

ANNUAL REPORT 2022



Rays of Hope Hospice Jinja

Executive Summary

2022 has been a year which has seen a great expansion of the services of Rays of Hope Hospice Jinja (RHHJ). We continue to strive to improve the quality of life for people with life-limiting diseases and their families and in response to the great need for palliative care services especially in the rural parts of Busoga, RHHJ opened this year our first field office in Buyende District. This rural field office has significantly contributed to the increase of patients cared for in 2022 as compared to 2021 and this year we plan to expand with the same to other rural parts of the Region.

In 2022 RHHJ cared for 1244 patients, which is a 16% increase from last year. We have enrolled 667 new patients, a 30% increase from last year 2021. Given the very high prevalence of cervical and breast cancer and inadequate access to free quality screening, RHHJ has this year intensified our efforts towards eliminating cervical cancer in the Busoga Region. Since 2020, RHHJ has helped establish 4 screening clinics where screening is now part of the routine service at the health centers. Two of these centers were established in 2022. A total of 2906 women were screened, 1,759 at RHHJ outreach screenings in collaboration with government health centers and 1147 from the four established screening centers. 4.7% of the women tested positive for either pre-cancerous cells or suspected cancer were treated on site or referred and helped to go for further care.

The Fight Women' Cancer event on 29th October was a great success bringing 500 participants together. On that day businesses, organisations and government stakeholders joined hands with RHHJ committing to continue the awareness creation and promotion of early detection services in the region.

With the excellent and committed staff of Rays of Hope Hospice Jinja and the support extended to us by donors, friends and partners, we were able to keep our doors open and not turn away any patient in need of care. In 2023 we will continue working hard on reaching the unreached peripheral districts of Busoga, where we find very sick patients, who have suffered too long.

We invite each of you reading this report to partner with us. Alone none of us can do much, but together we can even make a miracle.

Mr. Balikomyeeyo Sebastian

Chairperson of the Board

Ms. Nakami Sylvia

Executive Director



Patients in Focus

CLINICAL TEAM 2022 at a glance

1,244 patients cared for (16% increase from 2021) - avg. 671 per month
66.4% women 33.6% men 10.3% children

62 % Cancer
7% Cancer & HIV
11% Severe HIV/AIDS
20% Other

667 new patients enrolled (30% increase from 2021) - avg 56 new patients per month
8027 patient contacts (28% increase from 2021)
245 patients improved and were discharged
368 patients passed away - RIP
13 patients were lost to follow-up

2022 was a year of remarkable expansion in terms of patients enrolled for care as well as cancer prevention activities and training. The patients we see are still all too often very sick and have suffered too much when we first see them, so in every aspect of our programme RHHJ is striving to make access to our services easier.

The Buyende field office was opened in March 2022 in order to better reach out to the people living in this far rural district. From its inception, the Buyende Field Office received very strong support from the Local Government including provision of a small house for the field office. Being closer to the rural based patients has proven very successful and the Field Office is now caring for 22.5% of all patients enrolled with RHHJ.

The severely sick patient is central in all we do and patient care is the core of RHHJ's work. Behind each number presented in this report is a mother, a daughter, a sister, a husband, a father - with the same human needs and rights as anyone of us. The staff of RHHJ is grateful that we can work with and very often learn from our patients - and grateful to those who support our work.



Early Detection and Screening of Cervical Cancer

In any given month, around 42% of all women enrolled with cancer will have cervical cancer. e.g. in December of the 324 women enrolled with cancer 137 (42%) had cervical cancer and of these 18 women (13%) also had HIV/AIDS. 65 (20%) of women enrolled with cancer had breast cancer.

1759 women screened for cervical cancer at 31 health centres

**137 women had precancerous cells / suspected cancer
108 women were treated on-site**

RHHJ has since 2018 screened 5,546 women for cervical cancer. In 2022, 1759 women were screened from RHHJ outreach screenings in collaboration with 31 local health facilities in Busoga Region, Buikwe and Kayunga Districts. 137 or 4.7% of the women tested positive for either pre-cancerous cells or suspected cancer. 108 were treated with thermos-coagulation on site, the remaining 29 with suspected cancer were referred - for further investigations and treatment.

RHHJ has also helped establish four screening clinics where screening is now part of the routine service at the health center. Two of these centers were established in 2020/21 (Buyinja HC IV and Banda HC III) in Namayingo and another two in 2022 (Butagaya HC III and Kakira HC IV) in Jinja . A total of 1147 women were screened in 2022 from the four established screening centers. RHHJ continues to support the centers with monthly supervisory visits and regular re-fresher meetings where experiences, problems and solutions are exchanged



Training

RHHJ has for years given training and capacity building to improve the quality of care provided by RHHJ staff and volunteers as well as training provided to health care workers and stakeholders in Busoga Region. In 2022:

- 105 health workers from 72 health facilities in 4 districts were trained in a 3-day practical introduction to palliative care.
- 5 Staff plus eight nurses and midwives from three health centers in Jinja and Buyende District were trained in a 4 day course in cervical and breast cancer screening.
- Eight women from communities of the two newly established screening facilities were trained as screening and treatment advocates.
- 2 clinical staff were trained as screeners.
- Five clinical staff members, two staff from social support team, and three from administration team were enrolled in further studies. The programmes range from diplomas to master degrees programmes.
- 87 RHHJ community volunteers have received training on a quarterly basis.
- Quarterly refresher training and update meetings with screeners.

Treatment Support

The third UN Development Goal calling for ‘access to health, when you need it, where you need it and without financial hardship’ – is very far away from the reality the RHHJ team meets when visiting our patients. The access to health care has very many obstacles on the way – one of them is the financial costs. When a patient comes to RHHJ we evaluate whether the patient would benefit from treatment – be it full or palliative treatment which may give less pain and relieve symptoms hence improve quality of life.

This year RHHJ has supported 189 patients with economic hardship to access diagnosis and treatment. 33.3% men, 66.7% female, 11% children. Most common diagnosis for treatment is breast and cervical cancer. Many of these patients are now no longer on programme as they have improved and don’t need palliative care anymore. In most cases it is not only the individual but the whole family that benefits from treatment.

Irene is Playing Again



Five-year-old Irene was a happy little girl until March 2022 when she developed a swelling in the mouth. It grew quickly and became very painful, so she was taken to hospital and referred to Uganda Cancer Institute for further investigations. But Irene’s family could not afford the travel, let alone the cost of the tests, so she was taken back home – and the pain and swelling got worse by the day.

Thankfully a relative of another RHHJ patient referred her to us in July 2022. Irene was enrolled on programme for pain and symptom management and she was helped financially to go to Uganda Cancer Institute who confirmed the diagnosis of Burkett’s Lymphoma. RHHJ also helped the family with funds for transport, other investigation costs and meals. Chemo therapy was initiated quickly taking away the swelling and pain. Irene is now again a happy little girl playing with her siblings and friends – and the family is very appreciative for getting their little girl healthy again.



Emotional and Material Support for Patients and their Families

Psychosocial support is a key component of palliative care including counseling with bereavement and spiritual support. The very poor are helped with food, school fees, housing, clothing and bedding in order to restore and maintain their human dignity.

COUNSELLING

Patients and their families receive counselling during every visit. For very complex cases, counselling is done by the social worker or counsellor. Bereavement counselling supports the family before and after the death of their loved ones

SCHOOL FEE SUPPORT

Grateful that the schools finally opened after almost 2 years lock-down for COVID-19, RHHJ supported **130** children in school - 102 children in primary school, 20 in secondary school and 8 in vocational school. All our students were facilitated with fees, scholastic materials, meals at school as well as monitoring them while at school at least once a term.



FOOD SUPPORT

On a monthly basis **120** families are receiving a food basket of 3 kg rice, 2 beans, 1 kg sugar and a 1 kg bar of soap. 100 patients, who have difficulty swallowing, also get 1 kg porridge mix. 140 patients receive UCX 10,000 / \$ 2.75 in monthly support to make them able to provide basic items and transport to health center to collect AIDS medicine. 300 patients and 120 students received a special gift of food for Christmas.



DAY CARES

18 day cares for **646** patients and caretakers were held to share experiences, receive health talks and share a meal.



INCOME GENERATING ACTIVITIES

The lack of income combined with extra expenses in relation to severe disease often brings the very poor patients into a deep hole of poverty, which is very difficult to get out of even after they have been treated and regained health. **Seven** patients received support (average \$100) to start a small business so as to start a life after disease.

SHELTER

10 houses were built - 6 two-room and 4 one-room.

OTHER SUPPORT GIVEN

43 mattresses, **44** blankets and **53** bedsheets were given to the very poor, **64** re-usable diapers and **52** mattress covers for incontinent patients, **52** patients were supplied with colostomy bags **77** families were given clothing

WHEELCHAIRS

6 patients were supported with wheelchairs, and **9** crutches were given out.



Research and Internal Capacity Building

- A study on *Effects of a Group Peer Advocacy Intervention on Cervical Cancer Screening* done in collaboration with Makerere University SPH, African Palliative Care Assoc., and RAND (California) finalized the initial pilot study with encouraging results showing that if the structural barriers are removed, women will get screened with encouragement and information provided by screened women who they know and respect. A 5 year multi-site study to follow up these results is expected to be started in the coming year.
- A retrospective study on Risk factors for precancerous lesions and cervical cancer in Busoga Region, Uganda 2019-2021 is being conducted in collaboration with University of Aarhus, Denmark
- Seven members of RHHJ attended the *7th International African Palliative Care Conference* in August. RHHJ contributed with two oral presentations and 4 poster presentations.

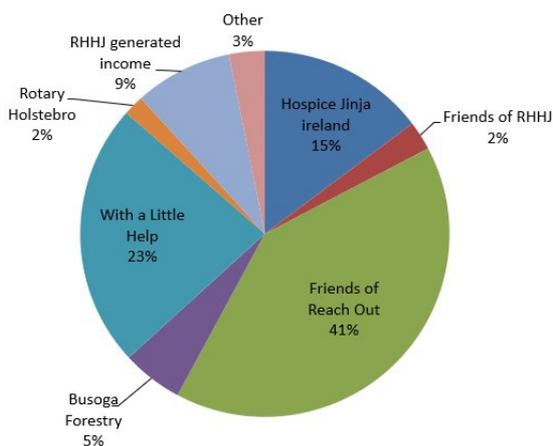
Fight Against Women's Cancer

For the fourth year in a row RHHJ arranged the Fight Women's Cancer month in Jinja to raise awareness around women's cancer. Information about cervical and breast cancer was shared throughout October on radio and other media. The importance of routine screening was highlighted and promoted. It all climaxed on Saturday 29 October when Jinja was painted pink when close to 500 people of all ages gathered and walked, rode and ran through Jinja to show commitment to the Fight Against Women's Cancer in the region. This year many businesses and organizations and politicians joined hands with RHHJ in this worthy fight.



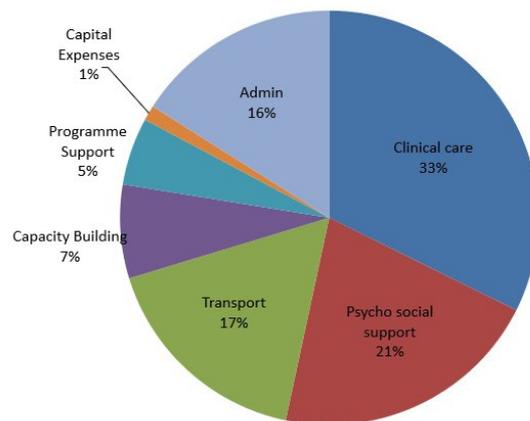
What does it cost?

Sources of Income - 2022



Total income: UGX: 1,360,781,369
 US\$ 377,994 / € 344,501 / DKK 2,585,484

Expenditure by Programme Category



Total expenditure: UGX: 1,406,548,901
 US\$ 390,708 / € 356,088 / DKK 2,672,442

All Included:

Cost/patient/year:

UGX 1,130,000 / US\$ 314 / € 286 / DKK 2148

Cost/patient/month:

UGX 94,000 / US\$ 26 / € 19 / DKK 179

Thank you to our partners in Uganda:

African Palliative Care Association, Busoga Forestry Company Ltd, Kawempe Home Care, Kyabirwa Surgical Center, Life Giving Stream Tabernacle Church, Lugazi Sugar, Makerere University School of Public Health, Ministry of Health, Palliative Care Association of Uganda, Rene Pharmacy, Rotary Club Jinja, St. Francis Health Care, Transport for Uganda Sick Children, Uganda Bikers, Uganda Cancer Institute, Uganda Cancer Society, and many individual partners.

Thank you to all our international donors:

Bovey Baptist Church(UK), Friends of Reach Out, Friends of RHHJ in Portugal, Global Partners in Care, Hospice Jinja Ireland Project, International Women's Club of Copenhagen (Denmark) , Love4Uganda (Sweden) Omnibus Solutions Ltd., PJ Broderick memorial Foundation, Ragnhild Bruuns Fond(Denmark), Reach Out Schools Everywhere (ROSE), Rotary Club of Holstebro, University of Aarhus, With a Little Help, and many individual donors.

Contact Us:

Phone: (+256) 771 619 991

Email: raysofhopehospicejinja@gmail.com / hospicejinja@yahoo.co.uk

Website: www.raysofhopehospicejinja.org

Facebook: RHHJ - Rays of Hope Hospice Jinja

Twitter: @raysofhopejinja

Instagram: rhhj_raysofhopehospicejinja