



How to Increase Awareness

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September 20th 2014

SICKLE CELL DISEASE ASSOCIATION OF CANADA ASSOCIATION D'ANEMIE FALCIFORME DU CANADA (SCDAC/AAFC)

Who We Are

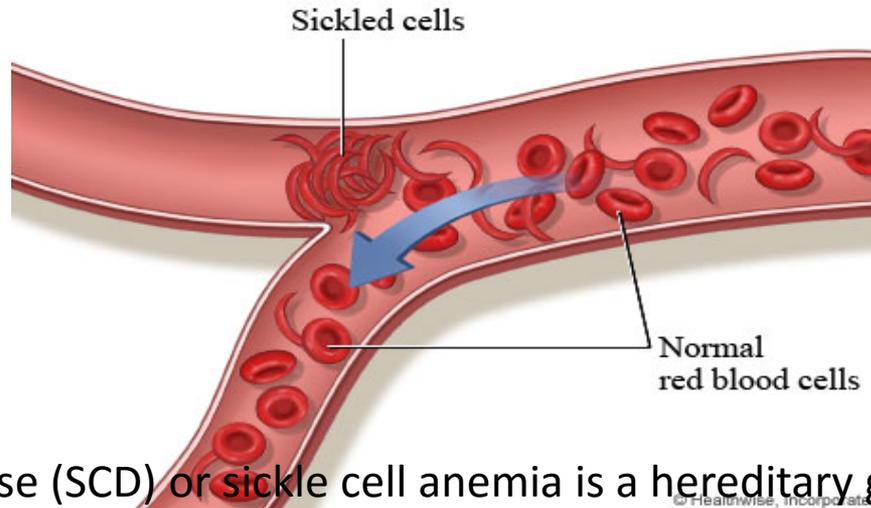
Created in 2012 as an effort to combine local associations across Canada, the SCDAC is committed to:

- Increasing awareness about Sickle Cell Disease (SCD)
- Enhancing methods of identification, diagnosis, and treatment towards improving the quality of life of affected individuals and their families

The SCDAC/AAFC represents:

- Patients with SCD
- Parents, carriers, and families of patients with SCD
- Provincial, regional and municipal sickle cell organizations
- Health Care Professionals
- Educators & Advocates
- Community representatives

ABOUT SICKLE CELL DISEASE



- Sickle Cell Disease (SCD) or sickle cell anemia is a hereditary genetic disease characterized by the presence of abnormal crescent-shaped red blood cells.
- Although a disorder of the blood, SCD is a **multisystem disease**:
 - Predisposition to **life-threatening** infant and childhood **infections**
 - **Severe** bone **pain** from necrosis of the bone marrow
 - **Affects all vital organs** of the body
 - **Stroke** is seen in **>10% of children and >25% of adults**

ABOUT SICKLE CELL DISEASE

- Canada's ethnic diversity has resulted in **SCD** being **one of the most frequent genetic disorders**
- It is quickly overtaking other well known disorders as **cystic fibrosis and hemophilia.**
- **It is estimated that 3500-4000 individuals have sickle cell disease in Canada**
- **3000-3500 patients** are currently **being followed for SCD**, half of whom are children
- **Life expectancy** of patients with SCD is **reduced by ~25 years** compared to normal population. Quality of life is also severely affected.

SICKLE CELL DISEASE: BURDEN OF THE DISEASE

BURDEN to the Individual:

1. Frequent hospitalization resulting in reduced contribution to society
2. Absenteeism from work- inability to hold a steady job
3. Financial stress/Mental health issues
4. Marriage breakdown- 95% of time especially in high-stress societies
5. Self confidence/ self esteem
6. Feelings of guilt as the cause of family breakup; parents' stress etc.

Burden to Family members especially the parents and siblings:

Feelings of guilty/responsible for the patient's disease.

Absenteeism from work- inability to hold a steady job

SICKLE CELL DISEASE: BURDEN OF THE DISEASE

- Burden to the healthcare resources:

Emergency Department visits, Inpatient days, ICU care, OR time....

- US study evaluated the cost of SCD care to be US\$ 900-2500 per patient per month, and US \$500,000 lifetime
- In Canada, without the provincial health coverage, one week's admission in an hospital for a sickle cell episode known as a crisis may cost the patient approximately \$15,000- \$25,000 (Non-ICU admission)

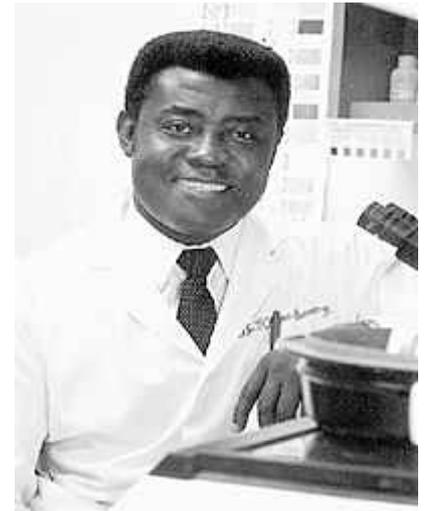
In Canada, health care is provincial; and the various provinces are to be applauded for covering the health cost of their citizens.

SICKLE CELL DISEASE: WHAT DO THE PATIENTS WANT?

Cure:

Bone Marrow Transplant is currently the only curative treatment for SCD, but is only available for a small minority of individuals and may have some side effects considered unacceptable to some.

Dr. Kwaku-Ohene-Frempong of the Sickle Cell Disease Association of America says "gene therapy is the ultimate cure of sickle cell disease."



SICKLE CELL DISEASE: INCREASED AWARENESS

- In the absence of a readily available viable cure for all; there is a need for:

Increased awareness among researchers: Research for a cure

Increased awareness among the law makers: Policies and laws to support the disease

Increased awareness within the community:

1. Preventative measures- to reduce # of new births
2. Fundraising – to support programs and research

Increased awareness among the medical & allied health professionals

Improved care & treatment (disease modifying therapies-hydroxyurea, blood transfusion etc)

Increased awareness among the individuals with sickle cell disease- Better management of health

SICKLE CELL DISEASE: HOW TO INCREASE AWARENESS

To achieve increased awareness among researchers; SCDAC and CanHaem must work closely with CIHR/ICHR

To achieve increased awareness among law makers, SCDAC must continue to educate and lobby policy makers both at the national and provincial levels.

To attain increased awareness among the medical and allied health professionals, SCDAC must work with medical and allied associations such as CMA, OMA, BPAO, CASW, CPA, CNA etc.

To enhance patient/public awareness and knowledge, SCDAC must work closely with the patient community, the health care practitioners and the general community.

SICKLE CELL DISEASE: BENEFITS OF INCREASED AWARENESS

- **Patient/Public Awareness-** Outreach activities will expose more people to the disease with the resultant benefit of increased support for those living with hemoglobinopathies.
- Patients are empowered to advocate for themselves
- Improved family involvement in the care and management of the disease
- Reduction in the stigmatization and the shame culture that surround sickle cell disease
- Reduction in the number of births and deaths
- Reduction in the number of complications; marriage breakups etc.
- Better understanding and management of the disease by the patients will result in a new level of well being.

SICKLE CELL DISEASE: BENEFITS OF INCREASED AWARENESS

- **Medical and Allied Health Care Providers:** Increased access to medical and allied health professionals with enhanced understanding of the disease



- Patients having improved access to disease modifying therapies such as hydroxyurea, blood transfusion and iron chelation
- Improved psycho-social and physical health of patients
- Enhanced quality of life

SICKLE CELL DISEASE: BENEFITS OF INCREASE AWARENESS

- **Researchers-** Increased interest among researchers and young investigators



- Increased interest among pharmaceuticals to produce life enhancing drugs
- Eventual development of a cure in the form of a vaccine or a cure for SCD
- **Law makers-** Policies and laws favouring sickle cell disease

SICKLE CELL DISEASE: HOW CAN I GET INVOLVED

Volunteer and/or join the member organization of the SCDAC in your province

Raise awareness in your community- religious institution, work place, school

Get familiar with your MPP and MP

Advocate for a patient-centred care

