

# ROWAN'S DOWN SYNDROME AWARENESS CENTER

rowansdscentre@gmail.com [www.rowansds.org](http://www.rowansds.org)

120 People with  
Down Syndrome  
registered so  
far

## 2024 NEWSLETTER



Members like 20-year-old Jenniper Tumuhaise, who received vocational training through RDSAC's support, are now thriving. Once unable to communicate, she is now employed as a shoemaker and living a normal, independent life

Rowan's Down Syndrome Awareness Centre has been in existence for only five years: achievements are many, just as the challenges.

**Vision:** That people with Down Syndrome are independent, self-sufficient and generally accepted by society, overcoming stigma and daily challenges that they and their families face.

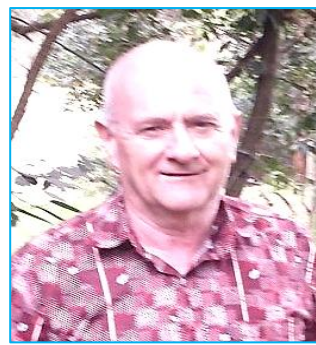
**Mission:** *To run a Centre providing high quality, affordable, services which enable people with Down Syndrome in Hoima, Bunyoro and Uganda at large to live normal and full lives.*



*Patron: Hon. Dr. Ruyonga,  
MP, Hoima West*



*Founder: Mildred  
Katusabe, CEO of RDSAC*



*Co-Founder: Christopher  
Cripps, Urban Expert*



*Board member: Dr Nantulya,  
paediatrician, Nakasero  
Hospital*

RDSAC is in the process of reviewing its MoUs with the Hoima, Masindi, and Kikuube Districts to enhance collaboration and service delivery. Currently, RDSAC is officially working with health workers and Village Health Teams (VHTs) at 46 Health Centre IIIs to improve the recognition, registration, assessment and provision of therapy and medical support for individuals with Down Syndrome (DS)

### Quarterly members' and care givers' meetings

Members and their care givers share their isolation, challenges and how they have benefited from RDSAC services especially speech therapy and self-support groups. Even meeting each other gives great relief:

*"a problem shared is a problem halved..."*



*Members at the Annual Christmas Basket  
Party - 2024*

**Speech Therapy:** Currently, at least 30 children benefit from RDSAC's medical therapy services in both Hoima and Masindi Districts. Monthly speech therapy sessions are conducted by **Alyce Nalukwago** in Hoima City, with a partner **Violet Kyalisiima** overseeing similar sessions at Masindi Main Hospital.



*Alyce taking some of our members through Speech  
Therapy*





## Raising Awareness

World Down Syndrome Day 2024 was celebrated in Masindi under the theme *“Ending the Stereotypes”*

Through this initiative, RDSAC partnered with several media houses, including **Bunyoro Broadcasting Services** and **TTV**, among others. The event significantly boosted public awareness of Down Syndrome and received strong support from local and national NGOs and we were joined by the team from **Down Syndrome Consortium**, **Angel’s Centre**, **Embrace Kulture**, **Mukisa Foundation**, **Uganda Down Syndrome Association**, **Global Livingstone Institute**, **Ubuntu**, **Masindi School of Hand capped**)

RDSAC organized and celebrated the Down Syndrome Awareness Month in October at Hoima Booma Grounds. We had engaging activities where people living with Down Syndrome were directly involved such as; **ball sorting**, **holler hoops** and **chair dancing games**, **zumba**, **bicycle riding** and a **marathon**. All these were intended at creating more awareness in the region.

Additionally, brochures have been placed in hotels and large retail outlets to reach a wider audience. To strengthen our digital presence, we have also hired social media personnel to create engaging content and share updates about its activities.



*Sylvia, receiving a package. She was also supported through an Endoscopic Sinus Surgery*



*Our members engaging in Play activities during the Awareness Month Celebrations*



*Visiting the Poultry Project of our members in Kigorobya*



*Our member Edward taking part in the cycling during the Awareness Month*



*Masindi Support Group after their Group and financial management training*



*Attending the Africa Disability Summit on Assistive Technology*

## Medical support

RDSAC is actively seeking financial support for two members who need to undergo open heart surgery in India

Unfortunately, due to financial constraints and delays in fundraising, five members have passed away while awaiting necessary medical procedures, including tests, medication, and surgery, most of which require treatment abroad. We also supported one of our members at RDSAC who went for an expensive **Endoscopic Sinus surgery** at Mulago Hospital

We supported our member in Masindi who was taken on Hernia surgery in the umbilical cord. Finally, we also facilitated **Irumba Dan’s** karyotype test which was carried out at **MEDILAB Diagnostic Centre Kampala**

## Networking and Fundraising

Over the past year, RDSAC has participated in various events organized by different organizations, including the **US National Down Syndrome Convention Congress** held last year in Phoenix, Arizona which was organized by the **Global Down Syndrome Foundation**. This event was a significant milestone, as it allowed RDSAC to establish a relationship with the University of Colorado. Through this partnership, RDSAC has facilitated connections between the university and Makerere Research Institute to explore specialized research on individuals with Down Syndrome in Uganda.

**Additionally**, RDSAC has established relationships with organizations such as the African Disability Collaboration. Through HUDIP, RDSAC was introduced to a new partner, the **Abilis Foundation** of the Netherlands. Furthermore, long-time partner **Kyaninga Child Development Center** connected RDSAC with the **Tawingo Fund**, which partially financed the organization’s travel to the Global Down Syndrome Convention in Phoenix, USA. Furthermore, we attended and also did a presentation at the **Summit on Assistive Technology: inclusive innovations hosted by Special Children’s Trust in Kampala**. Finally, we organized a webinar for the African Disability Collaboration (ADC), which joins five African countries, under the theme: Collaborating to Support Children with Down Syndrome





*the DHO, DCDO and members of RDSAC cutting the cake at the WSDS 24 celebrations in Masindi District*



*Marching during the WSDS Celebrations In Masindi*



*Our members Celebrating the Christmas Basket*

***RDSAC's development has been a huge voluntary effort, using support from whoever and wherever possible.***

This has been especially because of the generous support of committed, mostly individual partners. RDSAC will continue to rely on these as it grows into a strong enough organisation to get mainstream funding from Governments and UK-USA fiscal sponsorship (charities) its long-term goal.

Linking up with RDSAC funding partners such as **M3 Housing (UK)**, **Marafiki (DK)** (Christmas Food basket for Members), numerous other individual supporters incl. the Founders, and **Ms. Catherine Nangendo**, **Rachel** and **Dr Barney Rosedale**, **Tess Swithin**, **Judith Heyer (UK)**, **Francis Cripps (TH)**, **Mary Begg-Safar and her husband (FR)**, **Mr Kato Magara and Family**, **Ms Julie Kimuli Kaliisa (M3)**, **Mukisa Foundation**, **Global Living Initiative**, **Embrace Kulture**, **Ms Mpewa Elizabeth**, **Aunt Sue Kaliisa**, and **Stella Kaliisa (UG)**, **Iziba Lodge**, **Radio 7**, **Down Syndrome International(UK)**, **Ostafrikas Venner (DK)**, **Ubuntu**, **Talk Gadgets** and **Talk Mud**



*DFCU Bank sharing packages with our members*



*Advocating for Inclusivity in Schools - Kigorobyia Town Council*



*We presented on an African Disability Collaboration webinar on the theme: Collaborating to support children with Down*

Developing RDSAC by following and updating the 2021 - 2025 strategic plan, guided and supported by Mollie Van Horn from Tawingo Foundation, USA, we were able to rent and set up new premises, kept up-to-date with NGO Bureau, URSB, URA returns filling, administration, financial and operating procedures excellently supported by Faustine Kizza. RDSAC has developed a model of working with Health Personnel as Focal persons and Members Support Persons in each District, centred on care-giver groups.

### **Care-givers' Support Groups:**

Project Manager Didat Ahmed has successfully renewed the certificates for our support groups in Hoima City, Hoima district, masinid and Kigorobyia and tirelessly working to implement the **Abilis Goat Rearing Project** in Masindi. Through these efforts, RDSAC secured a 5 million UGX grant from the Government of Uganda for the Kigorobyia District group, which has been invested in a poultry project that currently has 91 birds and a fully constructed poultry house. Similarly, the Masindi group received a 37 million UGX grant to launch the goat project mentioned earlier, now in its third quarter of implementation. As part of this initiative, 31 members from two sub-counties will each receive two female goats to support their livelihoods. Meanwhile, the Kikuube caregivers' group is in its early stages of development.

***RDSAC remains committed to supporting individuals with Down Syndrome, expanding awareness, and improving access to essential medical and social services.***

## Pending Plans

- ❖ **Members and Caregivers:** We usually have quarterly meetings with our members and their caregivers. However, we would like to extend these meetings to at least monthly so that we can continue to empower them in different fields. To have this put in place, we are fundraising for:

Tents	3m
120 plastic chairs	2,400,000
PA system	3m
<b>Total</b>	<b>8,400,000</b>

**OUR 2025-26  
TARGETS**

- ❖ **Speech and Play Therapy:** We conduct two speech therapy sessions each month in Masindi and Hoima Districts, supporting at least 30 members with speech and language needs. We provide free therapy and due to long travel distances to health facilities, financial support covering 50% of our members' transport costs. We are also planning to introduce play therapy and are currently fundraising UGX 44 million to implement this.

Item	Rate	Cost
2 speech therapy sessions (1year)	2,000,000	24,000,000
Play Therapy (swings, slides, bouncing castle, trampoline)	20,000,000	20,000,000
<b>Total</b>		<b>44,000,000</b>

- ❖ **Raising Awareness:** We always carry out awareness sessions throughout 5 districts in Bunyoro Sub-region. However we are short of funding and facilities which has limited the districts we have visited in the past 12 months. For that reason we are carrying out a fundraising of the following:

Item	Rate	Cost
IEC Materials	3,000,000	3,000,000
Info pamphlets for new members	20,000 x 100	2,000,000
Interpretation of IEC materials	1,500,000	1,500,000
3 Radio talk show sessions	600,000 x 5 = 3,000,000	9,000,000
<b>Total</b>		<b>15,500,000</b>

- ❖ **Down Syndrome Day Celebrations:** Every year we host World Down Syndrome Day which celebrates people living with Down Syndrome. This day is recognized by the United Nations on the 21<sup>st</sup> day of March every year. As RDSAC, we organize and celebrate the event with our members. For sponsorship of this particular event, our budget is usually **10 millions**
- ❖ **Caregivers Support and Self-Help Groups:** Over the years, we've developed a caregiver empowerment program through self-help groups, enabling members to save and start income-generating projects overseen by RDSAC. We currently run 5 groups, one in each of our operational districts. Each group undertakes a unique activity based on their collective decision—Hoima City: liquid soap and craft making; **Kigorobya: poultry; Bugambe: piggery; Masindi: goat rearing.** We are fundraising UGX 5 million per group to strengthen these projects, improve livelihoods, and involve our child members in project management.
- ❖ **Networking and Fundraising** We are currently carrying out both local and international Networking. These activities require a lot of traveling and we are fundraising for a **van which will cost us between 45 million to 75 million** depending on the type and size that we shall be able to obtain. Another of our biggest costs at the moment is international networking which requires of us to travel abroad. For example, our directors travel for the Down Syndrome Convention Congress in the USA which happens every year and this costs us **approximately 25 million** as broken down below;

Item	Rate	Cost
2 Air tickets and transfers	5,500,000	11,000,000
2 Registration Fees	2,000,000	4,000,000
Accommodation & meals for 2	2,500,000	10,000,000
<b>Total</b>		<b>25,000,000</b>

**A SPECIAL THANK YOU TO OUR DONORS, SPONSORS,  
VOLUNTEERS, WELL-WISHERS MEMBERS, CARE-GIVERS AND  
STAFF FOR YOUR LOVE AND SUPPORT!**

Contact RDSAC on +256 770 443947

Donate to RDSAC on GoFundMe:

<https://gofund.me/3437fce6>

Website: <https://www.rowansds.org>

For USA-Based Donors

<https://www.every.org/rowans-down-syndrome-awareness-centre/>

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