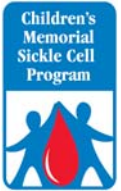


INSIGHTS

Sickle cell news you can use

Spring 2011
Issue 4



A Publication of the [Children's Memorial Hospital Comprehensive Sickle Cell Disease Program](#), Chicago, IL

Sneak peek at the New Hospital!

The new hospital will be located 225 E. Chicago Avenue, just west of Prentice Women's Hospital between Chicago Avenue and Superior Street



The Comprehensive Sickle Cell Outpatient clinic will be located on the 18th floor of the building.



This is a sneak peak of an inpatient room. Out inpatient rooms will be on the 17th floor!

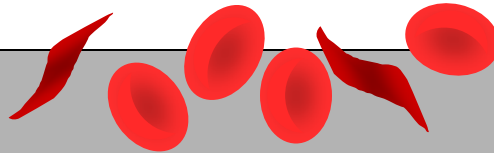
Save the Date...

August 6th- Teen Transition Day

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Remember our social worker, Al Howard, is always available to talk to you about school or insurance issues!



New Recommendations for Your Child

Clinical research is extremely important for advancing the care of children with sickle cell disease. Previous clinical research studies have found that children with sickle cell disease often have low levels of Vitamin D, poor bone health as well as problems with lung and

heart function. This important research has changed the way that doctors and nurses want to treat and care for children with sickle cell disease.

Your doctor may now recommend your child receive the following tests yearly, depending on your child's age:

- Vitamin D blood test
- DXA bone density test
- Pulmonary function test
- ECHO heart test

If you have any questions about these new recommendations, please ask your doctor or nurse at your next comprehensive clinic appointment!

Teen Transition Symposium August 6, 2011

It is important that children with chronic medical conditions are ready to take care of themselves as adults or while away at school. Healthcare should not end once a child becomes an adult.

Our ***Sickle Cell Disease Transition Program*** will help children prepare for independent and adult-centered healthcare. When you or your child turns 14 years old, your sickle cell team will approach you or your

child about enrolling in the transition program.

If you or your child is older than 14 years old and are not in the program, please ask your sickle cell doctor or nurse about how your family can receive transition educational materials.

The sickle cell transition program has materials available on insurance, choices about education after high school, adult sickle cell care centers, and more to help your

family through the transition process.

This year, we will be hosting a teen transition symposium at Children's Memorial Hospital. This will be a fun-filled day to teach teenagers and their parents the important life skills needed to be independent in their sickle cell health care.

The teen transition symposium is scheduled for August 6th! Save the date!

O N YOUR SIDE...



Alexis Thompson

Sickle Cell Doctor and Head of Hematology

What is your role in the program?

I am the Head of Hematology at Children's Memorial Hospital and am responsible overall for the research and patient care programs in nonmalignant blood conditions, including sickle cell. I am one of the sickle cell doctors in clinic and sometimes in the hospital. I also work with Diane Calamaras our nurse practitioner on managing patients with sickle cell who need transfusions.

When can my child and I expect to see you?

I am present in most of the sickle cell clinics including the comprehensive sickle cell clinic and the newborn cohort clinic.

What is something else we should know about you?

I have a very sweet old chocolate labrador retriever named Cyrus.

How to reach us

Emergencies
Hematologist on Call
773 880 4000

To make or change your child's sickle cell appointment
773 880 4618

Janice Beatty, RN
773 880 4618

Diane Calamaras, APN
773 868 8953

Physicians
Alexis Thompson, MD, MPH
Horace Smith, MD
Robert Liem, MD
A. Kyle Mack, MD
773 880 4562

Kristin Clemenz, MS
Genetic Counselor
773 880 4125

Alfred Howard, LSW
Social Worker
773 880 4315

Bed Wetting and Sickle Cell Disease

Bed wetting or *nocturnal enuresis* is a common problem in children with sickle cell disease. Boys with sickle cell disease experience bed wetting more frequently than girls.

Although the exact cause of bed wetting is not known in sickle cell disease, children with sickle cell may have several risk factors that might make it worse. As

some children with sickle cell disease get older, their kidneys may have a harder time concentrating urine, which may result in bed wetting. Older children who snore or have trouble sleeping at night may also experience bed wetting.

Although it is important to drink plenty of water, we recommend limiting the amount of fluids or caffeinated drinks at

night before bed if you have or your child has this problem. Also, setting an alarm to wake children up once at night may help them remember to use the bathroom.

We encourage you or your child to talk to the sickle cell team about this problem, even though it can be embarrassing to discuss. There are treatment options available.

Patient Spotlight: Khen Carter and the HOT Healthy Living Initiative!

Living a healthy lifestyle is important for all families, whether or not family members have sickle cell disease. Eating healthy foods and getting exercise help all children!

The Division of Hematology, Oncology and Stem Cell Transplant is proud to present a new program focused on promoting healthy lifestyles in all children with chronic illness. You will see new bulletin boards in clinic that will provide valuable information for you and your family on how a healthy lifestyle can help you and your

child. You will also see new "hands on" events in clinic that will show your children how being healthy can be fun.

One of our patients, Khen "Kay Kay" Carter is doing her best to live a healthy lifestyle by helping her mom cook and prepare healthy meals. We are proud to spotlight Kay Kay and one of her healthy recipes.

Name: Khen Carter
Nickname: Kay Kay
Age: 11years old
Diagnosis: Sickle cell disease (SS type)
Grade: 6th grade
Favorite subject: Math
Favorite things to do:

Shopping at Water Tower Place, hanging out with her sister, ballet, and cooking!

Kay Kay's Veggie Rolls

Put sliced red peppers, carrots, bean sprouts, green onions and tofu (or your favorite veggies) in a large mixing bowl with sesame oil, soy sauce, garlic powder, pepper and ginger. Mix everything together and put half a handful of veggies on a spring roll sheet. Tuck in the sides and roll. Put in deep fryer to add crispiness or skip the frying step to make these rolls even healthier!