HOUSE OF COMMONS
CHAMBRE DES COMMUNES
CANADA

# Standing Committee on Health

HESA • NUMBER 029 • 1st SESSION • 41st PARLIAMENT

## EVIDENCE

## Thursday, February 16, 2012

## Chair

**Mrs. Joy Smith**

# Standing Committee on Health

## Thursday, February 16, 2012

● (0845)

[*English*]

**The Chair (Mrs. Joy Smith (Kildonan—St. Paul, CPC)):** I call the meeting to order.

Good morning, everybody. Welcome to the committee.

We're very pleased to have this very important bill before us. Pursuant to the order of reference on Friday, February 3, 2012, Bill C-278, an act respecting a day to increase public awareness about epilepsy, is what we're going to be putting through today.

Before we do that, we have a couple of things to do.

The first thing we're going to do is hear from our witnesses. One of our witnesses today is the Honourable Geoff Regan, from Halifax West. Mr. Regan, we're very happy to have you on the health committee this morning. Welcome.

From the Canadian Epilepsy Alliance, we have Madame Aurore Therrien, a member of the board of directors and executive director of Épilepsie Montréal Métropolitain. Welcome; we're very glad that you're here.

From the Epilepsy Association of Nova Scotia, we have Ms. Iris Elliott, and she is with us via teleconference this morning. Welcome. Can you hear me?

**Ms. Iris Elliott (Executive Director, Epilepsy Association of Nova Scotia):** Yes, I can.

**The Chair:** When we go to questions and answers, Ms. Elliott, raise your hand so I know that you want to make a reply or ask a question, okay? You're on big screens here and we can see everything, but sometimes we get quite interested in our topics, and I might miss you.

We also have, as an individual, Ms. Sarah Ward. Thank you so much for joining us today.

We will begin with a ten-minute presentation by Mr. Regan.

**Hon. Geoff Regan (Halifax West, Lib.):** Thank you very much, Madam Chair, and I thank the members of the committee.

I must say that I was delighted and surprised, even shocked, at how quickly after passing second reading the bill was able to come before this committee, so I really appreciate the committee giving its time to this bill so quickly.

I'm also delighted to be here with three witnesses who know much more about this topic than I do. I expect they may get many more questions than I will, but I'll do my best, obviously.

It is a pleasure to be here. It's strange to be on this side of the table as a witness rather than among my colleagues. I am very grateful for the support that you, Madam Chair, and your colleagues, as well as all members of the House, have shown for Bill C-278. I think it's a great example of how members of Parliament from all parties can come together, put our partisan interests aside, and push for a bill that has an impact on a policeman in Ottawa, a dad in Edmonton, or a little girl in my riding.

In 2008 nine-year-old Cassidy Megan founded Purple Day for epilepsy and started a global trend. I understand that she's actually listening today by radio, so hello, Cassidy.

Purple Day is now recognized in 47 countries; Canada has really been a leader in epilepsy awareness. I'm pleased to hear, and I'm sure you also will be, that other legislatures such as the State of New Hampshire and others around the world are following this with Purple Days of their own. I understand that Purple Day is celebrated in more than 60 countries, and I'm sure we'll hear more about that later.

I think we owe a great debt to Cassidy. I wouldn't be here today without her vision and dedication. In fact, for me it's just a coincidence that she happens to be in my riding. That's really the only reason I'm associated with this initiative. I'm very happy to be associated with it, but obviously it is she who deserves the credit. Bill C-278 is a direct result of her commitment to this cause and of her imagination, as a nine-year-old, to think, “Why shouldn't I start something like this?” Now look at it: it's in over 60 countries in the world. Isn't that remarkable? What a great and inspiring story that is.

This bill is a pretty simple act, as you know. Bill C-278, I think, will help increase public awareness about epilepsy.

● (0850)

[*Translation*]

The bill will officially designate March 26 as Purple Day in Canada and will ask Canadians to wear purple clothing. Purple Day is not a legal holiday, but it touches a lot of lives.

Epilepsy affects 300,000 Canadians and more than 50 million people worldwide. That's more than the number of people living with multiple sclerosis, cerebral palsy, muscular dystrophy and Parkinson's disease combined. A better understanding of this condition would allow people to be more aware of what to do to help someone having a seizure, which will help people suffering from this illness and ensure that they are safer.

[*English*]

Before I go on,

[*Translation*]

…I would like to thank the members who noted that changes needed to be made to the document. For example, in French using *lavande* instead of *pourpre*, and *condition* instead of *maladie*. I want to express my appreciation and say that I support those changes.

[*English*]

This is important for a young dad who wrote recently about his son, who began having seizures at the age of five months. His words were profound and powerful: “As a parent, a professional, and a Canadian, I ask you to please pass Bill C-278 and make the world our son will grow up in a little more friendly and understanding of the condition that affects him, and us, in every moment”.

I also heard from Marcel Allen, an Ottawa policeman who is in the last stages of developing a training program for front-line officers on how to respond to someone with a seizure disorder. This is something you'd understand, Madam Chair, as you were telling me earlier, from your experience as a teacher and having a student with epilepsy who often had three grand mal seizures a day.

Mr. Allen has created a lesson plan focusing on training, recognition, and response. It will be the most comprehensive training of law enforcement on this subject in North America.

Let me wrap up by thanking Cassidy; the Epilepsy Association of Nova Scotia, which has been so helpful; the Canadian Epilepsy Alliance; and the many other organizations that work hard to promote Purple Day and increase awareness about epilepsy.

I'd also like to thank Dr. Fry, who brought a number of amendments to committee. I thank her for these improvements to my bill. Bill C-278 will bring Cassidy's dream to fruition. We hope we can count on the support of all parliamentarians in the House, as we certainly have so far, as well as the Senate, to make this happen.

I want to mention that I distributed cards from the Canadian Epilepsy Alliance to everybody. You'll find them in front of you. I think you'll find them helpful in terms of what to do when someone is having a seizure.

I'll be happy to answer, or try to answer, any questions. Thank you.

**The Chair:** Thank you so much, Mr. Regan, for your very insightful presentation and your commitment to this cause.

We'll also hear from Madam Therrien, please.

[*Translation*]

**Mrs. Aurore Therrien (Member of the Board Directors, Executive Director, Épilepsie Montréal Métropolitain, Canadian Epilepsy Alliance):** Ladies and gentlemen, members of the Standing Committee on Health, good morning. I'm pleased to be here today and to represent the Canadian Epilepsy Alliance, as well as everyone served by our 25 member associations in Canada.

Épilepsie Montréal Métropolitain is a founding member of the Canadian Epilepsy Alliance, which has changed a lot in the past 11 years. Our umbrella group is the result of an innovative project that has enabled us, in the past 11 years, to pool our best local achievements and stay in touch almost daily in order to carry out our mission, which is to improve the quality of life of people living with epilepsy. We have also shared our essential values, our governance principles and our many resources.

In the past 11 years, we have conducted two surveys, created two papers *Question d'épilepsie* and *Parlons d'épilepsie*, launched an annual awareness campaign, which takes place in March, created two websites—"Epilepsy Matters" and "Purple Day"—and a phone number 1-866-EPILEPSY, designed various brochures and a number of projects. Our material has been published from the very start in both official languages—English and French. Over the past few years, we have had a representative at the International Bureau for Epilepsy. We have also established several partnerships with, among others, the Canadian League Against Epilepsy and with Neurological Heath Charities Canada, to name but two.

It's already been five years since the first Epilepsy Day was held on March 26 thanks to the initiative of young Cassidy Morgan, with the support of her family, her school and her local epilepsy association in Nova Scotia. She also received the unfailing support of Deirdre Floyd, who I'd like to say hello to today. Since then, she has been responsible for the national Purple Day committee and the international Purple Day committee. Ms. Floyd would have been with us today, but she is awaiting surgery to change a neurostimulator implant. So I commend her today for the significant amount of work she has done in the past five years. This initiative snowballed and today exists in many countries and, as of this year, on five continents, including the scientific research stations in the Arctic and in Antarctica.

I invite you to take a look at the video on www.purpleday.ca, showing images of children, adolescents and adults from around the world proudly wearing purple clothing in their daycares, schools, and workplaces. Today Cassidy and her many friends can say that they are no longer alone. At little Cassidy's request, they have all—in very large numbers—become ambassadors for epilepsy. They can finally dare to talk about this neurological condition in public, and that's just the beginning.

This is undeniably the largest awareness campaign dealing with epilepsy. So you'll understand why Bill C-278 is so important for all people living with the effects of epilepsy in Canada.

The colour purple has been associated with epilepsy for a few years now. It traditionally evokes isolation and solitude, but for little Cassidy, who was 9 years old when she created Purple Day, all shades of this colour were the same. That's why we kept the name "Purple Day" in English, because it was Cassidy's choice, it was her creation. We did not change the name in English. We kept the colour "*lavande*" in French for all French speakers in Canada. Our materials are created not only for Quebec, but also for all French speakers in Ontario, Nova Scotia, New Brunswick and Manitoba. So they are very pleased to receive our materials.

Once again, thank you for your invitation and for your attention to our request.

Thank you very much.

● (0855)

[*English*]

**The Chair:** Thank you.

By video conference, we now have Ms. Iris Elliott. She is the executive director of the Epilepsy Association of Nova Scotia.

Ms. Elliott, you have a 10-minute presentation, and we'd love to hear from you.

**Ms. Iris Elliott:** Thank you. Thank you very much for giving me this opportunity to speak to the committee.

I would also like to thank Mr. Regan and his staff for the great cooperation we have received in developing Purple Day.

When I walked into the Epilepsy Association of Nova Scotia in June 2005, I knew virtually nothing about epilepsy. Actually, the only creature I ever knew that had anything to do with epilepsy was a dog that used to have what we called fits. I very soon learned that we don't use that term anymore. Another thing I learned very firmly that first day from Ms. Floyd, our president, was that we do not talk about people as being epileptics; we talk about people with epilepsy. Those were two very interesting things that I learned my very first day, because I knew nothing. I would say that I'm as reasonably well informed as anybody else. I knew nothing about epilepsy, and this is one of our problems: the general public knows so little about epilepsy that they fear it. They fear the results, both what they see and what they don't know.

One of the saddest things I have heard—which I heard when I first started with the Epilepsy Association of Nova Scotia, and it's with me to this day—was that people with epilepsy say that the attitudes of people around them cause them as many problems as their condition does. I really think it's very sad that people dealing with this condition, which can sometimes be very violent, find that it's the attitude we have that causes them more problems. I very soon realized that these attitudes had to be changed and that the mandate of the Epilepsy Association of Nova Scotia was to change attitudes to make life better for those people. There are 10,000 people in Nova Scotia who have epilepsy.

In common with all of the agencies in the CEA, the Canadian Epilepsy Alliance, one way we do this is through a classroom education program. When I first started at the epilepsy association, I was not the executive director. I was in charge of outreach. One of the basic things I did was go out to schools to try to start changing the attitudes of our young people, in this case in grade 5.

I was the person who went out to Cassidy's school. Cassidy, of course, is the founder of Purple Day, but we didn't know it then. I went out to her school to give a presentation to her class because her mother wanted her class to know a little bit about epilepsy, even though Cassidy had not told anyone other than her closest friends. She was afraid people would laugh at her and that nobody would want to be her friend.

I gave the presentation to the children, who were quite little. They weren't in grade 5, which is the grade we normally give the presentation to. I read a story, and I had a sock puppet, a rabbit. The story was called *Lee: The Rabbit with Epilepsy.*

I gave the presentation and showed them the puppet and everything. Afterwards, Cassidy, quite out of the blue, stood up and said, “I want to tell everybody that I have epilepsy.” Her mother was absolutely floored, because Cassidy had never told people in public.

That was the beginning of it all. Cassidy then went home and said to her mother, “Is there any time that people can find out more about epilepsy, a special day when we can support people with epilepsy?” She said she felt that she didn't know anybody else with epilepsy. She didn't know any kids with epilepsy. She thought she was the only person with epilepsy. Her mom said, “Well, I don't think so.”

Cassidy, who was nine years old, had this idea that she would start something called Purple Day. She asked her school principal if she could have a day at school when they would get people to wear purple. As you can see, I'm wearing purple today. I'm wearing my lovely Purple Day T-shirt. Whenever I go out to the schools, that's what I wear. The kids always comment on it. They say, “I like your T-shirt.”

Cassidy had this idea. She talked to her principal. It was the principal who decided on March 26, purely arbitrarily. He looked at his diary and said, “All right, Cassidy, you can have March 26.” This is where it all started.

● (0900)

Cassidy, her mom, the Epilepsy Association of Nova Scotia, Mr. Regan, and many more people—eventually, the whole of the CEA—as well as people in the States, all over Canada, and all around the world now celebrate Purple Day.

To go back to early on, one of the things I want to tell you a little bit about is what I do to try to raise awareness, which is what Purple Day is all about. When I go out to the schools, one of the things I do with the kids—it's an interactive presentation—is to show them a video of a tonic-clonic, or grand mal, seizure. I get volunteers to act out the commercial, and they act out the little boy or the little girl having the seizure and what the people around the child do. Do they know what to do, or do they not know what to do?

The children act this out, and in this way they learn what to do if somebody is having a seizure. I also talk to them a little bit about how they think that person would feel, having a seizure in front of all of his or her friends. What do you think you could say to this person to make him or her feel better? If the person says to you, “Oh, I feel so embarrassed. I just had a seizure, and everybody thinks I'm stupid now”, what would you say? I get the children to come up with answers, and they always do. They always begin to think of how it would feel.

This is part of what we do. We're trying to get people who don't have epilepsy to realize and feel what it's like to have this condition, to be more empathetic towards people who have this condition, and to learn more about it, so that if they see somebody having a seizure, not only do they know what to do, but they're also not scared by, it because they know what to do. It's not the great unknown.

The wonderful thing about Purple Day is that there are so many levels of involvement. We can just say to people, “All right, Purple Day—can you just wear purple on Purple Day to show people with epilepsy that you care?” That would be your basic level. Then it grows, and you can get people, as well as wearing purple, to hand out ribbons, hand out cards, do fundraisers, or make purple cookies or cupcakes. It's whatever they feel comfortable with. It's all involving and it's all-encompassing. Anybody can do it. This is how Purple Day has grown: you can just get involved a tiny bit, and then next year maybe you can do more.

This is what's so wonderful about Purple Day. What would be so wonderful about having the Purple Day Act is that Purple Day would be officially recognized so that everybody would know that this is the day when we wear purple, we learn more about epilepsy, and we support people with epilepsy.

Among the many things people with epilepsy have to contend with is the fact that people don't know much about it. Sometimes people may think that because someone has epilepsy, they are stupid or not very smart. One of the things I do during my presentation is get the students to look at pictures of people with epilepsy who have accomplished marvellous achievements, so that the students recognize that people with epilepsy are not necessarily stupid. Some people with epilepsy probably aren't too bright, and other people with epilepsy are very bright. It's just like the general public.

A lot of the time, epilepsy is misconstrued. If someone has a seizure in public, people think the person is drunk or stupid. People with epilepsy have been arrested, thrown in drunk tanks, and tasered because they were having a seizure and the first responders who reacted did not know the person was having a seizure. The responders thought the person was drunk or stupid.

This is the big thing about Purple Day. Not just on March 26 but all the year round, what we in the Epilepsy Association of Nova Scotia, the Canadian Epilepsy Alliance, and people around the world are trying to do is raise everybody's awareness so that people with epilepsy will have a better life.

In conclusion—

● (0905)

**The Chair:** Ms. Elliott, I'm sorry to interrupt, but you do have just 30 seconds left, and then we go into our next presentation.

Thank you.

**Ms. Iris Elliott:** I'm just winding up, Madam Chair. Thank you very much.

I'd just like to thank the committee, once again, and to say that the 300,000 people in Canada, including the 10,000 people in Nova Scotia, will thank all of you very much for passing this bill, which will make Purple Day an official Canadian day.

Thank you.

**The Chair:** Thank you so much, Ms. Elliott. That was very helpful. We appreciate your presentation very much.

Now we'll go to Ms. Sarah Ward.

**Ms. Sarah Ward (As an Individual):** Good morning, everyone.

As Madam Chair mentioned, my name is Sarah Ward. I'm here to speak to you today about why I'm such a huge supporter of the Purple Day initiative.

I'm currently a first-year medical student at the University of Ottawa, and prior to my studies here in medicine, I was at Dalhousie University in Halifax, working on my master's project in medicinal chemistry.

It just so happened that my assigned project was specifically focused on the design and synthesis of antiepileptic drugs. Prior to my graduate studies, like the majority of the population, I didn't really know a lot about epilepsy or what it would be like to live with the disorder, and I soon became aware of just how little I knew when I started doing the background reading for my project. I also realized that a lot of what I thought I knew was actually wrong.

My project piqued my interest in the subject, and I soon felt compelled to get out there and become more involved, so I started volunteering at the Epilepsy Association of Nova Scotia. I went there and I met with Iris. She found the perfect position for me; as a volunteer, I ended up working with the fun club, which is a social group for people with epilepsy. It allows them to meet other people with epilepsy and experience activities in the city that they otherwise might not be able to afford.

I had the chance to work closely with many of the members there who have epilepsy. They're a very inspiring group, and they're actually a big part of why I ended up applying to medicine. I was also involved with a number of fundraising efforts there, and I eventually became a general member of the EANS board of directors.

I don't have epilepsy and I can't give you a first-hand account of what it would be like to live with the disorder, but hopefully through my research experiences and my time at the EANS, I can convince you that having an official day for epilepsy awareness would have an immensely positive outcome.

I know these statistics were already mentioned, but I think they're worth mentioning again, because they're very important and impressive: epilepsy affects 0.5% to 1% of the population, which translates to approximately 50 million people worldwide, and as Mr. Regan mentioned, there are more people with epilepsy than there are with cerebral palsy, Parkinson's, MS, and muscular dystrophy combined. It's an impressive figure. It's quite a common neurological condition.

Interestingly enough, the word “epilepsy” is derived from the Greek word “epilepsia”, which literally means “to be seized or taken hold of”. This demonstrates the once-popular belief that seizures were a result of demonic possession or punishment from the gods. This isn't a common belief today, but I think there is a significant amount of stigma still associated with the condition.

For example, members of the adult population often have a negative image of epilepsy because it's sometimes incorrectly associated with mental health issues or anti-social issues, or even with violent tendencies. I think, in most cases, the stigma concerning epilepsy arises simply from ignorance. People fear what they don't know, so I think having a day designated to raising awareness about epilepsy would certainly help fix this problem.

Furthermore, I think Purple Day would also make individuals who have epilepsy feel much more accepted. I think it would provide them with a sense of belonging and a sense of empowerment. I think it would make them feel more comfortable with being open about their condition and perhaps even encourage them to become spokespeople within their own community, thus increasing awareness further.

Not only would Purple Day improve the psychological health of individuals with epilepsy, but I think it would also really benefit their physical health. Educating the public on proper first aid techniques would debunk some of the potentially harmful myths surrounding seizure first aid. For example, despite what many people think, it is physically impossible to swallow your tongue, even if you are having a seizure, so don't stick anything in someone's mouth while they're in a seizure; if you do, you could actually cause them to chip their teeth or choke.

That's just one example; there are many. Something I wasn't aware of, which I think is very important for the public to know, is that if a seizure lasts longer than five minutes, you should call 911, because a prolonged state of seizure, also known as status epilepticus, can cause permanent brain damage and even death.

I also think educating the public on the clinical manifestations of seizures is very helpful, because it can result in earlier recognition and diagnosis and, consequently, earlier treatment and control of seizure disorders.

● (0910)

Again, contrary to popular belief, seizures don't always involve the typical convulsions that you see on TV shows like *House* or *Grey's Anatomy*. As has already been mentioned, this is only one type of seizure; it's known as a generalized tonic-clonic seizure, but there are many other types, many of which don't involve convulsions. For example, a seizure type that's common in children that often goes undiagnosed for a long time is the absence seizure. It can manifest as simply a blank stare and can be accompanied by absent-minded movements like picking at clothing or chewing. As you can see, this could often mistakenly be dismissed by parents or teachers as daydreaming. I think these facts are important for the public to know.

Lastly, I believe that Purple Day would also promote more public participation in epilepsy organizations. In the same way that I decided to volunteer for the Epilepsy Association of Nova Scotia because of my exposure to the disorder through my master's research project, I think that increased public awareness may too encourage other people and the public to become more involved.

Just as importantly, I think it would promote more public donations to various epilepsy-related causes. I know more funding would definitely be beneficial on the research front. Over one-third of individuals with epilepsy are actually unable to control their seizures with medication, and those who do often experience many awful side effects. Much about epilepsy is still unknown, so research is certainly still needed.

Additionally, more funding for organizations like the CEA or like the Epilepsy Association of Nova Scotia would also be extremely beneficial. I've seen what these organizations can do. They have wonderful outreach programs. They provide immense support for individuals and families affected by epilepsy. They've improved the lives of a great many people with this condition, so more funding for them would allow them to expand and just do that much more.

In conclusion, I think that government endorsement of Purple Day is advantageous in many ways. Passing this bill would be a very great step forward. Thank you very much for letting me speak.

● (0915)

**The Chair:** Thank you very much for your presentation, Ms. Ward.

We'll now go into our first round of Q and A. Each person will have seven minutes. We will begin with Ms. Davies.

**Ms. Libby Davies (Vancouver East, NDP):** Thank you very much, Chairperson.

First of all, thank you so much to the witnesses today, and to Mr. Regan for bringing the bill forward. I feel that we've learned a geat deal already, just in the course of half an hour, about epilepsy. I think one of the things that the witnesses have shown us today is the importance of language, in that language itself can be very stigmatizing. If any of us makes a mistake today with language, I'm sure it will be out of lack of knowledge rather than intention, but as you've said, I think that's very much one of the issues around awareness. Making people understand about the way they speak about an issue is really important.

I have two questions. I'm very interested in knowing about people living with epilepsy, particularly in the work environment. Nobody really touched on that. What is the response of employers? What is the work environment like for people living with epilepsy?

We could even begin with our own jurisdiction, the federal government.

Mr. Regan, I don't know whether you've had any opportunity to find out the situation in the various departments of the federal government. We are an employment equity employer. We have a duty to accommodate in the workplace. These are all things that are enshrined in law, but as we know, often translating those commitments into daily practice and awareness and understanding is not so easy.

I'd be very interested if any of the witnesses could talk a little bit about what the workplace is like for people living with epilepsy, what kinds of issues they face there, and whether you have any good models to show us. Do you know of employers that have taken on this issue? You've talked about schools, which I think is wonderful, but can you offer anything about workplaces?

Then, if we have time, I'd be fascinated to know about the medical side and whether research is currently under way in terms of treatment, medication, and so on.

**The Chair:** Who would like to start?

Go ahead, Ms. Therrien.

[*Translation*]

**Mrs. Aurore Therrien:** The workplace always represents a major challenge for people with epilepsy. A number of them have both the potential to work and the training they need. Everything is fine as long as they do not have a seizure. But the moment they do have a seizure, everything can change.

One girl I assisted had a very good education, she had passed an interview and she had got the job. Though she had not had a seizure, out of honesty, she decided to talk to her employer about it, and she was let go. That was a real shame for her because her epilepsy had never really affected her. When she was younger, she had been able to study without too much difficulty. When she mentioned it, she was fired, without really being told why. She was supposed to get married six months later and so was counting on that first job.

A lot remains to be done in this regard. Epilepsy is a neurological condition that still causes a lot of concern, because people are not aware of it and come up with their own ideas of what it might be without really knowing. So we have to work with employers on workplace awareness.

Sometimes, people have told me how open employers are. Epilepsy is such a common problem that it is not unusual for someone to know someone else who has it, a family member, a neighbour, a friend. In cases like that, employers are more receptive, but they are not in the majority. So an awful lot remains to be done.

I know one person with epilepsy who has not had a seizure for 15 years and has never told her employer. She was afraid of making a mistake that the employer might attribute to her epilepsy rather than to simple clumsiness. It causes people to keep their condition hidden. When a seizure happens, it surprises everyone. Sometimes it is not just the employer who can lack understanding, it can be the co-workers as well. This is a very important point and I thank you for drawing attention to it. There is a lot of work to be done.

● (0920)

[*English*]

**Hon. Geoff Regan:** Very briefly, Madam Chair, I think “lack of knowledge” is a very appropriate phrase to use. You mentioned that you've learned something today; I think we all have. That's the whole idea. If we are having a day that creates more awareness about epilepsy, what to do in case of a seizure, what the cause is, and so forth, all of this adds to knowledge.

I think it also helpfully highlights to employers what's involved and to not be afraid of someone who has epilepsy. In the same way that people with disabilities can often be fairly easily accommodated and make a great contribution in workplaces, the same is true of people with epilepsy, obviously. However, knowledge is important.

I'm afraid I can't answer your question about the Government of Canada's programs in this regard. I don't know if Mr. Carrie could get some information on that from the department at some point, but I'll leave that to the committee to work out. As I said at the beginning, there are witnesses here who have much more knowledge about this than I do, so I'm glad there are others to answer questions. As an example, what is happening in medical research?

**Ms. Sarah Ward:** I'm not so up to date on the medical research side of things. I'm not doing research in that field anymore, but I know there are a lot of people involved in research. My previous supervisor is certainly working on some new things.

It's much needed. As I mentioned, a lot of the medications aren't successful in many cases. There are other treatment options, such as surgery, but I think it can only be used in about 10% of cases and only for certain types of epilepsy. The ketogenic diet is another treatment, but it's often ineffective. Certainly more research needs to be done, and I know there are active researchers out there working toward that goal.

**The Chair:** Thank you.

Dr. Carrie, I think you're sharing your time with Mr. Lizon. Would you like to begin?

**Mr. Colin Carrie (Oshawa, CPC):** Yes, I am, Madam Chair. Thank you very much.

I want to thank my colleague Geoff for bringing this forward.

In particular, Cassidy, if you're listening, I want to thank you, because I'm actually one of those Canadians who was diagnosed with epilepsy. I don't know how it started, but I think it had something to do with a head trauma that I received when I was younger.

I remember my seizures as a young child. I was diagnosed petit mal, but I used to pass out and at times I would lose bladder control, which, when you're five or six years old, can be quite embarrassing. It probably would be quite embarrassing right now as well if I had a seizure, but I remember being in playgrounds and passing out. The other kids would just stand around me. They wouldn't know what to do. After I recovered, I remember walking home in a groggy state. As a child, it was something that was really difficult to deal with, because I didn't understand it.

I remember that one of the places where I used to have my seizures was church. I don't know what it was about the lights, or maybe it was something about the atmosphere, but I soon realized that I could use it to my advantage. It was interesting that Sarah brought up demonic possession—

**Voices:** Oh, oh!

**Mr. Colin Carrie:** —but it worked to my benefit as a great excuse for not having to go to church on Sunday.

Anyway, I wanted to ask you how common epilepsy is among children under five years old and how it affects the learning and growth of kids.

● (0925)

**The Chair:** Who would like to take that?

Ms. Therrien, go ahead.

[*Translation*]

**Mrs. Aurore Therrien:** Epilepsy often occurs with elementary school children. The first seizures often occur between the ages of six and 12, but they can occur at any age. But it is a little more frequent among elementary school children. That is why we have such a big presence in schools. We are creating awareness.

[*English*]

**Hon. Geoff Regan:** Madam Chair, I hope that other young people and children are listening along with Cassidy today, because I think Mr. Carrie's story would be inspiring for them: he has epilepsy, and here he is, a member of Parliament doing work in the Parliament of Canada.

**The Chair:** Mr. Lizon, you may go ahead.

**Mr. Wladyslaw Lizon (Mississauga East—Cooksville, CPC):** Thank you, Madam Chair.

Thank you, witnesses, for coming here this morning.

Actually, I would like to make a few comments on epilepsy in the workplace. I hear that some people are afraid to admit they have epilepsy, but we have to realize.... I supervise people, some of whom have epilepsy. It's very important that the employer know if a person has the condition, especially when the person performs work that can endanger him or her and others around them. It's very important that it be known, because if they have a seizure, it may be very dangerous for themselves and for others.

I have a very interesting point about silent seizures that I didn't know about, but my wife, who works with special needs kids, told me. A girl in her class has to be watched very carefully to see that she doesn't choke. I didn't know that existed.

I have a question: what suggestions do you have for training people to deal with seizures? I was trained in high school; it was part of the curriculum, among other things, as first aid in different cases. How would you suggest that we not only raise awareness, but train people properly to deal with cases of seizure?

[*Translation*]

**Mrs. Aurore Therrien:** I think it has to be done very simply. Actually, most seizures last only a few seconds and need very little intervention. What is much more important, as the hon. member said, is the attitude of people in the vicinity. That is what we work on most. Educating people is an important aspect of the work we do with associations. We have to educate people in the workplace, the people responsible for others.

When someone is having a seizure, the reaction counts for a lot. The person having the seizure is very vulnerable. You have to make sure that the person has fully regained consciousness, and not let them go if they have not completely recovered. The seizures and the recovery periods vary from person to person. It is probably important to train employees. In my opinion, companies that do so are already showing how open they are. The people with epilepsy working in those companies are affected, but also the people around them, or who spend time in public areas. I think that that is part of the education.

This year, we have a little card that gives clear explanations. I have some here. We give them out everywhere. Part of our approach to education is to provide a description of the first aid, of what to do in case of a seizure. It is very simple. This little card tells you everything you need.

Simply put, action and reaction are crucial.

[*English*]

**The Chair:** If you want to ask some more questions, you have about another minute.

**Mr. Wladyslaw Lizon:** I would like to thank Mr. Regan for the introduction of this bill. It's very important that people be educated, because part of the reason people react in certain ways is that they don't know any better. That's why it's very important that people get educated and not get scared if they ever witness a seizure. That's my comment.

● (0930)

**The Chair:** Very good.

We'll now go to Dr. Fry.

**Hon. Hedy Fry (Vancouver Centre, Lib.):** Thank you very much, Madam Chair.

I want to thank Mr. Regan for bringing this bill forward. I also want to congratulate him on the beautiful purple tie he's wearing today. He always has great ties, but today's is really stunning.

**The Chair:** Dr. Fry, don't you think he should have brought one for all of us? I'm just asking.

**Hon. Hedy Fry:** Yes, he should have, or a shirt or something like that.

Colin asked a question about children under 5. In fact, 50% of cases of epilepsy actually occur in early childhood or adolescence, with the majority within the first few months of life, which is a very high incidence. Then about 25% occur after age 60, which may be the result of little strokes, but no one really knows. Also, of course, in a huge number of cases, nobody knows the cause. Quite often, fevers will cause it in children. Sometimes a little bit of an injury during delivery can cause it, and then it will go away and won't remain with them.

With regard to the workplace, I don't know the percentage of people in the workplace who actually tell their employers, but I think Mr. Lizon was right in stressing that when we educate, it is especially important to educate employers. Because of the stigma and because people are afraid they won't be hired, they won't say it, yet if you are operating machinery or driving a bus or a car, or if you are an airline pilot, people need to know if you have epilepsy. Even though a lot of seizures are controlled, they're not necessarily cured, so they can occur at any time. We know there are triggers that may cause seizures; if you happen to be driving a vehicle, flashing lights coming at you can sometimes trigger a seizure.

This is really important. I can't say enough about how important this bill is, because the first thing is to de-stigmatize, but the second thing is that we also need to explain to people what the issue is and what to do when you have a seizure.

As a physician, I've seen people with seizures. I remember coming out of the lobby of a hotel about two years ago; a young man was standing talking to someone, and in the next moment he was on the ground having a seizure. I was just coming out of the elevator. All kinds of people were running to him, and they were trying to hold him down, which of course is the worst thing to do, and then they were asking if anybody had anything to stick in his mouth to keep his tongue from going.... They had all of those old-fashioned myths about what you're supposed to do, all of which can actually do more harm than good.

It's really important to deal with this issue. I'm glad to see that it was a young woman who started this movement and had the courage to move on it.

There is one thing that I wanted to ask. I didn't know if Madame Therrien might have the answer, or Dr. Ward.

Are you Dr. Ward yet?

**Hon. Geoff Regan:** She's soon to be, or eventually.

**Hon. Hedy Fry:** Okay. Let's pretend you're Dr. Ward.

**Voices:** Oh, oh!

**Hon. Hedy Fry:** Here's the question. I know that brain injury can be one of the trigger causes. Does anyone know what the percentage is of persons with epilepsy as a result of brain trauma, of acquired brain injury due to some sort of head trauma? Do we know what that percentage is?

[*Translation*]

**Mrs. Aurore Therrien:** No, I do not know the exact percentage of people who have suffered brain trauma as a result of traffic accidents, workplace accidents, and so on.

We know that about 30% of people with epilepsy have more acute, more refractory seizures. We know that these refractory, more acute forms of epilepsy can in some cases be caused by underlying conditions such as brain problems related not only to accidents but also to infectious diseases in infancy. The percentage is about 30%, but I cannot tell you the exact number of people. That would be something important to consider.

[*English*]

**Hon. Hedy Fry:** Thank you.

That's actually—

**The Chair:** Ms. Elliott, did you have a comment to make on this particular question that Dr. Fry asked?

**Ms. Iris Elliott:** I don't have any statistics. The people I know either just had it happen to them or were born with it, but in a significant number it is a result of trauma. We can find that information and make sure Dr. Fry has it.

● (0935)

**The Chair:** If you send it to the clerk, I will make sure that everybody gets a copy.

**Ms. Iris Elliott:** Yes, we'll do that.

**The Chair:** Thank you.

**Hon. Hedy Fry:** That's an important question. It was asked of me by the Brain Injury Association of Canada. The cause is preventable, mainly because if we had appropriate CSA-approved helmets, we could prevent what we now know are concussions that go on and on as people play a sport—they ski, toboggan, or whatever. They think they may be protected by current helmets on the market, but we now know those helmets could be as useful as wearing a toque for the amount of protection they give.

I know we've seen it in the case of Sidney Crosby when we've looked at hockey. Everyone used to think it was machismo not to wear a helmet, and we now know that this is a preventable injury. We know acquired brain injury has something to do with Alzheimer's. I do know that it is one of the etiological factors in epileptic seizures.

**The Chair:** Thank you so much.

We're just about out of time, Dr. Fry, so I think I'll go to Mr. Brown and Mr. Strahl. You're sharing your time, I understand. We'll begin with Mr. Brown.

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

As some of the other questions have said, Geoff, this bill is a great idea and I thank you for putting it forward. I think of Jeffrey White, who runs the local epilepsy chapter in my riding and has done some great work fundraising for epilepsy. I look forward to voting in favour of this bill on his behalf. I know you are a fellow hockey player; Jeffrey did a hockey fundraiser in Barrie to help raise awareness. Obviously, this bill will raise awareness, and that's why it's helpful.

Is there anything you wanted to add about the benefits of this bill that you haven't been able to mention so far in your allocated time?

**Hon. Geoff Regan:** Madam Chair, I don't think so, but since Mr. Brown has mentioned our mutual enjoyment of hockey, I want to tell you that we obviously do wear helmets when we play. I'm sad to say that Mr. Brown gives the Conservative team a big advantage. I can recall the last time we played. I thought I had a two-on-oh; the other player and I were racing toward the net, when out of the blue from behind me, at some incredible speed, came Mr. Brown, and took the puck away. I did manage to get a couple of goals in that game, I think, but he usually scores a bunch, a handful of goals.

**The Chair:** Mr. Brown, do you have anything epilepsy-related?

**Voices:** Oh, oh!

**Mr. Patrick Brown:** No. I just want to say that I think this is a great initiative. You mentioned the young girl in your riding. I know that in every city in every riding in the country there are young Canadians for whom this bill will make a big difference. Thanks for the great initiative.

I have no hard or pressing questions because I think you're going to find universal support from your colleagues on what is a positive initiative.

**The Chair:** Thank you.

Go ahead, Mr. Strahl.

**Mr. Mark Strahl (Chilliwack—Fraser Canyon, CPC):** Thank you, Geoff, for the bill. I am a Vancouver Canucks fan, and even though you are a Boston Bruins fan, I will be voting in favour of the bill. Quite by accident, I did wear a purple tie today; I think there's even some lavender in there too, so my version of the tie is bilingual.

I have a friend who has epilepsy. He underwent surgery after many years. It was experimental surgery at the time and it greatly relieved the symptoms he faced. He spoke about his time in high school when he was on medication. He had just enough energy to get through to the end of the day and then he would go home to sleep, because the side effect was severe drowsiness, I assume to try to keep things under control. This was 20 years ago.

Have there been any improvements in the pharmaceuticals available for people with epilepsy, or are they the same treatments that have been around for a number of years?

● (0940)

**Ms. Sarah Ward:** There have been some improvements. Some of the newer drugs have fewer side effects, but most of them still do have at least some side effects. Phenytoin, or Dilantin, isn't a newer drug, but it's one of the more common drugs. It doesn't cause the person to be drowsy, but it causes a lot of other side effects. It can cause facial hair growth in women and it can cause pretty severe gum overgrowth. I don't know all the medications, but I know there has been some improvement. With more research, there will be more improvement.

**Hon. Geoff Regan:** Madam Chair, if I'm not mistaken, some epilepsy drugs have been among the drugs for which there have been shortages. You've probably looked at this issue as a committee, or heard about it. When a drug suddenly goes out of production for a period of time, from what I've heard—and I'm sure you have heard it as well—it can have a great impact on patients, who normally would need time to shift gradually from one drug to another but don't have time to do that in the case of a sudden shortage.

**The Chair:** Mr. Strahl, is that the end of your questions?

**Mr. Mark Strahl:** I'm good. Thank you.

**The Chair:** Before we go into the second round, with the permission of the committee, there's just one question I have.

Like you, Mr. Regan, I had a student in grade 9 who had three seizures a day, and if I remember correctly, they were called grand mal. I'm wondering if someone on the committee could describe that type of seizure. You described how someone looks into space or picks at their clothes or whatever, but can you also describe, first of all, what a seizure looks like? Some people have not seen a seizure, and it's very scary when you first see one, especially if it's a grand mal seizure. As well, can you describe what to do? I remember that as a teacher I was told by someone, "Oh, Mrs. Smith, grab a belt and put it between his teeth." I didn't think that was very good, so I didn't do it; I just cleared the way around him. That was before I had information about what I really should do; fortunately, it wasn't too far from what I really should have done.

Could you go into that a little bit? Let's say that while walking home or whatever, you see someone who is having a seizure. What does it look like and what should you do? I ask because many well-intentioned people injure people they're trying to help.

Who would like to respond? Okay, Ms. Therrien, go ahead.

[*Translation*]

**Mrs. Aurore Therrien:** You can also ask Ms. Iris Elliott that question, because she wanted to say something about it too.

There are different kinds of seizures. There is the family of generalized seizures, the first of which is called the absence seizure. Absence seizures are not really visible; they are characterized by small losses of consciousness, of which there can be many in the course of a day. They may not disturb people close by, but this kind of seizure can be a great disruption to the life of a child or an adult.

There are also simple partial and complex partial seizures. Simple partial seizures have involuntary movements, as you mentioned earlier. So the person can move, do common actions like getting up and walking around, but there is no context. So they can pull at their clothes and move around. In a simple partial seizure, the person is conscious, whereas in a complex partial seizure, the person is completely unconscious. A complex partial seizure can become more generalized. It can be the beginning of a seizure called the aura. Lastly, I think that everyone knows about the convulsive seizure, which can take different forms. The person suddenly loses consciousness, falls to the ground and goes into convulsions. For people who have complex partial seizures—the ones you were talking about—I think…

[*English*]

**The Chair:** I'm talking more about the complex ones. What should people do? This is where people seem to make mistakes.

[*Translation*]

**Mrs. Aurore Therrien:** You should not try to restrict the person's movements. You have to follow them. If the seizure happens in a room, good. But if the seizure happens outside, it is different. We have seen a young woman get up and walk quickly outside. It's rare, but it happens. Someone must be at the person's side to make sure that they don't hurt themselves by falling down a staircase or anything like that. Seizures are very short. You should not try to restrain the person or sit them down. You must follow them, make sure they are safe and talk to them, because that is how you can tell when the person is no longer unconscious.

● (0945)

[*English*]

**The Chair:** Thank you.

Ms. Elliott, did you want to make a comment?

**Ms. Iris Elliott:** Yes. I'd just like to describe what it looks like when somebody has what you referred to as a grand mal seizure. We actually call them tonic-clonic seizures these days.

What happens is that the seizure is happening all over the unconscious person's brain. They become rigid. They become unconscious. They fall down. They begin to shake. Every muscle in their body is clenching and unclenching, clenching and unclenching. This can go on for a long time, but most seizures last less than five minutes. Of course, if it does go on longer, you call the ambulance.

That's basically what it looks like: the person's lying on the ground, totally unconscious, and they're unclenching and clenching their muscles and moving in a very spasmodic way. That would be the kind of seizure you're mentioning. It used to be called a grand mal seizure.

**The Chair:** Well, it's been a while since I've been in the classroom; it was grand mal when I was in the classroom.

Go ahead, Mr. Regan.

[*Translation*]

**Hon. Geoff Regan:** Madam Chair, I would like to add something to what Mrs. Therrien said.

It is good for one or two people to be present when someone is having a seizure, but it is not desirable for a lot of people to be very close, as Ms. Fry described earlier. Just imagine the person seeing all kinds of people crowding around when the seizure is over. The space around the person must be kept clear.

[*English*]

**The Chair:** Thank you. I think that might be helpful.

Ms. Ward, did you want to make a comment?

**Ms. Sarah Ward:** Yes. I have something to add that hasn't been mentioned yet.

Commonly after grand mal and other types of seizures, there's a post-ictal phase. There's commonly vomiting, and they're still half unconscious. An important part of the first aid is to make sure they're in the recovery position, on their side, so they don't aspirate and choke.

**The Chair:** I think this would be helpful to the general public if they ever saw something like that, and especially in schools, where children are unaware.

We'll now go to the second round. Ms. Quach has five minutes—Ms. Fry?

**Hon. Hedy Fry:** I'm sorry. Very quickly, the symptoms you present with depend on what part of your brain is affected. If it's a part of your brain that has to do with movement, your large limbs, you will get the tonic-clonic seizure

The term “woolgathering”—this is just a piece of trivia—comes from that. Sometimes you'd see people doing picking at their clothes, and it came to be known as woolgathering. Now when we see someone lost in thought, we say they're woolgathering, but there was a different reason for calling it that.

**The Chair:** Thank you, Dr. Fry.

Please go ahead, Ms. Quach.

[*Translation*]

**Ms. Anne Minh-Thu Quach (Beauharnois—Salaberry, NDP):** Thank you, Madam Chair.

I would like to thank Mr. Regan for introducing this bill. I would also like to thank all the witnesses. You have taught me a lot about this.

You say that people crowd around a person having a seizure. That is true. I experienced that as a teacher. Someone had a seizure in the classroom. Children have all kinds of reactions. But most of them are curious. They want to see what is going on, but when they do see, they become very afraid and they turn away. It's very traumatic for everyone. Some kids start crying; others ask what is going on, whether the person is going to die.

I would very much like to know what is happening neurologically. What are the physical reactions, the physiological reactions, of someone having an epileptic seizure? You often hear that the person is exhausted afterwards because the seizure uses up a lot of energy, but I am not really aware of what is happening.

In terms of the awareness campaign, I was wondering, given that people do not know how to react, if you had also thought of presenting things like improvised sketches in public areas, in supermarkets, in the subway, in the street and on buses. The idea would be to make people aware of the fact that it can happen anywhere at any time, and of the proper way to react. You could then give out the cards. That could create awareness.

● (0950)

[*English*]

**The Chair:** Who would like to answer that?

Ms. Ward, would you?

**Ms. Sarah Ward:** Yes?

**The Chair:** I have to warn you that you can't scratch your ear here without having to answer a question.

**Voices:** Oh, oh!

**Hon. Geoff Regan:** It's like an auction.

**Ms. Sarah Ward:** Seizures are a result of aberrant electrical activity in the brain, and often it arises from a seizure focus. If it's a very small focus, it can stay localized, and you can actually have a seizure—this is also something I didn't know—in only one part of your body. If it's just a small focus in your brain and it doesn't spread, your arm could shake and you might not even be aware.

My supervisors told me stories about a guy who had his arm shake for weeks, and he didn't know why. He was actually having a seizure—for weeks.

It can stay localized, and if it does, that's when surgery is an option. If you can locate that focus, you can remove it and prevent the aberrant electrical activity from starting. However, it's more often the case that it will spread, or the focus isn't localized and is everywhere, it will involve your whole brain, in which case it would be a generalized seizure.

**Hon. Geoff Regan:** What do you remove?

**Ms. Sarah Ward:** That's a good question. I'm not sure. I know that temporal lobe epilepsy is very common, but I'm not sure what the most common part is that's actually removed.

**The Chair:** Thank you very much for that.

**Hon. Hedy Fry:** Madam Chair, brain surgery is only recommended when drug therapy fails.

**The Chair:** Dr. Fry, this committee is getting out of hand. You have to just wait your turn.

Ms. Quach, you go ahead.

**Hon. Hedy Fry:** As well, it's only when brain tissue can be removed safely. I just wanted to answer the question. You don't want to go into a part of a brain where removing tissue is going to affect the person's ability later on.

**The Chair:** Well, this is a most interesting committee today. I don't think I've ever had this happen before, but it's very useful.

Thank you, Dr. Fry.

Ms. Quach, I'm going to give you another minute because I think you were robbed by Dr. Fry.

**Voices**: Oh, oh!

[*Translation*]

**Ms. Anne Minh-Thu Quach:** Thank you, Madam Chair.

Let's go back to the attitudes that we have to change. What are the main attitudes that have to be changed when people see someone having a seizure? What is the worst attitude, the most harmful reaction?

**Mrs. Aurore Therrien:** I think the best reaction is similar to the one I recently saw from a bus. I saw a young man fall to his knees outside a metro station. A lady came up, knelt down with him and stayed with him. I feel that was the best possible reaction. It's the same thing at work. Sometimes, a person doesn't feel comfortable talking about it to all his co-workers, but he can confide in one person with whom he has a special relationship and talk to them about it. Then, if a seizure occurs, that person is going to be able to be there for him.

In terms of the general public, I think that education is the best thing. I was not expecting to take about that this morning, but it is a very good thing. There is no better place to talk about it than at the Standing Committee on Health. If we can talk to the government about it, and to the media—the people listening to us at the moment —that's significant. Everyone wants to learn and we are continuing to develop good attitudes of compassion, understanding and caring.

So the worst reaction is the one from well-intentioned people that I once saw on another bus. One person had a seizure and everyone wanted to help. Everyone was giving advice on what should be done and that's not always the best thing. Some people were handing the person a bottle of water, and so on. You could see that there was a lot of compassion on the part of the people who wanted to help, but it was not always in the best way. So the most harmful reaction is to jump in and crowd around the person. When the person having the seizure comes to, it can cause them to panic.

[*English*]

**The Chair:** Thank you, Ms. Therrien.

Now we'll go to Mr. Gill.

**Mr. Parm Gill (Brampton—Springdale, CPC):** Thank you, Madam Chair.

I don't have any pressing questions, but I do want to thank Mr. Regan and all the witnesses for being here and providing us with very valuable information, and Mr. Regan for taking up this wonderful cause. I really appreciate your efforts.

I will pass the rest of my time to Mrs. Block.

**Mrs. Kelly Block (Saskatoon—Rosetown—Biggar, CPC):** Thank you very much, Mr. Gill.

Thank you, Madam Chair.

I would like to thank our witnesses for being here this morning and my colleague for bringing this very important issue forward through the opportunity that you've had with the private member's bill. I had the privilege of being a junior youth sponsor at my church, and we did have a young lady who had epilepsy. She's grown into a beautiful young woman with two children. She had those pregnancies managed, obviously, with some medication to ensure that those babies were carried safely to term, and as I said, she has a beautiful young family now.

I don't have very many questions, but one of the questions I would have is this: during a person's lifetime with epilepsy, are there periods of time when these seizures happen more often? Is there a time when they maybe subside? What is the impact for elderly people? As well, does epilepsy have an impact on a person's lifespan?

● (0955)

**The Chair:** Go ahead, Ms. Therrien.

[*Translation*]

**Mrs. Aurore Therrien:** As I mentioned earlier, epilepsy can occur at any time of life. Though we see it in elementary school children, we also see it in the elderly. I got that information from a neurologist. It is also quite common in the elderly because of different problems. However, it can happen at any age. Unfortunately I do not have exact percentages. But you see it most in elementary school children.

Epilepsy is an entire spectrum of disorders. There are benign epilepsies, like Rolandic epilepsy, that will completely disappear at puberty. These days, a first seizure is not even treated. Seizures must be recurrent before we talk about epilepsy. The acute syndromes on the other end of the spectrum will appear very early in infancy and will be extremely disruptive. Those epilepsies are difficult to treat and can cause the child a great deal of distress.

[*English*]

**The Chair:** The last question Ms. Block asked was about lifespan. Do you know if it affects lifespan in any way? I think, Ms. Block, that was the last question you asked.

[*Translation*]

**Mrs. Aurore Therrien:** Right.

There is what is called sudden unexplained death in epilepsy. Because of the losses of life, I think, we have started to talk about it in recent years. It can occur with males and females from a young age to early adulthood. We are hearing about it more and more. It is not common, but it is important to say that, when it occurs, it can end the life of relatively young people, people who have young children themselves. It is important to study it in order to know what we can do to avoid it. Basically, it's a question of properly managing the seizures.

The other aspect to consider is medication. This is important. There have been deaths in the Montreal area. They were people who were not taking their medications properly, either because they had problems with their memory and forgot to take their medications, or because they had associated dependencies that neutralized the effect of the medications, or because they were not taking the medications regularly as directed by their doctor, or because they stopped taking them themselves. We often see that. People do that. Basically, they are hiding the difficulty they have in accepting their epilepsy. It can lead to seizures that do not stop and can lead to death. It is not common, but people have to be aware of it. So we really encourage people to take their medications properly, and, if they have problems, to not hesitate to speak to their physician.

[*English*]

**The Chair:** Thank you so much.

Dr. Morin is next.

[*Translation*]

**Mr. Dany Morin (Chicoutimi—Le Fjord, NDP):** Thank you for your excellent bill, Mr. Regan.

I also thank Mr. Carrie very much for telling us what he went through at school.

Thanks also to Ms. Smith for telling us about your experience as a teacher when your students had seizures.

It all got me thinking about when I became familiar with epilepsy for the first time. I had never seen a case personally, but I remember that, 15 years ago, when I was young, I used to watch children's programs on television. Between the programs, there were awareness advertisements about epilepsy. One showed a schoolyard situation where a student had a seizure. We were shown what to do and what not to do. A young girl was in charge of the situation, she got lots of bad advice and replied that that was not what needed to be done.

But if more education is needed, the younger generation, people in their 20s like Anne and myself, are perhaps more aware of what must be done and what must not be done. So I think that the situation will get better. This bill will also help generations to come. As a society, I feel that we are getting better in this regard. That was my little story.

It has been said that epileptic seizures can be set off by an excess of visual stimuli, especially from light. Are there other triggers that we should know about, other risk factors that also cause seizures?

● (1000)

**Mrs. Aurore Therrien:** Lack of sleep is a major factor. Of course, not following the treatment, not taking the medication properly is another. Stress is yet another factor. There are a number of factors, but lack of sleep is one of the most significant ones. Most people still do well. As organizations, we always recommend that they maintain the lifestyle they want and that they get to know themselves, so that they know what triggers their seizures. The bottom line is that they have to try to avoid all the factors that can cause a seizure.

In terms of the ads, the Canadian Epilepsy Alliance created them, and we are very happy about that. So we are going to continue down that road.

**Mr. Dany Morin:** The fact that I still remember them 15 years later shows it was a good approach and money well invested.

[*English*]

**The Chair:** That was very good.

Have you finished, Dr. Morin?

Thank you for your very good comments.

Go ahead, Dr. Sellah.

[*Translation*]

**Mrs. Djaouida Sellah (Saint-Bruno—Saint-Hubert, NDP):** Thank you, Madam Chair.

Thank you for introducing this bill, Mr. Regan. I have already stood in the House and said that I would support your bill. I was glad that it was referred to this committee for discussion. I personally think that's really great. With the exception of a few amendments that we are going to make in the French version, I feel that it is perfect.

Having said that, as a doctor, I have heard everything about what epilepsy is, and what the causes and factors are. I would like to explain that it is an electric discharge in the brain—and the “brain” is the powerhouse that controls all the muscles and the nerves. As Mrs. Therrien and Ms. Ward have said, it depends on the affected region. I was a general practitioner and I saw people with epilepsy in public as well. Ordinary people do not recognize the various types of epilepsy. What people see in public are tonic-clonic seizures with all the symptoms: aura, the seizure, and the aftermath.

In line with what my colleagues Colin and Anne were saying, I remember going to the market with my grand-mother one time when I was very young. This was back in my country of origin, which is a developing country. I saw a crowd of people around a person lying on the ground, foaming at the mouth. As a way to break the tension, the people were holding out keys. I was young and I told myself that there was probably a housing crisis and that is why they were doing that. I am just telling you this to point to the stigmatization of people with epilepsy.

I feel that public education is crucial. As I said, I know people do not only vomit and foam at the mouth, but they sometimes also urinate. I haven't seen it myself, but I can only imagine when the person regains consciousness and is surrounded by people making comments, and so on. So I think that it is not just about educating the public. Educating health care providers is equally important.

Your idea about the cards is just wonderful. Experts in the field should also work on providing information, the way they do in other areas. For example, when kids have fever, we ask mothers to give them regular doses of medication, and to go see a doctor after three days. I think there is work to be done to raise awareness about how to treat a person with epilepsy. That is also an issue.

I have another question. I know that 70% of people with epilepsy manage to treat it with medication. Mrs. Therrien, as you rightly said, compliance with treatment and follow-up play a role. Unfortunately, 30% of people do not respond to treatment, and some might have to undergo surgery. It is important to note that surgery is the last resort. The fact remains that some people do not respond to treatment.

● (1005)

Unfortunately, some pharmaceutical companies are more interested in making profits than curing people. Why don't they just stick to one treatment, such as phenytoin, a drug that has been proven to work? Why is there a shortage of phenytoin? I know these types of drugs do not bring in a lot of money. But they have demonstrated results. Why do we let some companies come up with drugs that have not been proven to work, despite all the promises? That is what I wanted to ask.

**Mrs. Aurore Therrien:** That is a broad question that deserves an answer from a number of people. It is a concern for everyone, not just...

[*English*]

**The Chair:** I'm sorry, but we're quite a bit over time. Could you, as quickly as you can, give an answer?

[*Translation*]

**Mrs. Aurore Therrien:** I think Mrs. Sellah was trying to point out that this is a major question that concerns everyone. She wanted to ask it publicly because it concerns large pharmaceutical companies. And who can reach them? Who can get information to them and who can persuade them? I think it is appropriate to ask this question here today.

[*English*]

**The Chair:** It's a very important question. Thank you, Dr. Sellah.

I'm going to say thanks to the witnesses and especially to Mr. Regan, who brought this very important bill forward.

I'd like to do the clause-by-clause consideration so that we can report the bill back to the House, I hope, on Friday. If you will step back, I'm going to suspend for only one minute and go directly to the bill. We'll suspend.

● (1005)

(Pause)

● (1005)

**The Chair:** Committee, we'll get this wonderful bill together and get started.

For now, we will postpone looking at the preamble and the short title. We will first go to clause 2 and the amendments.

(On clause 2—*Purple Day*)

**The Chair:** On clause 2, I want to note this amendment. This is Dr. Sellah's amendment.

Could you speak to that, Dr. Sellah, please?

● (1010)

**Hon. Hedy Fry:** Just to save us some time, I want to point out that Dr. Sellah and I have the exact same amendments, all six of them, so perhaps we could just deal with them as amendments and....

**The Chair:** I was going to have Dr. Sellah read out the amendment. Then I'm going to try to get them all together so we can get them done all at once.

Thank you, Dr. Fry.

Dr. Sellah, would you go ahead?

[*Translation*]

**Mrs. Djaouida Sellah:** Yes. I move that Bill C-278, in the preamble, be amended by replacing, in the French version, line 5 on page 1 with the following:

> sensibiliser davantage à leur condition,

[*English*]

**The Chair:** Dr. Sellah, you're not moving the right one. Could you go to amendment NDP-1? You're on the wrong one. We have to do the other one first.

[*Translation*]

**Mrs. Djaouida Sellah:** I am sorry, Madam Chair.

[*English*]

**The Chair:** That's okay.

[*Translation*]

**Mrs. Djaouida Sellah:** The amendment says that Bill C-278, in Clause 2, be amended by replacing, in the French version, line 11 on page 1 with the following:

> désigné comme « Journée lavande ».

[*English*]

**The Chair:** Thank you.

Amendments NDP-1, NDP-2, NDP-4, and NDP-5 all propose to make the same modification to the bill—that is, to change the reference to colour in the French version of the text from “*pourpre*” to “*lavande*”.

If the modification proposed in amendment NDP-1 is accepted, the bill will be inconsistent if this change is not made everywhere the word "*pourpre*" is mentioned. Likewise, if the amendment is rejected, it would be inconsistent to accept the change elsewhere, so the committee could decide to apply the result of the vote on amendment NDP-1 to amendments NDP-2, NDP-4, and NDP-5.

Because they are all basically the same, it would be consistent within the whole bill, and we would get this done in one fell swoop.

Are you all in agreement?

(Amendments agreed to [See *Minutes of Proceedings*])

(Clause 2 as amended agreed to)

(On clause 3—*Wearing Purple*)

**The Chair:** On amendment NDP-3, who would like to speak to that one?

[*Translation*]

**Mrs. Djaouida Sellah:** The amendment says that Bill C-278, in Clause 3, be amended by replacing, in the French version, lines 15 and 16 on page 1 with the following:

> de sensibiliser davantage le public à leur condition.

[*English*]

**The Chair:** Thank you.

Is there any discussion?

(Amendment agreed to)

**The Chair:** Very good.

In the same manner, amendments NDP-3 and NDP-6 propose to change the word "*maladie*" to "*condition*" in the French version of the bill. In order to maintain the consistency of the wording of the bill, the committee can decide that the outcome of the vote on NDP-3 should also be applied to NDP-6. Is that agreed?

**Some hon. members:** Agreed.

**The Chair:** Is there any discussion?

(Amendments agreed to)

(Clause 3 as amended agreed to)

(Clause 4 as amended agreed to)

**The Chair:** Shall clause 1, as amended, carry?

(Clause 1 as amended agreed to)

**The Chair:** Shall the preamble, as amended, carry?

**Some hon. members:** Agreed.

**The Chair:** Shall the title carry?

**Some hon. members:** Agreed.

**The Chair:** Shall the bill as amended carry?

**Some hon. members:** Agreed.

**The Chair:** Shall I report the bill, as amended, to the House?

**Some hon. members:** Agreed.

**The Chair:** Shall the committee order a reprint of the bill, as amended, for the use of the House at report stage?

**Some hon. members:** Agreed.

**The Chair:** My intention is to report this bill on Friday to the House. Is that acceptable to the committee?

**Some hon. members:** Agreed.

**The Chair:** Thank you very much.

Thank you, committee.

We have one more thing to do before you leave. It is that in relation to the study of Bill C-278, the proposed budget in the amount of $6,500 be adopted. I need someone to move that motion.

**Mr. Mark Strahl:** I so move.

**The Chair:** All in agreement?

(Motion agreed to)

**The Chair:** Thank you, committee.

The meeting is adjourned.

**Published under the authority of the Speaker of the House of Commons**

## SPEAKER'S PERMISSION

**Reproduction of the proceedings of the House of Commons and its Committees, in whole or in part and in any medium, is hereby permitted provided that the reproduction is accurate and is not presented as official. This permission does not extend to reproduction, distribution or use for commercial purpose of financial gain. Reproduction or use outside this permission or without authorization may be treated as copyright infringement in accordance with the *Copyright Act.* Authorization may be obtained on written application to the Office of the Speaker of the House of Commons.**

**Reproduction in accordance with this permission does not constitute publication under the authority of the House of Commons. The absolute privilege that applies to the proceedings of the House of Commons does not extend to these permitted reproductions. Where a reproduction includes briefs to a Committee of the House of Commons, authorization for reproduction may be required from the authors in accordance with the *Copyright Act.***

**Nothing in this permission abrogates or derogates from the privileges, powers, immunities and rights of the House of Commons and its Committees. For greater certainty, this permission does not affect the prohibition against impeaching or questioning the proceedings of the House of Commons in courts or otherwise. The House of Commons retains the right and privilege to find users in contempt of Parliament if a reproduction or use is not in accordance with this permission.**

---

**Also available on the Parliament of Canada Web Site at the following address: http://www.parl.gc.ca**

**Publié en conformité de l'autorité du Président de la Chambre des communes**

## PERMISSION DU PRÉSIDENT

**Il est permis de reproduire les délibérations de la Chambre et de ses comités, en tout ou en partie, sur n'importe quel support, pourvu que la reproduction soit exacte et qu'elle ne soit pas présentée comme version officielle. Il n'est toutefois pas permis de reproduire, de distribuer ou d'utiliser les délibérations à des fins commerciales visant la réalisation d'un profit financier. Toute reproduction ou utilisation non permise ou non formellement autorisée peut être considérée comme une violation du droit d'auteur aux termes de la *Loi sur le droit d'auteur.* Une autorisation formelle peut être obtenue sur présentation d'une demande écrite au Bureau du Président de la Chambre.**

**La reproduction conforme à la présente permission ne constitue pas une publication sous l'autorité de la Chambre. Le privilège absolu qui s'applique aux délibérations de la Chambre ne s'étend pas aux reproductions permises. Lorsqu'une reproduction comprend des mémoires présentés à un comité de la Chambre, il peut être nécessaire d'obtenir de leurs auteurs l'autorisation de les reproduire, conformément à la *Loi sur le droit d'auteur.***

**La présente permission ne porte pas atteinte aux privilèges, pouvoirs, immunités et droits de la Chambre et de ses comités. Il est entendu que cette permission ne touche pas l'interdiction de contester ou de mettre en cause les délibérations de la Chambre devant les tribunaux ou autrement. La Chambre conserve le droit et le privilège de déclarer l'utilisateur coupable d'outrage au Parlement lorsque la reproduction ou l'utilisation n'est pas conforme à la présente permission.**

---

**Aussi disponible sur le site Web du Parlement du Canada à l'adresse suivante : http://www.parl.gc.ca**