

Name \_\_\_\_\_ Date \_\_\_\_\_

School \_\_\_\_\_ Grade \_\_\_\_\_

## **Children / Adolescents with Sickle Cell Disease School Planning Recommended Accommodations / Modifications**

The following are examples of **“Reasonable Accommodations”** for students with sickle cell disease who have been identified as eligible, via Section 504 of the Rehabilitation Act of 1973 (“504 Plans”) or pursuant to the Individuals with Disability Education Act (“IDEA”). Planning for these accommodations works best when parents and students have conversations with school personnel through 504 teams, Planning and Placement Teams or through Student Assistance Teams with discussion of the following:

- Unlimited access to the school nurse.** (The school nurse is an important team member in the development of an **Individualized Health Care Plan** and **Emergency Care Plan**).
- Parent provides consent for physician orders to administer necessary medications during the school day.**
- Access to fluids throughout the day** (to prevent dehydration). **Parent to provide a water bottle.**
- Bathroom privileges as needed** (due to the effect of the disease on the kidneys).
- Rest breaks may be needed during the day.**
- Transportation to and from school is especially important during the cold-weather months** (for some children certain complications can be precipitated by exposure to extremes in temperature and by overexertion).
- An extra set of books to keep at home** (Students may not have physical strength to carry heavy books, especially following periods of acute illness or pain. This is also beneficial if the student is absent from school so that they have access to their course work).
- Time extensions on assignments or tests may be required during/ following acute episodes when absent from school due to complications of their sickle cell disease, hospital admissions, medical appointments or emergency department visits.**
- Curriculum modifications may be required.**
- Availability of a modified school day – with progressive steps to return to full-day. Planning for this will include parent, physician or health care provider and school personnel** (for use during or at the end of an acute episode).
- Absences are excused when parents notify the schools that the child is absent due to sickle cell disease and related complications.**
- Parents and schools will work together to set up a system to obtain missed assignments and homework.**
- Tutoring may be needed for the student to achieve academic success** (Sickle cell disease is a life long, chronic illness with episodes of acute complications. The cumulative effects of experiencing acute episodes, combined with sporadic absences from school, often effect learning and make it difficult for students with chronic illness to catch up on their course work on their own. Scheduled, ongoing tutoring in the home can ameliorate this problem and can promote academic achievement).
- CMT/CAPT accommodations may be required.**
- Modified gym class during episodes of illness and the option for child to rest, as needed.** Physician statements regarding physical activity should be honored. Student should be allowed to participate to the extent that they feel physically-comfortable. If an alternative educational option is planned, it should be related to the educational content of the class to enable a student to work towards the earned credit for the class.
  - Students with sickle cell diseases are not typically allowed to participate in contact sports.
  - The student should not be required to participate in the Presidential Physical Fitness Testing.
  - Student may need to be excused from swimming if pool is not adequately heated and/or if child is not able to dry/warm immediately and change into dry clothes.
- An elevator pass may be needed** (during/after acute episodes or if student has avascular necrosis or chronic pain issues).



- 
- Minimize time outside in severe weather** (too cold/too hot) **with alternative activity provided. Student should be properly dressed during cold weather.**
  - Access to warm, safe place during fire drills.**
  - Seating away from drafts or air conditioners. Permission to have alternative/comfortable seating, as needed** (pillows, cushions, etc).
  - An adult in the school will assist the student to reacclimate to the social environment of the classroom following absences**
  - Parents and students will be made aware that there are social and emotional supports available in the school system** (please consider consultation or referral to the School Social Worker or Psychologist, if indicated).
  - If child is required to participate in summer school, accommodations may be needed** (air conditioned classroom or transportation).
  - Notify parent of outbreak of contagious illness** (chickenpox, measles, influenza, etc.)
  - All necessary school personnel should have access to printed educational materials about sickle cell disease.**

***Additional Resources:***

- New England Pediatric Sickle Cell Consortium [www.nepscc.org](http://www.nepscc.org)
- Understanding the Child with Sickle Cell Disease – A Handbook for School Personnel [www.vahealth.org/sicklecell/docs/SchoolHandbook\\_SickleCellChild\\_](http://www.vahealth.org/sicklecell/docs/SchoolHandbook_SickleCellChild_)
- St. Jude Children's Research Hospital [www.stjude.org/sicklecell](http://www.stjude.org/sicklecell)
- Emory Sickle Cell Center [www.scinfo.org](http://www.scinfo.org)

**Connecticut Children's Medical Center - Hemoglobin Disorders Treatment Center**

Tel. 860.545.9630/ Fax 860.545.9622

Nancy M. Caperino, ACSW and Michele O'Neill, MA, CCLS  
with Provider and Family Advisory Board

November 2009

The information contained on this page is for informational and educational purposes only. Always consult with your physician or other qualified health-care professional or educational consultant for questions about the health and education of your child and family members.

