

## **ANNUAL REPORT 2020**

The Goal of PCAU is to increase access to culturally appropriate palliative care through strengthening health care systems in Uganda in collaboration with partners.

## The 3<sup>rd</sup> Uganda Conference On Cancer and Palliative Care

## Cancer and Palliative Care in Covid-19 and Other Challenging Situations

Hosted by
The Uganda Cancer Institute (UCI) and
The Palliative Care Association of Uganda (PCAU)

23<sup>rd</sup> - 24<sup>th</sup> September 2021 Kampala Serena Hotel and Online









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    - www.conference.uci.or.ug



PALLIATIVE CARE ASSOCIATION OF UGANDA (PCAU)

**ANNUAL REPORT 2020** 

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#### **OUR VISION**

Palliative Care for all in need in Uganda



#### **Our Mission of PCAU**

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

#### **REGISTER AS A PCAU MEMBER**

PCAU is Com posed of 24 Member Organizations and 1200 Individuals. You too can join PCAU. Our Membership is open to Senior Professionals, Junior Professionals, Community Based Health Workers, Community Health caregivers, volunteers and leaders at all levels.

	Membership Category	Subscription (UGX)
1	Individual Member	20,000
2	District Palliative Care Initiative/ Community Based Organization (CBO)	500,000
3	Life Member	1,000,000
4	Institutional Members/Non- Governmental Organization/ Hospital	1,000,000

#### **REACH US ON**

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#### **Brief information about PCAU**

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



#### **OUR CORE VALUES**

**Service Provider Focus:** We are committed to the development and empowerment of Palliative Care providers to their highest professional potential. Service providers are the principle target of PCAU work.

**Collaboration and Networking:** We seek to use the limited resources to maximum advantage through partnerships and collaborations, pursuing networks and harnessing the potential of all our partners and members for the common good.

**Integrity:** We carry out our duties in a responsible, honest and accountable manner to all stakeholders including donor, government, members as well as patients and families.

**Volunteerism:** We recognize the support and commitment of volunteers as an essential element in scaling-up of Palliative Care work and empowering service providers.

**Professionalism:** We strictly observe the highest ethical and professional standards in providing training, mentorship, supervision and support.

#### The Key Focus areas of PCAU





## **The Board of Direcetors**



	Name	Designation on the Board
1.	Dr. Henry Ddungu	PCAU President and Board Chairperson
2.	Mr. John Muwonge	Vice Chairperson
3.	Mrs. Dorah Kiconco Musinguzi	Board Secretary
4.	Mrs. Josephin Kampi Tatyabala	Board Treasurer
5.	Dr. Ekiria Kikule	Boad Member
6.	Dr. Andrew Ocero	Board Member
7.	Hajjati Dr. Safinah Musene	Board Member
8.	Hajjati Mwazi Batuli	Board Member
9.	Mr. Gerever Niwagaba	Board Member

## **PCAU Staff Members**



#### **2020 PCAU Secretariat Team**

	Name	Designation	
1	Mark Donald Mwesiga	Country Director	
2	Joyce Zalwango	Ag. Programs Manager	
3	Ritah Nannyomo	Finance Officer	
4	Lisa Christine Irumba	Research & Advocacy Officer	
5	Cynthia Kabagambe	ICT and Data Quality Officer	
6	Lydia Nakawuki	Program Officer Road to Hope	
7	Zaitun Nalukwago	Communications Officer	
8	Zipporah Kyomuhangi	Administrative Assistant	
9	Doreen Nalwada	Accounts Assistant	
10	Stephen Kasula	Program Assistant Road to Hope	
11	Margaret Kabajungu	General Assistant	
12	Jaffa Mohamed	Driver	
13	Ismail Kyagulanyi	Security Officer	
14	Tom Echodu	Security Officer	
15	Ronald Kanyike	Volunteer Driver	
Staff	Staff Supported by PCAU at New Life Hospice Arua		
1	Lucy Agaboru	Palliative Care Nurse	
2	Ejoii Stanley	Administrator	

## **Message from the Board Chairperson and Country Director**

#### **Dear PCAU Members and Friends,**

Greetings to you all.

Thank you for your continuous support to PCAU. Welcome to the PCAU Annual Report 2020.

Due to the COVID-19 Pandemic, we had to reorient our governance practice and the delivery of our activities during 2020. This report gives highlights of the work. A separate detailed report on COVID-19 interventions was issued in December last year. The online version of the report can be downloaded from our website (https://pcauganda.org/).

Amidst the pandemic, the team at the secretariat advocated for and supported the continuity of palliative care as an essential healthcare service. The team mobilized and extended some financial support to hospices in the country.

The achievements realized last year were possible due to the full support of the PCAU governance structures. Amidst the lockdown, PCAU Members convened for the AGM online. All scheduled Board meetings for the year were held with high attendance.

At this year's AGM, we shall select 4 new people to join the Board. The selected will join 5 who are on the current Board to form a new Board. The outgoing Board has done a tremendous job over the past 3 years. According to the PCAU Constitution, one can only serve on the Board for up to six consecutive years. The outgoing Board Members are Mrs. Dorah Kiconco Musinguzi, Dr. Ekiria Kikule, Dr. Andrew Alyao Ocero, and Dr. Hajjati Safinah Musene. They all deserve our appreciation and recognition for their great contribution to the growth of PCAU.

We thank the PCAU partners and donors. They are: Open Society Foundation (OSF), Open Society Initiative for East Africa (OSIEA), Centre for Hospice Care (CHC), American Cancer Society (ACS), Global Partners in Care (GPiC), African Palliative Care Association (APCA) the World Hospice and Palliative Care Alliance (WHPCA) and Hannah & Joseph Gonzalez.

We also thank all of you who have decided to subscribe as Life Members of PCAU too. The resources generated through life membership subscriptions will be utilized to strengthen PCAU sustainability initiatives.

Dr. Henry Ddungu

PCAU President and Board Chair



Mark Donald Mwesga
Country Director PCAU



## **Capacity Building**

By the end of 2020, a total of 107 Districts in Uganda had at least one health facility accredited to offer palliative care. A total of 39 districts had no accredited health facility offering palliative care. Our work has been central in reaching the Districts to initiate provision of palliative care in our country. Everything we do under the focus area of capacity building is aimed at supporting comprehensive integration of palliative care services in every district of Uganda. The 4 pillars of our capacity building initiatives are: focused training, mentorship, support supervision and scholarships for palliative care education and training.

### Scholarships for Palliative Care Education and Training

Since 2010, PCAU has been offering scholarships to health workers to advance training in palliative care. In 2020 PCAU offered a total of 13 full scholarships to students to undertake the Advanced Diploma in Palliative Care Nursing (ADPCN) at Mulago School of Nursing and Midwifery.

#### Our 2020 accomplishments on capacity building:

Activity	Participants/ beneficiaries
Offered Scholarships for Advanced Diploma in Palliative Care Nursing (ADPCN) and Diploma in Clinical Palliative Care.	23
Accomplished implementation of Pain Free Hospital Initiative (PFHI)	3 (hospitals)
5 Days Course palliative care training for health workers in private hospitals in Kampala.	19
Held 4 National Palliative Care Update Meetings for Continuous Medical Education (CMEs)	333
Conducted Mentorship and support supervision to hospitals in Districts	40 (hospitals)
Conducted training on Infection Prevention and Control (IPC)	300
Developed and Disseminated SOPs for continuity of palliative care amidst COVID-19 Pandemic.	100 (copies)
Developed Module on Continuity of PC as an essential service amidst COVID-19 Pandemic	



Pioneer class of the Advanced Diploma in Palliative Care Nursing with Rose Kiwanuka the Former Country Director of PCAU.

## Targeted Short Course for Health Workers in private hospitals

In February 2020 PCAU held targeted short course training for health workers from private health facilities in Kampala and Wakiso Districts. The course was attended by a total of 19 professionals from the following targeted hospitals: International Hospital Kampala (IHK), Lubaga Hospital, Mengo Hospital, St Francis Hospital Nsambya, Kibuli Hospital, Case Hospital and Our Lady of Consolata Kisubi Hospital.



Short course participants celebrating with their certificates upon completion in February 2020.



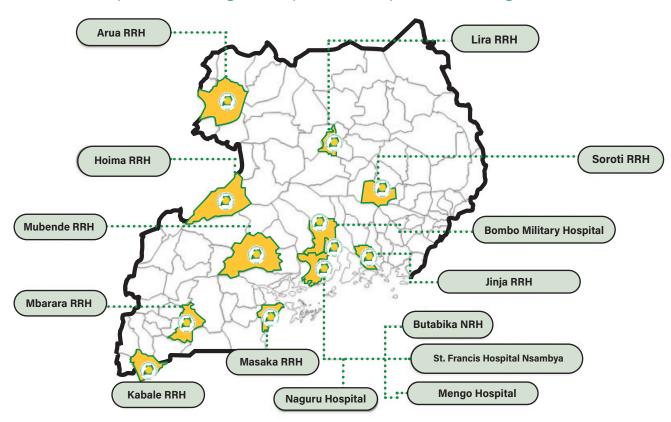


#### The pain Free Hospital Initiative

Over all, PCAU has supported 14 hospitals across the country to implement the Pain Free Hospital Initiative (PFHI). These include; 9 Regional Referrals Hospitals, 2 National Referral Hospitals, 2 major private non-for-profit hospitals and the Military Referral Hospital in Uganda. In these hospitals, over 3,532 health workers were equipped with knowledge on pain management. In 2020, we implemented the PFHI project in 3 hospitals in Kampala: Mengo Hospital, St Francis Hospital Nsambya and China-Uganda Friendship Hospital Naguru.

The PFHI is a one-year hospital-wide quality improvement initiative to integrate pain treatment into service delivery by providing education for hospital staff, raising motivation and awareness, measuring and documenting pain levels, and improving medicine supply.

### Map Showing Hospitals Implementing PFHI



Map showing the location of hospitals which have been supported to implement the PFHI in Uganda



#### **National and Branch Update Meetings for Continuous Medical Education**



## **National Update Meeting**

THEME: Community Engagement Strategy for COVID-19

27th November 2020



**Dr. David Okello**Director Health Systems Program
The African Centre for Global
Health and Social Transformation



Dr. George Upenytho
Commissioner Community Health
- Ministry of Health
Panelist



Richard Tumwesigye
Senior Hospital Administrator
- Uganda Cancer Institute.

Moderator



Dial \*165\*3# Inter Merchant Code 315849

Panelist

REGISTRATION LINK: https://zoom.us/meeting/register/tJctcuiprjlpH92EHmzhV8kFtKSMGn2mJmY9

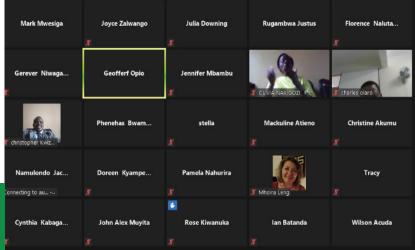






Our quarterly **update meetings for the year 2020**were mostly held **online due to the COVID-19 Pandemic.**Only 1 (in February) of the 4
national update meetings was attended physically at PCAU secretariat. Physical meetings at all 10 PCAU branches were also affected. Given this effect of the Pandemic on public gatherings, we decided to conduct more national online sessions.





Screen shots of PCAU Online update meetings



PCAU National Update Meetings & Webinars: Topics	Facilitators
Palliative Care In HIV/AIDS Care And Treatment In Uganda.	<ul><li>Mildmay Uganda</li><li>Rays of Hope Hospice Jinja</li><li>TASO Uganda</li></ul>
Strategies For Continuity Of Palliative Care As An Essential Service Amidst A Lock Down.	<ul> <li>Mark Donald Mwesiga, Country Director PCAU</li> <li>Dr. Jackson Amone, Commissioner Clinical Services Ministry of Health</li> </ul>
Psychosocial Support For People Affected By COVID 19 Pandemic.	<ul> <li>Dr. Hafsa Lukwata, Head of committee on psycho-social support &amp; mental health on the COVID-19 National task force.</li> <li>Dr. Laban Kashaija Musinguzi, lecturer Makerere University, Department of Social Work and Social Administration.</li> <li>Fatia Kiyange, Deputy Executive Director, Centre for Health Human Rights and Development</li> </ul>
Cancer Service Amidst COVID-19 In Uganda	<ul> <li>Dr. Jackson Orem Executive Director Uganda Cancer Institute.</li> <li>Dr. Sammuel Guma Executive Director Kawempe Home care.</li> <li>Ms. Antonia Kamatte, Health services coordinator Mbarara Hospice.</li> </ul>
Palliative Care Providers At The Frontline	<ul> <li>Dr. Anne Merriman – Founder, Hospice Africa Uganda.</li> <li>Dr. Henry Ddungu, Board President, PCAU</li> <li>Rose Kiwanuka, Founding Country Director, PCAU</li> <li>Mark Mwesiga, Country Director, PCAU</li> </ul>
The Right To Palliative Care In Uganda During COVID 19 Pandemic	<ul> <li>Dr. Charles Olaro - Director Clinical Health Services - MOH</li> <li>Geoffrey Opio Atim - Program Officer, Health and Rights Program, Open Society Initiative for Eastern Africa.</li> <li>Justus Rugambwa - Executive Director, Kitovu Mobile.</li> <li>Florence Nalutaya - Palliative Care Nurse - Makerere Palliative Care Unit</li> </ul>
Improving Access To Palliative Care For The Older Persons In Uganda.	<ul> <li>Katherine Pettus, PhD - Advocacy Officer for Palliative Care IAHPC.</li> <li>Emily Ajiambo, Ag. Commissioner Disability and Elderly Ministry of Gender Labour and Social Development</li> <li>Rosemary Bongole Nakasinde, Focal Person for Older Persons Health - Ministry of Health and Member National Council for the Older Persons</li> </ul>
Research In Palliative Care	<ul> <li>Eve Namisango - APCA</li> <li>Dr Edward Mukooza - UCU</li> <li>Dr Ekiria Kikule - UCU</li> </ul>
Community Engagement Strategy For COVID 19.	<ul> <li>Dr. David Okello – Head of Non-communicable Diseases (NCDs) at ACHEST Uganda</li> <li>Mr. Richard Tumwesigye- Senior Hospital Administrator Uganda Cancer Institute.</li> </ul>



We organised and held webinars on topical issues in relation to COVID-19 during the year to ensure continous information dissemination to PCAU members across the country.



#### **Mentorship and Support Supervision**

Our support supervision activity is geared towards empowering palliative care providers to offer quality services. The activity also aims at motivating continuity of service. In 2020, we interacted with over 90 health workers in 40 hospitals where we held physical visits. Due to COVID-19, we also engaged palliative care providers virtually through zoom meetings, WhatsApp chats, telephones and email. **Key highlight on findings by Support Supervision team:** 

- Palliative care trained professionals in Local Government Settings are often transferred to different facilities, some without palliative care units.
- The Palliative care trained professionals in health facilities without designed palliative care units are assigned other roles.
- Most Public health facilities without designated palliative care units do not stock morphine.
- Hospices have reduced and some stopped providing home care services due to the COVID-19 Pandemic.









## STANDARD OPERATING PROCEDURES (SOPs) FOR TEAMS AT HOSPICES AND PALLIATIVE CARE ORGANIZATIONS DURING COVID-19 PANDEMIC

#### **SEPTEMBER 2020**



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Ministry of Health COVID-19 Helplines 0800203033 and 0800100066







STANDARD OPERATING PROCEDURES (SOPs) FOR TEAMS AT HOSPICES AND PALLIATIVE CARE ORGANIZATIONS DURING COVID-19 PANDEMIC



### GENERAL OPERATIONS FOR ALL HOSPICES AND PALLIATIVE CARE ORGANIZATIONS

All Hospices and Palliative Care organizations should:

- Maintain operations to ensure the continuity of palliative care service delivery.
- Create and maintain a screening area manned by appropriate staff near the entrance of the facility.
- Conduct training for all staff and volunteers on Infection, Prevention and Control (IPC) and to have a designated IPC Staff on duty at all times.
- Ensure that routine screening triage of all Health Care Workers (HCWs) and volunteers attached to the facility is done as stipulated in the National Guidelines on COVID-19. Check Annex 3.
- Use communication channels like telephones, social media platforms and toll-free lines where possible to continue assessing and providing appropriate guidance and support to patients and their families.
- Schedule patient appointments systematically to avoid over crowding .
- Ensure that HCWs, Volunteers, Patients, Care Givers and other persons in reach of the facility with symptoms of suspected COVID-19 are put at the facility isolation as the designated IPC staff contacts the District Task force/Ministry of Health.

We worked with the Ministry of Health to develop, disseminate and build the capacity of staff in hospices to implement COVID-19 SOPs. We also worked with the Ministry of Health and other stakeholders to conduct sessions on Infection Prevention and Control (IPC) for staff working in Hospice and Palliative care organizations across the country.



## **Advocacy for Palliative Care in Uganda**

All our work on advocacy is aimed at increasing the understanding of palliative care among stakeholders and creating a supportive environment for the providers and the services.



PCAU Country Director presenting to the Parliamentary Committee on Health in February 2020 on the matter of the National Health Insurance Scheme.

#### National Health Insurance Scheme Bill

February 2020. we appeared before the Parliamentary Committee on Health at Parliament of Uganda. We made a submission on the Health Insurance National Scheme Bill. We appealed for inclusion of cancer and palliative care services among services to be covered by the scheme.

#### **Empowering persons with Palliative Care lived experiences to be advocates**



We worked with selected member organizations to identify and empower persons with lived palliative care experiences to become advocates. The focus of these advocates who operate at District and local community levels is to voice out palliative care as a key component of Universal Health Coverage (UHC). They include; patients, caregivers and health workers. They are linked to 3 organizations: Kitovu Mobile, Hospice Africa Uganda (HAU) and Rays of Hope Hospice jinja (RHHJ).



PCAU supported one of the empowered patient advocates linked to Kitovu Mobile to conduct a day's advocacy workshop for leaders of Kabonera Sub County in Masaka District. The activity was done as part of the PCAU's overarching work on strategic advocacy for Palliative Care in Universal Health Coverage Processes in Uganda.



## The National Palliative Care Children's Essay Contest 2020

We received 40 entries from children in primary schools on a question about what the government and community should do to address the needs of adults and children living with life-limiting illnesses. Children gave us great advocacy messages. We handed in the best essays to the Ministry of Health as part of the advocacy work.

Ambrose Kazibwe of Makd Nursery, Daycare & Primary School (in yellow T-shirt) receiving his certificate for the best palliative care essay of the year.



#### **Commemorating the World Hospice and Palliative Care Day 2020**

Amidst the COVID-19 Pandemic we joined the rest of the world to commemorate the World Hospice and Palliative Care Day (WHPCD) 2020 on Saturday 10th October 2020. The theme of the day was **Palliative Care: it's "My Care, My Comfort."** 



Panelists at the World Hospice and Palliative care day from left is Dr. Emmanuel Luyirika, Dr Amone Jackson Commissioner for Clinical services MoH, Martha Rabwoni a palliative care nurse, Dr. Henry Ddungu, Kiconco Imeda a care taker of a patient with cancer.



Dr. Charles Olaro, Director Health Services-Office of the Director of Curative Services represented the Minister of Health as Chief Guest at the WHPCD high level discussion on October 10th 2020.

#### Strengthening supply chain for controlled medicines for pain control in Uganda

One of the key advocacy activities for PCAU focuses on strengthening the supply chain of essential medicines for palliative care and pain relief. PCAU coordinates meetings of the Morphine partners in Uganda. The partners who meet bimonthly focus on the continuous availability and access to oral liquid morphine for patients in need. In 2020, amidst the COVID-19 Pandemic, oral liquid morphine was available in the country with no major stock out reported in national hospitals, regional hospitals or hospices.

The Morphine Partners Meetings in Uganda are

attended by designated officers from the following key institutions:

- Ministry of Health (MoH).
- National Medical Stores (NMS).
- Joint Medical Stores (JMS).
- Hospice Africa Uganda (HAU).
- National Drug Authority (NDA)
- Three National Referral Hospitals (Kawempe, Kiruddu and Mulago which represent the larger consumers of the medicine.
- Uganda Cancer Institute (UCI)
- Palliative care Association of Uganda (PCAU).



Dr. Meg O'Brien (front row in the middle) the Vice President, Global Cancer Treatment at the American Cancer Society (ACS) with other ACS staff in photo with Ministry of Health Officials and PCAU staff in January 2020. Others in the photo front raw from right are Rinty Kintu the ACS National Coordinator for Uganda, Dr. Neville Oteba, Commissioner Pharmaceuticals at Ministry of Health, Dr. Fred Sebisubi, Assistant Commissioner and Mark Mwesiga.

#### Working with different stakeholders to mitigate serious restrictions on access to controlled pain medicine.

Following the passing of the Narcotic Drugs & Psychotropic Substance (control) Act, 2016, PCAU has been engaging various stakeholders who are concerned with the enforcement and implementation of the Act. The engagements are purposed on the principle of "balance" which represents the dual obligation of governments to establish a system of control that ensures the adequate availability of controlled substances for medical and scientific purposes while simultaneously preventing their nonmedical use, diversion, and trafficking, two primary goals of the international control system.



Uganda Morphine Partners meeting at fairway hotel chaired by Dr. Neville Oteba Commissioner Pharmaceuticals at Ministry of Health in December 2020.



Participants who attended a meeting on the Regulations for the Narcotic Drugs & Psychotropic Substance (control) Act, 2016 Held at Palliative Care Association of Uganda (PCAU) on August 2020. Participants at such meetings represent institutions including: Ant Narcotics Department of the Uganda Police Force, Ministry of Health, Uganda Harm Reduction Network, Human Rights Awareness and Promotion Forum - Uganda (HRAPF) and PCAU.



#### **Care to Child Care Givers**

Activity/Item Description	Children supported in 2020 / numbers
Children supported in 2020	56
Children –attended Road to Hope Camp 2020	52
Boys on the program	29
Girls on the program	27
In Primary Schools	33 in 17 Primary Schools
In secondary Schools	16 in 10 different schools
In vocational Schools	4 in 2 vocational schools
In apprenticeship training	2
In University	2
Total number of people in families reached with support	152 in 32 families
Children supported on homeschooling during COVID-19	40

On our Road to Hope Program, we supported 54 children and their families in 2020. This program supports children who are the sole caregivers to their sick parents or guardians. Current children on the program are from 19 districts of: Arua, Yumbe, Lira, Moyo, Luweero, Tororo, Mayuge, Butaleja, Buseesa, Kaliro, Jinja, Kamuli, Buikwe, Kibaale, Kakumiro, Kyankwanzi, Kikuube, Hoima and Kanungu.

The children supported by the program are among the most vulnerable in their communities. At the beginning of the year, we held the annual Road to Hope camp. Children came together for a weekend and held a series of activities. The camp was intended to address psychosocial needs among the children.



Children on the Road to Hope Program with Staff and volunteers during the Road to Hope Camp in Febuary 2020. The program offers educational, healthcare, basic needs, legal and psychosocial support to enrolled caregives.

The COVID-19 Pandemic and accompanying restrictions to control the spread of the virus has had huge impact on the livelihoods of the indigent like those supported by the Road to Hope Program. At the height of the Country's lockdown in 2020, almost all families on the Road to Hope required basic needs support including food relief. Schools were closed and children were at home trying hard to undertake caregiving roles of their deprived dying parents or guardians. PCAU intervened with basic relief support to children and their families.





#### Establishment of a Palliative Care Unit at the Uganda Police Force Main Health Facility

In parternship with the Management of the Uganda Police Medical Srvices, PCAU supported the establishment of a palliative care unit at Nsambya Police Health Center. In 2020, at least 150 patients were seen at the palliative care unit. These include community members in Nsambya where the unit is located. The unit has 6 disgnated staff.





## **Strengthening Data collection and** information on Palliative Care in Uganda

PCAU work on Research and Information is aimed at making PCAU a hub of palliative care research and information to inform decision making for improved services.

In 2020, PCAU sought to work in partnership with the Ministry of Health to strengthen national palliative care data collection and use. Our main activity was therefore to support the integration of palliative care data collection tools in the District Health Information System (DHIS2) and the Health Management Information System (HMIS).

Item	Brief detail	Numbers	Comments	
The Unit Palliative Care Register.	Developed, approved, coded as: HMIS OPD 008 Unit Palliative Care Register.	<b>120</b> copies of the register printed in September 2020.	Will be primary source of palliative care data for both public and private health facilities	
	Capacity Building for health workers and distribution of data tools to accredited health facilities	<b>32</b> copies of the Register distributed to 16 health care facilities in the 11 districts of Northern Uganda	Implementation slowed down due to COVID-19	
Health Unit Palliative Care Monthly Report.	Developed, approved coded as: HMIS 105C Health Unit Palliative Care Monthly Report.	<b>60</b> Copies of Report Books printed and <b>25</b> were distributed so far to the trained <b>16</b> health facilities in Northern Uganda.	Will contain monthly aggregated palliative care data.	
Workshops on Sensitization and Information dissemination on data collection	West Nile Region	19participants attended	Advocacy for district and hospital leadership support of palliative care data collection.	
tools for District Health Officers (DHOs), District Biostaticians and Hospital Directors	Lango and Acholi Sub regions Regions	9 participants attended		
Workshop on Training on data collection tools for palliative care focal persons and medical records	West Nile Region	18 participants attended	Key Regional Referral Hospitals and accredited facilities reached. Trained participants are	
Officers	Lango and Acholi Sub Regions	14 participants attended	palliative care data champions for a cascading effect.	
Districts reached with Palliative	West Nile	5 districts reached		
Care Tools	Lango and Acholi	6 districts reached		
Number of Health Facilities received	West Nile	9 health facilities received data collection tools		
palliative care data collection tools	Lango and Acholi	7 health facilities received data collection tools		

Brief statistics on trenthening Data Collection and Information on Palliative Care in Uganda





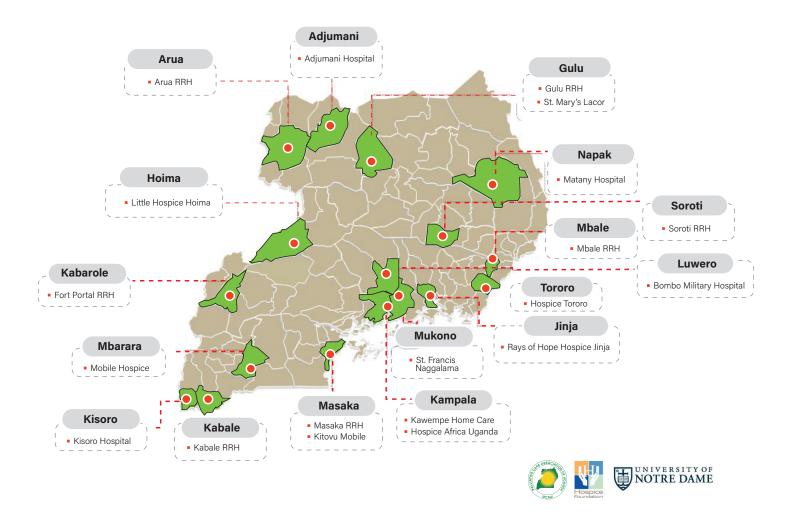
Some of the participants during the training on palliative care data collection tools.

With the coordination and administration from PCAU, the process of development of the palliative care tools involved several meetings with palliative care stakeholders including Minsitry of Health, African Palliative Care Association (APCA), Hospice Africa Uganda, Makerere Palliative Care Unit, Kawempe Home Care, Kiruddu National Referral Hospital, National Medical Stores (NMS), Joint Medical Store (JMS), China-Uganda Friendship Hospital Naguru, and other key palliative care stakeholders.

#### The PCAU mHealth Project

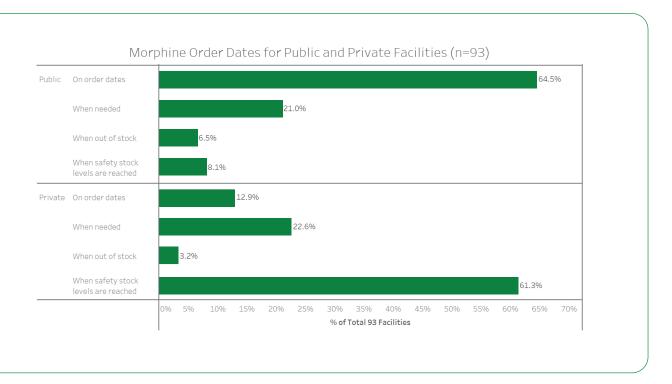
The work of strengthening data collection for palliative care in Uganda commenced when PCAU launched the Mobile Health (mHealth) data collection process in 2015. The pilot phase at 5 health facilities was successful and the project was scaled up to 10 health facilities. Currently the project is being implemented in 20 health facilities. Progressively, lessons from collecting aggregated data on palliative care services using mobile phones has improved. The evaluation reports of the project informed the development and integration of data collection tools into the DHIS2 and HMIS.

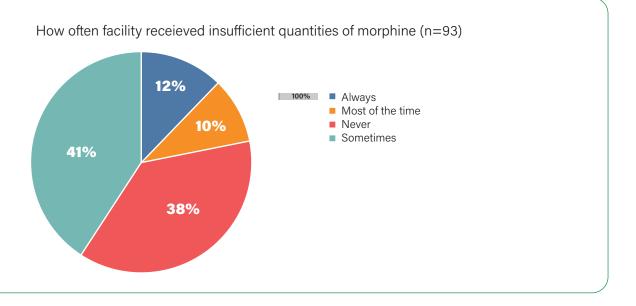
## Map of Uganda showing Location of PCAU mHealth implementing Health Facilities 2015-2020



## A survey on the availability of Oral Liquid Morphine at the accredited facilities in 2020 in Uganda

In 2020, we conducted a survey on the availability of oral liquid morphine at accredited health facilities in Uganda. The online survey tool was sent to at least 150 health facilities and 106 filled in submitted responses. The findings indicated that majority of the accredited facilities had adequate facilities for storage of Oral Liquid Morphine. The survey revealed that majority of the health facilities were ordering for oral liquid morphine on order dates (for public health facilities) and when safety stock levels were reached (for private facilities). The percentage of facilities submitting orders on experiencing stock outs was below 10% for both public and private facilities. Progressively, PCAU notes improvement in the morphine supply chain. Fewer accredited health facilities face stock outs. The survey showed that at least only 12% of the facilities that responded always received insufficient oral liquid morphine whenever they pressed orders. There is however accredited facilities that do not order for morphine and PCAU will seek to study this further in the next year.



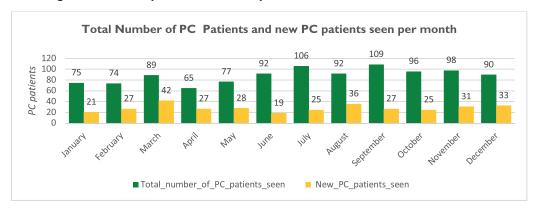




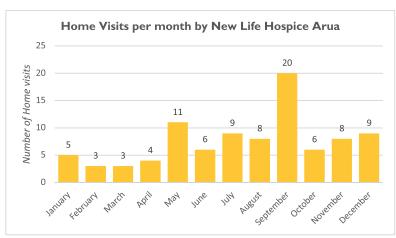
#### **New Life Hospice Arua**

PCAU supports the work and establishment of New Life Hospice in Arua (NELIHA). The Hospice which is ran as a satellite facility of PCAU operates within the premises of Arua Regional Referral Hospital on a well-established understanding. The hospice is therefore well supported by the Hospital Structures. PCAU maintains two staff at the facility: a Palliative Care Nurse and an Administrator. These are supported by other volunteers and designated hospital staff to run both the hospital palliative care unit and the hospice. PCAU has been supporting the palliative care unit to improve data collection to inform decision making since 2015.

At NELIHA There were a total of 1063 patients in need of palliative care seen in 2020. Of the total, an average of 23 New PC patients were seen per Month.



In 2020, NELIHA team conducted a total of 92 Home Visits with an average of 8 visits per month





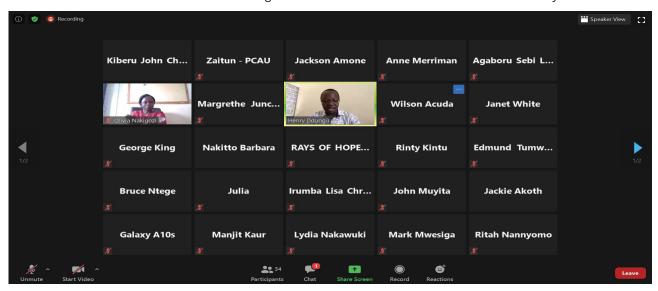
PCAU Country Director Handing over a computer to Dr Filbert Nyeko, the Hospital Director Arua Regional Referral Hospital. Others in the photo are staff of the hospital, volunteers working with New Life Hospice Arua and Dr Amandua Jacinto who is the patron of the hospice.

#### **Governance and Resources Mobilization**

Our activities on the focus area of Governance and Resources Mobilization are aimed at strengthening our governance structures and improving resources mobilization for the sustainability of palliative care services in Uganda.

#### **PCAU AGM 2020**

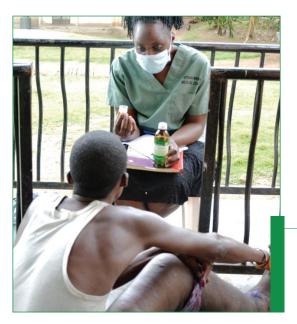
Due to COVID-19 Pandemic, we held our Annual General Meeting for the year 2020 online. The meeting was well attended by 64 Members from across the country. The Annual Report, Audited Books of Accounts for financial year were received and approved by members present. It is a PCAU Constitution mater to hold the Annual General Meeting in the first six months of the PCAU financial year.



#### **Small Grants to PCAU Member Organizations**

In April 2020, PCAU offered small grants to Hospices to support the continuity of palliative care as an essential service under three broad areas of:

- Purchase of Personal Protective Equipment (PPE) for teams offering care.
- Support to connectivity and communication.
- 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 8 hospice and palliative care organizations. 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 because of the financial resources from donors and contribution from PCAU.

Jackie Namulondo a Nurse at Kitovu Mobile during a home vist in Masaka. In addition to advocacy and capacity buiding work for the contiunity of palliative care amidst the COVID-19 Pandemic, PCAU also offered small grants to Member Organsiations like Kitovu Mobile.

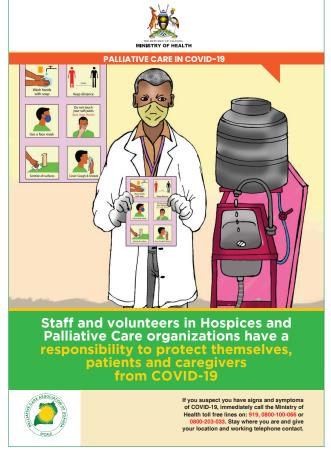


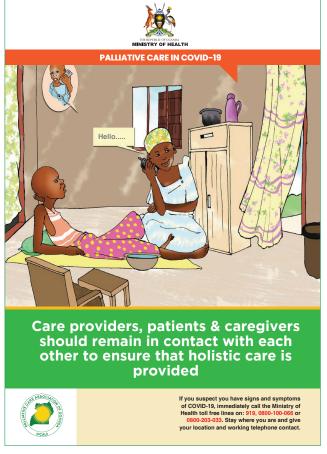
#### Look out for our detailed report on intervention in response to COVID-19

With the advent of the COVID-19 Pandemic, PCAU developed a strategy of interventions to benchmark the process of ensuring the continuity of palliative care as an essential service amidst the pandemic.



To access our detailed report on **PCAU Interventions in response to COVID-19 Pandemic** please visit our website or email us for a copy.





## **Partnership engagements**

#### The PCAU Annual Get Together and Prayer Breakfast Meeting 2020

Unlike in the past when we held the PCAU Dinner to mark our members annual get together, we held a virtual event in 2020. We worked together with the Inter Religious Cancil of Uganda (IRCU) to hold a virtual prayer breakfast. Led by spiritual laders of different religions in Uganda, we paryed together with members on line. We also initiated a fundraising drive for new PCAU vehicle at the same event.



Only a few of the partcipants met physically at fairway hotel for the annual getogether 2020. Other 60 members were on zoom while others followed the live broadcast on NTV Televsion.

Rev. Canon Dr. Rebecca Margret Nyegenye - Provost All Saints Cathedral Kampala Diocese, Msgr. Charles Kasibante - Vicar General Kampala Archdiocese, His Eminence Shk. Muhammad Ali Waswa - 2nd Deputy Mufti of Uganda Supreme Council and Bishop Herbert Buyondo - Bishop of Kampala Born Again Faith in Uganda, assisted by Rev. Diana Nkesiga - Associate Chaplain St. Francis Chapel Makerere and Founder Nkesiga Cancer Foundation let the event.



PCAU Staff participated in the 2020 Mildmay Uganda Saving Lives Marathon on March 1st 2020.



At the sidelines of World Cancer Day 2020 commemoration in Arua District in February 2020, the PCAU Country Director interacting with Dr Jacinto Amandua and the Executive Director of Uganda Cancer Institute (UCI) Dr Jackson Orem. The event was organized by the UCI and Uganda Cancer Society (UCS).





Margret a staff at PCAU interacting with community members at a health camp activity organized by Lweza Community Health Program in partnership with PCAU in February 2020



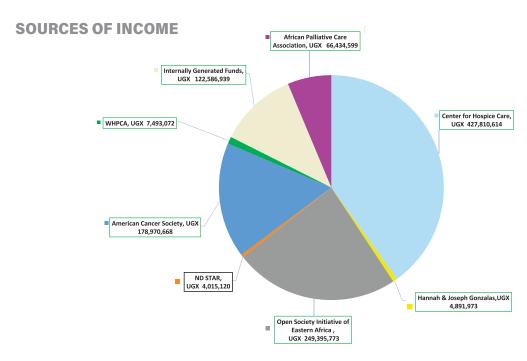
Mark handing over a cash contribution to staff of the New Hope Children's Hostel and initiative of Kawempe Home Care. The donation was made through PCAU as a contribution to meals for children with cancer under treatment at Uganda Cancer institute (UCI).



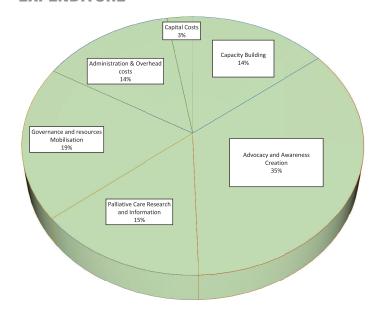
In partnership with Letshego Microfinance Uganda and Mengo Blood Bank and Lweza Community Health Program, we held a two days blood donation drive in Kajjansi town.



## Brief of the Finance report on Income and Expenditure the year 2020



#### **EXPENDITURE**



In 2020, we spent more financial resources on advocacy and awareness creation work. As reflected this report, we had great achievements on our advocacy work both the national and district levels. Majority of our work on advocacy in 2020 centered on the continuity of palliative care and access to pain relief medicines amidst the COVID-19 Pandemic. The expenditure on governance and resources mobilization included small grants offered to PCAU Member organizations (hospices) to support COVID-19 related interventions and continuity.

We thank all PCAU partners and donors who have rendered us financial support in 2020. These were: Open Society Foundation (OSF), Open Society Initiative for East Africa (OSIEA), Centre for Hospice Care (CHC), American Cancer Society (ACS), Global Partners in Care (GPiC), African Palliative Care Association (APCA) and the World Hospice and Palliative Care Alliance (WHPCA).



## PALLIATIVE CARE ASSOCIATION OF UGANDA STATEMENT OF FINANCIAL POSITION AS OF DECEMBER 31, 2020

DETAILS	2020	2,019	% Change
FUNDS BALANCE Accummulated fund	1 002 0/1 200	0/2 25/ 111	4%
, , , , , , , , , , , , , , , , , , , ,	1,002,861,200	962,356,111	4%
Represented by			
Non - Current Assets			
Property & Equipment	367,218,486	358,752,768	2%
Current Assets			
Receivables and prepayments	3,658,948	6,536,958	-44%
other current Assets	820,131,522	545,060,175	50%
Cash and Cash Equivalents	159,023,669	219,242,495	-27%
	982,814,139	770,839,628	27%
Current Liabilities			
Payables & Accruals	22,985,140	34,391,000	-33%
Deffered income	324,186,285	132,845,285	144%
Net current Assets/Liabilities	347,171,425	167,236,285	108%
Accumulated Fund	1,002,861,200	962,356,111	4%

## STATEMENT OF INCOME AND EXPENDITURE FOR THE YEAR ENDED DECEMBER 31, 2020

Income	2020 Ushs	2019 Ushs	%change
Restricted Income	941,354,665	922,015,438	2%
Unrestricted Income	120,243,999	247,366,450	-51%
TOTAL INCOME	1,061,598,664	1,169,381,888	-9%
EXPENDITURE			
Staff Costs	418,771,070	457,344,913	-8%
Capacity Building	83,418,620	211,718,287	-61%
Advocacy & Awareness creations	232,610,976	246,393,398	-6%
Reasearch & Information gathering and Sharing	66,121,863	215,446,676	-69%
Governance & Resource Mobilisation	92,032,639	32,424,400	184%
Administration & Support Service	99,584,565	142,807,325	-30%
Exchange Loss	1,907,659	-	
Capital Purchases	24,911,900	-	
TOTAL EXPENDITURE	1,019,359,292	1,306,134,999	-22%
Surplus/ Deficit	42,239,372	(136,753,111)	-131%

#### Partner with us



During this time, we are seeking partners to support us to take palliative care and pain relief services to the most underserved communities in Uganda. There are 39 districts without any health facility offering palliative care.

We need to reach these districts in the next two years and to initiate district palliative care teams at their main health facilities. These districts include the most (hard) to reach areas in our land including islands. They also include island areas. In order to reach these

to reach areas in our land including islands. They also include island areas. In order to reach these areas, we need a strong and efficient vehicle. We are therefore fundraising for a new staff van. Every amount of money contributed counts.

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 **MTN Mobile Money** Platform on Telephone: **+256 789 737 786** Or through **MTN MOMO Pay** 





#### Send

a Generous contribution to PCAU Using

#### **Momo Pay**

Simply dial



**Enter Marchant Code** 

315849



Thank you for the continued support

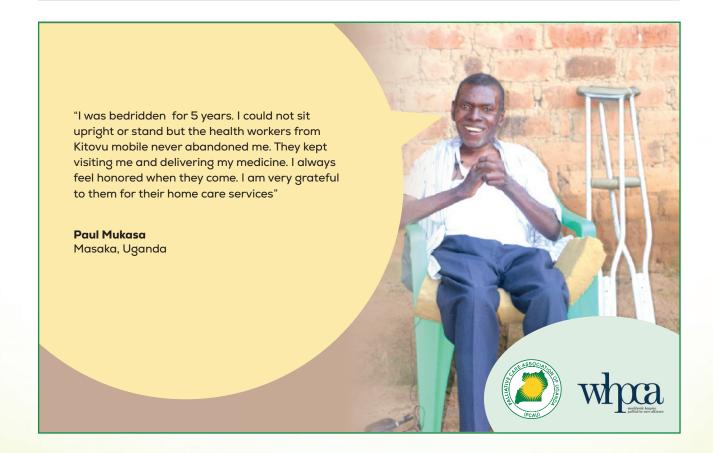
Palliative Care for all in need in Uganda

- f Palliativecare association of Uganda
- pcauganda
- www.pcauganda.org

### **Remembering Rose Nabatanzi (RIP)**

The late Rose Nabatanzi worked as the palliative care focal person at Kitovu Mobile. She was a dedicated palliative care person who was well known in greater Masaka area for her passion to serve. Rose served as a Member of the PCAU Board for 6 years. She passed on and was buried in June 2020. PCAU remembers her good works and *may her soul rest in peace.* 





#### INDIVIDUAL MEMBERS OF THE PALLIATIVE CARE ASSOCIATION OF UGANDA (PCAU)

INDIVIDUAL WEWBERS OF		
Membership No.	Name	
PCAU001220	Dr. Paul Mugambe	
PCAU002520	Antonia Kamate Tukundane	
PCAU006620	Alice Nakanyike Muddukaki	
PCAU014820	Kennedy Ochan	
PCAU019120	Ian Batanda	
PCAU020020	Charles Emiriat	
PCAU024520	Stephen Nyakajo Abitegeka Dr. Emmanuel	
PCAU024620	Tugaineyo	
PCAU026520	Phenehas Bwambale	
PCAU029620	Sr. Penina Alia	
PCAU030820	Lucy Sebi Agaboru	
PCAU031820	Grace Nayiga	
PCAU036520	Jackie mugide	
PCAU037720	Beatrice Awor Ongom	
PCAU038920	Rose Eva Namukasa	
PCAU040020	John Muwonge	
PCAU040720	Denis Wonasolo	
PCAU041020	Edmund Bikosa Tumwesiga	
PCAU042120	Cosiate Abenawe	
PCAU047920	Josephine Nabitaka	
PCAU048720	Bernadette Basemera	
PCAU049120	Teopista Lule Beatrice Bungu	
PCAU051420	Buladina	
PCAU052720	Sr. Leonora Thorach	
PCAU052820	Edinance Gahwerra	
PCAU054820 PCAU065220	Lisa Christine Irumba	
PCAU003220 PCAU078520	Stella Agembi Rosette Kesande	
PCAU085220	Monica Kafuko	
PCAU087120	Mr. Caxton Bahemurwaki	
PCAU089320	Fr. Daniel Situka	
PCAU089720	Dr. Samuel Guma	
PCAU094320	Henry Tinkamanyire	
PCAU097120	Catherine Nakasita	
PCAU099120	Connie Harter Matovu	
PCAU099220	Dr. Eddie Mwebesa	
PCAU099320	Tom Echodu	
PCAU099620	Zipporah Kyomuhangi	
PCAU100120	Martin Turyamureba	
PCAU103720 PCAU104920	Manjit Kaur Dr. Doreen Birungi Agasha	
PCAU106320 PCAU106520	Cynthia Kabagambe	
PCAU106520 PCAU106620	Margret Kabajungu Lydia Nakawuki	
PCAU106620 PCAU106720	Gereva Niwagaba	
PCAU106720 PCAU106820	Ronald Mumbere	
PCAU106920	Julia Singa Kushemererwa	
PCAU107020	Zam Namulema	
PCAU107120	Joel Kibonwabake	
PCAU093520	Viola Ederu	
PCAU107220	Godfrey Obua	
PCAU107320	Rogers Mugerwa	
PCAU107420	Jude Matovu	
PCAU107520	Anthony Byarugaba	
PCAU107620	Isaac Sserwadda	
PCAU107720	Annet Mutibwa	
PCAU107820	Ms. Tanis Lianna	

Membership No.	Name
PCAU107920	Imelda Kiconco
PCAU108020	Doreen Kyampeire
PCAU108120	Jimmy Komalceh
PCAU108220	Stephen Kasula
PCAU108320	Dr. Richard Bugembe
PCAU108420	Janat Kisekka
PCAU000121	Collins Jackson
PCAU000221	Gilbert Aniku
PCAU000321	Richard Ekwan
PCAU000421	Richard Tumwesigye
PCAU000521	John Black Kabukye
PCAU000621	Sr. Esther Margret Chandiru
PCAU000721	Phelemina Agasiru
PCAU000821	Doreen Ayikoru
PCAU000921	Harriet Kabaalu Namugenyi
PCAU001021	Jacob Ampeire
PCAU001121	Fr. Simon Peter Omoding
PCAU001221	Maureen Namirembe
PCAU001321	Dinah Adeke
PCAU001421	Dr. John Bosco Byaruhanga
PCAU001521	Ambrose Tumwesigye
PCAU001621	Prossy Namaganda
PCAU001821	Racheal Sekisozi Nabuwufu
PCAU001921	Richard Male
PCAU002021	Beatrix Chekapserot
PCAU002221	Margret K. Kisaakye
PCAU002321	Irene Kibone
PCAU002421	Wilson Mande Kiprotich
PCAU002521	Ronald Kanyike
PCAU002621	Gilivasio Mugerwa
PCAU003121	Dr. Christopher Ddamulira
PCAU003321	Lawrence Tumwine
PCAU003421	Joan Laker
PCAU003521	Zaitun Nalukwago Shebah Rusoke
PCAU003621	Nyakaisiki
PCAU003721	Patience Birungi
PCAU003821	Fredrick Dickens Odongo
PCAU102920	Miriel Kabigarire
PCAU003921	Judith Nabasinga
PCAU004021	Mary Margaret Akarent
PCAU006920	Deogratius Kanyike
PCAU018820	Olivia Nakigozi
PCAU004121	Augustine Murangira
PCAU090120	Hajjati Mwazi Batuli
PCAU004221	Mary Florence Nalwanga
PCAU004321	Margret Nagawa
PCAU032820	Barbara Molly Ongoza
PCAU004421	Prossy Nakyanja
PCAU099520	Innocent Kasasa
PCAU004521	Aggrey Murangira
PCAU004621	Josephine Nakajubi
PCAU004721	Donata Muwonge
PCAU004821	Bob Tayebwa
PCAU004921 PCAU017320	Dr. Margrethe Juncker Dorish Asibazuyo
PCAU006020	Grace Kamahanga
PCAU006020 PCAU044820	Jane K. Nalubowa
. 0/10077020	Jano IXI Nalabowa

Membership No.	Name
PCAU005021	Aisha Kagere
PCAU005121	Florence Lubega
PCAU005221	Dorothy Nakyanzi
PCAU038820	Irene Namudiba
PCAU066120	Davis K. Muwanguzi
PCAU005321	Elizabeth Mukasa
PCAU101520	Shivan Ashaba
PCAU005421	Lydia Nisiima
PCAU005521	Florence Nalutaaya
PCAU005621	Edward Bulolo Bbosa
PCAU106220	Mohammed Jaffar
PCAU005721	Betty M. Enangu
PCAU006121	Diana Basirika
PCAU067420	Francesca Aceng
PCAU006221	Florence Luboga
PCAU006321	Dorothy Nakayiza
P CAU004620	Esther Taaka
PCAU100520	Job Okitoi
PCAU006421	Leah Nasasira
PCAU047520	Loyce Tumuranzye
PCAU003620	Betty Bifabusa
PCAU006521	Fatuma Naggayi
PCAU006621	Florence Banempara
PCAU002420	Esther Beebwa
PCAU006721	Beatrice Chekapserop
PCAU006821	Sr. Ruth Kujo
PCAU006921	Anne Nanziri Kiwanuka
PCAU007021	Doreen Nalwadda
PCAU007121	Ismail Kyagulanyi

#### LIFE MEMBERS OF PCAU

Fully Paid Up	
Membership No.	Name
PCAU052520	Prof. Julia Downing
PCAU100320	Rose Kiwanuka
PCAU105220	Elvis Atibuni
PCAU105520	Dr. Vicentina Achora
PCAU018320	Mark Donald Bikosa Mwesiga
PCAU005220	Dr. Janet B. White
PCAU002921	Roberta Spencer
PCAU003221	Dr. Irene Atuhaire
PCAU098720	Dr. Henry Ddungu
PCAU003021	CPA Dr. Timothy Basiima
PCAU001721	Joyce Zalwango
PCAU104820	Ritah Nannyomo

#### **Partially Paid**

Membership No.	Name
PCAU002721	Dr. Nathan Kenya- Mugisha
PCAU005921	Dr. Andrew Ocero
PCAU002821	Dr. Jackson Amone
PCAU005821	Dr. Ekria Kikule
PCAU006021	Christine Ebong Akullo



# Road to Hope



## Road to Hope Road to Hope

### Palliative Care Association of Uganda (PCAU)

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