

**2023**

**Sickle Cell Association Uganda  
Strategic Plan (2023-2028)**





## **Contents**

1.0	Executive Summary.....	4
1.1	Background.....	4
1.2	This Strategic Plan.....	4
2.0	Where are we now .....	5
2.1	Contextual analysis .....	5
2.1.1	Policy Framework .....	5
2.1.2	Current stakeholders.....	6
2.2	Achievements and challenges .....	6
3.0	SWOT Analysis.....	9
4.0	Strategy Direction (where we are going).....	11
4.1	Vision .....	11
4.2	Mission.....	11
4.3	Strategic Commitments .....	11
4.4	Shared Values.....	11
5.0	Strategy Matrix.....	13
6.0	Monitoring and Evaluation of the Strategic Plan .....	16
7.0	Organisational structure .....	17
8.0	Appendices .....	18
	Appendix 1: SAU’s 5 Year Budget.....	18
	Appendix 2: SAU BOARD OF DIRECTORS.....	26
	Appendix 3: SAU Contact .....	26



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## **ACRONYMS**

S.A.U:	Sickle cell Association of Uganda
MSRH:	Maternal Sexual Reproductive Health.
SP:	Strategic Plan
MH:	Maternal Health
HSSIP III:	Health sector strategic investment Plan III
UN:	United Nations
NUDIPU:	National Union of Disabled Persons of Uganda
BOD:	Board of Directors
CSO:	Civil Society Organization
DHF:	Dansk Handicap Forbund
CBO:	Community Based Organization
NGO:	Non-Governmental Organization
MOH:	Ministry Of Health
UNAPD:	Uganda National Action on Physical Disability
MoGLSD:	Ministry of Gender, Labour and Social Development
SWOT:	Strengths Weaknesses Opportunities and Threats
SIDA:	Swedish International Development Agency



## **FOREWARD**

This five-year SAU Strategic Plan (2023-2028) sets out a bold and ambitious vision and defines the organisation's priorities to achieve the vision of "A sickle cell free Uganda". This Strategic Plan is the ultimate collation of the strategic interventions that will provide direction for the SAU.

Through this Strategic Plan, SAU reassures its commitment to create awareness of the sickle cell disease, provide accessible and affordable screening and treatment of the disease while offering support and advocacy for those affected by the disease.

This Strategic Plan is a forward-looking masterpiece that goes beyond a five-year period – helping to lay the foundation for an even higher-performing and sustainable association for many years to come.

Finally, this Strategic Plan is 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 Board members, all staff and S.A.U members whose individual and collective efforts to fight Sickle cell disease "the neglected enemy" have led in the development of this Strategic Plan.

**Ruth Nankanja Mukiibi**

ED and Founder

Sickle Cell Association of Uganda



## **1.0 Executive Summary**

### **1.1 Background**

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 advocates for the rights of sickle cell patients, awareness of the disease and the improvement of the diagnostic and clinical services for patients. It is also a registered member of the International Alliance of patient's organizations (IAPO). 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, mpigi, Hoima, Mbale, Soroti, Arua, Bugiri, Jinja, Masindi, Kampala, Masaka, Lira, Kumi, Iganga, Kabalore, and Mubende.

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 into inefficiency and infectiveness of the organisation.

### **1.2 This Strategic Plan**

The purpose of this Strategic Plan is to set the strategic aspirations and direction of Sickle cell Association of Uganda over the years 2023 to 2028. It comes 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. This Plan will guide the implementation of various strategic initiatives of SAU.

In this strategic plan, SAU has committed to a mission that seeks to "Creating awareness and early screening of the sickle cell disease while ensuring a healthy life for those suffering from the disease" and a vision that seeks "A sickle cell free Uganda". In order to achieve the vision, the following values will guide the organisation: Transparency, Care, Resourceful, Excellent and Devoted.

Over the next 5 years, SAU will pursue the following strategic objectives:

- a) Create AWARENESS of sickle cell disease
- b) Provide ACCESSIBLE and AFFORDABLE screening and treatment of the sickle cell disease
- c) Offer SUPPORT and ADVOCACY for those affected by the sickle cell disease

In pursuing these strategic objectives it is hoped that the following outcomes will be realized:

- a) Reduced Sickle cell Incidence rate; and
- b) Reduced mortality rate among those with the sickle cell disease.



## **2.0 Where are we now**

### **2.1 Contextual analysis**

Sickle cell disease contributes substantially to mortality in children younger than 5 years in sub-Saharan Africa. In Uganda, 20,000 babies per year are thought to be born with sickle cell disease in Uganda with 80% dying before their 5th birthday.

Uganda Sickle Surveillance Study (US3): a cross-sectional study found that the overall number of children with sickle cell trait was 12,979 (13.3%) in Uganda and those with the disease were 716 (0.7%). Sickle cell trait was seen in all districts of Uganda and Eight districts had prevalence greater than 20.0%. These districts were Bundibugyo 21.9%, Buliisa 22.1%, Alebtong 24.3%, Jinja 18.9%, Gulu 19.6% and Lira 20%. Sickle cell disease was less common in children older than 12 months or who were HIV positive, which is consistent with comorbidity and early mortality<sup>1</sup>.

13.5% of the Uganda Population has the sickle cell trait. Out of every seven people, at least one has the sickle cell trait and out of every 150 people, at least one has the disease. 6 to 12 people out of every 100 people living with Sickle Cell disease are affected with Stroke. Sickle Cell disease varies per region; with the Mid North a sickle cell prevalence ranging from 17-21%, East-Central 16.7%, Mid-Eastern Uganda 16.5%, South-Western region 4.1% and Kampala 13.63%.<sup>2</sup>

People living with sickle cell disease especially infants and children experience harmful infections such as pneumonia, meningitis, Eye disease, A vascular necrosis (breakdown) of the hip which leads to lameness among the people living with sickle cell. Every 1 in 50 disabled people in Uganda has been disabled by Sickle Cell disease.

#### **2.1.1 Policy Framework**

Currently, SAU operates under different policies and frameworks. These are listed below:

##### **a) Ministry of Health– Health Sector Strategic Investment Plan (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 had indicated that there would be a policy on Sickle cell disease by 2014/15. This however was not fruitful. 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**

<sup>1</sup><https://www.sciencedirect.com/science/article/pii/S2214109X15002880>

<sup>2</sup><http://capitalradio.co.ug/tag/capital-fm-uganda/page/120/>



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.

## **2.1.2 Current stakeholders**

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

### **a) 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, DHF, NUDIPU, UNAPD, VHR, FHRI, CHAIN and corporate institutions such as Barclays bank, East African Breweries, to mention but a few.

### **b) 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

## **2.2 Achievements and challenges**

Having served for 18 years now, SAU has registered a number of achievements and faced various challenges:

### **a) Key Achievements include:**



- ❖ Mulago hospital believed in SAU's vision and provided space to offer counselling services to those affected by the sickle cell disease. This has helped the organisation reach and impact positively thousands of people.
- ❖ SAU was able to fundraise 54 million which it used to purchase a Haemoglobin Electrophoresis machine for Mulago National referral hospital. This machine has aided in the screening of different blood disorders including sickle cell anaemia. Unfortunately, this machine worked for only 3 years when the association fundraised money for reagents. Government has not taken up the role of buying reagents for this machine and therefore the sickle cell clinic in Mulago has not been in position to test for sickle cell disease up to today.
- ❖ With support from the British Department for International Development, the SAU invited Prof Graham Serjeant, previously director of the Sickle Cell Unit at the University of the West Indies, Kingston, Jamaica who conducted twice yearly advisory visits from 2000-2005. Using experience gained in Jamaica over the previous 40 years, these visits contributed to the organisation of local sickle cell facilities and research infrastructure addressing the variability of sickle-cell disease with special emphasis on developing models of management suitable to countries with large numbers of patients and limited resources. This invitation enabled him to conduct many studies in Uganda like the sickle cell patients in the steady state.

First and foremost, he taught health workers about the removal of the dead spleen among sickle cell children. This was in cases where children had enlarged spleens and had, had over 5 transfusions. Other interventions included teaching mothers the colour of the children's palms, eyes and the lips to check for anaemia in the home setting.

For the adolescent, he taught the association to take care of any slit on their ankles thus preventing the complications of leg ulcers. He was the first person to talk about the issue of priapism (painful crisis in the penis) among male sicklers which makes them impotent if not attended to in the first 48 hours; the prevention of the hip damage by avoiding hill climbing, standing for long, walking long distance and avoiding weight bearing.

He was the first doctor to give us statistics concerning Uganda which were unavailable in Uganda. He gave us the daily dos and don'ts for sickle cell disease. He donated a book called A guide to sickle cell disease to the major facilities namely: Mulago, Lubaga, Mengo, Kibuli, Mbale, Jinji, Hoima, Masindi, etc.

- ❖ SAU has managed to create awareness outreaches in many parts of Uganda including: Wakiso, Jinja, Iganga, Bundibugyo, Kasese, Mbale, Palisa, Soroti, Kumi, Lira, Serere, Hoima, Masindi, Bugiri, Mpigi and Kayunga among others.





- ❖ SAU was able to sign a memorandum of understanding with the Ministry of Health as a partnership to work hand in hand in fighting the sickle cell disease. Through this partnership, SAU's Executive Director was appointed to the committee of Non-Communicable disease under Ministry of Health.
- ❖ SAU 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.
- ❖ SAU participated in the formulation of the National Anaemia Strategic Plan.

**b) Challenges faced include:**

- ❖ 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 Barclays Bank to mention but a few. Therefore SAU has been operational through the service of well interested individuals.
- ❖ Lack of 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
- ❖ Inadequate 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 in 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 despite the gravity of Sickle cell disease burden of Uganda and its economic situation at the moment.
- ❖ Ignorance about Sickle cell disease. Awareness has been done 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 2014 by the Ministry of Health etc. This means that the current incidence and prevalence are not known.



### 3.0 SWOT Analysis

In developing a strategy for the next five years, SAU took stock to appreciate what its key strengths, weaknesses, opportunities and threats are. This was aimed at providing realistic options that SAU ought to consider for the achievement of its objectives while mitigating areas deemed to be of weakness in order to increase the likelihood of success in achieving organizational objectives.

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>❖ Ability to handle donor funds.</li> <li>❖ Big memberships i.e. sickle cell patients and families.</li> <li>❖ Willingness of members to pay membership fees</li> <li>❖ Infrastructure (Office space). We have the office space; we just need to pay for utilities.</li> <li>❖ Partnership and networks with other CSOs that offer sickle cell awareness services.</li> <li>❖ Existence of a dynamic BOD well qualified.</li> <li>❖ Availability of Land for the construction of the sickle cell centre at Kawanda Namalere</li> <li>❖ Availability of equipment for effective coordination/ communication; Computers,</li> <li>❖ Existence of a website. (we will activate it soon)</li> <li>❖ Wider coverage with fair representation at community level. <i>i.e. North, East and Central region where our members come from.</i></li> <li>❖ Existence of organizational systems.</li> </ul>	<ul style="list-style-type: none"> <li>❖ Inadequate funding and resources. Resource mobilization is still a big challenge to the organization.</li> <li>❖ Poor staff remuneration. The organization does not pay salaries because we do not have funding.</li> <li>❖ Lack of confidence among some members to take up leadership roles. This is due to stigma of many members to come out and serve.</li> <li>❖ High expectation of members which cannot be achieved e.g. the organization to pay for their personal bills like health, education, shelter etc.</li> <li>❖ Inability to reach all the beneficiaries due to limited resources.</li> <li>❖ Lack of documentation</li> <li>❖ Limited research</li> <li>❖ Inadequate space</li> <li>❖ Lack of Equipment</li> <li>❖ Absence of resource mobilization strategy</li> </ul>



Opportunities	Threats
<ul style="list-style-type: none"> <li>❖ Existing relationship with various ministries; Ministry of health, ministry of Gender Labour and Social development,</li> <li>❖ Existence of the HSSIP III that clusters sickle cell disease and morbidity.</li> <li>❖ Government programs towards NCDs that offer opportunities to sickle cell patients</li> <li>❖ Supporting policy framework for health care service provision.</li> <li>❖ Media</li> <li>❖ Present papers at global and national scientific conferences</li> <li>❖ Communities eager for more information.</li> <li>❖ Existence of partnership with Pharmaceutical Society of Uganda</li> <li>❖ Technology advancement. SAU should be ready and aware of the improvements happening globally</li> </ul>	<ul style="list-style-type: none"> <li>❖ Weak governance structures at the lower levels, because SAU committees that were created in North, East and Central regions to run Association activities could not stand due to absence of funds.</li> <li>❖ Pace of technology advancement. Uganda is too slow in terms of disease management.</li> <li>❖ Unfavourable regulatory restrictions. The processes to get registered with the NGO board are unnecessarily long.</li> <li>❖ Lack of support and encouragement from the local government which hinders SAU's activities for example local governments have HIV, disability programs within their activities but rarely do they talk about sickle cell disease.</li> <li>❖ Low literacy for the majority of members, this hinders resource mobilization and advocacy for their rights. Many parents do not educate their children with sickle cell disease thinking they are going to die soon.</li> <li>❖ Creation of new districts. It's a challenge in terms of coverage.</li> <li>❖ High death rates of members</li> <li>❖ Health workers are not interested in sickle cell because there is no funding even by government, they prefer working in programs that have government commitment e.g. HIV, cancer</li> <li>❖ Limited knowledge and interest about sickle cell disease among the professionals</li> <li>❖ Poverty, most of the members are very poor.</li> <li>❖ Absence of sources of funds</li> </ul>



## **4.0 Strategy Direction (where we are going)**

### **4.1 Vision**

This vision is not only short and memorable but also inspiring - capturing both mind and heart, and leaving a clear mental image. The vision is both purpose-driven and directional to guide decision-making. Overall, the vision that invites Sickle cell Association to greatness has been simply stated as:

**“A Sickle cell Free Uganda”**

### **4.2 Mission**

To secure the achievement of the challenging vision, SAU has formulated its mission statement as:

**“Creating awareness and early testing of the sickle cell disease while ensuring a healthy life for those suffering from the disease”**

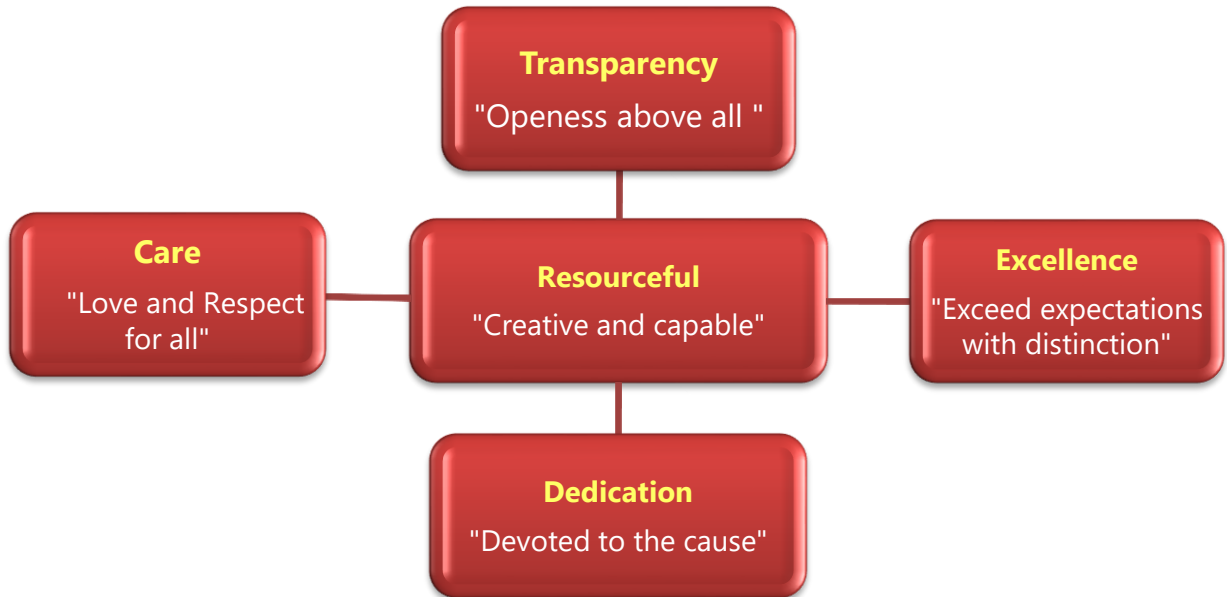
### **4.3 Strategic Commitments**

Sickle cell Association makes the following strategic commitments. We commit to:

- ❖ Create **AWARENESS** of the sickle cell disease
- ❖ Provide **ACCESSIBLE** and **AFFORDABLE** testing and treatment of the sickle cell disease
- ❖ Offer **SUPPORT** and **ADVOCACY** for those affected by the sickle cell disease

### **4.4 Shared Values**

To achieve SAU's Vision, Mission and Strategic Commitments above, the members shall strive to demonstrate the following values:





## 5.0 Strategy Matrix

Having ascertained the *Strategic Commitments* of the Association and bearing in mind *where we are now*, below is a **Strategy Matrix** including the *Strategic Initiatives* that SAU shall focus on, the relevant *Indicators* that shall demonstrate success and the realistic *Targets* that SAU has set for the period 2023 – 2028.

Outcomes	Indicator	Target
Contribute to the reduction of sickle cell incidence rate	Number of new born babies with sickle cells	10,000 new born babies
Contribute to the reduction of mortality rate among those with the sickle cell disease.	Number of deaths by sickle cell patients	30% reduction

	Strategic Commitments	Strategic Initiatives	Indicators	Targets
1	Create <b>Awareness</b> of the sickle cell disease	<u>Outreach programs</u> <ul style="list-style-type: none"> <li>❖ Develop and distribute brochures with information on sickle cells</li> <li>❖ Hold routine health talks at different schools, universities, hospitals, churches and at national events.</li> <li>❖ Produce documentaries, music about the sickle cell disease.</li> </ul>	<ul style="list-style-type: none"> <li>❖ More people aware of sickle cell disease in Uganda.</li> <li>❖ Reduced carrier couples</li> </ul>	<ul style="list-style-type: none"> <li>❖ Nationwide reach of 4million people</li> </ul>



	<ul style="list-style-type: none"> <li>❖ Make presentations at various conferences in the country</li> <li>❖ Increase visibility on social media platforms, the association website, and media broadcasts – TV, Radio, newspapers, magazines etc.</li> </ul> <p><u>Information Hub</u></p> <ul style="list-style-type: none"> <li>❖ Collaborate with research institutes e.g. Makerere to Carry out research and studies on the sickle cell disease in Uganda and be a one stop center on all information related to the disease.</li> <li>❖ Develop manuals about care, management and support of sickle cell disease</li> </ul>	<ul style="list-style-type: none"> <li>❖ SAU launching a country wide sickle cell study/research</li> <li>❖ Manuals developed</li> </ul>	<ul style="list-style-type: none"> <li>❖ 1 nationwide sickle cell study launched by 2019</li> </ul>
2	<p>Provide <b>Accessible</b> and <b>Affordable</b> screening and treatment of the sickle cell disease</p> <p><u>Accessible</u></p> <ul style="list-style-type: none"> <li>❖ Set up free quarterly sickle cell screening and health check drives around Uganda – in schools, universities churches, hospitals, organizations etc.</li> <li>❖ Partner with churches to offer pre-marital sickle cell screening and counseling.</li> <li>❖ Distribute home care management handouts on how to live a healthy life with the sickle cell disease</li> <li>❖ Increase the number of mobile sickle cell clinics in Uganda</li> <li>❖ Develop and implement maternal Health care package for Sickle cell mothers</li> </ul>	<ul style="list-style-type: none"> <li>❖ Increased percentage of Ugandans knowing their status i.e. from 1%</li> <li>❖ Reduced incidence rate of sickle cells</li> <li>❖ Number of home care management handouts distributed</li> <li>❖ Number of mobile sickle cell clinics conducted</li> <li>❖ Maternal health package</li> </ul>	<ul style="list-style-type: none"> <li>❖ Free quarterly sickle cell screening drives</li> <li>❖ 25% of the population aware of their sickle cell status</li> <li>❖ Increased number of sickle cell patients with better management skill</li> <li>❖ 20 Mobile sickle cell clinics conducted quarterly</li> </ul>



		<p><u>Affordable</u></p> <ul style="list-style-type: none"> <li>❖ Build a sickle cell lab and offer daily sickle cell screening at a subsidized fee. These labs can be equipped to carry out other tests at subsidized fees to raise money for the association.</li> <li>❖ Seek partnerships with Donors and other organizations funding or supporting the fight against sickle cell disease around the world so as to get money to subsidize sickle cell screening and medication.</li> </ul>	<p>developed and implemented</p> <ul style="list-style-type: none"> <li>❖ Increased number of funding and implementing partners</li> </ul>	<ul style="list-style-type: none"> <li>❖ 5,000 sickle cell mothers reached</li> <li>❖ 2 sickle cell labs</li> <li>❖ 10 partners</li> </ul>
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## 6.0 Monitoring and Evaluation of the Strategic Plan

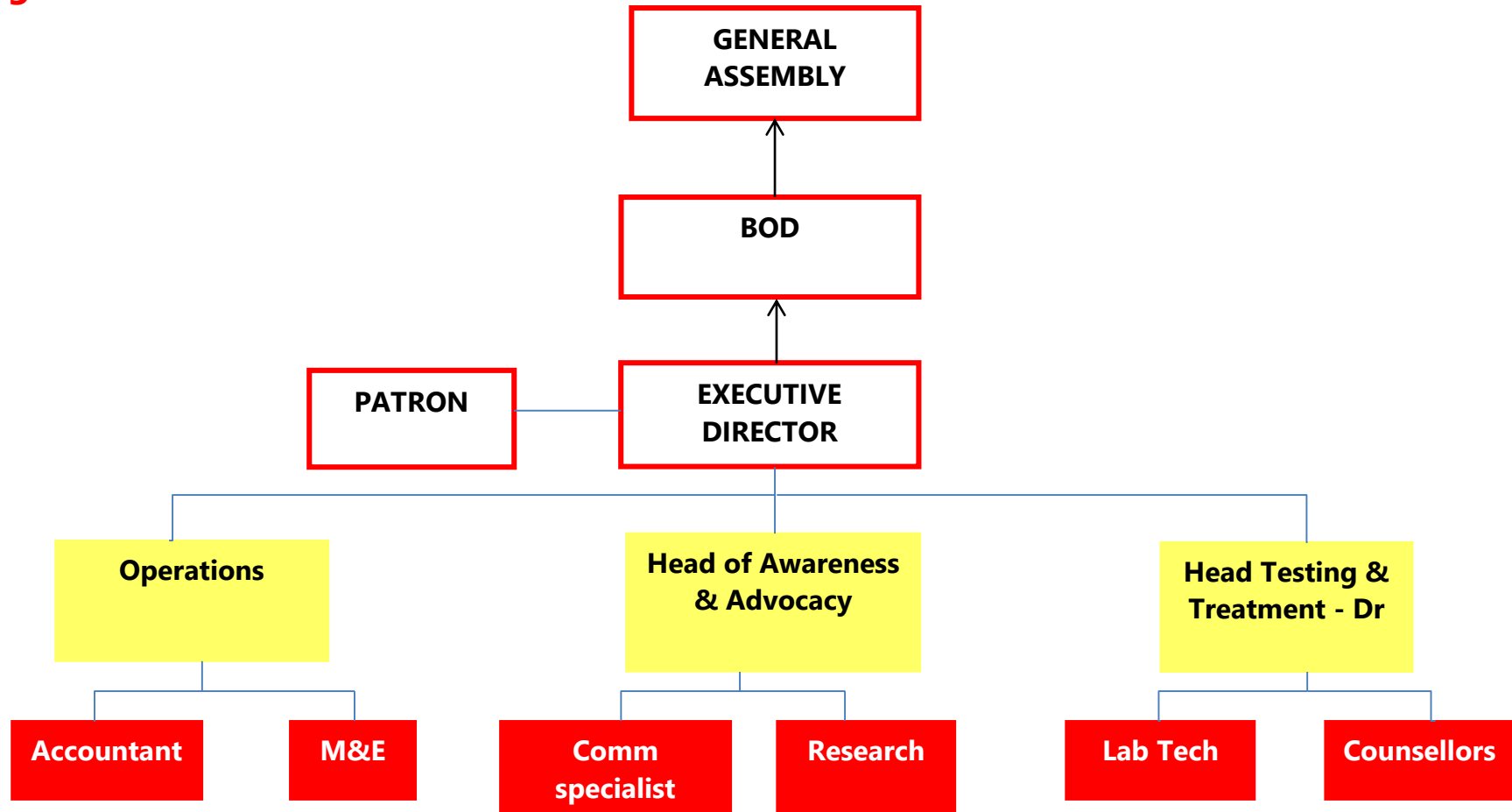
In order for SAU to realize its goals and aspirations, establishing a robust monitoring and Evaluation system will be critical and the M&E governance framework will be established and embedded in the day to day processes of the organization. The monitoring and evaluation function will be evidenced by the following:

### M&E overall Governance framework for SAU

	Focus Areas	Frequency
<b>General Assembly</b>	<ul style="list-style-type: none"> <li>• Fundraising</li> <li>• Performance of key result areas</li> </ul>	Annually
<b>BOD</b>	<ul style="list-style-type: none"> <li>• Performance of strategic (key) result areas</li> <li>• Programme and project performance (result areas at output level)</li> <li>• Budget performance</li> <li>• Risk management</li> </ul>	Quarterly
<b>ED</b>	<ul style="list-style-type: none"> <li>• Fundraising</li> <li>• Budget performance</li> <li>• Narrative programmatic performance (all result areas)</li> <li>• Performance of output and activity result areas</li> </ul>	Quarterly Monthly
<b>Service Teams</b>	<ul style="list-style-type: none"> <li>• Budget performance</li> <li>• Activity performance (All activities against target)</li> </ul>	Monthly Weekly



## 7.0 Organisational structure





## 8.0 Appendices

### Appendix 1: SAU's 5 Year Budget (UGX)

Strategic Commitment	Strategic Initiatives	Unit cost	Annual target					Total budget
			Year 1	Year 2	Year 3	Year 4	Year 5	
<b>Create Awareness of the sickle cell disease</b>	Develop and distribute brochures with information on sickle cells	2500	50,000,000	57,500,000	66,125,000	76,043,750	87,450,313	337,119,063
	Hold routine health talks at different schools, universities, hospitals, churches and at national events	2,285,000	27,420,000	31,533,000	36,262,950	41,702,393	47,957,752	184,876,095
	Equipment to run the strategic plan e.g. Double cabin (Hilux), projector, 2 laptops	506,000,000	506,000,000	-	-	-	-	506,000,000



**SAU Strategic Plan  
2023-2028**

Strategic Commitment	Strategic Initiatives	Unit cost	Annual target					Total budget
	Community Sensitisation about sickle cell disease	11,895,000	142,740,000	164,151,000	188,773,650	217,089,698	249,653,153	962,407,501
	Produce documentaries, music about the sickle cell disease	5,500,000	22,000,000	25,300,000	29,095,000	33,459,250	38,478,138	148,332,388
	Make presentations at various conferences in the country	6,800,000	20,400,000	23,460,000	26,979,000	31,025,850	35,679,728	137,544,578
	Increase visibility on social media platforms, the association website, and media broadcasts – TV, Radio, newspapers, magazines etc	14,850,000	101,200,000	116,380,000	133,837,000	153,912,550	176,999,432	682,328,982



**SAU Strategic Plan  
2023-2028**

Strategic Commitment	Strategic Initiatives	Unit cost	Annual target					Total budget
	Collaborate with research institutes e.g. Makerere to Carry out research and studies on the sickle cell disease in Uganda and be a one stop centre on all information related to the disease	500,000,000	500,000,000	-	575,000,000	-	661,250,000	1,736,250,000
	Develop manuals about care, management and support of sickle cell disease	5000	100,000,000	115,000,000	132,250,000	152,087,500	174,900,625	674,238,125
<b>Total</b>			<b>1,469,760,000</b>	<b>533,324,000</b>	<b>1,188,322,600</b>	<b>705,320,991</b>	<b>1,472,369,141</b>	<b>5,769,096,732</b>
<b>Provide Accessible and</b>	Set up free quarterly sickle	13,330,000	53,320,000	61,318,000	70,515,700	81,093,055	93,257,013	359,503,763



**SAU Strategic Plan  
2023-2028**

Strategic Commitment	Strategic Initiatives	Unit cost	Annual target					Total budget
<b>Affordable screening and treatment of the sickle cell disease</b>	cell screening and health check drives around Uganda – in schools, universities churches, hospitals, organizations etc.							
	Partner with churches to offer pre-marital sickle cell screening and counselling	220,000	220,000,000	253,000,000	290,950,000	334,592,500	384,781,375	1,285,323,875
	Distribute home care management handouts on how to live a healthy life with the sickle cell disease	2500	50,000,000	57,500,000	66,125,000	76,043,750	87,450,313	337,119,063
	Open and	15,110,000	60,440,000	69,506,000	79,931,900	91,921,685	105,709,938	407,509,523



Strategic Commitment	Strategic Initiatives	Unit cost	Annual target					Total budget
	increase number of functional sickle cell clinics in Uganda							
	Develop and implement maternal Health care package for Sickle cell mothers	62500	62,500,000	71,875,000	82,656,250	95,054,688	109,312,891	421,398,829
	Build a sickle cell lab and offer daily sickle cell screening at a subsidized fee. These labs can be equipped to carry out other tests at subsidized fees to raise money for the association	100,000,000	100,000,000	80,000,000	60,000,000	40,000,000	20,000,000	300,000,000
	Seek partnerships with Donors and	38,000,000	38,000,000	-	-	43,700,000		81,700,000



Strategic Commitment	Strategic Initiatives	Unit cost	Annual target					Total budget
	other organizations funding or supporting the fight against sickle cell disease around the world so as to get money to subsidize sickle cell screening and medication							
Total			584,260,000	593,199,000	650,178,850	762,405,678	800,511,530	3,192,555,053
<b>Offer Support and Advocacy for those affected by the sickle cell disease</b>	Provide counselling services to patients and care givers	760,000	9,120,000	10,488,000	12,061,200	13,870,380	15,950,937	61,490,517
	Follow up Sickle cell disease cases	100,000	1,200,000	1,380,000	1,587,000	1,825,050	2,098,808	8,090,858
	Carry out home and hospital visits to sickle cell patients	7,440,000	7,440,000	8,556,000	9,839,400	11,315,310	13,012,607	50,163,317





**SAU Strategic Plan  
2023-2028**

Strategic Commitment	Strategic Initiatives	Unit cost	Annual target					Total budget
	Follow up the inclusion of sickle cell disease policy in the next HSSIP	50,000	300,000	345,000	396,750	456,263	524,702	2,022,715
	Raising funds for SAU. This can be through: Increasing member contributions Holding fundraising drives – car washes, marathons, yard sales etc. Go fund me – website	15,000,000	15,000,000	17,250,000	19,837,500	22,813,125	26,235,094	101,135,719
	Develop and maintain dialogue with different partners e.g.	5,500,000	22,000,000	25,300,000	29,095,300	33,459,250	38,478,138	148,332,688



**SAU Strategic Plan  
2023-2028**

Strategic Commitment	Strategic Initiatives	Unit cost	Annual target					Total budget
	MOH, health workers, district heads							
<b>Total</b>			<b>55,060,000</b>	<b>63,319,000</b>	<b>72,817,150</b>	<b>83,739,373</b>	<b>96,300,286</b>	<b>371,235,814</b>
<b>Administration Costs</b>			700m	700m	700m	700m	700m	3,500bn
<b>Grand Total</b>			<b>2,809,080,000</b>	<b>1,490,743,000</b>	<b>2,611,318,600</b>	<b>2,251,466,042</b>	<b>3,069,180,957</b>	<b>12,832,887,599</b>

**NB: we have put 15% increment from year 2 to year 5 to cater for inflation**



## **Appendix 2: SAU BOARD OF DIRECTORS**

<b>Name</b>	<b>Position</b>	<b>Contact</b>
Bishop Kityo Wilberforce Luwalira	Patron	0712942161 / 0715904444
Mrs. Ruth Mukiibi	Executive Director And Founder	0702637144
Mr Kawalya James	Board Member	0772614575
Mr. Basajj Paul	Vice Chairperson	0756610152
Sserwanga Hafuswa	Treasurer	0701324529
Ms Nankanja	Board Member	0706399244
Mr. Desmond Owinyo	Borad Member	0703453227
Ms Nankanja Doreen	Board Member	0706399244
Ms Nankanja Doreen	Board Member	0706399244
Betty Namirimu	Board Member	0753401195

## **Appendix 3: SAU Contact**

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

P.O. Box 22805, Kampala Uganda

Tel: +256-702637144

Mob:+256-712815978

Website: [www.sicklecelluganda.org](http://www.sicklecelluganda.org)

E-mail: [hello@sicklecelluganda.org](mailto:hello@sicklecelluganda.org)