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Wednesday 28 September 2005

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Mercredi 28 septembre 2005

**Standing committee on
regulations and private bills**

**Comité permanent des
règlements et des projets
de loi d'intérêt privé**

Chair: Marilyn Churley
Clerk: Tonia Grannum

Présidente : Marilyn Churley
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ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

**STANDING COMMITTEE
ON REGULATIONS
AND PRIVATE BILLS**

**COMITÉ PERMANENT DES
RÈGLEMENTS ET DES PROJETS DE LOI
D'INTÉRÊT PRIVÉ**

Wednesday 28 September 2005

Mercredi 28 septembre 2005

The committee met at 0932 in committee room 1.

**HEALTH INSURANCE AMENDMENT ACT
(SUPPLEMENTAL NEWBORN
SCREENING), 2005**

**LOI DE 2005 MODIFIANT LA LOI
SUR L'ASSURANCE-SANTÉ (DÉPISTAGE
COMPLÉMENTAIRE DES NOUVEAU-NÉS)**

Consideration of Bill 101, An Act to amend the Health Insurance Act / Projet de loi 101, Loi modifiant la Loi sur l'assurance-santé.

The Chair (Ms. Marilyn Churley): Good morning, everybody. I'm Marilyn Churley, Chair of the standing committee on regulations and private bills. I call the meeting to order.

We are here today to consider Bill 101, An Act to amend the Health Insurance Act. I'm going to start by asking the sponsor of the bill, Mr. John Baird, MPP, to make a presentation.

Mr. John R. Baird (Nepean–Carleton): Thank you very much, Madam Chair.

I want to thank all members of the committee for travelling—I look around the room, and I think we're all out-of-towners, so I appreciate all of you coming to Queen's Park when the House isn't sitting to consider input on this bill. It means a lot to me, and I know it means a lot to all the presenters who will be here today.

I wanted, at the outset, to make one very strong point with respect to this bill. I'm certainly not approaching this bill on a partisan basis. I think all of us, in all three political parties from every region of the province, want to see this issue addressed, irrespective of our political persuasion. It's in this sort of spirit that I'm presenting the bill today.

I first became interested in this issue more than a year ago, when I was visited by a constituent, Tammy Clark, whom we will hear from later today. Tammy had lost her infant daughter Jenna, a beautiful young girl, due to a condition that was not diagnosed at birth. Had they known about the condition, they might have been able to undertake various diets or other regimes that would hopefully have better protected Jenna.

As MPPs or political actors, we hear from a lot of people who come in really looking at self-interest, some-

thing they want that will benefit themselves. What I find so remarkable about Tammy is that she has no self-interest. Her advocacy, and the advocacy of so many people in this area, is on behalf of others, so that others won't go through the same tragedy, the same grief they've gone through. I find that to be something I have a lot of regard for.

When I began to look into this issue, I discovered, and want to put on the table, that this bill was initially tabled some time in 1999, near the end of the previous Parliament, by our colleague Dwight Duncan. What I have done is simply reintroduced his bill as a method to get this on the public policy discussion table, to get this on the agenda, but Dwight initially tabled this bill.

More than a year ago, I introduced Bill 101, and hearings were set in June for now. It's funny: When we set the hearings in June, there was a lot of interest among many people in the community across Ontario, but we've seen a real snowball of interest, not just from stakeholders, not just from the Ombudsman, but also, I'm pleased to note, from the Minister of Health. His ministry has also gotten involved in this issue in a much more substantive way.

As I understand it, Ontario was a real leader in newborn screening in the 1960s and 1970s. For a variety of reasons that I won't rehash, I think we've lost that leadership. We're now really near the bottom of the pack in Canada and the United States in terms of the number of conditions we screen for in Ontario. We've fallen behind.

I read with great interest the Ombudsman's report yesterday. Before he was Ombudsman, he lived in my riding of Nepean–Carleton. So we've seen two people from Nepean–Carleton being big advocates for this issue, and I don't take issue with much of what he said. What he really does is present a strong case, not just for the government but, I think, for the legislative branch as well, to focus on this issue and make sure that when we move forward, we get it right.

I very much appreciate—I would like to underscore this—the Minister of Health's recent work on this issue. When many of the stakeholders were having a press conference here in the spring, his staff certainly told me that was something that was on their radar screen and that they would be coming forward with a plan on this issue. I think his announcement is good news, and I'd like to acknowledge that publicly.

It might be a bit presumptuous, but I would suggest to all the members of the committee that our task today would really be to hear from stakeholders and reflect on what they have to say, and then look at the government's plan and ask, is it enough? Are we going to screen for enough conditions, diseases and whatnot? How could we recommend that it be done better operationally? Also, the timeline: The simple goal is, how do we see Ontario going from the bottom of the pack not just to joining the pack but regaining Ontario's leadership in this area, which is something we all want to do?

It's a fair issue, I think, to question that this is so complicated, so technical that the expertise is so limited. We're fortunate enough to have some people who work within a mile or two of this place, people in Ottawa and some people in various parts of the province who have some experience. There are also some people with a lot of experience in western Canada and in various parts of the United States. I'd like to see the government's plan, which I think it's safe to say is a good one. I think we can improve it—if we, as MPPs, can approach it from the perspective of what recommendations we might be able to give the minister on how he might make a good plan even better.

I think that too often we get mired in just backing up the plan. I can remember dealing with the Attorney General on the same-sex marriage legislation. We came forward with ideas on how it could be strengthened. He listened and made changes to the bill, which got it passed rather quickly and made it a better bill. I think it was better for the government, better for the opposition and better for the people of Ontario. I'm hoping we can take that same approach here today.

0940

I would want to underline a local issue: There is a significant amount of expertise at the Children's Hospital of Eastern Ontario. CHEO is located in the riding of Ottawa South and enjoys the active support of the local member in Ottawa South and, I think, the active support of all members in eastern Ontario. At some point I'd like to discuss how I think CHEO could play a strong role in this effort.

I see many people here: Judy, you're here from Hamilton; Maria is from southwestern Ontario; and Mr. Brownell is from eastern Ontario. So many services are regionalized, whether in Hamilton, London or Ottawa, but so many services are centred in Toronto. If there are rare and specific things, the expertise comes together in Toronto. Here's an example where geography doesn't really matter; it could really be headquartered anywhere. There are a number of researchers, clinicians and physicians at the Children's Hospital of Eastern Ontario who have expressed a real interest in CHEO perhaps being a centre of excellence for this screening. If the medical devices and equipment that are required too, so we have some redundancy in the system—CHEO would be an excellent place for this to be headquartered. That will be something I will perhaps raise at various points of the presentation.

Again, I want to thank all members for coming. Sorry, I missed another member from Hamilton and another member from London, who I know share my concern about children's health and its regionalization.

I'm looking forward to hearing from the presenters.

The Chair: Thank you, Mr. Baird. We'll now have five-minute statements from each of the other parties. We'll start with the government.

Mrs. Maria Van Bommel (Lambton–Kent–Middlesex): As government, we certainly recognize the need for newborn testing and the expansion of that program, and we're trying to move from worst to first. This is just the beginning of what we're doing. We're moving to become a leader in North America and in the world in this endeavour.

When I was reading the background, I found that it has been 27 years since anything had been done about this. That is a real concern for me as a mother and as the aunt of a young man who has PKU. This certainly has needed to be done, but the decisions we are making as a government have to be science-based.

We're moving, and we made the first step in our announcement of 19 new tests, but this is just the beginning. We are waiting for the advice of our advisory committee on newborn screening to give us more indications of the kinds of tests that need to be done. As I say, as a government, this is just the beginning and we are moving forward.

On September 7, the Minister of Health made an announcement that he was going to expand newborn screening and that 19 new tests for inherited metabolic disorders would be phased in for all newborns beginning in 2006. The new tests would fall under three categories: organic acid disorders, fatty acid oxidization disorders—and that includes the MCAD, which is mentioned in Bill 101—and amino acid disorders.

In addition to expansion of the testing, three new tandem mass spectrometry machines are being purchased to do these. We know that TMS machines have great capacity to do further testing, so we are waiting on the advice of the advisory committee to let us know how to proceed with that.

I certainly appreciate member Baird's recognition of the fact that Dwight Duncan brought this bill forward first and that he has been trying to move this. As a government, we are certainly happy to be able to say we are moving and have acted on that. The Ombudsman in his report has also said he appreciates the fact that we, as a government, are finally moving on these things.

I'm looking forward to hearing from our deputants as well. As a mother and a grandmother, I understand how critical these kinds of tests can be to the welfare and the future of our young children.

The Chair: I will now move on, if it's OK with Mr. Baird, to the third party response.

Ms. Andrea Horwath (Hamilton East): It's my pleasure to be here this morning representing the New Democratic Party at these hearings about newborn screening for inherited genetic disorders.

I think everybody would recognize that medical evidence shows very clearly that early screening makes a huge difference for children with many, many disorders, like sickle-cell anemia and PKU. In fact, infant screening can enable these children to lead very healthy lives by making sure that they get the right treatments to them in the very earliest stages of their young lives.

The Ontario Ombudsman, André Marin, has been mentioned already this morning because, of course, he released his report on this very issue late yesterday. It was interesting that the first person I met walking in this room was a gentleman named John Adams, and of course the first two words in the text of the Ombudsman's report are "John Adams."

I was reading through the report, and there is one very interesting quote that I thought I would raise, because I think it sets a tone for what this is all about today. It says here, "John Adams was 'bang on' in identifying the primary ingredient that has been missing in some government quarters for the past decade or more that parental participation would have supplied, namely, the personification of misery." It's that very misery that we want to make sure we eradicate through doing the right thing around infant screening in the province of Ontario.

I know that John spoke to the Ombudsman, and many others did as well, during the process of the investigations that led up to the report. He said that Ontario performs "like some Third World country" when it comes to newborn screening. That's a sad state of affairs, when in fact things were quite different a couple of decades ago in this province.

He said, "It is a matter about unnecessary illness, suffering and the death of real children," and that "parents have a right to be impatient" when it comes to Ontario providing the testing their children so desperately need.

Of course, in response to the growing public pressure, the McGuinty government has finally promised to increase the number of genetic disorders that it screens for. But as was noted by the Ombudsman in his report, we're far from the finish line, and it's certainly not a time to sit on our laurels. Until this week, the McGuinty government left sickle-cell anemia and thalassemia off its list, even though the US and Great Britain already have programs for universal screening that can be easily applied in the Ontario context. During Sickle Cell Awareness Month in Ontario, the McGuinty government refused to start screening for these conditions. Sickle-cell disorders are predominant in people of African, Caribbean, Mediterranean, Middle Eastern and South Asian descent. Given Ontario's diverse cultural makeup, a cultural makeup that we are always lauding and celebrating, the province should be implementing newborn screening for sickle-cell disorders right now.

The Ombudsman believes that political pressure from parents, doctors, opposition parties and advocacy groups has also helped to turn the tide in Ontario. So we should thank Mr. Baird, first of all, for introducing this bill, and of course all of you for all your hard work in making sure

that this issue gets addressed. But we have to keep the pressure on and hold the government accountable for its promises.

The Ombudsman has found that this government and its ministries have a disturbing "lack of leadership" in this area and have abdicated their responsibility. They have "a general lack of courage to display 'an appropriate sense of urgency.'" All of these are direct phrases from the Ombudsman's report, which is in fact a harsh condemnation of the government's practice and a wake-up call for those of us that are fighting for change.

The Ombudsman reported that "in an October 12, 2004 ministry briefing note to the assistant deputy minister it was again noted that the failure to detect inherited metabolic diseases other than PKU and CH, results in 20-25 deaths annually," deaths that can be prevented if only we do the right thing.

I want to close by saying that we should all keep fighting so that kids at risk of inherited conditions are given the best possible chance for leading healthy lives.

The Chair: Thank you very much. Now we move back to the official opposition. Mr. Baird.

Mr. Baird: I'll think I'll just make one or two quick comments. I just want to thank both members for their comments, and I welcome the member for Lambton-Kent-Middlesex's comments about the government's desire to go from worst to first. I concur with her issue with respect to decisions having some basis in science. That is important.

I guess I'd also just underline something: I would hope that all the wisdom, and there are a lot of great folks at the Ministry of Health and there's a lot of expertise there, doesn't necessarily lie within the Ministry of Health. I think we as legislators can listen to the presentations that we hear today and perhaps challenge them. It's not a partisan issue, I don't think anyone is going to vote on this issue, but if we can make their plan better, I think everyone would acknowledge that there would be a really meaningful role for us as legislators.

0950

I think that too often it comes down to an acknowledgement, and it was just the same when we were in government, "Well, this is what the minister says. We'll just trust him." I know that the minister cares deeply about this issue, and I see some of the members of his staff are here. I know he would welcome our advice and suggestions if they are put forward in a constructive fashion.

I'd also just like to underline, as the Ombudsman did, the work of John Adams. Mr. Adams came to see me as health critic for the official opposition, which I was at the time, to push me on this issue. He was unaware that I'd already tabled a private member's bill on the issue, so his energy and enthusiasm toward this issue are to be acknowledged. I appreciate that, John. Thank you.

The Chair: Thank you very much, Mr. Baird.

CANADIAN ORGANIZATION
FOR RARE DISORDERS

The Chair: We will now in fact move on to Mr. John Adams, who is our first presenter today. He is here representing the Canadian Organization for Rare Disorders.

Mr. Adams, you can take a seat. Please introduce yourselves. You have, as an organization, 20 minutes. If you want to leave time for questions, you're certainly free to do that, but you have a total of 20 minutes.

Mr. John Adams: Thank you very much. Joining me at the witness table today is Dr. Diane Wherrett, who is a senior endocrinologist in the Hospital for Sick Children. She was too busy in her clinical practice to make an appointment for her own time slot, so I've been happy to accommodate her in the cause of the endocrine disorders that are not yet part of the newborn screening expansion plan.

I am a passionate parent advocate for comprehensive newborn screening, and as of last night became the treasurer of the Canadian Organization for Rare Disorders. I just want to say let's make history together today, because this is the first public hearing ever in the province of Ontario into health screening of babies. Thank you, John Baird, PC MPP, for this bill and thank you, Dwight Duncan, Liberal MPP, for the original version in 2003. Thanks through you to all the House leaders, to all the parties, for making this hearing possible today.

I am the father of child with a rare genetic disorder. I am so thankful that my son was spared a lifetime of severe mental disability because Ontario screens all newborns for three disorders: hearing, congenital hypothyroidism, and my son's condition—phenylketonuria, or PKU. PKU is inherited, affecting about one baby in 15,000. Treatment is a special medical diet for life. My Ontario scholar is at class today in university. My kind of newborn screening is inclusive and checks a baby for deafness, which we have been doing since 2002.

Years ago, total strangers set up a universal public health system to safeguard my baby and all the other babies from preventable harm, harm from a disorder I knew nothing about. Like almost all parents, I had never heard of PKU until after my son was born and the condition was detected. Ontario's newborn screening program is 40 years old, and this important universal public health program has saved at least 1,400 babies from preventable lifetime harm.

Private members' public bills are crucial to newborn screening. Forty years ago, NDP leader Stephen Lewis introduced a bill to start newborn screening. Thank you, Stephen, for seeking and obtaining all-party support. Now I have praised every party at least twice. Mr. Lewis looked to innovation in other jurisdictions to keep Ontario babies healthy. He looked to the doctor and scientist in Buffalo, Bob Guthrie, who had a retarded son and who figured out how to screen babies for PKU. Stephen Lewis looked to the state of Massachusetts, the first jurisdiction to figure out how to screen every one of

its newborns. It took Ontario less than two years back then to follow the example of Massachusetts. That was in 1965. Over the decades we lost our way, and governments of all three parties stopped adopting best practices in newborn screening learned by others. Now I've criticized all three parties.

Today, babies die or are damaged needlessly in Ontario because we fell so far behind. Today, Ontario is tied for last. I am heartened that the minister's spokesman here today said that the goal is "from worst to first." I am heartened, and I want to make that real and I want to make that happen fast.

Ontario does not yet have a simple brochure on newborn screening, such as is available in the United States. There is a paucity of information on the Ministry of Health Web site. There's an explanation for that. The special expertise earned by parents the hard way, living day and night with a child with a rare disorder, too frequently not properly diagnosed, has not been fully valued. Parents are the experts in the wasteful odyssey once a child starts to exhibit non-specific signs and symptoms before there is a diagnosis of a rare disorder not identified at birth. If you set out to design an expensive and ineffective health care system, you would start by waiting for a patient to go into crisis before trying to diagnose the problem; you would not spend a nickel or a dime on early detection, so that we can spend thousands of dollars on intensive and acute care later on. That is our newborn screening non-system today, except for the three disorders. It wastes taxpayers' money and it is child abuse caused by government neglect.

Why is early detection so important? There are about 7,000 different rare disorders, but newborn screening is a very small subset of those, where the condition is silent and the disorder shows no clear signs or symptoms while preventable but irreversible harm occurs.

I advocate comprehensive and inclusive newborn screening, which is, sadly, not yet planned, but I hope we have a commitment to do that. The plan makes a start with too few metabolic disorders, but its sin of omission overlooks life-threatening disorders of the endocrine and blood systems. I'm ashamed of the government plan that leaves out life-threatening congenital adrenal hyperplasia and the sickle-cell diseases.

At this point I'm going to ask Dr. Wherrett, an expert in endocrine disorders, to make some comments.

Dr. Diane Wherrett: I'm going to make some comments specifically about congenital adrenal hyperplasia, because that's one of the conditions that I care for. I also care for children with congenital hypothyroidism, which we do screen for in Ontario, and I can tell you about how successful that program is.

First, I'm going to tell you a little bit about what congenital adrenal hyperplasia is. It's an inherited condition caused by the lack of an enzyme involved in making two crucial body hormones, called cortisol and andolsterone. Those hormones help maintain blood pressure and the body's normal levels of sodium and potassium. It's a reasonably common disorder: about one

in 16,000 in populations similar to Ontario, so similar to some of the other conditions we're talking about.

What happens if you don't have these hormones is that a child will initially look perfectly healthy at birth; within the first few weeks of life will begin to feed poorly, lose weight, start to vomit and eventually develop complete collapse; come into an emergency room desperately sick, require admission to an intensive care unit, and hopefully will recover from this uneventfully; but in the meantime, this obviously has been a very sick infant.

We also know that children die without diagnosis. The reason we know is that this is a condition that happens 50-50 in boys and girls, but when you actually look at children who are diagnosed with the severe form of the condition, there are always more girls. I'll tell you a little bit later why it's easy to diagnose in girls and much harder in boys.

The good thing about this condition is that it's very easy to treat. We have replacement hormones that can be bought in any pharmacy that are inexpensive, the treatment works very well, and these children lead perfectly healthy lives once they're on good treatment. So it's not something where we can't make a difference. We can.

1000

The reason girls are diagnosed early is that when this enzyme is defective, we have a buildup of other products in the same pathway, which are male-type hormones. So when girls are born with this condition, often their genitalia look much more male. They're brought to medical attention because people examine a newborn and see that this girl's genitalia don't look like a typical girl's. In fact, sometimes this is so severe that girls are actually thought to be boys at birth, and this also can lead to a delayed diagnosis.

Why screen for this condition? As I've said, these babies look perfectly healthy at birth. They go home from the hospital as perfectly healthy newborns. What happens to those who come in in the usual way we diagnose these babies is that they deteriorate over the first few weeks of life. Usually by two to three weeks of age, they've developed vomiting, they've had multiple visits to their doctor and eventually they get so sick that they land in an emergency room. They have low levels of sodium and high levels of potassium, and as I've said, they require intensive care and a hospital stay of a number of days.

If you contrast that with what happens in Manitoba, in states in the United States, and in Europe and Japan, where screening is done, these babies are generally diagnosed by about seven days of age. They still have normal blood tests, normal levels of sodium and potassium. They can get their confirmatory blood work checked and get started on treatment, and ideally would not even need to be admitted to a hospital but actually just have an outpatient visit. There's a huge contrast in what would happen if we had screening versus what happens now.

The other reason to screen is that this is feasible. This is done around the world. Abnormal hormone levels can be found by two days of age. So you can start screening

any time after two days of age, and we know that it usually takes two to three weeks for the illness to show up. So we do have the opportunity to do the test practically, get the test result back and get the baby treated before the baby gets sick. We know the technology exists around the world to do these tests. Unfortunately, it's not easily done by the tandem mass spec. technology that is already part of this proposal but would require an additional type of testing, but this is done and it's feasible.

I think those are the main points: We really can make a difference by diagnosing this early and preventing illness and by preventing boys who don't show any signs of the condition from dying without ever being diagnosed.

Mr. Adams: The government plan, as announced on September 7, needs some work. The plan would start slowly, increasing the number of disorders in March 2006—six months from now—to an eventual total of 21, plus hearing. It looks like Ontario is going to take until 2007 or 2008 to get to all 21 of the announced disorders. That slow meander into the future is unacceptable.

How many babies will die or be disabled needlessly between now and the March start-up of expansion or the eventual completion of the 21? It's too little, too late and too slow. Saskatchewan screens babies for 29; Quebec screens 90% of its babies for 28.

But the best practices today are not in Canada, just like Stephen Lewis pointed out in 1965. Few would think to look to the state of Mississippi for best practices in health care, but today a baby born in Mississippi is screened for 57 of these rare disorders. When will Ontario innovate and catch up with Mississippi in this field?

A baby born close to here, in Buffalo, today is screened for 44 conditions by the state of New York at no charge to the family. They added 33 conditions this year and plan to add more conditions next year.

Governor Arnold Schwarzenegger's health department screens 500,000 babies a year for 75 conditions in California and sends its overflow and tricky problems in blood disorders to a special hospital lab in Hamilton, Ontario. This fact is little known to Queen's Park policy-makers.

There is a standard of care in this field, and it is in the three-year study by the American College of Medical Genetics. I have it here with me; it was published in April. Well-funded by the US government, they examined 84 rare disorders and recommended that 54 be included in comprehensive newborn screening, given the current state of knowledge. The report is only 329 pages long, and I'm happy to share it with you.

This report and its recommendations are endorsed by the American Academy of Pediatrics, the American College of Obstetricians and Gynecologists, the American College of Family Physicians, the US national association of genetic counsellors and, most importantly, by the US federal advisory committee on newborn screening. They have a national consensus. Mississippi was the first jurisdiction to adopt this approach, as Massachusetts was the breakthrough leader 42 years ago.

Not a single Canadian or Ontario medical organization has taken a public position on comprehensive newborn screening. We are out of step. Last night, the organization I represent, the Canadian Organization for Rare Disorders, unanimously adopted the following: "CORD urges all provinces and territories to implement, as soon as possible, comprehensive and inclusive newborn screening within each jurisdiction at the highest prevailing international standards." From worst to first, you might say.

The Ontario plan, as it is, is too slow in getting going. I advocate a quick-start strategy. It will take time, I acknowledge, to get up to speed in Ontario because we are so far behind. But for the sake of saving babies' lives and preventing lifelong damage, we can swallow our pride a little bit and buy the necessary services from outside for a few months as a transition measure until we can build up Ontario's capabilities. Babies will die or be harmed needlessly every week that slips by. It's a matter of conscience.

There are lab services available to handle all Ontario newborns for the full ACMG panel starting tomorrow, not in March, at a cost of no more than US\$35 per child; that's what we're talking about. The government should really look at this with a sense of urgency.

The Ontario plan says its list of 21 disorders will identify one case in every 2,000 babies, but the American College of Medical Genetics plan says its list of 54 disorders will identify one case in every 800 babies. Ontario has about 130,000 births a year. The difference between the two plans is about 100 babies a year. That means two dead or damaged babies every week, while we fail to lead the rest of Canada.

There is no national strategy or process for newborn screening in Canada, and I hope in due course to work on the federal side of this with the chairman and the sponsor of the bill in their new positions in the House of Commons. There is a national process and a recommended strategy in the USA; there are no federal activities or funding for newborn screening in Canada. The word "screening" does not appear in the Canada Health Act. The government of Canada contributes not one penny to any province or territory for the cause of newborn screening. I will say that Carolyn Bennett is Canada's Minister of State. I and others have asked her to seriously consider becoming a national champion for newborn screening. I hope she does; she was the doctor who delivered my PKU son.

There are major federal activities and federal funding in the USA from the administration of George W. Bush. I participate in meetings of the US federal advisory committee on newborn screening. Because of my interest as a parent, the Office of Rare Diseases at the US National Institutes of Health has invited me to participate in an international effort to foster collaborations among researchers, health care providers, parents and lay advocates. Other governments welcome the active participation of parents in newborn screening; we don't. We don't have an office of rare diseases anywhere in Canada;

we don't have a policy for orphan drugs and other treatments for rare disorders. We operate like a Third World country in this respect.

The process the government used to seek advice is flawed, and it lacks openness and accountability. That's one key reason why the results are not acceptable so far. You have a chance to fix that today. Give us an advisory and oversight process that is open and inclusive.

The health officials who make the administrative rules have lost sight of something. The babies don't belong to the government and they don't belong to the doctors. Parents are here today asking for a voice at the table, to participate as equals in giving advice and providing insight, oversight and feedback.

1010

I beg all political parties to work diligently together on this life-saving and brain-saving issue. This is a public health emergency. The gaps in newborn screening in Ontario mean we have a silent Walkerton tragedy repeated every year in terms of health, human costs and suffering.

Newborns are our most vulnerable population. Leave no baby behind today who can be saved by comprehensive and inclusive newborn screening. Cherish and protect every baby. Make us proud to live in Ontario. For God's sake, catch up to Mississippi. Thank you.

The Chair: Thank you very much, Mr. Adams and Dr. Wherrett; I hope I got your name right. We have literally about a minute left for questions. What I'm going to do is ask Mr. Baird in this round, if people are agreeable—

Mr. Baird: I have met with Mr. Adams and am in regular receipt of all his e-mails, so if there is a member of the committee who would like to ask, I'd certainly yield my time.

The Chair: Would anybody like to take the minute to ask a question? No. It means you must have been very succinct. Thank you very, very much for your presentation.

HEMOGLOBINOPATHY GROUP OF ONTARIO

The Chair: We now move on to—let's see if I get this pronunciation right—the Hemoglobinopathy Group of Ontario, McMaster Children's Hospital, Hamilton Health Sciences, and Dr. Isaac Odame. Doctor, if you could—you are a doctor?

Dr. Isaac Odame: I am a doctor.

The Chair: Please state your name for the record. You too have 20 minutes.

Dr. Odame: My name is Isaac Odame. I'm a pediatric hematologist/oncologist at McMaster Children's Hospital in Hamilton. I'm here representing the Hemoglobinopathy Group of Ontario, a group of professionals, doctors and nurses who treat patients with inherited blood disorders.

Before I introduce my topic and educate the committee about this disease, I just want to give you a bit of background as to why I think the process of advising the

government is flawed. If you look at the background to the current advisory committee, it was set up solely because of a crisis in the old PKU testing. The testing is antiquated, so antiquated that out of 10 positive results, nine are false. The need to change that technology was not actually on the government's initiative but because the company that provides the reagents is going out of business because, really, it's an antiquated technique and not many people are subscribing to those reagents.

So the timeline for the government's initiative was started because of a crisis; it wasn't because they perceived the need for a comprehensive program. Because of that, the committee that was supposed to advise the government was a very narrow committee. As Mr. John Adams has already outlined, you need an all-inclusive committee that has all the interest groups at the table, including parents and advocacy groups, so that you can have a comprehensive program. My preamble to this is that the advisory committee that the government is depending on at this moment I think lacks legitimacy to be able to provide comprehensive advice.

Having said that, the American College of Medical Genetics produced its list of disorders under these headings: (1) disorders of fatty acid metabolism, (2) disorders of organic acid metabolism, (3) disorders of amino acid metabolism, and (4) disorders called hemoglobinopathies. It is lamentable that when the government announced its expansion program, it dropped the hemoglobinopathies. That's what I'm going to talk about today.

What is sickle-cell disease? It is an inherited blood disorder seen mostly in people of African, Caribbean, Indian, Mediterranean and Middle Eastern descent. As you can see, it's a disease of people of ethnic minority. I'll make you aware that a recent caption in a leading newspaper said that ethnic minorities in the cities of Toronto and Vancouver would top 50% by the year 2013, so this is no longer a rare problem. The ethnic dimensions of immigration to this country reflect that these disorders are going to become even more important: 75% of new immigrants to Canada come from ethnic groups in which these globin disorders are prevalent.

There's a single mutation, a single change in the molecule or the protein called hemoglobin, which is really the protein that gives blood its red colour. The function of this protein is to carry oxygen from the lungs and deliver it to the tissues. What happens in sickle is that there is an alteration in the protein, and instead of the protein remaining a single unit to be able to carry out this function, it forms gels, and the gels distort the red cell from its normal doughnut shape to a sickle shape. This abnormal shape really leads to a blockage of the blood vessels, and as the small blood vessels are blocked, there's starvation of oxygen to the tissues. Eventually, every organ in the body is affected by this blood disorder: brain, lungs, heart, kidneys, bones and joints, liver, spleen, the eyes. Oxygen is the fuel that every single cell in the body needs to maintain viability.

This is the abnormal shape you see. A normal red cell should be a nice, rounded doughnut shape able to squeeze its way through the blood vessels and off-load the oxygen to the tissue. When it turns into that kind of shape, it is no longer able to do that, and that leads to blockage. This is where the name "sickle" came from. It describes the abnormal shape of the red cell, hence the name sickle-cell disease.

It was the first disorder in humanity in which the cause was attributed to a protein. That was as early as a few years after the Second World War that this discovery was made. Not only that; it was the first disease for which the genetic cause at a DNA level was identified. I want you to focus here. The building block for that unit in that protein is 146 amino acids. At position 6, what happens—you need the genetic blueprint; that gives the message. It's a G, an A and a G; that should produce this amino acid. What happens in this disorder is that instead of the A in the middle, you have a T, and that gives a message to make a different amino acid called valine. This one single mutation in a 146 block of protein causes all the havoc. It makes the cell unable to carry oxygen.

What is the history of newborn screening for this disorder? As early as the 1960s, doctors had realized that patients with this disorder have an increased susceptibility to infection, in particular one called pneumococcal septicemia. It's devastating in that the patient is ill for only a few hours before they die, usually less than 12 hours, with a case fatality of 35%. So the potential benefits of screening for the disorder were actually identified as early as the 1970s, but there was no evidence to really point doctors to the need for screening.

Another complication that these children have is that suddenly the blood pools in an organ called the spleen. So the blood is all pooled in the spleen, and the patient gets short of blood supply and goes into shock and heart failure. This can be so sudden: A child is well the night before and suddenly is gasping for breath.

It was not until 1986—somebody has mentioned science, and the Holy Grail of clinical science is a randomized, placebo-controlled clinical trial. That is, you run the trial, you don't assume you have the answers, and it's blind for the patients and the doctors; they all think they are taking the sample, but one half is taking a placebo and the other half is taking the drug. That's the Holy Grail of clinical science.

1020

This study, which was published in the prestigious *New England Journal of Medicine* in 1986, was a study randomizing children with less than three years with this disorder into two groups: One group received penicillin to prevent infection; the other group received a placebo. They were blinded, so you could not be biased. Of the penicillin group, two had an infection; whereas 13 had an infection in the placebo group. Not only that: Whereas there was no death in the group that took penicillin, three deaths occurred in the group that took the placebo. There was an 84% reduction in the incidence of infection. This study had to be terminated eight months early because it

was no longer ethical to continue the study; as you can see, deaths were occurring in the group that was taking the placebo.

This study was published, and soon after it was published, there was a National Institutes of Health consensus that developed a plan that newborns should be screened for sickle-cell diseases and other globin disorders.

Newborn screening, when linked with timely diagnostic testing, supplemented with parental education and comprehensive care, markedly reduces morbidity and mortality from sickle-cell disease in infancy.

It is so common. These disorders occur in 5% of the world's population: 1.92% will carry the sickle gene and another 1.6% will carry the thalassemia gene. All over the world, out of every 1,000 births, about 2.4 will have severe forms of these disorders. So they are not uncommon disorders at all. We talk about rare disorders; these are not rare disorders at all.

This is the staggering figure: Among people of black origin, one out of every 10 black Americans carries the gene. About 10% to 14% of people of Caribbean origin carry the gene. Of people of direct African descent, one in four carries the gene. The risk of sickle-cell disease in a person coming from Africa is one in 100. You hear figures being quoted of one in 15,000, one in 20,000. This is one in 100. If you are of African American origin, one in 400 people carries the severe form of the disease.

What about Ontario? Based on laboratory data, out of 100,000 births, 13.2 will carry this mutation, which means that in Ontario, using conservative estimates, up to 20, 25 children are born with sickle-cell disease every year. The prevalence of this disorder among a population of 100,000 would be about 6.4%, which means that we have over 1,000 patients today in Ontario with sickle-cell disease.

This has already been outlined, but I'm showing it in a visual form. Ontario was a leader in catching up with newborn screening. Soon after the introduction of newborn screening for PKU, Ontario was only two years behind. We caught up in 1965. For newborn screening for congenital hypothyroidism, which my eminent colleague talked about, Ontario was in within four years. Newborn screening for sickle-cell disease has been done in most jurisdictions in the United States and the UK between 1989 and 1992. What about Ontario? Not yet. We are decades behind. This is simply not acceptable.

This is not the fault of experts. This is not for lack of advice. The ministry's own advisory committee and the chairman of that committee—the eminent colleague who is here today and will be speaking later—advised the Ontario ministry at the time that congenital adrenal hyperplasia, which my colleague spoke about, and sickle-cell disease should be added to the screening panel. Thirteen years later we're still talking about it.

We talk about science. The science is there; the expertise is there; the advice has been given. It's one thing to get advice; it's another thing to implement it. This is where the government of Ontario has failed its

people. That is really sad. If I were a doctor and if I failed my patients this way, my licence would be at stake, but it's OK if policy-makers ignore it. I think this is unacceptable.

The Agency for Health Care Policy and Research recommended universal screening. Therefore, states like Utah, Dakota and Idaho, where the percentage of ethnic populations with this disorder is far lower than in Ontario, are compelled to universally screen for this disorder. All states in the United States, except for New Hampshire, do universal screening at the source where every child is born. In Canada, the advisory committee on screening for inherited disorders recommended it. In 1994, the Canadian Task Force on Preventive Health Care also recommended that screening should be done. So there's no need for more advice on sickle, and I get impatient. I've been invited to join the committee to provide advice that has been there for decades in the *New England Journal of Medicine*, in a randomized, placebo-controlled trial, the best evidence of clinical testing you can have. Let's not vacillate and ask for more and more advice. The advice has been there; let's implement it.

The testing is not sophisticated. We've heard about tandem MS. Tandem MS is a sophisticated technology. The technology for testing for sickle-cell disease is much, much simpler. It has been here with us for decades, and we can do it even today.

What do you do for a positive test? Within two months of age, you educate the parents about medical evaluation, how to treat fever when the child is ill, and signs and symptoms of the pooling of the blood in the spleen, because it's the mom who can save her child by discovering that a spleen is suddenly enlarged. We teach them how to feel for it, and they can rush their child to emergency and ask for a blood transfusion immediately. Penicillin: the cheapest antibiotic you can get. It does not cost; it's as simple as penicillin.

Pneumococcal vaccination: I have to give credit to the Ontario government, because the Ontario government has decided that every child born in Ontario should be vaccinated against pneumococcal infection.

Comprehensive care: What does comprehensive care mean? It means that you screen, follow up, confirm the diagnosis, provide centres of excellence to treat the disease and to manage it, and you evaluate the entire system. This is what we are asking for. It is not asking for the moon; it is a simple test.

To add insult to injury, one of the best-equipped reference laboratories, where jurisdictions in the United States send their confirmatory testing to, is based here in Hamilton, at McMaster. It's a laboratory that is sponsored and financed by the Ministry of Health.

The Chair: Thank you very much, Doctor. We have about four minutes for—

Mr. Baird: On a point of order, Madam Chair: Might I suggest that, given this isn't a partisan issue, rather than going around from party to party, you just ask members of any of the three caucuses for questions.

The Chair: If that's OK with all members, certainly. We've got about four minutes. Anybody? Ms. Horwath.

Ms. Horwath: Thanks, Madam Chair. I have one question. First of all, thank you so much for the presentation. It was very powerful and makes one think, "What the heck are we doing?" You had indicated that the process has been flawed and the previous speaker indicated that the process has been flawed. But I get nervous that that just justifies another whole new process that is then going to continue to stall Ontario from moving forward. So from this point, what would you recommend, Doctor, in terms of what can be happening immediately?

Dr. Odame: My recommendation would be an immediate expansion of the committee to bring in an endocrinologist, as my eminent colleague just said, to bring in an expert in blood disorders. Actually, this is a public health issue, and you need experts in public health. You need parents and advocacy groups. You need people who are experts in education, because it's a public health issue. The committee, as it is now, is made up solely of metabolic experts, specialists in metabolic disorders. This is a public health issue, and you need an all-inclusive committee. I think they can do that immediately, expand the committee. I agree that you don't want to stall the process by saying that we're reconsidering the committee, but you can expand it immediately and make sure you have the best possible advice you can get.

The other point I want to make is that we are so late in joining this area that it makes no sense to reinvent the wheel. Jurisdictions are far ahead of us, and their expertise has been accumulated. What we do is to take it from where they are. It's already done. Committees have been set up. Let's look at the way they are constituted and do the same so we can move immediately from worst to first.

1030

The Chair: Ms. Van Bommel.

Mrs. Van Bommel: Thank you very much for your presentation. It's wonderful to have—this is the second time this morning that mention has been made of McMaster in Hamilton and that they have the facilities there. I wasn't aware of it. As you say, it's very heartening to know we have that expertise here already.

One of the things I do know, though, is that the test for sickle cell is already available, and parents just have to request it. Even the cost of the testing is paid for by the Ministry of Health. I understand the urgency about making it mandatory, but are parents aware of the fact that this is available to them? How much awareness have we got that parents really only have to ask for the test and they can have it, that there's no cost to them for this? I'm just wondering about the education and awareness process around this for new parents.

Dr. Odame: Certainly, if I have a patient from that ethnic origin, I ask for testing on that. So my patients are all tested.

Mrs. Van Bommel: You take the initiative as the family doctor.

Dr. Odame: That's right. You ought to know that there is only one hospital in the whole of Ontario—there's coverage in our hospital, and I have to congratulate our hospital. Our hospital took the decision that because of the population, every newborn, whether they are white, black or yellow, gets their blood tested for sickle-cell disease, and they've been doing this for six years. So one, single hospital took the challenge and decided to do screening. That shows you that it can be done.

The lack of education is also very prominent, even among our own professional colleagues. My group, which brings together all the experts in their field, has a challenge to educate doctors, nurses and health care professionals about this disorder so there will be far more awareness in the public so that every person who needs to be screened can be. But you can circumvent all this by mandating screening, which is what Congress did in the US.

The Chair: Mr. Ramal, if you could ask a very quick question.

Mr. Khalil Ramal (London-Fanshawe): Actually, my question has been asked, but I want to take the opportunity to thank Dr. Odame for his presentation. That's it. Thank you.

The Chair: Just very briefly, Mr. Baird.

Mr. Baird: One of the things that comes to mind for me is that it's almost the KISS principle, with science: How do you keep it simple? By having almost a conveyor belt of screening, it's done, it's universal, and I think it probably would be a lot cheaper, in the end, than on a test-by-test basis. That's one of the things that I find so compelling.

The Chair: Thank you very much for your presentation, Doctor.

SICKLE CELL ASSOCIATION OF ONTARIO

The Chair: I would now like to call on the Sickle Cell Association of Ontario. Thank you very much. It was a pleasure meeting you earlier, before the committee meeting started. If you could state your names for the record, you have 20 minutes for your presentation.

Ms. Dotty Nicholas: Thank you, Madam Chair and committee members. My name is Dotty Nicholas. I'm a registered nurse. I'm the president of the Sickle Cell Association of Ontario and I'm also the nurse coordinator of the sickle-cell satellite clinic at the Rouge Valley Health System, Centenary site.

Since February 1981, the Sickle Cell Association of Ontario has been serving the community as a recognized voluntary agency which endeavours to optimize the quality of life for individuals and families with sickle-cell disease. The care and comfort of individuals and families in our community are our primary efforts.

Some of our main objectives and activities include increasing public awareness of sickle-cell disease; educating the population and health care practitioners about sickle-cell disease; liaising and collaborating with schools and other agencies; advocating on behalf of

individuals and families regarding issues arising from sickle-cell disease. We provide counselling to individuals and families with sickle-cell disease. We support research programs and advocate support for newborn screening, and screening of the population at large for each person to know what their red blood cell status is, to enable them to make informed choices. One of the many primary concerns of the Sickle Cell Association is the lack of a newborn screening program, both at the local and universal level in the province.

The Sickle Cell Association has over the years made several representations to the government of the day regarding testing for sickle-cell disease, for a universal newborn screening program. In 1993, the Sickle Cell Association wrote to the then Minister of Health, Frances Lankin of the NPD, with no response. In 1997, the Honourable Jean Augustine was the first member of Parliament to bring the awareness of sickle-cell disease to the attention of the government, but no action was taken. On April 21, 2004, a letter was sent to the present Minister of Health, the Honourable George Smitherman, to which the Sickle Cell Association has had no response.

On an individual basis, we cannot overlook the contribution that Dr. Bob Frankford has made and continues to make toward the improvement of the health care system for the treatment of sickle-cell disease.

With all these approaches to the government and given the diverse population of Toronto and Ontario, it would seem a foregone conclusion that testing for sickle-cell disease would become mandatory.

I am a registered nurse who works at the Centenary Health Centre. I also give counselling to parents whose child is diagnosed, either by coincidence or by a crisis. This concern is particularly relevant because of the devastation of sickle-cell disease on a newborn child's life if left undiagnosed. Many of these children are left undiagnosed until a crisis occurs. Newborn screening for sickle-cell disease is an effective way of reducing morbidity, mortality and disability in infants born with this disease.

Infants born with sickle-cell disease are at risk of complications such as sepsis; severe infection; acute splenic sequestration, where you have a pooling of exudate in the spleen; and acute chest syndrome, where there is bacteria built up in the lungs. Penicillin prophylactic treatment can be initiated at birth if diagnosed at this early stage. There can be a dramatic change in life expectancy of children with sickle-cell disease if early diagnosis is made.

As the Sickle Cell Association embarks on this important initiative to bring awareness of the need for this important service and diagnostic intervention, it is my hope that today this message will receive the attention of the government, which will listen to our concerns and take some action. This important step is a great one today in the lives of those who are at risk of sickle-cell disease or any other genetic or metabolic disorder that can be diagnosed and treated at birth.

I'd like to recognize all the other agencies and individuals who are here today in support of universal newborn screening.

1040

The Chair: Thank you. Are you going to make a statement as well?

Ms. Lillie Johnson: Yes, I will. My name is Lillie Johnson. My background is both teaching and I am a person committed to community health nursing and health promotion. I also served at the Ministry of Health as a maternal and child health consultant and in that position I was able to see the importance of what education and health promotion meant to parents and the population at large.

I am really the founder of the Sickle Cell Association. That was because of what I saw happening, especially to the parents and individuals who could not get any good medical treatment and, more so, because I am committed to prevention.

I got my information from Graham Serjeant, who came up here in 1993, having started newborn screening in Jamaica in 1970. So you see, I want you to do a little bit of qualification about what the Third World is doing, because they started it long before you. As well, I want to tell you that they realize the importance of having newborn screening. Graham Serjeant has visited with us here at all our annual conferences, except for a few, to impress on us the real meaning of what it is to have newborn screening.

We also had a good friend at McMaster University by the name of Dr. Chui; he's now gone to Boston. You see, we keep going back to McMaster because we're not getting any help, after all the appeals from the doctors here to the University of Toronto. So we were like a lone wolf here, trying to say, "Let us do something about sickle-cell disease, although it cannot be cured." On that score, Dr. Chui informed us, "You leave the medical part to us; you go educate the families," and that is what we have done.

Today is a great day for us, to see so many people, parents and relatives who are so interested. Since that report came out and we were not among the 19 who should have testing done, they have been speaking out. That is a great day for us, so we don't need to go back and reinvent the wheel. The education is there. We are going to continue to do education on the importance of newborn screening, not only to the people and parents, but also to the nurses. I just must say to the doctors that another good reason for this great day is that at last we have some doctors who have come out and want to be counted, to speak up for sickle-cell disease.

I am really a happy person today to see a meeting like this, after nearly 25 years. Please let the day go on and the years go on. We don't need to go back and do research on this and that; the figures are there. People are suffering. That is my word for today. Thank you.

The Chair: Thank you very much, Ms. Nicholas and Ms. Johnson. We have lots of time for question. Who would like to jump in?

Mr. Baird: I'll just make a comment: very well said on both your parts. I think it is incumbent upon all of us, having heard everything you and the previous speaker said with respect to the timeline and the way we go on, to say, "What are we going to do about it today?"; not what we are going to do, rehashing the past, but what can we do positively today on this issue. I think that's the thing we've got to focus on. So thank you very much for your presentation.

Mr. Jim Brownell (Stormont-Dundas-Charlottenburgh): First of all, I would like to say thank you for your presentation, the excellence of it and the excellence of the two we've already had this morning. You have reaffirmed the need for what's being done in this province, and that is to move forward from worst to first. I think that was clearly stated by my colleague down the table, that we need to make that effort and make it as quickly as possible so that those people who are out here, who are supporting and suffering, do get the treatment. We heard from John Adams that it should have happened yesterday, that kind of idea.

We heard from Dr. Isaac Odame about what this sickle-cell anemia is all about and what should be done, and the same from your presentation. We have a very good understanding of the diagnosis; there's just one little question on the treatment. I did hear in Dr. Odame's presentation about blood transfusion very quickly. I think that's part of it. And I heard in your presentation about penicillin. How quickly does the treatment resolve problems in babies and these young people who have been diagnosed? We heard that the blood should be a doughnut shape and then you have the sickle cells and the odd shapes and whatnot. How quickly does it happen and do they turn to doughnut shape? I'm just curious. I don't know a whole lot about this. I spent 32 and a half years teaching in elementary school. I'm not in the medical profession, so I'd just like to know.

Dr. Odame: Can I answer that question?

Ms. Nicholas: Yes.

The Chair: We have three other people who want to ask questions, so welcome back. Would you like to state your name before you answer the question.

Dr. Odame: My name is Isaac Odame. I'm a pediatric hematologist.

That's a good question. It's a genetic disorder and you're not going to cure it, as I said, by bone marrow transplantation. People say there's no cure; we know there is a cure. The future for us is gene therapy. This has been piloted in animals and we are hopeful that gene therapy will be the future. But let's leave that aside.

It's curable. It can be fixed by bone marrow transplantation. You can avoid early deaths from infection by providing antibiotic prophylaxis and vaccination. You can avoid early death by educating the mother, because these children don't have anything about them that shows they have the disease. The very first time the parents know they have the disease, the child may have sequestration crises, the blood pooling in the spleen which I described, leading to shock and death, or they have

severe pneumococcal infection which leads to death or severe illness. These early causes of death are preventable by simple techniques: education, penicillin, vaccination. It's a no-brainer.

Ms. Horwath: I have to say that as a person who was not only raised in Hamilton but had my child at McMaster University, it was good to hear some of the great things that are happening at the medical centre there.

I wanted to focus a little bit on what Ms. Nicholas and Ms. Johnson had to say about the fact that the children they deal with are ones who, by coincidence or because of crisis, are determined to have sickle-cell disease. I guess it's similar to what Dr. Odame is saying in terms of the fact that it's not something we're necessarily looking to cure but rather to reduce the impact on families and children and increase their wellness over their lifespan.

It brings me to the issue that I think Ms. Johnson was raising about the gentleman who came from Jamaica in the 1970s. It seems to me that because of the propensity of the disease to occur in Jamaica, they've already achieved best practices, which in fact isn't education, or educating parents to make sure they get their children tested because they happen to be in one of these particular ethnocultural groups, but universal screening. So if it's necessary in Jamaica to have universal screening where the propensity for the disease is so high, then it would seem to be even more so in Ontario.

1050

Why is it, in your opinion, that legislators keep talking about, "Well, we just need to educate people so that they can then go and get tested," or "We just need to let the community know, and then the community can take it upon themselves to have their children tested," because the likelihood is that they're in a group that's more likely to be diagnosed?

Ms. Nicholas: There are many individuals who have the sickle-cell trait and just don't know they have the trait. When these individuals get married and have a child, the child may be born with the disease and they don't know.

Recently, I ran across a baby who came into our institution—this baby was three months old—and the only thing the mother noticed was that he was having constant high fever. She had no education on sickle-cell disease. So she brought the baby to see the doctors, and his fingers and toes were swollen. The doctor who saw the baby, because of his knowledge, knew right away that this was sickle-cell disease. Now, if this mother did not take this child to the doctor, this child could have developed other complications, or she could have had this baby at home and treated him with Tylenol while an infection was brewing, which can cause death.

Ms. Horwath: So just for confirmation, the best practice is screening at birth for this disease and not trying to doff it on to the individual responsibility of the parent or the family.

Dr. Odame: I will just comment on that. There's one dictum in public health, and that is, if a condition is devastating and will lead to death, you don't place

primary responsibility on either the mom or society to do it. That's the whole point of screening. It's the same with PKU or congenital hyperthyroid disease. You pick it up by mandating it, and that's what we have to do.

Ms. Johnson: May I just give you a few examples that have occurred because infants were not screened at birth? We have twins in our caseload. They were born in a reputable hospital, very ill, premature, by Caesarean section. The mother was sent home with one baby who was very ill; the other was sent on to the maternal grandparents. That child was in and out of hospital, misdiagnosed, although they knew the mother was carrying the trait and the father was carrying the trait. They were 19 months old before the twins were diagnosed with sickle-cell disease.

The Chair: Thank you. We are out of time. However, we're a little ahead of schedule, and because I consider you to be trailblazers in this area, I'm going to give people a little extra time. I have questions from Ms. Marsales, Mrs. Van Bommel and Mr. Baird. I'd ask people to be very brief, however.

Ms. Judy Marsales (Hamilton West): Rarely a day goes by when I'm not singing the praises of McMaster, and today you've reinforced my pride in McMaster. Lillie, your passion and your articulate presentation speak volumes for the medical leadership that's being demonstrated on a daily basis at McMaster. Of course, as you know, it's in my backyard.

I welcome you here. I thank you for your dedication and for your interest. All of you, thank you.

Mrs. Van Bommel: Thank you, Chair, for the indulgence. I just want to make a quick comment. I want to first of all commend all of you on your dedication and determination. As Lillie has said, it took 25 years. Many of us have had to fight on certain fronts for certain things, and there is a real dedication that's needed for that. I commend all of you on that.

I certainly want to let you know that you've been heard. Premier Dalton McGuinty said just this week that he fully expects that the advisory committee on newborn screening will recommend mandatory sickle-cell testing. I know that all of you are looking forward to that. Thank you very much for your presentation and your dedication and determination.

The Chair: Mr. Baird.

Mr. Baird: Just three points: I'd have to say to Ms. Marsales that I briefly worked at McMaster's faculty of health sciences before I was elected, so I will sing its praises as well.

I'm a big believer in personal responsibility: that people can make choices and bear the consequences. If I choose to start smoking cigarettes today and I develop lung cancer, there's a certain amount of personal responsibility there. If I choose to go parachuting and am injured, at the end of the day, that's life in the big city. But I'll tell you, young infants, on a scale of one to 1,000, are a zero on the personal responsibility side. That's why it's so important for us to acknowledge that, particularly when it comes to children's policy. Perhaps

with no child more than an infant is that case more relevant.

I'm struck by your presentation when you talk about what Jamaica is doing. I think that there is a tendency in government—and it's not a partisan tendency—to say, "Well, how do we address this issue?"

I remember when I was Minister of Social Services we were looking at literacy testing to help those who were unemployed. We were going to set up a panel to develop a request for proposals so that we could have experts develop a test to determine whether people can speak English, and then that would come back and we would consider the contract, and there would be a panel to look at the considering of the contract, and then we would award the contract and it would go out. I said, "Surely to God, there's got to be somewhere in the world that has some sort of test on the English language that we could just steal." We actually got it from the Niagara region. The Niagara social services branch had a great test. We phoned them up: "Do you mind if we use this?" "Go ahead; photocopy it." We had it in 24 hours.

That's a rather simplistic notion but, again, we heard from you, Doctor, that 49 states are testing for sickle cell. I agree with what Ms. Van Bommel said, that the Premier has certainly indicated hope that the panel will recommend it. I would think we could just pick up the phone and phone Massachusetts ourselves and do what they're doing. It's not rocket science. I think that too often in government we try to reinvent the wheel and have panel after panel after panel reinvent the wheel, when it really is simple. People say, "It's just never that simple." Well, sometimes it is.

You made a powerful statement, and I appreciate it.

The Chair: Thank you very much for your presentation. On behalf of all of the committee, I can say that we want to thank you for your pioneering work, your trailblazing work, and for coming forward here today.

WILLIAM HANLEY

The Chair: I'd now like to call on Professor William Hanley. Good morning, Professor Hanley. If you could state your name for the record, you have 15 minutes total as an individual. You can reserve some of that time for questions or use it all up in your statement.

Dr. William Hanley: I'm William Hanley. I'm a professor emeritus at the University of Toronto and an honorary physician at the Hospital for Sick Children in Toronto. I was the director of the phenylketonuria, or PKU, program at Sick Kids Hospital from 1963 until 1997. I was a member of the advisory committee—appointed by order in council, by the way—to the Ministry of Health on newborn screening from its inauguration in 1968 until 1999. I was the chair of that committee from 1990 to 1999, when I resigned.

I've given you a handout of four pages, and it's going to take more than 15 minutes to read that, but I just want to make two or three points. When you get to be an old guy, you reminisce and you talk about history.

The history of screening for PKU in Ontario: When I was asked to take over the PKU program at the Hospital for Sick Children in 1963, there were about a dozen and a half patients involved. Most of the children were retarded because they'd been diagnosed late. There was no such thing as newborn screening at that time. The treatment had just been developed in the late 1950s by Dr. Horst Bickel in Manchester, and later in Heidelberg, and we were just starting to treat these patients.

1100

Reviewing the literature, it was absolutely obvious that what we had to do was screen them as newborns, because treatments started after two or three weeks of age are too late: They're permanently—often profoundly—retarded. So Dr. Hugh Cameron and I—Hugh Cameron was chief of pediatrics at East General—went to the Minister of Health and said, "Look, we've got to start universal screening for PKU." They looked at us and said, "Are you crazy? There's no way. Go away and don't bother us."

Fortunately, we had a very strong PKU parent association. The reason they were strong was that they knew that this mental retardation that their children were suffering from could have been prevented had newborn screening been available to them. They were a very active and strong-willed group. They went to the top; they didn't start at the bottom like we did. They went to the politicians, Stephen Lewis in particular, and several others. They went to the media, and we got a lot of press and television coverage. Then we got a private member's bill introduced for PKU screening by Stephen Lewis. Lo and behold, on June 1, 1965, newborn screening for PKU started in Ontario, and there have been over 400 cases diagnosed and mental retardation prevented.

Does this story sound familiar? History repeats itself.

Mr. Baird: I'm no Stephen Lewis.

Dr. Hanley: The doctors had no power, but the patient advocates did. That was my observation.

In 1991 or 1992, the advisory committee realized that Ontario was surrounded by jurisdictions that screened for up to eight diseases. We were still stuck at two. Under the auspices of the public health branch, we invited experts from the United States and Canada to come to our meetings and present their field of expertise regarding newborn screening. We looked at sickle-cell disease, cystic fibrosis, congenital adrenal hyperplasia, muscular dystrophy, toxoplasmosis, maple syrup urine disease, galactosemia, biotinidase deficiency, homocystinuria, neuroblastoma and others.

We made a decision that we would recommend to the ministry through the public health branch that screening be started for congenital adrenal hyperplasia and sickle-cell disease. I've got a whole file drawer full of files on sickle-cell disease. We spent many, many hours and much effort to try and get this off the ground. We even had a meeting with the Deputy Minister of Health. At that meeting, the endocrinologists scuttled us with congenital adrenal hyperplasia, saying they weren't ready for that yet. So we forged ahead with the sickle-cell

screening recommendation, but we got nowhere. For many complicated reasons that we can't go into here, it finally died in 1998. About that time, Tandem MS, TMS, became a viable, precise, wonderful technology for screening the diseases that have been listed, so the committee's interest switched to getting TMS going.

The final thing, a little story I want to mention, is about Robert Guthrie, whom John Adams mentioned. Robert Guthrie had a son who was retarded. He didn't have PKU; I think he had fragile X, actually. In any event, he had a niece in Chicago who was diagnosed with PKU at 12 months of age, and he had read the literature. He was a cancer researcher, Robert Guthrie. He was kind of eccentric. He said, "We've got to be able to diagnose these kids with PKU as newborns." He developed this test, bacterial inhibition assay, the Guthrie test, and he started promoting it. Everyone thought he was crazy, just like the ministry thought we were crazy in 1963. He wrote a paper, wrote a manuscript, showing how this could work. The first journal he sent it to turned it down: "impractical." Fortunately, the second journal accepted it. It became universal in the 1960s, and in the year 2000, his paper was declared the most significant paper of this past century in the field of genetics.

On the second-last page of my four pages—I can read part of this—I am indeed extremely pleased that the Ministry of Health has announced expansion of newborn screening to 21 conditions, prompted and promoted, to a great extent, by parent advocates, some politicians and the media. The doctors didn't have much to do with it.

Now what needs to be done? I would like to see a stand-alone program for payment of treatment products for inherited metabolic diseases include adult patients. There is a proposed business plan for this initiative, introduced by the advisory committee in 2001, which hasn't resurfaced. At the moment, they're claiming that they don't want to pay for adults with PKU and other inherited metabolic diseases. Provision should be made available for immediate introduction of new, proven products, not a six-month or a year delay to decide whether they're viable, and a detailed computerized program, plus personnel, for prompt and proper follow-up of initial positive tests. There are a significant number of "lost to follow-up" tests in the current program, which sooner or later are going to surface and cause some problems, including medical/legal problems.

There needs to be a further expansion of newborn screening in Ontario and, indeed, the rest of Canada, to include the remaining conditions recommended by the American board of genetics, i.e., cystic fibrosis, hemoglobinopathies, congenital adrenal hyperplasia, biotinidase deficiency and galactosemia—this would get Ontario up to the mark—and a properly appointed advisory committee on newborn screening to involve all stakeholders, including the public, hematologists, endocrinologists, chest and GI physicians that look after cystic fibrosis. The committee, as Dr. Odame said, until they all resigned about a year and a half ago in frustration, was involved with clinicians who look after the inherited

metabolic diseases, the aminoacidopathies, organic acidopathies, fatty acid oxidation defects and so forth. There should also be a detailed plan for quality assessment and regular review of the expanded newborn screening program. Thank you.

The Chair: Thank you very, very much, Professor.

Are there any questions? Yes, Mr. Baird.

Mr. Baird: Just a comment: I think too often when it comes to social policy, people will use—you haven't—"Well, we'll save money in the long run." It sort of underlines the fact that if we didn't save money, would it still be worthwhile? You talk about young children who, as a result of lack of diagnosis in the past, develop a developmental disability. We spend, as a province, more than a billion dollars directly—a billion dollars directly—on supporting services for people with developmental disabilities, and that doesn't even include the Ontario disability support plan, which would be a significant amount more. For someone to have a group home bed, that can cost \$50,000 or \$60,000 a year, plus day programming. Plus, if they have more advanced needs, it can even go to, in our three remaining institutions, \$110,000 a year. So there's a considerable amount of financial cost, and that's annually. People with developmental disabilities now, different from the past, are now living. We now have for the first time, significantly, a generation of senior citizens, people with developmental disabilities. We've got to keep that in mind.

1110

So if we're talking about an academic argument of should we or shouldn't we include the advancements of these tests—and I kept a log from the first presenter of the number of conditions tested in other jurisdictions—I think we've got to start asking ourselves, "Why not?" How much is it going to cost to do it incrementally? It's so minor and insignificant. If you're going to test for three diseases, now going to 21 or 22, what is the additional cost of going to 23, or from 44 to 45? It's so marginal. We're going to need a scalpel to split the difference, and that's something that I think we should bear in mind as we consider this issue.

Thank you very much for your presentation.

The Chair: Would you like to respond briefly to that?

Dr. Hanley: The cost-effectiveness of TMS has been reviewed in several jurisdictions, including the Kaiser Permanente people in Los Angeles, and they find a positive cost-effective benefit to the universal expanded newborn screening.

Mr. Baird: It's not the reason, but it's a reason.

The Chair: Thank you very much, Mr. Baird. Thank you, Professor.

WAYNE SUNG

The Chair: I would now like to call on Wayne Sung. Good morning, Mr. Sung. If you could state your name for the record, you have 15 minutes for your presentation.

Mr. Wayne Sung: Hi. My name is Wayne Sung, and I'm a concerned parent. Thanks a lot for letting me share my experiences as a concerned parent.

My wife and I were fortunate to have a baby boy last December. He was healthy. We were not knowledgeable about newborn screening at all until a Toronto Star article, which you may all be familiar with, that came out earlier this year. Upon reading up, doing more research and contacting the parent advocacy group, Save Babies, it was a real eye-opener to find out just how big a topic this is. In contacting members of the advocacy group, they pointed me to the Hospital for Sick Children to get more information on obtaining tests for my baby. I contacted the office—I believe it's the office of metabolic disorders—and they actually said they did not know of any method in Toronto to get testing.

Through the Sick Kids' office, they actually suggested that I contact parent advocate John Adams, who was very helpful in providing additional information and pointing me in directions on how to obtain tests. I first tried to find test kit vendors. There was none in Ontario. In the US, one particular vendor, Pediatrix, apparently offers the most comprehensive test kit. However, they were at first unwilling to provide a kit, since I was a Canadian. Subsequently, I believe it was through other advocates, they actually changed their policy and were willing to provide a kit.

The other problem we had was finding someone who was willing to perform the test. Our pediatrician, whom we hold in great respect—an excellent doctor—was unwilling to perform the test initially, not because of perceived accuracy or medical benefit, but based on policy. He had stated that it was not standard Ontario medical practice. So again, through the help of concerned parent advocates, I was able to obtain the contact information for a pediatrician who was willing to help us out and perform these tests.

All said, from the point where my wife and I began investigating newborn screening to when we were finally able to obtain tests—which were, fortunately, negative—it took over three months for us to get tests. I guess the concern is, in spite of all our efforts, there does not appear to be any source in Ontario or Canada to obtain tests. There's a debate about two-tier health care and all that, but if there's no source in Ontario or Canada to do these tests, it's essentially no-tier. So I'm very encouraged to hear that the ministry does plan to proceed with some supplementary newborn screening. But from our experience, until that's available, there are very few alternatives for parents—or at least it's not easy to obtain these additional tests.

The Chair: Thank you for giving a parent's perspective to the committee. We have plenty of time for questions.

Mrs. Van Bommel: My question, and I don't expect you'll have the answer because this is probably a bit more of a medical question: I know that in the case of PKU, it's time-sensitive in terms of the testing. It's important that the testing be done within 48 hours for

people to realize the full preventiveness of the testing. How many of the newborn screening tests are time-sensitive? How many need to happen within 24 hours or 48 hours of the birth? Does anyone have an answer to that?

The Chair: If the committee and presenter would like, we could bring an expert back to the table to answer that question. Is that OK with you?

Mr. Sung: Certainly.

Mrs. Van Bommel: Thank you, Chair.

The Chair: Just state your name again for the record.

Dr. Hanley: Bill Hanley, formerly from Sick Kids.

Most of these diseases need to be diagnosed in the first few days or couple of weeks of life. They're virtually all time-sensitive. That's the rationale for newborn screening. If you test them when they're a year old, that's a different story.

Mrs. Van Bommel: Mr. Sung's story about his pursuit of a test and the time that must have gone by while you were doing that—I wondered, at the point that you've gotten to the testing, if you would have had the full benefit of the test any more.

Dr. Hanley: If it's one of the organic acidemias or amino acidemias where they can deteriorate, precipitated by a mild viral illness, and go into coma, that may not happen until they're six months, nine months, a year, two years, three years of age. So it depends on the disease, but you don't want to wait until the child goes into coma before you make the diagnosis because, even if they survive, there's often significant damage to the brain.

Ms. Horwath: I wanted to remark on the courage of Mr. Sung to come here. It must have been a very difficult and frustrating and heart-breaking process for you to have to go through the self-advocacy, if you want to call it that, to get something that you needed for your newborn child. I thought it would be important to acknowledge that you took the time out of your day to come here and inform us about what it's really like to have to go through that experience. I just wanted to say thank you for doing that.

1120

Mr. Sung: Thank you very much. Actually, I think the people who really should be thanked here are the concerned parents, the advocates and people such as the doctor here, who have really pushed this cause; they're the ones who are continuing the public knowledge. With the official sources from our hospital where we gave birth and the people we came in contact with for delivery this never came up, so I think it has very much come up as a grassroots type of initiative.

The Chair: Thank you. Mr. Baird?

Mr. Baird: I guess it just points to the need. We have a publicly funded health care system, but I think this issue is almost aside from that. When you go to rent a car and don't want to take the insurance, they make you sign so that you know it. I think most parents would pay a \$10 or \$20 fee for the test. It's just that they lack the knowledge. I guess what is so disheartening to hear from you is that even when a parent has the knowledge—you

mentioned reading it in the Star, which has been a big champion of this issue—the rigmarole they have to go through and the costs associated with every contact that they made, from the health care practitioner to the hospital etc. The conveyor belt approach would just make such great sense. There's such an argument for it that I think it would probably be cheaper in the end just to do it for all people. They didn't have the money to charge parents for it. I think it would be cheaper in the end to just do it for everyone rather than charge them for it, because you'd have to do it on a selective basis. But you make a powerful argument about how difficult it can be, even when someone—we heard folks from the sickle-cell association earlier talking about the public education that they do, but when you have to go through this type of rigmarole, I think few parents would know enough and then have the endurance to go through that type of bureaucratic maze. So I appreciate your testimony.

The Chair: Thank you very much for your presentation.

MOLLY CHIN

The Chair: I will now call on Ms. Molly Chin. Hello, Ms. Chin.

Interjection.

The Chair: Yes, we're a little ahead. If you could state your name for the record. You have 15 minutes.

Ms. Molly Chin: My name is Molly Chin, and I'm a full-blown sickle-cell patient. I was a little worried I wasn't going to get here today because I just recently got out of the hospital after 10 days.

One of the reasons I'm here too is, I look around the room, and typically when the words "sickle cell" come up, it's traditionally black people that are mentioned. I'm here to say that I'm one of the few that do look the way I do, and probably one of the healthier ones right now. I'd say that 70% of my friends that had sickle cell have passed away, and a lot of the young ones I know now are having a rough time with it.

I have had my rough times with it as well. My mother recently passed away, and she told me that the guilt on her when she found out what sickle cell was ripped her apart, because I'm from Jamaica, and back home they diagnosed me with rheumatic fever. It wasn't until I came here and needed to have my tonsils taken out that I was taken to Sick Kids. They did the blood work and came up and said, "Your child doesn't have rheumatic fever. She has sickle-cell anemia." That floored my mother. My mother didn't know what that was to begin with.

Throughout the years here in Ontario, to this very day, if I go in and I don't tell them I have sickle cell, they will not treat me for it. Even when I tell them, they will treat me or look for other things because I'm not black. The first thing they'd say is, "OK, who in your family is black?" or "Where did you get it from?" So I've gone through all the things. If she had had screening and more knowledge to prevent a lot of the illnesses I went

through, I guess it would have helped. I believe it was Dr. Olivieri that started the hydroxyurea and stuff and wanted me to get in that program. But at that time, I was so ill that I couldn't partake in it.

I've always had doctors tell me that because of having sickle cell, I would have a secondary lifestyle. I asked, "What was that?" They said, "Well, you'd go to school, but you'd miss a lot of school. You might graduate, hence you might not graduate." I didn't want to believe that. I thought, well, everything I started in life I wanted to finish. But I also noticed that with everything I started, just before graduation or just before an exam, because of the stress and everything that sickle cell brought on, it would stop me dead in my tracks. Then I got the scare where I needed a lot of blood transfusions; there was that scare with AIDS and transfusions and stuff. To this day, I still need transfusions to balance out my life.

I think my mother was told that I'd be lucky if I made it to age 20. Then, after I passed 20, she said, "You'll be lucky if she makes it to age 30." So on my 40th birthday I threw myself a big party, invited my friends and said, "Look, I'm 40 and I'm still here." This was a big endeavour for me.

I've made decisions over the years because we weren't informed from the get-go. I had my tubes tied because I thought I would never want to bring a child into this world to suffer the pain I've suffered, on top of which I have other problems that precipitated from the sickle cell, where I have a narcotic allergy, so I can't take a lot of medication that you give for pain.

Just a recent incident: A very good friend of mine knew that I have this illness, but she had never experienced it, like taking me to the hospital. She had to do this and she was literally traumatized. She said, "I don't know how a mom could handle that if it was a young baby," when she saw me go through the agony and the pain.

I've had the opportunity just in the last two weeks to ask friends and colleagues—and I purposely asked black couples first, white couples first, Filipino couples. I sort of picked and chose, and I said, "You know, if you knew you had this trait in you or your spouse or your partner who you're planning to have a child with, would you want to be screened?" A lot of them said, "Well, yes, that makes sense." If it's something where you can get screened and prevent a lot of attacks or fix a lot of the problems before they get worse, yes, then that's what they'd want.

I find that with sickle cell, we have knowledge. We're doing the education and it's a no-brainer. It's something that should just be out there, that with an illness like the way it is now we should have screening. Why not? There's a lot of the stuff that you can prevent for babies. I've lived this long. Maybe it's just because I had really good doctors taking good care of me. We didn't have screening, but it's so important to inform parents and let them know, "We can do this, this and this to lessen the child's outbreak with sickle cell."

I don't know if any one of you here has seen a sickler go through the agony and the pain, and you're helpless

and you sit there. There's not a thing that you as a mom or dad can do, and you watch your child. My pain is so bad that I would try to break my wrists, which I've done, to defer the pain, just so that I wouldn't have to feel that pain. From one day to the next, I don't know if I'm going to be in pain. I'm having a good day today. Probably by tonight I'll be in agony. I say, "OK, I've got a six-hour window." If the pain doesn't ease with the medication within six hours, I know I'm going to the hospital. Thank God for nurses like Lillie and people who are educated. In a lot of the hospitals now, when a sickler comes to the emerg, they say, "OK, we have a sickle-cell patient," so right away it's oxygen. They get you hooked up to the IV. The pain meds have to start, and all of these things. If they get started right away, bang, bang, bang, it lessens, I find, the sickler's time in hospital. The longer a child has to wait in the emergency department to get medication to get it under control, the longer that child is going to stay.

1130

We also have to live a lifestyle where any little cuts or infections—and we have overprotective moms and dads who won't let their kids go and play because they're so scared that the little one is going to pick up something and they're terrified. Then you become this overprotective parent, and your child doesn't get to do what they need to do. So when Camp Jumoke was brought in, it was like, "All we want to be is normal kids, but every time we want to do something normal, mom and dad are so terrified that we're going to end up in an attack." I think that if we have the screening and we can stop a lot of the things from getting worse than what they could be from the beginning, and monitor and help the system, as we help the system, the system can work for us as well. I say, why not have the screening? It's a no-brainer idea, I think, and it would help tremendously a lot of people.

The Chair: Thank you for sharing your personal experience with us, Ms. Chin. It's very much appreciated. Are there any questions?

Mr. Brownell: Just a comment, basically: We just heard from Mr. Sung, and I heard from John Adams about the necessity for education very early on. I think that the profile has been raised in the press and the fact that this is an all-party committee hearing is going to raise the awareness of Ontarians, and that's important.

The three of you have made statements about education, and I think it's extremely important. I know that Mr. Adams held up a brochure. Maybe there's enough in that brochure, but now there has to be more in the brochure with regard to what's coming, and hopefully what's coming in the very near future. When we say as a government, "Move from worst to first," I think that's extremely important. Education is going to be a big part of it, just as it is in the campaign to alert people to smoking in the workplace and the problems with smoking. Once again, education is very important. A very fine message. Thank you for your personal comments.

Mr. Kim Craitor (Niagara Falls): Just one question, Molly: As I sit here, listening to your story, I just can't

imagine. If you had been tested at the beginning, what difference would it have made, just so I can understand it?

Ms. Chin: At the beginning, back home or here?

Mr. Craitor: Yes, if you had been tested and they had understood.

Ms. Chin: Back home, my mother still didn't know what sickle cell was back then.

Mr. Craitor: Just so I understand, if you had been tested, what would have been the difference in your life if they had known you had it and given you the treatment?

Ms. Chin: The treatments would probably be different. I probably would not have had to go through a lot of what I did go through, from what my mother tells me. I can't remember far back as a child myself, but I know I was in pain a lot and she hired nursemaids 24/7 to watch over me. I know that she went to her grave with the guilt on her of thinking that this was something she caused or did. If she had had more knowledge, maybe she could have helped me. I don't even know if they had pre-screening back home then. I left Jamaica when I was 10 years old.

There was also the stigma that was placed on sickle cell. When I first came here, everyone called it the black people's AIDS. You know? Even the Greek people did not want to know that Greek people could have sickle cell. It was called Mediterranean anemia. They gave it another name. It was a stigma to know that you had it. To this day, it's the same way. No one wants to know that you have sickle cell because "Oh, it's out of Africa; it's AIDS."

Like I said, even the doctors here—recently I went in and I was having trouble with my spleen, because I'm one of the few who still have their spleen, and the doctor refused to give me treatment for the—I don't know how you say that word—

Interjection.

Ms. Chin: —that long word. He refused to treat me or believe that I had sickle cell because I didn't fit the criteria: I wasn't black; I was Oriental. He wanted to make sure that all the tests were right. I said, "Have my tests come up from the other hospital." His idea of treating me was to put me to sleep and put a catheter in, which was all the wrong things to do because by putting in the catheter, I ended up with a severe infection, which triggered a violent attack. This was a hematologist doing this.

The Chair: Thank you very much, Ms. Chin.

TAMMY CLARK

The Chair: I'd now like to call on Tammy Clark. Welcome, Ms. Clark. If you could state your name for the record. You have 15 minutes.

Ms. Tammy Clark: My name is Tammy Clark and I'm a parental newborn screening advocate. I'm also the founder of the Save Babies Through Screening Foundation of Canada. But most importantly, I'm a mother who has experienced the loss of a child because of the

lack of a comprehensive newborn screening program in Ontario.

I believe that it is very important for me, as difficult as it is, to share my daughter's personal journey toward diagnosis of MCAD deficiency with this committee, for the purpose of showing or exhibiting what the consequences are of having this type of program—the discrepancies in the program. So if you would, bear with me. I will try my best to not break down.

I would like to share Jenna's journey with MCAD deficiency. I'll start with this: When I became pregnant with our third child, we realized that our home would no longer accommodate our growing family, so we decided to move. In the fall of 2001, we moved into our new home in the village of Kars, Ontario. Life could not have seemed sweeter. We had our new home with plenty of room for a new baby on the way. Who could ask for more?

Time passed, and the pregnancy went by without any complications. I did all the things that a pregnant woman should to help ensure a healthy baby. On February 17, 2002, our world would be forever changed with the arrival of our sweet baby daughter, Jenna. There were no complications with the birth. The only surprise was that she had red hair and blue eyes.

Jenna was a very sleepy baby when she was born. I had a difficult time trying to get her to breastfeed. The nurses reassured me that this was all very normal because of the delivery. After many attempts, I finally got her to nurse. The next evening, our pediatrician came to the hospital to examine Jenna. He listened to her chest, moved her legs and declared that she was a healthy baby. He told me to call his office to book Jenna's first checkup and then he was gone. Later that evening, the nurse took Jenna from me in order to do her heel prick test, which at that time, of course, was and still is for PKU and congenital hypothyroidism. Little did we know how important this test could have been for Jenna's very survival.

We were discharged from the hospital the following afternoon. We were ecstatic. Everything seemed so great. Our circle was complete. We felt truly blessed.

After we got settled at home, life went on and we carved out a new routine. From the day she was born, Jenna was a strong baby. She could hold her head up; it was like she didn't want to miss a thing. At two months old, she had learned to roll over on to her tummy; at four months, she had already cut two teeth; at six months, she had started on some solid foods and was enjoying the new sensation, as most infants do, of razzing when she had food in her mouth. At seven months, she was crawling all over the place. She especially loved to crawl toward the sunniest place in the room to bask in its warmth, almost like she remembered where she came from. At eight months, she was able to climb up stairs, and by nine months, she had started cruising around the furniture. We were certain that she would be walking very soon. She was a wonderful little girl who loved to babble, "Dadda," and melt her daddy's heart. She would

giggle with delight when he gave her raspberries on her tummy, and developmentally, she seemed to be reaching her milestones, and more.

1140

On the morning of November 21, Jenna woke up very lethargic. I hoped she wasn't coming down with the flu that had made my son, Justin, ill the week before. Later that day, for reassurance, I took her to the pediatrician. At 1:30, Thursday, November 21, 2002, I brought all three of my children to the pediatrician's office. When the doctor entered the examining room, I was holding Jenna in my arms, and she was quite sleepy. He commented that while she was quiet, he would look in her ears. I then placed her on the examining table, and she suddenly seemed more alert—a little Dr. Jekyll/Mr. Hyde thing happening. The doctor listened to her heart, and he informed me that Jenna was running a fever, and to give her Tylenol or Tempra. Her diagnosis was the flu. I was told to keep pushing fluids. The doctor then switched his attentions to my other two children. After reassuring me that they were fine, he left the room.

When we returned home from the doctor's office, Jenna's condition hadn't changed. She was still very lethargic, but she was drinking, so I took that as a good sign. When my husband came home from work, Jenna seemed to perk up a bit at the sight of her daddy. Later that evening, Jenna's fever had broken and she seemed a bit better. Reluctantly, at 11 p.m., I put her to bed. About a half an hour later, I heard her cry out. I checked on her and she seemed fine.

Around 4 a.m., Friday, November 22, a day forever engrained on my heart, Jenna cried out. I bolted from my bed to check on Jenna. I checked Jenna's diaper and tried to get her drinking again, but she was resisting taking a bottle. When I finally got her to take a sip of fluids, she seemed content. A while later, she started making noises as if she were going to vomit, and all I could think of was that something just wasn't right. I expressed my concerns about Jenna to my husband. We decided that if Jenna wasn't any better, we would take her back to the pediatrician's office when it opened. Unfortunately, we never got that chance.

At approximately 6:30 a.m., she stopped breathing. I tried to perform CPR on Jenna while my husband was on the phone with the 911 operator. After what felt like an eternity, the paramedics finally arrived at our home. They whisked Jenna off in the ambulance and told us to meet them at the children's hospital. My husband sped off after the ambulance in his car while I waited for someone to come and stay with our other children. Finally, a police officer arrived, and after some coaxing, he agreed to take me to the hospital. Of course, I couldn't understand why I had to coax a police officer, but I would later find out why.

It was the longest ride of my life. When I arrived at emergency, my husband was waiting outside for me, so I figured that this meant one of two things: that they were working on Jenna and he didn't know what happening, or

that Jenna had died, and unfortunately it was number two.

So, to say the least, we were in shock. How could this have happened to our baby, who only two days previous seemed so healthy? In all her nine months of life, this was the first time Jenna had ever been ill. Surely there had to be some mistake. As we were taken to the emergency room where Jenna lay dead on a stretcher, reality began to set in that this was not just a bad dream. There was a tube in Jenna's mouth from their efforts to resuscitate her. The emergency room doctor reassured us that they had tried everything, but they could not get Jenna back for us. We cried, and so did the hospital staff. They were so supportive; I can't say enough about Children's Hospital.

The coroner came in to confirm her death. We were then told that we could have some time with Jenna to say our goodbyes. We were ushered into a small visiting room with Jenna as they needed to clear the emergency room. Our pediatrician arrived at the hospital and stormed into the room, asking me, "How did this happen? She was perfectly fine in my office yesterday." We got to accompany Jenna's body to the X-ray room. Afterwards, we had one last goodbye.

The hardest thing we had to do was hand her over to the nurse who would take her up to autopsy. This obviously was not something we ever envisioned having to do with our child.

Next, we were advised that the police needed to question us for their investigation into Jenna's sudden death. The police questioned my husband and me separately about what had happened. While we were at the hospital, our house was seized by investigators, items taken from our home as evidence. We were told that we could not leave the hospital until the initial autopsy report was released. When the initial autopsy report came back, we were told that the cause of death was Reye's syndrome. We were advised that we were free to leave the hospital. It seemed unfair to be leaving with a little toiletted box and a blanket instead of our sweet little Jenna.

So there is Jenna for everybody to see. Can you hold it up for me, Anita, please?

Upon arriving at home, I kept thinking that somehow someone had made an error and surely the doorbell would ring and our daughter would be returned to us.

For a while afterwards, time seemed to stand still. I decided to research Reye's syndrome, as I didn't understand exactly what it was. I contacted the Reye's syndrome association in the United States. When I relayed Jenna's story to them, they told me that it didn't sound like our child had died from Reye's syndrome as there were no aspirin products administered. They mentioned that I should read about inborn errors of metabolism, of which I knew nothing.

I started researching these disorders and realized that if in fact this was an inborn error of metabolism, my two other children might also be affected, as these disorders are hereditary. I called the children's hospital and spoke

with the doctor who had helped us on the day Jenna died. After speaking to her, I realized that nobody would believe my concerns for my other children, because the diagnosis of death remained as Reye's syndrome.

Ironically, a few days later, I received a call from our local coroner advising us that Jenna's diagnosis of death had been misdiagnosed, and the correct diagnosis was now a disorder called medium-chain acyl-CoA dehydrogenase deficiency, MCAD, which is an inborn error of metabolism.

We were advised not to research information about this disorder on the Internet, that an appointment had been made for us to see a specialist at the genetics clinic at our children's hospital. Naturally, because I was told not to seek out information, I did. This is how I learned the heart-wrenching truth that this whole tragedy could have been avoided with a simple \$40 blood test similar to the heel prick test that is currently done for PKU.

MCAD is considered a very easily treatable disorder in most cases. The most important component to treating this disorder is knowing that a person has the disorder. I've been told by specialists in the medical community that of all these types of rare inheritable disorders detectable by a newborn screening, MCAD is the no-brainer for management. It is the one that absolutely should be included in an expanded newborn screening program.

At our first appointment at CHEO's genetics clinic, I presented the specialist with the facts that I had learned. He confirmed the information was correct. He then went on to mention sickle-cell disease, which, at that time, I didn't quite understand why; of course, now I do.

I signed some release forms so that samples of our other two children could be sent to Duke University in the USA for analysis to determine if they also had MCAD. So, you see, there is testing currently being done in the US for detection of these types of disorders, but only after the fact.

1150

I also signed a release form so that the specialist could send Jenna's specimen card from when she was a newborn to Nova Scotia for screening by a tandem mass to give further validation that indeed she did have MCAD. By the end of our appointment, the specialist tried to diffuse my concerns about the lack of newborn screening for rare disorders by telling me they were working on it with the Ministry of Health.

I left the appointment dismayed that something so common sense could go so wrong and that our child had paid such a high price. However, I thought, considering all the key decision-makers knew about this issue and that they were working on it, surely this kind of needless tragedy would not happen to another child. Of course, I've learned that this is not the case. This is still ongoing. Children are still dying to this day from MCAD and from the other disorders that are detectable via a comprehensive newborn screening program.

I went home and kept researching about MCAD and newborn screening in Canada. After making various

enquiries, I soon learned that some provinces in Canada were screening for MCAD at the time that Jenna was born. A family in Saskatchewan heard about Jenna's death and contacted me to offer up their support. Their son had recently been diagnosed with MCAD through that province's newborn screening program.

The next time I met with the specialist at Children's Hospital I mentioned that other provinces were screening for MCAD. He seemed unaware of this information. We discussed my other two children's screening results for MCAD. Thankfully, my son is a carrier and my eldest daughter is unaffected. We also discussed the results from the further screening of Jenna's PKU card. The results from Jenna's PKU card clearly indicated that if she had been screened for this disorder as a newborn, we would have known what we were dealing with right from the start. A treatment plan would have been devised and Jenna most likely would have had a healthy, normal life and she would still be here and all of us would probably not be in this room at this moment, I guess; I don't know. Hopefully that's not the case.

On the day our daughter died, we were expected to live up to a certain standard of accountability, yet the key decision-makers who knew of this issue did not have to answer to anyone.

While I am pleased that the government has recently announced the expansion of the newborn screening program, I approach this announcement with cautious optimism because the timelines were not clearly defined. Also of concern is that the announcement was not for a full, comprehensive program. The current gold standard is 50-plus disorders, and this means that some 29 disorders were excluded from the program expansion.

In closing, I'd like to say that it would seem to me that one of the main problems here is that all the parties involved with this issue lost focus of the importance of saving children's lives and putting children first, and that is what this meeting here today is all about: putting children first.

I appreciate this opportunity that I was given. Thank you.

The Chair: Thank you very much, Ms. Clark, for sharing—Chairs aren't supposed to cry; excuse me—your story and bringing your little girl alive for us here today to make this issue very real for all of us.

The next person has cancelled, so we have a little extra time here, if you feel up to answering questions.

Ms. Clark: Sure.

The Chair: Thank you.

Mr. Baird: I want to thank you for coming. I think the fact that you're championing this cause so that no other family has to go through what you've gone through is a wonderful thing.

In my 10 years here, all political parties have passed some pretty irrelevant bills. We had an Irish Heritage Day bill; I'm Irish. We passed bills to ban pit bulls. I'm not sure how many people have died from pit bulls compared to this. We passed some crazy Conservative

bills. We passed some crazy NDP bills. We passed some crazy Liberal bills.

One of the issues that it's going to come down to is that the ministry, I think, is going to do the right thing. The government wants to do the right thing. I'm very convinced of that. I think we want to do two things: (1) We want to make sure that we go as far as we can; and (2) we talked earlier about Stephen Lewis bringing in a bill in 1965. Do we want a process in place at the ministry that's good, or do we want a statute in the Ontario statutes which sets out clearly what is required, what is expected of government, what is expected of providers and what is expected of hospitals? That's the central issue we're going to have to consider when we look at debating the bill and voting on it in the House—sometime this fall, hopefully. Do we want a law on the books that will require this to happen rather than a good policy or a good practice? I think the answer is clear.

I got a copy to show committee members. This is a test done today for the two conditions. The blood goes there. We would simply have to expand that; nothing more. One piece of paper, literally, is the answer to this. We just want to make sure this never happens again.

Thank you so much not just for coming today but for being such a great advocate for so many kids out there who will never meet you, never know you and would never have known Jenna. So thank you.

Ms. Shelley Martel (Nickel Belt): Ms. Clark, I want to apologize to you. I'm the NDP health critic. I have been in the estimates for the Ministry of Health this same morning and we have just concluded. I was scheduled to sit in this committee all day today, but we ran late in that committee and so had to complete it this morning. That's why my colleague Ms. Horwath was here on my behalf, and now I'm in for the balance of the day.

I didn't hear all of the presentation, as you can appreciate. I can, however, tell from the tone in the room that it was very powerful and very compelling. It takes a tremendous amount of courage for a parent to come and share their story about the death of their child. I can't imagine what that's been like for you to do today, but I do want to say that as a member who has just come in on the tail end of it, it is very important that you had the courage to do that because it forces all of us to put at the front of our mind again what's really important, what we're here about and to have all of us really, I think, rededicate ourselves to ensuring that the screening process in the province is the best it can possibly be so that we're not letting parents and kids down. I suspect that is the feeling of all of us and all of those who heard the whole presentation, which I unfortunately was not able to.

I just want to share that with you. I don't have any questions because I think that probably none are required.

Ms. Clark: I appreciate that comment.

Mrs. Van Bommel: I just want to say thank you very much. Your story has personal meaning for me as well. I know that your family has paid a very high price. You said that Jenna paid a high price, but I think all of you

have. You've been very brave in coming here today to do this, but it's important for the committee and for the government to hear that because we need to hear and be reminded of what our decisions do to our people and to our citizens. So thank you.

1200

Ms. Clark: If I may, I want to say that on September 7, when the announcement came from the ministry that they are going to be expanding for 19 disorders and that MCAD was included among them, of course I felt a moment of redemption, let's say, for Jenna. But again, no clear timelines. Every day wasted is the life of a child, if I can just press that point.

Also, although MCAD is among the list of disorders included in the expansion, some people may say, "Well, Jenna's story is no longer valid because it's now included in the expanded newborn screening program." I just wanted to say that I felt the need to say Jenna's story on behalf of other children who have died from other disorders as well that are detectable by comprehensive newborn screening programs. It's just to highlight what happens to families when they go through this kind of needless loss. Although it might be a different disease, the stories are essentially the same. This is a needless loss. As Mr. Baird has pointed out several times, this is a no-brainer.

The Chair: Thank you very much, Ms. Clark, for coming today and sharing your story.

Our 12 o'clock deputation has cancelled, so I would like to ask if the committee would like to continue if the other deputants are here. Yes? OK.

BOB FRANKFORD

The Chair: I now call upon Dr. Bob Frankford.

Good afternoon, Dr. Frankford. If you could give your name for the record; you have 15 minutes.

Dr. Bob Frankford: My name is Bob Frankford. For those who don't know me—and I see some familiar faces and some I don't know—I'm a former member of the Legislature. I'm a retired family doctor as well. I took a great deal of interest in sickle cell when I was a member here.

I wrote these notes last night and I was looking at that day's Toronto Star, where there was a headline, "Province Likely to ... Include Sickle Cell Testing," referring to the list of diseases for which there is newborn testing. I was wondering whether, by the time I got here, the policy would have been changed—not quite that quickly, but I'm glad to hear the comments from the government side, which sound very reassuring or almost certain that change is going to take place and that sickle cell is going to be included.

As a member, I got involved with sickle cell. I had contacts way back with the Sickle Cell Association of Ontario, and I would like to speak very well of them. You heard from the two presenters today and you can tell what a wealth of experience there is in that community-based organization and how much they welcome the

opportunity to finally speak about it themselves in the Legislature.

Sickle cell is a relatively common disease with considerable political and public policy possibilities for relief of suffering. In my time here between 1990 and 1995, I presented petitions and made members' statements trying to raise awareness of the disease.

Why should it be on the list for newborn testing? Well, as you have heard, it's a common genetic disorder. Sickle cell occurs particularly in the black Afro-Caribbean population, of whom up to 10% carry the gene. Carrying the single gene itself causes no problems, but when this is the case in both parents the chances of having a child with the disease is one in four. Screening of newborns is quite cheap, and the figure of \$2 per test has been given.

It has also been pointed out that newborn screening is routine across 99% of the United States. Interestingly, sickle cell has been on the public legislative agenda since 1971. It was President Richard Nixon who approved legislation that produced research, treatment and screening. As in Canada, the federal government there can take a lead in health care but does not actually implement programs. Sickle cell has not been an issue for government either at the federal or provincial level.

An important and frequently cited study appeared in the *New England Journal of Medicine* in June 1986. It was a double-blind study of administering babies and infants under three with prophylactic penicillin. The study was terminated early because it clearly demonstrated deaths in the children not receiving the drug. The authors recommended newborn screening and penicillin prophylaxis by the age of four months. This is not a guideline that is in place in Ontario.

The justification for newborn screening is that early detection will make a difference. Metabolic disorders may require special diets or expensive drugs. Sickle detection enables carers to know disease is there and to anticipate crises and complications. In one of the petitions that I presented, the request was that penicillin should be considered an essential drug and be routinely available to all. One might compare the cost of some of the highly specialized drugs, which are certainly needed for some of the very rare disorders, and contrast with the very low cost of penicillin and how effective that spending would be.

Health Canada and other levels of government, in their wisdom, are undertaking an expensive print and TV media campaign regarding primary health care. This we are told will involve teams of providers, information, access and prevention through healthy living—all very desirable—and, I would say, in many cases these things are already in existence for those sickle-cell patients and their families already linked to well-established programs in hospitals and teaching centres, some of whom are represented in the room here.

In relation to the universalization of newborn testing, there will be a need to expand such facilities for follow-up and treatment, particularly in the 905 and outlying

areas where much of the growing population at risk lives. And we need to ensure that comprehensive programs with teams and prevention continue throughout an individual's lifetime and are not terminated at the age of 18 because of no longer being considered in the pediatric age group.

I look forward to the implementation of newborn sickle-cell testing, which will finally put Ontario back with what has been the practice in American states for years. There's an interesting study of federal-provincial politics documented in the book *Dying in the City of the Blues: Sickle Cell Anemia and the Politics of Race and Health*, which I have here, by Keith Wailoo, an American academic. Those members of the committee who may be planning to seek election at the federal level should look at the precedents south of the border and how the federal government could take a lead in setting standards for the benefit of Canadians from coast to coast. A reviewer of Wailoo's book states, "... one overriding lesson becomes especially clear: Diseases are best treated when medical information and resources are managed and distributed by experts organized at the federal level. Local control feels like a good thing, but too often, it leads to bad medicine."

Universality is the intention of the Canada Health Act, and clear definitions in relation to vital programs would improve the lives of many Canadians—not that I am suggesting transferring everything to the federal level. The provincial ministry, as we see from the Ombudsman's latest study, which I was able to read this morning on-line, will be very diligently, I'm sure, working on how to reorganize things and to make sure that they have some clearly stated, unified objectives.

I am very proud to have been involved with this issue for a long time and I compliment the introducers of this bill and welcome the rational melding of scientific knowledge and politics. To quote: "Medicine is a social science, and politics nothing but medicine on a grand scale." That's from the eminent 19th. century German physician and reformer Rudolf Virchow.

1210

As we move to universal newborn screening of treatable disorders, we must follow up and assess the outcome of what is being implemented and search for other ways of improving lives through government and public policy.

Thank you for the chance to speak this morning.

The Chair: Thank you very much, Dr. Frankford. I think we're all aware of the long-time leadership that you've taken on this issue. Thank you for coming forward today.

Are there any questions for Dr. Frankford?

Mr. Baird: First to commend you for your interest in this. Not many members, after they leave this place, come back to still push an issue, so I commend you for that leadership.

I guess the one thing to respond to you with respect to the federal government—members of the committee will know of my new interest to hold the federal government

to account perhaps more than I used to. Having said that, I don't think we really here in Ontario have much right to be telling other governments what to do, given that we have such an abysmally bad record on this. Jamaica can maybe go after the federal government, or Mississippi can go after the federal government, but I think that when we get our own house in order—as Mrs. Van Bommel said, the catchphrase is going to be “From worst to first.” Once we are first, certainly in Canada, then we'll have some grounds to go to the federal government and suggest its role. Health care being a provincial responsibility, I think that provinces should take the lead. Having said that, because this is such a basic issue, there certainly would be a huge advantage to every province having a uniform high standard, and maybe when we have the best standard, we can take nationwide a definite role for public health, and for the federal government as well. So thank you.

Dr. Frankford: If I can just respond, I would advise reading this book on the American experience. It was pushed up to the federal level and, as I mentioned, President Richard Nixon brought in the first National Sickle Cell Control Act. Of course, the feds don't implement state by state, and they vary state by state. But I think still there's federal leadership there and there's federal public health. I think there is a move to strengthen federal public health here, so maybe this can all come together and it's something for you to consider.

Mr. Baird: It's a remarkable day at Queen's Park when you have Conservatives speaking well of Stephen Lewis and New Democrats speaking well of Richard Nixon. If that doesn't say that this bill is the right thing to do, I don't know what else does.

The Chair: No comment. I believe we'll move on now. Are there any other questions for Dr. Frankford? OK. Thank you very much for your presentation and your ongoing advocacy on this issue.

I would now call forward Jackie Hayes. Is Jackie Hayes here yet?

KAI GORDON-EDWARDS

The Chair: If not, is Kai Gordon-Edwards here? If you're willing to come forward early, we could hear from you now. If you could state your name for the record, you have 15 minutes.

Ms. Kai Gordon-Edwards: Good morning. My name is Kai Gordon-Edwards and I would like to speak on behalf of my son, Asaiah Edwards.

Asaiah is a vibrant, two-year-old, active little boy, born August 22, 2003. Asaiah is our second child and has proven, while still in the womb, to be his own person. As a mother, while still pregnant, I instinctively knew that there was something different about Asaiah, something special about him. At three months, October 22, 2003, our pediatrician informed us that Asaiah had sickle-cell disease type SS, and he was placed on a daily dosage of penicillin to help protect him from infection. I truly believe that if it were not for the proactive thinking of our

pediatrician to request for Asaiah's umbilical cord to be tested for sickle-cell disease and other ailments, we would not have known whom to contact and how to care for Asaiah.

As parents of a seven-year-old, we were confident in our ability to care for a growing child. However, we have found that we have had to retrain ourselves in child care. We have learned to be vigilant with what many deem as the simplest things, such as a runny nose, lack of energy, and sleeping, eating and drinking patterns. We were taught these simple things through the sickle-cell clinic at the Hospital for Sick Children in Toronto.

Four months after Asaiah was diagnosed with sickle-cell disease, he was admitted to the Hospital for Sick Children for the first time with a high fever and a runny nose. If we were not aware of the protocol taught to us by the sickle-cell clinic, we would have attributed Asaiah's fever to the normal growing pains of infancy as opposed to the red flag of Asaiah's immune system being attacked or compromised.

In October 2004, we noticed that Asaiah's skin colour began to become pale and discoloured. He began to lose his vibrancy and his desire to eat or drink. He essentially became lethargic. We rushed him to the Hospital for Sick Children, where he immediately underwent several tests. Test results indicated that Asaiah would have to have an emergency blood transfusion due to a very low and dangerous drop in his hemoglobin, or blood count. Asaiah's hemoglobin sat at 57; normal levels are usually 120 or higher. He was experiencing a splenic sequestration—a crisis in the spleen. Asaiah received the first of his monthly blood transfusions.

Since being diagnosed with sickle-cell disease, Asaiah has been admitted to the Hospital for Sick Children nine times and has had 13 blood transfusions and three fibril seizures, which have led to an MRI and a referral to a neurologist. Young children with sickle-cell disease are at risk of stroke. Asaiah will undergo surgery within a few months to remove his spleen and to conduct a liver biopsy. One of the risks of Asaiah's many blood transfusions is a dangerous increase of iron in his liver, which will possibly result in another series of treatments for him.

The journey we have had with Asaiah has evolved through the initiative of one pediatrician who was experienced and vigilant enough to request the necessary tests at birth. He has been followed by a phenomenal team of doctors and nurses at the Hospital for Sick Children's sickle-cell clinic who have taught us how to care for a child with sickle-cell disease such as Asaiah. They have provided us with the tool of knowledge, empowering us with a voice to speak for our child and to request appropriate care and treatment for him. They have developed a sickle-cell passport in partnership with the Rouge Valley Centenary hospital and the Sickle Cell Association of Ontario for parents such as my husband and I to carry at all times with the important medical history of our child to prevent misdiagnoses and inappropriate transfusions

and treatments. There are many families who are not so fortunate.

Newborn screening will fill the gaps that many health care professionals have missed and will support the work of those who are aware and vigilant. For our family, Asaiah's early diagnosis has been a preventive measure that has saved him, and our family as a whole, from indescribable tragedies. Newborn screening in Ontario for sickle-cell disease will provide many parents with the opportunity to effectively care for their children and allow health care providers and professionals to provide appropriate and effective treatment to our children. With newborn screening, health facilities can save money and valued resources in the long run. One simple test could prevent many tests and needless misdiagnoses in the future.

Asaiah is extremely lucky, and we are grateful to his health care provider for educating herself regarding sickle-cell disease, for having Asaiah tested and for continually supporting us through this difficult life journey. My heart goes out to the children, individuals and families for whom sickle-cell disease was not diagnosed and who have suffered unnecessarily—physically, mentally and emotionally.

1220

The expansion of a newborn screening system that includes sickle-cell disease, thalassemia and other genetic hemoglobin abnormalities will be one step closer to a whole, inclusive, knowledgeable universal health care system.

My family and I, along with other families affected by sickle-cell disease and the Sickle Cell Association of Ontario, are requesting that no child go untreated for sickle-cell disease because newborn screening was not available. I ask all levels of government to examine the risk of not implementing a comprehensive newborn screening system. I believe that all will conclude that we cannot afford not to.

The Chair: Thank you very much for sharing your story with us today. I would ask if there are any questions or comments from any of the members.

Mr. Baird: Just a quick comment. Your experience and Asaiah's experience is just another reason on the sickle-cell side to have that testing done. So thank you very much for coming forward. It's appreciated.

The Chair: Any other comments or questions? Thank you very much for coming today. We really appreciate it.

JACKIE HAYES

The Chair: We have one more deputant left and we're ahead of schedule. I would ask if Jackie Hayes is available. Yes, she's here. Welcome, Jackie. Could you state your name for the record, and you have 15 minutes.

Ms. Jackie Hayes: I'm Jackie Hayes. I'm the mother of Brittany Hayes, an 11-year-old girl who has sickle-cell disease, Hb SC.

Born in the United Kingdom and socialized in a predominantly Caribbean community, I was very much

aware of the pain and suffering endured by people diagnosed with sickle-cell disease. From an early age I, along with my companions, were informed of the necessity of blood screening to determine our sickle-cell status. In 1993, in my first trimester of pregnancy, I was tested for this disease, along other generic disorders, and the results were negative.

In June 1994, while living in Queens, New York, I gave birth to a beautiful daughter, Brittany. Two days after her birth, while she lay in an incubator, I was told that my first and only child had sickle-cell disease, Hb SC. I was tested again, along with my husband. Days later I learned that I was a carrier of the C gene and my husband was a carrier of the S gene. The news was devastating. I had observed the hopelessness and fear associated with this disease from a distance all of my life. Now I would become intimately acquainted with its unpredictable nature and its multi-systemic scope.

My daughter's first major crisis did not occur until she was four and a half years old. She spent three and a half weeks in the hospital, where she had surgery, received a blood transfusion and had a severe crisis in her left lung which required intubation. Unfortunately, I had taken her to a local hospital that was unfamiliar with the disease and the potential danger it could inflict with very little warning. Two years ago, my daughter was unable to walk unassisted because of the excruciating pain she felt in her left hip. This occurred for just under two months.

Today, Brittany continues to suffer excruciating pain, primarily in her limbs, several times a year. Four weeks ago, while on vacation in California, without warning, she began to feel pain in both of her legs. Within six hours she was unable to walk, crying out in pain. I had oral morphine, Advil, heating pads, but nothing seemed to diminish the pain. As a result, she spent five days in the local hospital in San Francisco.

I hope these very small snippets of our experience shed light to you on this difficult disease.

For me as a parent to manage and care for my daughter without the support of my family, friends and medical practitioner, and the benevolence of my employer, would be impossible. As difficult as our journey has been at times, today I sit here and feel fortunate. Why? Because I knew of Brittany's diagnosis before I left the hospital. As a result, we have taken preventive measures from the time she was three months old to ensure a better quality of life. She received penicillin and folic acid daily until she was six years old. She has also received additional immunizations, such as Prevnar, to help fight against deadly infections. A fever is never ignored; we know how deadly they can be for her. She's seen by a doctor within 24 hours of a persistent fever—preventive measures that I believe have secured a brighter future and continue to give us hope.

Newborn screening has been an empowering factor in our lives. It provided valuable and timely information, coupled with genetic counselling. We were able to make informed decisions about our future, deciding not to have

another child because we felt that the risk was just too great.

Today, the doom and gloom surrounding sickle-cell disease is gradually diminishing in the black community, primarily because of the support, research and early detection programs that continue to improve the quality of the lives of these sufferers. Brittany is a prime example. As noted earlier, she is constantly monitored by medical specialists to ensure early detection of complications which could cause the loss of eyesight, lung damage, stroke and even premature death.

In closing, recognizing the importance of one life and valuing that life makes a difference. I believe newborn screening sends that message loud and clear.

Children with sickle-cell disease need parents who are informed, proactive and engaged in their care. Early detection makes a difference. The implications for not providing this support to parents will cause significant repercussions.

Thank you for taking the time to listen to my story.

The Chair: Thank you, Ms. Hayes, for coming forward and telling us Brittany's story.

I would now ask if any of the committee members—yes, Mr. Ramal.

Mr. Ramal: Thank you for sharing the story with us. I just have a question. You said your daughter was born in the United States and you learned about the sickle-cell disease when your daughter was born.

What preventive measures are being taken in order to prevent it, since we are talking about implementing the testing to detect the disease in newborns in order to prevent it in the future, and from escalating, and then something to correct the situation of the person?

Ms. Hayes: I think there are people who are at high risk, the black community. In England, I was screened, actually, before I went to the United States, but the type that I had was not known: sickle-cell C. I don't know all the rules and how the testing and screenings are done, but typically I think people are screened for S and not C, and that's why it wasn't detected for me. But in England, I was screened. When I was pregnant, I was screened again and it wasn't detected. But when Brittany was born, she was screened with a more thorough screening and it was detected that she had SC. It's important that that is known at birth, because it prevents her from having different illnesses, and being able to take penicillin or folic acid to strengthen her body to fight against infections.

Mr. Ramal: You mean, if they learn about the disease from the beginning, for yourself and for your husband, they then would be able to prevent what happened to—

Ms. Hayes: Absolutely.

Mr. Ramal: So are you asking for extending the testing to the parents and not just for the kids?

Ms. Hayes: Absolutely. In England, that's what happened for me, and it also happened in the United States in the first trimester. But if it happens at newborn age, 20 years from now we'll have a lot more informed people.

Mr. Ramal: If you learned about your disease as a carrier, you and your husband, you would go ahead and bring Brittany to life?

1230

Ms. Hayes: I would go ahead and what?

Mr. Ramal: Get pregnant and make a choice—

Ms. Hayes: No. I would get genetic counselling. I would see what the risks are. There are different risks for different types. I'd make sure that I know what the risks are and I would be more informed on my decisions. Knowing what I know about sickle cell, I would not have had a child. But having my child, I'm very happy.

The Chair: Are there any other questions?

Thank you very much for your presentation.

That ends the time for presentations. Before we move on, I would like to take this opportunity to thank all of those who came forward to share their expertise, but particularly the parents who came forward today to share with us their stories, making this a very real issue for all the committee members. Thank you so very much.

Mr. Baird.

Mr. Baird: First, I'd like to thank everyone who presented today. I know you've all taken time out of your careers and your families to be with us, and it's much appreciated.

I also want to thank all the members of the committee. With great respect to the Chair, other than her, all the other members came from various parts of the province to be here today, and that's very much appreciated. I think this is how the Legislature is supposed to work. It's a great credit that among the three parties there were some negotiations, discussions. The opposition let some bills go through and the government agreed to have other bills to go to committee. I think too often in the past—and it's the fault of all three political parties. But when something good happens, I think this is the way it's supposed to work, and I just want to acknowledge that.

I have a motion I want to move. I've shared it with both the government and the third party this morning just so that it didn't come as a surprise. We normally undertake the clause-by-clause portion of consideration of a bill after public hearings, but I think we've learned a lot at the public hearings and I'd like an opportunity to prepare some amendments. I have some prepared already, and I'd like an opportunity for the government to have the chance to review them ahead of time, so it's not just thrown at them haphazardly.

So I would like to move that Bill 101, Health Insurance Amendment Act (Supplemental Newborn Screening), 2005, be considered for the purpose of clause-by-clause consideration of the bill at the regulations and private bills committee meeting on October 19, 2005, and that members of the committee be requested to submit amendments for consideration to the committee clerk as soon as possible so that they might be distributed.

The Chair: We have a motion on the floor.

Mrs. Van Bommel: First of all, I also want to thank all the people who have brought in deputations. I think this is a very important issue.

“Worst to first” are Minister Smitherman’s words. He understands the importance of what we’re doing and he wants to be sure that we move forward, and we are. He is committed to moving forward on this particular issue. We have started with 19 additional tests. We will continue to look further and wait on the advice of the advisory as to what we will be doing.

On this particular motion, I have been sitting on this committee now for—I think this is the seventh bill. I’m not sure how far—boy, it’s terrible when you lose track of the time. This is a very important issue, but so have all the others been that have been before us in the last few days as a committee. I know there’s agreement among the House leaders about the clause-by-clause and that sort of thing. I think at this point, this is a procedural type of motion, and I would prefer that we proceed and allow all the bills to move forward together, as they were intended to do by agreement. So I’m going to have to say that at this point I want to be fair to all—

Mr. Baird: If I could.

The Chair: Just one moment, Mr. Baird.

Mrs. Van Bommel: I want to be fair to all the presenters and sponsors of the bills that we’ve been hearing and the ones we haven’t heard yet. There are still some to come. So at this stage, because we agreed as a committee and the subcommittee agreed that we would proceed in this way, I think I would want to stand on the subcommittee’s agreement.

The Chair: Any other comments? Ms. Martel.

Ms. Martel: I apologize. I don’t normally sit on this committee, so I’m not sure what agreement was made with respect to how the bills would move forward. Madam Chair, I would appreciate your comments or your intervention just to describe to me what is your understanding of the agreement about how these would all proceed, so I would have some sense of that.

The Chair: I’ll hear from Mr. Baird and, in that case, I’ll take a couple of minutes’ recess so I can inform myself specifically. It’s been some time since that agreement was made. Mr. Baird, if you’d like to proceed, and then I think all I need is a two-minute recess.

Mr. Baird: There was an agreement to allow a number of government pieces of legislation to be voted on in exchange for some public hearings on a number of private members’ bills and other issues. We’ve had the public hearings portion of this bill and I think it’s been very productive. At this time, I guess the agreement is concluded and that there was only agreement for the public hearings portion of the bill.

What I’d like to see, rather than this issue being discussed and being involved in political horse trading behind closed doors, is that we make a statement as a committee that we’d like to consider clause-by-clause of this bill. I think it would probably take an hour—60 minutes, or 75 minutes maybe. It’s not a partisan issue. At the end of the day, the bill would have to be voted on in the House before it would become law, and the government will be able to make the decision on whether it chooses to call it. Obviously, a private member’s bill

can never pass unless the government calls it for at least third reading.

Could I find out what the other bills are before the committee so we know what we’re competing with here?

The Chair: Yes. In fact, we don’t need to recess. I’ve just been reminded by the clerk that there are seven bills, and the clerk can name all the bills in a moment. We have one left to do tomorrow. The agreement between the House leaders was that we would complete these bills and then the subcommittee of the committee would meet to talk about how to proceed with all of the bills at the end of the seven private members’ bills, which will end tomorrow.

If you could please, Madam Clerk, read out the list of bills that we have deliberated and the one that’s left.

The Clerk of the Committee (Ms. Tonia Granum): Bill 123 is left for tomorrow, which is Ms. Di Cocco’s bill on open public meetings. We’ve done Bills 58, 101—

Mr. Baird: I apologize. Bill 58 is what?

The Clerk of the Committee: That was Jean-Marc Lalonde’s bill to—I don’t have my notes with me. I could go get them.

The Chair: Neither do I.

Mr. Baird: I really would like to know which bill. I just don’t know the numbers.

The Chair: We had the Niagara wine bill—

Mrs. Van Bommel: Bill 7 was yesterday.

Mr. Ramal: Transportation.

The Chair: Keep going. The transportation bill.

Mr. Baird: What transportation bill is that?

Mr. Ramal: Mr. O’Toole’s, for the safety measurements classifications and the tax credit. And also the boat one.

The Chair: Keep it coming.

Mr. Craiton: Impaired driving while you’re driving a boat.

The Chair: Oh, here we have the complete list. If the members of the public will bear with us as we go through this procedural bit here, we’ll soon be done. Do you have the list, Tonia?

The Clerk of the Committee: We had Bill 137, An Act to amend the Income Tax Act to provide for a tax credit for expenses incurred in using public transit; Bill 58, the Safe Streets Act, which was Mr. Lalonde’s; Bill 153, An Act in memory of Jay Lawrence and Bart Mackey to amend the Highway Traffic Act; Bill 209, An Act to amend the Highway Traffic Act with respect to the suspension of drivers’ licences, which is the motorized boats one; Bill 7, which was the VQA; Bill 101 is yours today; and tomorrow is Bill 123, An Act to require that meetings of provincial and municipal boards, commissions and other public bodies be open to the public.

Mr. Baird: Thank you very much. I appreciate that information. What I want to do, as Ms. Di Cocco is seeking with Bill 123 for open public meetings, is to acknowledge publicly that this issue is important and should be dealt with at the next meeting of the committee, which is October 19, the first day the committee

will sit normally when the House resumes. This is not a partisan issue. I think this motion is a public expression that it's action, not talk, that we want to consider this bill expeditiously. I know Mr. Hudak feels very strongly about his bill with respect to Ontario wines, and there are some other bills that are obviously very important.

1240

I know, on behalf of the official opposition, we would be happy to have all of the bills go to clause-by-clause and be referred back to the committee, but I'd like to send a message to the House: I'd like to see this bill reported back to the House as expeditiously as possible, but to allow, at the same time, a fair opportunity for all members of the committee, be they the third party or the government, to reflect on what we've heard, be able to draft amendments, be able to share those amendments so we're not considering them with no notice. That's why I feel very strongly that we shouldn't lose momentum.

There's such a tide of momentum on this issue. The Ottawa Citizen has published five or 10 articles on this by Jeff Esau. The Toronto Star has really championed this issue with respect to Rob Ferguson's comments. The Ombudsman has just come out with his report yesterday, which will be tabled in the House on October 13. I just don't want to see us lose momentum, and I feel very strongly about this.

I've tried to approach this in a very non-partisan way throughout the day, and what this motion does seek to do—and I fully acknowledge it—is to put our feet to the fire. It says we won't talk about it later; we'll speak now with hopefully one voice to allow this bill to be voted on by this committee so that the House leaders can then consider it. The House leaders can't really consider it until it comes back. The deal—I have a copy of the motion—in the House was basically to send the bills to public hearings, and I acknowledge and appreciate that effort, but let's go all the way. Let's send a message to the House leaders that what we heard today is important enough to report back the bill in as reasonably and expeditious a time as possible. So I would ask all members to reflect on that.

This should not be a partisan vote. We have regularly in the House of late seen people split. So I look at the government members and beg your help on this. I have on seven occasions stood in support of government bills in the last session. Sometimes I've been the only member of my party to do so. I was just talking to Ms. Churley earlier today about Bill 183, the adoption bill. I may be the only member of the official opposition—I don't know—who stands up and votes for that government bill. So I invite you.

This is an opportunity. It's a small, minor committee procedural vote. If we don't have an opportunity for people to stand up and reflect on what we've heard today on this type of issue, we really never will on any issue. So I've tried to be non-partisan on this. I'm regularly in the House. I said I've supported government initiatives, sometimes against my own party. I hope that all members

will reflect on that and be able to give a thumbs-up to what is a pretty reasonable motion.

The Chair: Ms. Martel.

Ms. Martel: I appreciate the information with respect to what your understanding is of the agreement that was made by the House leaders before the session ended, with respect to some of the bills that would carry over. So I appreciate that the understanding is that we would at least be given some opportunity to go to public hearings, and then what happened after that was essentially not sorted out. So I understand that, but I would make two comments, then, in support of Mr. Baird's motion, if I might.

The first is that in order for Bill 101 to have gotten to this stage, to be part of the trading that went back and forth with respect to what private members' bills would proceed, because mine did not, I think the government, in agreeing to at least bring this to public hearings, must have seen some value in it and must have had some sense that they wanted it to go forward in some kind of process, otherwise it wouldn't have been part of the package; it wouldn't be part of the consideration that this committee is giving with respect to public hearings over the last number of days, and again tomorrow. So I say that in order for the government to have accepted that at the outset as one of seven bills that would move forward, there must have been some inclination on the part of government to be supportive.

Secondly, of the bills that are being debated, I think—and someone's going to correct me if I'm wrong—this is the only one where the government, by its actions after agreeing that the bill go forward, has given a clear indication that it's supportive. The government, in recent weeks, has made it very clear that they will put in the funding that's necessary to increase testing, to increase the infant screening to some 21 conditions. There has been a partial timeline that has been unrolled for that. There has been some indication of the funding that will be made available. So I say that it looks like the government clearly has decided to move on this issue of infant screening, has made that very public and wants to do that.

My argument in support of the motion would be, unlike the other bills that this committee has discussed and will discuss again tomorrow, that I don't think the government has given any clear indication with respect to the other bills, either the government bills or the opposition bills, that they have the intention of moving forward themselves in the same way. So I think, from my perspective, that accords this particular bill a different status or a special status that the committee could use to support Mr. Baird's motion.

For those two reasons, the fact that the government gave the green light for this, among a number of other bills that didn't make it to the floor—the government gave this bill the green light. They must have had some support for it. Secondly, I think that support has been reinforced by the government's most recent announcements that in fact they do intend to go forward on infant screening. I think that is a much different position on the

part of the government than the other private members' bills that the committee has been considering.

I would support Mr. Baird's motion. That's good enough for me in terms of moving forward and that the committee then, at the next earliest opportunity, could move forward and deal with the government amendments, and the government could get advice from the Minister of Health, for example, about what he wants to see, what additional things he wants to see, given that he's made a commitment to move on this matter already. So I would be supportive of the motion.

The Chair: Mr. Craitor, or was it Mr. Ramal?

Mr. Craitor: I just had a couple of questions.

The Chair: Go ahead.

Mr. Craitor: I'm the new kid on the block. Whatever happened, I wasn't there when it did, and whatever didn't happen, I wasn't there. I'm just trying to help the people get it through.

Yesterday, when I was sitting at Tim Hudak's VQA bill, we finished the meeting and it was suggested by Mr. Hudak that the bill be dealt with immediately. It was explained to us that there was an agreement reached and it was coming back on the 19th, and the bills were all coming back on the 19th. We discussed that that was already arranged. So this is coming back on the 19th. Am I right or wrong? That's what was said to me yesterday, that private members' bills are coming back on the 19th.

The Clerk of the Committee: The subcommittee would have to meet and determine the order, the date and the deadline for amendments on each of these seven bills.

Mr. Craitor: So this motion is saying, "Don't do that. Just come back and go clause-by-clause." Is that what this motion is saying?

The Chair: This motion is very clearly saying to come back on the 19th to this—

Mr. Craitor: And go clause-by-clause.

The Chair: And go clause-by-clause.

Mr. Baird: Can I respond?

The Chair: Sure.

Mr. Baird: What the motion says is—I love Mr. Hudak. He's a great friend of mine. I support his bill. It's on wine. It's on whether we'll protect the name of Ontario wine.

This is on such an important issue about life and death. The government obviously sees its importance. I commend Mr. Smitherman. I commend the Premier for his comments on sickle cell. He's on board, by all accounts. But I feel so strongly about this. What this is designed to do is, rather than this just go off into Never-Never Land, that this committee say, "You know what? This is important. We learned a lot today. We want to take the time to get it right, but let's move expeditiously on considering this bill and send it back to the House, hopefully with some amendments, to deal with sickle cell, among other issues."

It's non-partisan. It's sort of giving a little helpful nudge to the House so that they can have this bill as quickly as possible.

The Chair: If I could—

Mr. Craitor: I still have the floor. Let me just—

The Chair: If I could, though, just make sure—

Mr. Craitor: No, let me have the floor.

The Chair: I'm answering your question.

Mr. Craitor: This is coming back on the 19th, no matter what we do.

Mr. Baird: The committee might not even meet on the 19th.

Mr. Craitor: Let me finish, John. Come on, now. Give me a break here. I wasn't here. If you wanted to get this thing done, it could have been done before I was ever elected. I'm on your side out there. This has been going on for years. I'm sitting here wondering what happened. If it was that important, it should have been done, and I shouldn't be sitting here having to debate this. It should have just been finished with. But I'm just trying to get it through. So on the 19th this is coming back, no matter what.

The Chair: On the 19th there will be a meeting of the subcommittee to determine the process for all seven bills, including this one. That was the agreement among the House leaders. What this motion does is choose Bill 101 to be one where we deal—

Mr. Craitor: Over all the rest.

The Chair: —with the clause-by-clause on the 19th specifically because of its importance. That is the difference.

1250

Mr. Craitor: Let me just say, then, that I sat in this room today, and I'm sure many of us around this room shed a lot of tears. I'm also going to tell you, I sat in this room last week and I was there when this gentleman spoke about his son who was killed because a drunk driver who drove a boat went through—he was on the tail end and his son died. He believed we had to get legislation through because there are still people being killed by boat drivers who are allowed to drive when they're impaired. You don't need a license. He wants to change all that. To that gentleman and to all the other people who spoke who had lost family members, that was important. When I sat in that room, it was important to me how you get it through as quickly as possible.

I guess I'm just saying that we want to get this through. You weren't here in the room when this other gentleman spoke, and he was just as passionate. He wants to get his bill through and he's been working on it for years. So the objective here is, how do we get it through as quickly as possible? But to just jump one over another, that doesn't seem quite fair to the other groups who were in here as well.

We're coming back on the 19th and the committee decides what the order is. They could decide this will be the number one and then it just proceeds on, is that right?

The Chair: Could I say that there is no reason why, notwithstanding the agreement by the House leaders, the subcommittee couldn't meet in the meantime to determine the dates.

Mr. Craitor: To recommend that this will be the first bill?

The Chair: The subcommittee can meet at any time. The scheduled meeting for the committee is the 19th, so the subcommittee can meet at any time to start the determination of the clause-by-clause for these bills.

Mr. Craitor: So that bill could then be recommended as being the first one to be dealt with, and then we get on with it.

The Chair: Absolutely, within a subcommittee, yes. It would be brought forward to the committee on the 19th.

Mr. Craitor: In the meantime, we've added 19 to the list already, from what I understand. We've added 19 tests to the list that already exists.

The Chair: I believe so. Mr. Baird, go ahead.

Mr. Baird: Just to be clear: There is no agreement with respect to the clause-by-clause; there was only agreement by the three parties to have these seven bills come for public hearings. So there's no agreement among the three parties to go any further.

The committee's regularly scheduled meeting date is October 19. Generally committees, more often than not, don't meet on their regularly scheduled days unless there is something that has been put on the agenda. The subcommittee can definitely meet, no problem at all, and ask that this bill or any other bill come before the committee on October 19. It also might not. What I'd like to do is, rather than hoping it goes well at the subcommittee—and that meeting won't be in here, it will be within closed doors among the three parties—we say that we support this going to clause-by-clause at an expeditious date and that it can be reported back to the House.

I think you make a very good point with respect to Bill 209, with respect to impaired driving and boating safety. This is a one-page bill, and half of it is in French, so it's really a half-page bill. There are only three clauses in the bill, so clause-by-clause would be very expeditious. I think in that same committee meeting, we could consider Bill 209 as well. I'd be very happy to move an amendment to the motion that Bill 101, the Health Insurance Amendment Act, 2005, and Bill 209, which is the impaired driving motion that you mentioned, Mr. Craitor, be considered for the purpose of clause-by-clause on the 19th. That would deal with both issues, which are, as you acknowledged, very serious life-and-death issues.

Obviously the wine issue, while very important for economic development, not just to the Niagara region but the whole province—no one's going to die if we don't declare a rule about wines. So I'd be very happy to have Mr. Zimmer's bill on impaired driving considered as well.

The Chair: OK, so we now have an amendment to the motion before us. Before you speak, I think we should read out the amendment. The amendment now says, "I move that Bill 101 and Bill 209 be considered for..."

Mrs. Van Bommel.

Mrs. Van Bommel: We talked earlier about momentum, that there's momentum here, and there definitely is. There's no question about it. This is an issue that has been important to our government for a long time. As you acknowledged earlier, Dwight Duncan brought this

forward back in 2003, and there's no denying the importance of this.

What I think, though, is that this bill already has one advantage over all the other bills that this standing committee is hearing, and that is the fact that the government has already started to take action on it. We're already moving forward. You talk in your bill about MCAD and the TMS process. The government has already acknowledged that and is moving forward on those things, so there's an advantage your bill has that none of the others have at this point.

Since the sponsors of the others haven't made this kind of request of the committee, I think we need to be fair in our approach and go with the process that was originally agreed to, which was that we would do the hearings, and the subcommittee would get together and make determinations after that. I think we need to move with that.

Mr. Baird: In fairness, there's no agreement with respect to the subcommittee prioritizing the bills afterward. That's never been part of the discussion. I have the motion that Mr. Duncan presented in the House authorizing the committee to sit today and it makes no reference with respect to clause-by-clause. I want to give a helpful nudge, a push to make sure this doesn't fall off the radar screen.

Mrs. Van Bommel: It hasn't.

Mr. Baird: I heard today from Ms. Clark probably the most passionate presentation I've heard in my 10 years here, and I just don't want this to fall off the radar screen. I don't want to see it dealt with as political horsemanship and horse trading. I'd like this committee to say that this is really important. We have the ability to do that, to say, "You know what? The government obviously feels this is a priority." It's almost like the government says, "We're going to put a belt on," and we say, "Well, could you put suspenders on, too?" "No, no, we don't need it. It doesn't matter." "Well, put the suspenders on, then."

If the government's going to do this, then there can't be any objection to wanting to have the committee consider it. At the end of the day, the government will be in the driver's seat as to whether they call it for third reading. That's properly so, I don't deny that, but this is a life-or-death issue with respect to the bill. They're running out of the materials to be able to conduct these tests in six months, so something has to happen very quickly. I just don't want to see this train leave the station with the 19 conditions that they've announced and leave the sickle-cell car sitting on the track at the station. Frankly, I know George Smitherman doesn't want that either. I really do.

The Chair: Ms. Martel, and then I'm going to try, as a neutral Chair, to make a suggestion that might help us along here.

Ms. Martel: I apologize, then, if I cause a problem for you, Madam Chair. I would only add this, if I might, for the benefit of the government members: It seems that if we work with the amendment to the amendment that Mr. Baird has proposed, then the government has a private

member's bill that moves forward and the opposition has a private member's bill that moves forward.

I was here for the presentation last week as well. It was very compelling. The only difference between the two—because both were a reflection of enormous personal tragedy on the part of parents—and it may be a small one, is that in the case of this bill, the government has publicly signalled its intention. I do not see the same with respect to the bill put forward by Mr. Zimmer. I have not heard the Minister of Transportation or another government minister indicate how the government feels or how they are prepared to move. That's the only difference I see, because both were very compelling.

In the second proposal that has come forward, I see that an important government private member's bill that has affected a parent would be dealt with at the earliest possible opportunity, and an important private member's bill by an opposition member that deals with parents and children, to try to stop the tragedy that has occurred, would also be dealt with. I see that as a win-win for everybody. Frankly, at the end of the day, Mr. Baird is right: The government will still have the final decision about what happens after clause-by-clause, so that control is still there in the hands of the government.

1300

The Chair: Go ahead, Mr. Ramal.

Mr. Ramal: Thank you, Madam Chair. I've been listening to all the presentations and to Mr. Baird and Ms. Martel talking about the urgency of forwarding this bill as soon as possible. As a member of the government and as a person elected not a long time ago—and I heard all the deputations and all the people speaking about it—I believe that this issue is very important to our government. That's why the Premier talked about it and that's why the Minister of Health is trying to speak about it as much as possible, in order to apply it to all the hospitals across the province of Ontario. It's very important to our government and to our party. That's why Mr. Dwight Duncan, the Minister of Energy today, brought it to life in 2003 in order to be implemented and to be applied in all the hospitals across the province—it's been rejected.

I listened to many deputants. This is the first time ever this bill went to public hearings. We're only talking about some kinds of technicalities in order to forward all the bills and deal with it in terms of order.

As you know—I'm going to mention for the record—it's very important to me. I've listened to a lot of people. It's very important to our government and we want to see it done not today, but yesterday. But we don't want to fight over a matter of a couple of weeks' time. People have been waiting since 1965, so I think just a couple of weeks' time is not going to make a difference at all to the people in this province who are suffering.

I agree that we don't want to be trying to politically hijack any issues. We believe in it. The Premier agreed 100%, and the issue is very important to us. Also, the Minister of Health ordered all the specialists in this area to go forward. It's just a matter of time to implement it in a professional way. That's what I see.

As Mr. Craiton mentioned a few minutes ago, if it was important to all the parties before us, why hadn't it been dealt with in the past? We just got elected two years ago, and since we learned and heard about it, we forwarded it, we talked about it, we want to implement it, and we want it to see light and want to also protect the children of this province.

We believe it's not just about protecting the children; it's about protecting our futures and maintaining our health care and saving a lot of families across the province from crises. We believe that the kids are valuable to their parents and valuable to the government and to our society. I think it's a very important issue for us, and I would like the third party and the opposition party to stick with the agreement and the procedure and we can go forward—

Mr. Baird: There is no agreement, though—

Mr. Ramal: OK, whatever—stick with the procedure. We don't want to just keep fighting in front of the wonderful people who came from different parts of the province in order to talk to us. I would tell them that I'm 100% in support of the issue, I'm 100% behind it and I think it should be done, and we are going to do it.

Mr. Baird: Then pass the motion.

The Chair: Mr. Baird, if you'd like the floor again. Hopefully, if we cannot find a resolution to this, we'll take a vote soon.

Mr. Baird: I think too often this place doesn't work. In my 10 years—and I blame the Conservatives just as much as the Liberals and just as much as the NDP. We've all been very bad actors.

As an opposition member, I have tried. I have voted for many government bills. I have split from my party, the majority of my party, many, many times to stand up for what I think is right. When the government does something that's good, I stand up and say that it's good. I've defended the government. They're now closing three institutions for developmental disabilities and I speak up publicly and defend the government. They're bringing in Bill 183 on adoption disclosure. I voted in favour of it, against the vast majority of my caucus. I may be the only one who votes for it. I voted for seven government bills, and I'd like to see just once, even on a little technical issue—as government members, you can vote. Ms. Van Bommel is ably representing the government. This can be an issue. We'll see when the vote takes place whether everyone lines up behind the government line.

If you don't want to consider it on October 19, would you consider it on October 26? Would you consider it on November 2, November 9, just something so that it can get debated on? I just don't want to see this shuffled under the carpet, and that's what happened. The committee may not even meet on October 19. It doesn't have to meet, unless the subcommittee agrees to it. I'd like to see us, the committee, give a little helpful nudge to Bill 101.

I say to Mr. Ramal, I'm not going to look at the past and say, "Gee, I blame Frances Lankin for not getting back on returning the letter of the Sickle Cell Associ-

ation,” or “I blame Tony Clement for not acting on this, or John Baird when he was minister of children,” or say, “Dalton McGuinty’s government took two years to address this issue.” There’s some gathering momentum. Let’s fan that flame of the fire that’s starting to spread on this issue and get this bill debated. I just don’t want to see it go and let politics—and I’ve tried on every occasion to be as non-partisan and constructive as I can on this issue. I have.

The Chair: Are we ready to take the vote? Go ahead.

Mr. Brownell: There seems to be, I won’t say an impasse on this, but comments were made about the importance of the subcommittee, that subcommittees can make decisions, and that if this motion that’s on the table didn’t fly today, tomorrow the subcommittee could meet or anybody could meet from that subcommittee and make a decision that on the 19th this does go to clause-by-clause.

I don’t know who’s on the subcommittee. I’m subbed into this committee today. I had some time and took on the subbing-in. I’m just wondering if there would be a chance that the subcommittee—because this is important. We had compelling evidence today. We had wonderful testimonies today from individuals who gave very heart-wrenching stories. But all the while, I think we have seen the movement of this government to add 19, with the commitment from the minister of going “from worst to first.” That in itself is certainly evidence that there’s going to be something done here.

With regard to having the clause-by-clause, could we in the next few minutes just take a recess and have the subcommittee—I don’t know who’s on the subcommittee—get together and have a discussion on it, and then come back and have their presentation to us?

The Chair: We have one more bill to consider tomorrow. I don’t know if, in taking a recess right now, we can find the Conservative subcommittee member to do that. I certainly don’t object—

Mr. Baird: I think that’s a very constructive suggestion.

The Chair: Pardon me?

Mr. Baird: I think it’s a very constructive suggestion, and I’d be happy to represent the official opposition on the subcommittee. Would you, Ms. Martel?

The Chair: If everybody’s in agreement, we will take a 10-minute recess.

Mr. Brownell: It is my understanding—I just want to be clear—with the honourable member’s motion here, or his bill, that it’s on the 19th that the House leaders get together. Is that correct?

The Chair: No, it’s the—

Mr. Brownell: Or the subcommittee.

The Chair: The committee actually meets. This committee meets again on the 19th.

Mr. Baird: It can meet. It doesn’t necessarily have to meet.

The Chair: Well, that’s right. It doesn’t necessarily have to meet, but that is the scheduled date for the meeting, as I understand it. So the subs for the subcommittee

can meet now, if we could take a 10-minute recess and reconvene the committee.

Mr. Baird: I want to thank you, Mr. Brownell. That’s a very constructive suggestion.

The Chair: Thank you very much.

Mr. Brownell: I look at this as being—we had all this evidence today. Around this table, as my good member from Niagara said, there were a lot of tears; absolutely the tears welled up and whatnot. I think that, as a sub on to this committee today, if the chance is that tomorrow, or after the last bill, the subcommittee could get together and say, “OK. This is number one on the 19th”—

The Chair: Were you suggesting—and there seems to be agreement—that we have the subcommittee meeting now?

Mr. Brownell: Exactly.

The Chair: OK. Let’s do that, then. So we’ll take a 10-minute recess. If those representing the parties would please stay behind, and we’ll have a quick meeting.

The committee recessed from 1308 to 1322.

The Chair: We’re going to call the meeting to order just for a moment. Somebody took my gavel. If I could have committee members reconvene, please.

After some deliberation among the subbed-in subcommittee, we haven’t reached a solution yet. I can tell all committee members that each party is trying to work in good faith to resolve this. What we’re going to do—and I apologize to those who are in the audience here—is take a longer recess and reconvene at 2 o’clock. So I will call this meeting recessed until 2 o’clock, when we will reconvene to further discuss the motion before us. Thank you.

The committee recessed from 1323 to 1406.

The Chair: I call the standing committee on regulations and private bills back to order. We had recessed to consider an amendment before us. We’re going to reconvene when Mr. Baird, who I believe had the floor, is ready to do so.

Mr. Baird, we’re going to pick up where we left off. We were dealing with your amendment. If people are ready to take a vote, we will vote first on the amendment to the amendment.

Mr. Baird: Would it be better just to have one motion? I could just move the main motion so that there’s only one vote. Would that be easier?

The Chair: Sure. So you’ll include Bill 209 as part of it.

Mr. Baird: Yes. I’ll withdraw both of those motions—

The Chair: OK. That makes sense. Could you do that, then?

Mr. Baird: I move that Bill 101, the Health Insurance Amendment Act, and Bill 209 be considered for the purpose of clause-by-clause consideration at the regulations and private bills committee meeting on October 19, 2005, and that members of the committee be requested to submit amendments for consideration to the committee clerk as soon as possible.

I would not debate it.

The Chair: Now we just have one motion. Are we ready to take the vote on this motion from Mr. Baird?

Mr. Baird: Recorded vote.

Ayes

Baird, Martel.

Nays

Brownell, Craitor, Marsales, Ramal, Van Bommel.

The Chair: The motion is defeated.

Mrs. Van Bommel: I recognize how important this whole matter is not only to the people in this room but to all the families and the parents in this province. In light of that, I would like to move a motion.

I move that the committee request that the three House leaders give priority to Bill 101, An Act to amend the Health Insurance Act.

The Chair: Any discussion on the motion? Mr. Baird.

Mr. Baird: This obviously doesn't go nearly as far as I'd like, but I appreciate the genuine willingness to fairly consider the issue. It may be not as much as I'd like, but I appreciate it. I know it's a difficult issue, so thank you.

The Chair: Further comments? All right, we'll take the vote.

Mr. Baird: Recorded vote.

Ayes

Baird, Brownell, Craitor, Marsales, Martel, Ramal, Van Bommel.

The Chair: The motion is carried.

I believe that brings us to the end of the meeting. Thank you very much.

The committee adjourned at 1409.

CONTENTS

Wednesday 28 September 2005

Health Insurance Amendment Act (Supplemental Newborn Screening), 2005, Bill 101, <i>Mr. Baird / Loi de 2005 modifiant la Loi sur l'assurance-santé (dépistage complémentaire des nouveau-nés)</i>, projet de loi 101, <i>M. Baird</i>	T-151
Canadian Organization for Rare Disorders	T-154
Mr. John Adams; Dr. Diane Werhrett	
Hemoglobinopathy Group of Ontario	T-156
Dr. Isaac Odame	
Sickle Cell Association of Ontario	T-159
Ms. Dotty Nicholas; Ms. Lillie Johnson	
Dr. William Hanley	T-162
Mr. Wayne Sung	T-164
Ms. Molly Chin	T-165
Ms. Tammy Clark	T-167
Dr. Bob Frankford	T-170
Ms. Kai Gordon-Edwards	T-172
Ms. Jackie Hayes	T-173

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