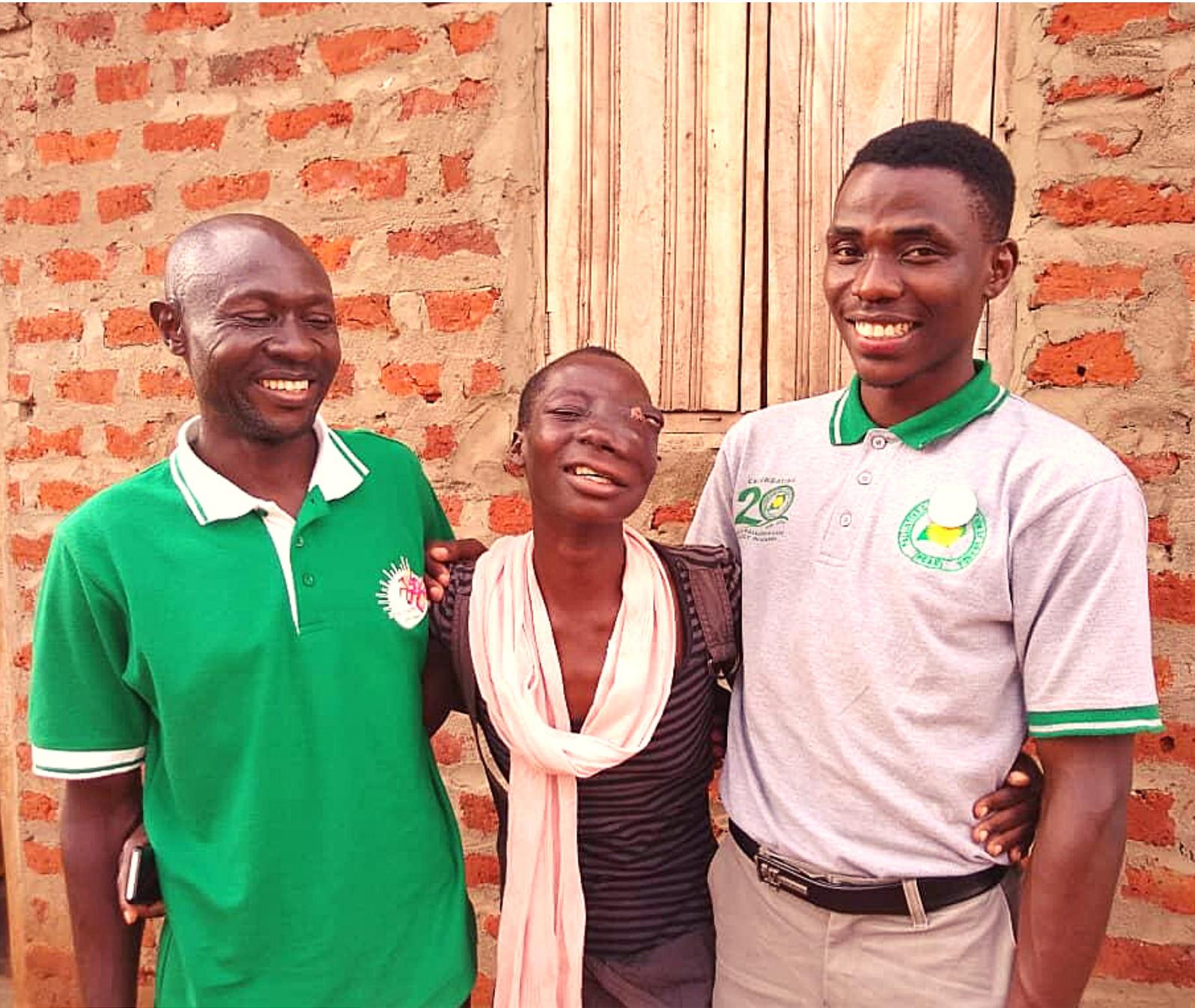


ANNUAL REPORT 2020



Rays of Hope Hospice Jinja

Executive Summary

With plans drawn, targets set and filled with energy, the Rays of Hope Hospice Jinja (RHHJ) team got off to a flying start in 2020. New patients enrolled, cared for and visited reached higher numbers than ever...and then the COVID-19 Pandemic reached Uganda, and everything changed. The fear of infection was huge, but the stringent prevention measures implemented in Uganda took the highest toll on the socio-economic status of our already very poor clients. The problem of limited access to health care became more evident than ever, and palliative care needs were – literally - painfully unmet.

In the face of this new situation, RHHJ adopted new strategies and made adjustments to ensure that our clients and their families continued to receive the uninterrupted care they desperately need. Activities with big gatherings were affected, and some have been postponed for now, but in spite of COVID our committed team reached the 2020 target as we cared for 1133 clients and enrolled 560 new patients.

Universal access to health, the UNDP development goal for 2030, seems very far away in the Busoga Region. Addressing the problem of limited knowledge about cancer and palliative care among health workers, RHHJ developed a 3-day training course for health workers from different health centres in the Busoga Region. Relevant referrals from health units have already increased in the three districts where 91 health workers have been trained.

The commitment and energy with which 2020 started is still alive as the year draws to an end. The RHHJ team is committed, hardworking, professional and fun-loving – the best team ever! We are very grateful for our supportive donors – new and old, national and international. They helped us steer through the COVID-19 challenges and continue serving the sick and their families.

RHHJ has, in 2020, made yet another good stride to reach the people with cancer and severe AIDS in the Busoga Region – but there is still a long way to go before we can even come close to universal access to health and palliative care here. Our quest comes with a cost in terms of manpower and of course also finances. RHHJ has the will, the skills and the drive to go forward. We are deeply grateful to you for supporting us this far and we are inviting you to keep walking with us - let us do it together.

Mr. Balikomyeeyo Sebastian

Chairperson of the Board

Ms. Nakami Sylvia

Executive Director



Patients in Focus

CLINICAL TEAM 2020 at a glance

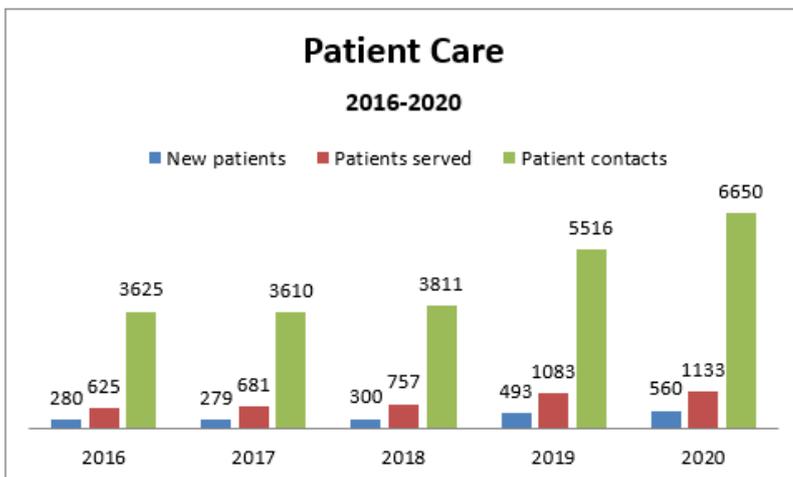
1133 enrolled patients
avg. 578 patients on programme per month
68.9% women 31.1% men 9.9% children

59.5% Cancer
17.6% HIV/AIDS
6.8% Cancer & HIV/AIDS
16.0% Other

6650 patient contacts
avg. 47 new patients per month
195 patients improved and discharged from RHHJ programme
377 patients passed away

Rays of Hope Hospice Jinja stands committed to holistic care of our patients and their families offering pain relief, symptom management, psychosocial support and help with treatment when possible. Every day, RHHJ faces and is challenged by the serious need for palliative care services in the Busoga Region in Uganda - an area of 10,000km² and 3.5 million people. Our aim is to increase access to quality palliative care for the rural poor.

Towards improving access to health care and palliative care – step by step



- Expanding Satellite Programmes with overnight stays has allowed for more time on site. Now, 47% of patients come from six distant 'overnight districts' or 8 out of 21 routes. The longer days give more time to work with patients, hospital and health center staff and community volunteers.
- Sensitizing and sharing knowledge with senior health administrators on cancer and palliative care has sharpened their interest in cancer and palliative care and has

facilitated our work with the health centers and hospitals.

- Bridging health workers' knowledge gap on cancer and other life-limiting diseases has given excellent results. A specially tailored 3-day training course has increased relevant and earlier referrals for palliative care.
- Equipping 100 community volunteers with refresher training on a quarterly basis has made them much better at identifying patients with palliative care needs as well as following up with patients.
- Providing 100 community volunteers with bicycles has helped and inspired them to reach much deeper into the villages, thus widening the area of access to care.
- Sensitizing and providing early diagnosis and treatment camps of cervical and breast cancer in the community has allowed women to access and benefit from important preventive measures.

Clinical Palliative Care of Patients and their Families

Clinical Palliative Care is relieving the pain and symptoms of patients with life-threatening/life-limiting diseases through holistic care. Training families and care-takers to better support the patients and care for them is also a vital part of our programme. Our main goal is to keep our patients as comfortable as possible, despite their illnesses. Our team has adopted home and outreach - based care models to best address the problems our patients face.



Jackeline – an inspiration and a source of joy

Jackeline is a 27-year-old single mother with a story of remarkable courage, determination and a beautiful character. At the end of 2018 Jackeline was enrolled with Rays of Hope Hospice Jinja with a swelling of the left nose and eye region. She was supported for further investigations at Uganda Cancer Institute at Mulago in Kampala. Unfortunately her cancer was too advanced for curative treatment, but RHHJ helped her with funds for palliative radiotherapy.

Despite being disfigured by the tumour, and suffering from the treatment side effects Jackeline is determined to keep up hope and be happy – and we have never seen her sad or complaining. She wants to advocate for better access to cancer care – and she wants her story to be known and never forgotten.

In July 2020, while in Mulago, Jackeline wasn't feeling well and a fellow patient, Joy, took care of her. When Jackeline a few months later learned that Joy was sick, she immediately travelled over 80km to take care of her.

Jackeline is such a kind, loving and giving person – she inspires people and spreads joy wherever she goes. We all have a lot to learn from her - how lucky we are to know her.



Treatment Support

Access to health care is a human right, but many of our clients cannot access treatment due to financial constraints. RHHJ helps clients with possibly treatable conditions to get the transport, testing and treatment they need. In 2020, RHHJ supported 122 patients to access diagnosis and treatment – 97 were new, and the remaining 25 were ongoing from 2019. 13% were children. The main diseases supported for treatment were: Cervical Cancer (17%), Breast Cancer (12%) and Kaposi Sarcoma (8%). The average support for treatment given was: UGX 581,060 (USD 159 / € 130 / DKK 970).

Early Detection and Treatment of Cervical Cancer

In Uganda, cervical cancer accounts for 20% of all new cancers and 35% of all female cancers. 41% of the 254 women with cancer enrolled in RHHJ in December 2020 had cervical cancer – most of them with advanced disease. Our screen and treat programmes, which started in 2018, continued in 2020 except during the COVID-19 lockdown.

1354 women screened for cervical cancer at 21 health centres

**6.6 % with precancerous cells / suspected cancer
76.6 % were treated on site**

Rural women are very interested in screening for cervical cancer. The 'test and treat' strategy is essential in order to increase accessibility to treatment as the majority of these women cannot afford to travel to distant referral centres.

Training



A three day, very practical training course for health workers, 'Working together towards better access to care' was developed and 91 health workers from 3 districts were trained. Relevant referrals from the health units involved has since increased remarkably ensuring earlier interventions for patients with cancer or severe HIV/AIDS.

Five meetings on 'Access to Universal Health Coverage' with special emphasis on palliative care were discussed with senior hospital administrations from five district hospitals/Health Center IV. Regular consultative palliative care days have since been established at each of these hospitals and at Jinja Regional Referral Hospital.

A one week training course in VIA screening and treatment for cervical cancer was conducted in Namayingo, including 11 participants from Buyinga HC IV, Banda HC III and RHHJ clinicians. Buyinja and Banda Health centers are starting regular screen & treat services for cervical cancer in early 2021.

All institutional education has been on hold since March due to COVID. This has affected three of our nurses who are in training in palliative care at bachelor or diploma level.

Emotional and Material Support for Patients and their Families

Disease in any family affects everybody in the household - emotionally and socially. Meeting physical needs enables patients and their families to live better quality lives during their illness, gives them a little comfort and provides hope for the future.

COUNSELLING

Patients and their families receive counselling during every visit.

For very complex cases, counselling is done by the social worker or counsellor

SHELTER

We built **9 new houses** and repaired **4 houses**



SCHOOL FEE SUPPORT

126 children affected by cancer or severe AIDS in their family were supported with school fees. During the school lock-out from March - December a special monthly programme was set up to support the children with counselling, training materials, clothing, and food. Special attention is given to the older girls who are at risk for exploitation.

DAY CARES

Due to COVID meeting restrictions only **7 day cares for 212 patients** and caretakers were held to share experiences, receive health talks and share a meal.



WHEELCHAIRS

14 patients were supported with wheelchairs, and 8 crutches were given out.



BEREAVEMENT SUPPORT

Visits were made to **101 families** during the loss of loved ones.

FOOD SUPPORT

120 patients received a monthly food basket of rice, beans, sugar and soap. **110 patients** got nutritional porridge. During the COVID lock-down a food basket was given to **350 patients**. **400 patients** received a special food package for Christmas. **110 of the most poor** received a monthly **comfort fund** (UGX 10,000 / USD 3) to afford their most basic needs.



OTHER SUPPORT GIVEN

87 mattresses, 74 blankets and 78 bedsheets to the very poor
61 re-usable diapers and 33 mattress covers for incontinent patients and 170 colostomy bags

COVID-19

The first COVID-19 case was diagnosed in Uganda on the 21st March 2020, and the country went into strict lock-down. Apart from protecting our staff, volunteers and patients, our priorities were to ensure continuing patient care with sufficient medicines; uninterrupted cancer treatment with the Uganda Cancer Institute, basic food supply and regular contact with patient and families.

Challenged not only by their disease but also their socio-economic status, our patients were at high risk during the lock-down. A survey conducted after the restrictions were eased showed that they felt they went through the lock-down fairly well physically. This may reflect on the provision of medicine, food and social support which RHHJ put in place, but it certainly also reflects the extreme tolerance to hardship our patients have. It remains a deep concern, that the majority of our clients – most already very poor - have sunken into even deeper poverty.

The COVID pandemic is still with us as we start 2021. The pandemic has exacerbated the problems we are facing at RHHJ – deep poverty and lack of access to basic health care services, diagnosis and treatment. It is our challenge to use the situation now - where these problems have become even more obvious - to join hands across civil society, government and donors. Together we must find ways to decrease the abyss of extreme suffering, poverty and inequity that we see all around us.

Uganda for the Roses

RHHJ hosted our second annual awareness and fundraiser event for women's cancer, Uganda for the Roses. People from all over the world participated in a virtual run/walk/ride/swim in support of screening and treatment of women's cancers in Busoga region.



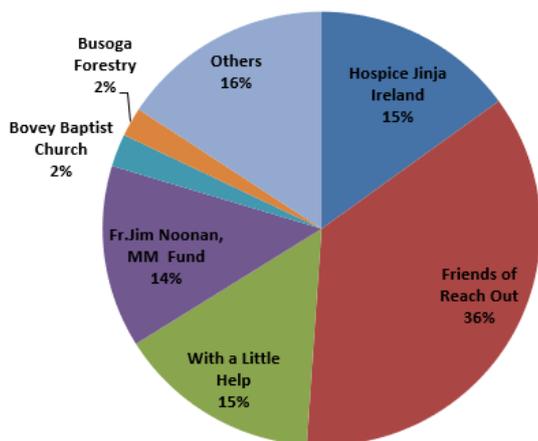
Source Graduation...



Rays of Hope Hospice Jinja completed the SOURCE (Strengthening Organizations for a United Response to the Cancer Epidemic) Program, through the American Cancer Society with a score of 100 % ! Over the last three years, RHHJ has gained invaluable knowledge and resources to make our organization efficient and effective - ready to continue the fight against cancer and access to palliative care. Thank you to all involved.

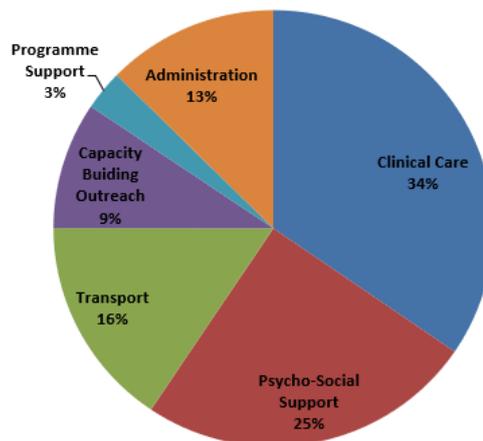
What does it cost?

Sources of Income - 2020



Total Income: UGX 1,350,585,367 /
US\$ 370,000 / € 337,000 / DKK 2,566,000

Expenditure by Programme Category



Total Expenditure: UGX 1,023,174,276 /
US\$ 280,500 / € 256,000 / DKK 1,945,000

All Included:

Cost/patient/year:

UGX 903,000 / US\$ 248 / € 226 / DKK 1716

Cost/patient/month:

UGX 75,255 / US\$ 21 / € 19 / DKK 143

Thank you to our partners in Uganda:

African Palliative Care Association, American Cancer Society SOURCE Programme, Busoga Forestry Company Ltd, CoRSU, Diplomatic Spouses Association, Global Outreach Uganda, Kawempe Home Care, Kyabirwa Surgical Center, Life Giving Stream Tabernacle Church, Makerere University School of Public Health, Ministry of Health, Nama Wellness Centre (NAWEC), Palliative Care Association of Uganda, Rene Pharmacy, Source of the Nile Union of People living with Albinism, 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, Fr. Jim Noonan's Memorial Fund, Friends of Reach Out, Global Partners in Care, Hospice Jinja Ireland Project, Omnibus Solutions Ltd., With a Little Help and many individual donors.

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