

Sickle Selections

a quarterly newsletter from the University of Rochester Sickle Cell Program

April 2002

Newborns with Sickle Cell Disease Surveyed for Health Care Status

The Strong Sickle Program surveyed the newborns identified by the New York Newborn Screening program with a hemoglobinopathy born in the 9 county² area for the 5-year period 1997-2001 to determine if these children were receiving routine medical care. An important part of the survey, which was requested by the New York State Department of Health, was to determine the number of children with potentially symptomatic hemoglobinopathies that were being followed by a pediatric hematology service. Of the 41 infants reported to us during this time period with a potentially symptomatic condition, 100% were located and identified as receiving routine primary care. Thirty nine of these children are currently living in the greater Rochester area and of these 39 children, 26 (63%) are receiving care relating to sickle cell at the Pediatric Sickle Cell Clinic and 13 (37%) are being cared for exclusively by their primary care providers.

Of the 26 children followed by the Pediatric Sickle Cell Clinic, 19 are 2 years of age and over and eligible for Transcranial Doppler (TCD) screening. Of these, 11 have been screened thus far. Two children from this age group had suffered a stroke prior to being referred to the clinic. Both these children are receiving chronic transfusion therapy and will require iron chelation in the near future.

Twenty five of the 26 children have received the pneumococcal conjugate vaccine (Prevnar) at the recommended ages. The one child not yet immunized with Prevnar has had this immunization delayed because of the diagnosis of a Wilms tumor.

In conjunction with the sickle cell specific care that is offered by the clinic, many children and families also have such basic needs as food and transportation. The clinic's outreach worker helps families meet these needs.

Children of any age with sickle cell disease can be referred to the clinic. The goal of the clinic staff is to work with the primary care provider to maintain the health of these children and to prevent complications from the disease.

Birth Statistics¹ for Newborns in HSA Region II of NY State²

The NY State Newborn Screening Program requires a blood specimen from every baby born in the state to test for 8 disorders. The hemoglobinopathies identified in HSA region II over the past 3 years are listed below.

Disease	2001	2000	1999
S no A ³	6	3	7
S/C	1	1	2
E/E			3
C/C		1	
Total	7	5	12
Trait			
A/S	190	221	209
A/Fast	44	48	78
A/C	47	47	46
A/E or O	16	10	22
A/D or G	5	5	4
A/Fetal	7	8	11
A/O Arab	1	1	
Total	310	344	384

Camp Kope Dates Changed

Camp KOPE (Kids Overcoming Pain Episodes), an overnight camping experience for children with sickle cell disease ages 8-17 years has announced a change of date for the 2002 session. The camp will be held at the Camp Good Days campus on Keuka Lake **August 26-29, 2002**. Camp brochures and registration forms are now available!

For more information or a brochure, please contact the Camp Good Days office at 585-524-5555 or visit their web site at www.campgooddays.org.

¹Source: NY State Department of Health

²The counties of Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Stueben, Wayne, Yates

³Includes sickle cell anemia (S/S), sickle/ β -thalassemia (S/ β Thal) and sickle hereditary persistence of fetal hemoglobin (S/HPFH). The way to distinguish among these is to test the parents.

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