

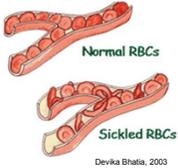
## Caring for Students with Sickle Cell Disease

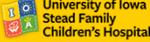
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### Sickle Cell Disease

- Most common inherited disorder in the United States
- Every baby born in United States is screened via newborn screen and diagnosis is confirmed with hemoglobin electrophoresis
- Inherited in people of ALL races and ethnic backgrounds
- Genetic disorder that alters the DNA of red blood cells (RBC) changing the shape from soft and round to sticky, hard, sickle (crescent moon) shaped cells
- RBC have decreased life span of from 120 days to 10-20 days
- Leads to vaso-occlusion, ischemia, infarcts, and tissue death





### Sickle Cell Disease

- Many different types
  - Most common: hemoglobin SS and hemoglobin SC

Genotype	Predicted Severity
HbSS	Moderate to very severe
HbSC	Mild to severe
HbS-β thal – 0	Moderate to very severe
HbS-β thal – + HbSD (Punjab)	Mild to moderate
HbS-O Arab	Moderate to very severe



### Everyday Needs at School

- Plenty of fluids
- Flexible bathroom privileges
- Avoid physical exhaustion
- Avoid extreme temperatures
- Transportation to and from school
- Allow positive peer-to-peer interaction

**Students with SCD can live a normal life!**



### Routine Medications

- **Penicillin:** an antibiotic taken twice daily for infection prophylaxis until about age five or fully vaccinated with meningococcal vaccinations
- **Folic acid:** a B vitamin taken one daily to help support red blood cells development
- **Hydroxyurea:** taken daily to decrease sickling and painful episodes for patients with genotypes HgSS or HgSbeta0
- **Acetaminophen:** taken as needed for pain control for mild pain
- **Ibuprofen:** taken as needed for mild pain
- **Opioids:** taken as needed for moderate to severe pain



### Support for Students

- Allow accommodations during physical education and recess activities
- Special care of injuries
  - NO COLD PACKS!
- Be aware of emotional well-being
- Maintain open communication with parents
- Create individualized care plans



**Pain Prevention** 

- Hydration
- Keep warm and dry
  - Students should remain inside if temperature is 34°F or colder or excessive wind chill that correlates to 34°F or colder
- Check in periodically with student to establish usual levels of pain
- Manage stress
- Reinforce coping strategies to utilize when pain worsens
- Prevention is important, although pain episodes are often unpredictable

Wong-Baker FACES® Pain Rating Scale



**Pain Management** 

- Eliminate any possible contributing factors
  - Cold/wet
  - Dehydration
  - Strenuous exertion
  - Stress
- Refer to patient's treatment plan
  - Medications
    - Acetaminophen, ibuprofen, opioids
  - Coping strategies
  - Non pharmacologic methods
- Functional pain assessment

**Non Pharmacologic Methods for Pain Relief** 

- Mediation
  - Applications
    - Calm
    - Stop, Breath, and Think Kids
    - Smiling Mind
  - Books
    - A Zebra Like Me
    - Master of Mindfulness: How to be your own Superhero in Times of Stress
- Guided Imagery
- Deep Breathing
- Distraction
- Aromatherapy
  - peppermint or lavender
- Heating pad/hot pack

**Guide for Functional Pain Assessment** 

- 0 = No pain
- 2 = Tolerable pain: able to perform all activities permitted
- 4 = Tolerate pain: able to perform some permitted activities; pain prevents full engagement in rehabilitative activities
- 5 = Tolerable pain that becomes intolerable and interferes with physically demanding activities (e.g. Physical Therapy)
- 6 = Intolerable: interferes with most activities requiring physical exertion, but not passive activities, such as reading, watching TV, talking
- 8 = Intolerable: Interferes with all "active" and most passive activities such speaking about pain
- 10 = intolerable: patient is unable to do anything or even speak due to their pain

**Comprehensive Sickle Cell Clinic** 

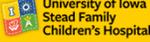
- Patients with sickle cell disease attend our comprehensive clinic at least annually to see our multidisciplinary team and complete routine testing
  - Hematologist
  - Social Work
  - Neuropsychologist
  - Pharmacist
  - Nurse
  - Genetic Counselor
  - Dentist



**Helpful Resources** 

- Our team!
  - Virtual in-service for teachers and staff
  - Discuss the disease with student's peer/classmates
  - Help with accommodations for individualized health plan
  - Address any concerns that come up

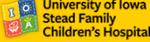
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**Helpful Resources** 

- Online resources
  - Centers for Disease Control and Prevention
    - <https://www.cdc.gov/ncbddd/sicklecell/index.html>
  - Sickle Cell Information Center
    - <http://scinfo.org/2015/02/24/faq-teachers-and-students/>
  - St Jude Children's Research Hospital
    - <https://www.stjude.org/treatment/disease/sickle-cell-disease/educational-resources.html>
  - U.S. Department of Education (DOE): A Guide to the Individualized Education Plan (IEP)
    - <https://www2.ed.gov/parents/needs/spced/iepguide/iepguide.pdf>



# Questions?

**References** 

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