

National Sickle Cell Awareness Day

The House proceeded to the consideration of Bill S-211, An Act respecting National Sickle Cell Awareness Day, as reported (without amendment) from the committee.

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The Acting Speaker (Mrs. Carol Hughes):

There being no motions at report stage, the House will now proceed, without debate, to the putting of the question on the motion to concur in the bill at report stage.

[Expand]

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Mr. Darren Fisher (Dartmouth—Cole Harbour, Lib.)

moved that the bill be concurred in.

(Motion agreed to)

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Mr. Darren Fisher

moved that the bill be read the third time and passed.

He said: Madam Speaker, I am proud to rise again today to speak to Bill S-211, an act respecting national sickle cell awareness day.

Bill S-211 seeks to establish June 19 as national sickle cell awareness day, bringing Canada on the same level, and in line with, international organizations like the United Nations, African Union, and the World Health Organization, all of which consider June 19 as World Sickle Cell Day.

Bill S-211 has been wholeheartedly supported by all members in this House and all senators in the other place, but no person has championed Bill S-211 more than Senator Jane Cordy of my home riding of Dartmouth—Cole Harbour.

Senator Cordy is a strong advocate for Canadians and has brought the voices of those affected by sickle cell disease to Ottawa. Senator Cordy understands the strength of awareness. We have the ability in this House, and in the other place, to bring Canada-wide awareness to sickle cell disease. Senator Cordy was back in Nova Scotia last week, and during a speech at a sickle cell workshop she said:

My fervent hope is that when S-211 passes it will provide the opportunity for Canadians and

especially those at all levels of government to learn more about sickle cell. The more we know about an issue, the more power we have to make changes, whether that change is creating policies and laws or changing our understanding.

In the spirit of that quote, I will do my best here to make sure that all members in this House understand what sickle cell disease, also known as sickle cell anemia, is, and what it means to be affected by it.

Most folks out there, if they were asked, probably would not know what sickle cell disease is. It is a disease affecting approximately 5,000 Canadians and their families. The number of Canadians diagnosed with the disease continues to increase. The Sickle Cell Disease Association of Canada now estimates that one out of every 2,500 children will be born with this disease.

Sickle cell is the most common genetic disease in the world. Sickle cell refers to the presence of abnormal hemoglobin resulting in crescent-shaped red blood cells. Unlike normal, doughnut-shaped red blood cells, sickle cells struggle to move easily throughout the body's circulatory system, and struggle to deliver oxygen to the organs. Sickle cells have a very limited lifespan compared to healthy red blood cells. The diseased sickle cells become stiff and break apart as they die, clogging the vessels and starving the body's ability to deliver oxygen to the organs. As the organs are starved for oxygen, patients experience extreme pain, especially in their bones.

I was reading an anonymous Q and A with sickle cell patients the other day where one participant, a young person, explained the nature of sickle cell pain so vividly. It really put the nature of the illness into perspective and I am going to share it now.

This person said, "You know the way the sky and the atmosphere changes gradually just before a major storm? That's how I feel my body changing just before an onset of pain crisis. It sucks knowing that it's coming and there's nothing you can do about it. When the pain hits you it takes everything away from you—you have no thoughts, desires, knowledge of anything, everything within you is focused on trying to get rid of the pain. Then the pain takes over. Completely. It might just be your arm, or your feet, or hips, or chest, but it chokes the life out of you, literally... The strongest painkillers don't really "kill" the pain—it only keeps it at bay and temporarily stops it from choking the life out of you. I am sure you've noticed the labored breathing just before the pain relievers take effect. It's not for show. You struggle to breathe, to live."

(1315)

Most of these people are experiencing lifelong debilitating pain. Some people affected by sickle cell anemia are confined to their homes, requiring around-the-clock care. Many folks with sickle cell are receiving regular blood transfusions and are taking pharmaceuticals to manage chronic pain. Numerous blood transfusions are not uncommon for someone with this disease. This speaks to the importance of donating blood. Canadian Blood Services calls donating blood "giving the gift of life", and it could not be truer. By donating blood, we could be giving someone who suffers with sickle cell disease a longer lifespan.

This disease primarily affects those with diverse ethnic backgrounds: African, Caribbean, Mediterranean, Middle Eastern, South American, and South Asian. In Canada, sickle cell disproportionately affects members of the African Canadian community.

Some time ago, I met with the Black Health Alliance and learned that black people were overrepresented among people with illness. I learned that discrimination could be one of the major reasons why sickle cell anemia lacked awareness. That lack of awareness results in individuals being underserved by the medical community.

I have heard loud and clear from folks, like my friend Rugi Jalloh, president of the Sickle Cell Disease Association of Nova Scotia, of the discrimination those patients with this disease experience. This disease can be debilitating and obvious, or debilitating and hidden.

These are folks like 16-year old Canadian Adeniyi Omishore, who says, "This disease is very limiting and many on the street look at me weirdly....Some kids in school even make fun of me." Contrast that with this anonymous statement by a Canadian sickle cell disease patient who said, "A good hospital stay is whenever I'm not perceived as a drug seeker/junkie. A 20 year old black kid asking for heavy doses of narcotics always triggers an alarm. I've been refused care many times because of this."

This shows the importance of increasing sickle cell disease awareness across our country, awareness for all health care providers to recognize and understand this disease, and the importance of recognizing discrimination and how it affects people with sickle cell. Time and again, when learning about this disease, I have heard that folks have gone to the hospital for care only to be turned away and treated as junkies looking for a fix. For someone to be turned away at the emergency room because he or she may appear to be an addict and not someone in major pain, we must do better. There are organizations across the country working hard to raise awareness.

The Sickle Cell Disease Association of Canada remains focused on building awareness of sickle cell disease. It is working to enhance methods of identification, diagnosis and treatment. It also partners with universities and researchers to help toward a cure.

The Sickle Cell Foundation of Alberta is doing great work by helping patients deal with the condition and helping improve their quality of life.

The Sickle Cell Anemia Association of Quebec is working to raise awareness among at-risk groups of this disease. It is promoting research and education, and working to support sufferers and their families.

The Sickle Cell Association of BC, led by Adobie McAllister, is working on an education handbook for sickle cell patients to help better inform them of treatments and to help handle their concerns.

The Sickle Cell Association of Ontario has educated the community about sickle cell and aims to reduce the incidence of sickle cell within at-risk communities. Its initiative on poverty deserves recognition also as chronic illness and poverty often go hand in hand.

As I mentioned, in my home province of Nova Scotia, the Sickle Cell Association of Nova Scotia, led by Rugi Jalloh, is working hard to support individuals with sickle cell and their families financially and morally. I met with this society and I was blow away by its incredible advocacy. I will admit that before our meeting, I knew very little about this disease.

(1320)

The Government of Canada recognizes the importance of rare disease research and has invested \$92 million since 2010. Close to \$1.3 million have been spent on sickle cell disease research, still some Canadians are living, undiagnosed, with this disease. Many Canadians have no idea they carry the sickle cell trait. Children of hereditary carriers of the disease who do not suffer any symptoms unfortunately have a 50% chance of inheriting the sickle cell trait and a 25% chance of inheriting the disease. These are frightening statistics and they speak to the importance of raising awareness. I firmly believe that, as a country, we can and will do better.

Some provinces are doing it right by automatically screening newborns for diseases like sickle cell, but many provinces still do not. We have a nationwide patchwork of testing programs, which is leaving Canadians with diseases like sickle cell undetected. Canadians are slipping through the cracks. This matters. If left untreated, sickle cell anemia not only leaves people with extreme pain; it can lead to organ damage, organ failure, and even death.

If members leave here remembering one thing they can share with their constituents today about sickle cell, I hope they will remember the importance of screening. We must encourage the screening of young children who are moving to Canada from countries with substantially higher risk of having sickle cell. We must screen all newborns in Canada for this disease and its trait. No one in Canada with this disease should go undiagnosed, and no one should go untreated. The earlier we diagnose, the better the outcome for individuals to lead a normal life.

Yes, Bill S-211 is an awareness bill, but awareness and understanding often lead to more research and less discrimination. For example, on the Sickle Cell Awareness Group of Ontario's website, Doreen Alexander wrote:

As a nurse, unfortunately I have heard the cries of many sickle cell patients in pain who are often misunderstood or dismissed by health care professionals while in desperate need for support.

Greater awareness could lead to more understanding and better training across Canada for health care staff. More people knowing about and understanding this condition could mean better, more supportive health care. Stronger research matters to sufferers of sickle cell disease. Every day, researchers are learning more about this debilitating disease. I have heard that doctors in Alberta are making progress with stem cell research and transplants, but we must continue to do more.

I would like to thank all my colleagues throughout the House for listening to me speak today about this and for their support, both past and continued, for Bill S-211. I ask all members in the House to continue supporting Bill S-211, an act respecting national sickle cell awareness day. Let us send a strong message to those who suffer with sickle cell that we support them, that we believe in stronger awareness for this disease, and that we hope greater awareness will keep sickle cell top of mind among our best researchers and health care providers.

(1325)

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Ms. Marilyn Gladu (Sarnia—Lambton, CPC):

Madam Speaker, I congratulate the member opposite for bringing awareness to this important issue. My question has to do with the association that promotes sickle cell awareness. Does it have specific asks of the government with respect to many of the things you have mentioned, like research and so forth, and could you elaborate on what those asks are?

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The Assistant Deputy Speaker (Mrs. Carol Hughes):

I would not know that, so I would say that the member is to address the question to the Chair.

The hon. member for Dartmouth—Cole Harbour.

[Expand]

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Mr. Darren Fisher:

Madam Speaker, we met with the Nova Scotia group and, at that time, its focus was on the awareness bill. That is where it wanted to put the emphasis. A fair bit of research is going on for sickle cell. Putting more focus on sickle cell specifically would drive more research toward finding a cure. Stem cell research is new on sickle cell. It is exciting and it is possible.

Right now, sickle cell patients need to have blood transfusions to extend their life expectancy. That is just not good enough. People can have a life expectancy of 40 or 50 years with sickle cell and they can extend it with blood transfusions. Imagine having 10 to 20 blood transfusions a month. Stem cell research is the direction researchers are looking toward right now. As I said, \$1.8 million were focused directly on sickle cell research, but more can be done.

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Mrs. Celina Caesar-Chavannes (Parliamentary Secretary to the Minister of International Development, Lib.):

Madam Speaker, my colleague from Dartmouth—Cole Harbour deserves kudos for championing this bill and for bringing it forward.

As someone who lives with the sickle cell trait, could he expand on what is necessary to ensure people are aware they have the condition? I knew I had it, so when I found a partner and had children, I was

able to do the test. How important is it to ensure that people are aware of their condition and are, therefore, able to address it when they find life partners and have children?

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Mr. Darren Fisher:

Madam Speaker, the true champion of this bill is Senator Jane Cordy, who brought forward a private member's bill in the Senate prior to the election being called in 2015, at which time it died on the Order Paper. It was reintroduced after the election. She is the true champion of this. She is the one who pushed this from the start and deserves the credit for the bill. She is also from the wonderful riding of Dartmouth—Cole Harbour, so it is always great to combine the two of us.

The number one thing we need to ensure is that we have newborn screening. It is absolutely important. When people are diagnosed with having the trait or having sickle cell disease, it is important to know from day one what kind of treatment plans are available. There are examples of young people being up to 20 years old before finding out they have sickle cell. They have gone through 20 years of excruciating pain. The way they manage their disease would be totally different if they were screened at birth and knew in advance.

(1330)

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Mr. Don Davies (Vancouver Kingsway, NDP):

Madam Speaker, in 2006, the WHO, of which Canada is a member, adopted a resolution urging support for sickle cell disease research. It is 10 years later. Would my hon. colleague inform us whether any progress has been made in Canada on this recommendation?

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Mr. Darren Fisher:

Madam Speaker, we are behind on deciding to designate June 19 as world sickle cell day or Canada's sickle cell day. We should have done this back in 2006 or 2008 when the UN declared it, but there is no time like the present. I hope and expect that next June 19 will be the first national sickle cell awareness day in Canada. I look to that. I hope it brings the awareness that drives us to further push research in a direction that will benefit Canadians and others in the world who suffer from sickle cell.

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Ms. Marilyn Gladu (Sarnia—Lambton, CPC):

Madam Speaker, it is a pleasure to rise in the House today to speak in favour of Bill S-211, an act respecting national sickle cell awareness day. This legislation seeks to designate June 19 national sickle cell awareness day in Canada. This is in line with many international groups that have also recognized the importance of raising awareness of this terrible disease. These include the African Union, the World Health Organization, and the United Nations, which designated this day for sickle cell disease in 2008.

There was a time when I was unaware of what went on in terms of the creation of these days and the benefits thereof, but since I have come to the House of Commons, nearly every day we have something presented as an awareness day for this or that topic. I have learned so much about the different needs of people suffering from various illnesses and about different causes. There is a lot of value in bringing forward and celebrating such a day when this kind of information can be brought to bear and the government can be informed of what the needs are to eradicate this terrible disease.

Today is not the first time sickle cell awareness has been brought before the House. A Nova Scotia senator brought a similar bill forward in early 2015. The same topic was brought forward by the current Minister of Science, who introduced Bill C-605 in 2010.

Designating June 19 national sickle cell awareness day would not give holiday status to this date. It would be used as a tool nationwide to raise awareness of this disease not only in the House but in schools, in workplaces, and at dinner tables across the country.

For these reasons, and many more, I would join my voice to those of my colleagues across the House and in the other House in favour of Bill S-211.

I would like to use my time today not only to show my strong support for the bill but to do everything in my power to educate Canadians about this little known disease.

[Translation]

Sickle cell disease is a condition people are born with. It is a hereditary disease caused by abnormal hemoglobin. Instead of being round like the letter o, in people with sickle cell disease, these cells look more like the letter c, similar to a farmer's sickle.

Hemoglobin is the part of the blood that carries oxygen and allows the vital organs to function. That ability is exactly what sickle cell disease affects. The red blood cells become hard and clog the blood vessels. Although normal red blood cells live for 120 days, sickle cells have a lifespan of no more than 20 days. The rapid breakdown of these cells often leads to anemia.

(1335)

[English]

Although there is no patient registry in Canada, it is estimated that approximately 5,000 Canadians live with sickle cell disease today. In the United States, the number is close to 100,000. Worldwide, sickle

cell disease affects almost 100 million people. However, many Canadians do not know the symptoms, effects, or treatments related to this painful disease.

Sickle cell disease causes complications in two ways. First is the breakdown of red blood cells at a rapid rate. Second is the blockage of blood flow in blood vessels. Both problems can cause immense pain, especially in the bones.

Sickle cell disease can also lead to a whole list of other complications, including damage to the liver, kidneys, and heart; infection; chest pain; acute joint pain; blindness; and stroke. It can also cause irreparable damage to major organs, going as far as heart failure. This multi-system disorder has also been known to cause premature death.

Sickle cell disease does not have a cure. However, it is treatable, and I would like to recognize all the medical professionals and caregivers who treat and support those who live with sickle cell disease across our country.

Simple lifestyle changes have been shown to make a tremendous difference in the disease, and those living with sickle cell disease are encouraged to exercise regularly, eat a healthy diet, and reduce the amount of stress in their lives. In fact, I think we could all benefit from doing those three things.

Many complications can be prevented or treated through regular blood transfusions and through powerful medication. Those living with sickle cell disease routinely have between 10 and 20 blood transfusions every month. As such, I want to encourage Canadians to donate blood whenever possible.

[Translation]

This is a disease people live with around the clock, and we need to do more to draw attention to the way it affects Canadians and the need to improve research and data collection. Many people say that education is the first stage in the process and that a national sickle cell awareness day is an important step.

Sickle cell screening tests are available, but many people do not know about them. Since sickle cell disease is hereditary, it is very important to get the word out to those who want to have children. Universal sickle cell screening now exists in every state in the United States and, in Canada, this test is available upon request in Ontario, British Columbia, Yukon, New Brunswick, Prince Edward Island, and Nova Scotia. Screening is available in a limited number of hospitals in Quebec, but plans are being made to make the test available across the province as soon as possible.

When a child is born with sickle cell disease, we do not always know what complications will develop. For the first six months of life, high levels of fetal hemoglobin in the blood help to prevent most complications, but things can quickly go wrong after that.

Infection is the biggest concern for children with this disease. According to the World Health Organization, sickle cell disease is one of the main causes of death in children under the age of five. We need to do more to ensure that sickle cell disease detection, awareness, and education become an integral part of our health system.

[English]

As I said in my speech, it is important that we bring awareness to this disease, do research into how we can prevent the disease or reduce some of the terrible effects it has on different organs in the system, support those who are living with the disease and those who are caregivers, and share with our global partners. As I said, we have only 5,000 people in Canada who have the disease, but there are millions around the world who have it.

There is research happening around the world. We need to be at that research table. We need to be collaborating. We have seen Canada lead in medical health research when it comes to vaccines, disease, and things like brain complications. We can contribute, but we also need to work with our partners around the world to have a big enough population to learn how we can combat this disease.

In closing, I would like to thank the sponsor of the bill. I encourage all my colleagues in this House to join me in support of those living with sickle cell disease and in support of those who care for them. With groups like the African Union, the United Nations Organization for Education, Science and Culture, and the World Health Organization, I want to recognize June 19 as sickle cell awareness day.

I believe Canada should take this step in the right direction and raise awareness about this important cause.

(1340)

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Mr. Don Davies (Vancouver Kingsway, NDP):

Madam Speaker, as the health critic for the New Democratic Party, and on behalf of my colleagues in the NDP caucus, I am proud to stand today and express our support for the bill as well. It would declare a special day to commemorate national sickle cell awareness day and to bring attention to this very important condition.

Sickle cell disorder is the most common genetic disease in the world. The WHO estimates that sickle cell anemia affects nearly 100 million people on the globe. Canada's first recorded case was published in 1966. In 2016, some 50 years later, it was estimated that between 5,000 and 7,000 Canadians live with sickle cell disorder.

In 1978, it was discovered that the gene responsible for hemoglobin is on chromosome 11. A prenatal genetic test for sickle cell disease was developed in 1980. To be affected, an individual has to receive the defective gene from both parents. If only one parent passes on the defective gene, that individual will be a carrier but not affected. If both parents are carriers, there is a one in four chance that the child will be affected by this disorder.

Fortunately, sickle cell anemia can be detected before birth, and couples who are both carriers may wish to consider prenatal testing for the condition. Sickle cell disease is more common among those whose ancestors come from certain parts of the world, including India, the Middle East, and from sub-Saharan African, Caribbean, and Mediterranean countries. However, it is very important to note that,

contrary to some common misunderstandings, sickle cell disease has no colour, because it also affects Caucasians from Europe and elsewhere. Getting all Canadians tested would be the best way to move forward.

Sickle cell disease is characterized by a mutation in the shape of the red blood cell, from a smooth circular shape to a crescent shape, which can result in the blockage of small blood vessels and the impairment of blood flow. This leads to a reduction in red blood cell survival and subsequent anemia. A sickle-shaped cell has a lifespan of only about 20 days, unlike a healthy cell with a lifespan of 120 days.

The problem of clogged blood cells and low blood count hampers the body's ability to bring oxygen to the organs. This starvation of oxygen most commonly manifests itself as severe pain in the bones and can damage shoulder and hip joints in particular, or cause chest pain. There can also be damage to the lungs, heart, liver, kidneys, and eyes.

The poor blood oxygen levels and blood vessel blockages that result from sickle cell disease can then lead to severe chronic pain, serious bacterial infections, and tissue death. The symptoms of sickle cell anemia can vary widely in number and severity. However, the most common symptoms are related to anemia and pain. Other symptoms are related to complications from those.

During painful crises, medications can reduce pain and help avoid complications, and extra fluids can prevent dehydration. Oxygen can be provided if there is not enough in the bloodstream. When anemia is severe, blood transfusions may be used to treat and prevent complications, and antibiotics are frequently administered when there are consecutive infections.

The lifespan of persons with severe sickle cell disease can be reduced by as much as 30 years. Currently, there is no cure. At this time, the only treatment options are to relieve symptoms by treating vaso-occlusive crises, preventing triggers, and administering blood transfusions to prevent anemia, and exchange transfusions to reduce hemoglobin S in the blood. Gene therapy is also being studied and holds some promise.

Many people with this condition are in reasonably good health and can live productive lives into their fifties and longer. Some people, however, develop severe symptoms and complications and require frequent hospitalization. The broad range of sickle cell disease symptoms may cause health care professionals to misdiagnose the condition.

In Canada, six provinces and two territories provide prenatal screening right now: Quebec, Ontario, B.C., Yukon, Nova Scotia, New Brunswick, P.E.I., and Nunavut. Currently, Alberta, Saskatchewan, and Manitoba are considering prenatal screening.

(1345)

While recognition of June 19 of each year as national sickle cell awareness day is important in order to promote awareness among Canadians of the disease, and the bill is a good start, it is not enough. We need more.

Since this disease can place a substantial burden on family members, better support is needed for caregivers, particularly the parents of children with the disease. Support for access to screening of

newborns and the genetic screening of adults at risk who wish to have children and improvements for diagnosis and treatment are long overdue.

Special awareness and communication plans for ethnic groups at risk are also important. Canada is, of course, one of the most diverse countries in the world. Many Canadians trace their roots to the Caribbean, sub-Saharan Africa, India, the Middle East, and the Mediterranean, which are regions where, as I have already pointed out, the SCD gene is more common.

We also need international co-operation and assistance to respond to requests from the WHO in a resolution adopted by the assembly in 2006 to help the most vulnerable groups identify and treat individuals with sickle cell disease. I think this is where all parliamentarians ought to be directing our attention after, hopefully, every parliamentarian votes in favour of the bill. It is not enough just to commemorate and recognize a disease. What is important in terms of government policy and what Canadians, whether they are at risk for SCD or not, expect from the government is action. We need to start seeing some meaningful resources devoted not only to SCD but also to other genetic conditions. I think that Canadians want Parliament to do everything it can to increase spending in research and treatment, so that we make the scientific and medical breakthroughs and inroads that are needed in order to find a cure for this condition and others like it.

I think health professionals need a special shout-out in terms of any bill before the House that deals with the health care field. Health care professionals are on the front lines of this disease and all others. We have to recognize the work that they do in what most Canadians would feel is the most important aspect of their lives, which is their health.

I know that many health care professionals, because of the relative rarity of this condition, are unaware of this disease, especially because of its uneven prevalence across the country, particularly in rural areas. Therefore, health care professionals need to be better informed about the prevalence of at-risk populations and the risk of misdiagnosis. We have heard other speakers in the House talk about the fact that people can present at hospital or emergency rooms with indicia that do not necessarily present as sickle cell disease, and in fact are often misdiagnosed, sometimes in a very stigmatized fashion.

Testing and treatment, and I will deal with testing first, should be available across Canada. In particular, we must not forget the rural and remote areas of this country, which are often left out of the equation. Treatment protocols and pain reduction strategies should be shared, since early treatment cuts the cost of care and sets out what steps to take.

I will focus a little on the international situation here, because I think most Canadians want Canada to play a responsible role on the world stage, take our place in proper form, and meet our responsibilities, particularly when it comes to health, and particularly when it comes to diseases, like sickle cell, which know no borders.

As I mentioned already, in 2006, the World Health Organization, of which Canada is a member state, adopted a resolution urging support for SCD research. Ten years later, I think it does no violence to any party in the House to point out that we have not made any progress in that regard. The resolution at that time stressed the urgent need for member states to:

design, implement and reinforce in a systematic, equitable and effective manner, comprehensive

national, integrated programmes for the prevention and management of sickle-cell anaemia.

Again, I congratulate my hon. colleague on moving this important bill forward. I think it is going to get all-party support to recognize this important day, but let us not leave it there. Let us heed the WHO. Let us do what we can in this Parliament to at least make a good start on fulfilling those obligations that the WHO called for and which Canada agreed to at the time.

(1350)

Transportation Modernization Act

Bill C-49—Notice of time allocation motion

[Expand]

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Hon. Bardish Chagger (Leader of the Government in the House of Commons and Minister of Small Business and Tourism, Lib.):

Madam Speaker, I would like to advise that agreement could not be reached under the provisions of Standing Orders 78(1) or 78(2) with respect to the report stage and third reading stage of Bill C-49, an act to amend the Canada Transportation Act and other Acts respecting transportation and to make related and consequential amendments to other Acts.

[Translation]

Under the provisions of Standing Order 78(3), I give notice that a minister of the crown will propose at the next sitting a motion to allot a specific number of days or hours for the consideration and disposal of proceedings of the said stage.

[English]

National Sickle Cell Awareness Day Act

The House resumed consideration of the motion that of Bill S-211, An Act respecting National Sickle Cell Awareness Day, be read a third time and passed.

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Mrs. Celina Caesar-Chavannes (Parliamentary Secretary to the Minister of International Development, Lib.):

Madam Speaker, it gives me great pleasure to stand in this place, in solidarity with my colleague from Dartmouth—Cole Harbour, to support S-211, an act respecting national sickle cell awareness day. I also want to acknowledge Senator Jane Cordy who brought the bill forward and was a real champion for the legislation.

I want to take some time at the outset of my speech to thank the member from Dartmouth—Cole Harbour. As he said in his speech, he did not know anything about sickle cell before. I alluded in my previous question that I live with sickle cell trait.

Last night was a very difficult evening with me. I was talking to my kids on the phone. I am an Ottawa mom and they are Whitby kids. I kept thinking how tough it was sometimes to be a mom when I was here.

I had the opportunity to start thinking about writing this speech. I thought where else in the world would someone from Dartmouth—Cole Harbour, who had no idea about this disease, meet up with someone who lived with the trait of this disease and be able to work together, along with every other member, to raise awareness, do some incredible work, and amplify the voice of Canadians who suffer day in and day out with this disease. I cannot thank the member and the senator enough for their diligent work in bringing this forward. I am so proud to be here to see this go across the finish line.

Other members in the House have spoken to the thanks we should give to our researchers and medical professionals. With this bill and this day, I urge them to continue to ring the alarm around this condition. Members have spoken to the tremendous pain individuals go through when they appear at the hospital, looking for help. Oftentimes very young children arrive at the hospital in excruciating pain, asking for pain medication. The automatic dial is set, that these people are addicts.

I urge health care professionals and researchers to continue to talk to their colleagues and use June 19 as the day to tell them to turn the dial the other way, to show compassion and humanity for individuals, knowing they may have a condition about which we might need a little more awareness.

As I mentioned, I live with sickle cell trait. I do not have any symptoms of the disease and go through my normal life pretty much fine. However, this disease affects individuals of the Mediterranean, Middle Eastern, South American, and South Asian communities, and it disproportionately affects members of the black community. Many different people are affected and impacted by this condition.

It is so important to have a day like this for a couple of reasons.

One is to create that awareness and to continue the advocacy for newborn screening. The fact that it has a patchwork across the country really does a disservice to Canadians. Again, we are talking about young people with this condition who suffer excruciating pain.

Second, we want to ensure that people who live with this condition are also able to talk about it. We have heard that they may undergo 10 to 20 blood transfusions per month. There are only 31 days in a month. They spend more than half their time in hospital getting blood transfusions.

At this point, I would like to take a page from both of the individuals who spoke to this, to give a massive shout-out to the Canadian Blood Services, and encourage people to donate blood. It really does save lives and makes quality of life for people a lot better, especially when we are talking about this disease.

(1355)

I am going to go back to the individuals, their caregivers and families living with this condition. I encourage people to use this day and every day to advocate, to talk to friends and to neighbours.

My colleague, the member for Sarnia—Lambton, said that it was a conversation we had in the workplace, at school, and at the dinner table. That is such a profound statement because we do not want this to just be politicians, researchers, doctors, or people who do not have access to everyday individuals. People live with this condition. They feel it. People should use this day to feel empowered to go out, talk to and advocate for themselves and their children, and tell their neighbours. They might need someone to give them a casserole a couple of days a month because they are in hospital. I have never made a casserole, but I could make a macaroni pie or something.

It gives people an opportunity to get together with their neighbours and really do what we do best as Canadians, and that is help each other out. Use this day to speak about it. Do not continue to suffer in silence or suffer alone.

I want to also speak to the importance of individuals in the community speaking to each other. Imagine being in hospital 10 to 20 times a month to get a blood transfusion. What does that do? That decreases a person's ability to go to school every day. It decreases people's ability to get good, stable employment. That decreases people's quality of life. If that happens, I assume these individuals need support. They need a community. They need, as they say, a village to help them in their suffering, in the transition they have with their family and their loved ones who are going through the condition.

It might be that a friend from school is able to bring homework home. It might be that individuals are able to get a hot meal from someone who shares that. It might be the fact that individuals are able to just breath for five minutes, because they are taking care of a child who is in exceptional pain.

Again, this bill and this day, June 19 would allow parents and loved ones the reprieve and the respite to say that they need help, or that they have this condition, or their sons or daughters or love ones have this condition.

Before I close, I want to give special kudos and shout-outs to the organizations that were mentioned by many of us today: the Sickle Cell Disease Association of Canada, the Sickle Cell Disease Association of Nova Scotia, and in particular, the Sickle Cell Association of Ontario.

Before getting to this place, I volunteered with a young woman in her nineties by the name of Lillie Johnson. Lillie Johnson is a force to be reckoned with and a staunch advocate for sickle cell disease. She received the Order of Ontario in 2011, the Toronto Public Health Champion in 2009, and was the first black director of Public Health. This woman is a tour de force in her advocacy for people with sickle cell. I worked in a research consulting firm. She solicited me to help her get the resources to advocate for research.

For my colleague who mentioned it, we do need continued and exceptional research dollars and funding for genetic conditions. We do need to continue to be that voice, to amplify the voices of those in our community who need our help, to continue to advocate for the funding to ensure Canadians can live the best possible quality of life.

I am so happy to stand with my colleague today. I am even happier right now to give a shout-out to his wonderful daughter, Ava, who is totally cool. I will do that right now.

(1400)

[Expand]

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Mr. Bill Blair (Parliamentary Secretary to the Minister of Justice and Attorney General of Canada and to the Minister of Health, Lib.):

Madam Speaker, I want to begin my remarks by building a little on the remarks made by my colleague from Whitby. She referenced a number of very important advocacy organizations for those who suffer from sickle cell disease, and it is important that we acknowledge their important work.

I would like to take the opportunity to bring to the House's attention another extraordinary organization in the city of Toronto. It is called Camp Jumoke. It is a charitable organization that has been operating since 1994. This is an organization that is entirely volunteer. It receives no government funding but does receive support from the community. Since 1994, it has organized camps every summer for children in our community suffering from sickle cell anemia. I want to acknowledge the extraordinary volunteers and the commitment of the organization for the great work it does. Over the past two decades, I have had the privilege of attending a number of events for this organization and of meeting the children who are affected by sickle cell disease.

As we deal with this issue and speak about declaring a day of awareness, it is important to keep in mind those young kids and their families who have been affected by this disease and to remember those who are working tirelessly in our communities to make a difference and support them.

Because of the nature of these kids' illness and the way they suffer, they miss, on average, 50 days of school each year. They are unable to participate in many things most kids take for granted. To have the opportunity to spend time with each other and experience the fun of a summer camp with people who understand the limitations their health condition places on them is extraordinary. It is a great privilege for the House to have an opportunity to call on all Canadians to keep at the forefront of their thinking those children, their families, and those who support them.

Now I will go to my prepared remarks. We welcome the chance to add our voice in support of Bill S-211. I want to reassure Canadians living with sickle cell disease that the government and the people of Canada support them and have their backs. This act respecting national sickle cell awareness day is a testament to our national commitment to increase awareness of sickle cell disease and to improve diagnosis and treatment as we work to find a long-term cure for those affected by this disease.

Sickle cell disease is a devastating disease, as I said, that cannot be ignored. It is diagnosed more than 100 times each year in this country when a baby is born with this rare blood disorder. Those children join the other 5,000 Canadians already living with this disease and the hundreds of millions of people like them suffering around the world.

These are people who learn to cope with tremendous pain from a disease that, to date, has eluded a cure. The pain episodes they experience are due to bone marrow necrosis. These are people who suffer frequent painful attacks that send them to hospital for blood transfusions and drug therapies to manage their disease. They are far more susceptible to infection and have an increased risk of stroke and vision loss. Perhaps most alarming is that these people expect to live shorter lives than other Canadians, because sickle cell disease can lead to serious bacterial infections and tissue death, which can frequently result in an early death. Life expectancy is calculated to be 30 years less than it is for most Canadians. Aside from the terrible loss of loved ones, Canadian society as a whole is shortchanged when this happens. First and foremost, we lose the valuable contributions of these individuals to our economy and our communities. We also pay the high cost to cover their frequent stays in hospital, an average of \$20,000 per week for a one-week stay, and there are generally many more weeks than one.

This does not begin to capture the debilitating impact this disease can have on those individuals living with sickle cell disease and their families and friends. Few of us can imagine how harrowing the diagnosis of sickle cell disease must be, yet it is a reality that a significant proportion of the population knows only too well. Approximately 5% of the world's population carries the gene for sickle cell, which means that it is bound to surface in some Canadian families and communities.

(1405)

In fact, given Canada's multicultural composition, it is sadly inevitable that we will see more babies born with this rare blood disorder. Studies suggest that the odds of a Hispanic person having sickle cell disease is one in 1,000, and that jumps to one in 500 for those of African ancestry. For a couple to have a child with sickle cell disease, both parents must be carriers. According to research, when both parents are carriers of the gene, each pregnancy they have has a one in four chance of the child being afflicted with sickle cell and a one in two chance that the child will be a carrier, even if he or she does not have the disease. The problem is that people with the sickle cell trait often do not know they have it, as they do not have the symptoms of the disease, even though they can pass the gene for the disease on to their children.

That is why we need all parliamentarians to lend their support to Bill S-211. It would create a national sickle cell awareness day each year on June 19 to promote awareness and to spur action to address this dreadful disease. A dedicated national disease day would help prospective parents understand the risks of being a carrier and potentially having a baby with sickle cell. It would also help to increase diagnosis among newborns to make sure that youngsters with sickle cell get the appropriate treatment as soon as possible. This can prevent the complications and improve the child's quality of life. Thanks to earlier advances in diagnosis and treatment, kids born with this inherited disorder can receive the right treatment and support as they grow up, to enable them to live active and productive lives.

Equally important, this national day would inspire researchers in their quest for a cure for sickle cell disease. As the parliamentary secretary noted earlier, some of this country's top scientists are already increasing our knowledge of these disorders and discovering new treatments. For instance, the Canadian Institutes of Health Research is involved in several clinical trials for the treatment of the disease, as well as in the treatment of sickle cell-related pain. This work is taking place under the International Rare Diseases Research Consortium, which we have helped to establish. The Canadian Institutes of Health Research is also engaged in international collaboration on rare-disease research

through E-Rare. That is the European Union's main initiative to fund research into rare diseases. This collaboration is enabling scientists in different countries to work together on a common interdisciplinary research project. These are the kinds of hopeful steps that can be inspired by a national sickle cell awareness day each June 19 in Canada, critical steps that would lead to promising results that can improve the lives of Canadians living with this disease.

Therefore, I take this opportunity to call on all parties to release this potential by supporting the passage of this important bill. Let us be part of the solution to this perplexing health challenge by standing up for Canadians already living with the disease and by helping to ensure that we protect future generations from it.