

African Palliative Care Association

## **ANNUAL REPORT**

APRIL 2023 / MARCH 2024



Art therapy is a technique used by Hospice Egypt to support terminally ill patients. One patient's wish was to sing along or listen to an old song. The photo shows a moment where a patient was singing and playing old classic songs on a guitar.

# "NOT ALL OF US CAN DO GREAT THINGS. BUT WE CAN DO SMALL THINGS WITH GREAT LOVE."

- Mother Theresa

## **TABLE OF CONTENTS**

List of acronyms and abbreviations	4	E. RESEARCH, INNOVATION, AND	
Background	5	DEVELOPMENT	21
Our values	5	<ul> <li>The African Palliative Care Research Network</li> </ul>	21
Introduction	6	International collaborative research	
Message From The Executive Director	7	engagements	
Message from the Board Chair	7	• Quality Indicators in End-of-Life	
Strategic objectives	8	Care for Children with Cancer in Low- and Middle-Income Countries.	22
A. INCREASING KNOWLEDGE AND AWARENESS OF PALLIATIVE AND COMPREHENSIVE CHRONIC CARE		<ul> <li>Catalysing impact in research through innovation</li> </ul>	22
AMONG ALL THE STAKEHOLDERS  • Advocacy	10 10	<ul> <li>Co-designing with children and young people processes for their engagement in research</li> </ul>	23
B. STRENGTHENING HEALTH SYSTEMS		<ul> <li>Student internship exchange programme</li> </ul>	23
BY INTEGRATING PALLIATIVE AND COMPREHENSIVE CHRONIC CARE AT ALL LEVELS	12	<ul> <li>Read more about APCA publications</li> </ul>	24
Palliative Care Financing	12	F. COMMUNICATIONS	25
<ul> <li>Platforms for interactive engagement and networking</li> </ul>	15	1. COM TONICATIONS	23
Health information systems	15	<ul><li>G. LEADERSHIP AND GOVERNANCE</li><li>Staff Development</li></ul>	26 26
C. HEALTH WORKFORCE	16	Risk Management	26
<ul> <li>Impact stories from three scholarship beneficiaries</li> </ul>	16	H. FINANCIAL OVERVIEW	28
Integrating palliative care through	. •	• Income	28
training multi-disciplinary health		Expenditure	28
professionals	19	• Financial Position	29
D. ACCESS TO ESSENTIAL CONTROLLED MEDICINES &		Donor Appreciation	30
TECHNOLOGIES	20	Make a Donation	31
<ul> <li>Catalysing innovation to test breakthrough solutions aimed at scaling up patient and family</li> </ul>		Take a Donation	31
access to palliative care.	20		

## **ABBREVIATIONS**

APCA	African Palliative Care Association		
APCRN	African Palliative Care Research Network		
ASSOPA	Senegalese National Association for Palliative Care		
СҮР	Child, Children and Young People		
GPIC	Global Partners in Care		
IAHPC	International Association of Hospice and Palliative Care		
ICPCN	International Children's Palliative Care Network		
NCC	National Cancer Control		
PallCHASE	Palliative Care in Humanitarian Aid Situations		
WHPCA	Worldwide Hospice Palliative Care Alliance		
WHA	World Health Assembly		
WHO	World Health Organisation		
WHO-AFRO	World Health Organisation Africa Regional Office		
WHO-EMRO	World Health Organisation Regional Office for the Eastern		
	Mediterranean Region		



#### **BACKGROUND**



The African Palliative Care Association's mission is to ensure that palliative and comprehensive chronic care are widely understood and integrated into health systems at all levels, to reduce pain and suffering across Africa.



Access to palliative and comprehensive chronic care for all in Africa.



#### **Collaboration**

We work collaboratively, by asking for, and giving support, coupled with sharing success with others.

#### **Integrity**

We are honest, trustworthy and straight-forward in all our dealings; and use time, money and resources wisely.

#### **Diversity and Inclusiveness**

We value others for their contributions, irrespective of their personal differences; and provide equal access to opportunities and discourage any form of unfair discrimination.

#### Respect

We involve and listen to, others; as well as show consideration and empathy to facilitate their emotional and physical well-being.

#### **Excellence and quality**

We always strive to provide services that meet or exceed the needs, standards and timescales of our internal and external stakeholders; and do always strive for excellence and quality in all areas.

#### **Reliability**

We deliver what we commit to, and keep our stakeholders informed of all progress.

#### Social justice

We strive to create an organisation that is based on the principles of equality and solidarity, that understands and values human rights, and that recognises the dignity of every human being.

#### **Cultural sensitivity**

We advocate for palliative care to be delivered in a culturally sensitive manner by respecting the values and beliefs of others even when they differ from our own.

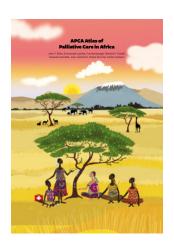
#### **Teamwork**

We strive to support one another, working cooperatively, respecting one another's views, and making our work environment positive and enjoyable as we work towards achieving our goal.

#### INTRODUCTION

By 2060, 83% of the world's health related suffering will be in low- and middle-income countries (LMICs), which represents a figure of over 20 million people experiencing avoidable suffering in their last year of life. Most healthcare systems, particularly those in LMICs, are ill-prepared to handle the changing dynamics in disease burden, and meet the growing need for pain and symptom management, which, in many instances, are coupled with higher life expectancy rates. The expansion of palliative care can potentially meet this need and prevent substantial, health-related suffering resulting from life-limiting and chronic illnesses.

Palliative care aims to control patient and family multi-dimensional symptoms and concerns as to improve their quality of life, and it can be given alongside disease transforming treatment. Evidence demonstrates that palliative care reduces the catastrophic financial costs associated with seeking institutional health care, and this reduces household vulnerability to poverty.



The APCA Atlas for Palliative Care in Africa, shows that over 98% of the hospices and palliative care services offer outpatient, community/home-based care services in Africa where the care providers interact with the patient and family

for only a few minutes or hours, while the rest of the tasks and burdens rest with their family carers (informal caregivers) or paid non-professional caregivers. Common roles here include wound care, turning and feeding patients, physiotherapy and rehabilitation support, giving medication, mobility around the household, toileting, as well as placement and use of patient support or user devices, supporting patients with advance care planning and to fulfilling their wishes during illness and after death. The informal care is also largely provided by women and girls; thereby pre-disposing them to socioeconomic vulnerabilities, as this labour is largely unpaid for. One of APCA's aims is, therefore, to support extending empowerment and recruitment and retention of male care providers into the field of informal caregivers to address the gender gap alongside advocating for the provision financial rewards for this unpaid labour.

#### PALLIATIVE CARE CONTRIBUTES TO THE FOLLOWING SUSTAINABLE DEVELOPMENT GOALS



I.No Poverty
3.Good Health and
Well-being
4. Quality Education
5.Gender Equality
8.Decent work and
economic growth
I7.Partnerships for the
Goals

# EXECUTIVE DIRECTOR

Dear APCA members, partners and friends,

I welcome you to yet another edition of the APCA Annual Report.

During the 2023/2024 financial year, we, at the African Palliative Care Association, have continued working to fulfill our obligations under our 2020-2030 strategic plan.

We wish to appreciate the generous support of all our partners and donors which has enabled us to deliver on our promises with a much leaner but more effective team of staff. I sincerely thank and congratulate all staff on this achievement.

APCA has maintained its accountability to members, donors, partners, and statutory authorities, and thus, we recorded yet another unqualified external audit this year, thereby retaining our record of fully accounting for all funds received over the years.

We look forward to another fruitful year as we embark on new projects, new partnerships and new innovations; as well as sustaining those already underway. We are also in great anticipation of APCA's 20th anniversary in the 2024/25 financial year and will use this milestone to propel forward our vision, "access to palliative and comprehensive chronic care for all in Africa."



Dr. Emmanuel Luyirika
APCA EXECUTIVE DIRECTOR

## MESSAGE FROM THE BOARD CHAIR

Dear APCA members, partners, staff, and friends,

It fills me with great pleasure to write this overview of the work done by APCA during the 2023/2024 financial year. The Annual Report is always a great opportunity for the APCA staff and the board of directors to reflect on the work done, identify any gaps, and formulate strategies to strengthen on-going work.

We wish to acknowledge the contributions made by our donors and strategic partners, without whose continued support the APCA team would not have been able to execute its mission so effectively.

I am equally delighted to report that once again the APCA obtained an unqualified audit, an achievement that we believe is a result of the dedication and capable leadership of APCA management team and the diligent and meticulous work of the Audit and Risk/Finance Committee of the board and the rest of the board members. Well done to all!



Thobekile Finger
APCA BOARD CHAIR

#### STRATEGIC OBJECTIVES

#### **OUR 2020-2030 STRATEGY IS GUIDED BY THESE 4 OBJECTIVES;**

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#### **AWARENESS**

Increasing the knowledge and awareness of palliative and comprehensive chronic care among all stakeholders 2

#### INTEGRATING

Strengthening health systems by integrating palliative and comprehensive chronic care at all levels 3

#### **EVIDENCE**

Building a sound evidencebase for palliative and comprehensive chronic care in Africa 4

#### **SUSTAINABILITY**

To develop and implement a financial sustainability framework for APCA, and palliative care as a discipline

## APCA's strategic objectives and strategies are informed by the WHO's six core components (building blocks) of health-systems-strengthening:



Health service delivery



Health workforce



Health information systems



Access to essential medicines, vaccines and technologies



Health systems financing



Leadership and governance

They are also aligned with the WHO's provision of palliative care using the Palliative Care Development Conceptual Model and indiactors based on empowerment of communities, health policies and research using essential medicines, and education and training with people with palliative care needs at the centre.

In addition the WHO's public health strategy for effectively integrating palliative care into a country's system which addresses four key pillars:

- Appropriate policies
- · Adequate drug availability
- Education of policy makers, health care workers and the public
- Implementation of palliative care services at all levels throughout society



IN THE SUBSEQUENT SECTION, WE PROFILE THE HIGHLIGHTS OF OUR WORK IN 2023/2024

15,282 HOME VISITS **CONDUCTED TO** REACH PATIENTS WHO COULD NOT MAKE IT TO THE FACILITIES

# **A.** INCREASING KNOWLEDGE AND AWARENESS OF PALLIATIVE AND COMPREHENSIVE CHRONIC CARE AMONG ALL THE STAKEHOLDERS

#### **ADVOCACY**

APCA engages in several advocacy campaigns and initiatives with global, regional, national and subnational partners to support the mission of increasing access to palliative and comprehensive chronic care for all across Africa. In the period under review, APCA's Executive Director, together with members of senior management held strategic meetings with WHO Botswana Country Office on the strategic inclusion of palliative care in the country's drive towards Universal Health Coverage. They emphasised the need to include palliative and comprehensive chronic care into routine care as the only way to make it sustainable. Botswana has one of the most comprehensive models of home-based palliative care in Africa, where the government finances the provision of home-based care with a defined and fully funded package with patient supplies and payment for informal volunteers caregivers. We were pleased that during this visit, the Ministry of Health in Botswana agreed to co-host the 2025 edition of the APCA triennial conference to take place in Gaborone from 23 to 26th September 2025.

To ensure that palliative care continues to be recognised as an important component of care in cancer treatment, APCA's Executive Director has continued to actively engage key regional and global players in the cancer space. He served on the 2024 World Cancer Congress's Palliative Care Committee, providing high-level representation of palliative and comprehensive chronic care themes at this important global congress. APCA also contributed to the development of the harmonised National Cancer Control (NCC) guidelines for palliative care and survivorship for Africa hosted by the American Cancer Society under the African Cancer Coalition, in September 2023, and continued to partner with the City Cancer Challenge in Ghana, Rwanda, and Kenya.



APCA Executive Director, Dr. Emmanuel Luyirika with the Director General of the WHO, Dr. Tedros at the World Innovation Summit for Health in Doha Qatar.

Other collaborations included contributions to the NCCN Harmonized Guidelines for Sub-Saharan Africa.

APCA continues to engage in conversations and lobbying activities bent on ensuring good access to essential controlled medicines for palliative care. We participated in the WHO technical working group on palliative care and served observers on the Committees on Controlled Medicines with UNODC and other stakeholders that were convened to mark the 10th Anniversary of the World Health Assembly (WHA) Palliative Care Resolution. APCA shared critical information on successful models of supply chain mechanisms and supported country level experiential visits for learning purposes.

APCA continues to support the teams in DRC to improve access to controlled essential medicines with support from the government of the Kingdom of Belgium through UNODC.



APCA CONTINUES TO ENGAGE IN CONVERSATIONS AND LOBBYING ACTIVITIES BENT ON ENSURING GOOD ACCESS TO ESSENTIAL CONTROLLED MEDICINES FOR PALLIATIVE CARE.

APCA is investing in strengthening the use photography in capturing telling stories and documenting the impact of interventions in ethically appropriate ways following the prescribed best practices for compliance with data protection ethos. APCA developed a three-module self-paced basic course, "The Art of Using Photography Effectively to Tell Stories: A Basic Course for Palliative Care Providers" in December 2023. The course was run by an experienced artist, Carolina Kroon and was an opportunity to improve skills in using photographs to tell stories and describe palliative care in one's own context and setting. The course is available on APCA's YouTube Channel.

#### Session I:

<u>Using Photography to Tell Great</u> <u>Stories – Think Before You Press</u> <u>the Button of the Camera</u>

#### Session 2:

Communication
Goals and Basic
Photography

#### **Session 3:**

Best Practices Once You Have Made Images -Tips for Postproduction



This image captures the smile of our patient. Our goal is to improve the quality of life of our patients; we make people smile even in the context of chronic illness.

## ANNUAL PHOTOGRAPHY COMPETITION

As part of its 20th anniversary commemorations, APCA will be launching an annual photography competition in Palliative Care to expand engagement with stakeholders and communities through creative art and culture starting August 2024. Members and stakeholders will participate to show the spirit of palliative care in the context ethics and culture.

# **B.** STRENGTHENING HEALTH SYSTEMS BY INTEGRATING PALLIATIVE AND COMPREHENSIVE CHRONIC CARE AT ALL LEVELS

The focus of our work is on ensuring that patients living with serious illnesses and their families receive the palliative and comprehensive chronic care they need to relieve distressing symptoms and concerns. We threfore run a Small Grants Programme which is funded by The True Colours Trust.

#### PALLIATIVE CARE FINANCING

The Africa Small Grants programme, funded by The True Colours Trust, provides grants to hospices and palliative care providers across Africa to support the development of palliative care. All work supported by this programme adheres to the WHO definition of palliative care. Twenty-Nine calls for applications have been made to date since the inception of the Small Grants' Programme in 2009, and a total of 1,634 applications have been received from 39 African countries, of which 275 small grants have been awarded to various organisations providing palliative care in Africa. The table below summarizes the organisations that APCA partnered with on this initiative, by country during the reporting period.

COUNTRY	NO. OF Partners Supported	DETAILS OF PC PROVIDERS SUPPORTED
Malawi	05	<ul> <li>Ndimoyo Palliative Care Trust</li> <li>Christain Way Church</li> <li>Lets' Be Transformed (MAGUFINA)</li> <li>Outreach Scout Foundation</li> <li>HAWIP Community Based</li> <li>Organization</li> </ul>
Uganda	03	<ul> <li>Kawempe Home Care</li> <li>Kabale Christian Care</li> <li>Rays of Hope Hospice, Jinja</li> </ul>
Kenya	03	<ul><li>Nyambene Hospital</li><li>Concerned Mind International</li><li>Meru Hospice</li></ul>
Zambia	01	Tiny Tim and Friends
Sudan	01	<ul> <li>Comboni College of Science &amp; Technology</li> </ul>
Togo	01	<ul> <li>Organisation Jeunesse pour le Développement Communautaire (ORJEDEC),</li> </ul>
Ethiopia	01	Hospice Ethiopia
BurkinaFaso	01	■ GreAS
Cameroun	01	Mengbwa: Actions Jeunes
South Africa	03	<ul><li>Msunduzi Hospice Association</li><li>Grahamstown Hospice</li><li>Ladies of Hope Hospice</li></ul>
The Gambia	01	■ Hands on Care
Tanzania	01	<ul> <li>Muheza Hospice</li> </ul>

2 PALLIATIVE CARE PROVIDERS SUPPORTED

Reports and stories of significant change demonstrate that the small grants are continuing to make significant impact on the capacity of organisations and networks providing and promoting palliative care services, and on the lives of patients and their families.

A summary of achievements from palliative care service providers who received funding and have completed their projects successfully.

2,660

NUMBER OF ADULT PATIENTS RECEIVING PALLIATIVE CARE THROUGH THE SMALL GRANTS SUPPORT

This includes those under home based care

623

NUMBER OF CHILDREN RECEIVING PALLIATIVE CARE

These received paediatric palliative care

1,664

NUMBER OF CHILDREN RECEIVING PSYCHOSOCIAL SUPPORT

These have been provided at organization/facility level for children.

15,282

NUMBER OF HOME VISITS
CONDUCTED TO REACH
PATIENTS WHO COULD NOT
MAKE IT TO THE FACILITIES

Number of visits have increased due to lapse of COVID-restrictions. Visits also include those conducted by Community Based Volunteers.

1,198

#### NUMBER OF HEALTH WORKERS TRAINED

This includes facility based and non-facility-based health workers. Training sessions delivered through formal workshops facilitated by experts, Online sessions and CME at health facilities.

23,951

NUMBER OF PEOPLE
REACHED VIA PALLIATIVE
CARE SENSITIZATION
AND AWARENESS AND
EDUCATION SESSIONS

This is done through media campaigns and community meeting

4,064 NUMBER OF PATIENTS RECEIVING ESSENTIAL PALLIATIVE CARE MEDICINE

These have received assorted medication as listed on the WHO Essential Medicines list

3,038 NUMBER OF REFERRALS

Referrals to Hospitals to enable patients receive additional treatment

## Infrastructure developments to improve patient comfort and practical support to patients.

- Two buildings modified to cater for palliative care patients
- · Telephone handsets
- Assorted Children's Toys
- Furniture and other items which includes
   Tables, Curtains, Sofa seats, Mattresses, Musical instruments
- Hospital Equipment which includes; Hospital Bedside tables, Mattress protectors, Surgical Sundries, Syringe Drivers etc.
- Other items purchased include; Masks, Soap, Sanitizers, Gloves etc
- Assorted PC Medicines as per WHO essential medicines list

Equipment purchased for patients and infrastructure improvements result into better patient experience and improved quality of care to patients from service providers.





Medicines and Diapers purchased with funding from the TCT small grant (Photo shared by Ranchhod Community Services and Hospice-a past grantee from Zambia)





A small grant recipient in Mozambique, MOPCA, used the small grant to construct a palliative care room at Hospital Rural de Chibuto (Photo shared by MOPCA)





In Eswatini the small grant was used to purchase medical supplies and training of staff. Eswatini Hospice at Home staff training on pressure sores and in the next photo, Regional Nurse receiving medical supplies for dressing pressure sores (Photos provided by EHAH)

## PLATFORMS FOR INTERACTIVE ENGAGEMENT AND NETWORKING

APCA provides a free platform for knowledge exchange for partners within Africa and globally. This is achieved through prioritised webinars. In this financial year we hosted nine webinars, which provide opportunities for Continued Medical Education for health professionals. A total of **577** professionals attended these webinars.

NUMBER OF WEBINARS HELD

NUMBER OF PARTNERS ENGAGED

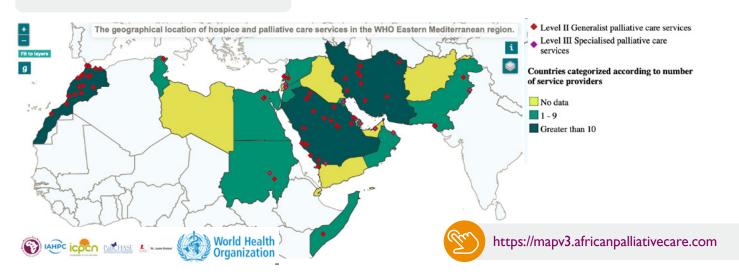
577 NUMBER OF PARTICIPANTS

#### HEALTH Information Systems

APCA is working in partnership with WHO-EMRO, IAHPC, ICPCN, and the St Jude Children's Hospital



to pioneer the use of Geographical Information Systems to increase the ease with which patients, families and care providers can locate service providers in the different geographical areas. We were able to map the various palliative care service centres, collecting information such as contact details, modes of care, availability of palliative care service spots in humanitarian settings, and the availability of opioids. This is a novel approach to catalysing the use of technology and health information to increase the visibility and location of palliative care service.



#### PARTNERSHIPS FOR GREATER IMPACT

2023/2024 was a year of spreading our wings and embracing the language diversity in Africa. We celebrate our regional partnership gearing at increasing access to education for our partners access to education in French-speaking African countries. This has been made possible through our partnership with PallCHASE, iECHO and the Senegalese National Association for Palliative Pare

(ASSOPA). Through these fora, we have been able to cover important education topics in the field of palliative care. More so, it was an opportunity for partners to form a community of practice with global network of individuals and organizations interested in promoting and improving access to Palliative Care in Humanitarian settings, including emergencies, natural disasters, conflict, and protracted crises.

#### C. HEALTH WORKFORCE

A trained health workforce is central to palliative and comprehensive chronic care service development and delivery. As noted by the World Health Organisation, Africa suffers a major human resource shortage with only 7 African countries meeting the WHO's recommended doctor-to-population ratio of 10 doctors per 10,000 people. The continent still averages only 2.6 doctors per 10,000 people, and equally high patient to nurse ratios.

The African Palliative Care Education Scholarship Fund, established in 2011by APCA and Global Partners in Care (GPIC), awards a limited number of scholarships for palliative care training opportunities annually. The scholarships support training of nurses,

clinical officers, music therapists and social workers to enhance their palliative care skills and knowledge.

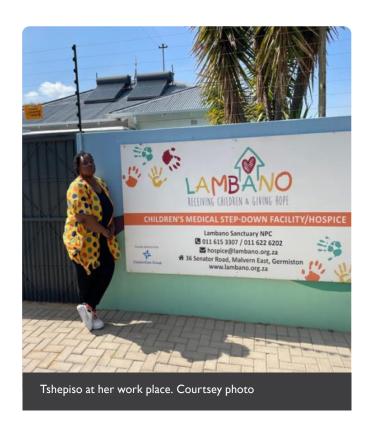
For 2023/24 a total of 11 education scholarships were awarded to nurses (9) and social workers (2) from across Africa. The recipients pursued courses of study ranging from Certificates, Diploma, Post Graduate Diploma, Bachelors and Master of Science in Palliative Care at various institutions within Africa which include the Institute of Hospice and Palliative Care at Makerere University in Uganda, Nairobi Hospice in Kenya, University of Cape Town in South Africa and Kamuzu University of Health Sciences in Malawi.

#### **IMPACT STORIES FROM THREE SCHOLARSHIP BENEFICIARIES**

#### **Tshepiso Makume, South Africa**

Tshepiso Makume is a Registered Counsellor from South Africa working with Lambano Sanctuary, a palliative care service provider who was awarded a scholarship to pursue a Post Graduate Diploma in Palliative Medicine with a specialist in pediatrics. Tshepiso completed her studies in November 2023 and passed with distinction. She graduated at the end of March 2024.

In her own words she notes, "During my studies at UCT I have been able to meet likeminded people on palliative care, especially pediatrics, where we were able to share the experience covering issues to do with holistic care, holistic assessment of patients, dealing with bereavement, working in a multi-disciplinary team and how to integrate palliative care in health service delivery. My plan is to integrate palliative care pediatric services in Home Based Care services in our institution".



#### Louis Kuleti, Malawi

Louis Kuleti is a Malawian male nurse working at Machinga District hospital who studied at Kamuzu University of Health Sciences (formerly known as College of Medicine). He was awarded the scholarship in July, 2023 which covered tuition fees for the final semester of his BSc in Palliative Care which he completed successfully in December 2023, and graduated in April 2024.

He says that "Undertaking palliative care course helps one to acquire knowledge that will help in identifying and managing palliative care patients well from diagnosis to death and bereavement. It also helps in acquiring problem solving skills that promote team work towards achieving patient care goals. Palliative care course prepares the learner to be self-reliant and build confidence to be a team player by sharpening interpersonal skills".

Kuleti lists the following as major achievements from attending the course:

"As an individual health care professional, I have acquired specialized knowledge, skills and attitudes toward palliative care which I would not attain if I had not enrolled on this undergraduate program.

It improved my understanding and enhanced my ability to identify patients with palliative care needs, defining care goals and making better care plans to achieve goals that will help in improving the quality of life of patients.

In addition, I am able to advocate for some improvements like supply of essential medicines from the pharmacy at our institution and also advocate or lobby for some patients who have some specific needs to be assisted to meet their individualized care needs.

Currently, at our institution, I am the only palliative care provider who attained advanced training in palliative care, so I am able to mentor some of my colleagues in important skills such as breaking bad news, pain assessment, morphine prescription, etc. so that we improve quality of the service and reduce suffering at the facility."





Kuleti at his working place on the left and on the right with a medicine box visiting a patient under the Home Based Care (all courtesy photos by Kuleti).

"I would like to thank APCA and GPIC, for considering me as a successful applicant for the scholarship. The scholarship came timely when I had no hope for tuition fees payment. Really, I would not have managed to finish my studies, but it really helped me a lot. Based on this reason, I pray that this scholarship program should continue because it is really helping in improving palliative care service through supporting needy students like me who really need support".

#### Cynthia Mwanchande, Uganda

Cynthia Mwanchande completed her Master of Science in Palliative Care at the Institute for Hospice and Palliative Care in Africa, an affiliate of Makerere University. She has completed her second year of the course and appreciates the support from APCA and GPIC which enabled her to meet her tuition requirements.

In her own words, Cynthia says that "It's interesting undertaking this course because it is helping me to gain knowledge and skills on caring for patients with chronic illnesses. I have so far leant how to communicate well with patients who are dying and their families and how to effectively assess for pain and manage it well. Not only that; I am also able to mentor other staff members who have passion in providing palliative care. I do make presentations to staff members to share the knowledge

that I have learnt so far. The main challenges I faced were sourcing funds to travel to Uganda for my face to face lessons. It is far from Malawi to Uganda and transport is so huge. Accommodation is also expensive as such I have really been struggling during my face to face lessons. Despite the challenges faced, I have learnt that it is still worthy it pursuing this program. Many people with palliative care conditions are neglected because a lot of health professionals focus on curative care. So it is satisfying to learn this course to make a difference in caring patients with life threatening illnesses. After finishing this course I will continue teaching others the concepts of palliative care through presentations. I will also continue mentoring other staff at the place where I am working and also staff from other health facilities. I am also planning to take part in research on different areas in palliative care to improve health service delivery".





THEREFORE, THE **SCHOLARSHIP** OPPORTUNITIES HAVE BEEN VITAL AND CONTRIBUTED TO ATTAINMENT OF KNOWLEDGE AND SKILLS IN PALLIATIVE CARE AND FURTHER PROVIDED AN OPPORTUNITY TO SHARE EXPERIENCES BY SCHOLARSHIP BENEFICIARIES INTERACTING WITH THEIR PEERS IN THEY MEET WITH IN THEIR RESPECTIVE INSTITUTIONS OF STUDY ACROSS AFRICA.

#### INTEGRATING PALLIATIVE CARE THROUGH TRAINING MULTI-DISCIPLINARY HEALTH PROFESSIONALS

APCA significantly contributes to in-service continued learning for multidisciplinary teams of health workers in Africa. We run online training programmes which come with CPD points, to equip

health workers with skills they need to address the emerging and re-emerging health problems faced by patients with palliative care needs and their families. For example, the need for palliative psychiatry is evident and is informed by the paradox of high prevalence of mental health illnesses in patients with palliative care needs, coupled with a high prevalence of palliative care needs in patients with mental health illnesses. In response to identified training needs, we delivered a course on Palliative Care Psychiatry in partnership with the Department of Psychiatry at Makerere University between January and May 2024. The training was delivered via the African Palliative Care Association online iECHO learning platform that provided an interactive and collaborative learning environment to participants. The course comprised 10 sessions which were held on a bi-weekly basis. The training sessions were facilitated by mental health professionals from Makerere University-Department of Psychiatry, the African Psycare Research Organisation and the Lake Side Hospital Entebbe in Uganda. A total of 109 health professionals were trained, with an average attendance of 95%. The health professionals reported improved ability to deliver palliative psychiatry services to patients, improved core competencies in diagnosing mental health illness, and in making referrals to specialists as needed.

APCA continues to host and a coordinate the 300member African Palliative Care Research Network



'Overall Review and Future Research in Palliative Psychiatry for Africa,' by Professor Seggane Musisi, Makerere University and Lake side Hospital

(APCRN). Our goal is to support the development of the research and knowledge translation echo-system for palliative care in Africa; and to provide a platform for researchers to connect, network and form a community of practitioners.

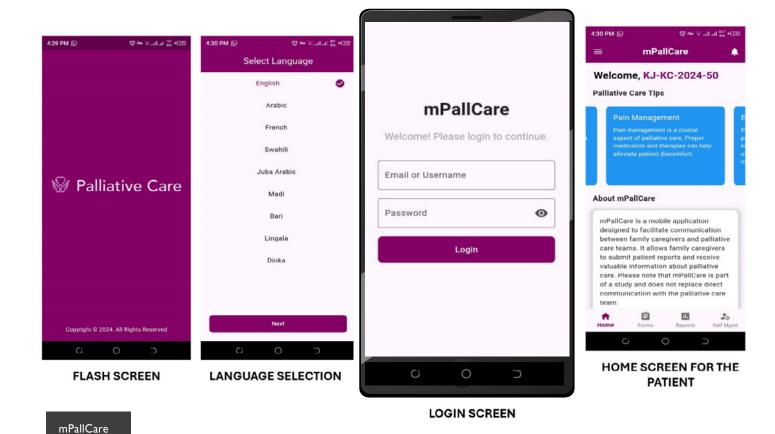
We held 4 capacity building webinars for Msc and PhD degree students in the region as part of our strategy of building a critical mass for researchers. In addition, in 2023-2024 financial year, we are proud to have co-hosted two webinars via the APCA, King's College London, University of Zimbabwe and Cape Town University collaboration. The APCRN, continues to seek funding to support strengthening the palliative care research echo-system in Africa. Through such initiatives, we continue to leverage on research partnerships to bring learning opportunities nearer to the doors of African scholars.

## **D.** ACCESS TO ESSENTIAL CONTROLLED MEDICINES & TECHNOLOGIES

## Catalysing innovation to test breakthrough solutions aimed at scaling up patient and family access to palliative care.

APCA and Leeds University are in the process of expanding a home-grown application (mPallCare) a digital health platform designed for palliative care providers in Africa. The platform includes a mobile phone application that can be used by a patient, carer or health worker. The mobile phone application allows the user to share information about the symptoms and concerns of a person living with a life-limiting illness.

These data are then transmitted to a clinical team's dashboard for quicker patient and family-led assessment for palliative care needs and concerns, and subsequently inform treatment and care plans, thereby promoting person-centred approach to care.



#### E. RESEARCH, INNOVATION, AND DEVELOPMENT

#### THE AFRICAN PALLIATIVE CARE RESEARCH NETWORK

APCA continues to host and a coordinate the **300-member** African Palliative Care Research Network (APCRN). Our goal is to support the development of the research and knowledge translation echo-system for palliative care in Africa; and to provide a platform for researchers to connect, network and form a community of practitioners.

We held **4** capacity building webinars for Msc and PhD degree students in the region as part of our strategy of building a critical mass for researchers.

In addition, in 2023-2024 financial year, we are proud to have co-hosted two webinars via the APCA,



King's College London, University of Zimbabwe and Cape Town University collaboration. The APCRN, continues to seek funding to support strengthening the palliative care research echo-system in Africa. Through such initiatives, we continue to leverage on research partnerships to bring learning opportunities nearer to the doors of African scholars.

## INTERNATIONAL COLLABORATIVE RESEARCH ENGAGEMENTS

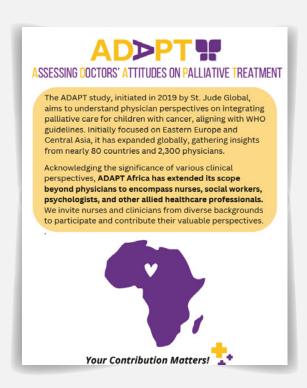
Under the United Nations Convention on the Rights of the Child, children and young people (CYP) have a right to express their views in all matters which affect them, including healthcare. Despite this, exploring decision-making preferences with CYP diagnosed with cancer can be complicated, due to variations in cultures and beliefs on disease disclosure or prognosis. In this study, we aim to develop a culturally appropriate participatory method to explore decision-making preferences among CYPs diagnosed with cancer in LMICs.



APCA is grateful to be participating in a multi-country study aimed at "Engaging Children and Young People Diagnosed with Advanced Cancer in Low- and Middle-Income Countries (LMICs) in Research through the Development of a Participatory Method" in partnership with St Jude Children's Hospital, Memphis USA, and the Uganda Cancer Institute.

## QUALITY INDICATORS IN END-OF-LIFE CARE FOR CHILDREN WITH CANCER IN LOW- AND MIDDLE-INCOME COUNTRIES.

Quality indicators are now increasingly used to assess and improve clinical care and provide a framework for evidence-based planning, accountability, and policy development. While there are over 200 end-of-life quality indicators for adults, there is a paucity of end-of-life quality indicators for end-of-life care among children living with cancer in resource constrained settings. The overarching goal of this project is to address this paucity by developing a new tool, the Pediatric Oncology Tool for End-of-life Care Treatment (PrOTECT).



#### CATALYSING IMPACT IN RESEARCH THROUGH INNOVATION

Our study on what person-centred care meant to patients, families and health professionals showed that the quality of the interactions between patients and care providers are more important than the structural aspects of the service provision.

A series of dissemination workshops led by King's College London and the African Palliative Care Association informed the uptake levels of personcentred care for people living with serious illnesses in Uganda.

Early findings had been disseminated in the first workshop in 2022, addressing the importance of person-centred care to patients, families and health professionals, and was attended by 50 stakeholders, including Ministry of Health, patients, caregivers, members of civil society, patient groups, and health professionals from Uganda Cancer Institute, Uganda Lung Institute, Uganda Heart Institute and Uganda's National Referral Hospital-Mulago.

In the period under review, we held two more workshops to disseminate final study outputs, each attended by 50-60 participants comprising patients,

caregivers, policy makers, commissioners, members of the civil society, academia and health professionals.

#### The workshops covered the following:

- a model of person-centred care for people living with serious illnesses and their families,
- a theory of change to underpin this care model
- a novel measure of patient reported experiences (the PEQ African version).

These events informed the uptake of person-centred care for people living with cancer, heart failure and chronic obstructive pulmonary disease in Uganda.

#### Examples of uptake include:

Two new centres, Kitovu Mobile Hospice and the St Francis Naggalama Hospital Palliative Care Unit, have begun using the adapted version of the patient reported experiences measure to collect data on patient reported experiences with care, and this has informed quality improvement initiatives for end-of-life care for patients with advanced disease. They are also implementing person-centred care for patients with advanced disease, to improve their End-of-Life Care experiences.

## CO-DESIGNING WITH CHILDREN AND YOUNG PEOPLE PROCESSES FOR THEIR ENGAGEMENT IN RESEARCH

Person-centred care focuses on individuals, families and communities as participants in health systems responsive to their needs. Children have the right to express their views on their health and care. Our engagements with the children and meant to co-design with children and young people the processes for them to meaningfully participate in research. We used a series of co-design workshops to develop the process for children and young people living with serious illnesses to participate in patient public engagement and involvement in palliative care research. The children were recruited from three tertiary care facilities providing care for cancer, HIV, neurological disorders, and other blood disorders. They co-designed a young people centred typical workshop agenda, which included play interludes, music, dance and drama, meals and refreshments, shared learning. We also co-designed the approaches to conducting the sessions these include working in groups, role play, use of films, visuals and illustrations.



#### Take home message:

Engaging and involving young people in research by using child co-designed approaches improves person-centredness in paediatric palliative care research.

#### STUDENT INTERNSHIP EXCHANGE PROGRAMME

## Gender and social norms: do they matter in palliative care?

We take delight in our student internship exchange visit initiative with Global partners in Care through which we get an opportunity to work with interns. This financial year, we hosted Emily Karalus from the University of Notre Dame whose research project on about Gender based violence in palliative care through the lenses of the palliative care providers in Africa. Emily's work revealed a notable experience of gender-based violence incidents in households with palliative care patients and, a need to train palliative care providers in this area.

Emily's work is in tandem with APCA's work: featuring psychosocial needs and experiences of patients with advanced cancer; where divorce,



separation, emotional and psychological abuse were reportedly common in these households. APCA is partnering with other NGOs in the region to develop and disseminate training materials and resources in this area.

#### **READ MORE ABOUT APCA PUBLICATIONS**

- Matovu JK, Wagner GJ, Juncker M, Namisango E, Bouskill K, Nakami S, Beyeza-Kashesya J, Luyirika E, Wanyenze RK. Mediators and moderators of the effect of the game changers for cervical cancer prevention intervention on cervical cancer screening among previously unscreened social network members in Uganda. BMC Cancer. 2023 May 11;23(1):428. doi: 10.1186/s12885-023-10924-0. PMID: 37170099; PMCID: PMCI0173559.
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- Kiyange F, Atieno M, Luyirika EBK, Ali Z, Musau H, Thambo L, Rhee JY, Namisango E, Rosa WE. Measuring palliative care integration in Malawi through service provision, access, and training indicators: the Waterloo Coalition Initiative. BMC Palliat Care. 2024 Jan 16;23(I):17. doi: 10.1186/s12904-023-01331-0. PMID: 38229044; PMCID: PMCI0790398.
- Can You Hear Us Now? Equity in Global Advocacy for Palliative Care. Rosa WE, Ahmed E, Chaila MJ, Chansa A, Cordoba MA, Dowla R, Gafer N, Khan F, Namisango E, Rodriguez L, Knaul FM, Pettus KI. J Pain Symptom Manage. 2022 Oct;64(4):e217-e226. doi: 10.1016/j. jpainsymman.2022.07.004. Epub 2022 Jul 16.
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- Wagner GJ, Matovu JKB, Juncker M, Namisango E, Bouskill K, Nakami S, Beyeza-Kashesya J, Luyirika E, Bogart LM, Green HD, Wanyenze RK. Effects of a peer advocacy intervention on cervical cancer screening among social network members: results of a randomized controlled trial in Uganda. J Behav Med. 2023 Dec;46(6):930-939. doi: 10.1007/s10865-023-00418-6. Epub 2023 Sep 13. PMID: 37702912; PMCID: PMCI0577098.
- Ghai I, Wagner GJ, Matovu JKB, Juncker M, Namisango E, Bouskill K, Nakami S, Beyeza-Kashesya J, Luyirika E, Wanyenze RK. Increased Knowledge Mediates the Effect of Game Changers for Cervical Cancer Prevention on Diffusion of Cervical Cancer Screening Advocacy Among Social Network Members in a Pilot Trial. Int J Behav Med. 2023 Sep 1. doi: 10.1007/ s12529-023-10217-7. Epub ahead of print. PMID: 37656308.
- Lin CP, Chen PJ, Namisango E, Musisi S, Gayton A, Efstathiou, N, Guo P (2023) Chapter 18.
   Current integration and challenges of palliative care into dementia practice: evidence and experience from Asia, Europe, and Africa. Edited by Michael Silberman and Ann Berger, The Impact of Culture and Faith in Dementia Care: Psycho-Social-Spiritual Healing. Cambridge Scholars Publishing, Cambridge, UK.
- Surgery: a crucial ally for universal palliative care access. Rosa WE, Lumati JS, Alatise OI, Namisango E, Bogale N, Pérez-Cruz PE, Rajagopal MR, Taylor L, Kingham

#### F. COMMUNICATIONS



#### **World Hospice and Palliative Care Day**

APCA engaged it partners to actively participate in raising awareness around palliative care through the world day activities. Themed Compassionate Communities, many national associations, small grant recipients, and other partners participated in the global campaign which also helped improving their visibility and recognition in the health sector.

APCA also delivered a keynote speech at the World Day event hosted by the Palliative Care Association of Uganda and participated in the advocacy activities that dominated the day, including visual awareness materials disseminated digitally.

#### **World Cancer Day**

APCA carried out an online awareness campaign that was aligned to the global theme of "leaving no one behind." This was closely linked to the advocacy messaging that we sent out on the International Childhood Cancer Day, also held in February 2024.

Routine Newsletters and social member engagements: APCA sent out 2 newsletters as well as several bulk email briefs to keep members up-to-date on: the announcements of key events, calls for small grants, scholarships, key world days, as well as other developments at APCA.

#### Social media & website

Members and stakeholder engagement via social media improved compared to the previous year: registering over 17,000 followers on Facebook, and 4,800 on X. We are continuing to build our content and profile on: You-tube, LinkedIn, Instagram, and are planning to run promotions to beef up our following.

APCA routinely provides strategic information, publications, research papers, articles and materials of interest on its website, including training resources and reference materials that members and different stakeholders access freely to keep uo to date with developments in the sector. During the year under review, our website visits registered a 2% increase compared to the previous financial year.



#### **EHOSPICE AFRICA EDITION**

APCA continued to subscribe to ehospice as the editor for the Africa edition where we received a steady inflow of articles from different stakeholders in all sub-regions of Africa to disseminate and share palliative care stories and developments with our global audience. Analytics show readership to be approximately 40% from Africa, with the remainder coming from other parts of the world.

#### G. LEADERSHIP AND GOVERNANCE

We are grateful to the APCA Board of Directors who have played a significant governance oversight role through the year, tirelessly giving advice and making time for meetings as and when called upon. The current board membership consists of Ms. Thobekile Finger (South Africa) – Board Chair; Prof. Ikeoluwapo Ajayi (Nigeria) - Vice Chair of the Board; CPA Frederick Kibbedi (Uganda) – Honorary Treasurer of the Board; Dr. Bernard Dornoo (Ghana) – Honorary Secretary of the Board; Prof. Rene Krause (South Africa) – member; Ms. Irene Among (Germany/Uganda) – member; Dr Zippy Ali (Kenya)-Member, Ms. Lidia Monjane Mondlane (Mozambique)-Member; Diederick Lohman (USA)-member; Prof. Liz Gwyther (South Africa)-Member.

#### STAFF DEVELOPMENT

Our staff remain the biggest resource at APCA. With a very small staff complement, we are thankful for the mountains that the staff have moved in creating long lasting milestones, through their commitment, resilience and tenacity as they delivered on their individual mandates. We congratulate, Dr Emmanuel Luyirika, who has effortlessly led the team, being supported by Dr Eve Namisango, Programmes & Research, Learning and Development Manager; Mable Namuddu, Finance Manager; and Patricia Batanda, Administration & HR Manager/ Personal Assistant to the Executive Director. In turn, these have been supported by Francis Kayondo, ICT Consultant, Wedzerai Chiyoka, Communications Consultant, David Kagoro Byaruhanga, Programmes Officer, Small Grants, Salim Ngira, Finance & Administrative Assistant, Dianah Hosannah, Research & M&E consultant; Vito Alithum, Siraje Lule & Pascal Maru Anyama as Office & Security Assistants.

APCA Staff continue to pursue personal growth and development both at an individual level and together as an organisation. We are intentional about times of staff reflections and learning initiatives, which integrate teamwork development, learning and wellness opportunities and experiences, through development sessions, small courses & trainings and team-building activities. These are usually the most favoured staff moments in the year.

We held two staff outings and one of these was a 2-day time of reflection and organisational planning, at the Nyange Resort, on the shores of Lake Victoria.

Over the years, APCA responded the need for human resource development in palliative care by developing an internship and volunteer policy which seeks to give opportunities to students and fresh graduates to acquire skills and experience-based knowledge while contributing to APCA's mission. We hosted 2 interns during the year who supported the Programmes and Research department, and their work has been published. We appreciate the contribution of the valuable internships and the sponsoring organisations.

#### **RISK MANAGEMENT**

APCA prioritises robust risk management to safeguard operations, reputation, and stakeholder interests. Our risk management framework is aligned with best practices and regulatory standards, ensuring that risks are effectively identified, assessed, and mitigated.

The Board of Directors holds ultimate responsibility for the oversight of risk management and internal control systems. However, the management team,

# OVER THE YEARS, APCA RESPONDED THE NEED FOR HUMAN RESOURCE DEVELOPMENT IN PALLIATIVE CARE BY DEVELOPING AN INTERNSHIP AND VOLUNTEER POLICY WHICH SEEKS TO GIVE OPPORTUNITIES TO STUDENTS AND FRESH GRADUATES TO ACQUIRE SKILLS AND EXPERIENCE-BASED KNOWLEDGE WHILE CONTRIBUTING TO APCA'S MISSION.

supported by staff across all functional areas, is accountable for the day-to-day ownership of the risk management process.

In addition, independent auditors provide assurance that our internal control systems are sound and capable of identifying and managing significant risks. APCA remains committed to maintaining a robust risk management framework that not only meets current needs but also anticipates emerging risks in a dynamic and evolving environment.





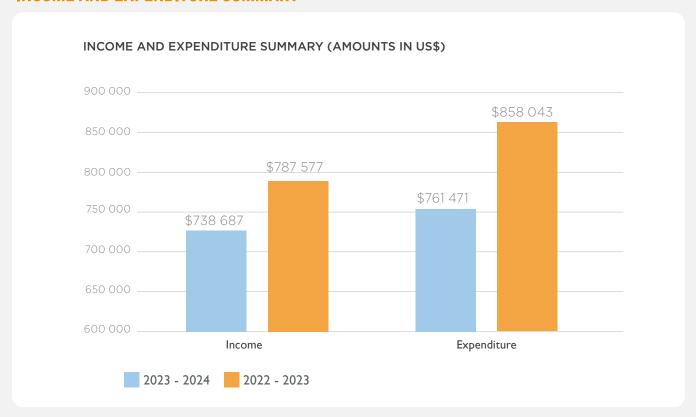


27

#### H. FINANCIAL SECTION

This section presents the financial performance and position for 2023-2024, alongside comparative figures for 2022-2023.

#### **INCOME AND EXPENDITURE SUMMARY**



#### Income

Total income for 2023-2024 was \$738,687, representing a 6% decrease from US\$ 787,577 in the previous year. The higher income in 2022-2023 was partly due to the 7th International Palliative Care Conference, held in August 2022, which attracted additional funding. Of the total income, 63% was raised from foundations and trusts, 31% from other donors, and 6% from general sources such as membership fees, interest income and technical assistance.

#### Expenditure

Total expenditure for 2023-2024 was \$761,471, an 11% reduction from \$858,043 in 2022-2023. This reduction is primarily due to the absence of the triennial conference, which significantly increased program-related costs in the previous year. Additionally, all board meetings in 2023-2024 were held virtually, resulting in further reduction in expenditure. Of the total expenditure, 33% was allocated to personnel costs, 9% to administration and capital expenses, and 58% to program expenses.

#### **FINANCIAL POSITION**

Balance Sheet Extracts for the Financial Year 2023-24 and Prior Year Comparatives (Amounts in US\$)

Assets	2024	2023
Non-Current Assets		
Property and equipment	185,667	88,859
Leasehold Land	60,866	62,351
Total non-current assets	146,543	151,210
Current Assets		
Cash and bank balances	133,044	64,394
Receivables	269,729	370,789
Total Current Assets	402,773	435,183
Total Assets	549,316	586,393

Funds & Liabilities	2024	2023
Funds		
Capital fund	146,543	151,210
General fund	165,530	1188,069
Restricted fund	228,309	228,554
Total Fund	540,832	567,833
Non-current liabilities		
Terminal Benefits	-	2,055
Current liabilities		
Payables	7,140	13,105
Terminal Benefits	1,794	3,400
Total Liabilities	8,934	18,560
<b>Total Funds and Liabilities</b>	549,316	586,393



Total assets decreased by 6% from \$586,393 to \$549,316. This was mainly due to a 27% reduction in cash and bank balances. However, there was a notable 107% increase in receivables, which includes working advances to staff and funds owed by grantees that had not yet been accounted for by the end of the year.

Total liabilities reduced by 52%, from \$18,560 to \$8,934, reflecting a significant decrease in short-term obligations to make by the end of the year.

The total fund balance decreased by 5%, from \$567,833 to \$540,832, driven largely by a 12% decline in unrestricted funds and reserves, alongside a 3% reduction in the capital fund.

#### DONOR APPRECIATION

WE EXTEND OUR DEEPEST
APPRECIATION TO ALL THE
DONORS THAT HAVE BELIEVED IN
OUR MISSION THUS FAR., WHOSE
DEDICATION AND GENEROSITY
HAVE BEEN THE DRIVING FORCE
BEHIND ALL OUR IMPACT AND HAS
ENABLED US TO IMPROVE THE
LIVES OF PEOPLE LIVING WITH LIFE
THREATENING ILLNESSES ON THE
CONTINENT.

#### WE APPRECIATE THE FOLLOWING DONORS:

- American Cancer Society
- · Global Partners in Care
- Global Institute of Psychosocial, Palliative and End-of-Life Care (GIPPEC)
- Irish Hospice Foundation
- King's College London
- Rand Corporation
- Open Society Africa
- The True Colours Trust
- United Nations Office on Drugs and Crime, with support from the Government of the Kingdom of Belgium
- · University of Birmingham
- · University of Leeds
- Veta Bailey Charitable Trust
- Other individual and institutional donors



# MAKE A DONATION

We value partnerships and support that can propel the development of palliative and comprehensive chronic care to shape future endeavours and ensure that our collective efforts create a better life for all people living with life threatening illnesses in Africa.

DONATIONS MADE TO APCA ARE USED IN A TRANSPARENT, ACCOUNTABLE, AND EFFICIENT WAY.

If you wish to support APCA financially, please visit the APCA website and follow the 'donate' tab, or contact us on info@africanpalliativecare.org.



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NGO Registration Number 4231





