

# National Sickle Cell Awareness Day Bill

## Third Reading

**Hon. Jane Cordy** moved third reading of Bill S-211, An Act respecting National Sickle Cell Awareness Day.

She said: Honourable senators, I am pleased to speak to third reading of Bill S-211, An Act respecting National Sickle Cell Awareness Day.

This bill sets out to follow the lead of the United Nations and establish June 19 of each year as national sickle cell awareness day in Canada.

Honourable senators, sickle cell disease is a multisystem genetic blood disorder. It affects every organ of the body, including the eyes, kidney, liver, spleen and brain, and it can lead to stroke in children as young as two years of age.

Sickle cell disorder is the most common genetic disease in the world. The World Health Organization estimates that the sickle cell anemia trait is found in nearly 100 million people worldwide. It is estimated that 5,000 people live with sickle cell disorder in Canada. Many others in Canada are carriers of the sickle cell trait, and most do not even know they carry this trait.

With sickle cell, the red blood cells become deformed. Normal blood cells are doughnut-shaped and designed to move easily through the body's blood vessels to deliver oxygen to the organs.

In patients with sickle cell, the blood cells become stiff and sickle-shaped and they do not function as healthy cells. A deformed cell does not flow easily through the blood vessels and can get caught up in the vessels and break apart. This can result in clogged blood vessels and low blood count or anemia. The sickle-shaped cell has a life span of only 20 days, unlike a healthy cell which has a 120-day life span. The problem of clogged blood vessels and low blood count hampers the body's ability to bring oxygen to the organs. The body cannot keep up with the rate of blood cell deterioration and is unable to replace the cells as quickly as they are breaking apart. This starves the body of oxygen and most commonly manifests itself as severe pain in the bones. This lack of oxygen to the organs can damage shoulder and hip joints and cause severe chest pain.

Infection is a major concern for children with sickle cell disorders, and an immediate regimen of daily penicillin is required to manage infection.

Older children and adults with sickle cell disease may have few problems or they may have a pattern of ongoing complications.

I had the pleasure of meeting a wonder young man, Adeniyi Omishore, who has just received a hip replacement because of sickle cell disorder. He spoke on September 29 during the Sickle Cell Disease Association Advocacy Day on Parliament Hill. He spoke to

parliamentarians as he reflected on the challenges of living a so-called normal life when you are a teenager with sickle cell. Honourable senators, a 17-year-old should not have to have hip replacement. Adeniyi is a courageous young man who remains positive about his situation. He is truly an inspiration to others.

Honourable senators, sickle cell disorder is hereditary. The disorder is passed on when a person inherits a sickle cell gene from their mother and another from their father. At this time, there is no proven absolute cure, but since 2009, the Alberta Children's Hospital has been performing non-chemotherapy-based hematopoietic stem cell transplant as a possible cure. The results to date have been positive. The sickle-shaped cells have been replaced with healthy cells and there have been no cases of transplant rejection or graft-versus-host disease. This is very encouraging. However, at this time, the treatment is not viable for everyone as not all those with sickle cell disorder are eligible candidates for this procedure.

For the vast majority of patients at this time, treatment consists of managing the symptoms. Research is showing that a healthy lifestyle and diet have a positive effect on quality of life. Of course, early diagnosis is the catalyst for the most effective treatment and managing quality of life.

Honourable senators, knowledge is power. The more we know about an issue, the more power we have to effect change, whether that change is in our policies, our institutions, or our understanding. The reality of sickle cell disorder and the sickle cell trait is that a staggering number of people who carry the trait are not even aware of it. There is also an alarming lack of knowledge of the disorder, not only among Canadians, but also within the medical community. However, this is starting to change.

I previously told the story of a mother and her experience with her young son who was crying because of extreme pain in his arm. She and her husband thought he must have injured his arm in a fall, but they couldn't find any signs of bruising or swelling. They brought him to the hospital for examination by the doctor. An X-ray showed nothing out of the ordinary, and the doctor told the parents to take their son home and give him Tylenol.

After three days with their child continuing to cry in pain, they returned to the hospital, and this time they were blessed. The doctor on duty that day had just learned about sickle cell disease. Because of this new knowledge, the doctor ordered a blood test. The boy's test came back positive for sickle cell. The parents were both carriers of the sickle cell gene, but they had not even heard of the disease before that day.

Now that the child's doctors and parents were aware of his condition, a suitable treatment and pain management plan was put in place. This doctor has changed the life, not only of this young boy, but also of his family. How fortunate they were that this particular doctor, who was knowledgeable about sickle cell disease, was on duty that day. Unfortunately, this is not an isolated experience. Many patients have similar stories to tell, and these experiences highlight exactly why an awareness day is necessary. Honourable senators, health care should not depend on being lucky.

Universal newborn screening for sickle cell and other genetic blood disorders would make a big difference. Newborn screening will identify those born with sickle cell and

also will identify children who are carriers of the sickle cell trait. Managing sickle cell disease is a life-long process. The logical first step is early and proper diagnosis. When people are made aware they are carriers of the sickle cell trait, it will help those individuals make informed decisions later in life when planning a family.

When asked about this in committee, Lanre Tunji-Ajayi, the President of the Sickle Cell Disease Association of Canada said:

How do we prevent sickle cell disease? By people even knowing that they carry the trait. I've heard parents say, "If I had known that I am a carrier and my partner is a carrier, perhaps I would choose a different partner." I've had parents say that when they go through the pain that their child goes through with this disorder, and they realize it's not worth it.

Again, we ask people to get tested and make their own informed decisions. Even if you still want to be with this person and possibly end up having a child with sickle cell disease, knowing ahead of time and educating yourself as to the treatments available. . . can help reduce the heartache and confusion that comes with being told out of the blue that your child has sickle cell disease.

This simple test provides the information needed to ensure early and proper treatment. Lacking this knowledge can lead to misdiagnosis or ineffective treatment as was the case for the parents of the young boy who experienced extreme pain in his arm on a visit to the hospital.

In some cases, because of the persistent pain and need and desire for pain management medications, it is not uncommon for doctors to dismiss a patient as someone just wanting drugs, especially if the patient is a teenager. Senator Stewart Olsen asked some excellent questions about this during the committee study of the bill.

Honourable senators, something as easy as a simple blood test at birth would prevent these situations and would provide medical personnel with the information needed to properly treat the patient.

At this time, Ontario, Quebec, British Columbia, Yukon, New Brunswick, Prince Edward Island, Nunavut and Nova Scotia currently perform universal newborn screening for sickle cell. Nova Scotia began screening in 2014. The one-year report card showed three babies flagged with sickle cell and another 63 babies were flagged as carriers of the sickle cell trait.

The Sickle Cell Association of Canada is aggressively advocating that the remaining provinces and territories begin universal newborn screening as soon as possible. The association is also advocating that the newborn screening program should be national in scope.

Universal screening for sickle cell disorder of all babies will provide doctors and researchers with the ability to track the disease. Honourable senators, because it is genetic, it can be tracked.

So why should we have a National Sickle Cell Awareness Day in Canada?

Honourable senators, the United Nations, the African Union and the World Health Organization have all recognized sickle cell disease as a public health priority. They also all recognize June 19 as World Sickle Cell Awareness Day to help raise awareness of the condition worldwide.

World Sickle Cell Awareness Day has been held annually on June 19 since 2008. The day, June 19, was chosen to commemorate the day on which a resolution was officially adopted by the General Assembly of the United Nations recognizing sickle cell disease as a public health concern.

I am pleased that my province of Nova Scotia has recognized June 19 as World Sickle Cell Day.

I would like to congratulate and thank Premier McNeil and Health Minister Leo Glavine and Rugi Jalloh the President of the Sickle Cell Disease Association of Nova Scotia.

Bill S-211 would add Canada's voice to this important cause by marking June 19 as National Sickle Cell Awareness Day in Canada. We are a diverse country, and many Canadians can trace their roots to sub-Saharan Africa, India, Saudi Arabia and the Mediterranean, all regions where the sickle cell trait is common. It is important that Canadians learn more about this disease.

I have been fortunate to meet many wonderful, courageous people who live with sickle cell. They would like Canadians to be more aware of sickle cell disorder. They would like newborn screening to detect sickle cell at birth so that suitable treatment can begin immediately. They want treatment that will improve the quality of life of those with sickle cell disease and their families. They would like more education of health professionals, caregivers and school personnel about sickle cell disorder, and, honourable senators, they would like to see a national strategy for sickle cell disease.

Honourable senators, Bill S-211 would recognize June 19 as national sickle cell awareness day. It is just a start, a small start on the road to making things better, but when I attended the sickle cell advocacy day on Parliament Hill, those present were excited and hopeful about this bill. They're excited because it means that people, particularly parliamentarians, are listening. It means that on June 19 of every year, there will be an opportunity to raise awareness about sickle cell disease to all Canadians.

Honourable senators, I may have introduced Bill S-211, and Bill S-227 before it, but this bill is far from being my bill. The credit for this bill belongs to those optimistic people I met who have sickle cell disease and who are advocates for sickle cell awareness and to all those Canadians across the country that they represent.

I must thank you, honourable senators, for the support I have received from so many of you including Senator Meredith, who spoke at second reading, and Senator Ogilvie and Senator Eggleton and the entire Social Affairs, Science and Technology Committee,

who engaged in such meaningful discussion on this bill and the issues surrounding sickle cell disease in Canada.

I must also thank Lanre Tunji-Ajayi, President of the Sickle Cell Disease Association of Canada, for her dedication and perseverance in promoting awareness of sickle cell disease in Canada. This bill is before you today in no small part because of the work she has done. Thank you.

**Hon. Carolyn Stewart Olsen:** Honourable senators, my remarks will be very brief. Sometimes the term "critic of the bill" is a bit of a misnomer. I support this bill, and I commend Senator Cordy for bringing it forward and for paying attention to her constituents in Nova Scotia, for working with them and coming forward and doing exactly what senators should be doing, in my opinion.

We name a lot of days, and sometimes people wonder why we do that, but in this case it was brought to us very clearly in committee that we're doing this because the awareness of sickle cell disease in Canada is very low, and I think anything that we as senators and parliamentarians can do to raise awareness of a disease which affects a lot of people and is carried by a lot of people who have no idea they have it is something we should be proud of doing, and we will work hard every year to raise the awareness of this.

Just the simple fact that the Senate is urging people to be tested for this is a really good thing, and I think if we pass this bill, and I hope we will, we should be very proud of having done so.

**Hon. Don Meredith:** Honourable senators, I also want to rise in support of this very important bill. Senator Cordy, thank you for your eloquent speeches on this particular bill.

Another region greatly affected by this is the Caribbean region, and as Chair of the Canada-CARICOM Parliamentary Friendship Group, I had an opportunity this August to lead a delegation to Jamaica, where I connected with the association and told them about this bill in this chamber and your initiative to make June 19 sickle cell awareness day in Canada.

It's important, honourable senators, that we look at how this particular day will affect those families who visited our offices, who went to the associations here on the Hill, and we saw the pain especially of that 16-year-old young man in a wheelchair and now having his hip replaced.

As I shared in my second reading speech, at 40 years old my friend Mr. Trench passed away of sickle cell. My wife's childhood friends were suffering as they thought of ending their own children's lives because they were unaware of how to deal with this.

I begin to reflect on the personal experiences that I have had with those individuals. This past summer I visited with Lillie Johnson but was unable to meet with other individuals because they were in crisis. There is also a stigma for young people with respect to those who interpret them and look at them as if they're seemingly well, yet

they're in crisis and need; they are on medication, and some health practitioners think they're just there for another hit.

This day, honourable senators, is so critical to so many communities who are affected by this disease. It's important to begin to look at how we can raise and support this national day just like the United Nations and the African Union has done. I think it's time that Canada did the same.

Honourable senators, I call upon you today to support Bill S- 211 and allow for June 19 to become sickle cell awareness day in this great country. This is the right thing to do. Thank you.

**The Hon. the Speaker:** Is it your pleasure, honourable senators, to adopt the motion?

**Hon. Senators:** Agreed.

(Motion agreed to and bill read third time and passed.)