





March – September 2020

🗩 PCAUganda 🛛 🕧 Palliative Care Association of Uganda 🛛 🙆 +256 772 535341





## **Brief information about PCAU**

The Palliative Care Association of Uganda (PCAU) is the National Association for Palliative Care providers in Uganda.

The Vision of PCAU Palliative Care for all in need in Uganda

## The Mission of PCAU

To accelerate the integration of palliative care in the Uganda health care system through capacity building, advocacy, research and resources mobilization.

## The Goal of PCAU

To increase access to culturally appropriate palliative care through strengthening health care systems in Uganda in collaboration with partners.



## Dear PCAU Members, Partners and Friends,

On December 1<sup>st</sup> 2019, a new virus that causes respiratory illness was first detected in Wuhan city, Hubei Province in China. The was claiming lives spreading fast to other provinces of China and other parts of the world. The World Health Organization (WHO) declared the Coronavirus outbreak a Public Health Emergency of International Concern (PHEIC). In February 2020, WHO named the mysterious virus: 'severe acute respiratory syndrome coronavirus 2' (SARS-CoV-2). In March, WHO declared coronavirus diseases (COVID-19) a pandemic. Given its highly infectious nature, it quickly brought the world to a standstill. Uganda registered her first case on March 21.

Because this was a new disease, without a cure or vaccine, countries, including Uganda announced lockdowns in a bid to mitigate transmission. Uganda closed schools and abolished mass gatherings at worship centers and other social places. Borders were also closed and flights were grounded, except for cargo. Public transport - buses, commuter taxis and boda bodas, were suspended. On March 30<sup>th</sup>, 2020 the President declared a nationwide curfew from 7:00pm to 6:30am and the country was under a total lockdown. Only vehicles for listed essential services and with special stickers and those of security forces were allowed to move. For private transport, one needed a special movement permit from the Resident District Commissioner (RDC) to move.

This came with several implications. Several families who had emergency cases had to bear untold distress and pain, as they had no way to move to hospitals. Up until May 24<sup>th</sup> when easing of restrictions commenced, emerging evidence revealed a decline in numbers of patient reporting to health facilities across the country.

A survey conducted by PCAU in May 2020 indicated a drop in the number of patients seen by 16 hospices and palliative care organizations that responded. One of the facilities registered a 50% drop between February and April 2020. Respondents to the same survey indicated that the key challenges which affected access to palliative care were: limited patient transport, limited transport for palliative care teams to work, lack of adequate personal protective equipment(PPEs), limited transport for palliative care teams to conduct home visits, competing priorities brought on by COVID-19 and poor communication.

By September 15th 2020, Uganda had registered a total of 5,266 cumulative number of people who had tested COVID-19.A total of 60 deaths had been reported.

The COVID-19 Pandemic has had negative effects on the social services sector and beyond. Related challenges that face hospice and palliative care organizations include: general reduction in financial resources, lack of adequate appropriate PPEs, inadequate training on infection prevention and control among staff and volunteers, struggle to reorient operations towards ehealth practices such as telemedicine, higher demands for home care services among others.

At the beginning of March, PCAU developed a COVID-19 Interventions Strategy to guide the tactical and strategic planning during the pandemic. The thematic areas of the strategy and what has been implemented under each are given in this report. With support from partners, we have able been to do a lot to stay afloat and to contribute to the national, district and community response to COVID-19.

However, given the unprecedented nature of the pandemic, it continues to place us in a difficult position. The need for more resources to support the work of PCAU and member organizations remains high. This includes a new PCAU vehicle which is a big need now.

We thank all PCAU partners and donors who have rendered us financial support during this period: Open Society Foundation (OSF), Open Society Initiative for Eastern Africa (OSIEA), Centre for Hospice Care (CHC), American Cancer Society (ACS), Global Partners in Care (GPiC), African Palliative Care Association (APCA), World Hospice and Palliative Care Alliance (WHPCA), Tom and Roberta Spencer.

We thank all PCAU Member organizations and individuals who continue to offer palliative care to patients and families in need amidst the pandemic. We also thank the Ministry of Health for the great partnership and strides registered in the response to COVID-19.

Welcome to this update report on our interventions in response to COVID-19 Pandemic. Please give us feedback. We will also be happy to give further clarification on any of the matters written about or more information you need about palliative care services in Uganda. Contact me through mark. mwesiga@pcau.org.ug and telephone also on WhatsApp +256 793 873 400.

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Mark Donald Mwesiga Country Director - Palliative Care Association of Uganda (PCAU).

## Re-orienting Operations and Safety of PCAU Secretariat Staff

By March, it was imminent that working remotely would be the norm at least for some time. Staff at the PCAU secretariat therefore prepared well for this. Orientation and training for staff to work virtually were held just before the lockdown. Essential ICT equipment such as laptop computers and MiFi internet were availed to all program staff to enable connectivity. The work of the PCAU secretariat entails coordinating the work of civil society member organisations and individuals who are spread across the country. This also involves enabling continued linkages for palliative care providers to line government Ministries, Departments and Agencies. The PCAU secretariat therefore remained open and supported the work of Member organisations. With support from partners, PCAU acquired Zoom licence, teleconference equipment and other essential ICT equipment. As a result, bi-weekly staff meetings, board committees' meetings and board meetings were held as scheduled. The PCAU General Annual Meeting (AGM) 2020 was held as per our constitution, the Annual Report 2019 was shared with members as well as the report on the audited books of PCAU.

# Advocacy for the integration of PC in the COVID-19 Response

On March 30<sup>th</sup>,2020, the President of Uganda declared a nationwide curfew from 7:00pm to 6:30am and the country was under a lockdown. Following this directive, PCAU convened a meeting with leaders of hospice and palliative care organizations in the country to evaluate the likely impact of the directive on both availability and access to services. The meeting held on April I<sup>st</sup> was attended by leaders and representatives from these organizations - Hospice Africa Uganda (HAU), African Palliative Care Association (APCA), Rays Hope Hospice Jinja (RHHJ), Joy Hospice Mbale (JHM), Peace Hospice Adjumani, New Life Hospice Arua, Kawempe Home Care (KHC), Makerere Palliative Care Unit (MPCU) and Hospice Tororo, Kawempe Home Care (KHC). The focal person at the Ministry of Health and representative from the National Medical Stores also attended.

The leaders discussed preparedness towards the pandemic; shielding the organizations against impending challenges; but most of all ensuring the continuity of palliative care as an essential service. The daunting challenges to the leaders that time were: lack of transport arrangements for patients and caregivers to access care, lack of transport for palliative care teams to work including home visits, lack of adequate personal protective equipment for staff and volunteers, challenges in accessing medical supplies and a general reduction in donor resources and limited information about the pandemic.

The leaders agreed to issue a joint statement as an advocacy tool to address some of the challenges. PCAU took the lead in the writing and issuing of this important document. The statement which was addressed to the Chairperson of the National Task Force on CoronaVirus. appealed to the government to ensure both the integration of palliative care into COVID-19 response and the continuity of palliative as an essential service amidst the pandemic. In addition to the statement, PCAU engaged key policy makers on the pertinent issues; enaged and sensitized the media: and held various meetings with the Ministry of Health. This sustained advocacy registered some successes including: a Presidential Directive to District Health Officers (DHOs) to handle matters concerning palliative care at district level during the lockdown https://youtu.be/E5HAXSuj\_x8; issuing of travel waivers for palliative care patients seeking medical attention and for palliative care providers; providing donations and food relief to the most vulnerable persons with support from government and individuals.

https://pcauganda.org/wp-content/uploads/2017/02/ Statement-by-Hospice-and-Palliative-Care-Organizations.pdf







## PCAU Survey on Access to Palliative Care During the Lockdown

In May 2020, PCAU conducted an online survey targeting districts with Stand-Alone Palliative Care Services to generate responses on access to palliative care during the lockdown period. A total of 16 participants responded.

In the survey, respondents indicated that the Resident District Commissioners (RDCs) maintained the role of issuing travel permits but there was a level of involvement by District Health Officers (DHOs) to support patients with palliative care needs when the President issued a directive.

"There's a patient who had to wait for three days before getting the letter to travel to Mulago" Respondent form a District in Eastern Uganda.

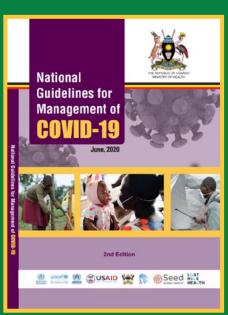
"Most patients got letters from RDC. As for Hospice Jinja we got permission from DHO for the two cars to help us reach to our patients "most are using boda-bodas which were okayed by the RDC as long as they have a permit to use that day from the RDC"

# Participation in COVID-19 Response at National and District levels

Staff at PCAU secretariate have been participating in particular meetings of COVID-19 Response at National level. These include meetings on the Case Management Pillar and its sub pillars: Mental Health and Psychosocial Support (MHPSS) and on Infection Prevention and Control (IPC). PCAU also participated in development of the National Guidelines for Management of COVID-19; and the Republic of Uganda Ministry of Health National Guidelines for Management of COVID-19. Further, PCAU participated in discriminating COVID-19 information as packaged by the Ministry of Health to Member organizations and the communities through use of our well-established structures from national to member organization, to community and to family or household level. PCAU has a strong social media presence and active mailing lists that have a also been used in disseminating information on COVID-19. Many PCAU members in Districts are the front line of COVID-19 response as part of the teams offering clinical care to persons with COVID-19 and psychosocial support to people in isolation, in guarantine and those discharged to go back to communities. PCAU Secretariat has maintained contact with Members at the front line to offer the much need information, support, counsel and solidarity.









## Work on the Continuity of Palliative Care Amidst Covid-19 Pandemic

When the committee on the Continuity of Essential Services was formed at Ministry of Health, PCAU led the development of the Guidelines on Continuity of **Palliative Care Services Delivery in the Context of** COVID-19 Pandemic. PCAU has appealed and made a stand that palliative care services need to be available and accessible to patients and families in need even as the country responds to the pandemic. The guidelines on the continuity of palliative care as an essential service are intended: to ensure that patients, their families and palliative care teams continue to engagement in a safe manner, to ensure that patients and their families continue to receive high quality palliative care, to ensure continued access to essential palliative care supplies and appliances including pain relief medicine, to build resilience and prevent burn out among the palliative care providers and to foster palliative care linkages in the healthcare system. The work of appealing to the government to ensure more investment and prioritizing the continuity of palliative care is going.

Through a consultative process, PCAU coordinated the development of **Standard Operating Procedures** (SOPs) for Hospices and Palliative Care Teams at Hospices and Palliative Care During COVID-19 Pandemic. The process of developing the SOPs entailed input by members of the National COVID-19 Case Management Pillar and sub Pillar of IPC.A total of 9 SOPs derived from the National COVID-19 Management



Guidelines were published. These are SOPs on: 1) General operations for Hospices and Palliative care organizations. 2) Screening area at the entrance of hospices and palliative care organizations. 3) Triage and OutPatient Care. 4) Delivering Home Care Services. 5) Delivering palliative care during community outreach. 6) Delivery of Medicines to patients' homes from Hospices and Palliative care organizations. 7) Delivery of Palliative care in Hospitals. 8) Transport for teams for home-based care and community outreach. 9) Environmental Disinfection and Cleaning. An orientation meeting on the SOPs was held with representatives from PCAU Member Organizations in Kampala before these were discriminated.

The National Guidelines for Management of COVID-19 and SOPs require the establishment of a screening area near the entrance of each health facility and this includes hospices. The guidelines also require all staff to undergo temperature and symptom screening on entry to and exit from work each day. These screenings should be logged in a paper log, to be checked by the Ministry of Health surveillance officer / symptom monitor who visits the isolation facility. This is very important to ensure the safety of all people who access hospices. However, not all hospices are ready with resources to set up these facilities. This is pausing a great challenge to access of palliative care services. PCAU is appealing for financial resources to support specific hospices to set up these facilities.



### Small Grants to PCAU Member Organizations

In April 2020, PCAU offered small grants to Hospices to support continuity of palliative care as an essential service under three broad areas of: 1) Purchase of Personal Protective Equipment (PPE) for teams offering care. 2) Support to connectivity and communication and 3) support to offer relief items and food to the most vulnerable patients and families during the lockdown. A total of \$10,000 was disbursed to support these interventions and the coordination of role of PCAU. This funding was a contribution to hospices as they endeavored to reach to patients and families during the lockdown. All hospices that received the small grants attested to the contribution as valuable. Some hospices were able to reach most of the enrolled patients due to financial resources from donors and contribution from PCAU. The funds support from PCAU were utilized by hospices to contribute to the following s: PPE for staff and volunteer, transporting teams to carry out home visits, transporting teams to work, motorcycle taxi/bodaboda fees to deliver essential medicines to patients at home, handwashing facilities/equipment and sanitizers, nutrition support for patients, telecommunications and internet, essential medicines and other medical supplies.

## Impact on utilizing small grants from PCAU

"Even with the restrictions on movements, we reached 584, 570 patients in April and May respectively. We had 594 and 616 in, Feb and March respectively. We are grateful to PCAU who during the early days of the restrictions supported us with some funding towards fuel, food for patients, communication and PPE.

"The advent of the pandemic saw a raise in prices for some medical supplies. Our budget was constrained. With funds contribution from PCAU, our attention quickly turned to PPE for staff in addition to the infrared thermometer, these were important needs to address at that time"

"The main challenge for our patients was access to care and follow up during the lockdown period as a result of the ban on both public and private transport. We therefore supported some of them to meet the costs of hiring a vehicle or motorcycle to get them to hospital for treatment"

Makerere Palliative Care Unit

"We referred and offered transport support to 10 children from communities to Mbarara Regional Referral Hospital for Cancer Treatment during the lockdown These children beriod. would otherwise remain in villages."

Kitagata Hospital

Joy Hospice Mbale

### **Kitagata Hospital**



Photo by: Nurse at Kitagata Hospital: Working with oriented boda boda rider to reach patients with supplies

#### **Kitovu Mobile**



Photos: by Kitovu Mobile Staff Hand washing equipment at facility entrance and reaching out to clients





**Rays of Hope Hospice Jinja** 

Photo by: Rays of Hope Hospice Jinja

Staff conducting a home vist.

## Trainings on Infection Prevention and Control (IPC) and Mental Health and Psychosocial Support (MHPSS) for Staff and Volunteers in hospices

PCAU working with the Ministry of Health (MOH) held a two-day Infection Prevention and Control (IPC) and Mental Health and Psychosocial Support (MHPSS) sensitization for palliative care workers in Kampala. The event held on 7<sup>th</sup> - 8<sup>th</sup> September 2020 was attended by 29 representatives from hospices across the country. They included Doctors, Clinical officers, Nurses and Social workers. The group forms a team of contacts who will introduce IPC and MHPSS guidelines and respective places of work. This will be followed up by training for the entire staff and volunteers at each of the hospices spearheaded by PCAU and the Ministry of Health. The aim of these trainings are: sharing updates on SOPs for IPC in response to COVID -19, equipping hospices with IPC Knowledge and skills and discussing MHPSS approaches during COVID - 19. With the increasing community transmission of COVID-19 in Uganda, the response to the pandemic is shifting to the community and household level. Hospices, just like other lower health facilities in Uganda have the responsibility of leading community and home-based responses because they are right there all the time. This empowerment is also intended to ensure safety for staff and volunteers in hospices across the country.

Uganda is at a critical stage in the COVID-19 response/control effort. The increasing community

cases also expose more health workers to the risk of contracting the coronavirus. This, in addition to long working hours, psychological distress, fatigue, occupational burnout, stigma, and physical and psychological violence that all need to be addressed by MHPSS. PCAU is appealing for more financial support to ensure more MHPSS approaches for hospices to be ready to respond better.

# Access to Controlled Medicines for Pain Relief

PCAU plays a central role in supporting the supply chain of palliative care essential medicines in Uganda. This includes supporting the supply chain for Oral Liquid Morphine. This is mainly done through hosting bi monthly meetings of the Morphine Partners meetings, receiving and addressing or referring and complaints about access from hospitals and public and supporting data and reporting requirements. Between the period March to September 2020, three meetings of the Morphine Partners Meetings were held. These important meetings are attended by PCAU, Ministry of Health, National Medical Stores, National Drug Authority, Hospice Africa Uganda, Joint Medical Stores and some of the largest facility consumers of morphine - Mulago National Referral Hospital and Uganda Cancer institute. Leaders and pharmacists from these facilities attend these meetings which have contributed to the success of Uganda's story of access to this important medicine for palliative care. Uganda has had stable supply of oral liquid morphine even a medicine that is available for patients in need free of charge during

the pandemic. There have been instances of lack of access especially due to challenges in transport for patients and caregivers for medicine refills. PCAU has appealed for telemedicine approaches, home delivery of medicines by palliative care teams, training of more community volunteers to support and more training of registered and well-known motorcycle taxi/boda-boda volunteers to support patients. This is an area under the appeals section by PCAU for partners and donor support to relieve the pain and suffering among patients and their families.









IPC Training for representatives from Hospices in Uganda.Training participants holding SOPs on continuity of Palliative Care as an essential service

PCAU Photos: Ministry of Health, Ant narcotics Police Officers, PCAU and other stakeholders after a meeting on access to controlled medicine. PCAU staff visiting the Palliative Care Unit at Uganda Police Health Facility. Palliative Care Nurses at Lira Regional Referral Hospital meeting a patient at the hospital.

PCAU photos.

# Information Dissemination and Webinars

In March 2020, PCAU initiated weekly Zoom meetings for the Palliative Care fraternity. The events which later in May turned into bi-weekly webinars were intended to offer avenues for sharing information updates, continuous medical education, and share ideas on how to overcome any challenges during the period of the lockdown due to COVID-19 Pandemic. A total of 11 meetings were held on topical issues, with an average 55 participants each meeting, and some of them were live streaming live. These discussions have been very helpful. They are well attended by an average of 55 participants from across the country, including the media. Topics covered include: Psychosocial support for people affected by COVID -19; Cancer Services in Uganda during COVID-19 response; Palliative Care in Uganda since 1993: who has been at the forefront, Right to Palliative Care during COVID-19; Palliative care in Universal Health Coverage (UHC) in Uganda; Improving access to palliative care for older persons in Uganda. Other topics t can be accessed on our website https://pcauganda.org/ The sessions were well attended by leaders and facilitators including key policy makers and leaders of key COVID-19 National Task Force. These successful engagements had great impact in creating harmonized flow of information to and feedback from PCAU Members and stakeholders in the palliative care fraternity. The engagements offered learning and capacity building opportunities to PCAU members and enforced the coordination role of the association.

# Supporting Families on the Road to Hope Program

The impact of this pandemic on the social economic wellbeing of individuals, families and communities has been grave across countries. The pandemic has disproportionately hurt those who are already indigent and yet living with a life-threatening illness. PCAU runs a unique program of supporting children who are the primary caregivers to their sick parents or guardians to attain an education. These children are the sole breadwinners for their households in almost all cases. Currently, the program supports 57 children in 46 families spread across regions of Uganda in over 20 districts. These children are categorized as the most vulnerable among the Orphans and Vulnerable Children (OVC) in Uganda. With the COVID-19 imposed lockdown on schools, children are home; some with guardians and others on their own. In addition to lacking basic needs, the uncertainty of when schools will open again has had an emotional toll on the children. This is because some of them are obviously older than classes they attend. PCAU with support from partners has reached out to all the children with relief food and other basic support, home schooling support, psychosocial support, and health care. PCAU has provided home study materials and linked children to teachers within the same communities for off school continuous guidance and counselling.



Screen shots of PCAU online meetings for Palliative Care fraternity discussions in Uganda.



### PCAU Photos: Reaching out to children who are primary caregivers to their sick parents or guardians and their families.

## Spotlight on Joy Hospice Mbale

On 23<sup>rd</sup> July 2020, when Uganda announced the country's first COVID 19 case it had happened at loy Hospice Mbale, a member of PCAU. This cast a spotlight on the center. The entire Staff at the hospice were immediately put under institutional guarantine. Two team members who had been in contact with the deceased tested positive of COVID-19 and were evacuated to the isolation facility of Mbale Regional Referral Hospital. The closure of the hospice was a blow to people served by Joy Hospice Mbale for some time. PCAU worked with stakeholders and support loy Hospice during this period. Staff under guarantine at the hospital facility required upkeep support because this had been abrupt. PCAU offered some financial support in addition to mobilising other actors. PCAU worked with the Ministry of Health to have a delegation to meet in Mbale and drew plans for continued access to palliative care in the region. With intervention of PCAU and the Ministry of Health and the support of the strong palliative care unit at Mbale Regional Referral Hospital, palliative care services continued in the region. After a period of guarantine, all staff tested negative. Those who had been under treatment were also cleared and discharged. The team has reconstituted after a period of occupational healing to return to work and the centre is now functional.



#### PCAU Phot:

Officials from Ministry of Health, Mbale District COVID-19 Task Force, Mbarara Regional Referral Hospital and PCAU Staff after a meeting on Joy Hospice Mbale in July 2020.

### Join us and contribute towards reaching our great vison of taking *Palliative Care to very one in need during this challenging period*

By all means, the pandemic has come along with negative impacts on access to palliative care especially the one of reduced financial resources for hospices. Hospices have reduced their operations especially community and home-based care (community outreach and home visits) yet these have been the most preferred mode of service provision. The future is uncertain in many ways. PCAU therefore appeals to partners, donors and friends to offer financial support. As the numbers of COVID-19 cases and death rise, the work of hospices is cut out because the people served are among the most at risk of severe disease and death when they contract the virus.

PCAU has a great vision and mission. We can only be able to attain our vision when we strengthen our current partnerships but also expand them to add more. We are therefore open to new partners.

During this time, we are seeking partners to contribute to our mandate of supporting standalone hospices to continue offering care to many patients and families in remote areas of Uganda amidst COVID-19 Pandemic. The 13 hospices in country have more than 10,000 patients enrolled on their programs. These hospices offer home care services which are critical during this time. Our mandate also involves reaching these hospices and 145 districts in Uganda to offer training, mentorship and support supervision. This requires us to have a strong running vehicle since some of the districts are located in very hard to reach areas with poor road network.

All donations to PCAU can be made through the organizations bank account: Account Number: 8708213487400 Account Name: Palliative Care Association of Uganda Bank: STANDARD CHARTERED BANK UGANDA LIMITED Swift Address/Code: SCBLUGKA Funds can also be received through NTN Mobile Money Platform on Telephone: +256 789 737 786 Or through MTN MOMO Pay



Partners can be part of our work by supporting us to meet costs of one or more hospices under the following cost centers:

Average		Description
cost USD	Item	
\$3	Cloth Mask for a Patient and Caregiver	Protection for patients and caregivers
\$356	Essential PPE for Team at Hospice for a week	Medical masks, sanitizer, face shield, Gloves, Aprons Disposable gowns, Masks and boots
\$150	support palliative care team to report to duty per week at a hospice	Fuel to pick and drop the clinicians
\$10	Support Motorcycle Taxi (boda boda) to deliver Medicine to a Patient at home once	Fee, fuel & telephone airtime for communication
\$42	One-week telecommunication costs following up on patients and families by palliative care team	Airtime and data to ensure communication among clinicians and hospices happens
\$156	Food relief to a vulnerable householdof 8 people for a month	2 modest meals per day for families that are not able to afford
\$250	Setting up a separate screening and triage space at hospice entrance	Small Tent, infrared thermometer, sanitizer, masks, Stationary, PPE, chairs, table
\$83	Offer Nutritional Support to a patient in need for a Month	A modest nutrition meal plan to enable drug adherence and healthy living
\$300	Support a Palliative Doctor to work for a hospice for a week	Basic pay for service
\$150	Support a Palliative Care Nurse to work with a hospice for a week	Basic pay for service
\$25	One Uniform ware for member of team reviewing patients at hospices for infection control	Medical ware for the clinical team attending to patients
\$194	Support to community volunteers to continue reaching out to patients and their families to offer basic palliative care and linkages	Two bicycles for each hospice to support movement of community volunteers from one patient to another in the community.
\$1250	Support supervision to other community volunteers as well as support patient access to care and delivery of medicines	I motorcycle for each hospice to support the lead community volunteer
\$150	Support transport for a patient and caregiver from upcountry for Cancer treatment at Uganda Cancer Institute in Kampala	Bus fare and other basic necessities for travel
\$600	Support one infection prevention and control training for 15 community volunteers at a hospice	Cover for demonstration PPE, facilitators travel, stationery and other training needs.
\$1000	Mentorship and Support supervision visit on infection prevention and control to one hospice upcountry	Cost of travel and other necessities for team of specialists.

PCAU has a great need of an organizational vehicle. PCAU's main and only reliable vehicle was purchased in 2010 and is now prone to numerous mechanical breakdowns and pauses a high cost of maintenance. The mandate of PCAU entails supporting over 200 established palliative are teams in both public and private health facilities across the counter. This necessitates reliable transport for specialists to conduct training, mentorship and support supervision. PCAU is seeking for at least \$ 85,000 to purchase a new vehicle and therefore appeals for financial support from partners and friends.



### **CONTACT US**

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