Celebrate World Sickle Cell Day 2016 by Donating Blood

To increase the supply of safe, phenotype-matched blood, SCDAC is celebrating World Sickle Cell Day 2016 by championing blood donation drives across the country. We are especially seeking donors with backgrounds from the Mediterranean, Middle-East, South-Asia, Africa and the Caribbean.

SCDAC Clinic Date: June 18th

For more information and questions contact:

GTA: secretary@sicklecellanemia.ca or call 416-745-4267.
Hamilton: Lynella Welcome: hw@sicklecellanemia.ca
Ottawa: Rachid Barry: southeastern@sicklecellanemia.ca

To find a SCDAC supported clinic near you, email us at: communication@sicklecelldisease.ca

Spread the Word- Donate on 06182016 using hashtag #EachReachSix and tweet back @sicklecellca.

World Sickle Cell Day 2016- SCAGO`s Supported Blood Drive Locations in Ontario

City	Address	Clinic Hours
Hamilton	*Hamilton Blood Clinic. 35 Stone Church Rd. Ancaster*	*8:00 AM–1:00 PM*
Mississauga	*Heartland Town Centre. 765 Britannia Rd. W.*	*8:00 AM–2:00 PM*
Ottawa	*1575 Carling Ave. Clinic Hours*	*9:00 AM–2:00 PM*
Toronto	*Canadian Blood Services @ Bay & Bloor. 2nd floor by the Movie theatre. 55 Bloor St. W-Manulife Centre.*	*9:00 AM–3:00 PM*

SCDAC AAFC
SICKLE CELL DISEASE ASSOCIATION OF CANADA · ASSOCIATION D'ANÉMIE FALCIFORME DU CANADA

SCAGO
Sickle Cell Awareness Group of Ontario

WORLD SICKLE CELL DAY JUNE 19TH

Canadian Blood Services

About World Sickle Cell Day

The World Health Organization (2006) and the United Nations (2008) recognized sickle cell disease as a public health priority and chosen the 19 of June every year as the World Sickle Cell Day in order to raise awareness of the disease. Here in Canada, increased awareness and access to comprehensive care by knowledgeable health care professionals are still needed and the SCDAC is doing its part in raising more awareness around the disease.

ABC OF SCD

What is Sickle Cell Disease (SCD)?
Sickle Cell Disease (also called Sickle Cell Anemia) is a group of red blood cell disorders you have inherited and are born with. Sickle cell disease is caused by an abnormal form of Hemoglobin. This is the part of your red blood cell that carries oxygen around the body and keeps your vital organs working. In sickle cell disease, the abnormal Hemoglobin (HbS) is not able to work properly. The red blood cells become stiff and block up the blood vessels in your body, causing pain and damage, and they also get destroyed quickly, leading to anemia and other complications. Currently there is no universal cure for sickle cell disease.

What makes the red cell sickle? There is a substance in the red cell called hemoglobin. It carries oxygen from the air in our lungs to all parts of the body including the blood cells. One little change in this substance causes the hemoglobin to form long rods in the red cells when it gives away oxygen. These rigid rods change the red cells into a sickle shape instead of the normal round shape

Normal red blood cells contain hemoglobin A. Hemoglobin S and hemoglobin C are abnormal types of hemoglobin. Normal red blood cells are soft and round and can squeeze through tiny blood tubes (vessels). Normally, red blood cells live for about 120 days before new ones replace them.

People with sickle cell conditions make a different form of hemoglobin A called hemoglobin S (S stands for sickle). Red blood cells containing mostly hemoglobin S do not live as long as normal red blood cells (averagely about 16 days).

What does sickle cell disease mean to me? It is something you will have your whole life, and need to learn how to live with it, so that you can continue living as normally as possible, with schooling, work, and family life. As it is inherited, you also need to know your partner's Sickle Cell status as you could pass it onto your future children too.

Types of sickle cell disease There are several types of sickle cell disease. The most common are: Sickle Cell Anemia (SS), Sickle-Hemoglobin C Disease (SC), Sickle Beta-Plus Thalassemia and Sickle Beta-Zero Thalassemia.

What is Sickle Cell Trait? Sickle Cell trait (AS) is an inherited condition in which both hemoglobin A and S are produced in the red blood cells, always more A than S. Sickle cell trait is not a type of sickle cell disease. People with sickle cell trait are generally healthy. A carrier has one normal and one sickle hemoglobin gene. A carrier does not have, and will not develop, sickle cell disease.

All races should be screened for this hemoglobin at birth.

What does it mean to have the sickle cell trait? A carrier of sickle cell disease is also said to have the sickle cell trait. This person has inherited a sickle cell gene from a parent, but does not

have sickle cell disease and is not more likely to get sick than any other person. They do not need special medical care and will not develop sickle cell disease at any time in their life.

Why is it helpful to know that I am a carrier of sickle cell disease, or whether my child is a carrier? Knowing whether you or your child has the sickle cell trait is important for several reasons. When you are ready to have a family, your partner can have carrier testing so that you know, as a couple, if there is a chance of having a child with sickle cell disease. By having this information, you can let your child know if he or she is a carrier of sickle cell disease in the future.

What does my child's carrier result mean? When a child is a carrier of sickle cell disease, it is very likely that one of the parents is also a carrier of sickle cell disease. More rarely, when a child is a carrier of sickle cell disease:

- Both parents are carriers
- One parent actually has sickle cell disease
- One parent is a carrier and the other has sickle cell disease

If I have more children, could they have sickle cell disease? Most often when a child is a carrier of sickle cell disease, only one parent is a carrier and the chance to have a baby with sickle cell disease is very low

When both parents are carriers, each pregnancy they have has:

- 1 in 4 (25%) chance of having sickle cell disease
- 1 in 2 (50%) chance of being a carrier (but not having sickle cell disease)
- 1 in 4 (25%) chance of not having sickle cell disease or being a carrier

You can have a blood test to find out if you are a carrier of sickle cell disease. If you want to have this test, talk to your health care provider. A carrier does not have, and will not develop, sickle cell disease.

How does someone get sickle cell disease? Anyone can have sickle cell disease or trait including Caucasians but it is seen more in people from Africa, the Mediterranean, Caribbean, Middle East, South East Asia, Western Pacific Region, South America, and Central America. Sickle cell disease runs in families and is caused by a problem with the hemoglobin gene. Genes are the instructions that tell our bodies how to grow and develop. Most people have two normal copies of the hemoglobin gene – one from their mother and one from their father. A person with sickle cell disease has two sickle hemoglobin genes, one from each parent. For a couple to have a child with sickle cell disease, both parents must be carriers. A carrier of sickle cell disease has one normal hemoglobin gene

What are the complications to look for? Sickle cell disease causes problems in 2 ways, by the breakdown of the red blood cell (hemolysis) and by blocking the flow of blood in the blood vessels (vaso-occlusion). This most commonly causes pain, especially in the bones. Other painful complications include priapism (see below), damage to shoulder and hip joints (avascular

necrosis), chest pain (acute chest syndrome). There are also a lot of problems that may not be painful. These include damage to the lungs, heart (heart failure, pulmonary hypertension), kidney, liver and eyes, and also stroke, leg ulcers, infections. Because it can damage all of these body "systems", sickle cell disease is an example of a "multisystem disorder".

How can I prevent developing these complications? Many complications can be prevented or reduced by either regular blood transfusions or Hydroxyurea tablets. However, both of these have side effects and there are simple lifestyle changes that can make a big difference. These include regular exercise, a good diet, not smoking and not drinking too much. Reducing the amount of stress in your life is also important, as is avoiding things that can provoke a painful crisis. Making sure you are up to date with vaccinations can help to prevent serious infections.

By seeing your doctor in clinic, when not in crisis, you have an opportunity to discuss these ways of coping with sickle cell disease, and reducing complications

Treatment of complications: Treatment of complications often includes antibiotics, pain management, intravenous fluids, blood transfusion and surgery all backed by psychosocial support. Like all patients with chronic disease patients are best managed in a comprehensive multi-disciplinary program of care.

Treatment Screening newborns for sickle cell disease is perhaps the first step to effective treatment of the disease. NBS will grant the patient, early enough access to penicillin prophylaxis, vaccination against pneumococcus bacteria and folic acid supplementation.