SICKLE CELL DISEASE - AWARENESS RAISING

I have made you and I will carry you. I will sustain you and I will rescue you. Isaiah 46:4

VISION:
At Toronto Catholic we transform the world through witness, faith, innovation and action.

MISSION:
The Toronto Catholic District School Board is an inclusive learning community rooted in the love of Christ. We educate students to grow in grace and knowledge and to lead lives of faith, hope and charity.
A. EXECUTIVE SUMMARY

The report outlines a plan to raise awareness amongst the TCDSB staff in regards to students struggling with Sickle Cell Disease.

B. PURPOSE

The purpose of this report is to outline a plan for raising awareness amongst the TCDSB staff regarding Sickle Cell Disease and also to include a communication plan to highlight June 19th as World Sickle Cell Disease Day.

C. BACKGROUND

At the February 6th Student Achievement and Well Being, Catholic Education and Human Resources Meeting, a presentation by Lanre Tunji-Ajayi, President and Education Director, Sickle Cell Disease Association of Canada, was received and referred to staff. Staff was to report on how to increase awareness of the Sickle Cell Disease in our schools and the possible recognition of June 19th as World Sickle Cell Disease Day.

Staff has met with Ms. Tunji-Ajayi to work out a plan to support awareness raising and also to develop a communication plan regarding this initiative.

D. EVIDENCE/RESEARCH/ANALYSIS

Sickle Cell Disease (SCD) is the collective name for a series of serious, inherited chronic blood disorders that can affect all systems of the body.

It is one of the most common genetic conditions in the World, with >25 million affected individuals and 250,000 children born annually. Although prevalent in malaria-endemic regions, due to immigration patterns and the rich ethnic diversity in Ontario, SCD is a significant disorder in our province too.

The lifespan of persons with these disorders can be reduced by as much as 30 years and it has a devastating impact on the quality of life, most pertinent to education being the risk of stroke and subtle neurological deficits.

People with Sickle Cell Disease have a type of Hemoglobin (called Hemoglobin S (H S) or sickle hemoglobin) which differs from normal hemoglobin. This can cause red blood cells, which provide oxygen to the body, to change shape and breakdown rapidly or cause blockage of blood flow in the circulation.
The two main consequences of SCD are:

Severe anemia resulting in tiredness, reduced exercise tolerance, and delayed growth. The student may appear pale and have yellow-tinged eyes from time to time. Vaso-occlusive episodes are blockages of the blood vessels anywhere in the body by deformed red blood cells. This causes a lack of oxygen in the affected area of the body.

In order to raise awareness regarding Sickle Cell Disease, staff will make available the “Sickle Cell Disease: A Practical Guide for Teachers” (Appendix A). Communication will go out to all principals regarding the information booklet and also additional resources available to schools from the Sickle Cell Disease Association of Canada. Principals will be reminded that if there is a current student in their school with this disorder, the school will develop an action plan to include within the Medical Condition Form. An individual safety plan could be created to provide the necessary accommodations and modifications for particular subject areas. If an individual safety plan is developed it will be included within the Ontario Student Record so that future teachers will have access to the plan.

Staff is currently working on a metapolicy related to medical conditions. Once the policy is completed and the operational guidelines are initiated, Sickle Cell Disease would be included within those guidelines and further supportive strategies should be developed.

A comprehensive communications plan will be developed by the Communications Department to both launch the first ever TCDSB official recognition of Sickle Cell Anaemia Awareness Day and to support ongoing awareness and information sharing throughout the system.

An integrated and multi-faceted communications plan will be orchestrated using all media modalities that will include, but not limited to existing online and traditional tools within the Communications Department inventory (Twitter, website, internal web portal, E-News, Director’s Bulletin, Weekly Wrap up, school newsletter features).

Additional actions include public and media relations promoting any school-based events (both secondary and elementary panels) being organized by students, teachers and CSACs in support of Sickle Cell Awareness Day.

- Communication to entire TCDSB system through official letter from Director and Chair recognizing and promoting Sickle Cell Awareness Day, to students, parents, CSACs, TAPCE, CPIC.
- Promotion of school-based events (both secondary and elementary panels).
- Advance news release and media story pitches (eg. Catholic Register and mainstream media as appropriate)

A communications plan will be developed to support both short and long term community engagement.
Short Term: Support Curriculum and Accountability Department efforts to communicate initial general awareness, information and learning through the celebration Sickle Cell Awareness Day on June 19, 2014.

Ongoing and Long Term: The Communications Plan will also support the TCDSB community of staff, students and parents in enhancing their awareness and understanding through the ongoing communication of evidence-based health information from the Sickle Cell Awareness Group of Ontario (posters, tip sheets, online information links, promotion of special events, or educational workshops and public information sessions).

E. METRICS AND ACCOUNTABILITY

The program coordinator will monitor the requests for further information from schools regarding this particular disease. They will connect with the President of the Association and determine the next steps after the initial awareness raising initiative has been completed. Communications Department will highlight and report on any specific events within the schools that have been planned to further support this initiative.

F. CONCLUDING STATEMENT

This report is for the consideration of the Board.
Sickle Cell Disease: A Practical Guide for Teachers

What is sickle cell disease (SCD)?
Sickle cell disease (SCD) is an inherited blood disorder. It is not contagious. Most children with SCD are of African ancestry, but children of Middle Eastern, Mediterranean, and South Asian ancestry are also affected.

Signs and symptoms of sickle cell disease
The two main characteristics of SCD are a long-standing anemia and recurrent episodes of vaso-occlusion:

- **Anemia** is a result of increased breakdown of red blood cells. Children may appear pale and have yellow eyes from time to time.
- **Vaso-occlusive episodes** are blockages of the blood vessels anywhere in the body by deformed red blood cells. This causes a lack of oxygen in the affected area of the body.

Symptoms depend on where the blood vessels are blocked. If a blood vessel going to the brain is blocked, for example, the child will show symptoms of a stroke, such as weakness of one side of the body. If the blood vessel going to a leg bone is blocked, the child will have pain in the leg.

Pain crises
The most common symptom of a vaso-occlusive episode is bone pain. Any bone can be affected, including the arms, legs, back, and skull.

These episodes, commonly called pain crises, are unpredictable. Some children do not feel well prior to the actual onset of pain and can let an adult know.

Possible triggers for a pain crisis include:

- infection
- stress/fatigue
- dehydration
- exposure to cold and very hot temperatures

Some pain crises happen without a known reason.

Preventing pain crises
Parents and teachers can help to prevent a pain episode by:

- Giving children lots of fluids to drink so they are not thirsty.
- Dressing them in a few layers of warm clothing in the winter when they are leaving home.
• Sending an extra sweatshirt and socks to school in case the student becomes wet during recess or at any time.
• Recognizing fever as a sign of infection and having the child seen immediately by a doctor.
• Avoiding vigorous exercise without the ability to take breaks and drink fluids, especially during hot days.

Even with these measures, though, children may still have a pain crisis.

What to do if your student with sickle cell disease is unwell

Temperature
1. First, have the student sit or lie down in a quiet place.
2. Take the student’s temperature. Parents are advised to have a thermometer in the child’s bag for use in school or to leave one with the teacher for that student’s use.
3. If the temperature is higher than 37.5°C under the armpit, or 38°C in the mouth, call the parents immediately to take the student to the closest emergency department.
4. If the temperature is less than 37.5°C, then do a pain assessment.

Vaso-occlusion in SCD

Healthy red blood cells are soft, round and flexible. Sickled red blood cells are sticky and hard and can block blood flow.
5. Is there any sign of breathing problems? If yes, call an ambulance. If no, do a pain assessment.

**Pain Assessment Numerical/Visual Analogue Scale**

Children are asked to indicate their pain intensity by putting a mark on the scale.

**Doing a pain assessment**

1. Ask the student what level his/her pain is on a scale of 0 to 10, with 0 being no pain and 10 being “the worst pain ever.” Ask where the pain is located.
2. If the pain is less than 7/10 and the parents have given the teacher or nurse a supply of pain medication, the child can have a dose given as prescribed.
3. If no medication is at school to treat pain or if it is greater than 7/10, call a parent to pick up the student.
4. If the pain is localized to 1 or 2 areas, a warm pack can be applied to the site of pain until the student is picked up by a parent.

ICE PACKS SHOULD BE AVOIDED.

**Children (5 to 8 years of age)**

Ask your student: "If 0 is no pain and 10 is the worst pain you can imagine, what are you feeling now?"

**Older children (8 years of age and older)**

Ask your student: "If 0 is no pain and 10 is the worst pain you can imagine, what are you feeling right now?"

**Pain management**

**Medications**

1. Morphine _____ mg. Repeat dose every four hours.
2. Before each dose, take your student's temperature. If his temperature is higher than 37.5°C under the armpit, go to the nearest Emergency Department right away.
3. Acetaminophen _____ mg. Repeat dose every four hours.
4. Ibuprofen _____ mg. Repeat dose every six hours.
5. Docusate _____ mL x one dose.

**Physical**

2. Gently massage the area.
3. Apply heat to the area.

**Tips for using heat**

- Use disposable, instant hot packs. Be sure to follow the instructions on the package.
- Warm blankets from the dryer.
- Warm baths.
Apply heat in 20 minute intervals.

- Babies and young children should not be left unattended with heat. Use heat with children 3 years of age and older.
- If the area becomes painful, uncomfortable, or a local skin reaction develops, remove heat immediately.

Psychological/Behavioural

- deep breathing
- relaxation exercises
- distractions (movies or music)
- imagery

### What to do when your student with sickle cell disease has a fever

Children with SCD are at greater risk of life-threatening infections than their peers. In part, this is because their spleen function is not as good at destroying the cell coating of some bacteria. **Fever in a child with SCD is considered an emergency and requires prompt treatment with antibiotics.**

A thermometer should be available at school for assessing the temperature of children if they are unwell while at school. A temperature higher than 37.5°C under the arm and higher than 38°C by mouth requires that the child be seen promptly at an emergency department. Call the child’s parents to pick up the child. If they cannot be reached in a short time (perhaps an hour), take the child to the closest emergency department.

Medicines such as acetaminophen and ibuprofen will reduce fever, but will not affect the infection that is causing the fever. Using them can lead to a false sense of security or to the fever not being taken seriously. Do not give a student with SCD these medicines to treat a fever.

### Fluid requirements and bathroom privileges for students with sickle cell disease

Children with SCD excrete higher volumes of urine compared with their peers because their kidneys cannot concentrate urine. Bathroom privileges are a must whenever the student needs to go. Attempts to hold urine will result in accidents and embarrassment to the student, with the potential for future teasing and bullying.

Correspondingly, when a child produces more urine than usual, they must also increase their fluid intake. This is particularly important in SCD, as dehydration can trigger pain crises. When patient child is dehydrated, blood cells also become dehydrated and change shape, causing blood vessel blockage and acute pain. Students with SCD should be allowed to have water bottles at their desks so that they will have easy access to water. This will reduce the disruption of leaving the classroom for the water fountain.

### Sports and extra-curricular activities for students with sickle cell disease

Students with SCD should be encouraged to participate fully to the best of their ability and according to their tolerance level. As a result of low hemoglobin level (anemia), they will tire faster than their peers with physical activity. They should be encouraged to try out for school sports and activities.
teams and participate in gym, but with more frequent rest periods and increased hydration.

It is a good idea for parents and their child with SCD to talk with the physical education teacher about the physical discomforts associated with SCD and any symptoms the student has had in the past with physical activity. The family and the teacher should reach an understanding about expectations.

Special precautions for swimming
Students with SCD can participate in swimming classes. However, they should limit the time in the pool to 30 minutes. After getting out of the water, the student must dry off and change into dry clothing right away. They should not run around in cold, wet swimsuits as their body temperature will fall, potentially resulting in bone pain.

Special precautions for hot weather
When exposed to very hot temperatures, such as during a sporting event in the summer, students with SCD can participate but with frequent rest breaks and increased hydration.

Special precautions for winter activities
Students with SCD should be allowed to participate, but they should be dressed well in layers appropriate for the temperature of the day. Areas of increased loss of body heat, such as fingers, toes, head, and ears should all be well covered. At temperatures less than -5°C, students with SCD should be excused from participating.

Academic performance for students with SCD
Most children with SCD will perform as well as their peers, so expectations for students who have SCD should be similar to those of their peers. Having a chronic illness at times results in reduced self-esteem and lack of confidence. Encouraging the student is essential.

There are several reasons why some students with SCD may have exceptionalities.

Missed school days
Students with SCD may miss school because of:

- scheduled clinic visits
- inpatient hospitalizations to treat the severe bone pain associated with SCD
- less severe painful bone crises being treated at home

This means that they have less instructional time. It has been proven that school attendance is directly related to academic performance. A parent could speak with the child’s teacher about setting up a homework buddy program for the whole class. Each student would have a “buddy” who would collect handouts and notify the absentee student of important future deadlines. Many teachers have websites where they post homework assignments and future dates for both parents and students. If these exist, please bring them to the attention of parents and students.

Neurological problems
One in 5 children with SCD has so-called “silent strokes.” These are small strokes in the frontal area of the brain which go undetected unless an MRI is performed. The frontal area of the brain
is responsible for executive functioning and this affects a student’s ability to focus, organize, plan, and memorize. As children move to the higher grades they may experience increasing difficulty.

One in 10 children with SCD under the age of 20 years old will have overt strokes. These result in diminished academic performance and various degrees of physical disability. Thankfully, most overt strokes can be prevented with a chronic transfusion program when children with SCD are identified early in life.

**If your student is having difficulty**

When a student is identified to be having difficulties academically, neuropsychological testing should be undertaken and appropriate IEP intervention done on an individual basis. Whenever a teacher is concerned about a student’s health, with the parents’ written permission they should seek out the health care team involved with the student as a resource.

Children with SCD are expected to have a life expectancy well into the 6th and 7th decade, so they should be prepared for the work force in a manner that is suitable for the adult with SCD. As a result of the anemia, most adults will not be able to pursue careers which involve heavy, sustained physical activity. It is therefore essential that they be steered away from such careers and into less physically demanding jobs. This makes achieving a good education even more important.

**How teachers can help students with sickle cell disease achieve academically and socially in the classroom**

- Learn about SCD and how it has affected your student.
- Provide make-up work for students who have missed days from school due to illness.
- If your student is not performing optimally, suggest a neuropsychological assessment so an IEP can be done to optimize learning.
- Have free and open communication with the student’s parents so you can work as a team to optimize performance.
- Dispel any myths or rumours about your student that may be in the classroom, such as reasons for the student’s eyes being yellow, or the disorder being contagious.

**Special situations where the teacher should call 9-1-1**

If any of the following occurs, call emergency services right away:

- difficulty breathing
- loss of consciousness
- severe headache
- difficulty speaking or slurring of speech
- weakness of limbs
- seizure activity
- fever greater than 39°C
- unexplained lethargy/sleepiness persistent vomiting

**Key points**

- Sickle cell disease (SCD) is an inherited blood disorder.
The two main characteristics of SCD are a long-standing anemia and recurrent episodes of vaso-occlusion.

Anemia is a result of increased breakdown of red blood cells. Children may appear pale and have yellow eyes from time to time.

Vaso-occlusive episodes are blockages of the blood vessels by deformed red blood cells.

Infection, fatigue, and dehydration are possible triggers for a pain crisis.

Do not use ice packs to treat pain.

If your student has a fever, call his parents immediately so they can take him to the nearest Emergency Department.

Understanding the difficulties associated with SCD and making the necessary accommodations will help your student achieve success in the classroom.