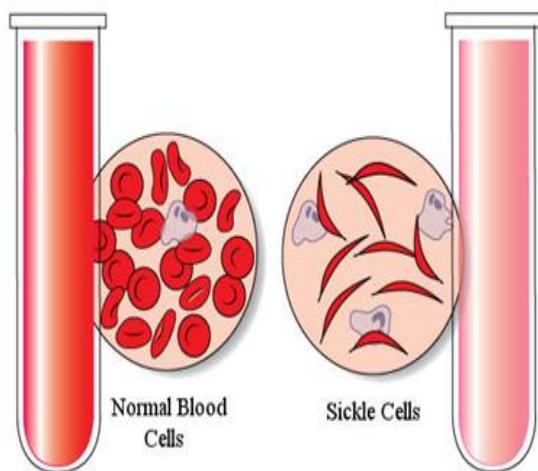


BE AWARE

Sickle Cell Awareness and Public Education

Sickle-cell disease is one of the most common severe monogenic disorders in the world. Clinical management is basic and few treatments have a robust evidence base. One of the main problems of sickle-cell disease in children is the development of cerebrovascular disease and cognitive impairment, and the role of blood transfusion and hydroxycarbamide for prevention of these complications is starting to be understood. Recurrent episodes of vaso-occlusion and inflammation result in progressive damage to most organs, including the brain, kidneys, lungs, bones, and cardiovascular system, which become apparent with increasing age. Infectious diseases have a role in causing increased severity of sickle-cell disease. More work is needed to develop effective treatments that specifically target pathophysiological changes and clinical complications of sickle-cell disease.



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Sickle Cell Awareness in the Community

Patient, a Parent, or At Risk...

1. Pregnant or thinking of having a baby? Ask for a screening test for sickle cell trait.
2. Send your partner for screening, too.
3. Remember to ask your baby's doctor about your new-born's screening results.
4. Educate yourself about sickle cell disease and its treatment.
5. Stay in touch with your/your child's doctors and follow their instructions to stay healthy.
6. Tell your child's school about special sickle cell needs upon enrollment.
7. Tell your employer about your sickle cell needs upon hiring.
8. Connect with a hospital that treats sickle cell BEFORE you have a crisis.

Family Member or Friend...

1. Understand that sickle cell families need support.
2. Stay in touch. Let them know you're there to help.
3. Offer child care and transportation when it's needed.
4. Encourage young adults to learn about their disease and stay up-to-date with self-care.
5. Ask for screening for sickle cell trait, and if possible, donate blood.

School Administrators...

1. Make sure your staff knows if a student has sickle cell disease.
2. Connect with Sickle Cell experts who can advise your students and staff about sickle cell.
3. Hold an "Awareness Day" to educate teachers, staff and students about sickle cell.
4. Coordinate with your students' parents and physicians to get help quickly in a crisis.
5. Have alternative learning plans available for students during illness.

Employers...

1. Make information about sickle cell available through your health services department.
2. Understand that your employees may have periods of absence when they or their children are in sickle cell crisis.

3. Support patients' efforts to obtain routine medical care so they can stay well and keep working hard.
4. Make family medical leave easily available.

If you're a Health Care Provider...

1. Include sickle cell trait and disease on your patient history form.
2. Become familiar with the protocol for treating a sickle cell crisis.
3. Use the sickle cell informational websites.
4. Identify a sickle cell expert in your area.
5. Refer patients with the sickle cell trait to a genetic counselor.
6. Post information about sickle cell disease in your office.

RESOURCES:

www.irelandscklecell.org

www.scinfo.org

www.wepsicklecell.org

www.sicklecellsociety.org