PCAU Annual Bulletin 2019

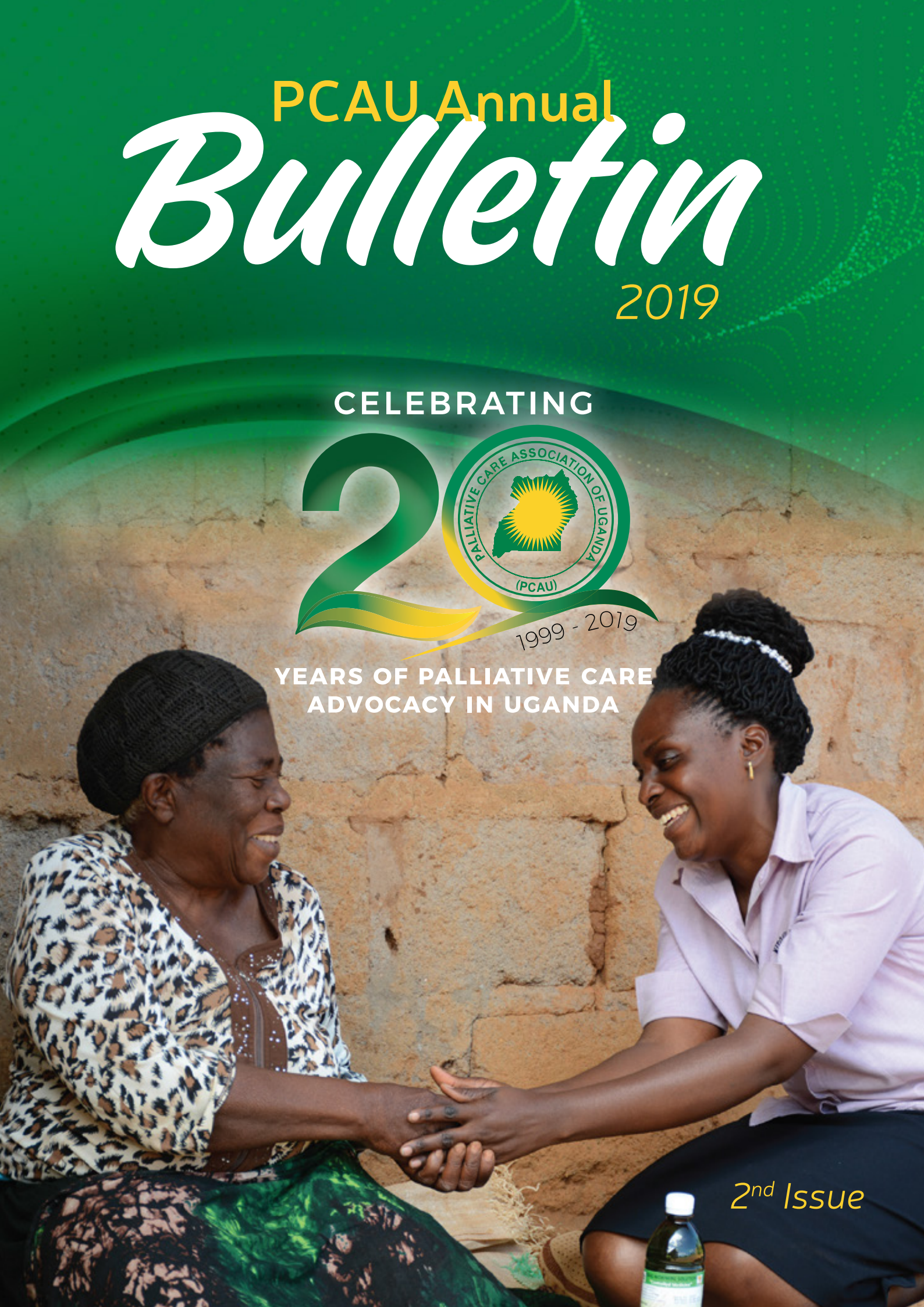
CELEBRATING

20

PALLIATIVE CARE ASSOCIATION OF UGANDA (PCAU)

1999 - 2019

YEARS OF PALLIATIVE CARE ADVOCACY IN UGANDA



2nd Issue

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COVER Photo Credit: **Moses Muwulya**

Jane Nabadda, 75 years (left) at her home in Lwanyi Village, Masaka District greeting Jackie Namulondo a Nurse at Kitovu Mobile. Jackie has been working alongside the amazing Palliative Care Nurse Rose Nabatanzi for the last 8 years at Kitovu Mobile. The two, Jackie and Rose have conducted a thousand community and home visits in districts reached by Kitovu Mobile seeing their patients. They need no guide to every village in their area of operation. Most of the patients they see are referred to them by organizations like Uganda Cancer Institute, Hospice Africa Uganda, Uganda Cares, Kitovu Hospital, Masaka Regional Referral Hospital and others. They have been visiting Jane since 2015 when she was diagnosed with cancer of the breast. She is always glad to receive the palliative care team at her home. Jane considers the two as her friends. She has shared her testimony with various other patients and to the media. The care and medicines provided to her by the palliative team have relieved her of much pain and fear.

Jackie says that she is always motivated by the fact that the services she offers bring peace and hope to patients and their families.

"The mere fact that we are able to turn around the situations of people motivates me. They are often referred to us with distressing symptoms in pain, fear and sometimes no hope. We treat the pain and offer psychosocial and spiritual support. It gives me courage and strength to continue whenever the patients and their families appreciate our work. I am always motivated to move on whenever I see a family working together to support a loved one even at the point of death".

Jackie Namulondo.

Dear PCAU Members, Partners and all friends.

Mark Donald Mwesiga

Country Director - PCAU

This is the 2nd issue of the PCAU Annual Bulletin allotted at the 4th PCAU Annual Dinner! See how time flies! Some of you must have been at our first Annual Dinner in 2016. Some of you are joining us for the first time. You are all welcome to read this issue. This particular edition is special. We have been intentional to bring you some memories down the lane. You will read about the journey of PCAU since its birth in 1999. You will find out about some personalities and institutions that have been part of the story. You will see how far we have come and tasks that we still have ahead to ensure *"Palliative Care for all in need in Uganda".*

Like the 19 years before, 2019 has been a busy one. We had numerous activities and among them, a great conference that was attended by 372 delegates. The Rt. Hon. Prime Minister of Uganda and the Minister of Health joined us. We are grateful to Uganda Cancer Institute and the Ministry of Health for the partnership to host the conference. We thank all the conference donors and sponsors. We have continued to offer full scholarships to 29 pioneer students in Advanced Diploma in Palliative Care Nursing. We supported the Ministry of Health to develop Palliative Care indictors for data collection. We also supported the process of costing the draft National Palliative Care Policy.

In this same year, we have had the transition from the founding Country Director Ms. Rose Kiwanuka. She did a great job and deserves all our praise and best wishes. She set a great example in leadership. PCAU and the Country achieved a lot on the palliative care scene with her leadership. The good news is that we won't miss her. She is a subscribed Life Member of PCAU. This means she will be available to support PCAU and she has personally pledged so. Thank you for your individual, institutional (government and civil society) support to her. Together with her, you natured PCAU and the fruits are evident.

I thank you all for the warm welcome accorded to me having been appointed as the second Country Director in mid-October this year. I thank the PCAU President and the entire Board for undertaking a thorough process of recruitment and selection. The type and magnitude of work ahead is cut out clearly. Only slightly above 11% of all patients and families in need, currently access palliative care services in Uganda. PCAU will have to continue strengthening partnerships and collaborations if we are to realize universal access. I will seek to work with all of you to accelerate the integration of palliative care into the Ugandan health care system. In the last close to five years, I have worked at PCAU secretariat as the Programs Manager. We are a small but an excellent team of 14 staff and volunteers. Continue to offer support to PCAU we appeal to you. Together, we will build on the successes have achieved.

Still in 2019, we continued to advocate for the establishment of the National Palliative Care Policy. We have the word of the Minister of Health that the policy will come soon. The palliative care trained nurses and clinical officers with Diploma in Clinical Palliative Care are not yet recruited and retained in the civil service structure as thus. It is not surprising to find a public health facility with a trained palliative care provider but without a functional palliative care unit. We still grapple with low budgetary allocation to palliative care especially at Primary Health Care level which includes home based care. There are still some challenges impacting access to controlled medicines for pain relief. We need to work together to raise awareness. We appeal to government to ensure National Health Insurance scheme covers the essential palliative care package.

As we commemorate 20 years and look ahead, we would like to connect with you even better. We need your feedback. Please renew your membership. Sign up to join the PCAU life Members Assembly today.

We Have a Bigger Vision for Palliative Care For Uganda – Dr. Aceng

As Palliative Care Association of Uganda marks 20 years, Uganda is in the process of formulating a comprehensive policy on palliative care. The Minister of Health, Dr. Jane Ruth Aceng explains the current state and efforts to improve palliative care services in the country in an interview with Agnes Kyotalengerire.

Hon. Dr. Jane Ruth Aceng

Minister of Health

Q. Why has the policy on Palliative Care taken long to get approved?

A. We are in the process of polishing up the policy on palliative care services in Uganda. It was developed by the Palliative Care association with support of our clinical services division at the ministry. The first time the policy came up, we did not have the palliative care division in the ministry. That made it difficult to fast track the policy because there was no person to follow it up with. However, we now have a Palliative Care division which is specifically following up on the matter. Perhaps in the next one to two months, we will be done with the draft proposal and then it will go through all the required approvals and consultations before it can be presented to cabinet.

Q. The quality of Palliative Care is critical if government is to achieve the national goals in the health sector. As government what are you doing to support the institutions offering palliative care services in Uganda?

A. As a policy, universities are encouraged and supported to offer special courses in line with Palliative Care. Universities offer Palliative Care training at diploma and degree levels. We also have people who are training in Palliative Care at masters' level. The only challenge is that the numbers are still low. We have to encourage more people to enroll and study Palliative Care. The good news is that the training ground is already conducive, we just have to put in more efforts in ensuring that more people train as Palliative Care specialists.

Q. How would you rate the quality of Palliative Care services in the country?

A. I think Uganda is doing a good job. In the entire African region, Uganda is leading in Palliative Care. Even at the global level Uganda is ranked high when it comes to Palliative Care.

As a country we appreciate the importance of palliative care in ensuring that Ugandans suffering from serious illnesses get the care and treatment they deserve. We have tried to roll out palliative care services across the entire country. You will recall that in the past Palliative Care was largely based on HIV care services because most patients with HIV/AIDS would become terminally sick and needed more care, now we do not have such people anymore because we have better medication like anti-retroviral drugs. Currently, the bigger number of people that require Palliative Care services are the cancer patients, the elderly and other terminally ill patients grappling with other conditions.

Whereas the ministry has tried to cover the entire country in terms of Palliative Care services, we are not yet at the level we want. We still have some parts of the country that do not have the services for Palliative Care. However, with the current drive to train the health workers to embrace Palliative Care, the situation will get better.

Marking Two Decades of the Palliative Care Association of Uganda.

The Palliative Care Association of Uganda (PCAU) is marking 20 years. Since its establishment in 1999, the association has registered several milestones. Dr. Henry Ddungu, a hematology consultant at the Uganda Cancer Institute is the current PCAU President and Chair of the Board of Directors. He shared about the journey of PCAU and what the future holds for the association in this brief interview with Agnes Kyotalengerire.

Dr. Henry Ddungu

Q. What exactly is the ministry doing to fully streamline Palliative Care in the health sector right from the grassroots?

A. The ministry officials traverse various regions in the country and train the health workers in Palliative Care. In addition, we encourage health workers to join the training schools and study Palliative Care courses. I believe we are on the right track and we shall cover the entire country.

Q. Who requires Palliative Care services?

A. Palliative Care is largely meant for the terminally ill. But health workers are trained to give care to the sick people including cases of terminal illnesses. So, you cannot separate general health work from Palliative Care, they complement each other. People need to be counseled, to understand their illnesses and whatever comes along they need to understand what the result is going to be. So, it only takes a little bit of mindset change for people to believe that palliative care is useful, and it is the right thing to do.

Uganda as a country has embraced Palliative Care and our health workers appreciate the importance of Palliative Care. What we need to do is to support those who are ready with scholarships so that they can train in Palliative Care.

Q. What would you consider the key achievements in your one year of service?

A. The biggest achievement has been being able to transition from the founding Country Director to a new one. It was a challenge, but we successfully went through it. It came unexpectedly when the retired Country Director unfortunately got unwell at the time everyone least expected. Upon recovering, she approached the Board and expressed her wish to retire. We had to find a way of getting a replacement. Rather than hand picking, we had to go through a process that is internationally acceptable. It wasn't just about interviews. We had an independent consulting firm that interviewed key stakeholders to get their opinion based on the values of the organization. It helped to know the things we were looking out for in an incoming country director. For example, a person who is able to fundraise for the organization, a person who is able to do advocacy for palliative care nationally and internationally.

Additionally, we have been able to organize a big conference in association with the Uganda Cancer Institute (UCI). We were able to host this successful international conference on cancer and palliative care that took place on 5th-6th September 2019 at the Kampala Serena Hotel.

At the time I became Chair of the Board, there was an ongoing process of trying to ensure that palliative care services go into government nursing institutions, the curriculum was being worked on and that was completed. So, a national advanced diploma in palliative nursing curriculum was developed and approved by the Ministry of Education and Sports. Early this year of 2019, the Mulago School of Nursing and Midwifery enrolled the pioneer students with both technical and financial support from PCAU.

Q. What are the major challenges in palliative care services in the country today?

A. Palliative care is still perceived differently by both stakeholders in terms of health care providers and consumers who are the patients. Some people think of palliative care referral as the end of life care. PCAU has advocated for increased access to palliative care in over 80 % of the districts in Uganda. But still the level of care in Uganda is still wanting.

There is a big challenge of funding. Many of the original home based palliative care providers are no longer able to do what they used to do because of lack of funding. They used to get funding from multi-national donors or charities in Europe or the US, which kind of funding has now dwindled. Consequently, many organizations have reduced on the amount of care they provide. This means people who used to benefit from advanced home based care, can no longer get it. As such, we see people dying in hospitals.

Advanced home care means; a time comes when a patient is reaching the end of life and they do not want to stay in hospital. They need to get a lot of attention from home where they can be visited more often; about thrice a week. Home based care is cheap but still requires a lot of resources.

There is no national palliative care policy in place to help draw guidelines, although we have been working on it. But we are optimistic that it will soon be completed.

Q. How are you addressing these challenges?

A. We are continuing with our advocacy work, working closely with the Ministry of Health and we have the support of the Minister of Health, the technical staff at the ministry and other stakeholders. These policy issues take time, but it will soon get better. When you hear Uganda being one of the countries that allowed nurses trained in palliative care to prescribe morphine drug it did not come immediately. We worked on it for a long time until when it was approved. So, we hope the national palliative care policy will come soon as we continue to engage our stakeholders.

We are also continuing to educate the public and the medical professionals so that they get better understanding about palliative care. To understand that when you use palliative care as an approach to treat life threatening conditions, you are likely to get better outcome. But not to imagine that palliative care is only for those who are dying and that you can use palliative care to make someone live longer and even get much better.

For instance, if someone was admitted with acute leukemia and did not get the support they need, you do not control the symptoms, the pain, you do not give them transfusion for life to support their treatment, they never improve. So, we want to continue advocating for it so that people know that it is the best approach to ensure that people live a better life. If they are going to die they die with dignity, preferably in their homes.

Q. What should be done to sustain the momentum in the growth of palliative care services in Uganda?

A. It all rotates around funding. Where we do not have adequate funding, the momentum goes down. We need to come up with better strategies; these may include moving away from donor dependency, to looking at palliative care as an insurable

Some of the Members of the PCAU Board from the right -front row: Dr. Andrew Ocero, Mr. Gerever Niwagaba, Dr. Henry Ddungu, Rose Kiwanuka (former Country Director), Hajjat Dr. Safiina K. Museene, Mrs. Josephine Josephine Kampi Tatyabala, Mr. Mark Donald Mwesiga (Country Director), back row: Hajjat Mwazi Batuli, Dr. Ekilia Kikure and John Muwonge. Photo taken after a Board Meeting in November 2019. The other Board Member not in the photo is Mrs. Dorah Kiconco Musinguzi.

problem. For example, those providing health care insurance should include palliative care in the package including funding for home based care. This can be done the way you go to the hospital and you contribute to health care. Similarly, palliative care services need to be included in the insurance scheme as well as funding for home based care. We appreciate the fact that people cannot afford, but if the social system takes care of them, then it can become a more sustainable program.

We cannot give up on advocating for importance of palliative care. **We need to do a lot of research to improve some of the interventions that we employ including social research.** If some of the interventions have proven not to be working, we can opt for something else. The same way it is done with medicine or cancer care.

Additionally, we have to continue advocating for palliative care training so that everyone in a health learning institution is equipped with the knowledge and skills in palliative care.

Q. Where do you see palliative care in 10 years from now?

A. I am looking at an integrated service. For instance, if you went into a hospital, it should have an aspect of palliative care as part of their health system. But also, to have specialists in palliative care who can offer in hospital services, but also home based care because it plays a big role in one's health especially when it is getting to end of life.

Palliative Care Association of Uganda; Our 20 year journey!

By Rose Kiwanuka – Founding Country Director of PCAU.

The Palliative Care Association of Uganda (PCAU) was established in 1999. It was registered as a Professional Association and Non-Government Organization (NGO) in 2003. It was the first palliative care national association to be formed in the African continent. It started from the premises of Hospice Africa Uganda (HAU) and was managed by volunteers for over six years. These volunteers, brought their experience from various facilities such as Hospice Africa Uganda, Mildmay Uganda, The AIDS Support Organization (TASO) and Kitovu Mobile Clinic.

In January 2006, PCAU moved out of Hospice Africa Uganda with a seed fund of 300,000 (three hundred thousand shillings) only to carry out its activities. It had only one employee, Rose Kiwanuka. The African Palliative Care Association (APCA) housed PCAU in one of its rooms for over 6 months and later given two rooms at the back of APCA house where it continued to operate for four years.

In February 2010, PCAU moved into a rented house on Kizungu lane in Makindye. The move helped to improve its visibility, the Ministry of Health then started to recognize its contribution to palliative care. Later in the same year, PCAU received funding from USAID to the tune of 150 million which continued annually for five consecutive years plus a vehicle (Landcruiser) through Hospice Africa Uganda.

- PCAU's partnership with Center for Hospice Care (CHC), Indiana USA, (which started in 2008) grew stronger and a sponsorship program was started for nurses and clinical officers to undertake a nine months Diploma in Clinical Palliative Care (DCPC) at the Institute of Hospice and Palliative care in Africa (IHPCA). The

aim was to increase opioid prescribers in the districts and to bring palliative care nearer to the people. The partners offered 8 scholarships per year. To date PCAU together with Center for Hospice Care Foundation (the partners in USA) have supported 68 nurses and clinical officers to undertake palliative care specialised training. These are legal opioid prescribers and palliative care focal persons in their work places.

PCAU then gained momentum and attracted other donors like; Diana Princess of Wales Trust Fund, Open Society Initiative. True Colors Trust Fund, Open Society of Eastern Africa, USAID, Center for Hospice Care, American Cancer Society.

In 2012 PCAU took a big step in its history and acquired a permanent home in Kitende which is located on Block 383 plot 8804 Kitende, Entebbe road.

The Roles of PCAU

The roles of PCAU have evolved over time. Initially it was capacity building through quarterly update meetings but with time they became more defined guided by the constitution and later by the strategic plans. The Four PCAU focus areas that have continued to guide the work of PCAU are;

Capacity building

This is directed towards accelerating the integration of palliative care services in the health care system of Uganda through education and training of health and non-health care workers.

Mentorship support supervision and encouraging development of new district palliative care initiatives/hospices as well as hospital palliative care teams is a major strategy to accelerate such integration. Currently, there are 13 standalone hospice/palliative care programs in the country. Fourteen of the sixteen Regional Referral Hospitals have hospital palliative care teams, which manage patients within the hospital and discharge through standalone hospices. And PCAU co-ordinates palliative care practitioners and organizations to enhance collaboration and networking.

District PCAU branches were also initiated to enhance health and none healtcare workers knowledge in palliative care for quality palliative care service provision. This is done through quarterly update meetings (Continuing Professional Development-CPD) which are supported by the secretariat. There are 10 district PCAU branches including; Mbarara District PCAU branch which was the first branch to be established, then Hoima, Busoga Region, Buddu Region, Uganda People's Defense Force (UPDF), Arua, Kibale, Mityana, Mbale and Kasese. These are mainly maned by Clinical Palliative Care Officers in the districts together with committed volunteer in form of branch committee members.

Advocacy and awareness creation

This focus area aims at increasing the awareness and understanding of palliative care among stake holders and the public, with an ultimate goal of creating a supportive environment for providers and the service. PCAU works with the Ministry of Health (MoH) to formulate policies and guidelines to enhance the scale up of palliative care service provision and integration in the health care system. As a result of advocacy, PCAU is coordinating the oversight of the morphine supply chain which is implemented by the Ministry of Health, Hospice Africa Uganda, National Medical Stores and Joint Medical Stores and palliative care service providers.

Along the way, PCAU started sponsoring vulnerable child care givers identified by palliative care practitioners to undertake formal education after their parent(s) have passed on. These children have become ambassadors of palliative care in their communities and increase awareness about palliative care services. Fifty-eight (58) children from 14 district have benefited from this program and one of them is in third year medical school.

Staff of PCAU in a photo with Charles Peter Mayiga Katikkiro (Prime Minister) of Buganda Kingdom in December 2014. This was after the team presented Palliative Care information resources and financial contribution to the Buganda Kingdom.

PCAU has also engaged various stake holders including religious leaders and cultural institutions to entrench the message on palliative care.

Palliative care research and information dissemination,

The aim is to make PCAU a hub of evidence based palliative care information. The intention is to host relevant research and lead the collection, storage, analysis of data and regularly disseminate information through quarterly update meetings, and the biennial conference to continually improve palliative care services.

Mike Wargo (middle) receiving the PCAU Organization Merit award on behalf of Centre for Hospice Care an organization partner with PCAU through the Global Partners in Care. The Partnership between PCAU and CHC was initiated in 2008.

PCAU is undertaking research in collaboration with Center for Hospice Care in Collaboration with University of Notre Dame, Indiana USA. PCAU hosts intern students from University of Notre Dame and work with them on identified researches. Some of the researches done include, geo-mapping of palliative care services that resulted into mHealth program which is now in 20 districts.

Governance and Resource Mobilization for Palliative care

For PCAU to remain relevant, resource mobilization is crucial, thus a resource mobilization strategy to support the implementation of the strategic plan was developed with the support of the American Cancer Society (ACS). It is being implemented to raise funds to for palliative care especially the district palliative care initiatives and the association itself. Resources support the district palliative care initiatives to provide mentorship and support supervision to palliative care service providers, to enhance their knowledge, skills and confidence in palliative care service provision. Activities that are carried out to raise funds include sales of PCAU T/Shirts, Caps. bracelets, branded books and pens. Annual dinner is also held for the same purpose. Three hospices including New Life Hospice Arua, Rays of Hope Hospice Jinja and Mobile Hospice Mbarara have benefited from the PCAU Annual fundraising dinner.

Rev. Fr. Peter Mubiru a Catholic Priest working with Jinja Diocese was one of the people who worked hard and with PCAU during the Founding of Rays of Hope Hospice Jinja in 2005.

Key milestones of PCAU since inception:

PCAU has registered a number of achievements over the years, some of the vital ones include;

- **2003:** Registered as a Non-Governmental Organisation (NGO).
- **2004:** A Statutory Instrument 2004 No. 24 that allowed specially trained palliative care nurses and clinical officers to prescribe oral morphine for patients in moderate to severe pain was gazetted on 24th April. This was an official task shifting which aimed at increasing opioid prescribers in the country, because initially it was only doctors who were legal prescribers.
- **2004/5:** Palliative care was included in the Ministry of Health Sector Strategic Implementation Plan.

- **2005:** Supported the inauguration of Rays of Hope Hospice Jinja on the 25th August. Rays of Hope Hospice Jinja now offers home based care and community outreach activities in the Busoga region.
- **2006:** Officially moved out of Hospice Africa Uganda (HAU) premises and acquired an office to improve its visibility.
- **2008:** Supported the development of Hospice Ngora. Palliative care services were provided by community volunteers and were supported by a Clinical Palliative Care Officer from Frider Car Hospital in Ngora.
- **2008:** Supported the development of Kagando hospital Palliative Care program.
- **2008:** Supported and launched Mulago Palliative Care Unit (MPCU) an academic unit within the School of Medicine, Makerere University College of Health Sciences.
- **2009:** Undertook a national palliative care audit with support from Princess of Wales Diana Fund. Districts that had palliative care practitioners and morphine were ascertained with a result of 34 out of 84 districts covered. This became a yard stick for determining the progress of palliative care in the country. As a result of the audit, formation of district Palliative care branches was emphasised. 10 district PCAU branches were formed to enhance palliative care services in the country.
- **2010:** Palliative care appeared in the national Health Policy for the first time, after a long struggle of convincing policy makers that palliative care should be in the MOH national Policy.
- **2010:** Developed 5 days national palliative care training curriculum for health workers with the support of USAID funds and they funded the trainings.
- **2010:** Received the mandate to accredit hospitals that met the standards to offer palliative care.
- **2010:** Initiated the formation of hospital Palliative Care units in 13 Regional Referral Hospitals with the support of OSIEA. These included Arua, Gulu, Jinja Kabale, Lira, Hoima, Masaka, Mbale, Mbarara, Mubende, Moroto and Soroti.
- **2010:** Sourced funding to start a sponsorship program for Nurses and Clinical Officers to attain a Diploma in Clinical Palliative Care (DCPC) at the Institute of Hospice and Palliative Care in Africa (IHPCA).
- **2010:** Established Partnership with the Uganda Network on Law Ethics and HIV/AIDs (UGANET) and with Support from the African Palliative Care Association (APCA), OSIEA and OSF and promoted palliative care as Human Right in over 30 districts of Uganda.
- **2011:** Supported the development of Hospice Tororo.
- **2012:** Published the history of palliative care in a book known as 'The Development of Palliative Care in Uganda"
- **2012:** Acquired a permanent home in Kitende on Entebbe road. Increased its visibility and now it is becoming small for the team and activities being done.
- **2012:** Started Road to Hope Program to support formal education sponsorship for child carer givers. These are some of the children of palliative care patients who passed on. The program has supported 58 children and four of them have completed their education.

Strengthening Partnerships

PCAU has worked collaboratively with regional and international actors in the field of palliative care since inception.

- **2015:** Piloted a Palliative Pare surveillance program in Uganda using mHealth technology.

Fatia Kiyange (left) the Programs Director at the African palliative Care Association and former PCAU President and Board Chair with Dr Stephen Connor, the Executive Director of the World Hospice and Palliative Care Alliance and Rose Kiwaka at the first ICPCN International Conference on Children's Palliaive Care which was held in Mumbai.

- **2015:** PCAU was represented at the United Nations General Assembly Special Session on drugs (UNGASS) in New York.
- **2017:** National Drug Authority extended the shelf life of oral liquid morphine to one year from six months following intense advocacy led by PCAU.
- **2017:** The Uganda Human Rights Commission (UHRC) reported on the enjoyment of the Right to Palliative Care in their 20th Annual report following advocacy and training by PCAU.
- **2018:** A National Advanced Diploma in Palliative Care Nursing curriculum was developed and approved by Ministry of Education and Sports. PCAU provided Technical Support for this milestone.
- **2019:** Mulago School of Nursing and Midwifery started training nurses on the Advanced Diploma in Palliative care Nursing (ADPCN) program. All current 29 students on the program are supported by PCAU with funds from Centre for Hospice Care Foundation in Indiana USA.

Rose Kiwanuka (in the middle) with some of the pioneer students on the ADPN at Mulago School of Nursing and Midwifery. In the photo also: Joyce Zalwango (extreme right) a staff of PCAU and Cyndy Searfoss of Center for Hospice Care Care/ Foundation.

PCAU growth and development in NUMBERS!

From the above account, it is evident that the organisation has grown and developed its programmes over the years. These last 3 years PCAU has been on a program known as Strengthening Organisations for a United Response to the Cancer Epidemic (SOURCE) from the American Cancer Society. This has ensured PCAU has strengthened all aspects of its infrastructure and has recently graduated with distinction from the program. In summary PCAU;

THEN	NOW
1 employee in **2006**	**12** employees in **2019**
Started with 300K/=	Annually Handles at least **1 Billion**
20 Individual members in 1999	1066 Individual members in 2019
4 organizational members Kitovu Mobile Home care program, Mildmay Uganda, Hospice Africa Uganda and The AIDS Support Organization (TASO)	**22** member organizations
3 accredited sites to stock oral morphine	**251** accredited Health facilities

Mr. Tom Duku (in middle holding an award) managed PCAU funds during the founding stages of PCAU. He later served on the PCAU Board for a period of six years from 2014.Durimg the PCAU Conference Dinner in September 2019, he was awarded for his great contribution towards the work of PCAU.

Some of the Challenges impacting integration and growth of Palliative Care services in our country.

Like any other organization, PCAU has challenges which will require collective effort to handle them. The board's effort and support to management in mitigating these challenges will be crucial.

- National Palliative Care policy for our country is not yet established. The development of this policy has taken many years. Once accomplished, this policy will help to change a lot of things.
- Palliative Care standards were developed to guide implantation of Palliative Care services at different levels of our health care system. They have never been implemented pending the endorsement of the National Palliative Care Policy.
- Low funding for Palliative Care. As we celebrate 26 years of palliative care services in Uganda, the country still relies largely on external funding for most of the Palliative Care work. There must be more government budgetary allocation to Palliative Care if these services are to be sustainable.
- To some extent there is still limited knowledge about palliative care among the public and healthcare givers. We still need to do a lot of sensitization and advocacy to help the public and health care workers understand palliative care.
- There is no adequate recognition, deployment and remuneration of Palliative Care providers in the health care system. This is inhibiting appropriate palliative care practices in health care facilities.
- Limited lecturers to teach palliative care as well as limited practicum sites. There is need to integrate palliative care in the health tutor's curriculum so that all tutors who qualify can teach Palliative Care.
- Palliative Care Units in all hospitals need to be strengthened so that they can support students from nursing, clinical and medical schools to practice Palliative Care
- Palliative Care is still viewed as a service for the dying by some quarters of policy makers, technocrats and administrators in the health care sector. There is need to demystify palliative care.

Access to palliative care for all in Africa: The African Palliative Care Association

Dr. Emmanuel Luyirika
Executive Director – African Palliative Care Association

The APCA board chair Mr Andre Wagner (4th from left) with APCA staff and outgoing board members.

The African Palliative Care Association (APCA) was formed in 2003 as a pan-African membership palliative care entity with 4580 individual members and 2600 institutional members from across Africa and the Palliative Care Association of Uganda is one of the institutional members. APCA aims to create palliative care awareness, strengthen health systems in Africa through integration of palliative care by improving access to essential palliative care medicines, palliative care human resource development, palliative care policy development and improving on palliative care service delivery.

To date APCA has supported 8 African countries to development overarching national palliative care policies namely Rwanda, Swaziland, Mozambique, Zimbabwe, Malawi, Tanzania, Zambia Botswana and Uganda is still in the process. In 2018 alone APCA supported close to 10,000 patients in 60 health facilities and training 1685 health workers and 50 community workers in palliative care and related-discipline from across Africa.

APCA convenes a triennial International African Palliative Conference which brings together over 500 palliative care practitioners, patients and disease survivors/ advocates, policy makers, researchers and academia from Africa and beyond to share best practices and research evidence. The most recent one was held in Kigali Rwanda in September 2019. Since 2013, APCA has been hosting the African Ministers of Health session on palliative care every three years with the first one being in Johannesburg in 2013, Kampala in 2016 and in Kigali in 2019. The ministers sessions have resulted into high-level palliative care initiatives in several African countries with ministers exchanged ideas and best practices and creating an environment of peer-to-peer information sharing and initiatives.

African Ministers of Health attending the APCA hosted 2019 African ministers of health palliative acer session in Kigali Rwanda in September 2019

The Palliative Care Association of Uganda PCAU, has been a great partner with APCA in bringing in teams from other African countries to learn best practices in Uganda especially regarding national level oral liquid morphine reconstitution and palliative care education.

APCA is happy to celebrate PCAU's 20 years of existence as a model national association.

PCAU Was Started to Help Coordinate Palliative Care Providers Countrywide

Dr. Merriman is one of the founders of Palliative Care Association of Uganda (PCAU). She had founded Hospice Africa (HAU) in 1993 to bring affordable pain relief to patients in some of the poorest parts of the Africa. The idea of starting PCAU was birthed at HAU and the two organizations continue to work collaboratively to enhance palliative care services. Dr. Merriman shared her thoughts on the purpose and journey of PCAU in a brief interview.

Q. Give us a brief background on how Palliative Care Association of Uganda was started?

A. When we started Hospice Africa Uganda in 1993 we did not foresee at that time that we would have enough people to form an association for the whole of Uganda. But as we moved on, different people joined us in providing Palliative Care. We realized that we needed to work together and move forward together and help each other so that the whole country could move forward.

Q. What inspired you to start PCAU?

A. Right from the beginning we had an idea of our ethos, but we did not write them down until PCAU was started in 2000. Everything we did medically or whether we were advising the Ministry of Health, we were to think of patients and families before making decisions. Secondly, we care for each other in our teams such that nobody in the team feels like an outsider to the organization. Thirdly, we care for each other and other organizations. We decided that we would work with other organizations and we would try to share with them what we knew and learn from them at the same time. So, these were the three pillars of our ethos. And we hoped that any organization that we started would carry on with that ethos and PCAU has carried on with this.

Q. What was the actual beginning like?

A. When we started in 1999, it was from the idea that we wanted to work together. We started with just a small office in the education department which was headed at the time by Rose Kiwanuka and Fatia Kiyaga and from there we called for a meeting of everybody every quarter. Our room at the time would hold 70 people, but soon they were overflowing into the corridors. In the end we would have meetings outside in the gardens to manage everybody that was coming to those meetings. The very first chair of the board was Dr. Lydia Mpanga, who was our consultant in Palliative Care at the time. She was somebody with great ideas and she helped us to move forward. PCAU was very much part of Hospice Africa Uganda, until 2006 when the funding came to start the palliative care association with its own offices.

Q. What was the state of palliative care like during the years when PCAU was founded?

A. We had had great support from the Ministry of Health right from the beginning which allowed us to bring in powdered morphine to able to control severe pain. Once pain is controlled then you can give holistic care.

Back in 1994 we had done research on HIV pain and found that it was responding to the same treatment as what we were giving to people with cancer. By 1999 we were known to many organizations including

HIV care provider organizations. So we put together a conference where we were trying to convince government that we did not have enough prescribers of morphine because at the time only doctors, dentists and vets could prescribe morphine. We had 1 doctor to 40,000 people; we now have 1 doctor to 19,000 though it is still not enough.

Q. What impact did that joint effort have?

A. Government agreed to set up a committee in the Ministry of Health that would look at allowing nurses trained in Palliative Care to become prescribers of morphine. It was decided then that we would start a diploma in palliative care. It was mainly clinical; they went to various organizations and learnt how to assess a patient, how to diagnose and how to prescribe morphine. In 2003 government passed a statute to allow nurses who were trained in Palliative Care to legally prescribe morphine. Palliative Care Association of Uganda started training people throughout the country. Now 90 districts out of 134 have palliative care and prescribers of morphine.

Q. What was the vision you had back in 2000 when you were starting and has it been achieved?

A. Our vision was palliative care for all. We have got support from government particularly with the manufacture of morphine for which they pay so that every patient who needs it can have it prescribed by a regular prescriber free of charge. We were found to be the best providers of Palliative Care in the whole of Africa in 2014 by the World Hospice Alliance together with the World Hospice Organization. So we have something to be proud of.

Q. What else has been achieved?

A. The main thing that has been achieved is the feeling of togetherness. Everybody is being updated with what is going on through the quarterly meetings where the audience decides what we would like to talk about next time. The publications as well have kept us up-to-date. In addition the people who are dealing with patients are visited by people from PCAU who have specialized training and are experts in clinical skills. And this has really made palliative care for patients exceptional.

Q. What would you change in providing Palliative Care in Uganda?

A. We need several kinds of care. Here in Uganda we have small hospices that have started but most of the patients and are in the hospitals. With Palliative Care you have to do for the patient what they need right away without having to go through a bureaucratic process, yet hospitals are bureaucratic. So we need to have nurses who are trained to stay in the job they have been trained to do rather than moving them to positions where they are not going to be able to practice palliative any more.

Palliative Care also needs time and the saddest thing is that we have got such a huge population and a few Palliative Care nurses. Sometimes patients are seen in a very rapid way and as a result they do not get to tell the whole story. To assess a patient properly you need up to an hour and a half for the first assessment. We need more trained people in Palliative Care so that there are fewer patients per provider.

One of the other gaps is that government of Uganda has not recognized Palliative Care as a specialty and this is a huge problem. It has been recommended by World Health Organization that Palliative Care be brought in as soon as a diagnosis of an end of life condition has been made. You cannot walk in, the day before a patient dies and help them because you do not know them. You do not know their life. It is more important to know the person who has the disease than the disease one has.

Q. What can government do better?

A. Government can start paying people in palliative care better by allocating more money in the financial budgets. To keep the palliative care vision going forward we need more resources and yet the donors are saying, 'what is the government doing'? Our government is not supporting us financially yet.

Also everybody has not heard of palliative care. We have people who say I never heard of it. My loved one died in agony. It is important that we are able to approach death with all the help we can get.

Q. In a sentence or two, at 20 years what is worth celebrating?

A. All that I have talked about is worth celebrating. The people at PCAU have really done a wonderful job. They have spread Palliative Care throughout the country. They have founded a model for the whole of Africa. We must celebrate all the nurses that have been trained by them, all the patients that have received care. We have to say congratulations to the team at PCAU for wonderful work over the last 20 years.

Palliative Care in Uganda, the achievements and what remains to ensure access for all in in need.

By Agnes Kyotalengerire

"My father passed on last year after a long battle with throat cancer. It is still difficult to cope after one year of his absence. He was always a string a jolly man. He was friendly and he loved us. One thing that keeps me going is the fact that my father never die in pain. He had a gentle death. He won the battle."

This is the testimony of Vanensio Natuhwera a staff member at New Vision.

Natuhwera recollects that in 2017 his late dad John Bagatireyo was diagnosed with cancer of the throat at the Uganda Cancer Institute (UCI). The detection was late because the cancer had advanced to fourth stage. The oncologist (doctor who treat cancer patients) recommended chemotherapy and radiotherapy treatment. But the hectic process of doing investigations (tests) had won out Mzee Bagatireyo.

"He told us that he was not afraid of death but his biggest problem was too much pain and spending long hours of waiting in hospital corridors even when he was told that that his disease was not being treated for sure. He wanted treated for pain and at home not in hospital"

Natuhwera narrates that it is at UCI that they met a nurse who referred them to Hospice Africa Uganda in Makindye Kampala suburb. They were well received at Hospice Africa Uganda and Mzee Bagatireyo was started on Oral Liquid Morphine.

This is a form of medication used to relieve moderate to severe pain. Morphine belongs to a class of drugs known as opioid (narcotic) analgesics. It works in the brain to change how your body feels and responds to pain.

Later, Natuhwera's father was referred to Mobile Hospice Mbarara for further management.

Natuhwera says the palliative care team in Mbarara offered his dad the best care possible.

"When my dad was very sick and we could not drive him to hospital to receive his medication, they continued coming home to treat him. May be my father was able to live for another year because the care he received. The nurses from Mobile Hospice Mbarara" he recalls and is quick to say, the continued treatment enabled his ailing father to live for one more year.

Natuhwera says the palliative care services rendered to his father enabled him to die pain free and a happy man in the comfort of his home just like he had wished.

It is a similar story is shared Philomena Okello, a retired Palliative Care Nurse and Board Member of the Palliative Care Association of Uganda (PCAU). She says that before her late father died, he benefited from palliative care services for 11 years.

"My father had chronic heart disease, hypertension and diabetes with all the associated complications. But what really makes me happy is that he died without pain and smiling after he was given palliative care," Okello recollects.

Natuhwera and Okello testimonies are few among thousands of people who have benefited from palliative care over the past years since the service was introduced in Uganda in 1993. The Palliative Care Association of Uganda was formed six years later to champion the role of advocacy to ensure that the service would grow and be available to all people in need in the country.

Achievements so far

Dr. Ekiria Kikule who is the current Board Member of Palliative Care Association of Uganda notes that the association has scored well in terms of supporting other organizations to provide palliative care.

"PCAU has been providing updates on new innovations, policies, law and regulations," notes Dr. Kikule who also doubles as a former Executive Director of Hospice Africa Uganda.

Dr. Kikule adds that PCAU helped to maintain that necessary bridge between the various palliative care actors who are mainly private entities and the Ministry of Health.

'PCAU has worked collaboratively with the Ministry of Health since it was formed. It is not surprising that the Ministry of Health has integrated palliative care into all key health sector plans since 2004" Dr. Kikule note.

Dr. Kikule says that over the years, the association has also provided health workers with training opportunities in palliative care. These palliative care trained palliative care providers have led to the spread of palliative care services.

For instance Philomena Okello who benefited from a scholarship offered by PCAU undertook Diploma in Clinical Palliative Care initiated the first Palliative Care Unit in a Government Hospital in 2003. The Palliative Care unit Lira General Hospital was a point of reference for many other public hospitals to start similar units.

Okello shares that beginning the palliative unit was not a very rosy venture. She says that even when she was equipped with the palliative care knowledge and skills, she lacked space; a room where to treat the patients. When shared her challenge with Dr.

Dr. Amandua Jacinto the retired Commissioner Clinical Services in the Ministry of Health is one of the Palliative Care Champions in Uganda.

Jacinto Amandua who by then was the Commissioner Clinical Services at the health ministry and very stronger promoter of Palliative Care, he advised her to start offering palliative care under a mango tree.

"There are many mango trees around that compound of Lira Hospital, if there is no space in the hospital buildings do not wait. Start offering palliative care under a mango tree," Dr. Amandua told Okello.

Fortunately, it did not take long before the hospital provided three rooms plus all the required drugs and equipment for Okello to start offering a palliative care. According to Okello the turn up was overwhelming. So many patients with pain who were earlier seeking treatment at Hospice Africa Uganda in Makindye and Mulago hospital started pouring in.

Alongside offering treatment, Okello also carried out a continuous medical education. Everybody including the Ag. Hospital Medical superintendent then Dr. Alfred Nyankori embraced palliative care. Dr. Nyankori was by then acting on behalf of Dr. June Ruth Aceng (current Minister of Health) who was Medical Superintendent and had gone for further studies. When she finished her studies and retuned, the services continued to be embraced. By that time the palliative care team had been fully constituted. Dr. Adrew Ocero, Sr. Winnie Elem, Sr. Gorreti Okello and others were all at the fore front.

Dr Samuel Guma the Executive Director of Kawempe Home Care which is a palliative care facility and a former President of PCAU notes that one of the achievements of PCAU has been the biennial palliative care conference. The conference has attracted delegates from the USA, Europe and other regions. Dr. Guma notes that the conference has given local researchers an opportunity to show case their work and learn from each other.

In 2017, PCAU and the Uganda Cancer Institute entered a strategic partnership to form the biennial Joint International Conference on Cancer and Palliative Care. This partnership, according to Dr. Guma has enabled better recognition of palliative care as a critical component in care for patients with cancer.

Some of the PCAU Members in a group photo after the Annual General Meeting (AGM) in May 2019 at Fairway Hotel in Kampala.

Mr. Robert Sentenza the District Health Officer (DHO) of Kakumiro District who is also former Board Member of PCAU notes that with support from donors, the association was able to move from a rented place in Makindye to a bigger permanent home in kitende, a milestone which members are proud of them. Additionally, Mr. Senteza says that the membership of the association was small but over the years it has grown over time. He credits credible leadership of the PCAU Secretariat for this growth.

"Often it is not easy to have the membership grow unless you have able; dedicated leadership, good advocacy and people working as a team," notes Mr. Sentenza.

Challenges

Highlighting the challenges, Dr. Kikule notes that there are still some struggles. For instance palliative care is not yet fully integrated in the mainstream public health structure. She adds that budgetary allocation by government towards palliative care is not adequate and there is need intense lobbying for this to happen if palliative care services are to be sustainable in Uganda.

Dr. Kikule adds that health workers who are trained in palliative care are not yet recognized in public service structure. Consequently, they end up deployed to do other activities. As such, they end up offering palliative care palliative care as a hobby instead of practicing palliative care to build a team around them.

Mr. Sentenza agrees with Dr. Kikule. He says that there is need to strengthen advocacy, stakeholder engagement to ensure that recruitment is done at policy level, so that people get motivated to do what they studied.

Although awareness has been done to some extent, Dr. Kikule says that there are still so many myths and misconceptions surrounding palliative care. For example when attendants are advised to take their patients to Hospice, they automatically think it's a death sentence.

As such, Mr. Senteza advises that there is need to sensitize people and let them know that palliative care services are available at health facilities. In addition to strengthened delivery of services, coordination to ensure that the biggest number of Ugandans know what palliative care is, its benefits and how they can access the services.

Dr. Guma notes that lack of a national palliative care policy is still a major challenge for the entire palliative care fraternity and that this has limited the steady progress of countrywide integration of Palliative Care into the health system.

Word of advice for PCAU @20

Dr. Kikule is grateful that PCAU has evolved from an idea to an organization that is growing over the last 20 years. She notes

Dr. Samuel Guma (on the left) and Dr. Henry Ddungu Co-chaired the 2nd Uganda Conference on Cancer and Palliative Care in September 2019 at the Kampala Serena hotel.

however that it is not time to celebrate entirely because there is a lot that needs to be done especially since many patients and their families who need palliative care cannot access them in Uganda.

Dr. Guma urges for continued advocacy for the establishment a National Palliative Care Policy. He also calls upon the Ministry of Health should to scale up the recruitment of palliative care workers into the public health system.

Dr. Guma advises PCAU to provide technical assistance in resources mobilization for member organizations in addition to playing a leading role in mobilizing resources and providing sub grants to member organizations.

Both Dr. Kikule and Dr. Guma hint on the need for need for PCAU to establish a research agenda and to strengthen the local knowledge base for evidence based programming. They note that collaboration with universities could help in increasing the number of Masters and PhD research papers on palliative care.

Dr. Lydia Mpanga Sebuyira is the founding PCAU President and Board Chair. As the association marks 20 years of existence, she reflects on the journey and what motivated the establishment of the association in an interview.

Starting Palliative Care Association of Uganda was a leap of faith - Dr. Sebuyira

Q. What motivated you to be among the brains behind the establishment of PCAU?

A. I got into Palliative Care by accident. I had been working in Newcastle when a friend who was working in Sunderland in a hospice got involved in an accident and was put on bed rest. So I was asked to step in for her for five months.

My motivation for Palliative Care was driven by the fact that it is holistic. It takes in the whole of you. I am a musician and also a born-again Christian. And all these aspects of me got involved in hospice. I could use music to fundraise for Palliative Care activities but also as a relaxation therapy for patients.

I love working with people and in Palliative Care you work as a family. So getting to know people and being part of the team motivated me.

Particularly, I was motivated to come back to Uganda, after seeing a card made from back cloth bearing a picture of a woman wearing *busuuti* that Rose Kiwanuka the former Country Director of PCAU had left in a small hospice in Sunderand in northern UK. Kiwanuka was the first nurse at Hospice Africa Uganda. It made me realize that we have a hospice in Uganda. So I wanted to come back and find out more about it. After returning to Uganda, I got recruited into Palliative Care.

Q. How did you conceive the idea of establishing PCAU?

A. Around 1999, we were already teaching health workers from the health ministry about Palliative Care. Around the same time, we decided to start the Palliative Care Association of Uganda (PCAU). Upon completion of the training program, the trainees definitely became the first members of the association.

Additionally, we had volunteers such as Rose Kiwanuka who had been in Palliative Care since 1993. The association comprised of a small committee and we did not have employees. We met monthly and the meetings included people who had trained in different areas to discuss different topics concerning Palliative Care.

The monthly meetings also aimed at advocacy because we believed that for palliative care to take root, we needed the public and health care providers to get educated and sensitized. Additionally, the availability of strong painkillers such as oral morphine which is regarded as a pillar of enabling patients with cancer or HIV to live without pain was critical.

Q. How did you manage to work without pay?

A. When you care about something, you are passionate about it and you want it to work. Besides, there are other areas of life where you volunteer. For example, you might be part of a choir or at a rotary club where you are giving in part of your time. So we got a strong conviction that palliative care was so important that we needed to start it. But the team of volunteers also worked at Hospice. We had a salary and we did this as part time with the mission to spread palliative care to all parts of the country.

When Kiwanuka became a full time employee, we had to raise funds for her salary through proposal writing.

To me, it all rotates around passion and pay comes later especially when you begin to see things working. Realizing that there is a structure that enables people to receive Palliative Care wherever they are in Uganda gives me satisfaction.

Q. What were the major struggles during your term of service?

A. The biggest problem was the phobia or myths about morphine that people thought caused addiction. But Dr. Jack Jagwe a senior physician was able to explain to people that giving a patient oral morphine does not kill. Instead it gives them a new lease of life and they are able to eat and sleep better.

The other trying moment was beginning as a small system and learning how to manage small firms. Luckily, Kiwanuka managed to grow the team and trained them on issues of accountability, which is key to the donors.

Currently, there is a problem of donor fatigue. Many donors have run out of money. Others are cutting down on the amount of money they are giving to Palliative Care associations. So we need to get more funding from Uganda to ensure Palliative Care services are available because no one wants to die in pain.

Also, a lot of people who have been running various specialties are retiring and leaving Palliative Care to be managed by young people. These may not have the desire to see Palliative Care grow.

Q. What would you consider as key achievements during your term of service as PCAU president?

A. A committee was started with support of the World Health Organization in five countries to enable the introduction of Palliative Care. These included: Uganda, Kenya, Zimbabwe, Botswana and Ethiopia. WHO funded the five countries and paid consultants to establish Palliative Care. I was a consultant for Zimbabwe and Tanzania while Dr. Jagwe was sent to Ethiopia. We had to form a committee at country level which had an advocacy role for the institutions.

There was an already existing law that allows nurses and midwives to prescribe pethidine a form of painkiller. With support from Dr. Jacinto Amandua who was the head of clinical services at the Ministry of Health, we used the same law too and managed to get a bill passed to allow nurses and clinical officers who had been trained in palliative care to prescribe oral morphine. It took us four years, but this was a great achievement making Uganda one of the first countries to allow

nurses and clinical officers to prescribe oral morphine.

During my tenure, Palliative Care Association of Uganda created a database for all health workers trained in Palliative Care across the country. These can follow up patients wherever they are and offer Palliative Care services.

PCAU sponsored nurses for training as part of the care nurses. Additionally, PCAU took part in curriculum development and has been conducting conferences regularly. Working with sister organizations such as Hospice Africa Uganda, Mildmay Uganda, PCAU has continued to grow. Currently, it is a model for other Palliative Care associations in other countries such as Kenya and Zimbabwe. Zimbabwe consults PCAU on issues of Palliative Care although they had established the Palliative Care much earlier than Uganda.

Q. What is your last take on the way forward?

A. We still need to get the young people involved in Palliative Care. We can do it through the schools, making sure the schools have tutors who are trained to offer palliative care. It is like baking a cake with fruit, instead of adding the fruit after the cake is baked. In addition, all tertiary institutions for health workers should have a strong component of palliative care. We must have palliative care at central level; at the health ministry and having people who are passionate about it.

Palliative care has largely concentrated on people with cancer and HIV, but there are people who are battling with terminal illnesses resulting from stroke, diabetes, and kidney disease among so many. But the challenge is that the funding is not there to cover everybody. That is why I still believe that palliative care needs to be streamlined into everything so that people who care for the elderly, people who care for children with cancer and ordinary physicians can still offer palliative care and only refer the difficult cases. Just like a physician can refer a complicated ear, nose and throat (ENT) case but can treat a sore throat.

The area of palliative education needs to be expanded. Hospice Africa Uganda has the Institute for Palliative Care for Africa which is now semi-autonomous. That needs to grow or be funded because we are not training for only Uganda but to serve across Africa.

The bereaved also require Palliative Care-Dr. Amone

Dr. Jackson Amone is the commissioner Clinical Services at the Ministry of Health spoke to Agnes Kyotalengerire talked about the importance Palliative Care. Dr. Amone emphasizes the need for holistic care while focusing on the patient, the immediate family and the community while offering palliative care.

Dr. Jackson Amone

The thought of having a loved one fighting for life against a terminal illness is a painful experience. Looking at a loved one counting their last days can equally take a toll on the family. That is why Palliative Care goes beyond looking at the patient. It also encompasses how family members of the patient are prepared for the eventual bad news.

Dr. Jackson Amone, the commissioner Clinical Services at the Ministry of Health, agrees with this assertion.

"The family of the patient has to be prepared psychologically to accept the reality that the patient is going to die," he explains.

According to Amone, the care-taker should equally prepare the patient for this eventuality.

It is not only about managing pain. The social and psychological aspect of the patient are also considered as an illness, he says.

"You know that the patient is going to die, so prepare the patient and the relatives to deal with the tragedy." Dr. Amone Says.

Amone argues that the relatives need to know that the morphine given to the patient is meant to relieve pain but not to cure the pain. It is unfortunate that some caregivers tell the patient the contrary.

Studies show that family care givers need Palliative Care when the patient is still alive and when they die.

A study dubbed: "Care grieving in palliative care: Opportunities to improve bereavement services" by Palliate Medicine, published in December 2018 shows the need to meet the psychological needs of family caregivers.

Explaining the study findings, Dr. Amone says Palliative Care needs to continue during the period of grieving—when the relatives are mourning—and when the patient passes on also termed as bereavement.

He describes bereavement as an overall adaptation to death. It is the process associated with loss and grief, the state of having suffered a loss through death and responding to the loss, learning to live with the loss and dealing with the pain of death. This process does not have a time limit. It is influenced by different factors ranging from the relationship of the bereaved person to the deceased, the cause of the death, the age of the deceased, past experiences of the bereaved in handling crises and support systems.

From the left, Dr. Amone Fatia Kiyange the Programs Director at the African Palliative Care Association (APCA) together with Ruth Omondi and Geoffrey Opio Atim both staff of the Open Society Open Society Initiative For East Africa (OSIEA). Photo was taken at a meeting convened by APCA on Universal Health Coverage and Palliative Care in April 2019 in Kampala.

As a top technocrat, Dr. Amone says that he has engaged many leaders in the health sector to ensure that their medical staff are well equipped with knowledge and skills to offer palliative care. He says that when a person dies, the bereaved should not be abandoned, as if Palliative Care is only for the patient and family members. He notes that according to the Universal Health Coverage guidelines, the failure to provide care services to the bereaved as well means the package is incomplete.

Refugees in need of palliative care:

Studies indicate a great need for palliative care among refugees and the displaced population.

"Some refugees come in with chronic illnesses, others with psychological issues that require palliation," Dr. Amone explains.

Uganda hosts the largest refugee population in Africa, according to the UN refugee agencies. The number is estimated to be over 2 million refugees mainly from South Sudan.

History of Palliative care in Uganda:

The palliative care journey in Uganda has not always been smooth. Dr. Amone says when it was first introduced in Uganda, health workers, especially doctors, resisted it. "They thought the medicine (pain killer) was meant to kill the patient gradually," he narrates.

While doctors kept off, nurses and clinical officers, quickly embraced the services. Now many people and providers have come on board after concerted sensitization by the government.

The health ministry went a step further; it supplied oral morphine to health facilities to

support patients in need of palliative care. It also acquired a statutory instrument to allow nurses and clinical officers to start prescribing morphine, a drug that only doctors were authorized to administer.

Once the ministry embraced the services, Dr. Amone says, NGOs quickly joined the effort. Among those was the Palliative Care Association of Uganda (PCAU), an umbrella organization that promotes palliative care services in Uganda.

Ministry of Health collaboration with PCAU

With NGOs in the drive, Palliative Care services has continued to improve. The ministry opened a Palliative Care unit in the department of clinical services. It was upgraded to a division, headed by an assistant commissioner to strengthen the coordination of Palliative Care services.

"We also have a Principal Medical Officer and a Clinical Medical Officer. The three officers will be coordinating the work of NGOs engaged in Palliative Care services," Dr. Amone explained.

The services can only improve even further as hospitals also jump on board. For instance, Kirudu and Kawempe hospitals have set up Palliative Care departments. While they do not have the mandate to admit patients, the patients can consult them for treatment, Dr. Amone notes.

Message for PCAU @ 20 years

Dr. Amone notes that the Ministry of Health is committed to working with the PCAU and other development partners. In September 2019, during the sixth international African Palliative Care Conference in Kigali, health ministers committed their countries to promote Palliative Care. Uganda was represented by Hon. Sarah Opendi.

This, according to Dr. Amone, shows how the ministry is committed to working together with the actors in the civil society to enhance palliative care.

"We appreciate the work that PCAU is doing because they are filling the gaps; doing activities on behalf of the ministry. Together, we have developed guidelines and policies for delivering of palliative care services. But most important is the commitment to work together to provide cost-free morphine." Dr. Amone concludes.

Now there is Palliative Care in over 100 hospitals in Uganda- Dr. Sebisubi

Dr. Fred Sebisubi Musoke is the Assistant Commissioner for Pharmacy in the Ministry of Health. His job puts him in charge of quality assurance within the pharmacy sector. He has previously held the position of Principal Pharmacist in the same ministry and has been engaged with PCAU's work since it was founded. We spoke with him about the access to Palliative Care medicines in Uganda.

Dr. Fred Sebisubi

Q. How was the Ministry of Health handling the need for Palliative Care in the country before PCAU was founded?

A. At that time there was a big gap in terms of the knowledge about Palliative Care as well very little or inadequate provision of services. We had challenges of capacity in terms of the human resource and medications for provision of palliative care. PCAU came in to assist

by working with the Ministry of Health to address those gaps. My role as a government pharmacist was to see how we could improve the supply of medicines which are very critical. That is how I came to be very active in the activities and operations of PCAU.

Q. How serious was the problem of lack of Palliative Care medicines at the time?

A. There was no accessibility to morphine, yet the World Health Organization (WHO) recommends utilization of opioid medications like morphine and other analgesics in management of chronic and severe pain. What were available were simple pain killers and yet management of pain is very critical to palliative care. Nothing can be done without the appropriate medications. We were trying to find ways to make these opioid medications accessible to those who need them because palliative care is supposed to be for all.

Q. How did the collaboration between the Ministry of Health and PCAU work to make medications available to those who need them?

A. Initially we worked with Hospice Africa Uganda which introduced the morphine powder. PCAU came in to join hands. After some studies and the evaluation of the costs involved, we found out that utilization of the liquid morphine was far cheaper than procuring morphine tablets. We jointly identified where we could reconstitute the morphine powder into an oral liquid solution. We initially identified *Joint Medical Stores* which had a reconstitution facility. They were reconstituting powdered morphine for us into a solution and packing it for patients. It was however very challenging because health workers needed to travel from their facilities where we had introduced palliative care to the Ministry of Health headquarters to get their orders sanctioned and thereafter move to *Joint Medical Stores* to get their supplies. Another challenge was that that morphine had a very short shelf life of three months. That meant that they had to reconstitute it as soon as they received the orders. So it involved moving back and forth. And even then, after three years the unit at the *Joint Medical Stores* was shut down and we had to identify another facility.

Q. How then did you move forward?

A. We identified Mulago Hospital which had another IV unit. We engaged them and they started reconstituting this solution, but we continued with the same challenges of health workers moving up and down. Because of those challenges we identified Hospice Africa Uganda to do the reconstitution, while at the same time we engaged National Medical Stores to do the distribution. At the same time, a lot of research has been done to increase the shelf life of the liquid morphine. Right now the liquid morphine we have has a year's shelf life. This has greatly improved its availability. Before that we were loosing a lot of money because a lot of it was expiring at the health facilities.

Q. Prescription of morphine was also a challenge. How did you address it?

A. Because it is a Class A medication, only medical doctors and dentists could prescribe it. Collaboratively with PCAU, the ministry reviewed and improved the National Drug Policy to come up with a statutory instrument which has allowed other health workers, specifically nurses and clinical officers to prescribe this medication. That has also greatly improved accessibility.

Q. Morphine is a very expensive medication, how do you make it accessible to the poor people who need it?

A. We did a survey in terms of costing. When you are procuring tablets, it is very expensive. The powder and the cost of reconstituting it as a solution is slightly cheaper and with a cheaper medicine we reach more people who are in need.

Q. Considering Uganda's health structure, at what level is morphine prescribed to patients with severe and chronic pain?

A. If you look at Uganda's health structure we have levels from the National Referral Hospital, Regional Referral Hospitals, General Hospitals and Health Centre IV, III and II. We are currently accrediting facilities where morphine can be prescribed up to Health Centre IV. We have several health workers, including nurses and clinical officers who are qualified in management and dispensing this medication up to that level.

Q Have Ugandans been receptive to using morphine for pain management given that it is a highly classified medication?

A. PCAU has done a lot of sensitization including bringing on board politicians at all levels right from the grassroots up to parliament, which has helped people understand the need and manner in which morphine may be prescribed. Even health workers used to fear to prescribe it because

it is a Class A medication which has to be recorded. In addition, the liquid oral morphine solution that we opted for as a country, which we have been monitoring, has not had any cases of addiction. So that fear for oral liquid morphine is not really justified.

Q. As a health worker what more would you like to see improve in terms of providing Palliative Care in Uganda?

A. From the Ministry of Health our vision is to ensure that we avail medical supplies and that the people responsible for diagnosis and prescribing these medications are there. Right now, we have over 100 districts where palliative care is being provided which was not the case was before. It is a result of collaboration with PCAU that we have managed to achieve this. In terms of training health workers, accrediting health facilities and collecting data to inform decision making, they have been key actors. We want to ensure that all districts in the country offer palliative care services and that all clinical officers have the skills to diagnose and offer palliative care services. We want to ensure that all health care training institutions have modules on palliative care within their training programmes.

Q. Would you consider the collaboration between PCAU and the Ministry of Health a success?

A. Yes, because here at the Ministry of Health we may not have enough capacity therefore we have seen a very big input and impact while working with PCAU.

Reflections of the Past & Dreams for the Future.

By Roberta Reynolds Spencer, Volunteer; Center for Hospice Care, Inc., South Bend, Indiana, USA

Roberta with Margret one of the children supported by PCAU on the Road to Hope Program

"Once You Have Faith, God Will Show You How"- Rose Kiwanuka

As the Palliative Care Association of Uganda celebrates its twentieth year, I join everyone in congratulating all the many staff members and supporters who have helped make these past two decades so extraordinary. I'm grateful to have been involved for part of this journey and I'm especially honored to be asked to share a reflection on this special occasion.

My first visit to Uganda occurred in March 2009 as part of the newly established partnership between The Center for Hospice Care in South Bend, Indiana and the Palliative Care Association of Uganda (PCAU). No one could have foreseen from that initial meeting how this partnership would grow. There have been many tangible success stories since, but it never would have occurred without the strong leadership, friendships and relationships between the staffs of PCAU and Hospice. The partnership has thrived because it is predicated on trust, honesty, camaraderie, teamwork and an open mindedness to learn from mistakes.

One of the many joys I have had on this journey is getting to know so many wonderful people. I consider the PCAU staff as my teachers. They have taught me about patience and persistence, simplicity and sacrifice, and doing what you can with the resources you have. When I think of the tireless dedication of everyone at PCAU to help the people of Uganda I'm reminded of a quote from St. Francis of Assisi: "Start by doing what is necessary; then do what's possible; and suddenly you are doing the impossible."

I'm especially grateful for my friendship with Rose Kiwanuka who has taught me so much about the people and culture of Uganda, but more importantly how to make the "impossible" happen. Her wisdom, guidance and compassion laid a solid foundation for programmatic growth.

It has been gratifying for me in my decade of working with PCAU to see the message of Palliative Care take a stronger hold in the Ugandan Health Care System. The ongoing effort to correct false notions in relieving all aspects of pain associated with terminal illness, has been a long and arduous one. Yet, after accompanying Rose and other staff members on so many trips throughout the country and watching them deliver the message of Palliative Care to doctors, nurses, hospital administrators, area clergy, government leaders and anyone else who will listen, I know that Palliative Care in Uganda is more firmly established.

The number of lives touched by the services of PCAU are widespread and unimaginable**. If I had one dream for the future it would be that when PCAU celebrates its 25th anniversary, Palliative Care will be available throughout the entire country. Yes, it's a dream, but as St. Francis said, doing the impossible begins with doing the necessary.**

I have been especially humbled to have traveled to so many areas throughout Uganda witnessing the immense needs facing so many. As an American I initially looked at things through middle class values, but quickly learned in doing so leads to frustration and disappointment.

It was when I stopped comparing that I was quickly able to see things as they were. People were welcoming and friendly. They met their day to day challenges with integrity and fortitude, perseverance and determination and a sincere appreciation for what they have rather than what they don't have. I have been fortunate to have visited people's homes, listened to their stories, and shared their vision for a better tomorrow.

I have played with children, attended their classes, and found in their dreams a brighter future. I have participated in parades at the launching of palliative care, in educational training programs, in District Meetings, in meetings with the Ministry of Health, and a host of community leaders.

I never thought I would make a difference, but I did believe we, the Center for Hospice Care and the Palliative Care Association of Uganda, could make a difference. Together we have! My dream is that this togetherness will be carried into the future.

No reflection would be complete without mentioning something near and dear to my heart, the Road to Hope Program. When I made my first visit ten years ago, I never would have imagined that there would today be an educational program for child caregivers.

It is a further testimony to the dedication of our partnership that we have been able to look at the long-term effects of families facing terminal illness and death by addressing the "bigger picture" of the future, the children. The program currently provides, or has provided, for over 60 children educational opportunities and optimism to reach their dreams.

The challenges for the Road to Hope are numerous with rising educational costs, increased needs, and expanding services. Another dream I have for the future is that the Road to Hope will be able to sustain itself with the necessary financial resources and sponsorships to continue to provide education for children who otherwise would not have it.

Each experience is a reminder of the precious value of life and most importantly to look for God in the faces of others. I'm reminded of how good my life is and how much better I could do in living more simply and with less waste, the need to be more compassionate and understanding and to look for ways to create a deeper appreciation and acceptance of diversity.

My experiences have taught me that while it is important to make big changes and big differences, it's in the simple day to day acts of charity and kindness which affirm our humanity and commitment to one another.

It's part of the challenge we all have if we are to live out our spiritual beliefs remembering: "The deed you do may be the only sermon some persons will hear today." (Saint Francis of Assisi) God will show the way!

Uganda's Renewed Efforts to Improve Access to Palliative Care as part of UHC.

By Agnes Kyotalengerire

Without appropriate palliative care, terminal illness usually comes with too much suffering and pain. Experts say that lack of or provision of poor palliative care is one of the reasons why people with terminal illnesses die sooner than they should.

The Deputy Speaker of Parliament, Jacob Oulanyah met some members of the palliative care fraternity in Uganda in May 2019. He commended PCAU and other Civil Society Organizations that provide palliative care and tasked them to engage Government to avail more funding to the sector.

In Uganda, out of the 135 districts in the country, palliative care services have spread to only 97 districts. Even then, palliative care services are not fully integrated into health care systems in all the 97 districts. As a result, only 11% of Ugandans who need pain control and palliative care access it. The country's Health Sector Development Plan 2015/16 - 2019/20, shows that palliative care services are being offered in only 4.8% of the public hospitals.

Despite the challenges, government has renewed efforts to scale up access to palliative care across the country.

Honorable Sarah Opendi, the Minister of State for Health (General Duties) notes that palliative care is considered a priority area in health care provision in the country.

"When one talks about universal access to health care, that package should include palliative care. That is why it is a priority for government to ensure access to palliative care services across the country," says Sarah Opendi.

Universal health coverage (UHC) means that all people and communities can use the promotive, preventive, curative,

rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.

What is palliative care?

According to World Health Organization, palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through prevention and relief of suffering. It includes treatment of pain and other distressing symptoms, both physical, psychosocial and spiritual.

Medical experts say that while the Government has put much effort in providing holistic health care services, there is need for more sensitization about palliative care. This requires Government and all stakeholders to put more efforts in ensuring that palliative care is provided for every Ugandan with chronic illness.

Many Ugandans are ignorant about palliative care. Those who are aware of it are frustrated because the services are not readily available. Health ministry statistics show that non-communicable diseases account for 33% of all deaths in Uganda. For instance, cancer is increasingly becoming a challenge to many families. In 2018, there were 32,617 new cancer cases and 21,829 cancer deaths were recorded in Uganda. These conditions require palliative care.

Development of Palliative Care in Uganda

Rose Kiwanuka, the former Country Director of the Palliative Care Association of Uganda reechoes the importance of Palliative Care in Universal Health Coverage. She explains that Palliative Care as a component of UHC has a central place in achieving the Sustainable Development Goals (SDGs) by 2030. The majority of adults in need of Palliative Care have chronic diseases such as cardiovascular diseases, cancer, chronic respiratory diseases, AIDS and diabetes explained Kiwanuka, in reference to the WHO classification.

In Uganda, Palliative Care has just recently been integrated in medical courses that are offered at degree and diploma levels at Makerere University. Some nursing institutions also teach the course under diploma levels.

However, sector players say there is need for more funding for the health sector to be able to take the services closer to those in need of Palliative Care, especially given that a big majority of Ugandans live in rural areas. With this in mind, the Government will work towards extending Palliative Care services to health center IIIs and IVs.

Way forward

Ultimately, Uganda's healthcare system needs to establish a palliative care policy whose aim would be to ensure that palliative care challenges are mitigated. There is also a need for adequate funding to run these services. That said, one must appreciate that at ministerial level, a division for palliative care under the department of clinical services was set up to meet these needs. Therefore, it is this division's cardinal responsibility to push for palliative care services to be carried out in health facilities. As of November 2019, this division was not yet operational. Key staff had been recruited to manage the division. Although the policy was drafted pending stakeholder discussions and benchmarking, it stalled after a commissioner who was handling it retired.

"During the last African Palliative Care conference in Kigali, I realized that Uganda had not made much progress as far as providing Palliative Care services was concerned. This was unacceptable because we had earlier pledged that we would deliver these services to the people of Uganda. Therefore, my team will ensure that by the end of 2020, the health ministry will have presented the drafted policy to cabinet to be debated and passed," Opendi pledges.

She further notes that the presence of many Ugandans grappling with terminal illnesses calls for practical and professional methods to give citizens proper Palliative Care services. Drugs like morphine, which is supplied by the National Medical Stores and the Joint Medical Stores, should be readily available to those who need it – people in extreme pain due to severe illnesses like cancer.

"We need to create awareness, especially among political and religious leaders, so that they can sensitize their communities about these pain relief services. Ultimately, the goal of the health ministry is to see that no Ugandan lives and dies in pain," Opendi says.

Scaling up *mHealth* Palliative Care Surveillance in Hospitals and Hospices.

Cynthia Kabagambe
ICT & Data Quality Officer

With support from our partners- Centre for Hospice Care, University of Notre Dame and Uganda Martyrs University, PCAU has been piloting a palliative care surveillance using smart phones for the last four years.

In this surveillance, smart phones are used to collect and send data on a monthly basis on palliative care services at different health facilities. The information obtained from this exercise provides evidence for decision making that enhance the availability and use of palliative care services in Uganda.

The surveillance was first piloted in May 2015 with 4 health facilities and was later extended to 6 more facilities in September 2016. In April 2019, the surveillance was further expanded to cover 20 facilities including both Government hospitals and Private not for Profit hospices and organizations.

Facilities currently on surveillance are;

Arua Regional Referral Hospita, Gulu Regional Referral Hospital, Rays of Hope Hospice, Jinja Kabale Regional Referral Hospital, Kawempe Home Care, Kitovu Mobile Health Care, Little Hospice Hoima Masaka Regional Referral Hospital, Mbale Regional Referral Hospital, Hospice Tororo, Adjumani District Hospital, St. Mary's Lacor Hospital, Matany Hospital, Soroti Regional Referral Hospital, Kisoro Hospital, Fort Portal Regional Referral Hospital, Bombo Military Hospital, St. Francis Naggalama Hospital, Hospice Africa Uganda and Mobile Hospice Mbarara.

Some of the representatives from PCAU mHealth Project implementing hospitals in Uganda in a group photo after a project meeting in Kampala.

Palliative care providers from these facilities have been trained on the use of ODK Collect and Ona applications that are used to collect data.

PCAU is working towards having the mHealth Palliative Care Surveillance in at least 40 health facilities by 2021.

We greatly appreciate all the support and collaborations received from donors and partners.

A NEW HOME FOR RAYS OF HOPE HOSPICE JINJA

BY Sylvia Nakami, Executive Director

New Home

A dream came true for Rays of Hope Hospice Jinja on September 1, 2019, when we took over our new home on Kiira Rd 18 B. A beautiful house which will allow us to grow and expand our activities, which are so needed in Busoga region.

The need for a conducive working space for Rays of Hope Hospice Jinja began with the inception of our organization in 2005. We were blessed when the DMO's office gave us a space for our operations in 2005, but we have always had a desire to have our own home for our offices. In 2015, the board started to seriously pursue the dream. The different options that were looked at included Church of Uganda and at Jinja Regional Referral Hospital.

Rays of Hope Hospice Jinja and the Palliative Care Association of Uganda organized a fundraising dinner for the purposes of securing a home for Rays of Hope Hospice Jinja, where 13,682,000UGX was raised.

In April 2019, Fr P.G. Picavet generously offered Rays of Hope Hospice Jinja his house at half its market price. With the funds secured from the dinner, we still needed 98.6% to have the house.

A miracle happened when Friends of Rays of Hope Hospice Jinja in Ireland offered to pay for the house.

Rays of Hope Hospice Jinja is now proud in its house thanks to FR P.G. PICAVET, HOSPICE JINJA IRELAND and many others including PCAU. A recognition tablet has been developed with all the funders of the house, recognized specially for their support.

Staff and Volunteers Cut Cake during House Warming event

One step at a time with Road to Hope

By Mark Donald Mwesiga.

Julius Emukule, 17 is a tall, handsome, confident and brave 'young man'. He is athletic and therefore a fast walker. The distance from his home village of *Morekebu* in *Kwapa* sub country to Tororo Hospital is about 8 miles. This is the distance that he has walked many times back and forth during three harsh episodes of his young life. He recounts the episodes thoughtfully with stature of an old man.

In one of the tribes in Uganda, there is common proverb which can be paraphrased as ***'stories of tribulations are not only told by elders but even by children who have lived through trouble'***. Of course the norm is that it's the old who tell stories. All sorts of stories. In fact, for this particular tribe, many homesteads still have fire places where young children gather every evening to listen to escapades of their grandparents.

The story of Julius is an adventurous one. He tells it brashly and with confidence of a conqueror. He has seen and experienced what some adults are yet to. Julius doesn't know his biological father. All he knows is that his father was from some distant district and that he was not a good man. Stories are told about the man mistreated his mother until she left the marriage. She travelled back to her parents with two boys. So Julius and his elder brother have grown up at their maternal ancestry home.

Jullius Emukule (second from left) with his brother (on his right) narrate their story to a team of visitors to their home: Mark and Steven from PCAU, Martha from Hospice Tororo.

Julius remembers few days of fun with his mother. The few days are memorable though short. For the larger part of her stay with her two boys, she was tormented by a 'strange sickness' as everybody in the village called it. Together with his two boys, she trenched 8 miles to collect her medicine refills from Tororo Hospital. Months before she died, she was unable to walk that long for her medication. This was Julius' first episode of walking the 8 miles to collect medicine for the one he loved. He had to do this in turns with his brother. One had to remain home to care for the sick mother as the other walked. The journey would begin before sunrise and end at dusk. Almost all the time, there was no meal between the hours of walking. Sometimes there was a piece of sugarcane as an 'energy booster'. Later on, the mother succumbed to AIDS and was buried in front of the house they live in up to now. At least she had escaped the horrendous pain she endured.

"She is resting in peace... " Julius says.

After the death of their mother, Julius and his brother lived with their old grandparents. Soon, the grandmother's health deteriorated. She had been sickly hitherto though not bed ridden. They were in and out of Tororo Hospital. Soon the second episode of walking the 8 miles resurfaced. This time, the walking was not as often because a team from Hospice Tororo visited and delivered the medication regularly. But sometimes it would be investable to walk. On all occasions, Julius picked Oral Liquid Morphine. The lack of this medicine caused sleepless nights at their house. The availability of it meant peaceful rest to their dying grandmother and to everyone in the home. Later on, the grandmother died of liver disease and was buried near her daughter's grave.

The house was now left to three 'men', the young Julius and his brother and their sickly grandfather. The old man became weaker by the day. His energy was giving way. But he often confided in every visitor that he was a happy

man. He was happy because 'good Samaritans' had offered to support his grandson Julius through school. He had been assured that Julius would be supported to continue school even after the death of his parents and guardians. A team from Hospice Tororo visited the old man regularly. Julius and his brother trekked the 8 miles for the 3rd episode to pick medicine refills for another person they loved. The old man died due to prostate cancer in April 2019 and was buried near the graves of his wife and daughter.

The episodes above have an average of three years between each. Whereas Julius was on and off for his school days during that period, his elder brother dropped out of school completely. He got married and started another life of struggle with his young family.

The main reason for Julius's stay in school was the Road to Hope Program by the Palliative Care Association of Uganda (PCAU). The program supports child Care Givers on a range of interventions including Health Care, Psychosocial Support and Education Support. This program is supported by PCAU's partner the Center for Hospice Care in Indiana USA under the arrangement of the Global Partners in Care.

Julius's story is unique but every one of the 58 children being supported by PCAU has a profound story. Suffice to say, these stories are not exclusive to children on this program. There are many other children who are vulnerable in Uganda. Statistics by the Uganda Bureau of Statistics showed that in 2014, of the 17.1 million children below 18 years (over 50.7% of the population) in Uganda, 11.3% were orphans, 8% were critically vulnerable and 43% are moderately vulnerable. Of those who were orphaned, 46% (1,108,080) had lost their parents through AIDS.

The story of Julius is therefore the story on the lips of many children in Uganda. What is paramount to note is that each of these stories can be changed. This year (2019), Julius sat his Primary Leaving Exams (PLE). He is extremely excited that he has attained some level of education. To him and his entire community, this was never envisioned given the circumstances surrounding his upbringing. Julius is an influence to his peers in the community. When a team from PCAU visited Julius at his home recently, he had just returned from giving a talk at his former primary school. As he waits for his PLE results, he has decided to offer his time to counsel his peers on virtues of endurance up to the end. In his former school he is famed for his confidence at public speaking and presentation. Julius is hopeful that he will pass his exams to join secondary school in 2020.

About the Road to Hope Program

The palliative Care Association of Uganda (PCAU) in partnership with Center for Hospice Care (CHC) in Indiana USA, established the Road to Hope project in 2012 with an aim of supporting child care givers for palliative care patients to enroll into or proceed with formal education.

The program was in response to a serious call by health care workers that PCAU should support them to address one of the key psychosocial pain cause among palliative care patients. The pioneer child on the program was George Bazeire who took care of his sick father till death and was thereafter left alone and frightened in a dilapidated house.

Steven Kasula (on the left) and Ronald Waako (on the right) in a photo with Rose Kiwanuka in November 2019. Steven and Ronald have been supported by PCAU under the Road to Hope Program. Steven is a Medical Student and Volunteer with PCAU, Ronald is in his vacation after Secondary School and is a Volunteer at Hospice Jinja.

To date, the Road to Hope Program supports 58 children from various districts. The children are identified in collaboration with palliative care practitioners especially in the rural districts of Uganda.

Key events at PCAU

PCAU is known for organizing big Palliative Care events in Uganda. Zaitun Nalukwago who has been at the forefront of these events gives some highlights about the PCAU Soccer Gala, the Bienniel Conferences and Update meetings.

Zaitun Nalukwago
Administrative Assistant

The PCAU Biennial Soccer Gala

The Palliative Care Association of Uganda (PCAU) has been organizing an inter organization soccer gala as an advocacy and palliative care awareness activity from the year 2009 to date. This has been held in commemoration of the World Hospice and Palliative Care Day (WHPCD). This is a unified day of action to celebrate and support hospice and palliative care around the world. To date, PCAU has held 6 galas bringing together different organizations working in Palliative care and promoting collaboration for advancement of palliative care in Uganda.

One unique thing about the soccer gala is the composition of the teams which should comprise of female players who should be more than the male players on the pitch, as a way of motivating ladies each goal scored by a female is doubled.

Hon. Sarah Opendi before handing over the PCAU Soccer Gala Trophie to the winners Mulago School of Nursing and Midwifery in October 2016.

At the end of the day, awards are given out to the most disciplined team, best female player, 2nd runners up, 1st runners up and the winners of the match.

Over the years, we have had over ten organizations taking part in this activity. Below is how the different soccer gala events have been unfolding in different areas around Kampala:

Year	Venue	Theme	Winners
October 2009	Lubowa grounds along Entebbe Road	Discovering your voice	Reach Out Mbuya
9th October 2010	Makerere University Business School grounds	Sharing the Care	Infectious Diseases Institute
13th October 2012	Makerere University Business School grounds	Living to the end	Hospice Africa Uganda
11th October 2014	Old Kampala Primary School grounds	Who cares! We do	Hospice Africa Uganda
15th October 2016	Old Kampala Primary School grounds	Living & Dying in pain: it doesn't have to happen	Mulago School of Nursing and Midwifery
13th October 2018	Makerere University Sports grounds	Palliative Care – Because I Matter	Reach Out Mbuya

The soccer gala further intends to strengthen networking, raise awareness, advocating for palliative care, exhibiting work done, celebrating achievements as well as exercising and keeping away from non-communicable diseases.

Among other activities during this day is an awareness walk with the band that kick starts the day, opening match between patients/ survivors and the executive Directors of participating organizations, exhibition stalls from different organizations and a health fair where services like HIV testing, Hepatitis B testing, blood donation among others are offered free of charge.

We thank all organizations who have been taking part in this activity, sponsors who have continued to offer support to make sure it happens and the different people from the general public who have turned up to support the matches.

The PCAU Biennial Conferences

The Palliative Care Association of Uganda (PCAU) has been holding National Palliative Care Biennial Conferences since 2003. To date a total of 9 conferences have been held. The conferences bring together people from all rounds of the world. With great support from the Ministry of Health, the conferences offer a planform for palliative care researchers, academicians and service implementers to share their discoveries, innovations and work.

The first conference was held in 2003 at Uganda Manufacturers Association, Lugogo (UMA hall), the 2nd conference was held in 2005 in Jinja at Jinja Nile Resort Hotel, the 3rd conference was held in 2007 at Hotel Africana. We then held the 4th conference in 2009, the 5th conference in 2011, the 6th conference in 2013 and the 7th conference in 2015 all at Imperial Royale Hotel,

In 2017, PCAU partnered with the Uganda Cancer Institute on their 50th anniversary and held the UCI – PCAU Joint International Conference at Speke Resort Hotel Munyonyo which brought together a wider audience in the Cancer and Palliative care world. It is this partnership that folded in to the 2nd Uganda Conference on Cancer and Palliative Care in 2019.

Rose Kiwanuka (right) welcoming Rt. Hon. Dr. Ruhakana Rugunda, Prime Minister of the Rebublic of Uganda at the Opening of the 2nd Uganda Conference on Cancer and Palliative Care in September 2019. Others in the photo are Hon. Dr Jane Aceng the Minister of Health second from left and Dr. Victoria Walusansa the Deputy Director of the Uganda Cancer Institute.

The theme of the conference was "Towards Universal Coverage" which was widely discussed about by the different key note speakers as well as presenters. The chief guest Rt. Hon Ruhakana Rugunda, Prime Minister of the Republic of Uganda appreciated the work being done in the Cancer and Palliative care fraternity, discussed some of the strategies that are being applied to strengthen cancer and Palliative Care service provision. He confirmed that the government of Uganda is dedicated to investing more in cancer and Palliative Care and making sure that we move towards Universal Health Coverage. In the end, he noted that the goal is to leave no one behind. He officially opened the conference.

Dr. Emmanuel Luyirika the Executive Director of the African Palliative Care Association was a plenary speaker at the opening of the PCAU 2019 Conference.

Dr. Jane Ruth Aceng, the Minister of Health deliberated on the new National Health Insurance Scheme, reassuring delegates that cancer and Palliative Care service provision has been included in the insurance scheme. She further stated that Palliative Care is now allocated a full division in the Ministry of Health and they have included Palliative Care consultant positions in the three major hospitals in Kampala including Mulago, Kawempe and Kiruddu.

The conference was also a celebration of 20 years of Palliative Care advocacy in Uganda which was done during the conference dinner dubbed PCAU@20. Rose Kiwanuka, Country Director for PCAU shared the history of PCAU, achievements, future plans among others and was followed by Dr. Victoria Walusansa, Deputy Executive Director Uganda Cancer Institute who congratulated PCAU on their 20 years and shared the latest achievements and plans of UCI.

Hon Dr. Jane Ruth Aceng, the Minister of Health was the chief guest at the dinner and she applauded PCAU for the work done over the 20 years. She presented Awards from PCAU to individuals and organizations in recognition of their contribution to PCAU and Palliative Care in Uganda at large.

Professor Julia Dawning rounded it off by thanking all delegates that were in attendance, presenters, sponsors as well as the committees that were driving all preparations for the conference.

The Uganda Conference on Cancer and Palliative Care is a platform to showcase cancer and Palliative Care research conducted, share strategies for standardization of cancer care across Sub-Saharan Africa, document resources available for care, research, and training, and promote collaborative work on cancer and Palliative Care research and training.

We look forward to many more of the coming conferences.

Implementing the Pain Free Hospital Initiative (PFHI) in Uganda.

By Joyce Zalwango
Capacity Building officer

PCAU in partnership with the Ministry of Health with support from Treat the Pain, a program of the American Cancer Society has implemented the Pain Free Hospital Initiative since 2016 where a total of 17 hospitals have been introduced to the program.

Pain management is largely undertreated and some of the barriers to appropriately address pain management includes subjectivity of pain, lack of knowledge and attitudes of health workers. However, this initiative which is a hospital-wide quality improvement initiative to integrate pain treatment into health service delivery has enabled great improvement in pain management for the last 3years.

PFHI was initially introduced in 4 regional referral hospitals and one general military hospital including Arua, Masaka, Kabale, Hoima and Bombo a general Military hospital between 2016 and 2017. Implementation in these 5 hospitals are now completed and we hope that pain management activities will be sustained into the daily routine care.

In 2018, PFHI was scaled up to more five regional referral hospitals and one National mental hospital. These hospitals include Jinja, Soroti, Lira, Mubende, Mbarara and Butabika Referral Mental Hospital. These hospitals have continued to receive support throughout 2019 by PCAU.

In April 2019, three more hospitals were added to the program including St. Francis Hospital Nsambya, Mengo Hospital and China Uganda Friendship Hospital Naguru.

Pain Free Hospital initiative Champions from implementing hospitals: St. Francis Nsambya Hospital, Mengo Hospital and China-Uganda Friendship Hospital Naguru together with Staff of the Ministry of Health and PCAU in a photo after a meeting at Ministry of Health in October 2019.

The goal of the Pain-Free Hospital Initiative is to integrate effective pain relief into hospital services by increasing pain awareness and pain treatment. The initiative has achieved this goal through motivating clinicians to evaluate and treat pain, empowering hospitals to stock appropriate drugs to treat pain, engaging hospital staff to create awareness about pain, equipping clinicians with the skills and tools to effectively assess and treat pain.

The program impact is measured by documenting patient's pain scores and clinician's knowledge. Between 2016 and 2017, 657 (88%) out of 750 clinicians and nurses did the pre and post-test on pain management in 5 hospitals and a total of 467 support staff had pain awareness. In April 2018, the other 6 hospital that joined PFHI were able to have a total 878(73%) out 1200 completed both pre and post-test. It is noted in figure 8 and figure 9 that there is knowledge increase in all hospitals with higher scores at the post-test compared to the pre-test. In 2019, the program was introduced in 2 private not for profit hospitals and 1 urban government hospital where 426(71%) of the 600 expected staff to be trained have completed their pre and post – test and the trainings are still on going.

PCAU has now established plans with all hospital staff champions on how best to implement the initiative with a focus to sustainability through Continuous Medical Education (CMEs), providing the necessary equipment like laptops, pain scales, USB Flash disk and data collection tools which were handed over to each of hospital.

Among all hospitals implementing PFHI, 82% (14) have rejuvenated their Palliative Care services and 1 hospital has been supported by PCAU to acquire a double locked cupboard to be able to order and stock morphine for patient's pain control.

PCAU Supports the Morphine Supply Chain in Uganda.

By Joyce Zalwango - Capacity Building Officer, PCAU.

In October 2010, Treat the Pain established a partnership with Hospice Africa Uganda to improve access to oral morphine for the treatment of moderate or severe pain. At the time of the agreement, Uganda's public sector had been without oral morphine for about six months and there was a huge gap that needed to be filled.

Bimonthly, PCAU brings together key partners such as Hospice Africa Uganda (HAU), Ministry of Health (MOH), National Medical Stores (NMS), National Drug Authority (NDA), Joint Medical Stores (JMS) and large consumers such as Uganda Cancer Institute and Mulago National Referral Hospital to monitor and follow the efficiency of the supply chain.

Rose Nabatanzi (R) a Palliative Care Nurse showing a morphine bottle to Janet Nabadda a palliative care beneficially.

PCAU provides support supervision for orders and distribution to public, private not-for-profit hospitals and hospices as well as the mentoring of health workers in pain assessment and management.

Staff at Hospice Africa Uganda Morphine Manufacturing Plant (HAU photo).

The supply of oral morphine had been greatly improved in Uganda although there are still some gaps in accessibility and availability. The implementation of the project has been a success with key improvement in availability of and access to moderate to severe pain relief medication through the following;

- Supporting health facilities to get accredited and mentorship to staff through CMEs on pain assessment and management thus expanding access of and availability of oral morphine in the districts.
- Improving availability to appropriate pain management medication by following up on orders and distribution submitted by the pharmacists from the regional referral hospitals and the private big consumers to quantify the estimated production need so as to prevent stock outs of morphine.
- PCAU secretariat provides a call Centre for reporting stock outs, challenges in ordering and capacity building to a number of facilities in need to access morphine.

One on one with Rose Nabatanzi Mubiru, Palliative Care Nurse at Kitovu Mobile.

Rose Nabatanzi Mubiru is the Palliative Care Focal Person at Kitovu Mobile. She is very familiar with the work of PCAU. She has served on the PCAU Board as well as leader of PCAU Buddu Brunch. Rose has made great personal contribution to the growth of palliative care services in Uganda and especially in Greater Masaka area. Bellow, she shares her thoughts about the palliative care service provision at Kitovu Mobile and the work of PCAU in an interview.

Rose Nabatanzi Mubiru

Q. Tell us about the experience of introducing palliative care to Kitovu Mobile?

A. Kitovu Mobile has been well known for providing HIV care services since 1987 and as a result we saw many patients with HIV dying in severe pain. Patients were suffering due to severe diarrhea, kaposi sarcoma and herpes zoster during late stages AIDS. We could give paracetamol, ibrufen and codeine but they were not enough. By 2000 we had a doctor called Dr. Cara Simons who had practiced Palliative Care in the United States but when she came to

Uganda, she could not get the required medicines. By then Hospice Africa Uganda had started providing Palliative Care and Dr. Simons was a friend to Dr. Anne Merimman, the founder of Hospice Africa Uganda. They met and discussed how they could bring Palliative Care to Kitovu Mobile and it is from that discussion that we went for an introductory course in Palliative Care at The Institute of Hospice and Palliative Care in Africa. Eventually the entire organization became aware of Palliative Care.

Q. How was the training helpful in introducing Palliative Care to Kitovu Mobile?

A. The staff started identifying patients in their homes and villages who were in pain and bringing them to us for care. We started getting oral liquid morphine and morphine tablets. We had already been visiting patients in their homes but were not doing pain management because we did not have medicines. So when we got oral liquid morphine, we actively started Palliative Care work. We visited many patients and although many of them died, they died with dignity. Their family members always came to us to express appreciation.

Q. How then did Kitovu Mobile become part of PCAU and what role did you play?

A Kitovu Mobile was part of the formative years of PCAU and Dr. Simons used to attend all the meetings. She was a board member. I was appointed a board member after Dr. Simons' term expired and my role was mainly to inform them of how Palliative Care was going on at the grassroots, especially of the problems patients were facing. We shared knowledge and experience with other members. Those PCAU meetings were very educative.

Q. What are the gains realized by Kitovu Mobile as a result of being part of the national palliative care association?

A. Kitovu Mobile has benefited a lot under the umbrella of PCAU because they brought our work into the limelight. And as we became a referral center, it helped us to raise funds to improve patient care and care for families. They also raised money to train health workers because many health workers were not trained. In Masaka, PCAU worked directly with Kitovu Mobile to sensitize the community about Palliative Care. Now people are seeking for the services. **It encourages us when we see people coming for services and tell us that they heard about Palliative Care from other patients we have cared for.** That gives us energy to continue to do this work.

Q. How would you like to see the future of Palliative Care in Uganda?

A. It is very painful to see patients dying in pain, so I would like to see Palliative Care being taken as a service for all just like treatment for malaria. If patients would access Palliative Care wherever they go, right from health centre III. That is where patients go first to seek treatment and they go there several times before they are referred. As far as training for health care workers is concerned, I have seen some positive change, but we still need to do more training in training schools.

Kitovu Mobile:
Offering Homebased care in the greater Masaka Region.

By Moses Muwulya ,
Communications Officer, Kitovu Mobile

Kitovu Mobile, a regional center of Palliative Care in the greater Masaka, has since the year 2000 committed to provide care to patients with life-threatening illnesses from the intense pains that come along with ailments like cancer, advanced AIDS, and sickle cell diseases.

In the last three years alone, 2139 patients have been care for although 615 have sadly died within the first year of referral but the important thing is that they did not die amidst pain and lost dignity.

Paul Lubega and his wife speak to Jackie Namulondo a Nurse Care Nurse at Kitovu during a home visit.

While we take pride in insulating these patients from the gross emotional and physical pain that they suffer, Kitovu Mobile truly recognizes PCAU for its amazing 20 years of work supporting all the Palliative Care Units in Uganda.

It has been through PCAU's relentless advocacy that Kitovu Mobile has ably offered Palliative Care to the rising number of patients in need of it in the region. PCAU has availed Kitovu Mobile with the Palliative Care medications including oral liquid morphine, the preferred drug for severe pain as recommended by the World Health Organization.

Kitovu Mobile cannot thank PCAU enough for the continuous mentorship and support supervision visits and above all, the well-organized update meetings. This has kept Kitovu Mobile Palliative Care team with new developments in Palliative Care. The testimonies from our patients and caretakers attest to this.

We congratulate PCAU upon its 20 years achievements and wish you great success in the coming years.

About Kitovu Mobile

Kitovu Mobile is a Faith-Based Medical and Community Empowerment Organization under the Diocese of Masaka. The organization was started in 1987 as an outreach Program of Kitovu Hospital. Its operations cover the 10 districts of Greater Masaka.

The purpose of Kitovu Mobile is to lead the provision of innovative, mobile health services and empower marginalized communities affected by HIV/TB, Cancer and other emerging life threatening chronic illnesses. Kitovu Mobile is widely known for pioneering Home-Based Care model in the earliest stages of HIV and AIDS by visiting patients within the confines of their homes, to provide care services in rural remote Lake Victoria areas of Uganda.

Mulago School of Nursing and Midwifery now offers Palliative Care training.

Mulago School of Nursing and Midwifery came into collaboration with PCAU because of the desire to address the growing need of palliative care services in the country. The emergence and re-emerging of diseases that compromise the patient's quality of life were noted to be on increase and it was estimated by then that only about 10% of all patients who needed Palliative Care could access it. This was mainly due to inadequate number of trained palliative care nurses in the country.

The Ministry of Health development plan 2015 /16 -2019 /20 projected a need of 700 palliative care practioners to be trained to handle Palliative Care services to patients.

Mulago School of Nursing and Midwifery was therefore identified by Ministry of Education and Sports to pioneer this training in the country due to its capacity and clinical attachments.

A technical team consisting of members from Palliative Care Association of Uganda Hospice Africa Uganda, (HAU), Mulago Hospital, Uganda Nurses and Midwives Examinations Board, Uganda Nurses and Midwives Council, National Curriculum Development Center and Mulago School of Nursing and Midwifery were involved in the curriculum development that was approved by the Permanent Secretary, Ministry of Education and Sports in 2018.

PCAU conducted a six weeks training of tutors at the school to be able to take on the role of training Palliative Care Nurses. During the training of students both class room and clinical teaching is support by PCAU.

Mulago School of Nursing and Midwifery has enrolled so far two intakes 2019 with a total number of 26 students being trained for Advanced Diploma in Palliative Care Nursing.

These have been sponsored by Centre for Hospice USA. The school received 20 refurbished computers.

Appreciation

We are grateful to the Ministry of Education and Sports BTVET, MOH Mulago School of nursing for accepting Palliative Care Nursing to be brought on board and all partners for having embraced the program.

More appreciation goes to PCAU for their good collaboration with the Institution.

Palliative Care Journey at Reach Out Mbuya Parish HIV/ AIDS Initiative.

Ofwono Opondo

Member of Staff – Reach out Mbuya

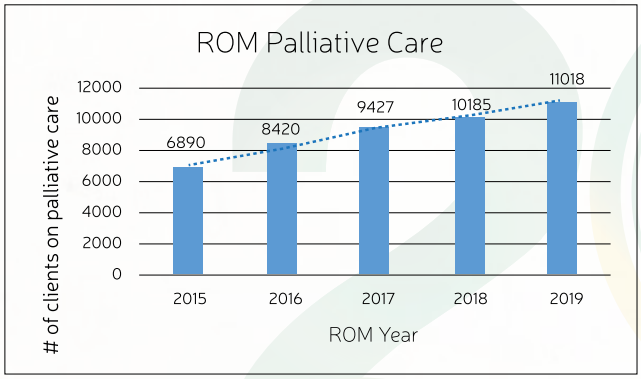
Reach Out Mbuya Parish HIV/AIDS Initiative (ROM) is a Community Faith-based Organization under Our Lady of Africa Church Mbuya Catholic Parish, Kampala. ROM provides holistic care to its clients through the provision of comprehensive health and social programmes. ROM also endeavors to share its knowledge and experience with other communities, in order to ensure that similar independent, community-owned programmes are successfully proliferated.

For over 18 years, ROM has offered palliative care services to over 11018 people. Most of these people are vulnerable and lack the ability to access adequate health services at a cost.

As a result, many of our clients come for services in critical conditions characterized by

pain. Besides the physical pain, these clients have also endured psychological pain caused by the situation surrounding them.

One of Reach Out Mbuya's Community ART and TB Treatment Supporter (CATTS) interacting with a client during home Visit.



The graph indicates an increase in palliative care services offered to clients in the last four years. (this is validated data available in the MOH Information System.)

ROM statistics on palliative care for the past four years indicate an increase in number of clients receiving palliative care from the main sights of Banda, Kinawataka, Mbuya and Kasaala. ROM uses a community-based approach of staff who reach to those in pain and those in critical conditions at their households and even follow them up in cases of hospitalization. Among the staff, we have CATTS (community ARV and TB treatment supporters) TAS (Teenage and Adolescent supporter), M2M (Mother to Mother) etc.

In addition, we have worked closely with partners like; Hospice Uganda, Mulago hospital, Uganda Cancer Institute to whom we have referred our clients for more advance treatment and care services.

Although Uganda still face factors slowing down palliative care service provision like; inadequate awareness and limited accessibility of palliative care in rural areas, the country has seen clients' lives change holistically through; improved wellness, economic status and psychological being.

ROM acknowledges the support of local council leadership, Palliative Care Association Uganda, Hospice Uganda, PEPFAR to mention but a few. We call for collective responsibility from all stakeholders to address issues related to palliative care in Uganda.

Health Centre & Hospice, Mbale

Promoting Palliative Care in the Elgon region of Eastern Uganda.

J.O.Y Hospice, which opened in 2000, is a vital part of the Deliverance Church Medical Services in Mbale. It is open 24/7 and sees many elderly clients with non-communicable diseases as well as actual palliative care (PC) patients. We are indebted to Hospice Africa Uganda for training three of our staff to diploma and degree level. Our first degree holder has completed and will graduate in January 2020 while a second clinical officer will graduate the following year.

Dr. Janet B White

Dr. Jane B. White (left) after receiving the PCAU Organization Merit award on behalf on the Management of Joy Hospice Mbale which has maintained up-to-date Membership with PCAU for over the years. The award was handed over by the Hon. Dr. Jane Ruth Aceng the Minister of Health at the PCAU Conference Dinner in September 2019.

Like other PC unit we make quarterly reports on our use of oral morphine which is still provide free of charge through a government programme. From 2017 the increased one year shelf life has greatly benefited ordering and storage. However, there can still be difficulties obtaining the 50mg in 5mls red morphine. Recently Sarah, one of our longstanding clients, finally lost her battle with breast cancer. Originally in 2015 she took green oral morphine 5mg in 5mls four hourly with a double dose at night. Over four years the dose of morphine needed to control the pain steadily increased until she needed over 100mg oral morphine 4 hourly. When red morphine was unavailable this meant the need for over thirty six 500ml bottles of green oral morphine each month!

Another vote of thanks goes to PCAU with its quarterly update meetings and biennial conferences. These keep us updated and facilitate networking with other PC providers. Meanwhile we remain proud to have a different model of palliative care with dedicated beds for PC admissions.

As Uganda has become more developed, some of our cancer patients have relatives with well-paid employment. They may desire those who are terminally ill to remain admitted avoiding their other relatives accusing them of neglect.

Providing Life Changing Surgery for PC Patients

Davide Naggi

Chief Executive Officer at CoRSU

On behalf of CoRSU Board and Management I would like to congratulate Palliative Care Association Of Uganda for their 20 years anniversary and for the fantastic work done in the past years.

The team of Palliative Care Association of Uganda works tirelessly to support and promote the development of palliative care and palliative care professionals in Uganda, and their passion and dedication towards their work is commendable.

At CoRSU we are glad and proud to be a partner to such an active and driven organization.

Thank you, Palliative Care Association of Uganda for the work you do and we look forward to further foster and continue our collaboration and partnership in the years to come.

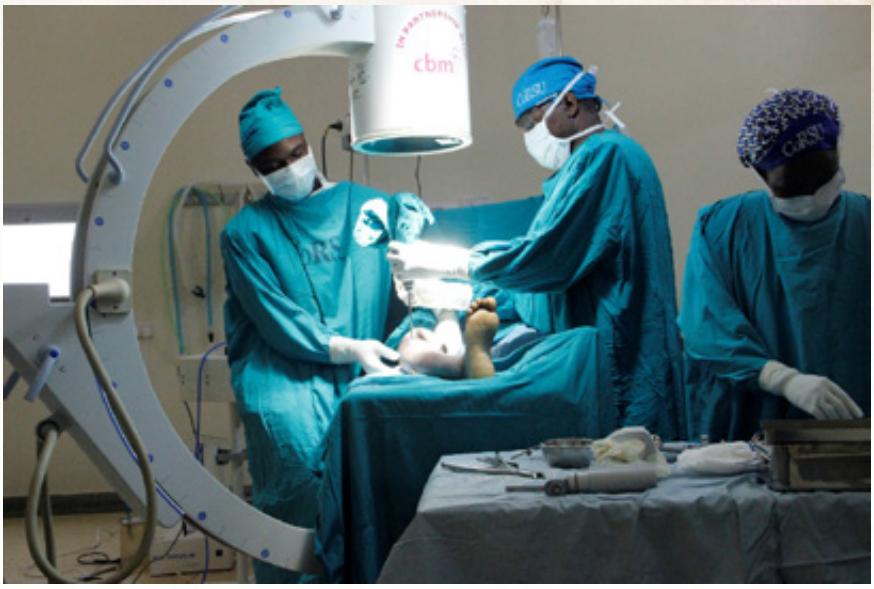
CoRSU is a private not for profit non-governmental organization that was founded in 2009 with a mandate to prevent disability and restore ability especially for children.

CoRSU provides subsidized life changing surgery and hospital stay to children with disability (80% of our beneficiaries are people below the age of 18)

Our Orthopaedic department offers treatment for Club foot, Osteomyelitis, Bowlegs & knock knees, Post injection paralysis, Congenital born deformities, Joint arthritis (Total hip & Knee replacement), Sports Injury (Arthroscopic Surgery)

We also offer Plastics and Reconstructive surgery services, Medical Rehabilitation Services, Vesco Virginal Fistula (VVF), Wheelchairs, Training for Mmed-plastic surgery at the hospital with MUST

The income from private patients is used to subsidize further the cost of surgery and rehabilitation services for children with disability.



Kawempe Home Care - A Community-Based Approach to deliver Palliative Care services.

By Nkurunziza Diana and Dr. Samuel Guma.

Kawempe Home Care (KHC) has been a member organisation of PCAU for the last 12years and through this partnership we have been able to offer palliative care to over 5000 patients with different life threatening and life limiting illness.

In September 2016, KHC opened New Hope Children's Hostel (NHCH) providing palliative care services for children who are receiving cancer treatment at Uganda Cancer Institute (UCI) in Mulago Hospital by securing a safe home environment whilst they undergo specialist treatment.

All our services build on the guiding principle of providing clients with compassionate holistic care especially psycho-social support that includes free accommodation, meals, and transport to and from UCI, transport support for vulnerable patients' from home and the Psycho-therapy support which includes regular counselling sessions for caregivers and their children, assisted play therapy, reading, writing, music therapy, spiritual care with dancing fellowship session for children.

The hostel has cared for 456 children since inception. Our follow-up studies show that 110 children successfully completed cancer treatment and are now on quarterly medical review, 195 are still on cancer treatment, 10 are receiving end of life care in their homes and sadly 99 passed away. Assessment with POS-C (Palliative Outcome Scale; APCA, 2012) indicates that children's and caregivers' quality of life improved throughout their stay at NHCH. The Children showed improved physical and mental wellbeing, indicated by reduced pain, symptoms and crying and increased feeding, knowledge, happiness and motivation to play. Caretakers showed positive emotional adjustment to their situation, improved knowledge and aspirations for the future. While all other indicators show constant improvement throughout four times of measurement, body problems in children and worries about their child's illness in caretakers increased slightly at visit three and then decreased further.

Two girls at the New Hope Children's Hostel during play time.

KHC also provides palliative care services for adults and children with cancer in our surrounding community. A team of community volunteers trained in home-based care also provides basic care services like bathing and turning bed ridden patients. A total of 31 patients were cared for and 14 (45%) were male and 17 (55%) female.

A community volunteer supports a patient to take some fruit.

The Table below shows the number of patients cared for during the year 2018-19.

Cancer Type	Number
Kaposis Sarcoma	17
Breast Cancer	07
Cervical Cancer	02
Squamous Cell Carcinoma	03
Others	02
Total	**31**

KHC started a supporter's club that gives an opportunity to both the local and international community to give whatever they can to support a child suffering from cancer.

Through PCAU biannual conference platforms, KHC advocacy messages on pediatric palliative care have facilitated penetration of both national and international audiences in the cancer care fraternity. For more information on how to support children with cancer please visit the link below. https://newhopechildrenshostel.org/supporters-club/

KHC therefore takes this opportunity to congratulate PCAU leadership, management, members & staff on this great 20-year milestone.

FOLLOWING THE HOSPICE ETHOS – WORKING WITH PALLIATIVE CARE ASSOCIATION OF UGANDA

Dr. Agasha Doreen Birungi Acting Chief Executive Director, Hospice Africa Uganda

Twenty years ago, Hospice Africa Uganda in following the vision, mission and ethos birthed the Palliative Care Association of Uganda (PCAU). PCAU was designed to be a National association that would coordinate palliative care organisations and health care workers in Uganda. PCAU was initially run at Hospice Africa Uganda offices. Today, PCAU has grown into a strong vibrant coordinating mechanism that brings together all hospices and palliative care providers in Uganda, creatively supporting our work and pushing palliative care forward in the country. The goal of PCAU is "To increase access to culturally appropriate palliative care through strengthening health care systems in Uganda in collaboration with partners". Led by this goal and hospice ethos, HAU has worked closely with PCAU to realise several shared achievements including but not limited to;

Advancing palliative care education in Uganda to include highly specialized courses and short courses offered at various teaching institutions in Uganda. Our own Institute of Hospice and Palliative Care in Africa (IHPCA) has received several scholarships from PCAU. PCAU has linked several national and international students to do placements at HAU.

Ensuring high quality evidence based palliative care delivery in Uganda through quarterly updates and conferences that target service providers among others. HAU team attend these sessions regularly.

Promotion of the simple and affordable solution to severe cancer pain by creating awareness about oral liquid morphine, supporting the Public Private Partnership arrangement that ensures widely available oral morphine through the national supply chain and engaging other national palliative care associations to adopt the Uganda best practice.

Active engagement in palliative care advocacy and resource mobilization

We surely wish PCAU many more decades. HAU pledges to continue working with PCAU to ensure that the PCAU mission 'To accelerate the Integration of Palliative Care into the Health Care System in Uganda through Capacity building, Advocacy, Research and Resource mobilization' is realized.

L-R: PCAU Country Director at the time Rose Kiwanuka; Founder HAU Dr. Anne Merriman; Ambassador of Ireland to Uganda, H.E William Carlos; HAU Chief Executive Director at the time Dr. Eddie Mwebesa and HAU board chair at the time Joan Kelly cut a cake at the PCAU dinner organised for fundraising for one of HAU's branches Mobile Hospice Mbarara in Dec. 2018.

WITH GRATITUDE TO PCAU FROM MOBILE HOSPICE MBARARA

December 2018 was our turn to receive from PCAU special support to renovate our premises. We have a conference hall which we use for meetings of different kinds and to host day care patients once a month. Our hall had a floor that was in dire need of repair. The cement was breaking away which made the floor dusty and rough. It was no longer the ideal place to hold or host meetings nor for day care patients. However, after the fundraising dinner for Mobile Hospice Mbarara organized by PCAU, enough money was raised to repair the floor of our conference hall. We are sincerely grateful to PCAU and all those who generously contributed during the fundraising. May God reward you all abundantly?

Love One Another

By Hanna Gonzalez

"This is my commandment, that you love one another as I have loved you" (John 15:12 ESV).

This is our commandment, brothers and sisters. To love one another; not just in our surrounding community but those who live abroad. My name is Hanna Gonzalez. I am an emergency medicine doctor from the USA, and my husband Joseph and I hope to follow this commandment in our short time here on Earth. Through a partnership with Palliative Care Association of Uganda (PCAU), we are thankful for the opportunity to be able to share love with our friends across the ocean.

Before my first trip to Uganda back in 2010, I met Rose Kiwanuka at a talk held at my undergraduate university, Notre Dame. She spoke with eloquence; she spoke of unbelievable change fighting on the frontlines of medical care access in a call for equity in pain relief and symptom management for the suffering. I sat there staring and thinking to myself, 'This woman has made a huge difference and I have so much to learn from her. Uganda is calling me.' I approached Rose, and since that day, my respect for and relationship with Uganda has exponentially grown and enriches every year. At Notre Dame, I studied pre-medicine and medical anthropology. I focused my research and field work on looking at the quality of life and access to palliative and disease-modifying care, as well as the relationship of western medicine with the traditional healers. I spent summers diving into these questions, exploring relationships, and making lifelong family members and friendships along the way.

In the summer of 2010, I spent time working with colleagues at Hospice Africa Uganda (HAU), Kawempe Home Care, Hospice Jinja, and other sites within the PCAU network. I joined providers on their home visits and on their workshops with traditional healers in the forest. I participated in the day events learning about the lives of the patients supported through the network facilities. I studied and was amazed by the providers' loving interactions and the resourcefulness they employed to care for patients with serious illnesses and complicated social circumstances. Upon return to the USA, I spent a year engaged in a directed readings and research with my academic mentor exploring the literature and studies in sociocultural and medical anthropology. I strove to understand the health disparities of those suffering from life-limited illnesses in Uganda and the complexities faced by those caring for them. The subsequent summer, I returned to Uganda to work more closely with PCAU and HAU.

My studies in Uganda were funded by an 'Experiencing the World' fellowship from the Kellogg / Kroc Institute at Notre Dame; for this, I am so grateful. Not only did they support my internship and field work in Uganda, but together, we founded an ongoing summer internship for Notre Dame students to work in various capacities.

In 2016, Joseph and I married, and in lieu of wedding gifts, we asked our guests to please donate to our cause. Joseph and I made a specific commitment to support PCAU and its initiatives. At this time, the focus is on identifying children in critical need of medical care and supporting the travel and accommodations of him/her and his/her caregiver(s) from their home village to medical and diagnostic services through PCAU and Kawempe Home Care. We hope to continue to expand and develop this partnership.

Hanna and Joseph Gonzalez

This past summer, as part of an independent international elective through my emergency medicine residency program, I brought Joseph to meet my family and friends in my second home in Africa. It was a joyous reunion! As a software engineer, Joseph shared his coding talents with PCAU on reporting tool initiatives. I spent time with the medical officers working in the emergency room at Nsambya St. Francis Hospital. We visited Kawempe Home Care and refined our vision for our partnership.

Through all these years, I remain amazed by the wholesome, loving work of PCAU which has been adhering by our most important commandment since 1999. I want to thank everyone at PCAU, Rose Kiwanuka, HAU, APCA, Hospice Jinja, Kawempe Home Care, Nsambya St. Francis Hospital, my amazing Ugandan host family, and so many more thoughtful of but not listed here. You all have not only changed the lives of so many suffering from life-limiting illnesses, but you have also impacted my life in a truly meaningful way. May the Good Lord continue to bless you and yours, and may He have us following our commandment together for many years to come!

With love,
Hanna Gonzalez, MD

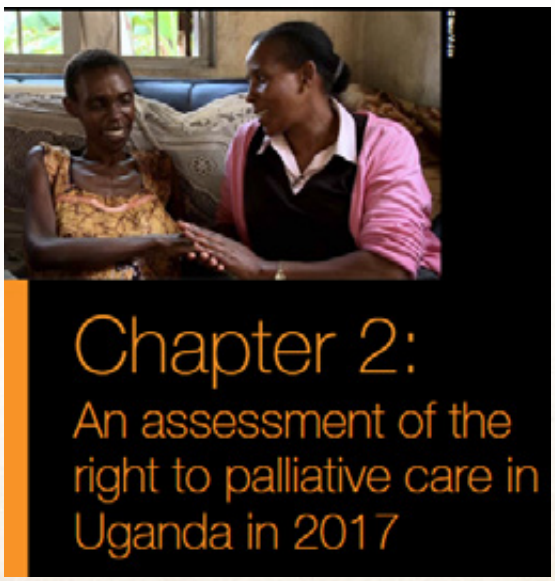
Palliative Care for the Deaf in Uganda

The Palliative Care Association of Uganda (PCAU) is working in partnership with the Uganda National Association of the Deaf (UNAD) to advocate for improved access to palliative care for the deaf in Uganda. There exists a communication gap between the deaf and most health workers who cannot use sign language. PCAU and UNAD working with the Ministry of Health have developed a Deaf Awareness Manual for health workers. The implementation of the manual includes sessions on basic sign language.

Details on the Right to Palliative Care in Uganda

In 2010, PCAU working with the Uganda Network on Law Ethics and HIV AIDS (UGANET) and with support from the African Palliative Care Association, The Open Society Foundations and the Open Society Initiative for East Africa started the work of promoting palliative care as a Human Right in Uganda. Various stakeholders have been brought on board since then. In 2017, the Uganda Human Rights Commission reported on the Right to Palliative Care for the first time in their 20th Annual report. Visit UHRC website for the detailed report.

https://www.uhrc.ug.



What the representatives of the current and former staff are saying...

Hello! My name is Tom Echodu.

It has been a great pleasure working with PCAU. I joined in March 2015 as security guard and having worked so hard and pleased the management, I was motivated with the award of the employee of the year 2016.

Also, in 2016 the director and management identified me as a person of integrity, hardworking and capable of heading the security department and was appointed Head of Security. I was so, so happy for this promotion.

This year the team went for a 2 days activity at Lake Side Adventure Park in Mukono where we had a lot of fun and activities that were meant to build our capacity as a team, example of the activities the team shared was warier climbing, passing information from top manager to lower staff, wasting resources at the work place etc.

PCAU also has a staff saving scheme and every year staff are free to vote for their committee of their choice and I was voted the chairperson for the scheme which is also a motivation for me.

I would like to encourage people who have not registered as members with PCAU to register to support the work of Palliative Care in Uganda.

I wish you all Merry Christmas and Prosperous New year 2020 as the struggle continues to see that Palliative Care reaches all in need in Uganda.

God bless you all.

---Tom is the head of security at PCAU and a registered member.

Tracy Tusaba

Working with PCAU shaped my Destiny.

My name is Tracy Tusaba. I worked with PCAU in the year 2010 as an administrative assistant and had a great opportunity of working closely with people of multiple gifts and diverse profession which gave me an opportunity to learn varous skills.

My work gave me the opportuniy to interact with key stakeholders of PCAU where I met people of all walks of life and from different parts of the country. I also managed several activities that impacted my life.

The Soccer Gala gala for example was quite engaging. Organising this event to success exposed me to vast learning beyond Palliative Care to public adminisration, good governance and respect for member organisations. The challenges in the shelves propelled my interest in teaching, so to be a change agent in helping society learn to multi task and adapt change. I realised that people need effort to change their attitude over tasks that yield a lot through team work and collective effort.

PCAU was then funded by USAID and all work flow was at its peak and I encountered a family challenge that necessitaed multiple surgeries for my son at CoRSU. Thank God it all went well though I painfully decided to end my services.

Getting back into the work force, landed me into Eskom. I enthusiastically joined the Energy sector to earn, extend horizons and learn about work dynamics outside Palliative Care. Enjoying all moments, I learnt that Business and Profit were key. This was short lived as I gained ground back into Palliative Care when I joined Hospice Africa Uganda. Where I worked for several years.

Currently, I lecture at the International University of East Africa, on the Public Adminstration program a superb ground to instil values and morals. I must say the motivation to get into teaching came while I worked with PCAU.

I congratulate PCAU on this 20 years anniversary and wish you a successful and sustainable journey ahead.

Appreciation to all Former and Current Board Members and Staff

As we celebrate 20 years, we are grateful to all individuals that have served PCAU on both governance and staff structures. Your vision and passion for our work has enabled us to grow.

The following persons have served on the Board of PCAU.

2006 PCAU Board	
1	Dr. Lydia Mpanga Sebuyira
2	Diana Opio
3	Dr. Carla Simons
4	Martha Rabwoni
5	Fatia Kiyange
6	Philomena Akello
7	Dr Anne Merriman
8	Dr Jacinto Amandua
9	Josephine Kabahweza

2018 PCAU Board	
1	Dr Ddungu Henry
2	John Muwonge
3	Josephine Kampi
4	Dorah Kicoco Musinguzi
5	Dr Ocero Andrew
6	Gereva Nuwagaba
7	Hajjat Mwazi Batuli
8	Hajat Safina Musene
9	Dr Ekiria Kikule

2008 PCAU Board	
1	Joyce Edith Agulo
2	Prof. Julia Downing
3	Dr. Carla Simons
4	Dr. William Musoke
5	Dr. Jacinto Amandua
6	Dr. Anne Merriman
7	Fatia Kiyange
8	Dr. Lydia Mpanga Sebuyira
9	Robert Senteza

2010 PCAU Board	
1	Fatia Kiyange
2	Robert Senteza
3	Prfof. Julia Downing
4	Dr. William Musoke
5	Dr. Lydia Mpanga Sebuyira
6	Carla Simons
7	Joy Edith Agulo
8	Dr. Amandua Jacinto
9	Dr. Anne Merriman

2014 PCAU Board	
1	Dr Sam Guma
2	Ekkie Kikule
3	Tom Dduku
4	Dora Kiconco
5	Rose Nabatanzi
6	Dr. Fred Sebisubi
7	Hajati Safina Musene
8	Dr Jacinto Amandua
9	Dorah Kiconco Musinguzi

Partner with Us!

The Palliative Care Associating of Uganda is a Membership Organisation. Interested Individuals and organisations engaged in health care service delivery can apply to become members by submitting a membership application form accessed on the PCAU website. PCAU remains thankful to its members both individuals and organizations who have continued to meet their obligation over the last 20 years through membership subscriptions. The funds raised from this initiative help continue to facilitate palliative care advocacy and the sustainability of PCAU.

You too can become a member of PCAU to partner with us. Palliative care is everyone's business and a time comes in life when all that one needs is care. Perhaps no other things.

Beginning 2020, the PCAU Life Members Assembly will convene once annually to discuss about the work of palliative care in Uganda and beyond. This is envisioned as the ultimate networking platform for all promoters, supporters of palliative care and the work of PCAU that you don't want to miss. So choose to become a life member today by paying UGX 1M. This can be paid at once or in installments in a period of 1 year.

All the important work of PCAU thrives on donations and gifts too. Interested individuals and companies can make generous financial and other resources offers to PCAU.

In addition, the work of PCAU depends largely on volunteers at the secretariat and in districts. Interested individuals can apply to become volunteer advocate through the website.

Contact us through +256 392 080 713 or pcau.admin@pcau.org.ug

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