

# Sickle Selections

a quarterly newsletter from the University of Rochester Sickle Cell Program

October 2000

## Early Intervention Program Available to Sickle Cell Children

Children with sickle cell disease are eligible for the Early Intervention Program offered by the Monroe County Department of Health. The tracking program, previously known as ICHAP, is now called **EI CARES** (Early Intervention Children at Risk Early Screening).

The purpose of **EI CARES** is to ensure that all children up to 30 months of age who are at risk for developmental delay have a "medical home" (health care provider), health insurance and receive developmental surveillance from a health care provider.

The program's workscope is summarized below:

- **Home visits:** Referrals made to **EI CARES** will initiate a home visit by a community health nurse from the Monroe County Health Department. The nurse will assess the family's health needs, assist with resources, offer developmental screening and educate the family about the provider's role in developmental surveillance.
- **Tracking:** Parental education packets, containing information on developmental milestones and community resources, are mailed out when infants reach 6 mo., 1 yr., 2 yrs. and 30 mos. of age. Families are encouraged to call **EI CARES** if problems with health insurance, health care or developmental concerns arise.
- **Liaison role with health care providers:** A pilot project with 4 health care providers has been initiated to promote developmental monitoring for at-risk children, to identify those disengaged from health care and to assess barriers to care via home visits.

Newborns with sickle cell disease are referred to **EI CARES** by the Strong Sickle Program. The home visit by the county nurse follows the visit by the Strong Sickle team.

Providers may call 716-530-5437 to refer a child or 716-530-4240 to ask questions.

## Influenza Vaccine Recommended for Sickle Cell Children

As the winter months approach, immunization for influenza becomes a concern. Production problems in the manufacturing of the vaccine, however, have limited its availability. It is anticipated that the vaccine will not be available until late October or November, with total numbers of doses uncertain at this time.

The Pediatric Sickle Cell Disease Program recommends that all children with sickle cell disease, 6 months of age and older, receive the influenza vaccine this year. Persons of any age with a chronic disease are considered at highest risk and should receive the vaccine first. Families of children with sickle cell disease are encouraged to contact their pediatricians or the Pediatric Sickle Cell Disease Program (275-9010) to schedule an appointment to have their children immunized.

## Birth Statistics<sup>1</sup> for Newborns in HSA Region II of NY State<sup>2</sup>

The NY State Newborn Screening Program requires a blood specimen from every baby born in the state to test for 7 disorders. The hemoglobinopathies identified in HSA region II over the past 3 years are listed below.

	Disease			Trait			
	1999	1998	1997	1999	1998	1997	
S/S	5	5	2	A/S	209	254	233
S/C	2	1	4	A/Fast	78	57	60
S no A <sup>3</sup>	1	2	3	A/C	46	53	57
S/β-Thal	1	1	1	A/E or O	22	11	19
S/E		1		A/D or G	4	6	5
E/E	3		1	A/Fetal	11	4	4
E no A <sup>3</sup>		1		A/O Arab	1	1	3
<b>Total</b>	<b>12</b>	<b>11</b>	<b>11</b>	<b>Total</b>	<b>371</b>	<b>386</b>	<b>381</b>

<sup>1</sup> Source: NY State Department of Health

<sup>2</sup> Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Stueben, Wayne, Yates

<sup>3</sup> An abnormal hemoglobin and no hemoglobin A can indicate either a homozygote for the abnormal hemoglobin or a compound heterozygote for the abnormal hemoglobin and β<sup>0</sup>-thalassemia. The way to distinguish these is to test both parents.

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**ROCHESTER**  
MEDICAL CENTER  
Strong Sickle  
Program  
Offers Help

Regarding treatment contact:

Dr. Norma Lerner or Pat Lamarche R.N., P.N.P. Department of Pediatrics 275-2981  
Dr. Karen Kaplan, Department of Medicine 275-3761

Regarding laboratory diagnosis, newborn screening and genetic counseling, contact:

Dr. Peter Rowley, Sandra LaBella or Starlene Loader, Division of Genetics 275-4602

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