



Legislative Assembly of Alberta

The 28th Legislature
First Session

Standing Committee
on
Families and Communities

Bill 204
Irlen Syndrome Testing Act

Monday, July 22, 2013
10 a.m.

Transcript No. 28-1-16

**Legislative Assembly of Alberta
The 28th Legislature
First Session**

Standing Committee on Families and Communities

Quest, Dave, Strathcona-Sherwood Park (PC), Chair
Forsyth, Heather, Calgary-Fish Creek (W), Deputy Chair

Brown, Dr. Neil, QC, Calgary-Mackay-Nose Hill (PC)
Cusanelli, Christine, Calgary-Currie (PC)
DeLong, Alana, Calgary-Bow (PC)
Eggen, David, Edmonton-Calder (ND)*
Fraser, Rick, Calgary-South East (PC)
Fritz, Yvonne, Calgary-Cross (PC)
Goudreau, Hector G., Dunvegan-Central Peace-Notley (PC)
Jablonski, Mary Anne, Red Deer-North (PC)
Jansen, Sandra, Calgary-North West (PC)
Jeneroux, Matt, Edmonton-South West (PC)
Leskiw, Genia, Bonnyville-Cold Lake (PC)
Notley, Rachel, Edmonton-Strathcona (ND)
Pedersen, Blake, Medicine Hat (W)
Swann, Dr. David, Calgary-Mountain View (AL)
Towle, Kerry, Innisfail-Sylvan Lake (W)
Wilson, Jeff, Calgary-Shaw (W)
Young, Steve, Edmonton-Riverview (PC)

* substitution for Rachel Notley

Bill 204 Sponsor

Jablonski, Mary Anne, Red Deer-North (PC)

Support Staff

W.J. David McNeil	Clerk
Robert H. Reynolds, QC	Law Clerk/Director of Interparliamentary Relations
Shannon Dean	Senior Parliamentary Counsel/ Director of House Services
Philip Massolin	Manager of Research Services
Stephanie LeBlanc	Legal Research Officer
Sarah Leonard	Legal Research Officer
Nancy Zhang	Legislative Research Officer
Nancy Robert	Research Officer
Corinne Dacyshyn	Committee Clerk
Jody Rempel	Committee Clerk
Karen Sawchuk	Committee Clerk
Christopher Tyrell	Committee Clerk
Rhonda Sorensen	Manager of Corporate Communications and Broadcast Services
Jeanette Dotimas	Communications Consultant
Tracey Sales	Communications Consultant
Janet Schwegel	Managing Editor of <i>Alberta Hansard</i>

10 a.m.**Monday, July 22, 2013**

[Mr. Quest in the chair]

The Chair: Good morning, everybody. I'd like to welcome everybody and call the meeting of the Standing Committee on Families and Communities to order.

I'd ask that the members joining us at the table introduce themselves for the record. Then we have quite a few with us by phone, so we'll get the callers to introduce themselves following that. We'll start with Mrs. Jablonski.

Mrs. Jablonski: Good morning, everyone. Mary Anne Jablonski, Red Deer-North.

Mr. Jeneroux: Matt Jeneroux, Edmonton-South West.

Ms Jansen: Sandra Jansen, Calgary-North West.

Ms DeLong: Alana DeLong, Calgary-Bow.

Mr. Young: Steve Young, MLA, Edmonton-Riverview.

Ms Sorensen: Rhonda Sorensen, manager of corporate communications and broadcast services with the LAO.

Ms Leonard: Sarah Leonard, legal research officer.

Dr. Massolin: Good morning. Philip Massolin, manager of research services.

Dr. Brown: Neil Brown, Calgary-Mackay-Nose Hill.

Ms Rempel: Jody Rempel, committee clerk, Legislative Assembly Office.

The Chair: Okay. And who's on the phone?

Mrs. Forsyth: Heather Forsyth, Calgary-Fish Creek.

Mrs. Leskiw: Genia Leskiw, Bonnyville-Cold Lake.

Mr. Wilson: Jeff Wilson, Calgary-Shaw.

Mr. Pedersen: Blake Pedersen, Medicine Hat.

Mr. Eggen: Dave Eggen from Edmonton-Calder.

The Chair: Dave has joined us at the table.

For the members that are calling in, you can speak up during the meeting, but we want to minimize the interruptions. If you've got something you want to talk about, if I could get you to e-mail Jody at any point in the meeting and ask to be put on the speakers list, that will make it a little easier for us with so many callers.

Just a few housekeeping items. Microphone consoles are operated by the *Hansard* staff. If you could keep your cellphones, iPhones, BlackBerrys off the table because they can interfere with the audiofeed. The audio of the committee proceedings is streamed live online, and it is all recorded by *Hansard*.

You all should have your agendas. Does anyone have any corrections or additions to the proposed agenda? If not, could we just get a motion that the agenda be adopted? Mrs. Jablonski. All in favour? Is everybody on the phone okay with the agenda? Okay. So moved by Mrs. Jablonski that the agenda for the July 22, 2013, meeting of the Standing Committee on Families and Communities be adopted as circulated.

The minutes from the meeting of May 13 have been circulated also. If there are no errors or omissions, I'd like a member to

move the adoption of the May 13, 2013, minutes. Ms DeLong. All in favour? Okay. Very good.

Mrs. Jablonski: Clarification.

The Chair: A clarification, Mrs. Jablonski.

Mrs. Jablonski: I apologize, Mr. Eggen. I just wanted to know if you are substituting for Rachel Notley or if you are a member of the committee. I'm sorry. I don't have my list in front of me.

Mr. Eggen: Yes, I'm substituting.

Mrs. Jablonski: So we should note that.

The Chair: All right. So noted.

At our last meeting the committee agreed to invite Mrs. Jablonski, the sponsor of Bill 204, to make a presentation to us about her bill. We've put aside 15 minutes of time for her presentation, to be followed by time for questions from the committee members of about another 15 minutes. I'd ask that the committee members hold their questions till the end of the presentation, but we will begin a speakers list.

Mrs. Jablonski, the floor is yours whenever you're ready.

Mrs. Jablonski: Well, thank you very much, Mr. Chair. Before I begin, I do have a few people that I would like to thank. I'd like to thank, first of all, all of you for being here and all of those on the phone for being here for our committee meeting and for this presentation. I'd also like to thank the people and the institutions who took the time and made the effort to send in written presentations. I'd like to thank my researchers Brian Senio and Ashleigh Niziol for their excellent service in finding the answers to all of my questions and again to Ashleigh for helping me put the PowerPoint together. I'd also like to thank Sarah Leonard, the legal research officer, for her time and effort to compile the crossjurisdictional comparison report. Thanks very much for all your efforts.

So why are we here today? We are here because two years ago I witnessed a miracle that can be repeated over and over again in the lives of children who struggle to read because they have Irlen syndrome.

You'll note that there is a PowerPoint presentation, and I have handed out some documents that are on orange-coloured paper. It's actually called goldenrod. The reason I handed it out on goldenrod paper is in honour of my grandson who can read better when it is on a goldenrod piece of paper than he can when it's black print on white. So that's why you have a goldenrod presentation in front of you.

We're here today because of that miracle I witnessed. We're here today because there are children in school who are told that they are lazy, unmotivated, and incompetent – you'll see that in submission 1 – because they struggle to read. We're here today because we need to answer the questions asked over and over again by frustrated parents and children who are finally diagnosed with Irlen syndrome and immediately see the results, and this is from submission 50. These questions are: "Why wasn't I told about this by teachers? Why don't the optometrists suggest this? Why didn't my doctor tell me about this? What can be done to change this for other families?" And the most critical question of all: "Where would my child be if I had found this earlier?"

The simple answer to the first three questions about not being told about this by teachers, optometrists, or doctors is because they didn't know. Although there are some teachers, optometrists,

and doctors who are aware of Irlen syndrome, there are not enough of them to recommend Irlen testing.

Two years ago teacher Bettylyn Baker came to my office to tell me about Irlen syndrome, its symptoms, and how a person suffering from Irlen's can be helped. She also told me that the educational system needed to do something about this because it was affecting the lives of students, their families, and high school completion rates, not to mention mental health issues and the criminal justice system.

As she described the symptoms of Irlen's, I thought of my seven-year-old grandson who was struggling with reading. During the previous summer his mom and dad had hired an excellent tutor to help him with his reading as he was not reading at grade level. They continued to have him tutored throughout grade 2, but he was still not reading at grade level. It baffled everyone that a child with so much ability and potential was struggling with reading. I would sit and listen to my grandson read, and as he hesitated at each word and struggled to complete each sentence, my heart ached for him. He was trying so hard, and it took him two or three times longer than normal to finally complete a sentence.

I asked this teacher in my office if she would test my grandson for Irlen syndrome. She agreed. Kaden was tested. He has Irlen's, and my daughter was amazed at the results when he was given coloured overlays to read with. He was given orange-coloured overlays to take to school so that he could lay them over the paper that he had to read. The most difficult words for someone with Irlen's are black printing on white paper, which is the real educational standard.

The next morning seven-year-old Kaden bounced out of bed, got ready for school, made sure he had the orange overlays in his backpack, reminded his mother that she had to talk to the teacher about Irlen's and the overlays, and headed to school with a smile. When Kaden got his new filtered lenses, his big sister asked him: so what do they do for you? He looked at her and simply said: they stop the words from moving. Like many others, Kaden's story is one of great success. Within six months he was reading at grade level, and he was achieving excellents and proficients on his report card.

I no longer worry about Kaden as he makes his way through school like any other normal kid his age. I don't worry about the fact that one teacher thought Kaden had ADHD and needed to be put on Ritalin. I don't worry that he will fail a grade and have his self-esteem attacked at every turn in school. But I do worry about all the other children who have Irlen syndrome and their families who suffer because they have Irlen's and there's no one to help them.

That's why we are here today. We are here today to make a decision on a process that can change the lives of children and their families. If you read through the 72 submissions that were sent to this committee, you will know about the tears of joy when the child is finally diagnosed and can read without stumbling and crying. You will know about the many people in Alberta who are hoping that we decide to pass this bill and become the leading light in Canada. I'm here to ask you to agree to send Bill 204 back to the floor of the Legislature to be debated by the entire Assembly.

10:10

I'm on slide 3 now. Thank you. The purpose of Bill 204 is to raise awareness of Irlen's, to ensure educators are aware of the symptoms of Irlen's, and to ensure there is a process in the school system for screening.

Slide 4. What exactly is Irlen syndrome? Oh, we're a little ahead. All right, we'll leave that up while I tell you what Irlen

syndrome is. Often referred to as Meares-Irlen syndrome or scotopic sensitivity syndrome or visual stress, it is a perceptual problem that is associated with the brain's ability to process images. It is a perceptual processing disorder, not a visual problem, a finding that the most current brain imaging research supports. The brain of someone who has Irlen's has difficulty or an inability to process certain wavelengths of light. In this way light, especially bright and fluorescent lighting, becomes a stressor on the brain. This stress causes certain parts of the brain, for example the visual cortex, to become overactive. It is this overactivity and inability to effectively process visual stimuli that creates a variety of visual, physical, cognitive, emotional, and neurological symptoms. You'll find that in submission 47.

A person may have 20/20 vision but still have Irlen's. They might be the smartest person in the class but still have Irlen's. You'll see that in Champ's presentation.

On slide 5 – maybe I'm out – we have the symptoms of Irlen's. Irlen syndrome has symptoms that are similar to dyslexia, attention deficit disorder, and attention deficit hyperactivity disorder. A lot of kids have been told they have ADHD or ADD, and for them they've suggested Ritalin when, in effect, if they were tested, they may have had Irlen's. Common symptoms of Irlen's include visual distortions on the printed page like words blurring or moving, difficulty with bright or fluorescent lighting, and physical symptoms such as headaches, fatigue, and eye strain. Many people go decades struggling with reading and light sensitivity which is misdiagnosed and needlessly treated with improper medication. That's in submission 55.

Now, on the one that says Examples of Irlen Distortions – there it is – you see the words in a wave pattern going up and down. That is something like what my grandson would have seen, so the reason he took so long to read a word is because he had to follow the wave to see the word and follow the wave to make the sentence. That's why it took him two or three times longer to see a sentence. Another example, over on the right-hand side, is with the blurring and the moving together of the words, also a reason why people with Irlen's use so much energy to try to read and to put the words together. Those are just examples. Imagine if you had to read like that.

The interesting thing that they find out about Irlen's is that when they test children – and we're talking about children, so nobody is faking this – they say: "Isn't that how everybody else sees? Isn't that how everybody else reads?" All along they've thought they've been slow and stupid because they couldn't get it and everybody else could, not realizing that they saw it differently.

Why is it important to test for Irlen's? A quote from submission 46 from two ophthalmologists who are research scientists at the second largest university in Brazil: "The economic impact due to special education class investments . . . and the aggravation it inflicted in the self worth image of our patients [is great]. The harvest of this bouquet . . . is criminal rates and parents & school conflicts besides personality disorders and transgression."

You can see on the screen that there is a prevalence in the population of children who have Irlen's to be misdiagnosed and in many cases not diagnosed at all.

Those are all the facts that you can read on your presentation, on your slide.

The next slide, I believe, is the cost of the screening process and diagnosis. It is a two-hour, noninvasive procedure which elicits symptoms that occur during reading in a more quantifiable way. This is the test itself. There are questions about the family history because Irlen's is hereditary. After my grandson was diagnosed, my son-in-law, who is quite intelligent and has great management

abilities but hates writing reports, actually waited for Kaden to bring home his first report card showing the improvements, and he said: I think I need to be tested because Irlen's is hereditary. There's a questionnaire to pinpoint inefficient reading actions, a questionnaire to elicit symptoms of strain and fatigue from reading.

One of the questionnaires had a maze on it, and in the maze were monkeys. It was white paper with black printing. My grandson was asked to identify all the monkeys in the trees, and he spent a few minutes, and finally, finally, finally – and my daughter is looking at this and seeing the monkeys, waiting for him to answer the question – it turned out that he could pick out three monkeys after about, you know, two minutes of trying to find them, which is a long time for a little guy. Finally, the screener put the orange overlay on the paper, and he said, "Oh," and he immediately picked out 10 monkeys because he could see them. So that's part of the screening process.

It is a simple, inexpensive test. It is a noninvasive, nonpharmacological, and low-cost approach. I think we have a slide that shows the cost. The initial cost is \$200 to \$250 for screening, for the overlays, for the information in the report. In this bill I am not asking the government to pay for that. Then there's the \$725 for a diagnostician testing report and purchase of prescribed filter lenses, so that includes the lenses.

There are many personal stories. If you went through the submissions, which I did – I have summarized each submission except for the last one, which just came in last night – you'll find that there are 50 submissions for and there are 20 submissions against. There is one unsure, and that totals 71. The reason we have 72 is because one person submitted twice. That was number 25, and then I believe he was in the late 60s. That was Dr. Charles Boulet from Lethbridge. We show 72, but it was really only 71 submissions. We just received another one last night, so I think in total you'll see marked 73 submissions.

I think it's really interesting for you to know that of the people who support the bill, there were 21 private citizens. Those will be the ones where you'll get all the testimonials saying: "Wow. This is what happened." Six of them were medical doctors in support, and one of them was an optometrist. There were 21 more, and these included diagnosticians, screeners, psychologists, reading specialists, educational therapists, the CNIB, and ophthalmologists.

Then against. There were no private citizens against this bill. There were four medical doctors who have concerns, there were seven opticians, and there were six others, including the Alberta School Boards Association, the Education minister, the College of Alberta School Superintendents, and a psychologist. There was one who was unsure whether to support the bill or not, and he was an optometrist.

One of the things that's really important to me is that we work together to help children, however that looks. I asked the registrar of the Alberta College of Optometrists if we could meet, and he was gracious enough to come and meet with me here at the Leg. because I was in the middle of a Commonwealth Parliamentary Association meeting, and I couldn't leave the Leg. He came to see me, and we talked about it.

10:20

The position of our optometrists is that a child should have a full and complete comprehensive eye exam first, which I totally agree with, and when I put the bill together I assumed that children would have had a full and complete comprehensive eye exam. When I spoke to the registrar, I agreed with him on that point. Of course, assuming that people would do that, he still

hesitated. When I asked if I amended the bill to include that a teacher recognizing symptoms of visual stress or Irlen's must recommend to the parents or guardians a complete and comprehensive eye exam, and if that doesn't find anything to be wrong – it's better worded than that – then they should be tested for Irlen's, the registrar actually agreed with me, and he is returning to his council to see if they could submit a different letter.

I know that if you look at all the optometrists' submissions, their very first concern is that a child receive a complete and comprehensive eye exam if there's a problem, and I totally agree with that because in the end what we want to do is to help a child, and we want to do it the right way. In order to make this better for everybody, I agreed that when I talked to this committee, we might include an amendment to the bill which includes, first, a complete and comprehensive eye exam. So the registrar was pleased with that discussion.

We were on personal stories. I've told you Kaden's story. Champ has come to the Legislature. I have introduced him to you in the Legislature. His story is one where he came home from school in grade 3 every day crying because he hated school. He didn't want to go back to school, and he was going to quit school. His mother had done everything she could to help him. Everything that she knew she could do, she had done. I said to her, "Well, what did you do?" This is Sarah Verbeek's submission. She said: "What could I do? I sat with him and cried."

Then somebody suggested, "Perhaps you should get him tested for Irlen's." Champ was tested. He has Irlen's. He wears a grey lens. He wore them when he was here in the Legislature along with his championship buckle from the rodeo. He's a junior champion. Champ went from wanting to quit school and hating school to being the number one person in his class because he was wearing Irlen's lenses. That's Champ's story.

Dr. Sharon Vaselenak is a doctor here in Edmonton. She struggled throughout school and throughout university but overcame all the difficulties, taking twice as long as everybody else to read the work she needed to read, and then discovered she had Irlen's. I'll be reading a quote from her at the end of the submission because she now as a doctor tests and diagnoses her own patients. You can also read Andrew's presentation. You'll find that the presentations from the private citizens are very compelling.

We're on slide 11, recent research. You can read that. I'm not going to go through it. Okay. I have to hurry.

The brain scans. I want to show you this very quickly. All the white areas are the energy and the activity that happen in the brain of a person with Irlen's who is overstimulated. Lights will trigger that. You can see all the activity and all the energy that they're spending.

On the next slide, when they're wearing an Irlen's filter, you can see that the activity in the brain is far less than it was when they weren't wearing the lenses. It creates a calming effect.

I want to address the stakeholders' concerns really quickly. I'm cutting into my question time. The use of school resources: this will save money for schools because you won't need the special needs teachers. The ones that are diagnosed and use the Irlen's lenses no longer will need a special person to sit with them. There was a school project done in Pioneer Valley in Acushnet, Massachusetts. By training two educators – it cost them a thousand dollars – one school district saved \$108,000. That's one school district.

The next concern is that the research is inconclusive, and I agree with that, but I have to tell you that I'm not willing to wait 30 more years for research to be conclusive and lose a whole other generation of kids that we can help. I know that 40 years ago I was told by my medical doctor that chiropractors were quacks and they were frauds and I shouldn't go see one. They still tell me that,

some of them. I know the relief that I have received from a chiropractor when I twisted my back. Anyway, that's research.

Comprehensive eye exam. I totally agree that we need to ensure that each child has a comprehensive eye exam. I think we can handle that one.

Those are stakeholders' concerns.

I am going to talk about possible amendments. But why should you support Bill 204? Because children need to read to succeed. Once you've been made aware of scotopic sensitivity syndrome, or Irlen's, you can't ignore the needs of children who are affected, and there are thousands of success stories of children and adults whose lives have been changed profoundly for the better because of being diagnosed with Irlen's.

Dr. Susan Leat and Dr. Daphne McCulloch, both from the University of Waterloo, as well as the Alberta association support testing after complete and comprehensive eye exams, which I'm willing to include in an amendment to the bill. And then there have been numerous other submissions.

In conclusion, there were many submissions by those who have been diagnosed with Irlen's and now are very successful, happy, and calm, who can more eloquently conclude than I can. So I'd like to end by quoting from one of the submissions, number 37, from Dr. Sharon Vaselenak, a family physician here in Edmonton. Dr. Vaselenak says:

As a family physician with Irlen syndrome, as well as two children affected by it, I have found myself in a very unique position to diagnose and help many children and adults who otherwise have had no idea as to the impact that the lighting environment was having on their ability to learn, work and even stay healthy. I feel that passing Bill 204 would be a huge step in increasing the awareness of not only the public and parents of affected students, but most importantly educators, psychologists and family physicians who can play a key role in helping all children affected by Irlen syndrome to achieve their full potential in school and in the workplace.

And that's why I think it's important for this committee to send this bill back to the Legislature for debate.

Thank you.

The Chair: All right. Well, great. Thanks, Mrs. Jablonski. That was a great presentation.

We have a couple of questions, but I would like to welcome Mrs. Towle and Mr. Goudreau to the table as well as Rob Reynolds from Parliamentary Counsel.

A question on the phones. Mrs. Leskiw, go ahead.

Mrs. Leskiw: It's not a question, just a comment. Being a teacher for as many years as I have, any tool teachers can receive to support their students should not be stopped. We should be encouraging it. I commend Mary Anne Jablonski on this bill, and if this bill helps even one student, it's worth having that tool within our school systems.

Mrs. Jablonski: Thank you, Genia. I think that's the very same comment that CNIB made in their submission. I think it was number 71.

The Chair: Okay. At this point I have no other questions. Anybody at the table or on the phones?

Ms Cusanelli: Can I ask a question? I didn't have the details about how to ask a question.

The Chair: Yes, you can. Absolutely. If anything comes up later, you can e-mail us – or you can pipe up any time – if you've got questions or comments later on. Please go ahead.

Ms Cusanelli: Thank you. My question is around the cost. I understand that the procedure is, according to the information given, fairly simple – a two-hour procedure, noninvasive, et cetera – and when you say that the cost would not be a part of what you'd be asking the government to pay, of course that would mean then at the school district level that they would have to be responsible for that. Is that sort of the implication there?

Mrs. Jablonski: In the bill as it stands and in the amendment that I'd like to bring forward, the responsibility remains with the parents to book the appointment and pay for the appointment. There is no indication in the bill about who is paying for it. I did speak to the Public School Boards' Association of Alberta. I spoke to Patty Dittrick and Mary Lynne, and they did indicate to me that if this is a learning concern for a child, some of the school boards would consider picking up the bill for testing, but that is not part of the bill itself.

Ms Cusanelli: Then my next question would be the duty of the board included in the bill that I have in front of me. Hopefully, this is the latest and greatest version. On page 2 it says, "A board must ensure that screeners are available to test for Irlen Syndrome." That's where my question comes in. If it's not up to the government to make sure that funding is available, then I would imagine it's going to have to be an issue of the board. Then when I see this, that they have to ensure screeners are available, what that says to me is that they would have to hire people in FTE status in order to do that, so that would become a cost to the board.

10:30

Mrs. Jablonski: Christine, thank you for that. After talking with Public School Boards' Association members, that was a concern that they had as well. When the time comes for me to talk to the committee about amendments to this bill, one of the things that I will change is the duty of the board, in that I will suggest an amendment to read: a board must ensure that a list of names and contact information of screeners who test for Irlen syndrome is available. I'm asking in the amendment that I'll bring forward when the time is appropriate that the board provide a list and contact information.

Ms Cusanelli: Okay. I say this in large part because of my role on the regulation review committee. Further down, within the regulations that the minister must establish, it also says in regulations, section 4:

- (a) establishing criteria, standards and policies concerning screeners;
- (b) prescribing any forms required under this Act, including consent forms;
- (c) concerning any additional matter or thing that is necessary in furtherance of this Act.

I guess that for me some of the red flags that pop up here are that now what we are asking the board to do is to ensure that the screeners themselves are kind of being vetted through the school district, which . . .

Mrs. Jablonski: Christine, thank you for those comments. I think that you're right on, but I want you to know that as part of the amendment that I will bring forward for this bill – and maybe I should just bring it forward since these are good questions that Christine is asking. As I make changes to the bill in suggesting an amendment, I have eliminated the entire section 4, which is the regulations.

The Chair: We're talking a lot about amendments and things like that. We're kind of really supposed to be on the bill, but I appreciate your sharing the information anyway, Mary Anne. Okay.

Ms Cusanelli: Is that a comment to me, Dave? Am I okay to be asking what I'm asking?

The Chair: Yeah. You're okay.

Ms Cusanelli: Okay.

Mrs. Jablonski: In other words, I recognize her concerns.

The Chair: Okay. Very good.

Ms Cusanelli: Okay. I guess the only other comment that I would have – I definitely see the value in that, and I have seen students that, you know, have been impacted. In one specific case, where a student did not use the lenses and refused to, et cetera, it never really worked out for him. I know he faces issues with the law and so on and so forth. I do understand that there are long-term consequences of not being able to diagnose appropriately any type of, I guess, issue where it relates to learning and certainly for reading.

In this case here, though, I think about Irlen's and the specificity behind, you know, naming a certain syndrome and, I guess, the responsibility on teachers, on schools, and on, of course, the boards and the minister in order for them to take on that responsibility to say: oh, yes, for us as a province, it's important that we single out Irlen syndrome. I just want to make the comment that on top of the other battery of exams or testing that's done, I wonder if Irlen's somehow should not just be included in sort of a regular process or procedure that we commit to as a province. I know that in a lot of school districts they determine what battery of tests are going to be used.

For example, if you have a student who is being tested for learning disabilities, typically they're going to have a WISC, they'll have a WIAT, they'll have maybe a Peabody. They'll have a battery of exams that they go through. I'm wondering if there's some way that we could almost insert the awareness piece on the Irlen syndrome aspect of things. I know that people will have an issue with the idea that Irlen's has a specific bill for it, yet attention deficit or dyslexia or other issues related to learning would not. That's the only comment I'd make on that.

Mrs. Jablonski: Christine, I want to thank you for that comment and just say to you that I think you're bang on. If they did include testing for Irlen's – and it's also called visual stress and in some cases scotopic sensitivity syndrome – and if there was an awareness, then I wouldn't even be bringing this bill forward. Part of the purpose of this bill is to bring that awareness so that when you test a child for any learning issues they may have, learning concerns they may have, you do include testing for Irlen's.

Ms Cusanelli: That's why I appreciate your bringing this forward.

I have to say that as a member I don't agree that we necessarily need a bill on this, but I do agree that there is a very big importance in making people across our province aware that this exists and that it is a part of the makeup of, you know, what we should be looking at in terms of diagnosing our students.

Mrs. Jablonski: Thanks very much.

The Chair: Okay. Very good.

Mr. Wilson, you had a question?

Mr. Wilson: Yes. Thank you, Mr. Chair. Perhaps I should qualify this with both you and Parliamentary Counsel before I move forward, seeing as you are somewhat opposed to discussing amendments. Is this not a stage where we should be discussing amendments? I guess, to Parliamentary Counsel: can the bill actually be amended at this phase of committee before being returned to the Legislature?

Mr. Reynolds: Well, with respect to your first question, it's up to the committee to decide how it wishes to proceed, but I'll just say that I believe that at this stage Mrs. Jablonski is making a presentation, and there will be other presentations to come. I mean, I would think that the time to discuss what you want in your report would be after you've heard the submissions, but that's just a suggestion.

With respect to whether you can amend the bill, no, you cannot. The bill is being provided here. It has not received second reading. If the committee recommended that the bill proceed, it could issue a report saying whatever it wants to say and perhaps suggesting some amendments, but the amendments could not be made until after the bill receives second reading, if it proceeds, and when it's in Committee of the Whole. In short, the committee can recommend amendments or how it would like to see the bill change, but it cannot actually amend the bill.

Mr. Wilson: Thank you. I appreciate the clarification.

You know, I do believe that that's probably the best step forward. I would have a very difficult time. Mrs. Jablonski, I honestly appreciate your passion and your presentation. It's so evident that you feel strongly about this, and I understand why. But I do believe that I would echo what Ms Cusanelli just suggested, that singling out this syndrome may not be the best thing to do in terms of a single piece of legislation. That being said, I would be much more comfortable discussing possible amendments because as the bill stands right now, I would have a tough time supporting this bill.

I'll just leave my comments at that. Thank you.

Mrs. Jablonski: Thanks, Jeff.

The Chair: The clock is ticking down on us a bit here, so if we can just go back to questions on the presentation.

Mrs. Towle.

Mrs. Towle: Thank you. Thank you, Mary Anne, for all of your hard work on this. My nephew has Irlen's, and I can appreciate your passion.

The one question I have is with the optometrists. I've done some chatting with them as well, and I've read your submissions from them. Would any of them consider implementing Irlen's testing within their own industry? Some of their submissions kind of insinuate that Irlen's isn't really an actual problem and that the solution to it doesn't actually work. Yet I know that with my own nephew – he has blue glasses. He went from an absolute dropout in grade 9, and he's now an honours student, so I can totally understand that there is some validity to this process. In the optometrist industry are they even open to this conversation?

Mrs. Jablonski: Yes, they are. There are a number of other companies besides the Irlen Institute in California that are now promoting different tools. There is something called – it's in one of our submissions. It's from Karen Monet. She's one of the directors of Opticalm. She's from Montreal. What she says is that there is a device that was invented by somebody from England, Dr. Wilkins, I believe, and that you can use this Intuitive Colorim-

eter tool to be able to diagnose. Up until recently it was the Irlen method. But as other people are recognizing the value of the testing and the need for the testing, we're finding that they're promoting other ways of testing besides just the Irlen process. So it's the colorimeter thing that's come out of England that is now coming into Canada, and there are other methods as well besides the Irlen method.

10:40

Optometrists have not been trained for this because it's not exactly visual. It's the neurosensory perception sending the message to the eye. There's nothing wrong with the eyes. It's centred in the brain. Really, if you go through some of the details, you'll find that optometrists and ophthalmologists don't even test for dyslexia, which is very similar to Irlen's. But as optometrists start to realize – I've talked to a number of them, my own optometrist and even Dr. Hensel, who's the registrar for the College of Optometrists. I've said to them: once you've done everything for a child, once you've done a complete and comprehensive exam of that child and you still can't find out why they can't see those letters properly, wouldn't you then recommend Irlen's testing? And each one of them has agreed with me, some hesitantly. But in the end if they've done their part, they too want to see a child succeed.

I know that some will suggest Irlen's testing outright and others will sort of mention to the side that maybe they should be tested for Irlen's. It's coming, but I don't want to wait for more children to fall through the cracks.

Mrs. Towle: Great. Thank you.

The Chair: All right. Thank you.

Well, we've got about three minutes and two more questions. Dr. Brown, followed by Mrs. Forsyth.

Dr. Brown: Thank you, Mr. Chair. Well, Mary Anne, I think that the most important hurdle that you have to overcome in moving forward with this bill is the strong opposition from the professional bodies, the Alberta Medical Association and the Alberta College of Optometrists. As a government we delegate the authority to those bodies to regulate their professions, to act in the best interests of the public. They are, quite frankly, the scientific and technical experts here. I mean, I am not, and I'm sure you'd concede that you're not an expert in these fields. So I'm wondering how you deal with that strong opposition of those bodies that made a lot of very specific criticisms of the bill and are clearly opposing it.

Mrs. Jablonski: Thank you very much for that, Neil. I think that you're right. We do have a lot of opposition from the professional bodies. I will remind you that 30, 40 years ago we had the same type of opposition to chiropractic care. I think they were off base then, and I think they're off base now. I would also say to you that if you look at all the submissions, you'll see there are ophthalmologists and optometrists who agree with this. I know there are some that laugh at it and throw it out, but I think that's disrespectful to the children who have needs.

One of the things that I decided to do to overcome the strong opposition, as you stated, Neil, is to talk to the College of Optometrists. That's why I called Dr. Hensel and asked him to come to see me. We had a chat. He understands that my concern is for the child. When an optometrist or an ophthalmologist can no longer conduct any more testing to find out why a child can't read, he did nod in agreement that we could then test for Irlen's. Remember, you called them the experts, Neil, but optometrists and ophthalmologists

do not test for dyslexia, which is a very similar disorder. So I'm questioning whether they are the experts. Visually, they are.

The Chair: All right. Mrs. Forsyth.

Mrs. Forsyth: Thanks, Mr. Chair. Mary Anne, your passion doesn't surprise me, as you and I go back a long way, and I appreciate everything you're trying to do to move this issue forward. I have read every presentation that's come through and spent a lot of time on this particular issue also. Dr. Brown and Ms Cusanelli have brought up some really good points.

You know, I reflect back on previous private members' bills, my bullying bill for one and several of yours, that had been questioned in the Legislature. It means you have to go back and get more work done for some of the people that are not supporting this bill: the AMA, the college of ophthalmologists, the College of Optometrists, Alberta Education. Health is warm to this issue.

I guess, at the point where the bill is written as it is now, I can't support it. You've talked about amendments, and I think probably the best thing for you to do is to start doing some work that needs to be done to get these people onside. Bring the bill back into the Legislature with your amendments, which we can't even consider because of the process of the committee, and do that.

Mrs. Jablonski: Thanks very much, Heather. Good direction.

The Chair: Okay. We're going to move on to item 5. Thanks everybody for your questions and comments. Just as to how we deal with the over 70 written submissions that we've had on Bill 204, right now these submissions are only available to the committee, and we need to determine how we wish to handle the release of these documents. Some of the submissions received did come in shortly after the posted due date, but they've been made available to the committee members, and the information they present has been included in the written submission summary with the exception of the one that came in over the weekend.

Does anyone have any concerns with the inclusion of all of the submissions received to date as part of the bill? I know we had a couple that were late, so that's my question to you.

Mrs. Forsyth: I have a question, Chair.

The Chair: All right, Mrs. Forsyth.

Mrs. Forsyth: It's just on the introduction, and maybe somebody can explain it to me. For the submissions it says that an erroneous press release had stated the deadline as July 5. I'm concerned about what happened there.

The Chair: We did have a deadline of July 5, so now it's up to the committee to decide if we want to accept the late ones or not, Heather.

Mrs. Forsyth: Okay. It says:

The deadline for submissions was June 28 . . . and 53 submissions were received by that date. However, 18 submissions were received the following week due to an erroneous press release that stated the deadline as July 5.

The Chair: Yeah. I'm sorry, Heather. Just to confirm here, we did have a press release that was erroneous that said July 5. That was supposed to be June 28. It was a mistake made here.

Mrs. Forsyth: Okay. I didn't know where the mistake came from, so I'm fine with the late submissions. I just wanted a clarification.

The Chair: Good catch. It was our mistake.

Ms DeLong: I just wondered whether we should consider essentially taking out people's names in terms of exactly how privacy works with children. Maybe I could get some guidance on that issue, whether or not children's names and thus their parent's names should possibly be taken out of the documents. I don't know. I just want to put that out there.

The Chair: That's an excellent question, and we are going to chat about that as the next item.

Mrs. Jablonski: Two comments. I think that I would have preferred that we would have stayed at the July 5 date; however, I feel that for anyone who has taken the time and made the effort to send in a written submission, I personally don't have any problem with us accepting those submissions up until today.

Then as far as the privacy issue is concerned, I know that there are some people who understand that these written submissions were going to be made public. I think that was something that was put on the website and in the press release, so they already know that they've subjected their names to the public, but I would recommend that for anyone who says, "I'll tell you my story, and I'll give you my name, but I don't want you to make it public," we should respect that, too.

The Chair: Okay. Well, we'll get on to that in a minute. For now we should really, just so we're all together on this, get a motion that

the Standing Committee on Families and Communities include all of the written submissions received prior to the July 22 meeting in review of Bill 204, Irlen Syndrome Testing Act.

That would also include the one that came in on the weekend.

Can I get that motion then?

Ms DeLong: I'll move that we do extend that deadline essentially to today so that those ones are covered.

10:50

The Chair: Okay. Very good. All in favour of that motion? Thank you. That's carried.

Now we'll get on to this privacy issue. We do need to provide our staff with direction regarding the public availability of these submissions. Many of the submissions on Bill 204 have been made by groups and associations. However – and this has come up several times – quite a few have also come from private individuals sharing stories of their personal experience with Irlen's diagnosis and treatment, and some of these personal stories do contain private information, medical information pertaining to minors or individuals other than the author of the submission.

Our call for submissions did indicate that submissions could be made public. I know that's our intent, but the personal nature of some of the information we've received should be kept in mind as we make decisions on the treatment of these submissions. There are several options for release that we could consider, and we've chatted about a couple already. The first and most obvious would be to post the submissions on the public website in their entirety with the exception of personal content information such as phone numbers and addresses, or we could choose not to release any submissions publicly, but I think our intent was to do so.

We also could come up with something in between these two. As has been mentioned here, we could protect people's privacy while allowing the public to have access to the information that we're using in our decisions. We could post all of the written submissions on our public website with the private information about third parties and minor children blacked out. We could also instruct staff to have this information redacted. Also, if necessary

we could withhold an entire submission. If we need to go the latter route, I think that at a minimum the name and location of the submitter would be available online.

So I just, really, throw that out for some discussion as to how we want to handle it, keeping in mind that when we go on to the oral presentations, you know, we could have some folks that would be disclosing a great deal of private information that we should probably caution them on in some way.

Back to the written ones, how do you think they should be handled?

Mr. Goudreau: Well, it seems to me that it would be appropriate, Mr. Chair, to certainly wipe out personal names of parents and children and provide the balance to the public.

I'm just wondering if Parliamentary Counsel has had experience in the past with similar kinds of presentations and what we've done before.

The Chair: Mr. Reynolds, do you want to respond, please?

Mr. Reynolds: Yes. Well, Dr. Massolin has actually prepared, I believe, some examples of what's occurred before. I mean, similar warnings have been issued to committees before concerning personal information and medical information that is provided to the committee, and the decision rests with the committee on whether to provide it. With children you have the added dimension of vulnerability to an extent. Dr. Massolin can tell you about some of the precedents that we've had.

Dr. Massolin: Yes. Thank you, Mr. Chair. I can tell you that in 2010 the former Standing Committee on Health, the former policy field committee, dealt with this issue when it was reviewing the Freedom of Information and Protection of Privacy Act, where the letter to stakeholders and other people making submissions indicated that submissions and names would be made public. However, the committee talked about whether or not to redact or black out personal information of a medical nature and third-party personal medical information. So they had a discussion about that, and they resolved to have that information redacted because they felt it wasn't in line with what the committee wanted to do in terms of making that information public. It wasn't, in other words, for the committee to sort of publicize that information when, really, they were looking at the individual submissions.

Other committees as well have gone that route, where there is a disclosure of third-party personal, often medical, information, and it decided to black that out in spite of this overall direction to make submissions public.

Mrs. Jablonski: I think that this is a really important decision that we have to make because there are a number of professionals who have sent in written submissions, and I think it's important that we know who they are. If you want, you can take their personal information off of the documents so you don't know to contact them. But it's their job, it's their profession, so I don't think they'll have any problem with us allowing their names to stand on the submissions.

The only ones that I would really be concerned about are the private citizens, namely the kids. In those cases, if you just wanted to take the names off and call them by their submission number, which we already have in place, I wouldn't have a problem with that.

Once again I do fall back on the fact that we did make people aware that this would be public. I know that there are some private citizens – and if we go ahead with the oral presentations, they'll probably come to present orally – who feel so strongly about the

success they've experienced that they'll be willing to stand in front of the committee and the world and proclaim the need for Irlen's testing.

I guess it would be up to the committee to decide whose names we would not allow, but I think the professionals would want their names to stand.

The Chair: Yeah. It's pretty much entirely the private submissions that we're thinking of.

Okay. It sounds like we're all thinking basically the same way. We still need a motion that the Standing Committee on Families and Communities make the submissions regarding Bill 204, Irlen Syndrome Testing Act, received available to the public with the exception of portions which contain personal contact information other than name and location of the submitter and where the submission contains personal information about a minor child or a third party.

Does that capture it?

Ms DeLong: I just want to make sure that we leave, essentially, the meat of the presentation in there. In other words, if we were to take out all the medical information or testing information, then that defeats, I think, the purpose of this. I think that what should be removed is the actual name and contact information on, essentially, any medical information that's there.

Dr. Massolin: I mean, I'm not trying to sway one way or the other, but I think that if you just take the name out, then, if you have the name of the submitter, you could possibly if you know some of the circumstances identify the individual regardless of whether or not that individual's name has been redacted. It's just a, you know, consideration. It's your choice, obviously.

Ms DeLong: I know that when it comes to medical research, that is the approach that's taken. The identifying information for that person is removed, and the medical information is kept in there. With extensive research, yes, you might be able to guess at who the person is, but essentially we take the same approach that the research community takes and remove the identifying information; in other words, the person's name and location.

Mrs. Jablonski: I would remind the committee once again that we did let people know that their submissions would be made public. I think that in some cases it's important to read what's in the document even if you want to remove their name and their location. I'm not going to object to that, but I would also say to you that on analysis of the 70 submissions there were 21 who were private citizens. I think those are the ones that we are most concerned about because anybody who has a professional affiliation is putting forward their professional opinion, and I don't think we need to remove their names from that.

I would suggest, just to throw it out there, that having given them the information that these would be made public, and they submitted anyways knowing that, if we are concerned – and I understand that. Because there are 21 private citizens, maybe they deserve a phone call, and we can request permission to put these publicly.

The Chair: Just going to get Mr. Reynolds, if it's okay with you, to comment on that option.

11:00

Mr. Reynolds: Yes. I'd want to look at it a little carefully. I mean, if you're talking about children's information, clearly it's about

Irlen syndrome. When you say professionals, I'm not entirely sure what you mean. For instance, if a doctor wrote in, if that's what you're referring to, one, I doubt if the doctor would cite specific patients because that would be a breach of his or her confidentiality. I imagine that there wouldn't be anything about an identifiable patient or client if that's who you're referring to, the professionals.

The other thing is that with professionals, I mean, they're writing in their capacity as a professional in their professional corporation or whatever, so their address could appear. As we said, we're just trying to be a little, you know, cautious about saying, if there was a submission – and I must say that I don't know if there is – that my son X is on such and such medication. We might be a little hesitant about that, but I don't know if there's an actual submission. It says that there is. That's where the hesitation might come in.

You're quite right that the letters that went out indicated, to my knowledge, that the presentations could be made public and that the individual would be identified, but having said that, it's just a matter of whether the committee wants to enhance the protections that exist. Obviously, all this information is available to the committee. I mean, we're not talking about that at all. You can see this information right now, and you obviously have. All we are talking about or issuing a concern about is what is released, if you will, publicly on the website to the world at large.

The Chair: Okay. I'm just going to get our clerk here to clarify what this motion would mean.

Ms Rempel: Just as it's drafted, and obviously it's at the discretion of the committee, what this motion would be intended to do would be to look at those submissions by private individuals. The ones by the various professionals and associations would be released in full – address, phone number, you know, everything – but as for the ones by private individuals, first and foremost we're taking off their private phone numbers, e-mails, that sort of thing. That's fairly standard.

As for redacting, the ones that we are concerned about are not the individuals that wrote in about themselves because – you're right – they were told that this information could be made public. It's the people that wrote in about others, very often their children. But, you know, they will also say, "Turns out my sister-in-law was tested, too," or something like that. So they're talking about people other than themselves, and they're potentially making medical information about other people available through their submission, so that would be the kind of information that we're looking at when we're talking about accepting the portions which contain information about a minor child or a third party. It's not people who wrote about themselves and wanted to share their own story. It would be basically people who talked about others in their submissions. That's what this motion would do.

Mrs. Jablonski: There is one submission, by Sarah Verbeek, where she included two statements from her two sons, who are minors. She knew that this was going to be made public because I've dealt with her in the past, and I've talked to her about it, and the two little guys signed their submission. If you want to take their names off, I suppose that you could.

But the other question is that there is another submission that does talk about an entire family. They signed it with all the family names. Would we be taking all the family names off because it's not the one person? The majority of the private citizen ones do refer to the experience they had with their children. I hope that whatever we decide to do as a committee, we don't alter the intent of the submissions.

The Chair: Okay. Mr. Goudreau, did you make that motion?

Mr. Goudreau: I did.

The Chair: Excellent. In that case, all in favour of the motion, please indicate. I'll just read it back. It was a few minutes ago. Moved that

the Standing Committee on Families and Communities make the submissions received regarding Bill 204, Irlen Syndrome Testing Act, available to the public with the exception of portions which contain personal contact information other than the name and the location of the submitter and where the submission contains personal information about a minor child and/or a third party.

All in favour of the motion?

Ms DeLong: It's still unclear what all this means. Maybe we need to break it up into pieces. It's just that I don't want to lose the medical information. Is it possible just for personal ones that the names and addresses be removed whereas the content remains there? So if you say son, the word "son" stays in there, but we just take out the names and contact information for the people.

The Chair: Yes. That would still be there, but anything identifying the minor child or third party is what we're looking at. It's for the protection of the third parties. Again, the committee will see all of it; it's the public that won't.

Okay. Can we throw that out one more time? All in favour? All right. Anybody opposed? Very good. Then that's carried. Thank you.

Now, the next item is the written submissions summary. I'll ask Ms Leonard to give us a brief overview of this document. We did get, say, 70 or 71 written submissions, so if we can just try and summarize what we can, that would be good. I would ask that we not have any comments or questions on the written submissions. We've all got them. It would be incredibly time consuming if we started opening up 71 written submissions today. The summary will be very beneficial, I think, to all of us.

Ms Leonard: The committee invited written submissions, both from specifically identified stakeholders and from members of the public, through the committee website and through social media. As you heard already, we received 71 submissions, 53 before the deadline and I guess it's 19 afterwards – we had that one over the weekend – bringing the total to 72. In the report we divided the submissions into two broad categories, those who support Bill 204 and those who oppose it.

First, I'll talk about the supporters. Forty-eight of the submissions supported Bill 204. All 47 of the submissions from individuals with either personal experience or professional involvement with Irlen syndrome or both supported the bill, and there was also one from the CNIB, who supported the bill as well. Twenty-nine were from people with personal experience – either they or one of their family members has Irlen syndrome – and the vast majority were from parents who have a child with the condition. Eighteen were from individuals who are involved professionally with Irlen syndrome; all of them are Irlen screeners or diagnosticians, and many of them are also professionals in other fields as well. Ten of those in those two categories actually had both professional involvement and personal experience.

Almost all of the submissions reported similar symptoms and alleviation of these symptoms once the individual in question started using overlays or lenses. Most reported that their reading skills improved. Quite a few described the improvement as significant or dramatic, and several also noted that the im-

provement was immediate. Many also reported improvement in academic performance and things like increased confidence and self-esteem, fewer headaches, better depth perception, and quite a few also described diagnosis and treatment of Irlen's as life changing or having a huge impact on their life or on the lives of their children.

The most common reasons given for supporting the bill: diagnosis and treatment would change the lives of individuals, students, and their families or it would benefit the community and society as a whole. Many also said that it would help raise awareness in teachers, parents, and the public and that it would reduce the number of children being undiagnosed or misdiagnosed with another learning disorder. Several felt that it would help children avoid limiting their choices in life and education or help them reach their full potential. A few said that it would reduce things like school failure, dropout rates, behaviour problems, poverty, and criminality. Quite a few referred to the cost-saving potential, that it would decrease money spent on unnecessary special education programs for children that had been misdiagnosed with learning disabilities, and several referred to the significant effects that could be achieved by what they described as a cost-effective screening method and low-cost accommodations.

11:10

There are also a few miscellaneous issues like heredity – quite a few had multiple family members with the condition – the cost of lenses, and also the focus on one perspective on the condition rather than that of other providers like Dr. Wilkins from the U.K. or other methods.

I'll now just go into the people who are opposed to Bill 204. Nearly all of the professional organizations, government bodies, and researchers that provided submissions opposed the bill, and quite a few expressed quite strong opposition. There were submissions from four researchers who specifically studied Irlen syndrome. Three collaborated on a study in Scotland, and they clearly opposed the bill. There was a fourth who supported aspects of the bill, but he had some concerns with it.

We had submissions from six professional associations, now seven with the one we received today from the Psychologists' Association of Alberta, and one government department, which was Alberta Education. The medical and optometric associations all strongly opposed the bill, and the submissions from the educational bodies raised concerns from an educational perspective. They all said that further research would be good.

We had 10 submissions from individual optometrists or ophthalmologists. Most of them opposed the bill. Nearly all of them suggested that it would be better to mandate comprehensive eye exams for children instead of Irlen's screening and that there was evidence showing that the symptoms of Irlen's can actually be caused by uncorrected optometric disorders.

A few of them discussed the link between reading disabilities and uncorrected vision problems. There were a few optometrists that did recognize that colour-based diagnosis and treatment methods, although not necessarily Irlen's, could be useful in a subset of individuals who had a comprehensive eye exam and had their optometric conditions treated but were still showing symptoms. They advised further research in this area. There were those two ophthalmologists from Brazil that believe that Irlen's screening is a useful part of a multidisciplinary treatment for visual disturbances and learning disabilities.

One of the most common reasons that was generally given for opposing the bill was the lack of evidence either for the existence of Irlen's as a condition or for the use of coloured filters. Many of

them pointed out this lack of evidence and said that at the very least these are very controversial claims. Quite a few pointed out that many professional bodies don't recognize it as a disorder. Some of the submitters were actually quite vocal in their criticisms. There is a lot of controversy in the research in this area, especially with regard to the efficacy of coloured filters. Opponents often criticize what I call pro-Irlen's research as having flawed methodology, small sample sizes, and not controlling for the placebo effect. Then in turn these same criticisms are directed back at anti-Irlen's research, I guess you would call it.

There were a few miscellaneous issues raised in the opponents' submissions. A few raised the issue of the proprietary nature of the Irlen method and what that means for cost. Some are concerned about the bill focusing on one perspective on the condition and one proprietary service. A number raised the issue of Irlen's screenings being unregulated and unlicensed. Some mentioned alternate evidence-based therapies that the government should be funding instead, that Bill 204 isn't cost-effective, or that it's not a good use of resources.

Several of the submissions that opposed Bill 204 included scientific papers, and they've actually been summarized in the appendix to the report if you want a brief description of each one.

For oral presentations we had 14 plus the one that we received over the weekend that indicated they were willing to make an oral presentation. Three of them weren't absolutely clear about whether they wanted to present, but we interpreted them that way and included them on the list. Dr. Kruk from the University of Manitoba said that since he lives in Manitoba, it would be hard for him to make a presentation, but he'd be happy to provide additional information if the committee has questions.

The Alberta Medical Association said that they're available for further consultation or to answer any questions the committee might have. The Minister of Education said that the committee should contact him if they'd like him to clarify his views or if the committee feels they would benefit from additional consultation with Education staff.

That's all. Thanks.

The Chair: Okay. All right. Thanks, Sarah.

We do have to decide what we're going to do about oral presentations. At the last meeting we determined we'd review the written submissions we receive before making any decision on holding oral presentations.

Oh, I'm sorry. There's one other note here. Dr. Swann, who was unable to join us here in person or by phone, had some comments that he had put in writing. We'll just circulate those around the table now. It's not a discussion item; it's just so you've got them.

Back to the oral presentations.

Mrs. Forsyth: Dave, are you going to e-mail those to us on the phone?

The Chair: We will, yeah.

Mrs. Forsyth: Thank you.

The Chair: Participants were asked to indicate in their submissions if they'd like to make an oral presentation. As Sarah has just said, we've got up to 15 that said that they were willing to make an oral presentation. Some were clearer than others. I guess, first of all, as a committee we're okay to go ahead with oral presentations? I see some heads nodding. Okay.

On the phones, everybody want to go ahead with the oral presentations?

Mrs. Forsyth: No. I am opposed.

The Chair: You're opposed. Okay.
Anybody else?

Mr. Wilson: Yeah. Mr. Chair, I would concur with Mrs. Forsyth. I think that without the wording or an understanding of the intent of the various amendments Mrs. Jablonski suggested she'll be bringing forward, I don't see much value or benefit to our committee hearing oral presentations. They really won't be heard in the context of the bill as it would read once amended. With that, I would move that Bill 204 be returned to the Legislature for consideration of second reading in the fall.

The Chair: Okay.
Any discussion on the motion?

Mrs. Forsyth: Well, if I may, Chair, just to add to what my colleague has made a motion on, we all have gone through pages and pages and pages and pages of documentation, and it has been an extensive read. We know how the people that are wanting to make an oral presentation feel. I, quite frankly, would like to see this hit the Legislature because I think Mary Anne has some work to do. I want to remind the committee that this bill came forward and took off the table something that we all had agreed on previously in regard to moving forward on mental health. I think that's a priority. I just am going to say that I support what Jeff has said.

The Chair: Okay. I'd just like to comment on that. My understanding, should we send out those invitations, is that I think the committee's expectation would be that we wouldn't get the same information that was presented in their written presentation. Understood, I mean, that would be kind of nonproductive, but if they've got more to bring forward than they put in their written presentation, that would be the intent.

Mrs. Forsyth: Well, Chair, if I may, I don't want to get into an argument, but you've got 14 presenters who have all made a written submission. I can tell you that if I was making a written submission on something that I was passionate about – they have included all the information, I would think, just to get through the first process.

The Chair: Okay. All right. We have a motion on the floor. Is there further discussion? Just a minute or two because I wasn't expecting a motion. Please, go ahead, Mrs. Jablonski.

Mrs. Jablonski: To the motion that has been presented to the committee, my goal is to have this bill go back to the Legislature to be debated. I respect the time and the effort of all committee members and, of course, all presenters as well. If it's the committee's will, I would be happy just to take this bill back to the Legislature.

The Chair: Just any further discussion on the motion on the floor? Please, Mr. Goudreau.

Mr. Goudreau: Well, thank you, Mr. Chair. I oppose the motion for one particular reason. It seems, you know, just the fact that we've already received a number of submissions that are for moving forward with the act, and there are quite a number against us moving forward with this particular one. It appears to be somewhat confusing for me, at least in my own mind, at this particular stage. I for one wouldn't mind getting more information and thoughtful presentations by individuals to allow me to make a

much better decision once the act gets back into the Legislature, if we choose to go that route.

The Chair: Very good. Okay.

I'm going to call the question. All in favour of the motion – can you just read it back, Jody?

11:20

Ms Rempel: I couldn't hear him completely, but I believe it was to return Bill 204, Irlen Syndrome Testing Act, to the Legislature.

Essentially, I believe that would be recommending that the bill proceed.

The Chair: Did we get it right, Heather?

Mrs. Forsyth: I'm sorry. I didn't make that motion. It was Jeff's.

The Chair: I'm sorry. It was Jeff's. You were commenting.

Mr. Wilson: I believe the intent is there, Chair.

The Chair: Okay. All in favour of the motion? All opposed to the motion, please? Okay. The motion is defeated.

Back to who we do invite to give oral presentations. Again, we've got 15 that have requested in some way, that could be invited. We could invite everybody that did a written submission and end up dealing with more. I don't think that we would want to spend more than one day on oral submissions. The more that we have, the more it's going to confine the time of the individual submitters. Any comments on which way we could go? Mrs. Jablonski.

Mrs. Jablonski: Thank you, Chair. Certainly, the 15 who have indicated that they would like to give an oral submission should be invited, but I would also open it up to all those who submitted. I don't think that we will get 72 people responding for an oral submission, but I believe some people were not aware that unless they asked to present orally, they would not be given that opportunity. I think it would only be fair that we invite all those who submitted to do an oral presentation. I don't think we'll get a response from all of them, but I think they should all be invited.

The Chair: We did, actually, when the invitations went out for the written presentations, did we not? Have we got that handy? I just want to confirm. I think we did ask them, actually, if they wanted to do an oral presentation.

Ms Rempel: Yeah. The section read:

The Committee may also be holding public hearings at a later date. All parties wishing to be considered for the opportunity to make an oral presentation to the Committee should indicate so in their written submissions.

Mrs. Jablonski: Thank you.

The Chair: Okay. Any other thoughts on which way we should go?

Dr. Brown: Mr. Chairman, I would like to suggest that we invite representatives of the Alberta Medical Association, the Alberta School Boards Association, and the College of Optometrists to provide some balance and that Mrs. Jablonski should choose three of the opposite view to appear before us so that there's some balance in what we receive in terms of oral presentations, somewhat limiting it to those that, I think, have the most critical opinions that we need to hear from.

The Chair: Yeah. If we spent a day on it, how does it work out for time for each presenter if we took everybody?

Mrs. Forsyth: Mr. Chair, if I may – I don't think you were part and parcel of the committee – we tried that when we were doing the mental health, and it ended up a very tedious and long process. I think that when we were supposed to be on six hours, it ended up eight. If the committee is determined to go through this process, then let's limit the presentations that are coming forward. I will agree with Dr. Brown, maybe get a balance. Mary Anne would know better than anybody, the true advocates of Irlen syndrome, and then maybe have the AMA, the College of Optometrists, or ophthalmologists, for that matter. You've got ASBA. Christine was concerned about where they were. Some sort of a balance. If we start trying to deal with 15, there is no way on God's green Earth you're going to get this done in a day.

The Chair: Okay. Well, keeping in mind that some of the requests – was it three of the requests there? – were sort of ambiguous one way or the other. We're probably actually talking a dozen. We'd have to have sort of some kind of rationale for inviting some and not inviting others that have requested the oral submissions.

Mrs. Forsyth: If you go to the private citizens, many of them have presented on behalf of themselves or a family member. I personally don't think you are going to find anybody more passionate than what Mary Anne has talked about with her grandson Kaden.

The Chair: Sure. Okay. Understood.

Dr. Brown: Do you want a motion, Mr. Chair? I'd be pleased to make a motion if that would resolve the thing.

But I wanted to point out that one of the parties from whom we should receive an oral submission was one of those parties that had not indicated on the list that they wish to make an oral presentation. However, I think they should be invited, and I think that they would definitely accept given their interest in the matter.

The Chair: Okay. Your motion would read?

Dr. Brown: I would move, Mr. Chair, that

the oral presentations to the committee be limited to representatives of the Alberta School Boards Association, the Alberta Medical Association, and the College of Optometrists and three proponents of the bill as selected by Mrs. Jablonski.

The Chair: Discussion?

Mrs. Jablonski: You've already invited people. Jody just read to us what was in the press release, saying: if you would like to have an oral presentation. The members that you speak about, the professional organizations, I think most of them have indicated to us that they would like to do an oral presentation as well. Certainly, I have no objection to any of them that want to do an oral presentation, but I don't want to cut off any of those that we invited and that stated they'd like to be here to do a presentation. If that means 14 or 15, then because we sent out the invitation, I don't think we should be picking and choosing.

I even think that after we sent out the invitation to the 15 who have indicated that they want to present, including the ones I believe that you've mentioned, Neil, which are important, for sure, there may be a few others that will have a burning need to present to us as well. Those are the ones that I think we need to be

discussing if we're going to allow any more than 15 who have already indicated.

Mr. Goudreau: Just for clarity, Mr. Chairman, I'm just wondering if Jody could reread the ad or the option. If we've promised that they have the opportunity, then we should follow up, but if we said they "may," then we can pick and choose.

The Chair: Just read it back one more time.

Ms Rempel: Certainly. Just to clarify, this was in the stakeholder letter that was sent out to identified potentially interested parties as well as posted online. The letter reads:

The Committee may also be holding public hearings at a later date. All parties wishing to be considered for the opportunity to make an oral presentation to the Committee should indicate so in their written submissions.

Mr. Goudreau: Thank you. I would support Dr. Brown's proposal.

The Chair: Okay. Any other discussion on the motion?

Mr. Wilson: I would support Dr. Brown's motion as well.

The Chair: Okay. So we've got some indication. We'll call the question now. If everybody could indicate, please, one more time. All in favour of Dr. Brown's motion? All right. Opposed? Okay. Then the motion is carried.

Mrs. Jablonski: May I have that motion read again, please?

Ms Rempel: Moved by Dr. Brown that the Standing Committee on Families and Communities invite representatives from the Alberta Medical Association, the Alberta School Boards Association, and the College of Optometrists to make an oral presentation on Bill 204 plus three proponents of the bill as selected by Mrs. Jablonski.

Mrs. Jablonski: So we will just be inviting those three professional organizations, then?

Ms Rempel: Plus three.

Mrs. Jablonski: Plus three I choose.

Ms Rempel: We can follow up with you afterwards on that.

The Chair: Okay. All right. Again, the motion was carried. Let's get some comments. We're onto research.

Mrs. Fritz: Can I just ask a follow-up question to the motion?

The Chair: Sure.

Mrs. Fritz: What will be the correspondence back to those who weren't chosen?

The Chair: Go ahead, Jody.

Ms Rempel: There wouldn't necessarily be any as a standard practice, but if there is something that the committee wished to direct . . .

11:30

Mrs. Fritz: If there's an invitation that they could make a presentation and they're not going to be selected and we didn't embrace what we had sent out to the public, then should we not know that they haven't been selected for a presentation? They're going to know that there are people, very powerful groups that

will be presenting, and then they're going to look to us as to why they aren't selected by the individual who wrote the bill, which is Mary Anne. So she's leaving out a number of people.

Ms Rempel: Well, perhaps, you know, if it was the will of the committee, what we could do is that once we actually have the next meeting scheduled and we've made the arrangements for the presentations and confirmed who's coming, we could send some follow-up correspondence either by mail or e-mail, depending on the contact information that we have, advising the groups or individuals who weren't selected of who was going to be presenting and when so that if they're interested, they can certainly follow along. We could also advise them, as we often would, where they could find more information about the committee, including the *Hansard* transcript of this meeting.

The Chair: Go ahead, Mrs. Jablonski. Then we're going to move on.

Mrs. Jablonski: Along with what Jody has just said, the three organizations that Dr. Brown has mentioned represent a number of people, so the three oral presenters that I select will also be able to represent a number of people.

My questions is: will the people that they represent be allowed to be here to witness the oral presentation?

Mrs. Fritz: As long as they're notified of that, I'd agree then.

The Chair: I guess with that being said, with the limited number of oral presenters I'd ask all committee members to go over the written submissions very carefully and make sure you understand everybody's position.

Okay. Research support. At the request of the committee a crossjurisdictional comparison has been put together by our research support staff. We'll get Ms Leonard to do a summary of what this crossjurisdictional comparison looked like, please.

Ms Leonard: Thank you, Mr. Chair. For the jurisdictions that we decided to look at for legislation or policy relating to screening for Irlen syndrome, we chose the U.S., the U.K., Australia, and New Zealand plus the other provinces and territories in Canada. We looked for policy and legislation at both the national and provincial or territorial or state level. We restricted the search to policy or legislation in the educational or learning disabilities context rather than the health or medical context primarily because of time constraints and also because Bill 204 itself is looking at screening within the educational system.

I just want to point out that while there are individual schools or even school districts that have Irlen screening programs, the report and the research didn't go into this much detail because Bill 204 is legislating at a provincial level, so we looked for policy or legislation at roughly equivalent levels of government.

For legislation there was no existing legislation that mentions Irlen syndrome in any of the jurisdictions that we looked at.

For proposed legislation in Canada there's only our Bill 204. In the States Massachusetts has a bill before its Legislature that goes before the committee in September. In the Australian House of Representatives a private member gave notice of a motion for the House to recognize dyslexia as a learning disability and Irlen's as a type of dyslexia and to support training for teachers to recognize these conditions, but the motion hadn't been voted on as of the end of June, and the House isn't sitting again until August, so we don't know the outcome of that.

For policy for each jurisdiction we searched the websites of their education departments, but generally there wasn't any

information available because they don't post those or make their policies publicly available, so we e-mailed the special education teams in each department to ask whether they had any existing policy. In Canada six of the provinces and territories replied. None had any policy or knew of any screening happening in their schools.

In the States none of the 28 states that replied said that they had any specific policy on Irlen syndrome or had a screening program or consider it to be a specific learning disability. A few states said that a child could potentially be referred externally for screening as part of a learning disabilities assessment, and two said that they'd consider an external diagnosis of Irlen syndrome when assessing a child for learning disabilities.

In New Zealand the Ministry of Education commissioned a research paper on Irlen syndrome but decided there wasn't sufficient evidence to support a screening program.

In Australia four of the education departments replied. None had any policy or recognized it as a learning disability. One state did mention that children will still get support in school regardless of any diagnosis, and another said that they would provide children who had been externally diagnosed with overlays and coloured paper.

The U.K. is the jurisdiction, I would say, that has the most familiarity with Irlen syndrome although they often call it visual stress or Meares-Irlen, and they often diagnose or treat it with alternative, non-Irlen methods like the Intuitive Colorimeter system.

I contacted the special educational needs teams and a number of their education authorities, which are the local bodies that are responsible for education in the U.K. Seventeen in England and Wales replied and said that they didn't have specific policy. One in England and one in Wales each said that they did specifically screen children for Irlen's although the one in England said that they use the Intuitive Colorimeter system rather than the Irlen method.

But it does appear that a lot of the special educational needs workers in schools are aware of the condition and its symptoms, and they said that they would recommend that parents take their children to a specialist if they see symptoms although they usually refer to an optometrist or orthoptist or a doctor rather than an Irlen screener. Most of the authorities don't consider Irlen syndrome to be a special educational need per se but said that they would support children who wanted to use overlays or coloured lenses.

In Scotland we got replies from about half of the 30 education authorities. A few of them do have specific policies on screening for Irlen's, but on the other hand a few specifically said that they refuse to screen for Irlen's because there is insufficient evidence of the condition or its treatment. Actually, one of the education authorities that had such concerns was Inverclyde, which is the site of the research study carried out by the University of Edinburgh that was described in the submissions summary. Most education authorities in Scotland say that their national learning disabilities legislation requires them to support children's learning needs regardless of diagnosis, which in practice seems to mean that they'll provide children with accommodations like overlays or coloured paper or make lighting modifications.

That is all.

The Chair: Thank you for that.

Communications update. I'd like to ask Rhonda Sorensen to update us on our communications strategy and share any suggestions she has regarding any initiatives we should consider based on the decisions that we made today.

Ms Sorensen: Thank you, Mr. Chair. At the beginning of this process we did issue news releases as well as put some social media posts up indicating that the committee was beginning its work. We didn't see a huge amount of activity on social media. However, our main objective with social media is always to draw people to the website, and we did see a significant amount of activity on the website, particularly on the days that we did release information and in the week leading up to the deadline for submissions.

Based on what was discussed here today, I, of course, will be looking for the committee's direction but would recommend sending out a similar type of information again, saying that these submissions are going online, and then once we determine a schedule for the oral presentations, doing a similar blitz, letting people know that the oral presentations are taking place.

The Chair: Okay. Any comments?

Mrs. Jablonski: I'll make it short and sweet.

The Chair: I thought you might. Go ahead, Mrs. Jablonski.

Mrs. Jablonski: Once again I do want to thank the research officer for putting this together. I think she did a great job, and I really appreciate the work she put into it. She mentioned that six of the provinces wrote back, and they have no policy, and they have no whatever about Irlen's. I would say to you that that's exactly why I've put this bill forward. There needs to be greater awareness. Thanks very much for all your work.

The Chair: All right. Very good.

Well, if there's nothing else on communications, thanks, Rhonda.

Is there any other business that any members want to bring up?

Mrs. Fritz: I just had one other question, Mr. Chairman. I don't know if it's relative to communications or not. Is there a time limit on the presentations?

The Chair: The oral presentations?

Mrs. Fritz: Yes.

The Chair: We'll have to see what the responses are first, Yvonne, and see how many are actually presenting and see what time is going to allow. We'll do that later.

Mrs. Fritz: Okay. Yeah. Thank you.

The Chair: We'll have to establish the date of the next meeting sort of based on some of that availability and everybody else's. I can just say that we will of course have this work complete by the time the Legislature reconvenes and probably not in August, to give everybody time to prepare. We know attendance in August can be difficult for many. The next meeting will be at the call of the chair.

I'm sorry. Rhonda has a question.

11:40

Ms Sorensen: Sorry, Mr. Chair. I just wanted to clarify that the committee is in agreement that I continue to make information public about its work.

The Chair: Yes. Please proceed.

Ms Sorensen: Yes. Okay. I just wanted to clarify. Thank you.

Mr. Goudreau: Mr. Chair, maybe concerning the selection of the next meeting date, as I'm travelling from the Peace Country all the time, I've got to come down Sunday afternoons and Sunday nights to be here on a Monday. So could I request that the meeting date be sometime during the week aside from a Monday morning?

The Chair: Sure. Yeah. Understood. We'll probably poll, I would think, but we'll take all that into consideration.

Mr. Goudreau: Thank you.

Dr. Brown: In September sometime?

The Chair: It'll be in September, yes. It has to be to follow the timeline.

All right. I need a motion to adjourn. Ms Jansen. All in favour? We are adjourned.

Thank you.

[The committee adjourned at 11:41 a.m.]

