



## September is Sickle Cell Month

### Get Informed

Find out more about the disease, its symptoms and how to recognize it in yourself, your child or a child you know. Right now, sickle cell disease is curable only through a very expensive bone marrow transplant. However, if your newborn has been diagnosed with the disease, there is a treatment that can be administered in the first few months of life that will ease the symptoms throughout his or her lifetime.



### Get Tested

If you are planning to start a family and don't know if either you or your spouse carries the sickle cell trait, ask your doctor if you can have a simple blood test that would detect the abnormal hemoglobins.

### Get Active

SCDAI has a variety of events throughout the year for you to come and meet other fun, energetic and friendly participants. From the Walk-Jog-Bike-a-Thon, to the golf outing, to the Theater Night, you will find lots of opportunities to enjoy good times with your peers. Children with SCD and SCT can find fellowship at our annual summer camp.

### Get Involved

Check out our website at: [www.sicklecelldisease-il.org](http://www.sicklecelldisease-il.org) to find ways to volunteer or donate funds to assisting people with sickle cell disease.

**Save The Date**  
SCDAI's 35th Anniversary Gala  
October 27, 2006



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[www.sicklecelldisease-il.org](http://www.sicklecelldisease-il.org)

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## Executive Director's Message Valerie C. Beckley

This is an exciting year for the Sickle Cell Disease Association of Illinois. It's our 35th Anniversary, and I am happy to report that the agency is healthier than ever and getting stronger. Our name recognition is growing along with our reach across the state of Illinois. I'll get into that more later, but first let me sing the praises of our friends and loyal supporters.

On Saturday, June 10th, I stood on Chicago's lakefront in the pouring rain at around 5 o'clock in the morning, thinking "why?" Why does this have to happen today, of all days? It had been beautiful weather all week long, but as I was getting ready at approximately 1 a.m. for SCDAI's 32nd Annual Walk-Jog-Bike-A-Thon (hey, that's the executive director's life), I heard nothing but thunderstorms rolling over the city.

Those of you who greeted me at WJBAT saw that I was decked out in near-impenetrable rain gear—including rubber boots, trench coat and oversized umbrella. I had hoped that this wouldn't be like the year our trucks got stuck in the mud, or the time that the water delivery didn't arrive until half the walkers were on the path. Yet, this time I did have a nail-biting wait on the supplier who was to set-up the booths for our vendors and sponsors that made me wonder, what next?

Well, what was next would surprise even a wizened non-profit administrator like me. Seven o'clock rolled around and the cars started arriving. The rain was still heavy, but so was the steady influx of vendors, volunteers, staff and walkers. I was moved. You all—or rather,

ya'll...because I love you—really came through! Our booths were filled, the music was pumping as participants did their warm-ups, food was on the grill, droves of people were on the path and we had a simply fantastic day.

If I ever again catch myself wondering why I'm rising at some ungodly hour for a SCDAI event, I just have to think of our many friends and think...because they're rooting for the program's success, care about our cause, won't let you down and, yes, they are getting up too. A million thanks would never suffice, but thank you anyhow.

Now, on to the other things we've accomplished. The Sickle Cell Disease Association of Illinois is becoming a force in our State. As you will read in the following stories, we have really reached out to our neighbors in central, northwest, southwest, eastern and the far southern counties of Illinois. For the first week in May, I traveled through many counties in Illinois and met with folks in Metro East (East St. Louis and Madison counties), Peoria, and a host of sites in the Southern Seven counties. Did you know that we have a huge State? Everywhere I went the people were receptive to my visit and eager to partner with SCDAI on creating programs, holding conferences and in-services, identifying sickle cell disease populations, and generally getting the word out about the chronic illness and treatments. Fortunately, I was able to utilize these newfound contacts to partner on several proposals to combine our efforts in reaching and creating a statistical database for our target population. Let's keep our fingers crossed that these initiatives come through.

## At 32, WJBAT Finishes First in SCDAI Fundraising Effort

The annual Walk-Jog-Bike-A-Thon was a resounding success. For the 32nd year, the endurance competition was held on the lakefront. At 8 a.m., the day began with participant registration. After an aerobic warm-up, walkers, bikers and joggers of all ages left the main checkpoint at 31st Street and proceeded along the lakefront's bicycle and walking path to 47th Street. The original plan was for the athletes to have a checkpoint at 67th Street, but the heavy rain caused a quick change of plans. After finally making a full circle back to 31st,



walkers could then relax while feasting on an array of energy-building foods provided by our sponsoring partners.

The event is one of SCDAI's largest sources of funding. The proceeds are used to support the agency's community outreach efforts and for programs designed to reduce the social limitations of sickle cell anemia, a genetic illness that is prevalent in approximately 5,000 households in Illinois. Even during pouring rain and thunderstorms, the cause drew approximately 800 walkers, over 20 corporate supporters, family members and a multitude of friends who just stopped by to say hello and donate money. This event has raised approximately \$150,000 for sufferers of sickle cell disease and sickle cell trait.

# Newborn Screening Grant Renewed for Fourth Year

The Newborn Screening Program (NBSP) has recently been re-approved for funding by the U.S. Maternal and Child Health Services Health Resources and Service Administration (HRSA) for another two years.

In 2002, the Sickle Cell Disease Association of Illinois was one of 17 agencies awarded a NBSP grant by HRSA to create a process to contact the parents of newborns testing positive for sickle cell disease or other abnormal hemoglobins and provide education and counseling.

From the beginning of this partnership, SCDAI set out to provide a system of integration and collaboration that would initiate and maintain linkages with community based sickle cell treatment centers, the Illinois Department of Public Health (IDPH), community based providers, public health providers and

any other entities affiliated with the NBSP. The goal of SCDAI was to develop a protocol to ensure that the families had received re-testing and were being followed in a medical home (a health center where the primary care physician had 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, the Sickle Cell Disease Association of Illinois has formed a Memorandum of Understanding with the Illinois Department of Public Health that assists us in receiving patient contact information from physicians and in providing training for doctors and other medical professionals across the entire State.

Over the course of the first three years, SCDAI received nearly 1,000 referrals for sickle cell trait and sickle cell disease from physicians, community hospitals, self-referrals and IDPH. Of those, the agency was able to make contact with 97 percent of the families.

# SCDAI Involved in Creating Illinois Sickle Cell Network

This summer, an opportunity arose for organizations to apply for a sickle cell treatment demonstration project grant through a federally released application from HRSA. The request for proposals asked that applicants form statewide collaboratives with federally qualified health centers (FQHCs) in identifying individuals with sickle cell disease and trait and assisting them in finding competent treatment options and medical homes.

Eager to capture these much-needed funds, SCDAI partnered with the Roseland Christian Health Ministries, which operates the Christian Community Health Center at 9718 S. Halsted, to create the Illinois Sickle Cell Action Network or I-SCAN. Our two non-profit organizations developed a statewide network including experienced hematologists, physicians, comprehensive sickle cell treatment centers, FQHCs, county and city health departments, and the Illinois Department of Public Health.

We do not usually tout pending grants, but this proposal represents funding that, if awarded, would allow SCDAI to realize a goal the agency has had since our founding as the Midwest Association for Sickle Cell Anemia. The Illinois Sickle Cell Action Network would provide us with the ability to counsel, educate, document and create a treatment protocol for all of the families in the State that have sickle cell disease and/or trait.

The funding is slated for more than \$300,000 and is renewable for five years. Roseland Christian Health Ministries and SCDAI have identified Cook County; including Thornton Township and Chicago's West Side, the city of Peoria, East St. Louis and the Southern Seven Counties as the first areas of concentration for services. In the following years, the Network will gradually include FQHCs in all of the counties in Illinois.

# SCDAI Presents In-Service in Metropolis

Metropolis. Do you even know where that is? Believe it or not, the place whose name invokes images of Superman flying high over the city and providing protection (indeed, they hold annual Superman festival) is actually located in the southernmost tip of Illinois. Executive Director Valerie Beckley found that out this year out after making a presentation on sickle cell disease at a March of Dimes conference in Chicago.

After her appearance, Beckley was approached to do the same for the Southern Seven Health Department—including Union, Johnson, Pope, Hardin, Alexander, Pulaski and Massac counties. She was informed about the lack of information regarding sickle cell disease and sickle cell trait in downstate Illinois, and quickly made plans to visit the area. On May 26, Beckley and staff delivered a presentation to a group of more than 25 health care professionals. The in-service was well received, with some staff receiving continuing education units (CEUs).

Though the downstate counties have a smaller number of residents than many Illinois counties, African Americans make up 12 to 16 percent of the populace in some areas and there is a new thrust in the health department to reach out to this community to provide sickle cell disease testing and treatment.

These new outreach efforts to more Illinois counties were made possible by the long-range vision of State Senate President Emil Jones. Thanks to a \$100,000 grant in FY2006 and renewed for FY2007, SCDAI has been able to plan more educational events and information dissemination in the southernmost counties of Illinois.

# SCDAI Management of Sickle Cell Disease Conference Held on September 21, 2006

"Multidisciplinary Approach" was the title of this year's annual conference for the management of sickle cell disease. The event took place at the Hilton in Oak Lawn on Thursday, September 21st from 8 a.m. to 5:30 p.m. Approximately 130 people attended the conference.

The agenda included three sessions. Morning Session presentations, included: the impact of stroke on students, update of sickle cell disease, update of SCDAI's Newborn Screening Program, case studies-pediatric management in the emergency room, case studies-nursing assessment of inpatient client, new research update on oral chelation and a lunch and parent panel.

Afternoon Session presentations, included: adolescent medicine psycho-social/sexuality issues, nursing case management pediatric school issues, prenatal counseling and post-diagnostic family education, management of chronic complications in adult SCD patients, new concepts in transition at UIC-easing on down the road from pediatric to adult care, and analgesic management in the emergency department.

The Evening Session presentation, included an introduction and welcome, pre-surgical clearance "drug interaction and anesthesia," and asthma in children with sickle cell disease.



# Upcoming Event

October 27, 2006  
35th Anniversary Gala

Time flies when you have a cause. It would be great to report that sickle cell disease and trait had been eradicated and there is no reason for SCDAI anymore. But, as you know, that is not nearly the case. Founded as the Midwest Association for Sickle Cell Anemia in 1971, we have come a long way. Today, the Sickle Cell Disease Association of Illinois is more relevant than ever as we approach our 35th Anniversary. Our services have been expanding statewide and the requests for additional services are mounting.

October 27th is a Friday. Save the date and get ready to celebrate. We will honor progenitors of our past and future success: Founder Howard D. Anderson, past Board Member Eugene Morris, Congressman Danny K. Davis, Congressman Jessie L. Jackson Jr., Senate President Emil Jones, Keepers of the Flame and Evera Ivy. The gala will be held from 5 to 10 p.m. at The (Marmon) Grand, a beautiful and classically styled banquet and meeting space, located at 2230 South Michigan Avenue. Single tickets are \$75.

