Third Session - Fortieth Legislature

of the

# Legislative Assembly of Manitoba

# Standing Committee
# on
# Social and Economic Development

*Chairperson*
*Mr. Dave Gaudreau*
*Constituency of St. Norbert*

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# MANITOBA LEGISLATIVE ASSEMBLY
## Fortieth Legislature

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| *Vacant* | The Pas | |

# LEGISLATIVE ASSEMBLY OF MANITOBA

## THE STANDING COMMITTEE ON SOCIAL AND ECONOMIC DEVELOPMENT

### Wednesday, June 4, 2014

***TIME – 6 p.m.***

***LOCATION – Winnipeg, Manitoba***

***CHAIRPERSON – Mr. Dave Gaudreau (St. Norbert)***

***VICE-CHAIRPERSON – Mr. Mohinder Saran (The Maples)***

***ATTENDANCE – 11 QUORUM – 6***

*Members of the Committee present:*

*Hon. Messrs. Kostyshyn, Lemieux, Hon. Ms. Marcelino, Hon. Mr. Swan*

*Messrs. Ewasko, Gaudreau, Goertzen, Marcelino, Mrs. Rowat, Messrs. Saran, Schuler*

***APPEARING:***

*Hon. Jon Gerrard, MLA for River Heights*
*Mr. Ralph Eichler, MLA for Lakeside*
*Mr. Cliff Graydon, MLA for Emerson*

*Mr. David Wright, Legislative Counsel*

***PUBLIC PRESENTERS:***

*Bill 74–The Public Sector Compensation Disclosure Amendment Act*

*Mr. Maurice Sabourin, private citizen*
*Mr. Mike Sutherland, Winnipeg Police Association*
*Mr. Gord Perrier, Winnipeg Police Service*
*Mr. Kevin Rampersad, private citizen*

*Bill 209–The Lymphedema Awareness Day Act*

*Ms. Kim Avanthay, Lymphedema Association of Manitoba*

*Bill 214–The Neurofibromatosis Awareness Month Act*

*Mr. Jeffrey Nykoliation, private citizen*
*Ms. Tracy Gregorash, Manitoba Neurofibromatosis Support Group*
*Ms. Shannon Goodall-George, private citizen*
*Ms. Doreen Loewen, private citizen*
*Ms. Annette Lissenberg, private citizen*
*Ms. Christa Degagne, private citizen*
*Ms. Rebecca Penner, private citizen*
*Ms. Nancy Anderson, private citizen*
*Ms. Connie Bart Hamel, private citizen*
*Ms. Kathleen Demers, private citizen*
*Ms. Carol Maione, private citizen*

*Bill 72–The Coat of Arms, Emblems and the Manitoba Tartan Amendment Act*

*Mr. David M. Sanders, private citizen*

***WRITTEN SUBMISSIONS:***

*Bill 214–The Neurofibromatosis Awareness Day Act*

*Brenda Marion-Gerula, private citizen*
*Karen Gail DePratto, private citizen*

***MATTERS UNDER CONSIDERATION:***

*Bill 64–The Court of Queen's Bench Small Claims Practices Amendment Act*

*Bill 72–The Coat of Arms, Emblems and the Manitoba Tartan Amendment Act*

*Bill 74–The Public Sector Compensation Disclosure Amendment Act*

*Bill 203–The Nurse Practitioner Day Act*

*Bill 208–The Drivers and Vehicles Amendment Act (Support Our Troops Licence Plates)*

*Bill 209–The Lymphedema Awareness Day Act*

*Bill 214–The Neurofibromatosis Awareness Month Act*

*Bill 300–The St. Charles Country Club Incorporation Amendment Act*

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**Mr. Chairperson:** Good evening. We will now call the Standing Committee on Social and Economic Development to order.

Before the committee can proceed with business, we must elect a new Vice-Chair. Are there any nominations?

**Hon. Andrew Swan (Minister of Justice and Attorney General):** Mr. Chairperson, I nominate Mr. Saran.

**Mr. Chairperson:** Are there any other nominations?

Hearing no other nominations, Mr. Saran is elected Vice-Chair.

This meeting has been called to consider the following bills: Bill 64, The Court of Queen's Bench Small Claims Practices Amendment Act; Bill 72, The Coat of Arms, Emblems and the Manitoba Tartan Amendment Act; Bill 74, The Public Sector Compensation Disclosure Amendment Act; Bill 203, The Nurse Practitioner Day Act; Bill 208, The Drivers and Vehicles Amendment Act (Support Our Troops Licence Plates); Bill 209, The Lymphedema Awareness Day Act; Bill 214, The Neurofibromatosis Awareness Month Act; Bill 300, The St. Charles Country Incorporation Amendment Act.

How late does the committee wish to sit this evening?

**Mr. Swan:** Just until the work of the committee is complete.

**Mr. Chairperson:** We have a number of presenters registered to speak tonight. As noted on the list of presenters before you, on the topic of determining the order of public presentations, I will note that we have out-of-town presenters in attendance and they are marked with an asterisk on your list.

With this in consideration–with this consideration in mind, what order does the committee wish to hear the presentations?

**Mr. Swan:** I'd suggest we just go in numerical order, and I would suggest that our out-of-town presenters be able to present first.

**Mr. Chairperson:** Agreed?

Before we present with presentations, we do have another item–another number of items and points of information to consider. First of all, is there any–if there's anyone in the audience who would like to make a presentation this evening, please register with the staff at the entrance of the room.

Also, for the information of all presenters, while written versions of presentations are not required, if you're going to accompany your presentation with written materials, we ask you provide 20 copies. If you need help with photocopying, please speak with our staff.

As well, I'd like to inform the presenters, in accordance with our rules, that a time limit of 10 minutes is allotted for presentations, with another five minutes allowed for questions from the committee members.

Also, in accordance with our rules, if a presenter is not in attendance when their name is called, they will be dropped to the bottom of the list. If the presenter is not in attendance when their name is called a second time, they will be removed from the presenters' list.

A written submission on Bill 214 has been received and distributed to committee members: Brenda Marion-Gerula, private citizen; Karen Gail DePratto, private citizen. Does the committee agree to have the submission appear in Hansard transcript of this meeting? *[Agreed]*

Prior to proceeding with public presentations, I'd like to advise members of the public regarding the process for speaking in–with–in committee. The proceedings of our meeting are recorded in order to provide a verbatim transcript. Each time someone wishes to speak, whether it be an MLA or a presenter, I first have to say that person's name, and this is the signal for the Hansard recorder to turn the mics on and off.

I thank you for your patience, and we will now proceed with the public presentations.

**Mr. Swan:** Just before you proceed, I wonder if you could ask the committee if there's leave to have Mr. Marcelino deal with Bill 203, The Nurse Practitioner Day Act, which is currently in the name of Ms. Crothers.

**Mr. Chairperson:** Is there leave from the committee for Mr. Marcelino to present The Nurse Practitioner Day Act? *[Agreed]*

Just before we start, a black Ford, your lights are on. So, if anybody has that, please go outside and turn your lights off and then come on back in.

## Bill 74–The Public Sector Compensation Disclosure Amendment Act

**Mr. Chairperson:** I will now call on Maurice Sabourin to present on Bill 74, The Public Sector Compensation Disclosure Amendment Act.

Do you have any written materials for the committee?

**Mr. Maurice Sabourin (Private Citizen):** No, I don't. It'll be an oral presentation.

**Mr. Chairperson:** Okay, please proceed with your presentation.

**Mr. Sabourin:** I'd like to thank you all for giving me the opportunity to address the committee. I'm here to speak in support of Bill 74, the amendment to the compensations list.

I've been a police officer for 24 years with the Winnipeg Police Service. In the last seven years, I have been the co-chair of the workplace safety and health committee.

Each year that the City of Winnipeg publishes the list for compensation, I always receive between 15 and 20 inquiries asking why police officers' names have to be published. The concern is that their identity becomes known; it's year after year that the members names are published, the salaries are all well above $50,000, and there is always the concern that their name being published puts themselves in danger as well as their families because, with the advent of the Internet and having proper spelling of everybody's names, it's very easy to obtain very detailed information about where our members live.

It's not uncommon for there to be retaliation events against our members. We continually see incidents when we are leaving work and walking to our vehicles because we don't have safe, secure parking. And that–the fact that people can find out where we live as a result of our names being published puts our members and their families in great danger.

I can tell you that if this bill passes that our members will be very, very happy, and it will preserve the safety of our members and we can continue to serve the citizens of Winnipeg and Manitoba.

Thank you.

**Mr. Chairperson:** Thank you for your presentation.

**Hon. Andrew Swan (Minister of Justice and Attorney General):** Yes, Mr. Sabourin, thank you for coming down and presenting to us this evening, and thank you for your long-time service to the people of Winnipeg as a police officer. Obviously, we've had good advice from both the Winnipeg Police Association and the Winnipeg Police Service. We do think this bill is a good thing for the safety of our officers.

I want to thank my own caucus but also the opposition caucus for being prepared to move this ahead, and I think your advice tonight just makes it so much more clear why this bill is necessary.

**Mr. Kelvin Goertzen (Steinbach):** Thanks very much for coming here this evening. More importantly, thank you for your service to the citizens of Winnipeg and also all Manitobans. We know that the job you undertake is difficult and sometimes dangerous, we don't know the day-to-day details and we don't hear all the stories, but we do appreciate the work that you do as well as all police officers in Manitoba.

When we had the discussion with government on this bill, it brought to mind a lot of the stories that I've heard from officers. I don't think this bill will–I don't know that anything could ever make the job safe, but if it makes it safer, we support it. And I was pleased to work with the government to ensure it will pass this session, and if there are other things we can do to help make you and your colleagues safer, we're always open to hear from that because we appreciate what you do and we want you to know that we appreciate it very much.

**Hon. Jon Gerrard (River Heights):** Thank you for your comments and thanks for coming here. I just want to let you know that this bill has the support of the Liberal Party as well as the Conservatives and the NDP, and we're behind it and behind efforts which can help make things safer for police officers.

**Mr. Chairperson:** Thank you very much for your presentation.

### Bill 209–The Lymphedema Awareness Day Act

**Mr. Chairperson:** I'll now move on to Bill 209, The Lymphedema Awareness Day Act, to the next out-of-town presenter, and that is Kim Avanthay.

Do you have any written materials for the committee tonight?

**Ms. Kim Avanthay (Lymphedema Association of Manitoba):** No.

**Mr. Chairperson:** No? Please proceed with your presentation.

**Ms. Avanthay:** Thank you.

Lymphedema is a chronic edema that results in fluid retention and tissue swelling as a consequence of an insufficient lymphatic system.

Primary lymphedema is the result of missing or impaired lymphatic vessels due to abnormal lymphatic development.

***** (18:10)

Secondary lymphatic–lymphedema is more common and occurs when lymph vessels are damaged or removed. Factors which contribute to secondary lymphedema can include trauma, burns, infection, inflammation, cancer treatments of surgery and radiation, tumours, reduced mobility, paralysis, venous insufficiency and obesity.

Good evening, all. My name is Kim Avanthay. I am here today representing the Lymphedema Association of Manitoba, also known as the LAM, and I'm here to speak in support of Bill 209, Lymphedema Awareness Day Act.

I would like to share with you a little bit about myself, which will lead to why I'm here before you. June 29th, 2005, my son, Austin, was born. It was a difficult birth and it wasn't until he was five weeks old that we got to bring him home. It was after we got him home–*[interjection]* Sorry, okay, thank you. Okay, here we go. It was after that we got him home that the swelling on his right hand and forearm was noticed. Through various health-care appointments–I'm not going to be dry now, thanks. It was through various health-care appointments–it was–still wasn't diagnosed and it was even suggested he might grow out of it. The road to find information about this condition was not easy. The information wasn't readily available, not even within the health-care providers, and it was just by luck that we found Edith Mulhul.

We found Edith, a registered nurse and certified lymphedema therapist, when Austin was nearly a year old. Throughout our journey with lymphedema it has been my mission to raise awareness about this condition so others wouldn't have to go through what we did. Even before the LAM I was sending requests to the minister of Health office and the municipalities in Manitoba to proclaim March 6th as Lymphedema Awareness Day.

Today there are 14 certified therapists in all of Manitoba servicing the city and some rural areas. The treatment for lymphedema requires someone specialized in training, and the lack of appropriate treatment often leads to lengthy and costly hospital stays.

This is a progressive disorder that does not go away on its own. It can bring with it its own unique set of complications such as loss of function, self-esteem, quality of life, dependence on caregivers and the health-care system in general. If left untreated the condition can have dire consequences.

In Canada we have only one dedicated lymphedema specialist, Dr. Anna Towers. This condition is most often picked up by physicians in other specialty areas who are already overworked by caring for their own demographic. This is potentially a serious disorder because it affects other systems in the body.

As I fast forward to the forming of the Lymphedema Association of Manitoba in December of 2011–since then we held our first annual general meeting and nominated a board of directors in May 2012. We collaborated with the Canadian lymphedema framework and the other provincial associations to publish Pathways, Canada's lymphedema magazine. The inaugural issue of Pathways, a quarterly publication empowering patients and professionals, was distributed in spring 2012. We hosted a stakeholders meeting and our first Lymphedema Awareness Day symposium in March of 2013. We created a position paper identifying three priorities in supporting individuals with lymphedema which include funding, awareness and universal access. We hosted our second Lymphedema Awareness Day symposium in March of 2014. We published an information brochure on lymphedema in April 2014 and we are now currently planning our third annual Lymphedema Awareness Day symposium to be held in Winnipeg in March of 2015.

The LAM continues to move forward to raise lymphedema awareness and this bill is another step in the right direction by proclaiming March 6th as Lymphedema Awareness Day. It was back in March 2011 when I was working with my MLA at the time, Gerald Hawranik, to bring information to our elected officials about lymphedema. He retired and those efforts were stalled. Today, Mr. Ewasko has brought to your attention mine, and now the LAM's, request to proclaim March 6th as Lymphedema Awareness Day.

Thank you, Mr. Ewasko, and thank you all for your time and your support. This passing of the bill shows Manitoba is a leader in providing public support to the lymphedema community, and I want to thank you all for taking this into consideration.

**Mr. Chairperson:** Thank you for your presentation.

**Mr. Wayne Ewasko (Lac du Bonnet):** Yes, and thank you, Kim, for sharing your story, and I thank you and the Lymphedema Association of Manitoba for all the work that you guys have been doing and you, of course, for championing it. I know that, again, awareness is key, and we've had a few events today here at the Legislature that proves that, again, it's not necessarily that people aren't caring; it's because they don't know what they don't know, and bringing awareness, and with the education component, is definitely key. And it–and with you continuing to work as hard as you do and the association and also with the March 6th being set aside as Lymphedema Awareness Day, it'll just bring more awareness to the topic to all Manitobans so that maybe we can help some more people who don't even know what they have.

So, with that and the brochures and the Pathways magazine, I mean, that's a–those are all pieces to the puzzle, right? And so, with that, I'd also like to thank my colleagues and also the colleagues on the other side of the House for helping with supporting this bill, and including Mr. Gerrard, as well.

So, with that, Kim, I thank you and I look forward to celebrating March 6th with you guys, as far as having it Lymphedema Awareness Day.

**Hon. Andrew Swan (Minister of Justice and Attorney General):** Great. Well, Ms. Avanthay, thank you for coming down and sharing your story. It's not the easiest thing to step up in front of a panel of MLAs, one of whom you know, a bunch of us that you don't, and it takes a lot of courage to stand up and let us understand a little bit about how you became involved in the organization and why, clearly, you're passionate about this.

The NDP government caucus is supporting this bill, and we will also be proud to recognize March 6th in each year as Lymphedema Awareness Day. Every day that we're in this building we learn something new, and certainly from your advocacy and your involvement I know personally that I, and I think I can speak for other people around this table, we've learned a lot more about this condition. I just–I want to thank you for your efforts.

**Hon. Jon Gerrard (River Heights):** Thank you for all you're doing in terms of advocacy. There are a lot of medical conditions which aren't found very often, like lymphedema, when–and having a champion like you makes a big difference. And so thank you for what you're doing and keep up the good work in terms of raising awareness and we'll look forward to celebrating Lymphedema Awareness Day in the future.

**Mr. Chairperson:** Thank you very much.

Yes, go ahead, Ms. Avanthay.

**Ms. Avanthay:** I did bring some brochures. If anybody would like to learn more about lymphedema. I could leave these here for you.

**Mr. Chairperson:** Great. Thank you very much.

### Bill 214–The Neurofibromatosis Awareness Month Act

**Mr. Chairperson:** I will now be calling on Bill 214, The Neurofibromatosis Awareness Month Act, and the next out-of-town presenter, which is Jeffrey Nykoliation. I think I see you're handling the materials to be handed out, so proceed with your presentation when you're ready.

**Mr. Jeffrey Nykoliation (Private Citizen):** Okay. I would like to thank the committee for allowing me the opportunity to speak in support of Bill 214, The Neurofibromatosis Awareness Month Act. My name is Jeff Nykoliation. I'm 34 years old and live in Brandon. I was diagnosed with NF around the age of 10. At that time, I had several café-au-lait spots on my body and have the Lisch nodules in my eyes.

As I have grown older, I've seen quite a bit of growth of tumors throughout my body. They're not always painful, but they do all–do hurt from–all hurt from time to time.

***** (18:20)

I decided to have surgery to have some removed in January of 2010. I had four taken out at once–from my chest, some at the back and leg, as these were causing me quite a bit of pain. Around the same time, I noticed that my vision had changed quite dramatically, as I had trouble seeing with my glasses. I went to see an optometrist and there was significant vision change in my right eye, as I had become more far-sighted than nearsighted. I had also found that the vision of my right eye had become distorted, as I could see things as being folded in my right eye.

The doctor suspected I had a tumour behind that eye and was pushing the eye out. I was referred back to my ophthalmologist, and an MRI confirmed that a tumour was indeed there. Surgery to remove it was quite risky, so it was decided it was best to monitor it. For a couple of years there was no significant growth. However, by the summer of 2012, the MRI had shown significant growth. I had an appointment with the orbital surgeon at the Misericordia Hospital on November 2012, but I needed to delay the surgery as my dad was not well and I could not be away until that situation became clear.

After my father passed away in February 2013, I decided it was time to get a surgery done. I had another appointment with the orbital surgeon in August 2013, and the CT scan was done so he could see how to operate. However, the results were not good, as my orbital structure was very small and there was not much room to do the operation. He was very honest and believed that he could not perform the surgery successfully. Either he could not get the entire tumour out or he could damage the optic nerve and I would lose my eye.

He referred me to Dr. Michael West in neurosurgery at the Health Sciences Centre, and I had an appointment to see him within a week. Dr. West had an MRI done that showed the tumour had grown to about the size of a thumb and was getting dangerously close to my optic nerve. He felt confident that he could successfully perform the surgery through the top. He would need to remove a piece of my skull and move my brain over to access the tumour. The skull would then be reattached with titanium plates. There were still risks associated with the surgery. However, without the surgery, it was inevitable that I would lose the vision in my right eye.

My surgery was on September 26th, 2013. The procedure took about four hours and was a success. Dr. West was able to completely remove the tumour without causing any other damage. I was released from the hospital after two days. However, my vision in my right eye will likely remain distorted permanently. However, it should not get any worse, but I will continue to monitor it. And right now I'm dealing with some bothersome tumours in my torso which I'm considering having removed.

I became aware of the Manitoba Neurofibromatosis Support Group in 2007, and I emailed Tracy Gregorash my story. This was the first time in my life that I ever told anybody outside of my family about me having NF. After my initial diagnosis, my family kept it quiet. At that time, there was very little information about NF, and I did not want NF to restrict me due to misconceptions on what it was.

Up until my contact with Tracy, NF had very little impact on my life. The regular checkups stopped once I turned 18. I had very few doctors outside of pediatrics deal with patients with NF. I was only going for regular field tests with an ophthalmologist.

After attending my first MBNF event, which was the annual picnic in Winnipeg, it became clear that I was far from the only person who had NF in the province, but I also learned that NF affects people in very different ways. We all have NF because we all have different issues to deal with. I also learned that keeping NF a secret was a mistake. It doesn't really help anybody. We need to raise awareness, as there are so many people with far worse problems than I do that can be helped.

Initially, sharing my story is the best decision I have made in my life so far. Being part of MBNF and subsequently becoming a director has had a positive influence on my life. As my symptoms have worsened in the last few years, I'm not sure how I would have gone through my surgery last year without being part of this organization.

Bill 214 is important as neurofibromatosis is not very rare as it affects approximately one in 3,000 people, but yet, very few people have ever heard about it. We have all heard of cystic fibrosis, muscular dystrophy and Huntington's disease, but yet NF affects more people than all three of those combined and can be just as debilitating. Increased awareness will mean more doctors are educated about NF, and they could provide better treatment to patients suffering with this disorder. Currently, it is very difficult to find a doctor who knows enough about NF to adequately provide proper care.

Bill 214 is also important as it will create more awareness in the general public. When more people become aware of what NF is and it becomes more accepted in society, and people who suffer from it will be less likely to hide from it and suffer in silence. And when NF becomes more recognizable, then more resources will be used for research and treatment and a potential cure for NF. If people are more familiar with something, they are more likely to be comfortable in giving donations. As NF becomes commonly known, then more doctors and research will devote time to NF to ultimately find a cure.

I'd like to thank the members of the Legislative Assembly for unanimously passing Bill 214 through second reading. Getting the month of May recognized as neurofibromatosis awareness month in Manitoba is a huge step towards bettering the lives of those suffering with this disorder. I once again thank the committee for your time this evening, and, if there are any questions, I am ready to answer them at this time.

**Mr. Chairperson:** Thank you for your presentation.

**Mrs. Leanne Rowat (Riding Mountain):** Thank you so much, Jeff. You did a great job on your presentation. You shared your personal story and the challenges that you faced, even putting your personal challenges aside to deal with family seriousness health issues. And I–you know, it just speaks to your character.

You nailed it today by saying that this is so important in creating awareness. And I just want to thank you for the leadership that you've taken with Manitoba NF association–or–and the work that you do. And being here last week was really important because you put a face to NF, and you're here today to show your support.

So thank you so much, and I wish you continued success.

**Hon. Andrew Swan (Minister of Justice and Attorney General):** Mr. Nykoliation, thank you for coming down and telling us your story. And, as I said to the last person who presented, every day there is an education. I've learned a lot more about this condition, and I think your point about the number of Manitobans impacted is something I didn't know before this bill was raised.

So I want to thank you. I know there's other people here to present on the bill. Spoiler alert: The NDP government caucus will be supporting this bill tonight and through third reading. And I want to thank you for your part in having that happen.

**Mr. Chairperson:** Thank you.

**Hon. Jon Gerrard (River Heights):** Thank you, Jeffrey, for coming today and to–sharing your story. You know, it is–neurofibromatosis is a condition that too often people have felt reluctant to come forward about. So it's refreshing and I think a very positive sign, for all the reasons that you point out, to have more awareness of neurofibromatosis.

And part of that is, indeed, that, in getting more attention, there be better funding for research. And the sooner we can get a cure, the better.

And, you know, there's a lot of good things happening. And the fact that, you know, you had the successful surgery is very positive.

So thank you for coming today. And, you know, I think it's a very positive step that we're getting this bill.

**Mr. Chairperson:** Thank you very much.

I will now call Tracy Gregorash.

Do you have any materials for the committee? No?

**Ms. Tracy Gregorash (Manitoba Neurofibromatosis Support Group):** I was a little late because I couldn't get it printed at the hotel before I came, sorry. And I thought I could get it–

**Mr. Chairperson:** It's okay, you can–

**Ms. Gregorash:** I'll read it off here the best I can–

**Mr. Chairperson:** Yes, no, that's totally fine. So, go ahead when you're ready.

**Ms. Gregorash:** Okay. Bill 214, The Neurofibromatosis Awareness Month Act, to the standing committee of–and I–this was blank too. You guys are the social–how do you say it, social economic–*[interjection]* Okay, sorry.

I want to thank you for allowing me to come and speak on behalf of The Neurofibromatosis Awareness Month Act and for allowing me to speak on our organization's behalf, the Manitoba Neurofibromatosis Support Group.

Our group would first like to thank Leanne Rowat for bringing this bill forward and to the attention of everyone here. Thank you so much, Leanne.

Our second reading moved along with a heartfelt feel and energy the other day, and we are so excited about that day. Thank you so much. It–to hear many of you just say the word neurofibromatosis correctly was kind of exciting. To listen to you share about what NF is was actually inspiring to us. To receive a unanimous vote was beyond our expectations that day.

And, finally, to learn that one of the members of the Legislative Assembly has witnessed first-hand how NF affects a family member kind of left us speechless that day. It was pretty incredible to hear her share her story. So we're thankful for her courage, as well. I don't know if I'm allowed to say names or not. She's not here though, is she? Okay. Kerri. But we were thankful that she was able to share her story and willingness to do that. So if you can thank her for me, that would be great. Thank you also to–you would–which one's Irvin–wait, sorry. I'll just carry on there.

***** (18:30)

We were–we're never happy to learn that someone has to live with NF, but the point that day was obviously taken that NF needs to come out of the shadows and into the light, because NF really isn't that rare. It has sort of just been missed by the mainstream of disorders, and that advocacy and awareness piece has been missing for far too long.

So we thank you, everyone, for giving us hope that you could help us make that not be the case in Manitoba.

The Manitoba NF group actually was formed in 2005. It received its charitable status in 2007. It started in desperation. Two mothers connected, myself and Christa, the president now, both were struggling with the reality of this progressive disorder. I'd learned of a very large tumour in my chest–or my son's chest. At the time, he was three. So the relief and peace of knowing we were not alone sparked and ignited the idea to form the group together, Christa and myself.

It's continued to be fuelled each year by a consistent growth in our membership since we started it. Today we support over 80 families living with NF in Manitoba. And, statistically speaking, there are still an additional 200 people either undiagnosed or still unaware that our group exists right now, but, we're trying real hard.

The Manitoba NF group, or MBNF, is actually very active. We hold two informational meetings each year: one in the Westman area in the spring and one in Winnipeg each fall. These meetings are well attended; we have approximately 30 to 50 people come each time. Some families travel to both each year, and others choose to go to the closest location. We also plan fun get-togethers like group picnics, coffee outings, we go to a Goldeyes games. With a recent addition–oh, we also host a variety of fundraising events: we do a dance; we do a golf tournament each year annually; we do a run for NF, which has happened in Minnedosa for eight years; and, most additionally, we've just added one in Winnipeg–actually, the same day as our second reading just was unanimously passed–and it was very successful, by the way.

The money 'raides' help–raised helps us provide the opportunity to send our younger member to a specialized NF camp in the United States, and it helps us send our members to NF forums; there's one in BC and there's one in, actually, Washington, where I'm leaving at 5 in the morning tomorrow to go.

And the reason this has all been so quick and hard for me also is my son just had a surgery that wasn't expected, only last week. And so I–we had a doctor's appointment today, and he's very sick right now. So, sorry for my tardiness, but we're living this stuff real–it's really–it's reality, and I'm trying to hold myself together, so just bear with me.

Anyways, our money goes to a good cause, and we help a lot of people do a lot of good things. We ask in return, when people do go to something like I am, to bring back that information so we can stay current with NF information and research and trials happening. We provide that information often to our members, community groups, schools, medical facilities. We publish an annual newsletter, maintain a website, Facebook page, Twitter and YouTube account. We continually look for ways to promote our group and increase awareness of neurofibromatosis, and this work has been done over the last eight years with volunteer efforts.

During the process of the second reading, we were so excited to hear many of you had gained a lot of insight on NF. I don't know, before this bill was passed–am I allowed to ask?–had anybody not heard of it before that day, or has it been brought before? I don't know.

**An Honourable Member:** I hadn't.

**An Honourable Member:** No.

**An Honourable Member:** I never heard of it.

**An Honourable Member:** Never.

**An Honourable Member:** Never. News to me.

**Ms. Gregorash:** So that's–thank you. Because that's so appreciated for us, as–when one more person hears it, it takes us a long way. So I thank you for that.

So I won't go over–because you've already done your research–it sounded like when we here–and you know a lot of the NF facts, and, I think, probably some of the people behind me that are going to share will say it. And you also say a lot of things like, why NF awareness would be important–education is key, better treatment, better hope, a cure–and I think you hear those type of things often. We understand how important awareness is.

But, for me, it goes a lot deeper than the obvious. It's over the years that I've grown to love and respect some of the people behind me right now, a lot of people in our group. I've heard a lot of stories over the last eight years because they normally call me first. And I've watched the joy and fear of couples as they struggle with the difficult decision of deciding to start a family, knowing NF is a possibility, as it is a genetic disorder. I've watched parents struggle with the new twists and turns of the unpredictable behaviour of NF, related to educational challenges, psychological challenges, and physical 'manisfestations' of NF. So I ask for your help in passing this bill for the obvious–the awareness–but also for my friends.

Annette needs help with pain management; 16-year-old Tyler needs to stop having seizures and has to be on a lot of pain medication. You've heard about Jeff, he doesn't want another brain surgery or to lose any more vision. Dane, 9-year-old Dane, his mother will be speaking, I believe–his rapid-changing personality and they're extremely worried right now. Lyndon, I love Lyndon. Yes, he kind of looks like he's a fighter, but you'll get to know him and he's actually a big, gentle giant, and we love him. Karen's daughter, who couldn't be here today, has had multiple surgeries and is–and she's now has to take care of her grandson because her daughter can't take care of her grandson, and they're taking the grandson to the States to get extra, additional care because a lot of the issues that are going on can't be helped right now here, it's more specialized.

Lisa's 18-year-old son is looking at cancer spots on his body right now and worrying about his future; they can't be here today either. Shirley also can't come. She doesn't drive, she doesn't have access, she's in Brandon. She has numerous–she's had numerous surgeries for breathing problems. She's disfigured after removing a large tumour in her throat and she's now having some heart issues. And a newer member I just met recently, Corinne, also can't come. She's a young parent. She's worried about a large plexi-formed tumour that they discovered in her four-year-old child's chest which is growing pretty invasively, and they just–on their own financial loss, I guess, but went to–travelled to the States to learn more at the Mayo Clinic.

And finally, you've just heard that I've just dealt with another surgery with my son. My 14-year-old son, Seth, does not want to go through another leg surgery, but it looks like that is probably–well, it will be the case. He's also lost, now, length on one side. He's been on crutches for two years with multiple surgeries and, yes, today was very rough because he's lost a lot of iron due to the–and blood with each surgery and, yes, he's been sick since.

So I ask for your help because I care for all these people and for many of the people in our group. I don't–how do I convince the people when they call me on the phone and they won't come to a meeting because they're so disfigured they don't like going in public. And I tell them, we're a support group, but they don't want to leave their house. They live isolated. I have a family who's lost a son to NF, a teenage son, and they won't come because they don't want to scare us–so I just talked to her on the phone. She's never met any of them because she doesn't feel it would be polite.

Raising awareness for this disorder that's relatively unheard of, progressing in nature, complicated with so many variables is really very difficult, and I believe–this is my own theory–that the altered gene that they may have that causes tumour growth has also done something to their hearts, okay? They have an altered gene that makes them so special, so sweet, so kind, when you meet every one of them you will–you would not believe the things that they've done, like an MRI CinemaVision to help people at the Children's Hospital for $25,000. Even though we could use those funds, we're helping other people in Manitoba, and I could go on and on about some of the things they've done: Rehabilitation Centre for Children, Ronald McDonald House we've also supported because they support us, and that's the kind of people that I have working every day with me. There's pretty special people who are very giving and they just want somebody to take notice.

So I thank you for giving us that opportunity to bring awareness out to something that so few people had heard of.

**Mr. Chairperson:** Thank you for your presentation.

**Mrs. Rowat:** Tracy you look tired–*[interjection]* No, and I just want to thank you, Tracy, for meeting with me for coffee and talking about Seth and your journey, and I know that you've been in–part of your–most of winter was in Montreal with Seth, and just coming out of surgery recently with Seth out of Winnipeg. So I just know that, you know, you live and breathe this. You've got a great network. You know, you've done what you need to do in creating awareness by having this bill support what you're trying to do is amazing.

So I just want to thank you for being here tonight. I want you to relax in Washington and share with us what you learn in Washington, and know that this bill is going to be moving forward as the minister has indicated, and we'll celebrate when you get back. Thank you.

***** (18:40)

**Mr. Swan:** Thank you. Well, you know, you've told us how special all the people you've helped are. It's pretty obvious you're a pretty special person to work on your family's challenges but also be out there to help other families with theirs is pretty awe-inspiring for all of us.

So, on behalf of all of us, best wishes for your son in what lies ahead, and we do thank you for being here.

Now, I've got to put something on the record. I do run a lot of races. I've never run the Run for NF, so you need to brief me on how hilly the course is. I do all of my runs in Winnipeg or along the shores of Lake Winnipeg, which are tabletop flat, so if I get down to the bottom of the hill, I might not make it up again. So I'll need your advice on that in the future.

**Ms. Gregorash:** Am I supposed to be speak to that? *[interjection]* Yes. Our Minnedosa run is June 14th. Come on down. *[interjection]* Ten o'clock in the morning at Minnedosa Beach Pavilion. Camping is great there, and–

**Mr. Chairperson:** Mr. Gerrard.

**Mr. Gerrard:** Thank you, Tracy, for what you've done for not just yourself but for so many people and families where there's a family member with neurofibromatosis. It's a big effort, but it's really, really important because your advocacy and your bringing people together is important in, you know, sharing information. It's important in helping other people. It's important in–oh, you'd be surprised how often there have been ideas which have come to help look after people with neurofibromatosis that have come from patients and family members, rather than from physicians. So thank you for what you're doing.

**Mr. Chairperson:** Thank you very much.

I will now call on Shannon Goodall-George.

And just while I have a second here as she's coming up–come on up–I'm going to hold up my pen when it's one minute, because I really hate interrupting when people are telling their stories, so I'll just kind of hold up my pen when it's one minute, so.

Do you have any material for the–

**Ms. Shannon Goodall-George (Private Citizen):** I have copies of my speech, if–

**Mr. Chairperson:** Sure. If you want to just–that–they'll hand it out for you, and then please proceed when you're ready.

**Ms. Goodall-George:** Okay. Good evening. My name is Shannon Goodall-George, and I want to start by thanking the committee members for allowing me this opportunity to speak tonight as a private citizen regarding Bill 24 proclaiming the month of May as neurofibromatosis awareness month.

Our son Dane is nine years old, and he has been diagnosed with type 1 neurofibromatosis, NF. We had a confirmed diagnosis the day before his second birthday. It had been suspected since shortly after his birth that he may have NF, as he had multiple café-au-lait marks on his body, but it was only confirmed after he had a bad fall. He had a CT scan because of the fall. The scan was clear for the bump on his forehead, but it did show something suspicious behind his right eye. Our family doctor ordered an MRI, and it was confirmed that he had an optical glioma behind his right eye. Meeting two of the eight criteria provided a positive diagnosis for type 1 NF.

The news of his diagnosis felt like someone had just hit us with a baseball bat. It sunk in very quickly how this was going to affect our lives once we started receiving appointment notices from doctor after doctor, from neurologists to geneticists to oncologists and child psychologists. We have had contact with almost every type of doctor we knew existed. Every step of the way, we have received the best care we could have asked for Dane.

NF is a just–excuse me–NF is a genetic disorder that affects one in 3,000 people, and its effects can vary from very mild to quite severe and life altering. For Dane, the majority of his symptoms have been mild to moderate. He has optic gliomas behind both eyes and multiple other non-cancerous tumours in his brain that so far are not dangerous but have affected his physical growth, his balance and have created some learning impairments. As Dane has gotten older, he has added the freckling to the list, along with absentee seizures and headaches.

The hard part is sharing what Dane's diagnosis is, and that is why the awareness is so important. People usually think that Dane is younger than he is because he is small, smaller than most of the children his actual age. An example would be when people would guess his age: Is your son about six? We would get a lot of shocked people when we say, well, Dane is actually nine. Wow, he's small. But that's okay. He'll grow. I'm sure he'll have a growth spurt.

That's the point where, as a parent, you can have a few choices. You can just spend the time explaining the diagnosis and the symptoms he has or just nonchalantly agree. If people could even hear the words on the radio campaigns or on TV or in–or print, it would make it easier to say, Dane has NF and this is how he is affected–not spend a lot of time even explaining what NF is.

As of more recently, that–we are really starting to feel the effects of Dane's diagnosis. His mood has changed dramatically. He is becoming more emotional with everything. He is struggling more at school than ever before and has started to regress in some of his areas, especially his speech. He just wants to be at home where he feels safe. Previously, he was an extremely outgoing, never worried about meeting new people or making new friends. His never-ending smile has disappeared and the twinkle in his eyes has faded.

Dane has emotional outbursts in inappropriate places or in an inappropriate manner or time, but instead of just being able to say this is because of his NF, we are also spending time having to educate people on what NF is. I feel that if we don't spend the time doing this, people are assuming that he's a badly behaved child who is not being disciplined appropriately for his outbursts. Having to spend the time making people aware and educating those takes time away from caring for Dane during this stressful time.

The word neurofibromatosis scares people when you first say it. They almost get fixated on the word, and then they're not really hearing what you're saying to them.

I would really appreciate your support for Bill 214, as we need to make neurofibromatosis a household name. That way, when I or my family have to speak, people–to people about Dane, they have at least heard the word before. Moving forward, it would also make it easier for our son when he has to explain his NF.

Again, thank you for your time this evening.

**Mr. Chairperson:** Thank you very much for your presentation.

**Mrs. Rowat:** Thank you, Shannon, for your presentation. And thank you for being here last week, as well.

You know, you share a very personal story and the challenges that a family faces in trying to deal with something that is something–an illness that is very new to a lot of people. You're a caring and loving mom, and I know that. You know, I pray for you, and I hope that, you know, you continue to progress. But, you know, rely on your friends and your family, and you've got a extremely strong network.

And I want to thank you for helping bring awareness to NF, and look forward to meeting you on a number of occasions going forward. Thank you.

**Mr. Swan:** Thank you very much for coming down and telling us about your family's situation, in particular Dane. I think your presentation really helped us see things through Dane's eyes. And I think that's very, very useful for us as MLAs, just to understand a little bit more about this condition. And it certainly helps us, too, to understand why this is so important for you and other people that have come down here tonight.

Thank you.

**Mr. Gerrard:** Thank you, Shannon, and thank you for sharing your story and, you know, helping to provide the broader understanding. And, you know, I think it's important that people know the name, but it's also important that people have a little bit of an understanding so that you can better emphasize. And I wish you all the best with your family and your son, and thank you for coming tonight.

**Mr. Chairperson:** Thank you very much.

I'll now call Doreen Loewen.

I see you have materials that are being distributed, so please proceed when you're ready.

**Ms. Doreen Loewen (Private Citizen):** Thank you. Doreen Loewen from Brandon, Manitoba, speaking to Bill 214, The Neurofibromatosis Awareness Month Act.

I come to this session this evening not with a personal struggle–story of a struggle with NF. I rather come as someone from the outside looking in. I don't have NF. I don't have any immediate family members with NF.

My first exposure to this was in the early 1990s when I met a young woman who was about to be married. Everyone knew that she had some kind of a disorder because of the unusual growths that were visible all over her skin. She didn't talk about it, so nobody really knew what it was. And we certainly didn't know that these same tumours that were growing on the outside of her body were growing on the inside of her body.

So here was the night of her bridal shower. She was walking out to the car, and in the parking lot, she fell and she couldn't get up. She had lost the use of her legs and her arms. She was unaware, as were any of the doctors, that she had a tumour growing on her spine which caused her to lose her motor abilities.

***** (18:50)

And you'll hear many stories tonight. Although it's not always possible to operate on those tumours, this gal was very fortunate. They were able to operate to remove the tumour and, with much physiotherapy and much patience, she learned to walk again and regain the use of her arms.

Then about five years ago, I travelled to a small town not far from Edmonton to visit my cousin and his family. We were looking at pictures of his grandchildren that were on the living room wall when we came to a picture of a pretty little girl about eight years old who had a rather unsightly scar just above one eye. He began to explain that she had a tumour on that eye that had been removed surgically three times but kept on growing back. Now you've heard tonight that if you have NF and you decide to have children, your children also have a 50 per cent chance of having NF. My cousin went on to explain that his wife had NF, that one of their three children, Cathy, had NF and that both of Cathy's children had NF. He further explained that his daughter, Cathy, was currently the vice-president of the Alberta NF association and that her organization was working feverishly to raise enough monies to keep their support group afloat.

Well, I'm sad to say that the Alberta support group folded in the fall of 2011. So the question is: Why did it fold? Was it because nobody needed a support group anymore? I don't think so. Was it because fewer people in Alberta suddenly had NF? I doubt it. The reason it fell apart was that the moms and the dads that did all the grunt work of organizing fundraising events and spend endless hours on the phone and in meetings supporting one another with the very challenges of NF and what it brings, these moms and dads simply got burnt out.

The reality today is that most families have two working parents. To juggle all the challenges of NF with the other stresses of daily living is taxing. Add endless fundraising and awareness building to that mix and you soon have a group of moms and dads who have nothing left to give. Right now in Manitoba–you've seen it tonight–we have a strong support group thanks to an amazing couple, Tracy and Troy Gregorash, and all the members who've stepped up to the plate to help out. But they can't carry the entire province forever. The only way we'll elevate this organization to where it continue–can continue to acknowledge their membership and support them with information and encouragement is to raise the awareness of this disorder within the general population. We need to raise the awareness in the minds of those working in the education system and those working in the health-care systems, and, most of all, we need to be there for those parents when they hear those words for the first time: Your child has NF.

Since I've been involved with this group, I have seen positive results of what this group does. I've been involved with NF for about a year and a half and helped organize a few of the fundraising efforts. We held our first annual, Let's Dance for NF, in Brandon in May of 2013, and our goal in doing that was twofold: to raise some funds, of course, and the other was to raise awareness. Well, approximately 90 per cent of the people at that event had never heard of NF before, so we were quite pleased with the fact that we'd certainly achieved one goal there by raising the awareness that evening. Also, through this event, two women who have NF came forward. In nearly 60 years, neither one of them had ever known another individual with NF. Learning that this group existed changed their lives.

I don't know the scientifics and all the details of the disorder like the families who deal with it on a daily basis. I just know that they need help to keep this organization strong and healthy. Yes, wouldn't it be great if we could find a cure, and, yes, wouldn't it be great if our membership was dwindling because fewer and fewer people were having NF and cases were showing up each week? That's not the case. We have people in every corner of our fine province. We need to educate all of these communities about NF and how it affects our citizens.

The City of Brandon proclaimed May 3rd NF Awareness Day this year. That was a huge step–to have May proclaimed to be the NF awareness month each and every year would catapult this organization to where it needs to be. This year we've been encouraged by a couple of media outlets who have shown an interest in educating the public about NF and who have helped us in our goal to spread awareness. There's a budding interest and a compassion out there for the people who have NF and for their families as well. We want to build on that as public awareness for NF is so important. Without awareness, there is no funding. Without funding, the activities of this group are simply not sustainable.

Let's not let MBNF be another casualty like the Alberta NF association. Let's keep Manitoba strong.

Passing the NF awareness month act would generate so much greatly needed awareness for so many individuals and families. I hope that with the support of government we can raise the awareness and cultivate an understanding of neurofibromatosis and eliminate some of the burdens that the families carry with them every single day. Thank you.

**Mr. Chairperson:** Thank you.

**Mrs. Rowat:** Thank you, Doreen, and thank you for coming out last week as well in support of second reading.

What you share here is an excellent story of an individual who's committed to an organization and identifying, through your journey in life, how you've met individuals who have been afflicted with NF. Thank you so much for your support, and I want to thank you for taking the time tonight to share your story.

**Mr. Swan:** Yes. Ms. Loewen, I'd also like to thank you for driving in and presenting to us at the Legislature this evening. You've given us a presentation that's been both very clear and also very, very positive, and I just–I want to thank you for coming in to inform us and educate us tonight.

**Mr. Gerrard:** Thank you for coming this evening and talking and talking a little bit about some of the things that one has to watch out for, right, that organizations that are families and support members of–in the areas of conditions like neurofibromatosis, that there can be problems of burnout that–but it's exciting to see how well the Manitoba group is doing, and, you know, knowing what can happen in Alberta, I think, will probably insulate you from some of the problems here. But keep up the good work and good luck.

**Ms. Loewen**: They're a small group at this point, but they've done a phenomenal job in a few years.

**Mr. Chairperson:** Thank you very much.

I'm now going to ask leave of the committee. For health reasons, Annette Lissenberg, No. 3 on the list, she's wondering if she can speak for–because of health reasons, not being able to sit too long. Do I have leave? *[Agreed]*

So I will now call Annette Lissenberg, please.

Do you have any materials for the committee?

**Ms. Annette Lissenberg (Private Citizen):** No, I don't.

**Mr. Chairperson:** Please proceed when you're ready.

**Ms. Lissenberg:** Thank you for allowing me to come up a little sooner.

I'd like to thank every–or open by thanking everyone who is present for your support. Last week, Thursday, I had the opportunity to be there. I want to thank Leanne in particular for the reading of the passing–or, sorry, the passing second reading of Bill 214.

My name is Annette Lissenberg and I am 44 years old. I was diagnosed with NF in 2007 at the age of 37. Even though I was diagnosed later in life, my journey with NF so far has been fairly intense, painful, not just physically but also emotionally.

Looking back, my symptoms became–or began to be noticeably manifest themself around 2003-2004. My family doctor at the time became frustrated with my ongoing medical issues, and rather than pursue more detailed testing such as an MRI, she dismissed me, telling me I was a hypochondriac, and, actually, the language gets a little more colourful from her, but I will leave it at that.

At the same time, my employer was also frustrated at the number of medical appointments and days away ill and let me go on–in September 2005. The next several months was one of the most devastating and depressing ones, I think, of my entire life. I knew there was something wrong, but with no medical support, I felt like I was going crazy.

Around that time I began seeing a new family doctor, and in March of 2006 I began a new job. My family doctor began working to address my medical issues one by one, and in October 2006 I had the first of what would become multiple MRIs.

On my 36th birthday, October 22nd, 2006, to be exact, I received the results of my first ever MRI. I had multiple tumours on my upper spine. It would be another six agonizing months of physical pain and waiting before I received the diagnosis of NF.

***** (19:00)

The diagnosis was given to me by a neurosurgeon, and I want to underscore neurosurgeon, that I would continue to see off and on for the next five years for follow-up MRIs. Whenever I would see this particular doctor and explain the physical pain I was experiencing as well as some of the other symptoms such as high blood pressure, he was dismissive and told me, in quotations, don't go looking for things.

When I tried discussing the same concerns with my family doctor, she would tell me she didn't know enough about NF and she would just move on to other issues. And because medical appointments for those of you in the room who are familiar, you know when you go in, you got to talk like an auctioneer. It's five minutes. You're in. You're out.

From spring 2007 through to spring 2012, I tried to understand NF, and I felt very alone and lost. I wasn't receiving the type of medical care I needed, and it wasn't as though I could go to a group support outside of MBNF or call a 1-800 number. To contrast my story, earlier this year my husband, who's here with me this evening in support, was diagnosed with diabetes. Our family doctor who we share in common immediately did a requisition for him to go to a diabetic specialist, was concerned about him, got him on medication and also connected him to our local ACCESS centre.

I remember when he came home telling me this, I thought to myself, how much it would have made a difference for me if I would have had the same support when I was diagnosed with NF, if I would have gotten to a specialist immediately as well as been able to go to group information and educational support. In early 2012 my work abilities were being impacted to the point where I finally requested to see a neurologist, underscore, and I was referred to Dr. Mallory Fast, who I would love to have had present here tonight. In a small but significant twist of fate, my manager at the time had a great-niece who happens to be Christa who's present here tonight, her daughter.

So my manager understood NF and was compassionate while being honest with me about, you know, Annette, this impacting your work to a point where I–we can't go on this way. After over 20 years in the financial industry, I walked out of the door with my employer not knowing it would be for the last time. I have since been put on permanent disability with Dr. Fast's support, and if it were up to my own family doctor, I would be back at work because she's indicated to me I'm too young to not be employed.

Part of my ongoing issue personally is with the medical community as well as the general public. I don't show the same outward signs of the disease. My problems are on my spine. Over the past two years, my focus has been on my health, researching the condition as well as treatment options which are very limited in our province.

I have faced and continue to face many, many obstacles as far as treatments go. For example, last year I went to physio treatments at Concordia Hospital for my allowable 24-appointment slot. It was one way for me to get at least a little bit relief from the pain even if it was only for temporary spurts. When I spoke to the physiotherapists about having my doctor complete a new requisition once my 24 was up so I could continue treatments, she told me not to bother since there was a waiting list of 2,000 people that needed to get in for treatment and, basically, I was wasting the time of the medical system as they were not able to deal with chronic issues.

I've been asked by insurance companies as well as my own family doctor to describe the pain I feel, and that's been a challenge too. In fact, I got a call from my insurance company again today. Just–it's like rehashing the same thing over and over again. My tumours aren't operable. There's nothing that can be done. So I'm constantly struggling to try to find the right words.

My NF has impacted my husband and 16-year-old daughter in many ways as our family unit is learning how for me to live with this condition. We went from a two-parent-working, full-time household down to one, and my husband works out of the house, so he's a little irritated that I'm around all the time.

The uncertainty of the future is always looming in the back of my mind. I think about–because my case they–I was told I was a spontaneous case, they couldn't find a connection genetically in the family. But I still–I'll say this because my daughter's not present–I still worry for her future. When she has children, is this going to impact her?

At the present moment, I'm grateful to be under the care of some wonderful individuals: my neurologist, chiropractor, massage therapist and acupuncturist. The sad part for me is Dr. Fast, who's semi-retired, he agreed to keep me on short term because he likes my sense of humour and said I'm a unique case and wants–he wants to help the cause however he can, but I do worry about starting over again once he's fully retired. And there's also the reality of the financial strain that's coming around the corner because I'll be off on long-term two years this September, and so my insurance is going to cut out. And there is treatment in the States, but it's just not feasible for me to go down there.

I'm hoping though–I have a chronic–or, sorry, a critical-illness policy with Great-West Life. They don't recognize the condition, but I'm hoping to have them change that. If not for me, for people coming in the future. So that's a whole project in itself.

I was thrilled to be, as I said at the second reading for this bill–and I'm just hoping that this is the beginning of making awareness to this disease, particularly to the medical community; for myself, that's what I would speak to. And the ironic part is that the NF awareness month would just happen to fall on the same month that I walked out of work for the last time of my life.

**Mr. Chairperson:** Thank you.

**Mrs. Rowat:** Thank you, Annette, and thank you for sharing last week and this week with us and helping us learn more about NF. Your story is a compelling one and it just speaks to your perseverance, your family support, and obviously is raising some red flags down the road where we need to continue to work together in ensuring that NF awareness continues outside of just this building and into your insurance and other areas as well.

So I know that you will work with us, you're not a quitter; I know that. *[interjection]* Yes, and I just want to thank you for putting your words and your thoughts on the record and for sharing your time. Thank you.

**Mr. Swan:** Thank you very much for coming and presenting. I'm sure when you were–received the diagnosis back in 2007, you didn't dream you'd be standing up in front of a committee of members of the Legislature, telling us about your story. It's been very helpful for us. I think you've expressed the journey you've gone through in a very forthright way, and I think the members of the committee are richer for it. Thank you.

**Mr. Gerrard:** Thank you for coming, Annette, and for talking about your story. It's not been an easy one, and unfortunately you've not had the smoothest ride with the medical profession. And hopefully out of you sharing your story will come, you know, a better realization of some of the issues and some of the problems. And hopefully in the future we need to make sure that physicians and nurses are well educated and don't dismiss these sorts of problems but really are much better at being able to help people like yourself deal with them.

**Mr. Chairperson:** Thank you very much for your presentation. All right, have a great night.

### Bill 72–The Coat of Arms, Emblems and the Manitoba Tartan Amendment Act

**Mr. Chairperson:** This is the–that the last of the out-of-town presenters, so now we're going to proceed back to the beginning of Bill 72.

We will now call on David Sanders.

**Mr. Ralph Eichler (Lakeside):** Yes, my understanding was we were going to do the three government bills. Is that correct, or–and then we'll finish up the private members' bills? Is that–

**Mr. Chairperson:** Is that the will of the committee? *[Agreed]*

So Bill 72 is the first of the government bills. So, yes, we will call David Sanders.

Do you have materials for the committee, Mr. Sanders?

***** (19:10)

**Mr. David M. Sanders (Private Citizen):** I do.

**Mr. Chairperson:** All right. Please proceed when you're ready.

**Mr. Sanders:** Mr. Chair, members of the committee, my name is David Sanders, and I'm appearing as a private citizen in support of Bill 72 and specifically the new provincial grass emblem, the big bluestem. I will add that my godfather was Gerald Malaher, who was director of game and fisheries for the province for many years, and I believe that he would approve of the selection of all three: the bison, the pickerel and the bluestem. He showed me how to catch them, but I could never copy it.

But I'm speaking out this evening to draw attention to the fact that the City of Winnipeg, with federal and provincial enthusiastic support or, at least, acquiescence, is poised to proceed with a billion-dollar boondoggle construction project which will threaten the field of tall grass prairie, including specimens of our new provincial grass, which is–are located in the Parker wetlands in the constituency of Fort Garry-Riverview. The Parker lands are located immediately east of the Winnipeg Humane Society, south of the CN main line, west of the Pembina Highway-Jubilee interchange and north of Parker Avenue. And I support the efforts of the Parker Wetlands Conservation Committee, the PWCC, to try to preserve this special natural area which includes wetlands, aspen forest and tall prairie ecosystems, including the big bluestem grass which is pictured on the cover of this submission. The picture you see was taken today.

For your information, I am attaching a copy of the web homepage of the PWCC, which explains why the local community and the broader community of citizens who are concerned with the preservation of green and open space are opposed to the proposed redirection of the southwest rapid transit corridor stage 2 on an illogical dogleg west through the Parker lands and south on the Manitoba Hydro right-of-way, where there are no transit riders, instead of following the original route directly south, along the CN Letellier subdivision rail line.

The majority of the Parker lands area used to be owned by the City of Winnipeg but, in 2009, the City swapped the land for a smaller area east of the first stage of the rapid transit corridor in Fort Rouge, and now the stated objective of the redirected rapid transit route through the Parker lands is to enhance the private development opportunity and value of the land in question and other similar lands at huge public expense. And the City is also going to have to reacquire about a third of the swapped land for the proposed transit dogleg route and a large retention pond to help meet the storm drainage requirements of the transit way and Pembina underpass.

Since the City seems to be pretending that it does not need a class 2 development environmental act licence, and fails to mention it at all on its websites, I would like to take this opportunity this evening to publicize the fact that the City has, in fact, filed a seriously flawed environmental assessment report with the provincial Environmental Approvals branch, and citizens have been given only until next Monday, June 9th, to submit written comments on the project. And I've attached some excerpts from the report referring to bluestem grass. You can see the complete report on the website, which I've put in my report. The fact is that the persons who did the environmental impact report did their inspection in October when there wasn't much growing at all.

The City is now proposing to proceed with the stage 2 of the southwest rapid transit corridor as a P3 public-private partnership, with the private sector paid to design, build, finance and maintain the project over the next 35 years at a total cost of more than $1 billion. And as required by the new Manitoba Public-Private Partnership Transparency and Accountability Act, the City attempted to hold the required public hearing yesterday. In my opinion, the so-called hearing failed to comply with provincial requirements. The City has not yet published the complete P3 business case, cost-benefit analyses of the value-for-money assessment and, despite the wording of the public notices published the bare minimum of 14 days before the hearing, the council and committee members and senior administrators refused to answer any citizen's questions. The City did not even attempt to make a serious presentation of the scope and magnitude of the project, its viability, risks, costs and benefits as promised in the notice and as required by law.

I've submitted applications for access to the various relevant documents which the City has failed to publish but, so far, I have received no response, and I will appeal to the Ombudsman if I must. I have to say that I did that earlier this year, and it worked, which was good.

To top things off, the city administrators admitted yesterday that they have already submitted an application to PPP Canada Inc.–that's the federal agency–for round 6 funding by the federal government, which has a deadline of Friday, June 13th, 2014, to be considered for approval by the board of the P3 Canada Fund and the federal minister by the spring of 2015. They have done so in spite of the fact that city council has neither seen nor approved the application.

Personally, I think the Province should revoke its offer to contribute $225 million in capital costs for this project until it can be satisfied with the objectives and justification from the project that technology and the routes selected, its environmental impact and its relative priority for funding and, to bring it back to the bill before you, when it's also satisfied that Manitoba's new grass emblem will continue to grow and flourish in the middle of the city in the Parker Lands. Thank you.

**Mr. Chairperson:** Thank you for your presentation.

**Hon. Ron Lemieux (Minister of Tourism, Culture, Heritage, Sport and Consumer Protection):** Mr. Sanders, thank you, David, for presenting. You are very much aware, and I'm not sure if everyone here this evening's aware, that Manitoba has a unique situation where we're one of two provinces in Canada–certainly, I think that we're the only one that has this type of system where citizens can come to present and let their views be known whether they support a bill or are against a bill, make recommendations for changes, additions, deletions.

But I just want to say thank you for taking the time to come out, and I've heard you very articulately present before on a number of different bills, and I really appreciate some of the items that you've pointed out. I certainly will be in conversation with my colleagues with regard to the points you've made this evening.

So thank you. I thank you for the support of the bison, of the pickerel, the walleye, the grass, which is really important. But you've made some other points this evening which we need to look into, and we certainly want to do everything we can to protect the environment and, of course, these species as well. Thank you.

**Hon. Jon Gerrard (River Heights):** Thank you for a carefully thought-out and well-documented presentation.

Perhaps you could give us a little bit of the, you know, big picture. I'm going to ask two questions. I mean, one is: How much tall-grass prairie is there left in Manitoba? How much is there in Winnipeg? How critical is this piece in the big picture? And second, do you think that in this bill, for example, which talks about the big bluestem, that there should be special measures added to the bill to protect the big bluestem? *[interjection]*

**Mr. Chairperson:** Mr. Sanders.

**Mr. Sanders:** Sorry. To answer the second question first, I don't think there should be anything in this bill on the bluestem. At this point, it's not an endangered species, but it is part of–parts of this site is tall-grass prairie, which is referred to as an endangered ecosystem. Beyond that, I'm not a botanist, but I know that there is, in fact, very little tall-grass prairie left in this province and it's certainly worth preserving a bit of it. That, of course, is not the only reason for being concerned about this project.

Your first question was?

**Mr. Gerrard:** Thank you, and bid–but I think that what you've said about this being an endangered ecosystem makes a very important point with respect to our provincial grass, if we're going to make it so. *[interjection]*

**Mr. Chairperson:** Mr. Sanders.

**Mr. Sanders:** Sorry, Mr. Chairman. It would be my hope that the Clean Environment Commission would decide that it is necessary to have a public hearing with regard to this project.

**Mr. Chairperson:** All right, thank you very much for your presentation.

## Bill 74–The Public Sector Compensation Disclosure Amendment Act

*(Continued)*

**Mr. Chairperson:** We'll now move on to Bill 74, and that's–next presenter I will call is Mike Sutherland, president of the Winnipeg Police Association.

Do you have any materials?

**Mr. Mike Sutherland (Winnipeg Police Association):** No, just an oral presentation.

**Mr. Chairperson:** Yes, for sure. Go ahead at any time you're ready.

**Mr. Sutherland:** First of all, it's certainly a great privilege for me to be here representing the men and women of the Winnipeg Police Association. We're, as many of you know, approximately 2,000 strong representing both staff sector and sworn police officers on the front lines here in Winnipeg.

***** (19:20)

I have to say I'm less distressed about being here than I might otherwise be in relation to hockey playoffs now that the Habs have been eliminated and, certainly, it's been educational for me as well to sit in the back and hear stories about NF, something that I absolutely knew nothing about. And some of the very passionate and eloquent presentations that were made before you, I think, illustrates the important work that you all do in terms of making legislative change for Manitobans.

And I'm here to thank you tonight in relation to bill C-74. And I want to thank you all for the leadership and the unanimous support of all the parties that are represented here in introducing and hopefully passing this very important piece of legislation.

I'm certain I don't have to emphasize to all of you in this committee that policing is an inherently dangerous profession, and in Winnipeg, the challenges of effectively combatting a crime problem that unfortunately few other jurisdictions must face compounds those dangers.

We've made some improvements, obviously, but unfortunately, Winnipeg remains persistently high in terms of the Crime Severity Index. And while police are at work here in this jurisdiction, in particular, the last time that StatsCan took a in-depth look at assaults on police officers, in particular, I want to just sort of give you an environment or a framework of what we're dealing with.

So from 1998 to 2009, assaults against peace officers rose nationally by 28.7 per cent. In Winnipeg, that rate increased by 63.5 per cent, which–and in many other jurisdictions such as Edmonton, for example, saw a 9 per cent decrease. So that's a little bit of a taste of the on-duty picture.

What I'd like to discuss with you now are some of the things that happen off-duty. And, as you probably may or may not know, because this is something that we don't want to discuss because in doing so, we fear that we may embolden certain individuals, certain misguided individuals, particularly in the criminal element, to carry out similar acts, or an inadvertent word by myself or by others speaking on behalf may provide an inadvertent guide as to how to go about successfully achieving those aims.

But I can tell you that there have been some very harrowing incidents where criminally motivated individuals have actively sought out our members at their homes and off-duty, and, in some cases, committed very serious attacks and conducted acts of intimidation, coercion, threats, retribution, not only to individual officers but on occasion to those officers' families.

So, thus, I will try to keep my comments very general, but I wanted to try to provide a small notion to you in terms of the very serious and real concerns that have been repeatedly raised to me by my members. And, again, to let you know how very pleased we are to speak in favour of this important measure.

Unfortunately, with the present-day dominance of the World Wide Web and the proliferation of easy-to-use search engines, an annually updated complete list of correctly spelled names of Winnipeg police officers is a very convenient and simple gateway into obtaining much more detailed and comprehensive information about an officer's personal life.

While my members understand and appreciate–and I would argue, much more so than many others–the importance of public accountability, we believe that this particular bill balances the right of the public to know the compensation provided to public servants but also recognizes the unique dangers and vulnerabilities faced by police, both on- and off-duty.

There's no doubt there's a higher standard of expectation of officers in both on- and off-duty conduct than what is expected of other citizens. However, there must be a practical realization that front-line officers routinely deal with the very worst of the worst on behalf of all citizens.

Now I can colloquially maybe refer to these individuals as our unfortunate customers, and I can assure you, after 27 years of policing, that they are and number amongst the most volatile, dangerous, unpredictable, sociopathic crew of individuals that, you know, fortunately, most citizens in this society do not happen to meet, and that is as a result of the work that our members do on a daily basis.

And I can tell you and assure you that these individuals really have no care or concern for any established law or regulation, the privacy rights of our members, and often, more often than the public knows, these individuals, rather than accept their own culpability, focus and fixate on the police, either generally or individually, as being responsible for their woes.

The fact of the matter is, police officers are human beings, and they and their families simply cannot be at professional–at a professional state of vigilance on a 24-7, 365 basis.

And I–and in discussions in relation to the bill and the background, yes, we realize it is not a foolproof measure. However, it does remove a very easy and virtually effortless method of obtaining that comprehensive list of police officer names, a list that not only compromises officers' safety off-duty but also compromises police operations in terms of undercover operatives and undercover investigations.

That list, we believe, was created with the best of intentions to provide taxpayers and the public with a level of knowledge in terms of compensation that was being provided on their behalf. However, it did have an unintended consequence of–which is being addressed today, and I and my members are very pleased that it enjoys the unanimous endorsement of all parties in the Legislature, and we look forward to its passing.

I do want to particularly thank all of you that are involved, but particularly the Minister of Justice, Andrew Swan, and opposition Justice critic, Mr. Kelvin Goertzen, for their collaborative efforts in moving this important legislation forward. And, as I said, we certainly hope that it enjoys the support of all of you in the Manitoba Legislature.

Thank you very much for your time and attention.

**Mr. Chairperson:** Thank you.

**Hon. Andrew Swan (Minister of Justice and Attorney General):** Yes, well, thank you, Mr. Sutherland, for coming down and presenting this evening, and thank you for all you do as the president of the Winnipeg Police Association. We really appreciate your advocacy, and it was you speaking on behalf of your members that are the reason that this bill has been introduced and is going ahead. I want to thank you for your ongoing advice as we work together to build a safer city in Winnipeg, and I also want to thank you for your co-operation on so many things that we're able to work on together.

I want to thank Minister Howard, the Minister of Finance, but, indeed, colleagues from all parties who, I think, are very supportive of the work that our police officers do, who are aware of the dangers that your members face in their work, and I think your presentation gives a little bit more colour and a little bit more flavour to why this bill is necessary. Thank you.

**Mr. Kelvin Goertzen (Steinbach):** Thank you, Mike, for being here tonight and for your comments. I'll let the Montreal Canadiens comments slide. I know you'll–you're a true Jets fan at heart, and the Montreal Canadiens were just there by convenience.

You keep us safe, and your members keep us safe, and so if this is a small way that we can help keep your members safe, then it's the right thing for us to do. I appreciated your comment about it being a balance. Certainly, we do support the public disclosure law, and it's important to have public disclosure of public sector salaries at the threshold that it's set at, or whatever threshold it should be set at.

And so, ensuring that there's a numeric indicator that doesn't reveal the police officers' names but still discloses salary levels, I think, meets the balance. That's the right balance.

Not everybody's going to like that balance. I've heard from some people on my phone who don't like the law. I don't think any of us got into politics to make people upset, but we also know that every decision we make, not everybody's going to agree with. But it's an important decision, it's the right decision, and we are happy to support it.

And I thank you for your comments along with this process as we've gone through the legislation to ensure it meets the needs of your members but ensures that there's balance and has the integrity of the disclosure act still maintained, so thank you.

**Hon. Jon Gerrard (River Heights):** Thank you very much for bringing this forward. I want to tell you that the Liberal Party is in full support of this as are the Conservatives and the NDP.

It's distressing to see what has happened in terms of the increase in violence directed toward police officers in Winnipeg, and I wonder if you have any other ideas to share with us that we could potentially act upon based on, you know, what Edmonton is done to decrease the problem there that we might learn from, for example. *[interjection]*

**Mr. Chairperson:** Sorry. Mr. Sutherland, go ahead.

**Mr. Sutherland:** Yes, sorry. I don't think that anybody has it particularly right yet. I know that in Edmonton they have their own struggles in relation to a number of issues that, in all likelihood, may have been a scenario involving a transition of prisoners from Manitoba to Edmonton under the federal system.

We have spoken with the minister on issues relating to the establishment of the warrant squad, for example, in order to ensure that individuals who commit crimes are going to be held accountable at some point and that by virtue of the fact that a significant period has expired, you don't necessarily have a get-out-of-jail-free card, that there will be some accountability for that offence. And, unfortunately, in my experience–and I don't think too many other officers will dispute it–5 per cent of the people are probably responsible for 95 per cent of the crime.

***** (19:30)

The difficulty is trying to find the balance between the deterrence factor, crime prevention and apprehension of repeat and dedicated offenders. We're doing our best on a variety of different fronts as a police service to deal with community-level efforts while maintaining a scenario whereby chronic dangerous offenders are going to be taken into custody and held accountable for serious crimes.

But police is just one aspect of the justice system, and it really is a partnership that trickles down from the Supreme Court to regional courts to Crown prosecutors and to police. And there are certain innovations, I think, that are promising on the horizon, particularly when dealing with street gangs and organized crime groups, and I'm hopeful that in the years to come that we will see a decrease.

We are seeing decreases now, so it's not an all bad news story. Unfortunately, here in Manitoba, and in Winnipeg in particular, we've enjoyed–I guess this is probably the exact opposite word in terms of expressing my intention, but we have always been perennially at the top for a–quite a long time of many crime categories. And if it was an easy fix or a quick fix, I'm sure it would have been dealt with by now, but all interested parties, I think, are working diligently to try to do that.

This piece of legislation is really a small piece, but it does reinforce to our officers on the front lines that they do have the support of government in relation to these types of safety issues.

**Mr. Chairperson:** Thank you very much for your presentation.

I will now call on Gord Perrier, Winnipeg Police Service, superintendent.

Do you have any materials for the committee?

**Mr. Gord Perrier (Winnipeg Police Service):** No, I don't. I'll just be making some verbal comments.

**Mr. Chairperson:** Please proceed when you're ready.

**Mr. Perrier:** Good evening. For those of you who don't know me, my name is Gord Perrier. I'm a superintendent with the Winnipeg Police Service. My area of responsibility includes support operations, and I'm a member of the executive management team with the chief. Thank you for the opportunity to appear today and make some comments, and it's certainly my pleasure to be here.

I know Chief Clunis considered coming today. Unfortunately, his schedule didn't really allow that, but he is watching this as it moves through the House with anticipation, and, hopefully, my comments will bring some full comment to the bill that you're considering.

Before I do make detailed comments, I do want to say that we do have a belief that the public certainly has a right and an expectation to certain information, including issues like compensation. And, as a police service, we certainly deal with that every single day, from media releases to communicating through the Winnipeg Police Board and communicating that information with the public. This can be difficult, but we need to find some balance.

So nothing I say today is meant to undo that principle, but as an organization, it may be different that we're appearing and making comment as a public service, as the police service, on this bill. But as an employer we also do have a expectation and we do have obligations and responsibilities to our employees, especially as it relates to safety and their well-being.

Association President Mike Sutherland gave you some statistical information, and I don't want to rehash that information because you've already heard it. But I did want to talk about threat assessments and share with you a story.

Threat assessments is when members of the police service receive threats to their life, to their family or to their property. We must look at those incidents, assess a number of factors and develop safety plans for those particular officers. I can say, to give you a gauge of how often that occurs, it once was only once or twice a year, if that, and now we budget for 10 to 12 of those incidents occurring in a year's period. It doesn't show too many signs of letting off. I can't share with you, unfortunately, the details of what we do in threat assessments, what we do in relation to safety plans and the processes that we look at when we investigate those incidents.

But I do want to share a story. And I was a little–I had a little trepidation in telling the story because it may provide a guide, as President Sutherland mentioned too. I mean, this story, the individuals that are involved have paid their debt to society. It does involve another organization, and I don't want to paint that organization with a black eye or anything like that as well, but given the situation of this bill, I think it's important to share this story. This has made its way around the news recently, and one of the comments that has come to me as a member of the executive management team is how exactly does the compensation act and the release of that name and that salary relate and provide to safety?

This story I'm going to share with you is a personal story. It happened to me and my family. A number of years ago I was running a drug operation that had an overlay into credit card trafficking and different levels of financial crime. It was a night not unlike tonight. It was nice. I was returning home from duty, not really paying attention, which, when we're in operational phases, I should be doing. About halfway home I did detect that I was probably being followed. We have provisions around counter-surveillance and techniques that we employ. I did employ those. I was certainly being followed, and I was able to, you know, get away from those people that were following me and return to my residence.

A short time later the individuals that were following me did find my vehicle, as when I detected them, I was close to home. You comb the streets, you find the vehicle. At that point those individuals knew exactly where I lived and there was a number of other things that they knew about me, is they knew my licence plate number, they knew my residence, they knew my address.

Now, what's shocking in this case is I had already arrested the individuals that we found to be responsible of this for a number of times. This was a project that was a continuation of a number of other projects, so they knew exactly who I was from court disclosure. From that information, I certainly felt intimidated by just the drive by and stop at my residence, but it didn't stop there.

What ended up happening is a number of weeks later, about three weeks later, I got a call from a security professional from a major banking institution in Calgary who knew me personally through conferences and work I had done with financial institutions around enterprise crime, and said, Gord, did you know that my banking institution is foreclosing on your home, that your bank accounts have been frozen and that you have no access to your finances? I was stunned.

What had occurred–and thankfully the individual who was head of security knew me personally and knew that I had nothing to do with what led to that action being taken. It turns out the members of this group that were associated with an outlaw motorcycle gang got jobs in my name. They used the information like where I live, how much money I make, my address and all kinds of other details that they gathered up. They never admitted to us exactly how they did those things, but through the investigation and the process, they needed those pieces of key information to perpetrate the acts they did, pierce the banking system and freeze my accounts and have my house foreclosed upon.

So, if you are looking for a direct correlation to how the compensation act would relate to that, a perfect crime–or a crime that would be directed directly at a police officer because they were investigating or doing their duty for the public, this is that incident. So I wanted to share that and I wanted to say thank you for tabling this, thank you for talking about it, thank you for hearing others talk about it. And well this compensation act won't solve all of those risk issues associated to my situation and the situation that occurred to me, it is a step in the right direction and I thank you for your attention today.

**Mr. Chairperson:** Thank you.

**Mr. Swan:** Yes, Superintendent Perrier, thank you for coming down and giving us the general perspective on behalf of the police service but also sharing with us the experience you had. I think it paints some very, very vivid colours, the importance of protecting our police officers from the exact sort of things that happened to you.

So thank you for coming down and for making an excellent–and a presentation that had a group of politicians remaining incredibly quiet, which doesn't happen all the time. Thanks.

**Mr. Goertzen:** Thank you for being here this evening. Give our best to Chief Clunis as well. He's doing a fine job and, I think, making some important steps with the City of Winnipeg police.

Your story, I think, was helpful because I've had those same sort of questions. And people say, well, where's the relation between the need for this legislation and what's happening with officers? And I understand why it's important not to speak about details and specifics, and so it's hard sometimes to respond to those questions. And so, you know, I appreciate you sharing that because it'll give me something to say in terms of, you know, the real experiences.

***** (19:40)

You know, you mention that the threat assessments have been going up over the years. You know, can you–do you have some either anecdotal or specific data in terms of why that is? Is it the nature of today's offender, is it more of a disrespect for police officers among those offenders, or why is it those threat assessments are going up?

**Mr. Perrier:** I can say the majority of threat assessments are related to organized crime and the work that we do in relation to that. So, that–organized crime–the money that's made from organized crime is huge, and groups especially want to protect their territory. And there was a time when, you know, police were sort of off-limits. And I think that time, as a country, has certainly passed, and we're all well aware of that by reading the news. So, you know, it's moved forward on police, as well, and that's just a reality, as an executive, that we have this other dynamic in there where we have to do threat assessments and we have to follow through on safety plans and put in different provisional measures for certain officers because of the job that they do.

And President Sutherland, of course, shared other areas and other incidents but, I mean, the Internet especially. You can open it up, and if you want to, you know, anyone wants to exact financial crime or something else, or financial stress on somebody, this is one way that they could do that.

In my story, there were other mistakes that were made. Financial institutions, credit agencies–they all made some mistakes. But the people that perpetrated this know how to leverage those institutions and they know how to manipulate those things. So it's not anyone's fault. It was those perpetrators' faults, and it certainly was targeted and it was meant to get me to back off on the investigation the third time that we did this group.

So, thankfully, they pled guilty, they served their four years, and they called me when they got out of the institution and said, you'll never see us again, don't worry. So, that was nice.

**Mr. Gerrard:** Thank you for sharing your story and for coming forward today and emphasizing how important this measure is. I want to give you an opportunity in the wake of, you know, what we're hearing in terms of increased violence against police officers and increased threats. Are there any other measures that we, as lawmakers, should be taking to help protect police officers?

**Mr. Perrier:** That's a very difficult question, and I know that's something that my colleagues and the chief, we talk about, and I think, as I'm representing the organization, I'd certainly go back to them and ask them to bring those things, rather than just share some other personal opinions. But I can say this is one of those steps. And more recently, some of the laws that were introduced nationally around interfering with a judicial participant were very welcomed and, as in other times, there is a grey area, and we weren't able to proceed because it may have not fit areas around uttering threats. And so, you know, those types of laws have been very positive in that, but it's–those incidents of assaults on police is increasing and, you know, we really hope and strive to drive those down over time.

**Mr. Chairperson:** Thank you very much for your presentation.

I will now call Kevin Rampersad.

Do you have any materials for distribution to the committee?

**Mr. Kevin Rampersad (Private Citizen):** No, Sir. Just–

**Mr. Chairperson:** No? Please proceed when you're ready.

**Mr. Rampersad:** Good evening, committee members. My name is Kevin Rampersad, and I'm 11-year member of the Winnipeg Police Service. It is both a pleasure and a privilege to be before you this evening. Thank you for providing me with this opportunity to address this important topic.

These days, with technology literally being at our fingertips, be it a laptop or a smartphone, information is quickly and easily accessible to almost anyone. Although in a majority of cases, this remains to be advantageous, in the case of having the ability to accurately identify police officers by name, this is not only a disadvantage but a safety risk. The publishing of police officers' names, as opposed to their assigned badge numbers, in terms of presenting salary information on a format such as the Internet is more than concerning, and not just to police officers but to their families, as well. Unfortunately, the criminal element at large have a growing lack of respect for police, and acts of retribution through intimidation, threat or attack are real.

In today's technological environment, a lot of information can be ascertained from a name. If information is obtained by someone with a questionable or adverse motive, it could have potential to seriously compromise the safety and security of that officer, his or her family members, children, spouses, as well as their property and expose them to an unwanted and unnecessary attention or damage.

I can tell you that privacy hits both the heart and the homes of police officers, especially when off duty. Publishing names of police officers as opposed to their badge numbers also disarms officers by taking away their ability to utilize discretion with respect to protecting their identities as they see fit.

I have spoke to some of the pertinent points in terms of my strong support of the amendments to this bill, and I believe that the numeric representation will represent officers accurately and deliver a degree of needed security while maintaining the content and purpose of the publication.

It is with the utmost respect I submit my thoughts and concerns on this matter, and I again thank you for the opportunity.

**Mr. Chairperson:** Thank you for your presentation.

**Mr. Swan:** Mr. Rampersad, thank you for coming and presenting to the committee and for your 11 years of service to the Winnipeg Police Service. I think every member of this committee was already prepared to pass this bill, but you being the fourth of four very strong presenters, you've–I believe you've made your point as to why this bill is so important. I just want to thank you for coming out and speaking to us tonight.

**Mr. Goertzen:** And I want to echo those words from Minister Swan. I know we said early on, and we said publicly, that we would support this legislation, so you may have wondered why you're still coming to present, but it helps us because there will be people who will disagree. There are always people who disagree with pieces of legislation, sometimes more strongly than others. But the presentations we've heard tonight, yours combined with the previous three, it does help us in terms of setting the picture that we don't always know because we don't operate in your world; we don't live in your world. And so I appreciate the fact you've come and given us sort of a window into that.

There are special exceptions that have to be made to get this legislation through because it came in late and because it wasn't part of previous agreements, but we will make those special exceptions happen and the legislation will pass. And it will pass more easily and to help us defend it more easily because of your presentation and your colleagues before you. So thank you very much.

**Mr. Gerrard:** I just want to add my thanks to you and appreciation. It makes a big difference when we've got several people of–you know, providing quality presentations like the four of you have done on this legislation. Thank you.

**Mr. Chairperson:** Thank you very much.

## Bill 214–The Neurofibromatosis Awareness Month Act

*(Continued)*

**Mr. Chairperson:** We'll now move back to Bill 214, and just for everyone's notice, that we have another presenter added to the bottom of the list, Carol Maione, private citizen.

But I will now call on Christen–sorry, Christa Degagne.

Did you have any materials for the committee?

**Ms. Christa Degagne (Private Citizen):** No, I don't.

**Mr. Chairperson:** No? Please proceed when you're ready.

**Ms. Degagne:** Thank you.

I thank you for the opportunity to speak in support of Bill 214 this evening. I don't want to repeat anything that's already been said, but I do appreciate the opportunity to share my family's journey with NF.

My 43-year-old husband and 12-year-old daughter have NF1. My husband was first diagnosed when he was six years old, which is actually surprising because some 36 years ago, NF was basically unheard of. It was just by chance that his pediatrician at the time had a son with NF, so my husband was diagnosed. Beyond his diagnosis, he knew very little about NF and he lived for the next 20-some-odd years ashamed of his diagnosis and also thinking that he was basically the only one out there that suffered from the condition.

Shortly after my 12-year-old daughter was born, when she was about three months old, we started to notice the café-au-lait spots. At that time we knew that she also had NF, and we chose not to pursue any medical treatment or diagnosis at the time, mostly because we wanted her to grow up living normally and not thinking that she was different from those around her. When she was about one and a half, we were convinced by her family doctor to take her to a neurologist and have a baseline MRI.

***** (19:50)

When the results from that MRI came back, I was called for a follow-up appointment with the neurologist. And sitting on her desk, before she entered the room, was the MRI report, and the words, multiple abnormalities, jumped right out and hit me in the face.

From there, she wasn't able to offer many answers and, is often the case with NF, there were more questions than answers.

We were unable to find what we were looking for here in Manitoba, so, with the financial support of Manitoba Health, we travelled to Toronto to take her to a NF clinic at SickKids. It was there that we were met with very knowledgeable physicians who ran this NF clinic and were able to offer us some of the reassurance that we so desperately needed.

There was no support available here in Manitoba. The only support I could find was a support group out in BC, and it was there that I found some of the other answers that we were looking for.

Since her diagnosis, and since the initial MRI, my daughter's been through multiple MRIs, numerous doctors' appointments and many procedures. We are so proud that she, to this day, continues to be an advocate for NF. She strives to increase awareness and she wholeheartedly supports the cause. Since grade 1, she stood up at the front of her classroom and shared her story and helped answer some of the questions that her classmates have about NF.

She's in the Louis Riel School Division and because of the overcrowding in Saint-Germain school, she'll be attending a different school next year in grade 7. And she said to me, Mom, I really don't want to do a presentation this year, and I'm really hoping that they don't hate me because I have NF.

It's things like this that an awareness would help alleviate. She's subject to the whisperings behind her back when she changes in gym class; the kids just not knowing what her multiple café-au-lait spots mean. So they talk behind her back. So she's worried about that as she enters the new school.

Increasing awareness of neurofibromatosis would make a big difference to my family and those affected by NF. An increased awareness and knowledge within the community would mean enhanced health care, hopefully, a collaborative inter-professional approach to assisting those who are living with NF, assistance for those with learning disabilities. I envision a clinic in Manitoba where we could offer the support for families, that inter-professional care that would help take away the need for families to travel to other provinces or countries for care.

I see, even with May being NF awareness month, the benefits of that lasting throughout the year. There's definitely things in life that we can't change, and a diagnosis of NF is one of those. But we know that we can move forward, increasing awareness, helping find the answer and educating those around us.

We envision a world without the physical and emotional pain associated with NF. And you might have seen our MBNF PSA that's been airing on CBC for the past few weeks. My daughter's the little girl that speaks at the end of the PSA. And, in her words, she says, there's no cure, but there's hope.

I'm confident that an increased awareness of NF will benefit all those affected, and Bill 14 is definitely a step in the right direction.

I thank you for your time, attention and support.

**Mr. Chairperson:** Thank you for your presentation.

**Mrs. Leanne Rowat (Riding Mountain):** Thank you, Christa, for your presentation. I know last Thursday you were very busy planning one of the fundraisers, but your presence was there. And I just want to thank you for you take–for the work that you do, for taking the leadership role that you have within MBNF.

And I know that when I talked to Tracy, she was–Seth was wondering if we had won when we passed first reading. Well, we've passed first reading, second reading and we're going for the home run. So you can tell your little girl that, yes, there's no cure yet, but there's lots of hope, and we're going to educate and just to keep strong and continue to be a strong advocate. She's an angel; her comments on CBC, the radio ad are amazing–or the TV ad is amazing.

So thank you so much for your presentation.

**Hon. Ron Kostyshyn (Minister of Agriculture, Food and Rural Development):** So, on behalf of this side, we really appreciate the information you've shared. Obviously, every presenter is a learning curve that you bring forward the commentary, and I know that there's always medical challenges, regardless of what we have. And I'm sure all of us sitting around in this room today have had family members who have suffered with a number of various diseases; obviously, this is very unique. And I think all of us in this room wish that the sooner we can find the secret medicine to do away with this, I think it'll be a success story for all of us.

So thank you for doing a presentation and, hopefully, your daughter, as she moves on in the education system is accepted by other students and that we minimize the challenges that she faces medically and physically.

So thank you for doing your presentation. Very well done. Thank you.

**Hon. Jon Gerrard (River Heights):** Thank you for coming and presenting, you know, and talking a little bit about the need of what I interpret as a multidisciplinary team of health professionals who can help with, you know, family members and with children and adults with neurofibromatosis.

I was involved with a multidisciplinary team looking after kids with cancer, and one of the things that we found that was very helpful was having a part-time teacher as part of the team. And she would be able to go out and be with a child and family in the classroom. Sometimes it would be when the child was initially diagnosed and the child wasn't actually there, and explaining what was happening so that the–and it really changed things around in terms of the kids having an understanding and making a lot easier for the child not having to do all the explaining herself or himself. So maybe, as you progress and look into that, that'll be something that you get to. Thank you.

**Mr. Chairperson:** Thank you very much.

I will now call Rebecca Penner. Did you have any materials for other people?

**Ms. Rebecca Penner (Private Citizen):** No, it's just oral.

**Mr. Chairperson:** Okay, please proceed when you're ready.

**Ms. Penner:** I'd like to start with thanking everyone for being here tonight. I am a resident of Southdale; my MLA is Erin Shelby; and I am reading for a private citizen for Bill 214.

Well, up until a few days ago I never really thought about what having an awareness month would actually mean, but I would have to say it would be–the biggest thing would be for future and better understanding about what NF is.

I was first diagnosed with NF when I was only a couple months old and there wasn't a lot of info about NF then, but, thankfully, I had a pediatric doctor who was very willing to learn. When I was 10, I had to have four weeks of radiation treatment for an optic glioma. At this time my family lived in Portage la Prairie, and my mom and I drove in daily for treatment. Because of this, I had to miss the majority of school days.

When I entered junior high, I started having chronic and severe leg pain. My orthopedic doctor gave me a note excusing me from gym. Fellow classmates thought this was unfair, and even my gym teacher thought I was trying to just get out of class, saying that it was growing pains and it would just go away. The pain continued into high school where I encountered the same problem with classmates as well as my gym teacher. There was no alternative for this class, so I had to just sit through it–sit through the duration.

Through the years of school I had well passed the maximum absences I was allowed. Even though they were excused, they would still call home daily, asking why I was absent, and my parents would then explain the situation again.

***** (20:00)

In my first year of university I had to have surgery for a brain tumour. The day I found out that it–this is what it was was the day of my stats exam. So I–my sister took me to the school where I frantically explained the situation to them, thus saying that I did not need to come down to the school to do this. But, in order to get the authorized withdrawal so it would not appear on my record, it took three doctor's notes and a two-page letter. The school said that they were just making sure that I was actually sick.

Now that I see adult doctors, there are times when I have to be the educator and inform the doctors about my condition.

Thankfully, my health is stable right now, but that's not to say that it can't change at any moment.

My hope is that more and more people will become aware of NF, and that it affects everyone differently and that there may not always be a physical outside appearance, like in my case.

The neurofibromatosis group has been an absolutely wonderful me, and I never would have met so many wonderful and courageous people who can relate to what I have been through.

Having a whole month dedicated to the awareness of NF will, hopefully, bring greater support and understanding, as well as letting those living with NF and their families know that they are not alone. Thank you.

**Mr. Chairperson:** Thank you very much for your presentation.

**Mrs. Rowat:** Thank you, Becky, for presenting tonight, and I thank you for coming last week as well, and, you know, being in the gallery and showing your support for Bill 214.

And just, you know, what you shared today shows your strength and your perseverance, and I want to thank you for that and for all that you've done with educating people, as you move through your journey in life.

You speak well of MBNF and, based on what we're hearing tonight, they are definitely a great organization and an extended family.

So I want to thank you for your support, thank you for what your leadership has done with the organization and with your family and your friends. So thank you for presenting.

**Mr. Kostyshyn:** Thank you so much, Rebecca, for being here today.

And, again, it's a great privilege to hear your side of the story, because there's a number of stories have been told, and it's all purely educational to one of us that never had the opportunity to experience it. And, you know, the beauty of human contact in presentations such as yours, it really makes a serious connection of the education component.

So I thank you for a great presentation and wish you well. And, keep up the fight, and, hopefully, the–we will find a cure sooner than later so we can deal with the future generations. So thanks again for your presentation. Very well done.

**Mr. Gerrard:** Thanks, Becky. It's good to see that you're, you know, pushing forward with your post-secondary education and that, you know, in spite of issues that you've come across, that you've been–managed to address them and do well.

So it's important that you shared your story; give all of us a better understanding of what it feels like to have NF, and, hopefully, it will help, you know, break down some of the barriers in understanding, and improve things in the future. Thanks.

**Mr. Chairperson:** Thank you very much.

I will now call Nancy Anderson, please. Do you have any materials for the committee?

**Ms. Nancy Anderson (Private Citizen):** No.

**Mr. Chairperson:** Please proceed when you're ready.

**Ms. Anderson:** Good evening. My name's Nancy Anderson, and I'm here to make a presentation in support of Bill 214, The Neurofibromatosis Awareness Month Act.

I'm going to tell you about my journey as a parent of a son, who's now an adult, but who was diagnosed with NF when he about 11 years old. His pediatrician had retired and we had an appointment to meet with a new doctor at our clinic, Dr. Alto. And, after the initial pleasantries, he asked me what my understanding was of my son's NF. Well, I guess I must have given him a, kind of, blank look on my face, because, you know, I didn't know what he was talking about.

Apparently, his early medical records did indicate our retired physician had been considering the possible diagnosis. There were some early symptoms. He had some café-au-lait spots and the auxiliary freckling. And, occasionally, the doctor would comment on these, and, well, you know, we both come from good strong British stock with red hair and freckles, in all our families, and my husband had a couple of café-au-lait spots, although not in the numbers normally present with NF. So those comments had never raised any red flags in the early days.

My son had been diagnosed in grade 1 with ADHD, but it was being treated as a singular condition and not a symptom, as it often is, of NF. And many of his neurofibromas were only beginning to present themselves at this age.

So, for whatever reason, the first physician had kept his observations to himself, so this new doctor's question came as quite unexpected news to me.

So, after a very preliminary discussion, Dr. Alto said, well, you strike me as a really engaged parent. You will go home and start to research NF, and you will scare yourself to death. Please try not to be too frightened. He also admitted that he had no prior experience with an NF patient and, in fact, had to ask my permission to consult with some of his colleagues and review my son's medical records with them.

Now, my son falls into the 50 per cent of patients who develop the condition through a spontaneous genetic mutation versus the other 50 per cent who inherit the condition from a parent with NF. But that meant that we had no familiar reference point. I'd never met anyone with NF. I vaguely remember some media coverage about neurofibromatosis, actually, a few years previous when the movie biography of Joseph Merrick came out. And you remember it, perhaps, by its title, The Elephant Man. At the time of the movie, they actually thought Merrick may have suffered from NF 1, although later it's speculated he suffered from Proteus syndrome or perhaps an exceedingly rare convergence of the two conditions. But that was my limit–the limit of my awareness of NF.

After the initial medical appointment with the doctor, there–was followed by a few months, a flurry of tests and specialists. I had this healthy kid who never missed school, or often never, and we're off for an MRI. And it was a bit of an adventure. The great folks at St. Boniface hospital even gave us a film image of his scan, and I have to admit, I've referenced it since: You know, I know you have a brain in there, and we've got the picture to prove it. But the scary part came a few days later with the phone call asking us to come in almost immediately for a repeat scan because there's something they wanted to take a better look at.

And those tests revealed he had an optic glioma or a tumour on his optic nerve. And then there was the succession that, you know, a lot of the parents here have mentioned: the pediatric neurologists, the geneticists, the ophthalmologists with a speciality in ocular oncology. And, yes, my son was officially diagnosed with NF1.

As the doctor had suggested at that first visit, I went off and did my homework. And now, this was a number of years back, so I headed off to my local public library, and there were a couple of listings, both biographies of Joseph Merrick. Today, if you search neurofibromatosis at the Winnipeg Public Library, there are three books, still just Merrick's life.

I'd had a previous connection with the Learning Disabilities Association of Manitoba through some of their workshops when my son was diagnosed with ADHD, but they were unable to provide me with any resources on NF, even though half of the children with NF1 also have ADHD or other related learning difficulties.

The web was less pervasive than today, but I managed to find a handful of hits, including a national organization in the States and the BC NF association. Today, you'd probably get 3 million hits. I did a little quick check earlier this week. I'm not sure, though, that awareness of NF has increased nearly as exponentially. After I was here for the reading of–the second reading of the bill, I headed back to work and, you know, told a few people in the lunch room where I'd been. Most of them had never heard of NF, except for a few that I had already talked to about it.

Now, we've heard about many of the physical and social impacts of NF that I learned about in my research, but, like many parents, I then had to take on the role of being the spreader of awareness, letting family members know, close friends, about his diagnosis. And then there's always those numerous opportunities that come up to do the education one on one, like the day camp supervisor who calls in a panic because she's taken the kids to the waterslides and suddenly notices your kid has all these freckles under his arms and these little bumps, and maybe he's having a reaction to the sun. Or the high school principal who called me one morning because my–I guess he'd missed my message at the school office, and my teenage son had arrived late for school and he didn't want to take his sunglasses off in class, and the teacher noticed his pupils were dilated. Well, he'd been to the eye doctor to check his optic nerve tumour, and they have to dilate the pupils.

So, you know, this goes on, and, you know, of course, there's that significant challenge of the year-to-year education of teachers, which becomes 'increafingly' difficult as students head to junior high and then high school, where, you know, you have one point of contact with a homeroom teacher while your student's trying to navigate multiple teachers.

***** (20:10)

I'd always tried, because of his ADD, to be a little proactive with teachers and having conferences and teaching them about that. And now I had something else new, and there wasn't anything for them to reference. I had to write away to places like the BCNF to find–search material that I could give to the teachers.

So now my son's an adult, and he has to continue this process. And he's a pretty private kid, and he really doesn't like doing this. But, you know, then he gets to the new doctor who says, well, how do you know you really have NF? He has to explain to employers why he sometimes has trouble with executive functioning and fine motor skills. And how do you tell a girlfriend what you've got the first time you try to get close?

The need for an increased awareness of NF has led–of course, you've heard–growing members of the community to come together in a support group, but it’s allowing us to do–spread education, create new 'parshionships', often in a reciprocal manner, so we can get someone like a special ed adviser come and talk to us at our meetings, who then goes away with a better awareness of NF that she can spread through her broader community.

So awareness is only going to help us reduce misconceptions and anxieties for people with NF and their supporters when they have to deal with daycare workers and teachers and medical professionals and employers and so on.

And, of course, our shared experiences as an NF group, which–I don't think I mentioned I'm also the vice-president of–means that we're also working to give back to our society as well. So you've heard about, you know, contributions to Ronald McDonald House, the Children's Tumor Foundation, raising money for MRI goggles that are used by all–can be used by all children undergoing MRI testing at the Children's Hospital.

So just imagine what we could achieve if, when we approached an individual, a service organization or a business to work with us, we were actually speaking with people who had an awareness of NF and the number of people it impacts in Manitoba.

So I urge the members of the community to continue to support this bill, as you've done so wonderfully up to this point, as it proceeds to final approval. Thank you.

**Mr. Chairperson:** Thank you for your presentation.

**Mrs. Rowat:** Thank you, Nancy, for your presentation, and thanks for your support last week and for your involvement as an executive member of MBNF. You have a tireless way about yourself, of what you get involved in and your commitment to, not only your child but the many children that are affected by NF in your community. And so I'm hoping this bill, you know, will provide some support for the work that you do within the province, and we'll continue to work together to promote awareness and make life a little bit easier going forward.

**Hon. Andrew Swan (Minister of Justice and Attorney General):** Yes, thank you, Ms. Anderson, for coming down and presenting, and your–for me, your presentation brought into focus how useful it can be if that information is available, and the flip side is how frustrating it can be if it isn't. And I believe, in your comments, you describe yourself as a spreader of awareness, which is a really appropriate term. And I want to thank you for your advocacy on behalf of families and your continued work as a spreader of awareness of NF.

Thank you very much.

**Mr. Gerrard:** Yes, thanks so much for coming down and painting such a clear picture of life with a child with NF. I think one of the things that, you know, we can learn, and, you know, this is not just typical of NF, but, in this case, you have not only an understanding of NF but that ADHD can be associated with that or it can be associated with other conditions, and that can be helpful in dealing with the ADHD as well as with the NF.

One of the things that's been discussed a little bit is the need for, you know, improved services here. What's your experience, and what do we have to do to better support people with NF and their families here in Manitoba?

**Ms. Anderson:** I know we found it very difficult, even with the ADHD, just to get any kind of a–because he wasn't as severely impacted as many people are, you know, just getting that little extra bit of help in the school system, getting them to make, you know, reasonable accommodations that might have helped him be more successful. And because, unfortunately, you know, the NF didn't come online until he was just, you know, about to get into junior high, and then you're dealing with, you know, a math teacher who isn't a, you know, specialist in this kind of thing, and I think just perhaps, you know, helping some of these kids to–giving them the supports they need throughout the school system that might help them be more successful.

**Mr. Chairperson:** Thank you, very much. I will now call Connie Bart Hamel.

Do you have materials for–okay. Please proceed when you're ready.

**Ms. Connie Bart Hamel (Private Citizen):** I'm a Wolseley-area resident under MLA Robert Altemeyer. My name is Connie Bart Hamel and good evening to you. I have a lot of work to do. We have a lot of work to do and we don't give up, so to hear–to have the honour of standing in your presence and having you listen is very gracious.

Bill 214, NF, another family journey regarding the Hamels: Neurofibromatosis, nervous system, pain, tumours. NF–it's time to come out of the dark with acknowledgement by our Province of Manitoba Legislature. We implore you to reduce the genetic discrimination. People walking up and saying, what's wrong with your face, at a bus stop, to a young man? Make public all the signs that each of us as a group have had to struggle with to diagnose and begin tracking critical health issues. Build a team of doctors that are congruent in treatment and education. Legislate Manitoba Health to cover pharmacy and support treatment. Regulate Blue Cross, Great-West Life and health insurance policies to not deny coverage through this lifelong, predominantly, but not always, genetic disease that never acts the same in two people. Educate teachers in schools that it is not just ADD, then their students that it's not okay to ridicule others because they are different in appearance, physical ability or think process. Example: you would not respond that way to cancer. Any of the multiple fibroma in the body can become cancerous.

We are the Hamels. Three of our family of four have NF. Jesse, 18, has fibroma in the spinal column and much of his body. He's undergone extensive surgery at 13 and is in pain most of the time. Last week I was absent because of an urgent MRI slated for comparison of the spine, again, recording complications. Calvin, now 21, has fibroma in the brain behind his eye that may become active at any time but is now latent. Both of our sons struggle with strength and mobility and fatigue. Dad, Paul, has never had an MRI but had fibroma removed as a teen. His cousin, a little older, whose mother is a twin to our ma mère, has had extensive surgery starting late in his life.

Like all parents herein, we lie awake with involuntary tears in our sleep, fearing the days ahead when our sons and daughters will no longer be sheltered as children and wondering who will attend to their pain-filled days and nights, lurking under the cloud of reduced services and denial of Pharmacare and insurance coverage because it's not listed or specified that we already endure. There are a great many more of us. Many who do not know about our wonderful group or the characteristics of NF. Please help us bring NF to the light through your acknowledgement and thank you for the opportunity to speak.

**Mr. Chairperson:** Thank you very much for your presentation.

**Mrs. Rowat:** Thank you, Connie, for your powerful presentation. That's why we're here tonight as–because we're moving this process forward, and we're going to do all that we can to ensure that awareness is raised so that the challenges that families like yourself are supported and are recognized.

***** (20:20)

So I want to thank you for your time tonight. God bless your family, and stay connected to MBNF.

**Mr. Swan:** Ms. Bart Hamel, thank you for coming out and presenting and for sharing about your family's story. It's very helpful for all of us, as members of the Legislature, to understand more about NF and understand a bit more about the impact on families. And, for that, I do truly thank you.

**Mr. Gerrard:** Thank you for talking about your husband and your two kids. And one of the things that you and quite a number of others have spoken about is the pain, and others have spoken about the fact that it can be sort of dismissed or written off. And I think the fact that you and others have spoken about it, you know, is a pretty important message, all right, in helping people to understand that this is very real and that it's important that people around know that and appreciate and, you know, don't lessen the impact of that. Thank you.

**Mr. Chairperson:** Thank you.

We'll now call Kathleen Demers. Do you have materials for distribution?

**Ms. Kathleen Demers (Private Citizen):** Yes, I do.

**Mr. Chairperson:** Please proceed when you're ready.

**Ms. Demers:** Good evening. My name is Kathleen Demers, and I wish I had a phone book to stand on because this podium's so high.

I wanted to say thank you to the committee for the opportunity to speak regarding Bill 214. I'd like to thank Mrs. Rowat for being the voice of Bill 214, and I'd also like to thank Tracy and Christa and all the directors of the MBNF group who are a big reason why we're here today. And I'm here to tell you my story as a parent.

On December 7th, 1987, my husband, Wayne, and I welcomed our second son, a beautiful, big baby boy. From his birth, doctors were puzzled by our son's health and development. Though many family physicians examined him and sent him for testing, it wasn't until we moved to Brandon, Manitoba, and met Dr. Emmet Elves, that he was diagnosed at the age of two and a half years old: neurofibromatosis. Neurofibro–what?

Neurofibromatosis, or NF for short, is a big word that became a part of our vocabulary in the spring of 1990. We had never heard of NF before and–nor had any of our family or friends. Apparently, a very common disorder, NF causes tumours to grow on nerves, internally and externally, as well as many other complications too numerous to name. How could we not be aware of a disorder that's more common than cystic fibrosis, hereditary muscular dystrophy, Huntington's disease and Tay-Sachs combined?

And so, rather than being relieved that we finally had a diagnosis, we actually had more questions than anybody had the time to answer for us. We wondered: What will our son's life be like? What can we do, as parents, to help him? How will he succeed in school? How will he handle the lifelong medical testing? How will the NF manifest itself in our son's little body? Will be–will he be accepted by his peers? Could we lose our little boy? Is the child I'm carrying in my womb also going to have NF? And the questions just went on and on.

After much family background research, it was determined that our son's case was not a hereditary form of NF, but was rather considered a spontaneous mutation. Our son's fine and gross motor skills were affected as well as his ability to learn and progress like other children. From learning to walk and talk, all the way to getting a high school and a college diploma, learning to drive a car, each of these steps took extra hard work for our son as well as for his parents, teachers and tutors. The doctors told us that the onset of puberty in males seems to bring on the growth of tumours more so than in females. So we wanted our little boy to stay small forever because we were handling what we had been dealt so far. However, in his teens, the doctors discovered that our son had three tumours in his brain as well as one tumoursome–troublesome tumour on his left temple. These could lead to headaches as well as seizures. At this point, fear became our constant companion. We were almost wishing his teenage years away so that he could–so that we would know what we would be facing by the end of it.

Due to my husband's work, we moved from city to city quite often, and our son has had many different teachers. None of them had ever heard of NF before, but they were all willing to learn. So that's what we did: We talked about NF.

Programs were put in place to ensure success throughout his education. His teachers were always amazed by his strong desire to learn and his positive attitude despite the learning challenges. Resource teachers were instrumental in his education. A lady named Leslie Siscoe was so important in our lives, and we love her dearly to this day, even though she's retired from teaching.

Our son's name is Lyndon Demers. Lyndon has grown up to be a happy, outgoing, fun-loving and handsome six-foot-tall man. We wish we could have known, when he was diagnosed almost 25 years ago, that he would successfully come through five operations in his lifetime to deal with the manifestations of NF, two of them being on the left temple; that he would warm the hearts and–of family and friends across the five provinces that we have lived in; that he would graduate from high school; he would successfully complete two college certificates; that he would maintain a full-time job for the last five years while also maintaining his part-time job for the last nine years; that he would drive his own car and actually live on his own. I would have lived a whole lot easier and not come out with so many of these grey hairs.

Lyndon, thank you for being an incredible son. Your persistence, your love of life, your hard work, your faith, your willingness to take on each and every challenge, and despite every obstacle, never ceases to amaze us. We are and always will be very proud of you, son.

In February of 2007, Lyndon discovered the MBNF Support Group on the Internet and attended his first meeting. At the age of 19, Lyndon finally met other individuals with NF. The support group has been the best thing that has ever happened to him and to our family. And, for that, I thank Tracy and Christa. With the support of his peers and the newfound friendships, he has found acceptance and is successfully living with neurofibromatosis.

In his part-time job, Lyndon works in the public. He often gets asked: What's wrong with your eye? Were you in a fight? What does the other guy look like? Although hurt and frustrated by these questions, Lyndon designed and ordered himself a new T-shirt, a picture of himself with a caption that read: Wonder about my eye? Ask me about Neurofibromatosis. And off to work he went.

Well, we think it's time to take the covers off of neurofibromatosis. Let's get the word out. It will help family physicians recognize the early signs and symptoms much, much sooner. It will help our educators provide the best services and programs possible. And it will also help employers understand what some of their employees might be going through.

Imagine what bringing awareness in our province could do for the population living with NF. We want individuals with NF to thrive, to be comfortable in their own community and to feel accepted by friends and strangers alike.

Awareness is the key to understanding. Knowledge is the key to acceptance. Please help us spread awareness of neurofibromatosis by passing Bill 214 and making the month of May NF month in Manitoba. Thank you for your time.

**Mr. Chairperson:** Thank you very much for your presentation.

**Mrs. Rowat:** Thank you, Kathleen. Wonderful job. And yes, we all are very proud of Lyndon as well. He's become, you know, a great support. And he's going to be the leader in awareness in Manitoba; there's no doubt. He's done so much, and that's through the love and support of his family and the love and support of the NF community.

And I just want to say that, you know, when people bring forward ideas on bills, you go with it. And this has been an amazing journey for myself. And I look forward to helping Manitoba become totally aware of what F–NF is and how we can help, you know, find a cure.

So thank you very much for your presentation.

**Mr. Swan:** Ms. Demers, thanks to you and your family for coming down and for you presenting to us. You tell us Lyndon is a very incredible son. I think he recognizes he's got a pretty incredible mother. So thank you for sharing with us your family's stories. I've discovered the grey hair starts to come in with kids, whatever the situation. But you've done an excellent job of presenting to us tonight, and I thank you.

***** (20:30)

**Mr. Gerrard:** Thank you for sharing your story and your son's story. And, you know, neurofibromatosis, type 1 and type 2 may be genetic conditions, they may be inherited, but, you know, even in the stories that you tell and some of the things that you talk about, the change at puberty, that there may be hormonal influences. We know that the growth of nerves is influenced by nerve growth factors and that in many cases in the past genetic diseases have been influenced, and found to be influenced, by outside factors that can improve the situation.

So, you know, I suspect there's a lot more hope than sometimes we may think, and I wish you well and your son and family and the whole organization well. Thanks.

**Mr. Chairperson:** Thank you. Ms. Demers, go ahead.

**Ms. Demers:** I just wanted to say one last time, I just want to thank you all again for your attention to this very, very important matter. Thank you.

**Mr. Chairperson:** Thank you.

I'll now call Carol Maione. Do you have any–

**Ms. Carol Maione (Private Citizen):** Yes.

**Mr. Chairperson:** Yes, you do. Good. Please proceed when you're ready.

**Ms. Maione:** NF has caused many problems in this person's life. His fontanelle did not close before four years old. There was slow growth, and at age 4 a tumour was removed from his throat. He had choked very badly for a long time before diagnosis. His speech was delayed and, at age 3, went to a special pre-primary school where he had speech therapy. At age 6, he went to a primary school for children with physical disabilities. He had remedial reading, and it was said he would never read. But with patience he had learned to read and became a fluent reader. He had a learning disability, although of normal intelligence.

For him especially riding a bicycle was difficult–sorry, I didn't go on. Probably from infancy he had sort of blank periods about 12 times a day. It was difficult for him, especially riding a bike. He took seizure medication which relieved him of this problem, but the sleep-deprived seizure neurological tests were especially trying for him. He was diagnosed with a small brain tumour at age 21, and at age 28 there was no sign of it, however.

He has many tumours everywhere under the skin, in the groin, along legs and arms, innumerable. As a teen, he said he didn't know how he would be able to cope with them growing and how he would cope in old age. So, after going away and reading about it, he said, oh, not to worry, with NF, there aren't many of them left in their 50s.

Yes, the depression caused by continually not being able to accomplish what you're intellectually able to do, pain terribly from scoliosis and the chiropractor's fees can be unaffordable. It may not be an NF problem–sorry, unaffordable. He's had a procedure with tubes down his nose, the bronchial tubes, just last week. It may not be an NF problem. We don't know the results as yet.

In one of the schools, there was a little girl I met who had NF. She had no joint–no joints at all. An–she was in a special wheelchair with an attachment to hold her head up. She could do nothing; she couldn't even feed herself.

But that's all I have to say, and thank you to all of you for listening. And, hopefully, we will get a lot of help with this, and thanks to Tracy and Jeff and all the MN–the NF crew and, we thank them very much. Thank you all very much.

**Mr. Chairperson:** Thank you. Do you want to just come back for one second, and we'll just have some questions for you or comments.

**Ms. Maione:** Oh, I'm sorry.

**Mr. Chairperson:** That's okay.

**Mrs. Rowat:** Thank you, Carol, for your presentation. We want to thank you for coming forward and sharing your story and–including how NF association–or MBNF has provided supports for you. But I agree: more awareness and more supports based on awareness would make life a lot easier for so many people.

So thank you for your presentation.

**Mr. Swan:** Ms. Maione, I would like to thank you for coming down and giving us more information. Everybody who has come forward tonight has presented information that's been very useful and informative for the members of this committee, and I thank you.

**Mr. Chairperson:** Just one more.

**Mr. Gerrard:** Yes, thank you, Carol. You know, everybody who's presented has got their own unique story, and each of those unique stories helps all of us to get a better picture of what happens, what can happen and what families go through. So it's really important that you were here. Thank you.

**Mr. Chairperson:** Thank you very much.

This concludes the list of presenters I have before me. Are there any other persons in attendance who wish to make a presentation?

Seeing none, this concludes public presentations.

* * *

**Mr. Chairperson:** In what order does the committee wish to proceed with clause-by-clause consideration of these bills? This–

**Mr. Swan:** I would suggest we simply go in numerical order as listed on the paper.

**Mr. Chairperson:** Agreed? *[Agreed]*

During the consideration of the bill, the table of contents, the preamble, the enacting clause and the title are postponed until all other clauses have been considered in their proper order. Also, if there's agreement from the committee, the Chair will cause clause by–oh sorry, clauses in blocks that conform to pages with the understanding that we will stop at any particular clause or clauses where members may have comments, questions or amendments to propose.

Is that agreed? *[Agreed]*

We will now proceed in the clause-by-clause consideration of the bills.

### Bill 64–The Court of Queen's Bench Small Claims Practices Amendment Act

**Mr. Chairperson:** Bill 64, does the minister responsible for Bill 64 have an opening statement? *[interjection]* Mr. Eichler.

**Mr. Ralph Eichler (Lakeside):** May we just have a five-minute recess so that we can reconvene here to get the critic back in?

**Mr. Chairperson:** Is the committee agreed to a five-minute recess?

### Bill 72–The Coat of Arms, Emblems and the Manitoba Tartan Amendment Act
*(Continued)*

**Mr. Chairperson:** The committee agree to move to Bill 72? *[Agreed]*

Does the minister responsible for Bill 72 have an opening statement?

**An Honourable Member:** No.

**Mr. Chairperson:** We thank the minister.

Does the critic from the official opposition have a opening statement? We thank the member.

Clauses 1 and 2–pass; clause 3–pass; enacting clause–pass; title–pass. Bill be reported.

### Bill 64–The Court of Queen's Bench Small Claims Practices Amendment Act
*(Continued)*

**Mr. Chairperson:** Does the minister responsible for Bill 64 have an opening statement?

**Hon. Andrew Swan (Minister of Justice and Attorney General):** Yes, it's not as brief as Minister Lemieux's. This bill will amend the Court of Queen's Bench Small Claims Practices Act. This comes as a result of discussion with the Court of Queen's Bench judges, who've suggested maybe we can move in a way that is more conducive to providing justice to Manitobans but also freeing up a number of Queen's Bench judges to work on matters that many people would agree would be more serious.

The result of this bill will be that people will continue to have their right to hearing before a small claims hearing officer instead of it being an appeal as of right to a Queen's Bench judge, there will be an appeal which is available on the law or on jurisdiction.

So we think it's a very appropriate way to move. We think it's proportional to the nature of cases in small claims, and the prospect of freeing up a certain number of Queen's Bench judges to deal with a number of more serious matters to help us move cases more swiftly through the system is a positive thing.

***** (20:40)

**Mr. Chairperson:** We thank the minister.

Does the official opposition critic have an opening statement?

**Mr. Kelvin Goertzen (Steinbach):** Just briefly. We certainly believe that the small claims court has an important role within our court system. It allows accessibility for individuals who have claims that are often of a smaller monetary value, but we recognize if there is an ability to have more significant claims that increase accessibility but don't reduce the due process of–that's necessary in more significant matters, then that's a positive step. So it's hard sometimes to know how things will always work out in the justice system when you're making changes. Sometimes things have to be road tested. So we'll look forward to seeing how this goes, and we hope that it will speed things through the system but not lose the accessibility of the small claims court.

**Mr. Chairperson:** We thank the member.

Clauses 1 and 2–pass; clauses 3 through 5–pass; clauses 6 and 7–pass; clause 8–pass; clause 9–pass; clauses 10 and 11–pass; clauses 12 through 14–pass; clauses 15 through 18–pass; enacting clause–pass; title–pass. Bill be reported.

### Bill 74–The Public Sector Compensation Disclosure Amendment Act
*(Continued)*

**Mr. Chairperson:** Does the minister responsible for Bill 74 have an opening statement?

**Hon. Andrew Swan (Minister of Justice and Attorney General):** Yes, well, very briefly. This bill would amend The Public Sector Compensation Disclosure Act. The bill will provide that in disclosures under that act, the names of police officers will not be disclosed and numeric identifiers are to be disclosed in place of their names.

I think tonight we heard from four very strong presenters representing our law enforcement community that have expressed very clearly and very cogently why what is being asked for in this bill is a reasonable accommodation for law enforcement personnel who do such a great job of keeping us safe.

**Mr. Chairperson:** I thank the minister.

Does the critic from the official opposition have an opening statement?

**Mr. Kelvin Goertzen (Steinbach):** Certainly, I think that the presenters tonight told the story better than any of us could. They did an excellent job of giving their perspectives from the different positions they hold within law enforcement in the city of Winnipeg, and we appreciated them spending their time here this evening to ensure that we can tell others who aren't involved specifically in police work why this is important, and I do believe it's important. It is a bill that falls outside of the sessional agreement, but we are willing to see this move through the process and will ensure that it makes its way through the process, despite the fact that it's not within the prescribed bills set within the sessional agreement.

I also think it's an opportunity to help police where we can. I know this isn't going to be a cure-all, but it eliminates one tool that those who are looking to identify police might be able to have and to–are trying to identify them for the wrong reasons. It is also, I think, an example that doesn't happen often in the Legislature but does happen at times where political parties can work together well, and there was trust exhibited between the Government House Leader (Mr. Swan) and Minister Howard and myself, and I appreciate that, and I think we kept that trust and came to the right solution on this bill. And I look forward to seeing it pass.

**Mr. Chairperson:** I thank the member.

Clauses 1 and 2–pass; clause 3–pass; enacting clause–pass; title–pass. Bill be reported.

### Bill 203–The Nurse Practitioner Day Act

**Mr. Chairperson:** Does the bill sponsor, the honourable member for Tyndall Park (Mr. Marcelino), have an opening statement?

**An Honourable Member:** A little.

**Mr. Chairperson:** The honourable member for Tyndall Park.

**Mr. Ted Marcelino (Tyndall Park):** Thank you.

The nurse practitioners are trusted health professionals who are integral to the goal of ensuring all Manitobans have access to a primary care provider, and there's a need to recognize and promote the awareness of the important role of nurse practitioners in the system. And they are, by virtue, nurse practitioners, because of their clinical expertise, judgment and compassion. They play a vital role in caring for Manitoba families in a variety of settings, including QuickCare clinics and emergency departments. Thank you.

**Mr. Chairperson:** Does any other member wish to make an opening statement on Bill 203? Seeing none.

Clauses 1 through 3–pass; preamble–pass; enacting clause–pass; title–pass.

Shall the bill be reported?

**Some Honourable Members:** Agreed.

**Mr. Kelvin Goertzen (Steinbach):** It would be good to put on the record that we appreciate the vital role the nurse practitioners play within the medical system and we honour their role as well and the work that they do. Thank you.

**Mr. Chairperson:** Thank you, so shall the bill be reported? *[Agreed]*

### Bill 208–The Drivers and Vehicles Amendment Act (Support Our Troops Licence Plates)

**Mr. Chairperson:** Does the bill 'sponsrible'–sponsor the honourable member for Lakeside have an opening statement?

**Mr. Ralph Eichler (Lakeside):** Very briefly. I just want to put on the record–

**Mr. Chairperson:** Mr. Eichler, sorry. Go ahead.

**Mr. Eichler:** Yes, I do, Mr. Chair. I do want to put on the record I want to thank all members of the House for their support on Bill 208. I know not only do the veterans and those family members that have been impacted through serving our great country and making it what it is today–just a small step in recognizing what they have done, and we look forward to the plates being manufactured and go on sale for those families that want to support the troops. And I think that all members of the House will have great pride once they have an opportunity to see them and be brought forward in a timely manner.

**Mr. Chairperson:** We thank the member.

**Hon. Andrew Swan (Minister charged with the administration of The Manitoba Public Insurance Corporation Act):** Yes, well, thank you, and I want to thank the member for Lakeside for bringing this bill forward. I will be proposing three amendments that I hope the member–all members of this committee will consider to be friendly amendments. In our discussions, I believe the member for Lakeside's intention to bring forward this bill was that the plates would actually raise money for an organization that would be able to provide support for military personnel and their families. So I will be moving three amendments that I think will assist in doing that. I'll give an explanation for them, and I hope the member will take them in the spirit in which they're presented.

**Mr. Chairperson:** Shall clause 1 through 3 pass?

**An Honourable Member:** Pass.

**An Honourable Member:** No.

**Mr. Chairperson:** Clause 1–pass; clause 2–pass.

Shall clause 3 pass?

**An Honourable Member:** No.

**Mr. Chairperson:** Hon. Mr. Swan.

**Mr. Swan:** Yes, I move

*THAT Clause 3 of the Bill be amended in the proposed clause 60.1(b) by striking out "*depicting a yellow ribbon and maple leaves*" and substituting "*symbolic of the message conveyed by those words*".*

**Mr. Chairperson:** It has been moved by honourable Mr. Swan

THAT Clause 3 of the Bill be amended by–in the proposed clause–somebody can say–

**An Honourable Member:** Dispense.

**Mr. Chairperson:** Thank you. Dispense.

The amendment is in order. The floor is open for questions.

**Mr. Swan:** By way of explanation, as we did research into this, we discovered that the yellow ribbon, which I believe the member for Lakeside (Mr. Eichler) and probably all members of the committee want to go on this plate, is actually copyrighted. And it is our intention that we will get to a point where we will have the ability to use that emblem on our licence plates, but I can't tell the member right now that's the case. So I can put on the record that we would like to have the yellow ribbon and, of course, the maple leaves that go along with it. If for some reason it's not possible, it would then be necessary to come up with some other symbols or other representation that will get the message across.

**Mr. Chairperson:** Any further debate?

Is the committee ready for the question?

**Some Honourable Members:** Question.

**Mr. Chairperson:** Amendment–pass.

Shall clause 3 pass, as amended?

**An Honourable Member:** No.

***** (20:50)

**Mr. Chairperson:** Hon. Mr. Swan

**Mr. Swan:** Mr. Chairperson, I move

*THAT Clause 3 of the Bill be amended by renumbering the proposed section 60.1 as subsection 60.1(1) and adding the following as subsection 60.1(2):*–entitled

**Use of funds**
**60.1(2)** The minister may direct that all or a portion of the charges collected for the speciality number plates described in subsection (1) are to be paid by the administrator to a registered charity specified by the minister.

**Mr. Chairperson:** It has been moved by the honourable Minister Swan, that–the–use of funds–

*THAT Clause 3 of the Bill be amended–*

**An Honourable Member:** Dispense.

**Mr. Chairperson:** Dispense. Thank you very much.

When is–the amendment is in order. The floor is open for questions.

**Mr. Swan:** Yes, I know that when the veterans' plates had been brought in, the intention was to give a low-cost plate to veterans and there wasn't a fundraising or charity aspect to it.

In this case, again, based on my discussions with the member and the understanding, I believe the intention is there will be money generated and the intention is to get that out to a registered charity. It will be providing active–support to active military and their families.

So I can put on the record that this minister will direct that the plates will be $70, and $30 will go into the fund which can then be paid out to a registered charity. The bill, as originally drafted, wouldn't actually allow for the collection of that money or the payment out, and I think this amendment will match what we all hope this plate will do.

**Mr. Chairperson:** Any further debate?

Is the committee ready for the question?

**Some Honourable Members:** Question.

**Mr. Chairperson:** Amendment–pass.

Shall clause 3 as amended pass?

**An Honourable Member:** No.

**Mr. Chairperson:** I hear a no.

**Mr. Swan:** I move

*THAT Clause 3 of the Bill be amended in the part before clause (a) of the proposed section 60.1, by striking out "*The registrar must make available a*" and substituting "*Upon receipt of an organization's application that is acceptable to the registrar, the registrar shall make available a specialty*";*

**Mr. Chairperson:** It's been moved by the honourable Minister Swan,

*THAT Clause 3–*

**An Honourable Member:** Dispense.

**Mr. Chairperson:** Dispense. Thank you.

The amendment is in order and the floor is open for questions.

**Mr. Swan:** Since the initial specialty licence plates were created, there now is an application process that's available on MPI's website that's very accessible. And, when we began discussing the best way to come up with the organization or organizations that would then administer the program and have a registered charity the funds would go to, we wanted to make sure that we have those organizations coming forward and providing the standard application.

As of right now, I can put on the record that although we've had some very good discussions with a very good organization, we haven't yet come to that agreement, and we'd like to leave this open, in the event it's–we're unable to come to an agreement.

So we just want to make sure that there's an application that's received, that it will meet all the circumstances set out in the regular plate program, and, upon receiving that, we'll be very enthusiastic about MPI then making available those speciality plates.

**Mr. Chairperson:** Is the committee ready for the question?

**An Honourable Member:** Question.

**Mr. Chairperson:** Amendment–pass. Clause 3 as amended–pass; clause 4–pass; enacting clause–pass; title–pass. Bill as amended be reported.

### Bill 209–The Lymphedema Awareness Day Act
*(Continued)*

**Mr. Chairperson:** Does the bill's sponsor, the honourable member for Lac du Bonnet, have an opening statement?

**An Honourable Member:** Yes, I do. So–

**Mr. Chairperson:** Mr. Ewasko, sorry.

**Mr. Wayne Ewasko (Lac du Bonnet):** I would just like to put a couple words on the record in regards to thanking Kim Avanthay and the Lymphedema Association for Manitoba for all their hard work that they've been doing to bring awareness to this illness, which is affecting many, many, many Manitobans.

***** (20:50)

And, as has been put on the record many times today, it's interesting on how many people actually go through this without even knowing, and then it takes some time, or it takes somebody to point out that, you know, maybe you should, you know, research this or talk to this person, because they've gone through a similar thing.

So I commend them for all the work that they've been doing in regards to bringing that awareness throughout the past few years. I applaud the municipalities that have grown in numbers to proclaim March 6th as Lymphedema Awareness Day, and now, of course, thanking the members on our side of the House, but also the members on the government's side, for allowing this bill to go through and bringing Lymphedema Awareness Day, as March 6th, for the years to come.

So, with that, Mr. Chair, I thank you.

**Mr. Chairperson:** Does any other member wish to make an opening statement on Bill 209? Seeing none.

Clause 1–pass; clauses 2 and 3–pass; preamble–pass; enacting clause–pass; title–pass. Bill be reported.

### Bill 214–The Neurofibromatosis Awareness Month Act
*(Continued)*

**Mr. Chairperson:** Does the bill sponsor, the honourable member for Riding Mountain, have an opening statement?

**Mrs. Leanne Rowat (Riding Mountain):** Yes. I want to thank all the members of the Legislative Assembly on both sides of the House for the support with regard to Bill 214.

I know that many of us learnt a lot about NF or neurofibromatosis over the last week and a half, and I think the families really appreciated tonight the opportunity to share their stories. As many of them said, they have very rarely had the opportunity or felt comfortable talking about NF to anybody outside of their family. So, for them to come forward tonight, I think speaks volumes; it shows their willingness to believe in us in helping them promote awareness towards the NF illness, and I just believe that only good things can happen going forward.

I know that they're looking at ways to provide financial assistance for NF clinical trials at the Health Sciences Centre in the future. They're looking at hosting an NF symposium in the fall of 2015. They’ve raised over $25,000 to help purchase a CinemaVision for the children's MRI machine at the Health Sciences Centre. So this is a group that is not looking for government handouts; they wanted to look at government support for awareness and then work together with Manitobans to make life easier for their families who are afflicted.

So, again, I just want to say, use the term that Tracy Gregorash has used at the bottom of her emails is, new friends make a difference, N meaning new and F meaning friends. New friends make a difference.

So I just want to say to all of you within the Manitoba Legislature I appreciate your friendship; I appreciate your support, as do the many families afflicted.

So thank you. That's my opening statement.

**Mr. Chairperson:** Any other member wish to make an opening statement on Bill 214?

Clause l–pass; clause 2 and 3–pass; preamble–pass; enacting clause–pass; title–pass. Bill be reported.

**Hon. Andrew Swan (Minister of Justice and Attorney General):** Very briefly, this is, barring some unforeseen circumstance, the last evening that we'll be sitting in committee. There may still be another long evening or two to come for various reasons, but I just wanted to thank the various chairs. I want to thank the clerks who've helped us out and I want to thank Leg. Counsel–perhaps a less painful year than last year but–for being there. I want to thank our Hansard staff, as well as the pages, and everybody else who's helped to shepherd us through the various committees.

**Mr. Chairperson:** Thank you.

***** (21:00)

## Bill 300–The St. Charles Country Club Incorporation Amendment Act

**Mr. Chairperson:** On Bill 300, we will first hear a report on the bill from David Wright, Legislative Counsel, in accordance with rule 158(1). *[interjection]* Go ahead, Mr. Wright.

**Mr. David Wright (Legislative Counsel):** To the Committee of the Assembly considering Bill 300, The St. Charles Country Club Incorporation Amendment Act, as required by subrule 158(1) of the rules of the House, I now report that I have examined Bill 300, The St. Charles Country Club Incorporation Amendment Act, and have not noted any exceptional powers sought or any other provision of the bill requiring special consideration.

**Mr. Chairperson:** We thank Leg. Counsel for that report.

Does the sponsor or the honourable member for Emerson have an opening statement?

**An Honourable Member:** Just a very short one.

**Mr. Chairperson:** Mr. Graydon, go ahead.

**Mr. Cliff Graydon (Emerson):** Very short opening statement, and I will let St. Charles Country Club know that you just stood in the way of the bill tonight and tried to–you may not get to sit on a balcony again.

This is a very simple bill, which basically brings the St. Charles Country Club into the 21st century and allows voting by proxy for all issues that they have come before them as a board, so, with that, Mr. Chairman.

**Mr. Chairperson:** We thank the member.

And does anybody else have an opening statement on Bill 300?

Clauses 1 and 2–pass; clauses 3 and 4–pass; preamble–pass; enacting clause–pass.

Shall the title pass?

**Mr. Kelvin Goertzen (Steinbach):** Just quickly, I believe this is the last bill on the committee register tonight. I–but I do want to echo–the Minister of Justice is often a man before his time, but I do think that he is correct, that we owe a bit of gratitude to the staff of this Legislature, who don't always get the credit that they deserve. But they sit here late nights with us and give good advice to the Chairs and they do a wonderful job. And we appreciate all the job that you do and to keep this place running and keep it functional.

This committee process went a little bit smoother this session than last session, but who knows what next year will bring? There's always hope for next year, as we go through the committees–go through the process.

But I do want to also thank all the staff for helping us in the jobs that we do, and you're making us look smarter than we usually–or that we actually are, so we appreciate that–at least, in my case, anyway.

**Mr. Chairperson:** Thank you, Mr. Goertzen.

Title–pass. Bill be reported.

The hour being 9:05, what's the will of committee?

**Some Honourable Members:** Committee rise.

**Mr. Chairperson:** Committee rise.

***COMMITTEE ROSE AT:*** *9:03 p.m.*

## WRITTEN SUBMISSIONS

Re: Bill 214

My name is Brenda, I am 36 years old and have Neurofibromatosis. I inherited it from my mother. We did try to do a family tree to see where it could have come from, so either it was never diagnosed to other family members or my mom got it through gene mutation.

I do have 4 children, of the 4, 3 for sure have NF, and our last child is not showing any signs of having the disorder. I have been fortunate to not have it as severe or suffer from huge medical issues, but have had my tumors multiply though my pregnancies. It makes me feel self conscious on certain clothing choices where I don’t like wearing a tank top with low back or if I do I put part of my hair done, thank goodness for long hair!!! I have several bumps on my arms, and neck, and often get asked what they are, and can’t I just get a cream to make it go away. And quite often innocent children touch them and ask if they hurt, but am getting better and learning to live with them. I’ve in the past not worn shorts as they show the bumps and I guess I am trying to just let it go and wear what I want, but it’s not easy. I then feel guilty as there are other friends of mine who have worse cases than me, and feel I am blessed and try not to be so focused on them. I do suffer from memory problems, not being able to do simple math quickly and gets me flustered which makes it even harder to concentrate. All and all I haven’t had to deal with severe medical issues with my children who have NF, we do annual appointments with an eye specialist and so far we haven’t had any issues.

Thank you
Brenda Marion-Gerula

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Re: Bill 214

Dear: Committee Members and all Legislative Representatives

It is my honour in respect to Bill 214, to pass this Bill 214 into becoming an act. This would mean that the month of May would respectfully be NF Awareness Month. Research and solid stats show that their are more people in Canada with NF, ( Neurofibromatosis ) than cystic fibrosis, Duchene muscular dystrophy, and Huntingtons disease combined. Less time and money are spent by the medical field in researching cure and treatments for NF than any other disease.

I, Karen DePratto, have dedicated twenty years researching NF, as my daughter has a severe case. My grandson has been referred to the Cincinnati, Ohio NF Clinic for treatments, as there are no options for him in his country. At this time the medical records are together and will be on their way to Dr. Weise in Cincinnati.

It would be a step in the right direction to make this bill 214 an act. We in Manitoba pride ourselves in our Legislative members and the achievements you all strive towards for all us citizens. Bill 214 would be a step forward for our NF association in saying we are out there willing to give support all the families living with NF, you have someone to turn to because our government believes in us. It is by the grace and acknowledgement by you that will make the difference for NF families in Manitoba.

Mr. Flaherty has now passed on and was a staunch supporter for me on NF when I lived in Ontario. Mr. Flaherty was in Whitby, Ontario at the time. I received much praise in his letters to the Health Minister of that time. He believed in my earnest plight to make NF more known and wanting others, especially doctors to be more educated about NF. Most of them are not. Bill 214 would be a beginning and set us ahead in awareness of NF in our province of Manitoba. We need your positive vote to make this become a reality. I urge you to be a part of history in our great province of Manitoba in passing this Bill 214. You may call upon me with any questions by phone. In your hands and hearts I leave these words of mine. I commend you all for your time and patients in reading my words of truth.

With respect and honour, I shall leave you to your task at hand.

Thank you.

Karen Gail DePratto

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