

ROWAN'S DOWN SYNDROME AWARENESS CENTER

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"Support for people with Down Syndrome"

ORGANIZATION PROFILE

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ORGANIZATIONAL STATUS:

Non-governmental Organizational

Registration number: 80020002241956

Permit number: FORP0004164NB



INTRODUCTION

Rowan's Down Syndrome Awareness Center is an initiative founded by Mildred Katusabe, a Munyoro from Hoima. After giving birth to her son Rowan in 2018, Mildred learned a few weeks later that he had Down syndrome. As she and her husband, Christopher Cripps, navigated the challenges of understanding the condition and providing the specialized care Rowan needed, including a traumatic open-heart surgery in India, Mildred was inspired to share her experience and raise awareness within her community.



Rowan's Down Syndrome Awareness Center was incorporated in 2019 (Registration No. 80020002241956). In 2020, it obtained a permit to operate (Permit No. FORP0004164NB) under the Non-Governmental Organizations Act.



Figure 1 Founders of RDSAC, Mr Christopher Cripps and Mrs Katusabe Mildred



RDSAC team of staff and volunteers

WHAT IS DOWN SYNDROME?

Down syndrome is a genetic condition caused by an extra copy of chromosome 21. It is one of the most common genetic disorders, affecting about 1 in 1,000 babies worldwide, regardless of race or social status. This suggests that an estimated 2,000–3,000 people in Bunyoro may be living with the condition.

However, awareness remains low, and many communities hold misconceptions, such as linking Down syndrome to curses, witchcraft, or incest. These beliefs often lead families to hide affected children or seek help from traditional healers instead of accessing early medical care, which is crucial for improving independence and quality of life.

Down syndrome is associated with distinct physical features, learning difficulties, and developmental delays. It may also be linked to health conditions such as thyroid disorders and congenital heart defects, affecting about 50% of children born with the condition.

RDSAC's VISION?

Our Vision is that the 50,000+ people with Down syndrome in Uganda become independent, self-sufficient, and generally accepted by society, overcoming the stigma and daily challenges that they and their families face.

MISSION STATEMENT

Our Mission is to create and run a national/regional centre of excellence, providing high-quality, affordable services that will ultimately demonstrate how people with Down syndrome in Bunyoro, Uganda, and across East Africa can lead normal, full lives.

STRATEGIC OBJECTIVES

1. **Centre of Excellence for Down syndrome in Uganda and beyond:** Develop premises and knowledge base with facilities for training, data, and therapy.
2. **Awareness:** Continued events, media campaigns, training HCs and schools
3. **Therapy & Medical Support:** Expand services to include pre-school support; train para-therapists; enhance database use.
4. **Partnerships:** Strengthen local (DHO, CDO), multi-disability service provider NGOs, and international (SCT, UDSC, ADC, GDSF, DSI) collaborations.
5. **Members, Database and Network of Groups:** Establish support groups and DS Network across other locations in Uganda; train groups to act as a conduit for diagnosis and treatment.
6. **Research:** Co-lead the Human Trisome Project in Africa; develop national policy and program with Ministries of Health and Gender Labour and Social Development, through evidence and data



Training Health Professionals, a Zumba exercise session, and a radio program

Registration of People With Down Syndrome

In their first two years RDSAC has registered, and is now supporting

148 people with Down Syndrome (DS). We aim to reach 1,140 members in Bunyoro within the next two years and 1,500 across the region within 5 years.

Counselling to new Parents and information about Health and Nutrition

RDSAC has come up with a guide that's provided to new parents of children with Down syndrome, and we are providing counselling to all of them. This is to help them cope with the traumatizing situations that most of them happen to go through. They are also receiving information about nutrition and feeding among children with Down Syndrome.

WHAT KIND OF SUPPORT IS RDSAC GIVING?

RDSAC is CONTINUALLY adjusting its services as it finds out more about members' needs.

- **Early Intervention Services**

RDSAC is providing physiotherapy, occupational therapy and speech therapy services which are crucial for children with Down Syndrome to achieve development milestones. These services are usually taken to the nearest Health facility which makes them easily accessible by parents, who would otherwise have to go to the main referral hospital. RDSAC happens to be the only organization providing Speech Therapy services in the whole of Bunyoro and hence we have to travel long distances for our community therapy outreaches.



Physiotherapy at Kigoroby



Speech Therapy at Office

- **Medical Support**

We are providing medications for health monitoring to our members for example those with thyroid challenges, sleep apnea, hirschsprungs disease, dental challenges among others which are common among people Down Syndrome.



Fundraising poster

with

- **RDSAC carries out fundraising for medical tests and heart surgery** on behalf of members. Those children that are born with Down Syndrome and a congenital heart defect often do not survive because they discover the problem too late, and their parents are too poor to afford heart surgery. RDSAC is trying to ensure that those born with congenital heart defect are being diagnosed early, connected to sponsors, and supported, with their care takers during passport/visa applications.
- **RDSAC supports the livelihoods of People with Down Syndrome and their care takers,** many of whom are living in extreme poverty. 5 livelihood groups are being supported in Hoima East, Kigorobya, Bugambe, Buhanika and Kibaire. Groups engage in carpentry, art and craft, poultry, piggery e.t.c. This is giving young people with Down Syndrome in both



urban



and rural areas an opportunity to engage in income-generating activities and to be seen as productive residents in communities which previously stigmatized them.

- **RDSAC is making referral for free surgery at Entebbe Children’s Hospital** – We are in partnership with some organizations which are supporting children and we can refer some cases that require surgery to Entebbe for free services because of our partnership.
- **RDSAC is advocating, developing partnerships, lobbying for** Government, Schools, Health Centers, VHTs, other NGOs, and businesses, to understand, include, and support people with Down Syndrome to live a fulfilling life.
- **RDSAC holds regular members’ meetings and an Annual Christmas basket for members:**

one of the main successes to date has been to get PWDS and their caretakers together for mutual support and to show them that they are not the only ones having the condition. This has had an immediate confidence-building impact. RDSAC has also started a culture of giving back to members every Christmas season. Gifts are collected in the form of money, foodstuffs, and many other Household items from well-wishers, families, and friends. These are distributed to the members as Christmas packages to make sure they share the happiness of the festive season just like every other person.



Members picking xmas gifts December 2021

www.rowansds.org