

**SICKLE CELL ASSOCIATION OF
UGANDA (SAU)**



**STRATEGIC PLAN
2010 – 2013**



SICKLE CELL ASSOCIATION OF UGANDA (SAU)

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Table of contents

Overview.....	
Acronyms.....	
Acknowledgement.....	
1.0 Background.....	
1.1 Vision.....	
1.2 Mission.....	
1.3 Goal.....	
1.4 Guiding Principle.....	
2.0 Contextual Analysis	
3.0 Achievements and Challenges.....	
4.0 Stakeholders Analysis.....	
6.0 Identification of Priority Program Area.....	
6.1 Program area 1 Awareness on Sickle cell Disease	
6.2 Program area 2 Psychosocial Support	
6.3 Program area 3 Advocacy and Networking	
6.4 Program area 4 Reproductive Health	
6.5 Program area 5 Capacity Development.....	
7.0 Institutional Capacity Development	
8.0 Monitoring and Evaluation of The Strategic Plan.....	
9.0 SAU's 3 year Budget Plan	
10.0 SAU's Organizational Structure.....	

Overview

Sickle cell Association of Uganda (S.A.U) is a charity organization that was founded in July 2000 by concerned patients. It was registered as a Non-Governmental Organization in February 2007. It advocates for the rights of Sickle cell patients, improvement of the diagnostic and clinical services for patients and creates awareness about the disease. It is also a registered member of the International Alliance of Patient's Organizations (IAPO).

For the previous years, SAU has been faced with some key challenges such as limited documentation, inadequate human resource, poor monitoring and evaluation systems, lack of a resource mobilization strategy resulting in inefficiency and ineffectiveness of the organisation.

In order for SAU to promote effectiveness and efficiency, it has laid down the following strategies:

Strategy 1: AWARENESS ON SICKLE CELL DISEASE
Objectives: <ol style="list-style-type: none">1. Conduct four Sickle cell outreaches each year in Uganda.2. To produce IEC materials on Sickle cell Disease: a documentary, music CD and 30,000 brochures.3. Media broadcasts (8).4. Website designing and posting.5. Educating patients and care givers at Mulago Sicklecell Clinic.6. Write/ develop abstracts on Sickle cell Disease to be presented in conferences.7. Increase subscription of people for Sickle cell screening.
Strategy 2: PSYCHOSOCIAL SUPPORT, i.e. improve the productivity and quality of life of Sickle cell patients and their families.
Objectives: <ol style="list-style-type: none">1. Provide counselling to patients and care givers.2. Follow up Sickle cell Disease cases.
Strategy 3: ADVOCACY AND NETWORKING
Objectives: <ol style="list-style-type: none">1. Increase functional Sickle cell Clinics in regional referral Hospitals2. Maintain partnerships with IAPO, VHR, HWAF, NUDIPU, UAPO3. Partner with Foundation for Human Rights initiative4. Establishment of a Sickle cell Clinic in Namalere5. Raise funds for SAU
Strategy 4: REPRODUCTIVE HEALTH
Objectives: <ol style="list-style-type: none">1. To increasing awareness and build capacity of individuals about MSRHR rights in Nalutuntu Sub County (Mubende District).2. Develop and implement Maternal Health Care package for Sickle cell mothers.3. Incorporate Sickle cell screening in pre-marital counselling and testing and genetic counselling and testing.
Strategy 5: CAPACITY DEVELOPMENT
Objectives: <ol style="list-style-type: none">1. Train professionals in the area of Sickle cell Disease2. Develop manuals about care, management and support of Sickle cell Disease.3. Establish Sickle cell curricula as a career path.

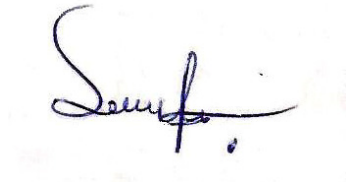
Acronyms

S.A.U	Sickle cell Association of Uganda
MSRH	Maternal Sexual Reproductive Health.
SP	Strategic Plan
E.C	Executive Committee
MH	Maternal Health
MDG	Millennium Development Goal
HSSIP III	Health sector strategic investment Plan III
UN	United Nations
SHA	Stakeholders Analysis
BOD	Board of Directors
CSO	Civil Society Organization
CBO	Community Based Organization
NGO	Non Governmental Organization
MOH	Ministry Of Health
MoGLSD	Ministry of Gender Labour and Social Development
SWOT	Strengths Weaknesses Opportunities and Threats

Acknowledgements

The 2010-2013 Strategic Plan of S.A.U has been developed as a result of the recommendation from the Kisaka Company on behalf of Sida and the capacity acquired from the Coalition of the Voices For Health Rights of 14 organizations.

We are grateful to the S.A.U Executive Committee members (E.C), all staff and S.A.U members whose individual and collective efforts to fight Sickle cell Disease, the neglected enemy, have in the development of this SP.

A handwritten signature in black ink, appearing to read 'Ruth Nankanja Mukiibi', is centered on the page. The signature is fluid and cursive, with a prominent initial 'R'.

Ruth Nankanja Mukiibi
Chairperson and Founder
Sickle cell Association of Uganda

1. Background and Introduction

Sickle cell Association of Uganda (S.A.U) is a charity organization that was founded in July 2000 by concerned patients. It was registered as a Non-Governmental Organization in February 2007. Its main aim is to advocate for the rights of Sickle cell patients, awareness of the disease and the improvement of the diagnostic and clinical services for patients. The association works closely with the staff and Sickle cell patients at the Sickle cell Clinic at Mulago Hospital by providing education and psychosocial support to patients and their families. S.A.U operates in the following districts: Wakiso, Bundibugyo, Kasese, Hoima, Mbale, Soroti, Bugiri, Jinja, Masindi, Kampala, Lira, Kumi, Iganga, Kabalere and in these 3 years we are including Mubende district.

Vision

God centered holistic Sickle cell care.

Mission

To empower masses (general public) about Sickle cell Disease so that the occurrence of the disease and its complications can be reduced enabling them to have a purposeful and meaningful life through understanding the principles of healthy living.

Core Values or guiding principles

- Reverence for God
- Transparency
- Care
- Excellence
- Dedication
- Service

2. Contextual analysis

SAU intends to contribute towards the Millennium Development Goals as declared by the United Nations and the Brazzaville Declaration of 2011 through implementing our strategies.

3. Policy Framework

A. MOH - HSSIP

There is no policy in favour of Sickle cell Disease in Uganda, however the Ministry of Health (MOH) through its Health Sector Strategic and Investment Plan 2010/11 – 2014/15 indicates that there will be a policy on Sickle cell Disease by 2014/15. In view of this SAU has taken on the lead role of advocating for the policy to be formulated and rolled out.

B. Social Development Sector Strategic Framework

Broadly, SAU's activities fall within the Social Development Sector (SDS) that strives to create an enabling environment for social protection and social transformation for the poor, vulnerable and marginalized groups. Within the SDS, the lead ministry is Gender, Labour and Social Development (MGLSD) that has defined a strategy called the Social Sector Development Investment Plan (SDIP). SDIP addresses inequalities, vulnerability and exclusion of marginalized groups including women, orphans and other vulnerable children (OVC) to develop their capacities to take advantage of

opportunities to improve their livelihoods for sustainable development. In addition, the MGLSD has addressed the challenging issue of OVC by developing a specific policy that promotes a multi-sectoral, integrated and gender sensitive approach to services delivered to vulnerable children and their families.

C. Ugandan Constitution

SAU ascribes to the Ugandan Constitution in advocating for the rights, privileges and freedoms of all her members.

4. Achievements and Challenges

4.1 Achievements

- a) S.A.U has served for ten years so far.
- b) We received a donation of a container from SDV-Transami and was refurbished by Uganda Breweries.
- c) Mulago hospital gave S.A.U an area for counselling where the container was placed and the counselling shade was put up by Roko Construction Company.
- d) It fundraised for 54 million and bought an Hb-electrophoresis machine for Mulago National Referral Hospital.
- e) SAU invited Prof. Graham Serjeant for the first 6 years and he conducted many studies for example the Sickle cell patients in the steady.
- f) Attended the global conference in Washington in the United States that discussed the Genome Study.
- g) Conducted awareness outreaches in Wakiso, Jinja, Iganga, Bundibugyo, Kasese, Mbale, Palisa, Soroti, Kumi, Lira, Serere, Hoima, Masindi, Bugiri, Mpigi and Kayunga.
- h) Operated a health education program on Sickle cell Disease at the Sickle cell Clinic Mulago Hospital.
- i) Signed a memorandum of understanding with the Ministry of Health to work hand in hand with them.
- j) S.A.U's Executive Director was appointed to the committee of Non-Communicable Disease Ministry of Health.
- k) We received 80 doses of pneumococcal vaccine worth 4 millions from the US embassy.
- l) S.A.U lobbied for equipment worth 22 million from the rotary clubs of Muyenga, Sunrise and Starrford Castle and we equipped the Sickle cell Clinic, laboratory and the Association.
- m) S.A.U received a donation of a Lucida van from the Uganda-American Sickle cell Rescue Fund.

- n) S.A.U Received a donation of land from a parent at Kawanda-Namalere and secured a land title in its name.
- o) Participated in the drafting of the National Health Policy and the Health Sector Strategic Investment Plan III of Ministry of Health that incorporated Sickle cell Disease for the very first time.
- p) S.A.U is Member of Voices for Health Rights (VHR) comprising of 14 organizations and the lead agency is the Uganda National Health Consumers/users Organization (UNHCO).

4.2 Challenges

- **Inadequate funding**

For all the years that SAU has been in existence it has survived on small donations and in-kind items from well wishers such as the Associations members, Uganda Breweries, corporate organizations and Barclays Bank to mention but a few. Therefore SAU has been operational through the service of well interested individuals.

- **Equipment**

SAU lacks equipment for office, laboratory and clinic. SAU's efficiency has been hindered by limited technology in terms of computer such as Internet, scanners – office equipment.

- **Space**

The provisional area that was gazetted for SAU as a counselling room is quite small but is also used as a store, kitchen and a dressing room. It provides no privacy what-so-ever because of the continuous movements.

- **National interest, political and religious leaders will is low**

Unlike with other infectious diseases (HIV and AIDS) where the government has come in to facilitate the counsellors and other volunteers in creating awareness and providing psychosocial support, the counsellors from SAU offer their services on a voluntary basis with no facilitation from anywhere despite the gravity of the Sickle cell Disease burden in Uganda and its economic situation at the moment.

- **Ignorance about Sickle cell Disease.**

Awareness has been spread by SAU but to a limited extent due to inadequate resources.

- **Limited research.**

We are interested in providing evidence based information to the general public however, the last research about the Sickle cell trait and disease frequency in Uganda was done in the early 70's. This means that the current incidence and prevalence are not known.

5.0 Stakeholders Analysis (SHA)

SAU implements its program with stakeholders at all levels. It enjoys the support of various stakeholders involved in Non Communicable Diseases in Uganda. Interacts with the following stakeholders who have been classified depending on the role they play in the organization's Program activities.

5.1 Primary Stakeholders

SAU works through and with government structures such as, Ministry of health, ministry of Education and Sports, Ministry of Gender, Labour and Social Development, Local governments (Mubende District) and health units (Mulago Sickle cell Clinic). In addition SAU works in partnership with organizations such as IAPO, SIDA, UNHCO, NUDIPU, VHR, FHRI, CHAIN and corporate institutions such as Barclays Bank, East African Breweries, to mention but a few.

5.2 Secondary Stakeholders

SAU also works through, with and among the Sickle cell patients and caregivers, Children Sickle cell Foundation Kenya, Sickle cell Foundation Tanzania, Holly Foundation.

6.0 SWOT Analysis

SAU's possesses a number of strengths and opportunities; however it also possesses some weaknesses and is exposed to a number of threats. SAU's achievements and challenges over the past eight years also denote the internal and external environment within which SAU operates.

6.1 Internal factors influencing success of SAU

a. Strength

- Ability to handle large funds.
- A big membership.
- Willingness of members to pay membership.
- Infrastructure (Office space).
- Partnership and networking with other CSOs that offer Sickle cell awareness services.
- Existence of resource mobilization strategy.
- Existence of a dynamic BOD well qualified.
- Availability of Land for the construction of the Sickle cell Center at Kawanda Namalere.
- Availability of equipments for effective coordination/communication; computers.
- Existence of a website.
- Wider coverage with fair representation at community level.
- Existence of organizational systems.

b. Weaknesses

- Inadequate funding and resources.
- Poor staff remuneration.
- Lack of confidence among some members to take up leadership roles.
- High expectation of members which cannot be achieved.
- Inability to reach all the beneficiaries due to limited resources.
- Lack of documentation.

6.2 External factors influencing success of SAU

a. Opportunities

- Existing relationship with various ministries; Ministry of health, Ministry of Gender, Labour and Social Development,
- Existence of the HSSIP iii that clusters Sickle cell disease and morbidity.
- Government programs towards NCDs that offer opportunities to Sickle cell patients.
- Supporting policy framework for health care service provision.
- Media.
- Present papers at global and national scientific conferences.
- Communities eager for more information.

b. Threats

- Weak governance structures at the lower levels.
- Pace of technology advancement.
- Unfavorable regulatory restrictions.
- Lack of support and encouragement from the local government which hinders SAU's activities.
- Low literacy for the majority of members, this hinders resource mobilization and advocacy for their rights.
- Creation of new districts.
- High death rates of members.
- Health workers not interested in Sickle cell.
- Limited knowledge and interest about Sickle cell disease among the professionals.
- Poverty, most of the members are very poor.
- Limited funding.

7 Activities for the program areas

SAU works to achieve its mission through these four program areas.

7.1 Awareness on Sickle cell

Objectives

1. Conduct four Sickle cell outreaches each year in Uganda.
2. To produce IEC materials on Sickle cell Disease that is; a documentary, music CD and 30,000 brochures.
3. Media broadcasts (8).
4. Website designing and posting.
5. Educating patients and care givers at Mulago Sickle cell Clinic
6. Write/develop abstracts on Sickle cell Disease to be presented at conferences.
7. Increase subscription of people for Sickle cell screening.

Activities

- Outreaches
- Develop brochures
- Produce documentary
- Produce music CD
- Developing abstracts

- Press conferences
- Routine health talks at Mulago SCC
- Mobilizing people for screening, membership and outreaches

7.2 Psychosocial support

Objectives

1. Provide counselling to patients and care givers.
2. Follow up Sickle cell Disease cases.

Activities

- Counselling
- Home visits
- Hospital visits
- Hot line case management
- Case follow up

7.3 Advocacy and Networking

Objectives

1. Increase functional Sickle cell Clinics in regional referral Hospitals.
2. Maintain partnerships with IAPO, VHR, HWAF, NUDIPU, UAPO.
3. Partner with Foundation for Human Rights initiative.
4. Establishment of a Sickle cell Clinic in Namalere.
5. Raise funds for SAU.

Activities

- Dialogue with MOH, Districts and Regional referral hospitals
- Lobbying
- Fundraising
- Open a Sickle cell Clinic at Namalere
- Attend meetings
- Submit reports
- Attend workshops, conferences.

7.4 Reproductive Health

Objectives

1. To increasing awareness and build capacity of individuals about MSRHR rights in Nalutuntu sub county (Mubende district).
2. Develop and implement Maternal Health Care package for Sickle cell mothers.
3. Incorporate Sickle cell screening in pre-marital counselling and testing and genetic counselling and testing.

Activities

- Sensitisation workshops
- Training
- Dialogue with District officials, community and health workers
- Radio talk shows
- Drama

- Supports supervision of resource persons
- Develop a Pre-marital Counselling manual
- Develop Maternal Health Care package for mothers with Sickle cell disease.

7.5 Capacity Development

Objectives

1. Train professionals in the area of Sickle cell disease.
2. Develop manuals about care, management and support of Sickle cell disease.
3. Establish Sickle cell curricula as a career path.

Activities

- 5 trainings annually
- Gather and compile information for manuals
- Lobby for developing curricula
- Teach professionals.

8.0 Monitoring and Evaluation of the Strategic Plan

The monitoring and evaluation function will be evidenced by the following

1. Monthly, quarterly and annual reports.
2. Audits.
3. Program and staff appraisals.

9.0 SAU's 3 Year Budget

Program Area	Total Budget for 3 Years in UGX
Reproductive Health	406,106,240
Advocacy & Networking	306,106,240
Awareness on Sickle cell	950,000,000
Psychosocial Support	650,000,000
Capacity development	1,267,500,000
Administration	459,400,300
Monitoring and Evaluation	520,000,000
Staff remuneration	1, 229,500,000
Building a Sicklecell center	2,000,000,000
Grand Total	<u>7,788,612,780</u>

10.0 SICKLECELL ASSOCIATION OF UGANDA ORGANISATIONAL STRUCTURE

