PRIVATE MEMBERS' BUSINESS

National Sickle Cell Awareness Day Act

Thursday, December 1st, 2016

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

moved that Bill S-211, An Act respecting National Sickle Cell Awareness Day, be read the second time and referred to a committee.

He said: Mr. Speaker, I am proud to rise 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, aligning Canada with international organizations such as the United Nations and the World Health Organization, both of which already recognize this date as World Sickle Cell Day.

I would like to commend, if I could, Senator Jane Cordy, who is from my home riding of Dartmouth—Cole Harbour, for introducing this important bill, and I would like to thank her for allowing me the honour to sponsor the bill in this House.

Coming here to Ottawa as a member of Parliament not only means that I get to meet fascinating people with fascinating stories to tell, but it also means that every day is a constant learning experience. I am hopeful that neither of these experiences will change during my time here.

Many people have not heard of sickle cell disease, and if they have, they do not understand what it means to have it. Allow me to briefly describe what sickle cell disease, also known as sickle cell anemia, is. Sickle cell disease is a hereditary genetic disease and refers to the presence of abnormal hemoglobin, resulting in crescent-shaped red blood cells. Normal red blood cells are doughnut-shaped, and move easily throughout the body's circulatory system, delivering oxygen to the organs. Healthy red blood cells carry out this important life function for up to 120 days, whereas sickle cell diseased cells have a lifespan of only about 20 days.

Sickle-shaped red blood cells unfortunately do not float easily in blood vessels and regularly become stiff and eventually break apart. The diseased red blood cells clog in the vessels and starve the body's ability to deliver oxygen to the organs. Because the organs are continually not receiving adequate oxygen, the result is severe pain, especially in the bones. Most sufferers feel that pain in their shoulder and hip joints as well as in their chests. I am told that the pain is truly debilitating.

Canadians affected by sickle cell disorders are those with diverse ethnic backgrounds: African, Caribbean, Mediterranean, Middle Eastern, South American, and South Asian. I was amazed to find out that it is the most common genetic condition in Canada.

The disease currently affects approximately 5,000 Canadians, and the number of Canadians diagnosed with this disease continues to increase. Here is a statistic that really stuck out for me. The Sickle Cell Disease Association of Canada estimates that one out of every 2,500 children will be born with this disease.

People affected by sickle cell anemia are living in chronic pain. Some are confined to their homes, requiring constant care, while others can live mostly normal lives. However, even those living close to normal lives, live with the realization that life with constant pain is most likely on the way. That pain will limit mobility and affect their quality of life. I am sad to say that people with sickle cell disease have a reduced life expectancy, 30 years lower than the national average. There is currently no cure for sickle cell disease. Research is desperately needed.

In late September, I met with Ms. Rugi Jalloh, president of the Sickle Cell Disease Association of Nova Scotia, along with her delegation, Mr. William Njoku, Mr. Ricardo Peguiro, and Dr. Jacob Pendergrast. Each of them had compelling and personal stories of how this disease has affected their health or the health of their family members.

Rugi herself has the sickle cell trait, meaning that she is a hereditary carrier of the disease. Though she does not suffer from any symptoms of the disease, a child of hers would have a 50% chance of inheriting the sickle cell trait, or a 25% chance of inheriting the disease itself. Imagine having to live with that frightening statistic.

William told us of how he lost a friend to the disease recently, and his grief was compounded by the fact that his sister is one of many sickle cell disease sufferers who live in chronic pain. She is mostly bedridden and receives home care. His sister has a diminishing quality of life.

As Dr. Pendergrast emphatically explained in our meeting, sickle cell disease does not have a cure. Researchers are working on therapeutic options for sickle cell disease sufferers. Dr. Pendergrast explained that sickle cell disease patients can receive regular blood transfusions and can take a powerful drug called hydroxyurea to manage their chronic pain. This may sound like an easy, solid solution for sufferers of sickle cell disease, but these folks are routinely having 10 to 20 blood transfusions a month. This is yet another reason why we must encourage Canadians to donate blood when possible.

It is important to note that sickle cell anemia is an inherited disease. We cannot catch it from someone. It cannot be communicated from one person to another. Due to a lack of awareness in Canada, I learned that many people who carry the sickle cell trait had no idea they did until they had a child diagnosed with the disease. I firmly believe that raising awareness could change this. Due to the lack of awareness, there are Canadians out there who are living with this disease and remain undiagnosed. These people are living with chronic pain and sometimes have their symptoms dismissed as just those of another would-be patient asking for pain killers. When left untreated, sickle cell disease can be fatal. Canadians in high-risk ethnicities for sickle cell who feel they have symptoms or feel that they have been misdiagnosed should be encouraged to take a simple and pain-free blood test. A diagnosis is that simple.

Earlier I mentioned that there is a high risk of babies born to sickle cell carriers inheriting the disease. Luckily, some Canadian provinces are moving in the right direction. I am pleased that newborn screening for sickle cell disease is available in the Yukon, British Columbia, Ontario, New Brunswick, Prince Edward Island, and now my home province of Nova Scotia.

I understand that the Sickle Cell Disease Association of Canada is advocating for a national newborn screening program, which would also help identify carriers with traits.

Since 2008, June 19 has been recognized internationally as World Sickle Cell Awareness Day. The awareness day was created to increase public knowledge and bring awareness to the struggle sickle cell disease sufferers endure on a daily basis. This date was chosen to commemorate the day on which a resolution was adopted by the United Nations General Assembly, recognizing sickle cell disease as a public health concern.

Sickle cell disease affects almost 100 million people worldwide, and according to the World Health Organization, it is one of the main causes of death for children under five years of age.

I am sure many folks out there would ask why we need to make another day of awareness for a cause. Why should Bill S-211 matter to Canadians? When it comes to health issues, especially when it comes to health issues that generally affect very specific demographics, we must raise awareness. There are Canadians out there who do not even know that they carry the sickle cell trait. Awareness will ensure that more folks are tested, that we have a better understanding of what it means when our friends or family are diagnosed with sickle cell, and what it means if we ourselves are diagnosed. By raising awareness, we bring attention to this serious hereditary genetic disease. We keep it top of mind among our best researchers, our fundraisers, and our communities.

I want to thank all of my colleagues from throughout the House for listening to me speak on Bill S-211. After sitting in my office and listening to the stories of those affected and suffering from sickle cell disease, I jumped at the opportunity to sponsor and support this bill.

Canada is a world leader when it comes to championing human rights and maternal and newborn health. We are known throughout the world for our optimism, compassion, and empathy. We have the ability here to shine a light on this disease and to change the lives of those who are suffering. If we, as parliamentarians and Canadians, were to adopt June 19 as national sickle cell awareness day, we would be lending a powerful united voice to the world stage in recognizing the devastating effects of this disease. Together, we can honour those who suffer in silence, those who spend 10 to 20 days per month sitting in hospitals getting blood transfusions, and those babies who are born every day with this debilitating disease.

I ask hon. members to join me in supporting Bill S-211 to establish June 19 as national sickle cell awareness day.

Ms. Christine Moore (Abitibi—Témiscamingue, NDP):

Mr. Speaker, private members' bills cannot propose the expenditure of public funds by the government. That is why we introduced a bill that focuses on raising awareness.

I would like to know what, specifically, the member is going to ask for from his government colleagues. Obviously, we need to raise awareness, but we also need to give more help to family caregivers, namely mothers and parents who are looking after sick children and children who need to be hospitalized frequently. They need more help.

What is more, what is my colleague going to ask for in terms of international aid so that we can do more? What, specifically, is he going to ask for from the government? What is he going to fight for?

Mr. Darren Fisher:

Mr. Speaker, I am merely asking for us to join other international organizations to recognize June 19 as international sickle cell awareness day. Other groups, other international organizations have already started the process. I would like to add the voice of our country and unite with those other organizations.

Mr. Garnett Genuis (Sherwood Park—Fort Saskatchewan, CPC):

Mr. Speaker, I thank my colleague for bringing the bill forward. It is certainly one that we are going to be supporting in the official opposition and one that I expect will get support from all parties and all members in the House.

I want to pick up on the issue of screening and its benefits. My understanding is that screening happens throughout the United States and in certain jurisdictions in Canada but not others. I wonder if he could comment as part of the awareness-raising exercise we are doing here, the importance of advance screening and maybe what steps could be taken throughout Canada to ensure the availability of that screening across the board.

Mr. Darren Fisher:

Mr. Speaker, four or five provinces in Canada are already doing the screening. Others will follow suit—

Ms. Christine Moore:

Mr. Speaker, six.

Mr. Darren Fisher:

Mr. Speaker, six provinces have already started with the screening process. I expect others to follow suit. I expect also the pressure on the other provinces coming from the six provinces that have already passed the advanced screening. This will provide that ability for people to know through a simple blood test and through newborn screening. The trait is out there. We want more people to know when they carry the trait. There are misdiagnoses going on all the time. People are going to hospital with pain in their bones and they are being sent home to take Tylenol. This is how important newborn screening is. We need that awareness. We need parents to know when this is an issue with their newborns.

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

Mr. Speaker, I would like to thank my hon. colleague for introducing the bill. As someone who lives with the sickle cell trait, I am really happy that this is coming forward. I have heard stories as well of individuals who proceed to emergency rooms only to be sent away because the health care professionals believe that they are looking for morphine for addiction purposes.

Could my hon. colleague explain why this awareness is so important not just for the individuals, but for their families, for communities, and for health care professionals?

Mr. Darren Fisher:

Mr. Speaker, we need to ensure that health care providers understand the number of people out there who could be carrying this trait or could have this disease. Just think of one person showing up with that problem being sent away, with the suggestion that they just go home and take Tylenol or that their child must have fallen somewhere and maybe hurt themselves. Think about how important being able to correctly diagnose this disease would be. It is not a perfect world. We are not able to cure this at this point, but correctly diagnosing this disease gives people the ability to be treated in the proper manner and have the understanding of what their options are. The options may not be perfect, but the options are much better when we are able to diagnose this properly.

Mr. Len Webber (Calgary Confederation, CPC):

Mr. Speaker, I am pleased to rise today to contribute to the debate on Bill S-211. The proposed legislation before us today will recognize June 19, on an annual basis, as national sickle cell awareness day.

Approximately 2,000 people living in Canada today have sickle cell disease. Increased awareness of their disease would be beneficial, given the low level of public knowledge at this time. It is a hereditary disease. It is not contagious. Carriers are usually not sufferers of the disease, but in combination with a carrier spouse, the disease usually becomes apparent in their offspring. This disease is most common among those with ancestors from India, Saudi Arabia, the Mediterranean, the Indian subcontinent, and the Sub-Saharan countries in Africa. However, it is still found in other cultures as well. Just to give people an idea, there are an estimated 43 million carriers, with 3.2 million people having the disease because both parents were carriers.

What is sickle cell disease? It is a group of red blood cell disorders. Those with the disease have abnormal hemoglobin. As many know, hemoglobin is the part of the red blood cells that carries vital oxygen throughout the human body. We know how important it is that tissues in the body receive a steady and life-sustaining supply of oxygen to work well. Hemoglobin takes the oxygen from the lungs to the parts of the body that need it. Normal cells are a disc shape, sort of like a donut. This shape allows the cells to be flexible. This flexibility and shape allows the cells to travel easily through blood vessels throughout the body.

Sickle hemoglobin is different. It forms stiff rods within the red cell, and this changes the cell's shape to something more like a crescent or sickle shape. As members can imagine, this creates enormous problems. The sickle-shaped cells result in blockages because the cells are stiff and unable to pass through the vessels easily. These resulting blockages mean that vital oxygen stops reaching the parts of the body that need it.

What impact does this have on the person with the disease? A lack of oxygen results in attacks of sudden and severe pain throughout the body. It is a horrible condition. These pains occur without warning, and often result in hospitalization. The pains usually last five to seven days. While not always the cause, it has been noted that pain crisis can be triggered by temperature changes, stress, dehydration, and even living in high altitudes. Of course, any infection that normally causes a rise the number of red blood cells triggers the disease as well.

Fortunately for most children with the disease, pain usually subsides between pain episodes. Nonetheless, many children known to have the disease take penicillin daily to help the immune system, and face a life-long regimen of daily folic acid. For teens and adults, the pain is usually chronic. The effects of chronic pain are well know. They have a huge impact on the education, the employment, and the human mind of the sufferers.

Due to the lack of oxygen to vital organs on a regular basis, sickle cell disease often begins to cause long-term damage to vital organs. It is common for those with the disease to develop serious issues with their skin, their brain, their bones, their spleen, their heart, their kidneys, their liver, their lungs, and even their eyes. The spleen is particularly susceptible because of its narrow blood vessels and its basic job of clearing old red blood cells.

If this was not enough, there is another layer of cruelty to this disease. Normal red blood cells have a typical 90 to 100 day existence. Sickle cells last only about 10 to 20 days. Imagine what a toll this takes on the human body when it has to replenish red blood cells at 10 times the normal rate. When the body cannot keep up, which is often, there is a shortage of red blood cells and this results in the sickle cell anaemia. The most visible side effect is fatigue. As I mentioned before, this also adds to the pain, the long-term organ and tissue damage, and the toll the disease takes.

Sadly, this disease is a lifelong illness, and when I say “lifelong”, we must not kid ourselves. Lifelong is not a happy story either. Sickle cell disease shortens lives, but it depends greatly on where one lives and one's access to help.

In first world countries like the United States, life expectancy can range greatly, from 40 to 60 years. This is about four times longer than it was 40 years ago. Now, about 90% of those with the disease can expect to see their 20th birthday, and 40% of those will die by age 50.

Is there a cure? There is a treatment and it is called hematopoietic stem cell transplantation, or HSCT. HSCT is the best-known option at this time. Unfortunately, most people with the disease are either too old for a successful transplant or do not have a genetically matched person able to make the donation. The success of this type of treatment is heavily dependent on having a great match.

For HSCT to be successful we need an early diagnosis and good medical treatment. Those who are willing to donate bone marrow should consider the positive effects that their donation could have. Given the need for the best match possible, I specifically suggest that those in affected cultural communities help promote donation of organs and tissue, bone marrow, and blood.

In the meantime, the disease takes it toll. There are increased chances of stroke, infection, gall stones, joint pain, low immunity, erectile issues, bone infection, leg ulcers, vision problems, preeclampsia in pregnant women, and heart and kidney failure.

The pain of the disease often means that patients are prescribed opioids to deal with the pain. The good news is that addiction among sickle cell patients to opioids is not any higher than among the general population. However, that said, opioid addiction is a reality for many with sickle cell disease. We have heard a lot in the House recently about the effects of opioid addictions, and it is alarming. This type of addiction is often deadly, and even when it is not, it results in many other significant problems for patients and their families.

There are an estimated 5,000 Canadians living with the disease and the rate is increasing. There is prenatal screening, but with the knowledge comes the difficult decisions that parents must consider, which I cannot imagine.

The Sickle Cell Disease Association of Canada does a lot of advocacy and awareness work. I applaud it for its efforts, which have have gone a long way toward bringing this disease into the fore and making it better known in our society. The association faces an uphill battle in finding a cure. Research dollars are not easy to come by, especially for a disease that is most prevalent in parts of the world that are not able to attract the attention of major pharmaceutical companies. It is still a disease that is very much not discussed, even within the communities most affected.

However, things are improving. There is an increase in research funding and awareness is slowly building.

Passing this legislation would go a long way to normalizing discussion about the disease. It would show those with the disease that we care and would help to educate those around them about their disease.

I will be honest that I knew nothing about this disease until I prepared for this speech. As I learned more about sickle cell disease and the thousands of Canadians who suffer from it, I wanted to share my comments with others. I applaud the hon. member for presenting this bill and the work that he has done on this. I give him my thanks. I am happy that I was able to talk a bit about it here today to help share awareness.

Let us support this legislation and keep spreading awareness and education.

Ms. Christine Moore (Abitibi—Témiscamingue, NDP):

Mr. Speaker, I am pleased to rise in the House to speak about awareness of sickle cell disease. One of the reasons I think it is important to talk about is that I had to treat people when I worked as a nurse intern in a small, remote village in Senegal. This disease is particularly prevalent in sub-Saharan Africa, so it was a big concern for us. I also studied this disease when I did additional training in the field of international health. I therefore think it is important to talk about it. This is the most prevalent genetic disease in the world. It affects approximately 100 million people worldwide and 5,000 to 7,000 people in Canada.

Although people from all ethnic backgrounds can have this disease, it tends to be more prevalent among those with ancestors from India, the Middle East, the Mediterranean, particularly Greece and Italy, sub-Saharan Africa, and the Caribbean. There is a connection between this disease and places where malaria is prevalent; however, since it is a bit complicated to explain, I will not elaborate any further right now. If anyone would like more information, I would be happy to explain it to them.

It is an autosomal recessive disease. That is kind of a complicated genetic term. Basically, it means that people have to inherit the defective gene from both parents to get the disease. A child who gets the gene from just one parent is a carrier but will not have symptoms. People who might seem perfectly healthy, who have no health problems, no pain, nothing, can have a sick child because they do not know they carry the gene. That is important, and I will come back to it later.

I will try to explain the disease in simple terms so that most people can understand. Red blood cells are usually round, kind of like a donut that has been squashed in the middle. They flow freely through blood vessels. When they enter capillaries, donut-shaped red blood cells fit together well and flow unimpeded. Normal red blood cells usually live for about 120 days.

Diseased red blood cells are sickle shaped. They do not flow through blood vessels properly. Although it may seem obvious, I still want to point out that a sickle shape has two points. When these blood cells flow through capillaries, they can cause tears and create problems. Also, these red blood cells live for only 20 days, so anyone with this disease becomes anemic. Anemia is a condition that happens when an individual does not have enough red blood cells. Oxygen does not circulate properly in the blood, because oxygen is usually carried by red blood cells.

As it has already been said, a lack of oxygen can cause all kinds of health problems and a lot of pain. It can also cause localized problems, such as a higher risk of infection wherever the problems are. Depending on the seriousness of the problem, people with this disease often have to receive blood transfusion and take medication for pain and other medication for infection, if any infection occurs. This can also cause dehydration, in which case an IV can be administered to rehydrate the patient. That about covers all the treatments.

While some patients might actually manage to live normal lives with very few hospitalizations, others will be hospitalized frequently. As this is a genetic disease that patients are born with, some very young children, and even infants, will have to be hospitalized.

This can be especially worrisome when a baby is suffering and crying endlessly and the parents cannot figure out why, especially if the parents did not even know they were carrying the gene and that they may have transmitted the disease to their children. That is why I think it is important to raise awareness about the disease, especially among health professionals.

One of the problems we have concerns people in remote regions in particular. Since the disease is more prevalent among certain cultural groups, most doctors and nurses in remote regions will have never seen a patient suffering from sickle cell disease. It is therefore not the first disease that will spring to mind.

They have studied and read about every disease in the book, but after a while, they often rely on their experience and on what they have already seen. It can be hard to have a patient who is suffering so much. A doctor might be quick to diagnose such individuals with fibromyalgia or any health problem other than sickle cell disease, especially when it comes to adults. Health professionals assume that if the adult had sickle cell disease he or she would have been diagnosed long ago. It is not something that health professionals will think of, especially in regions where there are very few people from the different cultural groups that I already mentioned.

One of the most important things to do is to raise awareness among health professionals, ensure that they know about the disease, and that they think about it in order to make a diagnosis more quickly and avoid misdiagnosis problems that delay treatments. That was the first important point I wanted to raise.

Another very important point concerns raising the public's awareness. Pre-natal screening is now offered in six provinces and two territories. Three provinces are considering it. Thus, we can hope that,

in two or three years' time, most or all provinces and territories in Canada will have their own pre-natal screening program.

The problem is that older individuals have no idea whether or not they are carriers because the screening was not done when they were born. It would be advisable to offer the test to couples thinking of having children, especially those from the cultural groups most susceptible to this disease. This would let them know whether or not they risk giving this disease to their child and allow them to make an informed decision.

Generally speaking, if both parents carry the gene, there is a 25% chance that the child will have the disease. If both parents know that they are carriers, they might choose to have only one child. If that child does not have the disease, the couple might not take another chance and instead limit the size of their family thereby avoiding having children with the disease. In order to make these decisions, couples must have that knowledge.

In addition to pre-natal screening, health professionals need to be able to talk to couples who are thinking about having a baby. These couples need to be told that the test exists and that there is information available. In order for that to happen, health professionals need to know about the disease and must be able to give people that option.

The last point that I wanted to raise is that people with sickle cell disease, particularly children, who live in remote areas may find it difficult to receive care. These young patients are often referred to specialized centres for children, which can cause a lot of problems for parents. It is therefore important to provide more support for family caregivers, particularly parents. It is often women who make the sacrifice to take care of the health of their children, who stay with them, and who do all the travelling. Often, these women are not compensated as they should be for all the help they give to society by making that choice.

We need to realize that there is an extremely high rate of divorce among couples who have a child with sickle cell disease because of the onerous care such children often require. We need to do more for family caregivers.

It is important to raise awareness, but we also need to go further and figure out who should be targeted for education and how this would actually apply in a health practice.

I was pleased to speak to Canadians to help them to learn more about sickle cell disease.

Ms. Kamal Khera (Parliamentary Secretary to the Minister of Health, Lib.):

Mr. Speaker, thank you for the opportunity today to voice my strong support for this very worthy and necessary legislation. I am proud to promote and support Bill S-211, an act that would make June 19 a national day to raise awareness for sickle cell disease, or SCD for short.

I want to thank Senator Jane Cordy and the member for Dartmouth—Cole Harbour for bringing this extremely important bill to the House.

By supporting the bill, we can join the African Union, the United Nations, and the World Health Organization in observing world sickle cell awareness day on the June 19 every year. Setting aside this dedicated day is not about joining an international club. It is about supporting people living with sickle

cell disease, a devastating genetic disorder that affects millions of people around the world, including an estimated 5,000 Canadians.

People with sickle cell disease experience frequent bouts of debilitating pain that damages their quality of life and which, very often, shortens their lives. This is a very complex disease that still baffles the medical community.

To try to explain it simply, people who have SCD inherit two abnormal hemoglobin genes, one from each parent. At least one of the two abnormal genes causes a person's body to produce an abnormal type of hemoglobin called “hemoglobin S”. When the person has two hemoglobin S genes, the disease is called sickle cell anemia. This is the most common and generally most severe kind of sickle cell disease.

Without getting too technical, sickle hemoglobin is not like normal hemoglobin. It can form stiff rods within the red blood cell, changing it into a crescent or sickle shape. These cells are not flexible and stick to vessel walls. This can cause a blockage that slows or stops the flow of blood. When this happens, oxygen cannot reach nearby tissues, leading to a long list of complications that can compromise the person's life.

Sickle cell disease provokes attacks of sudden, severe pain that can occur without warning. The person usually needs to go to the hospital for treatment. Blood transfusions and drug therapies are used to treat and manage the disease. Stem cell transplants are the only potential cure.

It is hard to watch a child suffering from a pain attack, but it is heartbreaking to know that this is something they will rarely escape as they grow older. Adolescents and adults with SCD often suffer from chronic pain that limits their ability to attend school or go to work. Needless to say, this has negative ripple effects on their families' incomes and housing.

However, even that does not capture the long-term consequences of SCD. Over a lifetime, the disease can cause major organ damage that eventually results in premature death. Tragically, most will endure excruciating pain for most of the years they have.

As much as this takes a terrible toll on the individuals involved and their loved ones, it also comes at a high price for the health care system. The lifetime cost for a patient with sickle cell disease has been estimated at $9 million. In Canada, the total cost to treat patients with sickle cell disease for their lifetime may be approximately $4.5 billion.

More than dollars and cents, common sense dictates that we must do whatever we can to improve the lives of these individuals. I have seen patients who suffer from this serious blood disorder. In every case, I can attest to the serious health challenges they face. Therefore, I know how crucial it is that we raise awareness of sickle cell disease.

I also know from experience the importance of genetic testing for prospective parents and the necessity of screening newborns for the disorder. Early diagnosis and regular medical care can prevent complications and improve the well-being of affected individuals and their families.

Sickle cell disease is most common among individuals whose ancestors come from India, Saudi Arabia, and Mediterranean and sub-Saharan African countries, but in rare cases, it also affects Caucasians.

One of the best ways Canadians can help is by donating blood to provide sickle cell disease patients with the blood transfusions they require, not just on June 19 but every day of the year. Donors are especially needed from ethnic communities whose heritage traces back to the Mediterranean, Middle East, South Asia, Africa, and the Caribbean.

We also need to find ways to better educate Canadians about this disease and explore ways to work more productively with our partners all across the country to provide better support for sickle cell disease patients and their families.

Especially important is to continue research programs that spawn new sickle cell disease treatments that will someday lead to a cure.

Advancing these goals is precisely what Bill S-211 sets out to do. Once passed, this bill would dedicate June 19 as national sickle cell awareness day in Canada. This would send a clear signal to everyone, as a nation, that we need to improve the diagnosis and treatment of sickle cell disease and demonstrate our unwavering support for Canadians living with this terrible disease.

Earlier this year, I had the pleasure of meeting with members of the Sickle Cell Disease Association of Canada. I am proud of the work already under way in this country to alleviate the chronic pain of sickle cell disease sufferers.

Through the Canadian Institutes of Health Research, the Government of Canada has invested resources in rare disease research, including $1.3 million for sickle cell disease research, since 2010. Top researchers across Canada are actively working to identify long-term solutions to the health problems facing people with sickle cell disease.

CIHR is also a founding member of the International Rare Diseases Research Consortium. It was established to explain the causes of rare disorders and to develop diagnostic tools and treatments. There are currently four sickle cell disease clinical trials under way as part of this major international research initiative.

These studies will contribute to increasing our knowledge about the disorder and hopefully lead to the discovery of new treatments while ultimately pinpointing the cure that people with SCD seek. Until that day comes, the Government of Canada will continue to work with our provincial and territorial partners. Together we will address the health challenges confronting Canadians as we transform Canada's health system to ensure that it meets the needs of each and every one of us.

It is now up to all parliamentarians to do their part by designating June 19 national sickle cell awareness day in Canada. I encourage all members to lend their support to Bill S-211, which would provide people living with sickle cell disease the national recognition they deserve.

Once again, I want to thank Senator Jane Cordy and the member for Dartmouth—Cole Harbour for bringing this extremely relevant piece of legislation to the House. Canadians with sickle cell disease are counting on us to improve their lives and livelihoods as we improve their health and quality of life. Let us make sure we do not let them down.

Mr. Garnett Genuis (Sherwood Park—Fort Saskatchewan, CPC):

Mr. Speaker, it is a pleasure for me to rise to debate this very important bill before the House today. I suspect I will breathe a little less fire in this speech than I did in the one I gave earlier this afternoon.

Oftentimes, we deal with issues that are relatively uncontroversial, on which we agree. All of us in the House are generally united, if not on means, certainly on where we want to go, which is to make life better for Canadians within our constituencies and across the country. It is nice when we can unite around certain common objectives that are important and that are transparently in the best interests of the country.

To say that this bill is not controversial does not mean it is not important. Even before we pass the bill, the fact of debating of it and putting some of the conversation around the issues of sickle disease onto the record is going to have a positive impact in awareness. I want to congratulate the member for Dartmouth—Cole Harbour on bringing it forward. This bill was originally brought forward in the Senate. I want to recognize the good work done by the senators. I had a chance to review some of the debate that took place there as well.

Why is this important? Awareness in general is good, but awareness of sickle cell disorders is particularly important because we know there is often a lack of awareness out there, that someone may be suffering from a sickle cell disorder and not be aware it. They may seek help in responding to it, and not receive appropriate care because of that lack of awareness.

Identifying June 19 as awareness day helps to move us in the direction of more people being aware when they experience what may be symptoms and to ask their physicians if they are related to the sickle cell issue. It helps to ensure that health providers are more aware of this issue as well. It gives us the opportunity in the House to have the debate and raise awareness of this issue. It also creates a focal point on efforts throughout the country to raise awareness around this.

Some of my colleagues have mentioned that June 19 was not picked at random. This is an awareness recognized in different parts of the world, and it aligns us with those broader international efforts around sickle cell disease.

Various colleagues have talked about some of the medical background on this, but it is worth revisiting and underlining it.

Over 5,000 Canadians live with sickle cell disease in some form. Estimates are that about one out of every 2,500 children born in our country has some sort of this condition. I am told that in the United States sickle cell disease is the most common genetic disease, as far as that country goes.

There are three predominant forms of it in this part of the world: sickle cell anemia, which is the one people may have heard the most about; hemoglobin SC disease; and then hemoglobin sickle beta plus thalassemia.

Essentially what sickle cell disease involves is a deformity of a part of the red blood cells, which makes those red blood cells not last as long. Therefore, people with sickle cell disease often suffer from reduced red blood cell count and other things that are associated with that.

These different kinds of diseases can be associated with a lot of pain. The associated misdiagnosis of that pain can be an exacerbating problem for people who are experiencing this. In some cases, we know of instances where people have been seeking treatment for their pain and have been dismissed because

the assumption is made that they are just seeking painkillers not related to pain but for inappropriate purposes. That is one thing that can happen to people legitimately seeking help for this. Another issue may be that people are simply being given painkillers that do not actually deal with the underlying problem they are facing.

These are some of the things we know have happened to Canadians who are experiencing this underlying problem, but there is not a sufficient awareness about where this is coming from.

It is really important that people who have one of these disorders know about it so that they can get the proper support. Although there currently is not a treatment, and I appreciate the comments made by various colleagues about the need for more research to be gathered, there are mechanisms for managing symptoms that exist, things like blood transfusions and various drugs.

These are challenges that are genetic. We know that some people are carriers and others have the disease. It is passed on genetically; it is not something that is contagious.

However, emerging research suggests that there is a positive impact associated with things like lifestyle and diet. Those things can have a positive impact on a patient's quality of life. While we are dealing with a problem that is genetic in its origin, it does not mean that lifestyle cannot have a positive impact for that person. A person's health status, generally, is the result of the interaction between their genetics and the environment that they are in, in the broad sense of it.

The other important aspect of awareness is that in children especially, but also adults, who are dealing with sickle cell disorders, it can influence their level of fatigue and their ability to concentrate. There can be a relationship between these challenges and memory lapses. Having that awareness helps a person navigate school or work environments. It helps with the awareness of those they are working with, perhaps a teacher, in the case of a student, in terms of helping accommodate the specific issues that a person has.

Having that awareness significantly helps with the accommodation and the ability to succeed and thrive in light of a challenge that a person faces.

This is why I think it is particularly important that, as we talk about awareness, we also move the discussion toward screening and how having newborns go through a screening process and being aware of a sickle cell disorder they may have and be able to plan and respond to it makes a very significant difference.

We know that in every state in the United States sickle cell screening occurs. In Canada, it is available in some places, but not everywhere. There is a good opportunity, I think, to discuss what the benefits of expanding screening would be.

We know, of course, as with any health service, there is a cost to it. However, when we look at the availability of specific health services, one of the metrics we can look at, although it is not the only one or the be-all end-all, is what are the dollars per life saved? In other words, with an investment in a particular kind of screening or treatment, what is the positive impact going to be, in terms of lives saved?

I have looked at some of the research on this, with respect to sickle cell screening. I think the evidence pretty clearly points to the fact that, on efficiency grounds, investments in this area really do

pay quite substantial dividends, in terms of lives saved. There is a pretty direct relationship there and, in terms of a dollars-per-life-saved metric, the impact is pretty good. The benefits there are clear, from advanced screening.

Sometimes when we talk about health care, we are more likely to put the dollars into the sort of end-stage treatments as opposed to the things in advance, the preventative, the screening things, but often investments in preventative-type of health care can pay, actually, the most dividends. This is one of those examples.

Just to add to the context, in terms of awareness, many of my colleagues have already pointed out that there is a disproportionate impact of this within certain cultural communities. I know others have listed them and I am running out of time, so I will just say that there is a disproportionate impact. It is important, especially as our country becomes more diverse, that we not ignore those diseases that particularly impact certain communities that may include more newer Canadians.

Also, it is important to be aware that it is not just those communities that are affected, but that all different kinds of cultural communities can theoretically have sickle cell disorder.

That basically covers it. June 19 would be an important day for us to mark this, as we continue the efforts in this House and beyond to raise awareness about sickle cell disorder and to look for solutions to it.

The Assistant Deputy Speaker (Mr. Anthony Rota):

Resuming debate, the hon. member for Central Nova. I want to remind the hon. member that he will have approximately five minutes, and when the bill comes before the House again, he can start off and take up the rest of his time.

Mr. Sean Fraser (Central Nova, Lib.):

Mr. Speaker, instead of cutting my speech in half, I will try to trim it down and focus on some submissions that I think add something new to the debate.

Before I begin, I would like to thank Senator Jane Cordy for her tremendous work in bringing the bill forward in the Senate, and of course my colleague, the hon. member for Dartmouth—Cole Harbour for ensuring that the bill had a sponsor and got to the floor of the House of Commons. He is a tremendous guy, I swear.

Very quickly, the prevalence of this disease has been covered to some extent. We know that somewhere in the range of 5,000 people are aware of their diagnosis in Canada, although I would submit that it could be far more significant, given the poor diagnostic record that we have around the world, and 100 million people may be affected worldwide.

The symptoms of this terrible disorder have been covered at some length and very eloquently. We heard about how the unique shape of the blood cells can cause blockages to the blood vessels and prevent oxygen from getting to tissues, leading to severe chronic pain, tissue death, and indeed, a reduced life expectancy of up to 30 years.

We have also heard about the disproportionate impact on ethnic minorities, particularly those who have ancestors from sub-Saharan Africa, the Mediterranean, India, parts of the Caribbean, and other parts of the world.

We have also heard some great submissions on the incredible cost to society of this disorder, coming in somewhere in the range of $9 million over the course of the life of a person who may suffer from this disease.

One of the things to which we could draw a little extra attention is the importance of early diagnosis as it relates to infant mortality. Newborn screening is extraordinarily important when it comes to sickle cell disorder, because without these diagnostic tools, without recognizing it early on, we may not be able to put newborns on the life support they so desperately need, so they can avoid the immediate symptoms and threats to their lives as they begin.

I would like to just hit on two points, if I could, in the little time that I have. The first is that, of course, this awareness day came to pass initially through a UN General Assembly resolution that urged all of the UN's member states to raise awareness for sickle cell disorder. We have an obligation, even though a General Assembly resolution is soft law, so to speak, according to the International Court of Justice, to consider it as a recommendation of the international community in good faith. I would suggest that, by hosting this debate, we are considering it in good faith, and I would submit to this House that we go one step further and actually adopt the bill into law, so that we can have an awareness day in Canada and do our part to raise awareness.

This disease is not well understood, and what I find somewhat offensive about it is that it may be a result of latent systemic racism that runs through our society. Many social problems do not have a light shone on them because they disproportionately impact ethnic minorities, and the world's western communities that are dominated by wealthy Caucasian culture do not often draw awareness. That simply is not fair.

I cannot help but think of an analogy today, on World AIDS Day. This was a disease, HIV and AIDS, that disproportionately impacted the LGBT community and minorities or other cultures from all around the world. It was not until Magic Johnson came forward in North America and announced that he was HIV positive that it drew the western-centric view to this disease and we started promoting research and searching for a solution to help those who suffered from it.

This is something I think is very important, and creating an awareness day can help raise awareness among our entire community. Even though it may not impact me or people of my ethnicity, it is nevertheless important that we raise awareness so others can benefit from the awareness day.

An awareness day can be used by advocates for this cause to organize blood drives, and they have done so. They can use it to help raise money for research. They can lobby those provinces that do not yet have newborn screening, to ensure that we bring down the rate of infant mortality, not just in Canada but around the world.

I am thankful for this opportunity, and I urge all members of this House to support the bill so we can have sickle cell awareness day in Canada.

The Assistant Deputy Speaker (Mr. Anthony Rota):

The time provided for the consideration of private member's business has now expired and the order has dropped to the bottom of the order of precedence on the Order Paper.