



Road to Hope COVID-19 Support Response September 2020 – July 2021



Submitted by the Hospice Foundation and Palliative Care Association of Uganda August 2021

This report is summary of a grant report that was submitted to the grantor. The report covers all activities from September of 2020 through July of 2021. We have secured an additional grant to extend this support to the RTH children and families through December of 2021.

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INTRODUCTION

The Palliative Care Association of Uganda (PCAU), in partnership with Center for Hospice Care/Hospice Foundation (CHC/HF), started the Road to Hope (RTH) program in 2012 to support vulnerable child caregivers with educational, psychological, social, emotional, and nutritional support. All children are enrolled in schools that can best meet their educational and emotional needs, and these are often boarding schools. It is the norm for children to be away at school much of the year.

Due to the COVID-19 pandemic, schools in Uganda were closed in March 2020 and PCAU redirected its efforts to support RTH children at home. Being at home without structured learning for an extended period presented an array of challenges for the children and their families. Additional financial support was needed to help address the physical and psychosocial well-being of the RTH children and their families during the pandemic. The additional support was needed for all 34 families of the 54 RTH children (some are siblings) across 18 districts in Uganda. A grant was secured to help with these costs.

During school closings, PCAU has provided support to the RTH children and their families in four main areas: I. homeschooling and educational supplementation, II. nutritional and basic needs support, III. psychosocial support, and IV. entrepreneurship/vocational skills development. Because of the unprecedented and uncertain nature of the pandemic lockdowns, PCAU has remained flexible in their programming and support to best meet the needs of each RTH child.

PROGRAM ACTIVITIES

I. Homeschooling and Educational Supplementation

All schools were fully closed between March and October of 2020. The Uganda government encouraged e-learning where possible and also provided lessons in the local newspapers and through radio and television stations. The RTH program provided scholastic materials such as newspapers, textbooks, and small radios to all 54 children on the program (34 in primary, 16 in secondary and 4 in vocational institutions). Qualified and experienced teachers were identified to teach children during the lockdown. Siblings of the RTH children (not on the program) also benefited from this is initiative. Grant funds support the educational supplementation of the 22 unsponsored children, and the other 32 children are supported by individual sponsors.

Uganda's Ministry of Education and Sports instituted a staggered schedule to reopen schools safely with different class levels reporting at different times to complete the 2020 academic year. PCAU worked with each child's family and school to arrange the best approach for the child. They continued to provide homeschooling support and made sure those returning to school were well-equipped with the basic and scholastic essentials, as well as additional safety supplies such as PPE. Below is the reopening schedule for completion of the 2020 academic year:

- October 2020: Candidate classes (primary seven, senior four, senior six and college finalists) resumed school. They also took their national exams in March of 2021 and received results in July. All RTH candidates passed their exams!
- March 2021: Primary six, senior three and senior five students returned to school. Vocational and college students were allowed to resume face-to-face classroom sessions in shifts.

- April 2021: Primary four, primary five and senior one students returned to school.
- May 2021: Senior two students returned to school.
- June 2021: Primary one, two and three students were supposed to return to school. Some RTH children in these classes returned to the boarding school earlier through a special arrangement with PCAU. Though they did not officially start classes, they were able to study with the guidance of teachers. Only two RTH children had not returned to school when the new lockdown was announced in early June.



RTH sisters Sanyu and Leah engage in homeschooling activities at their home in Jinja.



RTH child Sharon at her home with her grandmother receiving homeschool supplies.

Children in senior one (S.1) had just transitioned into secondary level education when the COVID-19 pandemic hit Uganda. At the beginning of 2020, the Uganda government had just rolled out a new secondary school curriculum and not many teachers were acquainted with it before schools closed. Few teachers were trained in the new curriculum and PCAU found it challenging to identify experienced teachers in the children's communities to homeschool the students in S.1. They managed to find a few teachers to help these students, but they also provided new curriculum books to these students along with other learning materials to ensure they were making some progress while at home.

During June and July, homeschooling was unable to restart given the strict lockdown and the need for program staff to focus primarily on the health and well-being of the children. The program has now restarted more rigorous educational support and at this point, expect it may continue through the end of 2021.

II. Nutritional and Basic Needs Support

Access to adequate and nutritious food is already a challenge for many RTH families, and the pandemic exacerbated the problem as the lockdown prevented means of income generation for families. Some RTH children and their caregivers suffer from chronic illnesses such as HIV/AIDS and are on treatment which requires nutritional support. To prevent hunger and suffering, and to continue to support the well-being of the children on the program, PCAU has ensured all RTH families receive help with basic needs and food (since September of 2020).

All RTH families are provided a monthly package of support containing food and basic supplies. The packages are provided based on individual family needs, including the number of family members.

Additionally, PCAU identified 16 of the 34 families as the most vulnerable. The guardians/parents of these families have lost their only source of income due to the lockdown and need more support to meet basic needs for their families. For most of the families, PCAU identified a local shop where they could order and pay for the food package, and it can be easily picked up by the family. For families that are harder to reach, PCAU worked with local palliative care teams to deliver the items.



Family of RTH children, Jeremiah and Fred, after receiving a supply of basic needs.



Viola, palliative care nurse in Yumbe Hospital, and Mark Mwesiga of PCAU meet with family of RTH child Sika.

The basic need for shelter is also a challenge for some of the RTH families. Two families (four RTH children) were displaced from their place of residence in 2020 by landowners converting their land to farming due to financial struggles brought on by the COVID-19 pandemic. Working with the families and local community leaders, PCAU helped them secure land for settlement where they will construct permanent homes. This process is still underway, though land is purchased and planning for home construction has begun. In the meantime, the communities are supporting the families with temporary residence.





The family of RTH children Rose and Deogratius talked with PCAU team and community members during the process of acquiring their one-acre piece of land. House construction should begin in September 2021.

III. Psychosocial Support

The RTH program already works with vulnerable children and families in difficult situations. The fear and stress created by the COVID-19 pandemic has added to the already pressing needs for psychosocial support and counseling for the children. Many are afraid for their parents and/or guardians with underlying health conditions. There has also been concern about food insecurity, loss of jobs, closure of schools, and gender-based violence.

The PCAU team and their resourceful network of palliative care colleagues across the country have provided this psychosocial support by frequently reaching out to children and their families to provide counseling. PCAU coordinated the respective hospice and palliative programs (i.e., Rays of Hope Hospice Jinja, Hospice Tororo, New Life Hospice Arua and Little Hospice Hoima) in the children's communities to provide periodic in-person counseling. PCAU also makes regular telephone check-ins on the children.



RTH children Oliver and Jackline in a counselling session with Joyce Zalwango of PCAU.



Stephen Kasula, RTH volunteer, checking on RTH children Aggrey and Ronald, at school in March 2021.

In addition to pandemic-related psychosocial support, there were other challenges faced by some children. Several had family members who needed urgent medical care during this time and PCAU has provided additional help where necessary. Some illnesses were milder and others more challenging. One RTH child was diagnosed with cancer and is currently undergoing chemotherapy and radiotherapy treatment at Uganda Cancer Institute.

Another child became pregnant during the pandemic lockdown – something PCAU has worried about with the RTH children during this time. PCAU has continued to provide her the much-needed psychosocial and health support to ensure a healthy pregnancy and delivery.

The mother of another RTH child needed surgery to address a pressing medical issue. The child was unable to concentrate on studies at home knowing the pain his mother was in. PCAU supported her through the treatment, thus providing relief to them both.

A palliative care nurse working in Jinja passed away in May. She had recommended two brothers to the RTH program and helped take care of them over the past several years. They had lived with her since 2015. Her death devasted the boys and caused a great deal of uncertainty about where they would live. PCAU engaged the family of this nurse to discuss the situation and they pledged to continue to support the boys with the help of PCAU.

IV. Entrepreneurship/Vocational Skills Development

PCAU planned on providing entrepreneurship support to RTH children as another way to keep them constructively engaged during school closings. During the early part of the initial lockdown in 2020, some children were supported with entrepreneurial funds, and they engaged in small gardening or

craft projects. Once PCAU established the homeschooling infrastructure and support, the focus shifted to learning, so no additional funds were used in this area.

Three of the four children in vocational school were supported by their sponsors. They received tablets to help them engage in distance learning and they were placed with businesses in their communities during lockdown for practical learning experience. The fourth is the child diagnosed with cancer. The focus has been on his treatment and health rather than schooling, though his caretaker has ensured he has some reading and activities to keep his mind occupied.





RTH child, Aggrey, during his skills training with the Electricity Regulatory Authority (L) and receiving a tablet to allow him to participate in e-learning at this vocational school (R).

The scope of educational support and entrepreneurship support was provided by both RTH sponsors and grant money that covered the unsponsored children on the program.

V. Administrative Support

PCAU's commitment to supporting the children and their families brought with it extra – but necessary – work and human resource needs. The grant allowed PCAU to engage a former RTH child, Stephen Kasula, as a program volunteer to support the program. Stephen is in his third year of pursuing a degree in medicine and surgery at university. Because universities, too, were closed, Steven had time to offer support to the program. He receives a stipend and facilitation for his transport and communication costs to enable his work with the RTH program.

Stephen's contribution continues to be invaluable, especially considering the departure of the RTH program officer in March of 2021. The increased workload was shared with the hospice programs located in the communities where the children live. They normally offer support to PCAU and the children, but more has been asked of them during the pandemic. Grant funds provided some extra support to these regional palliative care providers. PCAU has recently hired a new programs manager who will now oversee the RTH program. She began in August, and Stephen will stay on for the time being to provide support.



RTH child Mary and her grandmother receive a check-in and handwashing supplies from German, regional focal support from Little Hospice Hoima



Stephen guides the children on proper handwashing and other important preventive measures for them to take at home. They listen to and trust his guidance.

VI. COVID-19 Surveillance, Testing and Treatment Support

The RTH program covers basic medical costs for all the children. But in late May, as COVID-19 was spreading rapidly in the country, PCAU realized they would need to cover these necessary additional costs to keep the children and their families as safe as possible. With the second lockdown at the beginning of June, most of the children were at boarding school and had to travel home as schools closed again. This movement caused concern for their exposure and testing was needed. By this time, some of the children were already reporting symptoms of illness as well. Some families were reporting COVID-19 cases, and PCAU had staff (and their family members) that tested positive.



RTH child Julius being screened for COVID-19 at Tororo General Hospital in Eastern Uganda.



The mother of Paul and Peter washing her hands with a station brought by PCAU to prevent the spread of COVID19.

Given this environment, plus the underlying health conditions of some of the children and their families, PCAU needed to immediately establish screening and surveillance testing among the RTH children and their family members. Many families have small houses – sometimes only one room – and cannot quarantine or isolate appropriately. The RTH program offered masks, soap for handwashing and continuous messaging on caution to prevent spread. PCAU worked with the local hospice programs and some government officials to help with this effort. They also provided treatment to those who became sick. At the time of writing this report, two RTH children have tested positive for COVID-19, along with one family member of a RTH child. There are other children who presented with symptoms of respiratory disease. They all received treatment and seem to be doing well. PCAU is continuing the necessary support in this area.

CONCLUSION

During these unprecedented times, PCAU has brought significant value not only the lives of the RTH children but also to family members and the community at large. With support from sponsors and additional grant money, they have been able to be agile and responsive to needs as they arise. Children and their families continue to express their gratitude for support in keeping safe, healthy and engaged with their studies during this pandemic.

As the country is in the midst of another wave of COVID-19 and another stricter, country-wide lockdown, PCAU will continue the above support to the RTH children and their families thanks to an additional grant which will allow these activities to continue through December of 2021. Some aspects of support may continue to be adapted in the coming months as external factors require, and PCAU will be watching the pandemic situation closely to help guide these decisions. The ability to be flexible and meet the changing needs has given the RTH children a cushion of support that most of their peers across the country have not been able to receive.