

Sickle Selections

a quarterly newsletter from the University of Rochester Sickle Cell Program

April 2001

25 Years of Newborn Screening for Sickle Cell

In 1975 New York State mandated testing to identify newborns with sickle cell disease. Some statistics of interest are summarized below^{*}.

<u>New York State 1975-2000</u>		
Infants tested	6.71 million	
Confirmed cases of sickle [*]	3661	
Incidence	1:1833	
<u>Monroe County 1992-2000</u>		
DISEASE	Total	Incidence in black births
S no A [*]	38	1 in 495
S/S 19		
S/β-Thal 4		
undefined 15		
S/C	23	1 in 818
S/OArab	1	
S/E	1	
All Sickle Disease	63	1 in 298
TRAIT		
A/S	1792	1 in 10
A/C	469	1 in 40
A/E or O	130	
A/D or G	39	
A/OArab	8	

^{*} Source: New York State Department of Health

^{*} S/S, S/β-Thal, or S/Hereditary Persistence of Fetal Hemoglobin

Summer Sickle Camp Coming

After a successful program last year, Camp Good Days and Special Times has announced that the summer camping session for children with sickle cell disease (ages 8-17) will be a permanent program. Named Camp Kope (Kids Overcoming Painful Episodes) by last year's campers, this year's session will be held July 6-8, 2001 at the Keuka Lake camp facility. Children diagnosed with sickle cell disease from the

The Camp Good Days staff is planning a **Camp Registration Night**.
Tuesday, May 8, 2001 from 6-7:30 PM
 at the Pediatric Sickle Cell Clinic at Children's Hospital at Strong.
Pizza and soda will be served!

Contact Pat Lamarche at 275-2981 for more information

Rochester, Syracuse and Buffalo area were among the two dozen children who attended camp last year. It is hoped that this year will attract even more campers as the news spreads about the "fun time" that can be had at camp! Special attention is paid to the distinctive needs of these campers, including scheduled rest periods and opportunities for hydration. For a camp brochure, which includes the registration form, contact the Camp Good Days Office at 624-5555.

Outreach Worker Joins Clinic Staff

The Pediatric Sickle Cell Clinic is pleased to announce that Ms. Denise Houston has joined the staff. As the new Outreach Worker, she will be available on a part time basis to assist families of children with sickle cell disease. Ms. Houston completed a training program under the auspices of the Social Work Department at the Medical Center and has received instruction from the Pediatric Hematology clinical staff. Ms. Houston hopes to help families identify and overcome barriers to care, understand the medical problems of sickle cell disease, pursue preventive strategies, and feel comfortable in the medical center environment.

Ms. Houston can be reached by calling 275-2981.

UNIVERSITY OF ROCHESTER MEDICAL CENTER www.urmc.rochester.edu/genetics	Strong Sickle Program Offers Help	<i>Regarding treatment contact:</i> Norma Lerner M.D., Pat Lamarche R.N., C.P.N.P., Denise Houston, Outreach Worker Department of Pediatrics 275-2981 Karen Kaplan M.D., Department of Medicine 275-3761
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