01. **Organization Details:**

a) **Name of the Organization**: Uganda Sickle Cell Rescue Foundation – (USCRF)

b) **Address**: First Floor, BMK House Plot 4-5. Nyaboong road, Wampewo
   Avenue. P.O. Box 71887 Clock tower. Kampala
   Phone: +256 779 10 94 10 / +256 750 956008
   Email: info@uscrfuganda.org
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c) **Contact Person**: Mr. Tusuubira Sharifu Kiragga
   Secretary to Board & Executive Director
   Mobile +256 782 964153 / +256 70339 1515
   ed@uscrfuganda.org / ttksharif@gmail.com

d) **Board of Directors**: Dr. Bulaimu Muwanga Kibirige , Chairman BMK Group
   Dr. Sikander Lalani , Chairman Roofings Group
   Mr. Nsubuga Erostus, CEO & Chairperson AGT Group
   Prof. Christopher Ndugwa ; Sickle Cell Expert
   Dr. Kaggwa Lawrence; Health Systems Consultant.
   Sis. Annet Namirembe; SPNO Nsambya Hospital
   Major Lukia Mulumba , PhD; Family Nursing Practitioner

**Legal Status of the Organization**: Uganda National NGO Bureau

   i) **Registration Authority**: Uganda National NGO Bureau
   ii) **Registration No**: 10264
   iii) **Date**: 31.7.2013

02. **Background**: Uganda Sickle Cell Rescue Foundation (USCRF) is a non-governmental organization (NGO) founded in 2013 as an effort of the Mulumba family a Ugandan couple living in the USA together with Dr. Bulaimu Muwanga Kibirige (BMK) of BMK group. USCRF was founded to support sickle cell awareness while improving the quality of lives of people living with Sickle Cell disease. These were later joined by Mr. Nsubuga Erostus of AGT Group and Dr. Sikander Lalani of Roofings Group. The Technical team is comprised of Prof. Christopher Ndugwa an International Sickle Cell expert, Dr. Lawrence Kaggwa a Senior Consultant surgeon and Sister Annet Namirembe the Matron of Nsambya Hospital. These constitute part of the Board of Directors.

In Uganda, Sickle Cell disease is one of the neglected diseases. It affects every religious belief, tribe, community and social class. 13.5% of our population has a sickle cell trait with the Sickle Cell disease prevalence varying from one region to another. The North has the highest sickle cell trait prevalence ranging from 17 – 21%, East-Central 16.7%, Mid-Eastern Uganda 16.5% and South-Western region 4.1%. Sickle Cell disease contributes 25% to the Child Mortality Rate in Uganda, where 25000 babies are born with it annually. It is estimated that 80% of these die before their 5th birthday. However, the dilemma of the person living with sickle cell and their immediate family goes beyond grappling with the overwhelming health effects of the disease. The deeply-rooted stigma from society alone causes families to sometimes hide their sick for fear of being labeled cursed and eschewed from social functions. When known that a family has a sufferer, intimate relationships with any member of that family are shunned. USCRF seeks to address this burden.
03. **Year of Establishment**: USCRF established in 2013.

04. **Project Activities**: The USCRF activities started from 2013. These activities are funded by donations from the local private sector.

05. **Vision, Mission and Goal**:

5.1. **Vision**: To be a Centre of Excellence for sickle cell awareness, education and prevention

5.2. **Mission Statement**: USCRF is working “To improve the general quality of life for people with sickle cell disease through supporting management and treatment; providing awareness and information on Sickle Cell disease in Uganda and increasing advocacy against the stigma associated with Sickle Cell”.

5.3. **Goal**: “To have communities aware of sickle cell disease and its social connotations; to improve the economic empowerment of people living and affected by sickle cell disease and minimize stigmatization in Uganda”.

6. **Our Strategy**:

Over the last three years, we have been intensely focused on the discrete problems faced by the people living with sickle cell and their families most notably stigma, discrimination, extreme poverty, broken families and unemployment. These key areas are impediments to the envisioned improved quality of life of our people. There has been substantial progress in each area. But if we are going to achieve inclusion of the people living with sickle cell then there is more need for change.

USCRF is now focused on setting up community support groups throughout all the regions of Uganda, setting up sickle cell awareness clubs in schools at all levels i.e primary to tertiary together with our economic empowerment program for families affected by sickle cell disease.

USCRF major activities are organizing community campaigns to promote sickle cell disease awareness and advocate against the associated stigma; offering free sickle cell screening and testing; supporting sickle cell management and treatment; and economic empowerment for families affected by sickle cell disease where we worked with a local company.

USCRF also seeks to develop partnerships and networks in many other countries across Africa and the world over, with patient organisations, government agencies, businesses, investors, financial institutions, scientists and other allies committed to fight against stigma and discrimination.
8. **Objectives of the Organization:**

USCRF is working towards achieving the following objectives for the benefit of its target group the poor, socially and economically deprived people living with sickle cell disease in Uganda.

**Goal 1: Awareness and Advocacy**  
Objective: To ensure a reduction in the number of children born with sickle cell in Uganda.

**Goal 2: Screening and Testing**  
Objective: To allow people to know their sickle cell genotypes/status.

**Goal 3: Training in sickle cell disease**  
Objective: To provide awareness and information about sickle cell disease in Uganda.

**Goal 4: Partnerships and linkages**  
Objective: To foster innovative partnerships to stimulate policy, laws and encourage community participation in the fight against sickle cell.

**Goal 5: Sickle Cell Management, Treatment and Research**  
Objective: To improve the quality of lives of people living with sickle cell.

**Goal 6: Economic Empowerment of families affected by Sickle Cell disease**  
Objective: To contribute to the alleviation of poverty among families affected by sickle cell disease.

**Goal 7: Fundraising**  
Objective: To mobilize funds for the USCRF activities.

9. **Our Services in Numbers**

- Direct Services (sickle cell education and awareness): Over 40,968 people
- Support Networks: 10 support networks across the country
- Registered members: 10,123 and building on
- Free Sickle cell tests carried out: 8,400 people
- Free Medication (folic acid, multi vitamins, Basic pain killers): 6000 people

10. **Other Notable Achievements**

   i. Buganda Kingdom Partnership where we were able to secure the prestigious Kabaka Birthday run for promotion of sickle cell disease awareness in Uganda. This run will have Sickle Cell as a theme for the years 2017, 2018 and 2019. The run for 2017 was held on April 9th and 30,000 people participated.
   
   ii. Media Partnerships; USCRF hold partnerships with over major media houses namely Delta TV, Salaam TV, Pearl FM and Vision group. With the first three providing a monthly talk show for the promotion of sickle cell disease while Vision group offer media or press coverage for our events.
   
   iii. USCRF holds a Memorandum of Understanding with the Ministry of Health Uganda enabling USCRF to support sickle cell care /management in the government facilities across the country.
   
   iv. USCRF has organized 4 successful international sickle cell conferences attracting more than 5000 participants each since 2013 in commemoration of the World Sickle Cell Day. The first conference had the Speaker of the Parliament of Uganda, second had the Vice President of Uganda, and the third had the Prime Minister of Uganda as Guest of honor.
   
   v. USCRF has a teaming agreement with OMPT-USA to enable sickle cell awareness through use of Videos and mobile projectors in rural Uganda. (this project is yet to implemented)
   
   vi. USCRF has a partnership with Namasuba College of Commerce where people living with sickle cell or their immediate families can attain scholarships for vocational education.
   
   vii. USCRF is working with a local company AGT laboratories to provide free Banana planting materials and agricultural extension to a group of 40 selected families from slums in Kampala. This is a pilot project for poverty alleviation and economic empowerment.
USCRF has a partnership with International Health Sciences University to provide student volunteers in the project activities while champion sickle cell research during USCRF activities.

Our Work – Pictorial

Pic 1. USCRF Board with Ministry of Health team

Pic 2 – Second Sickle Cell conference 2015 at Hotel Africana (over 5500 participants)
Pic 3- Children living with sickle cell waiting for medication during the 4th sickle cell conference in Uganda (Gulu district) over 10,000 people participants.

Pic 4. Vice President of Uganda H.E Edward Kiwanuka Sekandi together with Dr Bulaimu Muwanga Kibirige (Board Chairman) passing out Sickle Cell counsellors.
Pic.5 – Free Sickle Cell screening at International Health Sciences University. Dr. Rose Nanyonga Clark Vice chancellor taking the sickle cell test.

Pic.6. Sickle cell screening Gulu – World Sickle Cell day – 2016 (1500 people screened)
Pic 7. Mr Erostus Nsubuga and Dr Bulaimu Muwanga Kibirige during the Kabaka Birthday for Sickle Cell awareness. (Part of our board)

Pic 8. Some of the participants in the Kabaka Birthday run held on April 9th 2017.