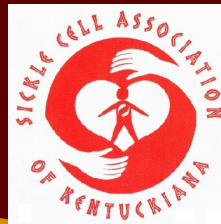


The Sickle Cell Association of Kentuckiana

2011-2012 Annual Report



2011-2012 Annual Report

The Sickle Cell Association of Kentuckiana, Inc. (SCAK) is a tax-exempt not-for-profit organization that provides education, support, and advocacy for individuals with sickle cell disease and their families. SCAK is dedicated to increasing awareness of this disease and supporting endeavors that assure prompt and appropriate medical care. Our target audience, however, is not limited to those personally affected by sickle cell. 2011 has been a remarkable year for Sickle Cell Anemia. Although a cure has yet to be discovered, recognition of the disease in sports and medicine has placed a great emphasis on the incidence and seriousness of the ailment. This past year our committee and board members have hosted various events to spread awareness of Sickle Cell Anemia. 2011 highlighted many first for the association, including but not limited, to the incorporation of the first annual Sickle Cell Anemia gala and the Glenda B. Collins Sickle Cell Anemia scholarship program.

The Sickle Cell Association of Kentuckiana

201 E. Jefferson Street, Ste. 120

Louisville, KY 40202

(502) 569-2070

www.theseak.com

Sickle Cell Registry: www.surveymonkey.com/s/theseak

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CONQUERING SICKLE CELL

"Our goal is to make the lay community aware of the issues that Sickle Cell patients and families face on a daily basis. In addition, we strive to increase awareness of this disease and support endeavors that assure prompt and appropriate medical care and overall wellness for our survivors".

SERVICE POPULATION

For many families in Kentucky and Southern Indiana, The Sickle Cell Association of Kentuckiana (SCAK), represents the voice of individuals directly affected by sickle cell. Whether providing support groups, events, or even assistance, The Sickle Cell Association of Kentuckiana enriches the lives of their patients and families. SCAK represents a great need for the Sickle Cell population and focuses on creating a promising atmosphere by educating families, the community, and health care providers.

SCAK-AT-A-GLANCE

“Conquering Sickle Cell, One Patient At A Time”

Sickle Cell Anemia is a hereditary blood disorder that causes an abnormality of the red blood cells.

We realize that until the day a promising cure arises our patients have to deal with the debilitating, painful disease the best way they can. Sickle Cell Anemia is a life-changing disease that enables its victims to live a pain-free, healthy, happy life. To ensure that patients are able to receive the best quality of life available, we have initiated the “Conquering Sickle Cell” program which encompasses the following:

Sickle Cell Registry (KY and Southern IN)- A database to register and track Sickle Cell patients in Kentucky and southern Indiana who frequent the Sickle Cell Associations programs and services. Before The Sickle Cell Association of Kentuckiana – Sickle Cell Registry, there was no know Census to keep track of patients living with Sickle Cell Anemia in Kentucky and Southern Indiana.

Education & Awareness- SCAK will continue to rigorously promote Sickle Cell related issues to the community, families, and Sickle Cell children. We will utilize updated educational materials, pamphlets, books, SCAK materials for health fairs and awareness initiatives.

Innovative Support Groups- The three support groups (SCA Children, SCA Young Adults, and Parents) focus on correcting stigmas one may have about their journey with Sickle Cell Disease. Throughout the support group meetings participants will receive a renewed strength of hope, support, and encouragement that will help eliminate some fears, stress, anxiety, and depression issues commonly associated with SCA.

SCAK, founded in October 2000, has been an advocate and resource for patients and families throughout Kentucky and Southern Indiana. Thus far, this has been achieved through support groups, community outreach opportunities, and efforts to establish a comprehensive Sickle Cell Center of Excellence. SCAK currently has approximately 50 members and is continuing to grow. The University of Louisville Medical Student Sickle Cell Project (MSSCP), in collaboration with Dr. Suzanne Ildstad and the Institute for Cellular Therapeutics (ICT), are founding members of SCAK and have been consistently involved with the association since its inception. A strategic plan is in place for the growth and development of SCAK’s success.

One major goal is to establish a comprehensive Sickle Cell Center of Excellence and to build the infrastructure to support that program. The center of excellence will provide comprehensive psychological, social, and medical care to patients and families affected by the disease. The existence of SCAK in establishing a network of communication throughout Kentuckiana to provide information to individuals and families living with sickle cell disease is a critical supporting component of this initiative. The Board of Directors and general membership continue to work toward securing the future of this exceptional organization. The establishment of SCAK played a major role in helping UofL to become one of ten designated National Institutes of Health (NIH) funded Sickle Cell Centers in the United States (4/1/03).



FACTS

Sickle cell disease affects millions of people worldwide. It affects over 70,000 people in the U.S.

Is most common among people of African descent. 1 in every 12 African Americans has the trait. 1 in every 400 has sickle cell disease.

It also affects people from Spanish speaking regions (South and Central America, Cuba). 1 in every 100 Hispanics has the trait. 1 in every 1000 Hispanics has sickle cell disease.

It also affects people from another regions; India, Saudi Arabia and the Mediterranean (Italy, Greece, Turkey).

Types of Sickle Cell Disease?

There are several types of sickle cell disease. The most common are:

Sickle Cell Anemia (SS)

Sickle C Disease (SC)

Sickle Beta-Plus Thalassemia (SB+)

Sickle Beta-Zero Thalassemia (SBO)

What is Sickle Cell Trait?

People with Sickle Cell trait inherit a normal hemoglobin gene (Hb A) from one parent, and a Sickle hemoglobin gene (Hb S) from the other parent. This results in hemoglobin AS or Sickle Cell trait. A person with Sickle Cell trait may also be called a Sickle Cell carrier.

Sickle Cell trait is not a disease. It does not turn into Sickle Cell Disease/Anemia. It is not contagious. People with Sickle Cell trait are not sick. They can lead normal lives and have minimal medical problems due to Sickle Cell trait. For a few people, painful episodes may occur if they fly in unpressurized planes at high altitudes. Some people with Sickle Cell trait may occasionally have blood in their urine. If these problems occur, a physician should be notified.

Counseling and education regarding the Sickle Cell trait are important because the sickle gene can be passed to any carrier's children.

PRESIDENT'S HIGHLIGHTS



Vision:

"Conquering sickle cell disease, one patient at a time".

Mission of SCAK:

We strive to broaden awareness and education about Sickle Cell Disease and its affects. To provide education, support, and empowerment to affected individuals and their families. To link patients and families with appropriate medical treatment. Promote activities regarding sickle cell research. To advocate for the rights and needs of affected individuals and their families.

Our Goals and Objectives

To establish a Sickle Cell Center of Excellence in Louisville, KY.

To broaden community awareness and education about Sickle Cell Disease and its affects.

To provide support and empowerment to children and their families through family-oriented activities and the support groups.

To link patients and families with specialized medical doctors and appropriate medical treatments.

To link patients and families with community resources necessary for healthy living and dealing with social issues surrounding SCA.

To enable the community (churches, organizations, schools, medical facilities) to understand the psychosocial and healthcare issues surrounding Sickle Cell Disease.

To enable the community to have an active role in eliminating healthcare disparities for these patients.

To provide temporary financial relief for children and their families.

Overall, the program is intended to bridge the gap between Sickle Cell Anemia patients and healthcare providers, educators (teachers), and the community. Sickle Cell is one of the oldest genetic disease noted however, little has been done to promote awareness, education, and support for Sickle Cell Anemia/Disease. Our vision is that people become knowledgeable about Sickle Cell Anemia and how it affects the physical, mental, and psychosocial components of the body.

For over a decade now, The Sickle Cell Association of Kentuckiana (SCAK) has been a intricate part of patient support and advocacy for sickle cell patients and their families. Each year we continue to grow and become better equipped to serve the community through education and awareness. In 2011, we served approximately 100+ families through direct services and events. We have also served over 20,000 in community education and health fair initiatives. The year 2011 brought many great accomplishments for our non-profit organization. September 2011 was especially a remarkable month as SCAK celebrated its very first Sickle Cell Anemia Gala. This event brought the much need support and exposure to the ever growing disparities amongst our sickle cell population. In 2012 we look forward to assisting 130+ families through direct services and reaching over 40,000 through community initiatives, health fairs, etc.

-Daphne Matthews-Johnson, SCAK President & Director



2012 SCAK COMMITTEE AND BOARD MEMBERS

BROAD OF DIRECTORS

DAPHNE L. MATTHEWS-JOHNSON

EXECUTIVE DIRECTOR

BRANDON BRISON

VICE EXECUTIVE DIRECTOR

DANET JARMON

2ND VICE EXECUTIVE DIRECTOR

DIANE BURNETTE

BOARD MEMBER

SAMUEL DAVIS

BOARD MEMBER

ROBERT A. WILLIS

BOARD MEMBER

MARITA WILLIS

BOARD MEMBER

PATIENCE NGWANG

BOARD MEMBER

SARAH PATTISON

BOARD MEMBER

VOLUNTEER COMMITTEE MEMBERS

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PHONE: (502) 415-6075 (CELL)

EMAIL: Stephaniefay@live.com

GET INVOLVED....

The committee members meet monthly to discuss, organize, and plan for the events and initiatives that will help support our Sickle cell anemia populations. The board meetings take place quarterly. Board meetings are scheduled for February 18th, May 19th, August 18th, and November 17th. If you are interested in joining the association visit www.thescak.org or contact (502) 560-2070 for details.

The Sickle Cell Association of Kentuckiana

Table: Planned Balance Sheet (Unaudited) (page 1 of 2)

Pro Forma Balance Sheet

Revenue	2011	2012
Wendys	\$650.00	\$1,000.00
Fund Raising Events	\$10,841.40	\$10,000.00
PNC Bank	\$500.00	\$1,000.00
Community Health Charities	\$3,591.00	\$4,000.00
Kosair Charities Gala Donation	\$1,000.00	\$1,000.00
Ronald McDonald House Charities	\$0	\$1,000.00
TJX Foundation (giftacards)	\$1,000.00	\$1,000.00
Chevron Humankind	\$1,193.00	\$0
TRUiST Citigroup donor	\$51.96	\$50.00
YUM BRANDS	\$1,000.00	\$1,000.00
Total 2011 Support and Revenue	\$19,827.36	\$20,050.00
Staffing Expenses	2011	2012
Total Personnel Expenses	\$0	\$0
Operating Expenses	2011	2012
Rent (includes utilities, phone, internet)	\$2,400.00	\$2,400.00
Educational Materials & Training	\$711.02	\$2,500.00
Miscellaneous	\$1,937.46	\$0
Dues & Subscriptions	\$334.20	\$100.00
Support Group Materials	\$500.00	\$800.00
Office Supplies & Event supplies	\$521.04	\$1,000.00
Educational (books & pamphlets)	\$499.39	\$1,500.00
Website (Windstorm & Godaddy.com)	\$45.00	\$95.00
Staff Appreciation Dinner & Luncheon	\$211.69	\$250.00
Business Cards	\$0	\$375.00
Printing Publications & Newsletters	\$182.06	\$100.00
Postage	\$300.00	\$300.00
Total Operating Expenses	\$7641.86	\$14,420.00
Gala Expenses	2011	2012
Gala Ticketprinting.com	\$66.78	\$66.78
JT Fredrick Band (performance & board)	\$1,294.00	\$1,000.00
Gala Digital Project	\$117.83	\$100.00
Gala Awards	\$98.85	\$98.85
KY Ctr Afr. Amer. Gala location rental	\$1,400.00	\$1,400.00
Masterson's Catering	\$5,044.30	\$5,000.00
Visual productions	\$450.00	\$400.00
Lavell White Videographer	\$100.00	\$100.00
Gala supplies/florals/centerpieces	\$249.76	\$200.00
Total Gala Expenses	\$8,821.52	\$8365.63

The Sickle Cell Association of Kentuckiana

Table: Planned Balance Sheet (Unaudited) (page 2 of 2)

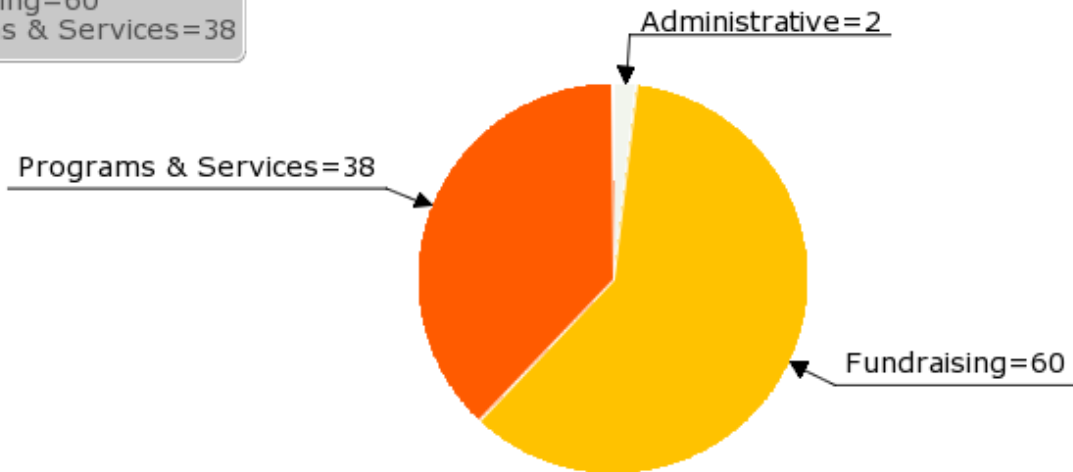
SCA Walk/Run Expenses	2011	2012
Metro Parks Reservations (Iroquois)	\$300.00	\$300.00
Print-tex USA run t-shirts	\$504.25	\$500.00
TOTAL WALK/RUN EXPENSES	\$804.25	\$800.00
SCAK Backpack to School Expenses	2011	2012
SKATE WORLD (Party Room Reservation)	\$89.00	\$80.00
Invitations (donated)	\$0	\$0
Little Ceasars Pizza (donated)	\$0	\$40.00
Desserts (Cakes)	\$12.00	\$38.00
Backpack & Supplies (donated)	\$0	\$0
TOTAL SCHOOL EVENT EXPENSES	\$101.00	\$158.00
Christmas Party Expenses	2011	2012
Party Location	\$0	\$0
SCA patients presents	\$578.38	\$1,000.00
Decorations & Supplies	\$205.12	\$100.00
Food	\$94.88	\$200.00
Gift card present (Visa)	\$240.00	\$0
Gift card presents (McDonalds)	\$150.00	\$0
Walmart (2) presents	\$71.91	\$0
TOTAL CHRISTMAS PARTY EXPENSES	\$2,458.67	\$1,300.00
SCAK DAY AT PARK Expenses	2011	2012
Location	\$0	\$175.00
Food	\$0	\$200.00
Activities	\$0	\$50.00
Invitations	\$0	\$30.00
TOTAL SCAK DAY AT PARK EXPENSES	\$0	\$455.00
TOTAL EVENT/PROGRAM EXPENSES	\$12,185.44	\$11,078.63
2011 TOTAL OVERALL EXPENSES	\$19,827.3	
NET ASSETS (Year end balance) Republic Bank Account	\$7,774.56	

The Sickle Cell Association of Kentuckiana

Note: The following breakdown is calculated in percentages.

2011 Sickle Cell Association Financial Expense Breakdown

- Administrative=2
- Fundraising=60
- Programs & Services=38



chartmaker.mathwarehouse.com

2012 Calendar of Events

All support group meetings take place at St. Stephen Church. All committee and board meetings take place at our SCAK office located at Med 3 Center

January

1-21-2012 SCAK committee and board meeting 12– 2:00 p.m.

February

2-18-2012 SCAK committee and board meeting 11:30-1:00 p.m.

March

3-17-2012 SCAK committee and board meeting 11:30– 1:00 p.m.

April

4-21-2012 SCAK committee and board meeting 11:30– 1:00 p.m.

May

5-19-2012 SCAK committee and board meeting 11:30– 1:00 p.m.

5-2012 (TBA) SCAK Day in the Park (Shawnee Park Pavilion)

June

6-16-2012 SCAK committee and board meeting 11:30– 1:00 p.m.

July

7-21-2012 SCAK committee and board meeting 11:30– 1:00 p.m.

7-2012 SCAK Car Wash Fundraiser (TBA)

August

8-4-2012 SCAK Back Pack to School Party (Details TBA)

8-18-2012 SCAK committee and board meeting 11:30– 1:00 p.m.

September

9-8-2012 3rd Annual "Who Will You Run For?" 5 K Walk/Run (Iroquois Park)

9-15-2012 SCAK committee and board meeting 11:30– 1:00 p.m.

9-29-2012 SCAK 2nd Annual Sickle Cell Anemia Gala (Details TBA)

October

10-20-2012 SCAK committee and board meeting 11:30– 1:00 p.m.

November

11-17-2012 SCAK committee and board meeting 11:30– 1:00 p.m.

December

12-1-2012 SCAK & MSSCP Annual Christmas Party (Details TBA)

12-15-2012 SCAK committee and board meeting 11:30– 1:00 p.m.

Support Group Meetings

Support group meetings typically take place every 3rd Saturday of the month from 1-2 p.m. unless noted on calendar. Call (502) 569-2070 to RSVP your attendance.

Location: St Stephens Church
1018 S. 15th Street
Family Life Center 3rd Floor
Louisville, KY 40210

January (no group this month)

February 18 (1:00-2:00 p.m.)

March 17 (1:00-2:00 p.m.)

April 21 (1:00-2:00 p.m.)

May 19 (1:00-2:00 p.m.)

June 16 (1:00-2:00 p.m.)

July 21 (1:00-2:00 p.m.)

August 18 (1:00-2:00 p.m.)

September 15 (1:00-2:00 p.m.)

October 20 (1:00-2:00 p.m.)

November 17 (1:00-2:00 p.m.)

December 15 (1:00-2:00 p.m.)

Proud Member of:



2011 Sponsors



The Sickle Cell Association of Kentuckiana

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