

# SCDAI

8100 S. Western Ave.  
Chicago, IL 60620  
773-526-5016

## SCDAI PROGRAMS:

- Newborn Screening (NBS) Program
- Illinois Sickle Cell Action Network (I-SCAN)
- Advisory & Support Group
- Combined Federal Campaign (CFC) Appeal. Listed under the Community Health Charities of Illinois Federation & Member Organizations SCDAl's Giving # 79914
- The Christmas Toy Drive has Begun! Please Donate New, Unwrapped Gifts to SCDAl for children with Sickle Cell Disease Ages 0-12!

## SAVE THE DATES!

|  |          |
|--|----------|
| SCDAI Open House                             | 11/7/09  |
| Advisory & Support Group Meeting             | 11/12/09 |
| Christmas "Gift Giving"                      | 12/19/09 |
| Golf Outing                                  | 5/2010   |
| Walk-Jog-Bike-A-Thon (WJBAT)                 | 6/2010   |
| Summer Activity                              | 7/2010   |
| Management of Sickle Cell Disease Conference | 9/2010   |

### A PROUD MEMBER OF:



Serving the community since 1971



# SICKLE CELL DISEASE ASSOCIATION OF ILLINOIS

QUARTERLY NEWSLETTER

FALL 2009

## SCDAI Has A New Home



**ATTENTION! ATTENTION!** As of July 1, 2009 SCDAl left our downtown Chicago home of 20+ years and made a transition to 8100 S. Western Avenue! With our new location we personally feel we can provide better services to the community and families. We welcome you to come out and tour our new space and find out what new plans and endeavors SCDAl has in store. **FREE PARKING!**

## NEWBORN SCREENING (NBSP) "Know Your Status"

**Did you know? Testing for Sickle Cell Disease and Sickle Cell Trait was added to the Newborn Screening in 1989. Individuals born before 1989 were not tested at birth!**

Newborn Screening by the Illinois Department of Public Health (IDPH) is required by state law, and every baby born in the state is screened for rare disorders. All babies must be screened before going home from the hospital. The process is done by collecting a few drops of blood from your baby's heel. The blood drops are blotted on a special paper form that is sent to IDPH laboratory.

SCDAI's Newborn Screening Program (NBSP) has recently been re-approved for funding by the U.S. Maternal and Child Health Services Resources and Service Administration (HRSA) for another three years! In 2002, SCDAl was one of 17 agencies awarded a NBSP grant by HRSA to create a seamless process to contact parents of newborns testing positive for sickle cell disease or other abnormal hemoglobins and provide education and counseling.

SCDAI continues to improve and expand our system of integration and collaboration that initiates and maintains linkages with sickle cell treatment centers, the IDPH, community based providers, public health providers and any other entities affiliated with the NBSP. SCDAl's goal is to develop a protocol to ensure that the families receive test results, re-testing, family testing and are linked into a medical home (a health center where the primary care physician has up-to-date knowledge of the treatment of children with sickle cell disease, sickle cell trait and other abnormal hemoglobins).

In order to meet our deliverables for HRSA, SCDAl has maintained a Memorandum of Understanding (MOU) with the IDPH since 2004 that assists us in receiving patient contact information, and in providing training for doctors and other medical professionals across the entire state.

**ASK QUESTIONS! GET TESTED! KNOW YOUR STATUS!  
WHAT YOU DON'T KNOW CAN HURT YOU!**



## I-SCAN "Changing-A Need"

### I-SCAN APPROACH:

The Sickle Cell Disease Association of Illinois, partners with Christian Community Health Center (CCHC) and the Advisory Board to form the I-SCAN (Illinois Sickle Cell Action Network). I-SCAN is a statewide network of hematologists, physicians, sickle cell treatment centers, Federally Qualified Health Centers (FQHCs), county and city health departments, the Illinois Department of Public Health (IDPH) and patients with Sickle Cell Disease and their families.

I-SCAN exists to unite patients, medical providers and program administrators in treatment, care and education surrounding Sickle Cell Disease and Sickle Cell Trait (Carrier status).

### I-SCAN AIMS TO ADDRESS:

- The knowledge gaps that exist in the FQHCs and other primary care settings

- The adoption of new developments in care and promote routine delivery of genetic counseling for hemoglobinopathies
- Redesign care to address access and quality improvement, in order to facilitate the prevention and treatment of complications of sickle cell disease.

### I-SCAN'S SERVICES:

- Training for health care professionals, including in-services at FQHCs, seminars and conferences
- Counseling and supportive services for sickle cell carriers and their families
- Prenatal counseling to pregnant women and to parents of newborns with sickling disorders or carrier status

- Community outreach, including informative presentations for churches, schools and health fairs
- Educational media and materials for distribution
- Referrals to Medical Homes and other supportive services in the I-SCAN network

### HOW CAN YOU HELP?

Individuals with Sickle Cell Disease can help by participating in the current study in which evaluation data is collected from you or your caregiver that measures quality of life in adults and children; measures client/caregiver satisfaction with the care received from their primary care provider; collects information on the demographic characteristics of clients enrolled; their health status, and the use of health care services and sickle cell disease treatments.

To schedule an appointment or for more information please contact Cortisa Howell or Yvonne Williams at 773-526-5016

**Website:** <http://www.sicklecelldisease-illinois.org>

**Facebook:** scdaillinois or the sickle cell disease association of Illinois

**Follow us on Twitter:** SCDAllinois