

# Rays of Hope Hospice Jinja



## Who We Are and What We Do



July 2022

# Who We Are

Rays of Hope Hospice Jinja (RHHJ) is a non-governmental inter-faith organization founded in 2005. We provide homebased, holistic palliative care addressing the physical, social, emotional and spiritual needs of patients with cancer and severe HIV/AIDS. Our aim is to relieve pain and improve quality of life related to life-threatening illnesses.

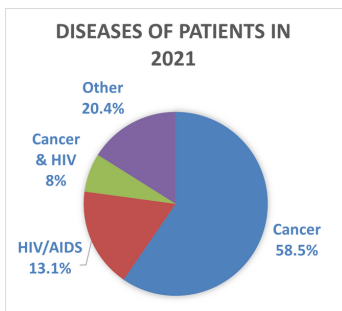
RHHJ is presently the only provider of specialized palliative care services in the Busoga Region in Uganda, an area of 10,000km<sup>2</sup> and a population of 3.5 million people (2014).

Distances to health centers are long and the absolute poverty and last-mile isolation of our clients means RHHJ is often their only hope for treatment and care. This makes our work an immense and crucial challenge.

In 2021 RHHJ cared for 1073 people, 66 % are women, 10 % are children. 60% of patients have cancer,

We have a staff of 28 highly committed and hard-working professional people. 85 community volunteers throughout the region identify and support patients in their area.

In March 2022 the first RHHJ field office was opened in Buyende District.



# The United Nation Sustainable Development Goal for 2030

**UNIVERSAL HEALTH COVERAGE: all people have access to the health services they need, when and where they need them, without financial hardship.**



Every day on home visits in Busoga Region RHHJ meets the present reality of little or no access to needed health care as described in the Lancet Commission Report "Alleviating the access abyss to palliative care."(2017):

"Poor people in all parts of the world live and die with little or no palliative care or pain relief. Staring into this access abyss, one sees the depth of extreme suffering in the cruel face of poverty and inequity."



**THE RAYS OF HOPE HOSPICE JINJA PROGRAMMES ARE DEVELOPED TO OVERCOME THE ACCESS BARRIERS TO HEALTH CARE AND PROVIDE MUCH NEEDED CARE FOR PEOPLE WITH LIFE-LIMITING DISEASES**

## Improving Access to Health Care

**RHHJ brings services closer to the patient.**



Patients are seen by a team of clinicians and social workers in their homes on regular, pre-scheduled visits. The stronger patients are seen at a health center close to them.

On an average we have 640 patients enrolled per month of whom more than 50 are new patients. In 2021 RHHJ had 6285 patient contacts. To reach out patients we drive on average 12,000 km per month.

We will help  
you where  
you are



The RHHJ Buyende Field Office, started in the first quarter of 2022, is developing and continuing to bring services very close to the people in the rural parts of Kamuli and Buyende. This field office contributes 25% of new patients every month and is caring for 24 % of all patients on program



## Improving Access to Health Care

# RHHJ provides needed medication for pain and symptom control



RHHJ provides all medication for pain and symptom control to help the patient live to the last day in dignity without pain, small or other difficult symptoms

Nobody  
should suffer  
in pain



Liquid morphine is provided free from the Ugandan Government and prescribed by our trained palliative care clinicians

## Improving Access to Health Care

# RHHJ trains health workers in better diagnosis and treatment of cancer and severe HIV/AIDS



Capacity building of health workers in the districts



Limited knowledge about cancer and severe HIV/AIDS among health workers in the districts remains an obstacle for access to diagnosis and treatment and referral for palliative care. Since 2019 RHHJ has conducted our especially designed and developed 3-day introductory course in palliative care for 364 health workers from more than 100 health centers in Busoga Region and Buikwe district.

Since introduction of the health worker training course referrals from hospitals and health units have increased from < 20% of all referrals in 2018 to 33.5% of all referrals in 2021.



In 2021 & 2022 RHHJ has trained staff and equipped and established routine cervical cancer screening at 4 government health centers in Namayingo (Buyinja HC IV and Banda HC III) and Jinja (Butagaya HC III and Kakira HC III). Two additional centers will be established in Buyende District in the second half of 2022.

## Improving Access to Health Care

# RHHJ trains the women in the community and provides screening for cervical and breast cancer



Cervical cancer can be prevented and eliminated with HPV vaccination and routine screening

In October 2021 373 women were enrolled on programme. 78% or 292 women had cancer. Of these 42% of women had cervical cancer, 13% had both cervical cancer and HIV/AIDS. 15% had breast cancer.

57% of women enrolled had either cervical or breast cancer

RHHJ offers free VIA cervical cancer screening in villages at the local health centers, so women can easily access services. Women are informed and mobilized by community volunteers and posters. From 2018 – June 2022 RHHJ screened 5,416 women for cervical cancer .The women are either treated on site or if cancer suspect helped to further diagnosis and treatment.

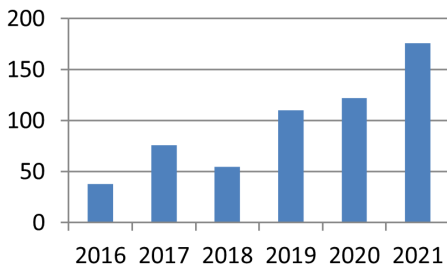
One in 15 women tested positive for precancerous changes with VIA or suspected cervical cancer

WHAT ARE  
WE WAITING  
FOR?

## Improving Access to Health Care

**RHHJ supports the cost for diagnosis and treatment for our poor patients who otherwise would not get the treatment they need.**

**Patients supported with treatment costs  
2016-2021**



**Access to  
treatment is a  
human right**

### TREATMENT SUPPORT, 2021

- 176 people have been helped to access treatment - 155 started treatment in 2021, 21 continued treatment started in 2020.
- 25.6% were children.
- The main diseases supported for treatment were: Cervical Cancer (21.7%) and Breast Cancer (13.1%)
- Average support for treatment given:  
UGX 717,578 (\$200/€180/ DKK 1375)





## Improving Access to Health Care

# RHHJ provides psycho-social and spiritual support - an essential part of palliative care



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.

Disease affects the whole family



School Fee Support:  
130 children supported

66 re-usable  
diapers and mattresses

Days cares  
11 day cares  
for 220 patients

Colostomy  
bags for all in  
need

Bereavement  
102 families  
visited

Food Support  
160 families  
per month

In 2021

30 sets of  
mattresses  
and sheet &  
blankets

Wheel chairs:  
6 patients  
Crutches:  
8 patients

Counselling is  
ongoing for all  
Special  
sessions with  
the most  
troubled

10 houses  
built

130 families  
clothed

# Stephen's Story



## You Come

When I smell, you still come!

When flies are all over my room, you still come!

When the weather is bad and the roads are impassable, you still come!

Even when there are Covid-19 travel restrictions, You still come!

What kind of people are You?  
What am I to you?

You have treated me like a close family member. Yet you barely know me.

At this point, I know am not going to get cured of this disease. But I thank you so much for continuing to come and check on me, asking me how am doing, taking away my pain, taking away the smell, taking away the flies, taking away the hunger and filling my heart with Joy. If it weren't for you, I would be dead 8 months ago

As for today:

The food, soap, and comfort fund you brought for me has helped re-affirm my status as a father and provider in my family. I am 1000 times happier than what my diseased face can express.

Thank you so much Rays of Hope. If you find me alive next time, we shall continue with the talk, if You find me dead, please know that you have been my dearest friends in the last times of my life. My family and I are very very grateful.

May God reward you abundantly,

Stephen



## Improving Access to Health Care

### **RHHJ seeks through research to better understand how we can improve and expand palliative care services.**

- A study on 'The risk of child undernutrition in households with life-limiting disease in Busoga region' was conducted with University of Aarhus, Denmark. Publication is in the process. Another study with University of Aarhus on cervical cancer will start in October 2022
- A study with Makerere School of Public Health, APCA and Rand Corporation in California on empowering women to promote cervical cancer screening in their network started in 2019 and is still ongoing. 2nd phase will start in the October 2022. .
- A retrospective study on childhood cancers in Busoga Region with Department of Pediatrics at Mulago Hospital is on the planning stage.
- RHHJ has had oral and poster presentation at every Palliative Care of Uganda/Uganda Cancer Institute Conference and of African Palliative Care Association Conference since 2019.

## Improving Access to Health Care

### **RHHJ promotes awareness of serious problems through fun events**



Since 2019 October has become a month of advocacy, awareness and fundraising for the fight against women's cancer.

Throughout Busoga Region – even outside Uganda - activities are going on - - We dance, run/walk/swim, share information and conduct cervical and breast cancer screenings. Every year more people are involved – from all corners of society - and amidst the serious problems, we also have fun together.

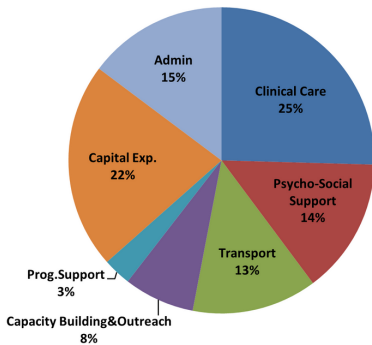
The fight continues - together we can do it.



# Improving Access to Health Care

## What does it cost?

### Expenditure by Programme Category



Help even just  
one person out of  
suffering - It is  
cheaper than you  
think!



**Total Expenditure: UGX 1,516,276,000 /**  
US\$ \$429,106/ € 379,069/ DKK 2,818,757

**All Included Cost/patient/month:**  
UGX 92,292 / US\$ 26/ € 23 / DKK 171

### **Thank you to our partners in Uganda:**

*African Palliative Care Association, Busoga Forestry Company Ltd, BIDCO, CoRSU, Kakira Sugar, Kawempe Home Care, Kyabirwa Surgical Center, Life Giving Stream Tabernacle Church, Lugazi Sugar, Makerere University School of Public Health, Ministry of Health, Nama Wellness Centre (NAWEC), Operations and Maintenance Energy Uganda Limited, Palliative Care Association of Uganda, Rene Pharmacy, Rotary Club Jinja City, 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, Cure Cervical Cancer, Fr. Jim Noonan's Memorial Fund, Friends of Reach Out, Global Partners in Care, Hospice Jinja Ireland Project, Omnibus Solutions Ltd., University of Aarhus, With a Little Help, and many individual donors.*

### **Thank you to our board of directors:**

*Chairperson Sebastian Balikomyeeyo, V/Chair Jane Bagambi, Secretary Esther Aliwayoki, Treasurer Faustine Ngarambe, other board members: Eric Kamunvi, Donato Laboke, Dr. Mumtaz Kassam, Samuel Ifuba. Ven. Rev. James Kivunike, Ex Officio board members: Geoffrey Alisengagha, Dr.Margrethe Juncker, Robinah Mwangale Mubeeke, & Executive Director Sylvia Nakami*

# A YOUNG MAN TO BE SEEN BY ALL



Waiswa came to Rays of Hope Hospice Jinja in January 2016 when he was 12 years old. He was not doing very well as he had developed skin cancer on his feet and legs.

Rays of Hope Hospice Jinja supported him with food to help strengthen him and in 2017 he was taken for cancer treatment at Mulago Hospital in Uganda's capital, Kampala.

Waiswa responded well to his treatment, and he was now ready to go back to school. As he comes from an extremely poor family, the mother could not pay for school fees, so RHHJ supported him to go to school.



In May 2019 Rays of Hope also helped the family to get a small house as their old house was falling apart.



In May 2019 Rays of Hope also helped the family to get a small house as their old house was falling apart. Waiswa is doing so much better now that the cancer is cured. Waiswa was discharged from the RHHJ medical programme in 2020, but he is still in the school support programme.



# A YOUNG MAN TO BE SEEN BY ALL



Waiswa has proven to be a very good and promising student and Rays of Hope Hospice Jinja is now trying to get him a stipend to a very good boarding school. After the school interview we received this beautiful letter from Waiswa – and we are now passing it on to you. No words could better express the importance of helping the people around us in need of care and support – one at a time. With a little help for body, mind and soul Waiswa is now flourishing, becoming the wonderful young man, that he was always meant to be – a young man to be seen by all!

APPRECIATION NOTE TO MY FRIENDS  
OF HOSPICE JINJA

I waiswa moses, hereby saying a word of  
Thanks through writing to you my friends  
of the group Hospice Jinja.

Nothing I can give but wisely I pray to the  
almighty God who blesses to bless you  
abundantly and widen all the plans for  
you towards me. These words of thanking  
are from the kingdom of my heart,  
because I even feel the tears of joy, hope,  
peace and stability that you brought to me,  
really I was joyless, hopeless when my  
heart was full of sadness tears. I was an  
unseen creature to the people, I thank you  
for having made me somebody to be seen.

Now I eat, drink, and even sleep well because  
of you, I totally say that thank you, may you  
succeed, be victorious in what ever you do  
and continue with that advocacy to me.

Your's faithfully  
waiswa moses  
WAISWA MOSES

## JOIN US

The absolute poverty and last mile isolation of our clients means that **RHHJ is often our patients' last hope for treatment and care**, making our work an immense and crucial challenge.



### YOU CAN BECOME A PART OF RHHJ

- Make a financial contribution on our website
- Volunteer your skills and time
- Tell others about RHHJ



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