but would welcome any and all commitments for greater education and awareness of Alzheimer's disease and other forms of dementia. We certainly do hope that the creation of an awareness week would not be the goal in and of itself, but would welcome initiatives during this awareness week, later this year, if this bill passes, to encourage Ontarians to be more aware of the risk factors for developing dementia. I certainly do hope this isn't the final step.

Mr. Adil Shamji: I agree with you on that. Thank you very much for your comments.

Turning now to Heart Valve Voice Canada, I'm curious to know: We declare Heart Valve Disease Awareness Day and Week. What do you think should happen next?

Mr. Len Crispino: Ellen, do you want to take that?

Ms. Ellen Ross: Sure. Thank you for your question. I think raising awareness around valve disease is the first step in the enormous activity that we need to tackle. Like I said, awareness levels are extremely low, and that's the first step in the patient journey pathway. It's awareness, then detection, diagnosis, treatment and recovery.

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We know there's been tremendous advancements in treatment options over the last 10 years—

The Chair (Mr. Steve Clark): One minute left in the round.

Ms. Ellen Ross: Okay.

And so the first step is for patients to be aware of what valve disease is, what the symptoms are, and so they can seek getting it detected through a simple stethoscope check and then start accessing care.

Mr. Adil Shamji: What do you think is the biggest barrier to awareness?

Ms. Ellen Ross: Oh, it's a great question. I think there are several. One is that the symptoms mimic the general signs of aging. Often we hear patients say, "I just thought I was getting older and that the extreme fatigue was part of it." I also think there is—valve disease affects four different valves, and so there are multiple conditions under the umbrella of heart valve disease.

We have an opportunity to reach those that are most at risk and let them know about heart valve disease.

The Chair (Mr. Steve Clark): We'll now move to the next round of questioning from the government. Ms. Wai.

Mrs. Daisy Wai: I have a quick response to Kyle first, and then I would like to ask a question to Mr. Len Crispino later.

First of all, thank you, Kyle, for representing the Alzheimer Society, for coming to meet with us today. We'll definitely be working very closely with you. If we have the bill passed this year, if we can do anything in time for November, we will try to do that sooner but definitely in a bigger space next year, the following year.

I just also want you to know that, being the parliamentary assistant for the Ministry for Seniors, the Alzheimer Society has been receiving different funds from us and also working very closely with the York Regional Police on this—and thank you very much. I look forward to partnering with you and continuing to get you to educate our community.

Now I have a quick, quick question for Len—or maybe for Ellen as well. I thank you for sharing with us your experience. Before I say anything, I just want to say thank you. For 28 years, you have been serving for the province and serving in the different ministries. I thank you for that, and I thank you for serving for the Ontario Chamber of Commerce. I've known you for so many years, and it's great for you to do something so meaningful now to speak on behalf of the Heart Valve Disease Awareness Week and on behalf of the association.

My question for you is: Last week we had a special announcement for York University having the medical school. Other than just having the awareness to the public, what will you be planning to have this as part of the training for the medical school—not the one that we're going to build or is being built, but all the medical schools that we have now? What can we do to train them so that they can diagnose this sooner and help people earlier?

Mr. Len Crispino: Thank you very much. First of all, the 28 years were the 28 most wonderful years I've ever had, so thank you for that.

In terms of what else can be done: I think it's our view that there is no panacea, that we cannot just rely on gov-

ernment. We can't just rely on ourselves. We all have to be able to work together, and so any attempts to assist in what I referred to earlier as that "circle of bravery," I think will go a long way. Each one of us has a contribution to make. The family doctors and other doctors obviously have an extremely important role to play. The education of those doctors is very, very important, but also educating patients, because they too are part of the mix, and they too have to bring to the attention and the awareness that perhaps they need to ask the questions that are required of them from time to time. So I don't think it's a panacea. I think it's all of us being able to work together and bring our resources in a way that will serve communities right across Ontario.

Mrs. Daisy Wai: Thank you.

The Chair (Mr. Steve Clark): MPP Cuzzetto.

Mr. Rudy Cuzzetto: I would like to thank Ellen and Len for being here.

In the next five years, Ontario's seniors population will increase by 15%. How will this impact your awareness of heart valve disease?

Mr. Len Crispino: Ellen, do you want to start and I'll continue on?

Ms. Ellen Ross: Sure, absolutely. I think it highlights the absolute need for us to increase our awareness, because we know that about 13% of people over the age of 75 have heart valve disease. So we need to reach the most at-risk population, and we need to change those agist assumptions that slowing down, fatigue and not being able to do what you were able to do three months ago or six months ago is just a normal sign of aging. That's why Bill 66 is so important, because it will really help further our work in educating those most at risk.

Mr. Len Crispino: I would just add to that that obviously the elderly is a very special group. But it's not confined just to the elderly. There are a lot of young people that are facing some of these issues, and there are a lot of communities that, perhaps through no fault of their own, are perhaps not aware, not involved. And I think all of us have a responsibility to engage all of these people within the whole gambit of trying to look at this question in a more holistic fashion.

The Chair (Mr. Steve Clark): MPP Kusendova-Bashta.

Ms. Natalia Kusendova-Bashta: Thank you very much to the presenters today.

I have a question for the Alzheimer Society of Ontario. With regard to planning for the silver years, can you tell us a little bit what you are seeing when families don't have a plan and then there is a progression of dementia or a new diagnosis of dementia? How does it impact that family in the vacuum of a plan? If there isn't a plan, what are the impacts felt by the family that has to deal with the decision-making?

Mr. Kyle Fitzgerald: Thank you, MPP Kusendova-Bashta, for the question. What we find universally is that a lack of planning leads to greater stress in an already stressful situation. So we find that individuals second-guess themselves. They have difficulty—

The Chair (Mr. Steve Clark): You've got about a minute left, Mr. Fitzgerald.

Mr. Kyle Fitzgerald: They have difficulty making decisions, where perhaps making that, with a clear mind, in advance, being able to have time to discuss that—as compared to when you throw in the stress of a neuro-degenerative condition and all that that entails, in addition to having to look ahead when you're struggling just to make it through the day. It is very difficult to plan for three, four, five years down the road. It is a very stressful situation when families don't have those conversations in advance of when they're needed.

The Chair (Mr. Steve Clark): We've got about 20 seconds left. Anybody want the 20?

Okay, we'll move over to the official opposition.

MPP Lise Vaugeois: Thank you for being here. My question is for Kyle about Alzheimer's. I think about how family members are impacted and how, many families, it's the families who actually carry the weight and try to keep things going. When people are older, it's often a senior—one partner who's carrying the weight of trying to look after the other partner.

I also see the Alzheimer Society in Thunder Bay doing incredible work, but they have very little funding. So I'm wondering, in terms of support for various Alzheimer societies around the province, whether you find that you're coming up against limitations in how much educational work you can do, given that funding has been frozen for such a long period of time.

Mr. Kyle Fitzgerald: Thank you for the question. What we find is, we're increasingly reliant upon the generosity of our communities, and depending on the location in the province, if you are in a community without great financial means and perhaps not a large business community who is able to make larger donations, our capacity to support is somewhat more limited. So we're finding there is certainly an unmet need, not only on the educational side but on the care provision side as well.

Unfortunately, the most intensive form of community care is usually an adult day program. In some regions of Ontario, wait-lists for those programs can stretch to over nine months. With dementia being a progressive disorder, if you're waiting nine months for a care option, you may no longer need that program once you are at the top of the wait-list. So, that does make it very difficult to plan ahead, because families don't know that the care they need is going to be available to them.

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What we see is individuals are being supported in environments that are either too intensive or less intensive for their needs. So, individuals are taking the first long-term-care bed they can because they don't know if it will be available for them in, say, two years, when they actually need it.

On the flip side of that, we're seeing clients with very intense care needs—so, clients who are at the later stages of dementia—are coming to our art programs or are coming to our music therapy programs. Certainly, they are welcome and we will care for them to the best of our staff's ability, but those are not meant for individuals who need round-the-clock care. That does make it exceedingly dif-

difficult to plan for the progression of your disease when you don't know that those transition points will be managed well.

MPP Lise Vaugeois: Thank you.

The Chair (Mr. Steve Clark): Go ahead, Ms. Gélinas.

Mme France Gélinas: So, my first question will be to Heart Valve Voice Canada.

So, in the bill, there are two parts: a day of recognition and a week of recognition. I kind of find it odd that we have two different dates, and I was wondering, do you feel this is the best way forward? I'll start by saying we're 100% in support. We want this bill to go through. We want it to receive third reading, royal assent. We want people to learn more and learn about heart valve disease, 100%, and I think you're going at it—it's a step in the right direction. Many other steps could be taken, but this is an important step that we will support. It's more a question of why a day and a week and the two of them separated by four months.

Mr. Len Crispino: Well—go ahead, Ellen. I can add on.

Ms. Ellen Ross: Okay, super.

That's a great question, and thank you for your support. The reason being is, as you know, we live in a very global world, from a communications perspective. The US initiated Heart Valve Disease Awareness Day, and it's recognized across the US, on February 22. A global organization initiated heart valve disease day for a week in September. So, we felt it was a good opportunity for us to contribute and raise awareness and share those messages on those days. Like I said, it's a global world and everyone sees those messages across social media etc. It also provides us extra time to—we often will be going out into communities, trying to host some stethoscope screening events and so we can do it both either on February 22 or for a week in September. So, it just provides us a broader opportunity to reach more people.

Mr. Len Crispino: I would just add that, given the low awareness of some of these issues, timely reminders at different points during the year are very, very important. And we also hold events such as stethoscope checks that could best be done during a longer period of time, so the one week provides a real opportunity to go into the various communities across Ontario and hold some of these events. I know a couple of you—Mr. Cuzzetto has been involved in one of these. These are inexpensive to do, and they're non-invasive, and they provide a very good track record of what is possible and to detect heart valve issues that otherwise would have gone undetected.

Mme France Gélinas: So, just curious, the stethoscope check—your organization provides of those? Who provides those?

Mr. Len Crispino: Yes, we do provide them, within the limits of our resources, obviously. Let me just give you one very quick example: We held one in Quebec about a month ago. There were somewhere in the order of 60 people, I believe, and we found that about 9% of those individuals had undetected heart murmurs. It doesn't sound like a big number, but when you look at the impact of that 9% on families, communities, it's extremely important.

The Chair (Mr. Steve Clark): You've got about one minute left.

Mme France Gélinas: You shared the statistics of 13% of people over 75 years old. Do we have statistics for people over 60, people over 65?

Mr. Len Crispino: Ellen?

Ms. Ellen Ross: Yes, great question. The data around heart valve disease is actually very difficult to get, mostly because we don't know how many people are actually walking around with it undiagnosed.

Why we target people over 60? For two reasons: They could be a care provider for an elderly parent that might have heart valve disease. So we're trying to increase awareness before they get to that critical stage themselves, but also as a potential care provider.

I also just want to acknowledge that when you asked about the stethoscope checks, we work quite closely with the Canadian Cardiovascular Society in hosting these stethoscope screening events and rely—

The Chair (Mr. Steve Clark): Okay, we're going to move, Ellen. Just hold that thought for the next round.

We're going to do the final round of questions for the independent members. MPP Brady.

Ms. Bobbi Ann Brady: Thank you to our three presenters this afternoon. Of course, thank you to MPP Cuzzetto and MPP Wai for your passion and your compassion on these two very important bills.

I'm going to start with Bill 66 because it's near and dear to my heart. Much like Mr. Crispino, I too at 16 was diagnosed with a heart murmur, and mine is benign, and I've been very lucky so far, but I have passed it on to my first-born, and I worry about her and what the future of her health care looks like.

I do want to follow up with respect to the stethoscope check and I'm going to build on some of the things that MPP Gélinas was talking about. I am supporting these two bills, but we need to work hard to make sure that we get the very best when we put forward this type of policy.

I'm just wondering—I remember when I was a child. The first thing the family physician did when you sat down in the office was he did a stethoscope check, and I feel that that has fallen by the wayside. I'm wondering if there's any work being done with family physicians across the country to ensure that that stethoscope check is done every time a patient walks into the office.

Mr. Len Crispino: Well, we try to work with all groups, obviously, and doctors play a vital role in this. Our view is that it's a symbiotic relationship with the doctor and the patient, being able to work together so that we can work on the awareness level to help the individual to raise the question of if they're not getting the stethoscope check, why not?

Ms. Bobbi Ann Brady: I think that's a good point in being a patient, to advocate for yourself, because I know—and I see on page 12 of your very good handout here that box 2 says, "The patient care journey is often different for women," and it talks about how women are often bypassed in this situation.

I know, as a female, I have presented at the doctor's office before, and I do have the heart murmur, and it's chalked up to anxiety, it's chalked up to stress—probably working in this business. I think that we do have to do more with respect to teaching the patient to really advocate for some of these things and I think the stethoscope—I have a hard time with that word today—check would go a long way.

Mr. Len Crispino: Thank you. That's certainly something of importance to us because everyone has a role to play in this.

Ms. Bobbi Ann Brady: Yes, absolutely. Okay, thank you very much.

I'll turn to Mr. Fitzgerald and the Alzheimer Society of Ontario. I want to thank you for all the work that you do on a daily basis across our province to support those with Alzheimer's and dementia, as well as their families, and of course, for being here today.

I just have a quick question with respect to Bill 137, and again, I am supporting this bill. How important do you see financial literacy being part of this advocacy?

Mr. Kyle Fitzgerald: Thank you, MPP Brady. I would say it's extremely important because getting old is expensive. Your financial means greatly impact the quality of life you have especially if you have care needs as you age.

The Chair (Mr. Steve Clark): You've got one minute remaining.

Mr. Kyle Fitzgerald: These situations we find ourselves in is if you have the means to pay for private in-home care, which can run north of a quarter of a million dollars a year, you're able to live at home essentially indefinitely. If you have the ability to drive to the United States and pay \$500 for an MRI scan, you're able to bypass that six-month wait time.

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So, financial literacy, from that respect—and also, as well, making sure that we are combatting financial elder abuse, individuals who have been and continue to be taken advantage of by their powers of attorney, who are not acting in their best interest; making sure that isn't something that we stumble into, but that Ontarians are being very conscious of who they would choose as their POA, what safeguards are being put in place; and making sure that Ontarians who have worked hard their entire life have their nest egg being used in their best interests.

Ms. Bobbi Ann Brady: Okay. And quickly: Do you see the majority of families before you—

The Chair (Mr. Steve Clark): That concludes the round, MPP Brady.

I'll turn back over to the government. MPP Jordan.

Mr. John Jordan: My question is around detection. I'll go back: In the 1990s, my father, like MPP Cuzzetto, had a heart valve replacement. Very active—he was MPP for Lanark–Renfrew then, and just happened to be in Ottawa and end up at the Ottawa heart institute. It was all successful, and he moved on. Now, three decades later, a friend and neighbour, two weeks ago, had a sudden heart attack and was not so fortunate.

So when we're talking about detection and getting a stethoscope analysis, if you will, what is there for the family

members, and how would this bill help for family members to identify symptoms of heart valve disease?

Mr. Len Crispino: Well—Ellen, you go ahead.

Ms. Ellen Ross: I was going to say that's a really great question, and we often hear that it's the family members that notice the symptoms a little bit clearer than the patient themselves. They notice that they're slowing down. Everyone, as we age, slows down a little bit, but as it has been described to me, if you used to be able to walk to the grocery store three months ago and now you're very winded and fatigued, that is not a normal window or period where you're going to slow down and get fatigued. So we really try to communicate to caregivers as well and educate everyone about the signs and symptoms and to help them advocate for their family member to ask for a stethoscope check and see if there can be a murmur that was detected.

Mr. Len Crispino: I would just very quickly add that, in many cases, individuals are asymptomatic, and so they may think they're doing well. So it's really important that the families and the individuals look at the whole idea of stethoscope checks on a regular basis, even though they may feel well.

The Chair (Mr. Steve Clark): MPP Quinn.

Mr. Nolan Quinn: Thank you for everything that both Len and Ellen are doing at Heart Valve Voice Canada.

As MPP for Stormont–Dundas–South Glengarry, I represent many seniors. We have an aging population. Is there something that we as MPPs could do to help raise awareness?

Mr. Len Crispino: Ellen?

Ms. Ellen Ross: Sure. Thank you. You have a network of many people that you can reach with a message. So first and foremost, I'd say, if you could utilize your various communication channels to share the message during our awareness campaigns, either through a newsletter or on your social media, that's a fantastic first start. As well, if you know of anyone with valve disease that's interested in sharing their story with us, we know that patient stories are truly inspiring for others that are going through valve disease. And also, let them know that they can go to heartvalvevoice.ca, our website, to find resources that will support them. But I would also welcome the opportunity to talk to you about potentially hosting a stethoscope screening event in your community, like MPP Cuzzetto did during valve disease day.

Mr. Nolan Quinn: Thank you.

The Chair (Mr. Steve Clark): Anyone else?

Ms. Natalia Kusendova-Bashta: Chair?

The Chair (Mr. Steve Clark): MPP Kusendova-Bashta.

Ms. Natalia Kusendova-Bashta: Back to the Alzheimer Society of Ontario: You've outlined the trends we're expecting in terms of our aging population and more seniors having a diagnosis of dementia. Can you tell us, maybe, what in your opinion and expertise is the biggest barrier to access to care for those seniors and their families?

Mr. Kyle Fitzgerald: I would go two directions here, the first being stigma. It can be extremely difficult for families to have conversations around dementia, especially in certain communities where that just isn't talked

about, where you don't discuss that openly. So if individuals are not open to even admitting that they are living with dementia, it can be difficult and it can stress relationships, as well, because you know something is wrong but don't know what it is.

Obtaining the diagnosis, as well, can be difficult. Actually, when Ellen was talking earlier in her testimony about how sometimes heart valve conditions are written off as a normal part of aging, the exact same applies to dementia. We hear consistently from older Ontarians who go into their doctor's office and express concerns about their cognition and are told, "You're just getting old." Certainly, some memory loss is expected, but forgetting the names of close relatives or consistently not showing up to appointments is not a normal part of aging, and when you have a trusted care provider dismissing your concerns, that can make you doubt yourself, undermine your confidence in advocating for your own care needs. So, there are those two directions around stigma and lack of access to a probable diagnosis for Ontarians living with dementia.

Ms. Natalia Kusendova-Bashta: Can you speak a little bit to the language barriers? We are in such a multi-cultural province, especially in the GTA. What kind of role can a language barrier play in obtaining a diagnosis, and then in the actual progression of the disease?

Mr. Kyle Fitzgerald: There are actually some cultures that don't have a word for dementia, in that, in some cultures, it translates literally to "losing one's mind." And obviously, that's not something you would want to talk about. So, just from that most basic language point of view, there's a different understanding of what dementia means.

Making sure that there is access to culturally appropriate care, both at home and in community and in long-term care, as well, is crucial.

The Chair (Mr. Steve Clark): There's about a minute remaining.

Mr. Kyle Fitzgerald: So, ensuring that when individuals walk into whether it's the Alzheimer Society or another care option, they have materials available in their language. That's something that we try to do at the Alzheimer Society. All of our materials are bilingual in English and in French, but we know that those aren't always the most spoken languages, so looking to translate more materials into languages of growing minority communities is work that we've undertaken. But we also want to make sure that families are able to access culturally appropriate care, as well, and that is something that we're working on.

Ms. Natalia Kusendova-Bashta: Our most recent budget had some investments for behavioural support units, as well as \$2 billion for home care. Is this a welcome investment by the Alzheimer Society?

Mr. Kyle Fitzgerald: Both of those investments are welcome, and I would say, actually, our CEO did give a supportive quote on those behavioural support units in long-term care. As a broader piece, keeping people out of long-term care should be the ultimate goal, but we, of course, support greater access to beds.

The Chair (Mr. Steve Clark): Thank you.

We'll now move to the official opposition for their final questioning. MPP Vaugeois.

MPP Lise Vaugeois: Okay, just a couple of short questions—about heart valves, I was diagnosed with a heart murmur when I was young. Apparently I have outgrown it, but I was told at the time I always had to take antibiotics if was ever at a dentist appointment, so I'm wondering if that's still there.

And then the second part of my question is, how do you go about setting up a stethoscope clinic? We have a medical school in Thunder Bay. Should I be knocking on their door and saying, "Let's do this"?

Mr. Len Crispino: Let me take that question. I happen to take, as well, antibiotics, because the fear is infections on the heart valve. So that's still ongoing. I will probably have to take those for life. I don't like to do that, but that's the reality.

Secondly, in terms of stethoscope—I would just leave you with one piece of imagination: Imagine 107 ridings across this province sponsoring stethoscope checks, and imagine the impact that that could have within this province.

I will stop there.

MPP Lise Vaugeois: Thank you.

The Chair (Mr. Steve Clark): MPP Gélinas.

M^{me} France Gélinas: I love your idea. There are 124. There used to be 107. We're now 124 MPPs. That's a beautiful, beautiful idea.

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My last question with heart valve disease is that I represent a riding in northern Ontario, mainly rural, 33 little communities—Biscotasing, Westree, Shining Tree. Nobody knows where they are, but I do, and 40,000 people do not have access to primary care, so there's always that little bit of anxiety that comes with—so I'm going to tell people that they are at risk, that they should get checked, but they have no access to primary care, so no way to get checked. How do you balance that?

Mr. Len Crispino: Ellen?

Ms. Ellen Ross: That's a good question. One thing I can tell you is that the University of Ottawa Heart Institute has just initiated a mobile screening clinic that goes to remote communities in Ontario. I think they have a nurse practitioner who goes with a handheld echo and checks not only for valve disease, but other cardiovascular risk factors. I would suggest you might want to connect with them, and I can connect you, because they are continuously looking for new communities to go to. They've had tremendous success. They just started a couple of months ago, and it's a great initiative, so that might be something that your community could do during Heart Valve Disease Awareness Week in September.

M^{me} France Gélinas: I'd love that. If you can send that—even if MPP Cuzzetto has this, if he can share that with me—I would much appreciate it. And congratulations to MPP Cuzzetto for bringing that forward.

My next question is to the Alzheimer Society. You started with lifestyle choices for health promotion, disease prevention, toward Alzheimer's and other cognitive im-

pairments and progressive neurodegenerative conditions. How can you make those better known? Why is it that once a person is on the journey to get diagnosed, they find out that, “Oh, if I exercise regularly, if I don’t drink as much,” etc.—but how do we bring this way sooner, when health promotion and disease prevention has the most possibility to have a positive impact?

Mr. Kyle Fitzgerald: That’s a good question. Your risk factors for developing dementia do start very early. We know that children who don’t have the same access to education, safe educational spaces, are at greater risk of developing dementia 60 years later, so making sure that there is awareness of those healthy lifestyles starts in school as well.

Part of it comes down to how there is disincentive in the health care system to have those fulsome conversations. Having a conversation about lifestyle choices, about prevention techniques, going through dietary and exercise choices all takes time, and unfortunately many care providers don’t have time for those conversations, so looking to ensure that there is just as much incentive to discuss prevention as there is to offer a prescription would be one place to start.

M^{me} France Gélinas: Does any group in our health care system do this well, to share health promotion, disease prevention, let’s say specifically for neurodegenerative conditions, but in general? Are there groups you work with that do a good job of that?

Mr. Kyle Fitzgerald: I think some other disease spaces—cancer comes to mind. There are progression points. When you hit—I believe it’s 50—in Nova Scotia, there is an at-home screening tool for certain types of cancer that is mailed to every Nova Scotian. Having those touchpoints to really get it in your face—it’s not just putting the onus on patients to go to a website or have a conversation with their doctor, but it is actually the health care system

proactively reaching out and saying, “We recognize that if you develop dementia or if you develop cancer, the health care system is going to have to spend tremendous time and money to care for you.” Spending a fraction of those resources earlier on in life by having those proactive touchpoints pays off further down the line. Looking to have regular touchpoints with individuals as part of their annual checkup once Ontarians enter their sixties so they’re conscious of that, but as well, incorporating dementia into other prevention choices.

The Chair (Mr. Steve Clark): There’s one minute remaining.

Mr. Kyle Fitzgerald: I think there’s generally good awareness that it’s important for your heart health to exercise and to eat well. There’s less awareness that that actually helps reduce your risk of developing dementia as well, so including that in other prevention tactics would also be helpful.

M^{me} France Gélinas: For people living with Alzheimer’s, is the home care system getting better or worse, like the time to gain access, the quality of it, the quantity of it? Are we getting up? Are we getting better, staying the same or getting worse in Ontario?

Mr. Kyle Fitzgerald: Worse, without a doubt. We’re seeing a cannibalization of the system between staff going to hospital and long-term care, staff going to private contractors as well. Unfortunately, unless you have the means to afford it—

The Chair (Mr. Steve Clark): I’d like to thank all three of our presenters for coming this afternoon. That concludes the public hearing portion and today’s committee business for Bill 66 and Bill 137.

The committee will stand adjourned until 9 a.m., Tuesday, April 9, when we’ll have clause-by-clause consideration of both Bill 66 and Bill 137 consecutively.

The committee adjourned at 1356.

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