



15 YEARS OF PARTNERSHIP



Dear Friends and Supporters,

It is with gratitude, awe and humility that we mark 15 years of partnership between the Palliative Care Association of Uganda (PCAU) and the Center for Hospice Care/Hospice Foundation (CHC/HF). The partnership has thrived because we invested in building strong personal relationships with one another from the onset. This fostered mutual understanding, flexibility, trust, respect and a compassionate focus on the real needs of PCAU and palliative care beneficiaries in Uganda. PCAU, supported by this partnership, has achieved strategic, national recognition while directly impacting the lives of individuals, families and communities.

Since 2008, PCAU has grown into a formidable organization with credible staffing and infrastructure, strong membership nationwide, an excellent reputation and recognition by the Ugandan government.

As you will learn in this report, the partnership has touched all six major pillars of advancing palliative care: palliative care education, access to essential medicines, research, health policy, empowering people in communities and promoting the integration of palliative care in the health care system.

One of our most significant achievements is that the government of Uganda has now established positions for trained palliative care doctors and nurses in the staffing structures of the nation's hospitals. Since the start of the partnership, we have focused on expanding the spread of palliative care. In 2009, only 34 districts in Uganda had a palliative care service. Few healthcare workers had trained as specialist palliative care providers. Many more children and adults then lived in pain and suffering. PCAU, with support from CHC/HF, has advocated and supported palliative care training over the past 15 years, and currently, 107 of 146 districts have at least one facility offering palliative care.

Uganda is among the pioneer countries in Sub-Saharan Africa to achieve full integration of palliative care into the national health information management systems as a result of this partnership and the involvement of university partners in this project. Consequently, PCAU continues learning and growing while offering valuable lessons to palliative care colleagues in resource-limited settings worldwide.

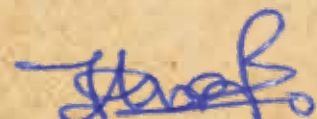
The partnership supported PCAU as it worked diligently to withstand the challenges of the COVID-19 pandemic. The commitment of CHC/HF to the Road to Hope program, which has touched so many children, was

extended to support the families of these children during this difficult time. In 2021, a mother traveled over 310 kilometres (193 miles) to the PCAU office to express her gratitude for the help PCAU gave her and her two children. The children are progressing excellently in school, and their health has improved.

There are a myriad of testimonies of gratitude in Uganda by health workers, patients, caregivers, policymakers and collaborative institutions due to this partnership. This has only been possible because of the generosity of individuals and institutions who support this partnership through Global Partners in Care. Many former and current staff at both CHC/HF and PCAU have committed to meeting the needs of PCAU and those we serve. To all of them, we extend our sincere gratitude and appreciation.

As we mark 15 years of the PCAU-CHC/HF partnership, we acknowledge that the need for palliative care in Uganda is still rising, yet the resources and attention to support it is not. Only 11% of people who face health-related suffering in Uganda currently have access to quality hospice and palliative care. As PCAU, we are committed to our vision of Palliative Care for ALL in Uganda. As CHC/HF, we are committed to continuing our support for this vision. Thank you for joining us on this journey.





Mark Mwesiga
Executive Director
Palliative Care Association of Uganda





Mike Wargo
Vice President/COO
Hospice Foundation



Why Palliative Care?

According to the World Health Organization, palliative care is an approach that improves the quality of life for patients and their families who are facing problems associated with life-threatening illness through prevention and relief of suffering. It treats symptoms that are physical, psychosocial and spiritual. Palliative care was first introduced to Uganda in 1993 with the start of Hospice Africa Uganda (HAU) during the country's struggle with a

Access to Palliative Care

The World Health Organization recommends that a country have a minimum of 4.45 physicians, nurses and midwives per 1,000 people. Uganda has approximately 1.84. Only 11% of those who are in need of pain control and palliative care in Uganda can access it (Lancet Commission, 2017).

Yet, Uganda has emerged as a leader in palliative care on the African continent. It was

high prevalence of HIV/AIDS. The service has grown to include others suffering from serious and chronic illnesses including cancer, diabetes and many others. PCAU has done tremendous work to increase access to palliative care services for Uganda's 45 million people, but the need also continues to grow as life expectancy (currently at 63 years) and non-communicable diseases increase.

the first country to allow nurses and clinical officers with specialized training to prescribe opioid analgesics which increased accessibility to essential medicines. PCAU is tasked by the government as its technical expert to accredit facilities to provide palliative care. PCAU also coordinates multiple stakeholders who collaboratively support access and monitoring of morphine in the country.



PCAU Strategic Objectives

PCAU was officially registered as an NGO in 2003 with a vision to ensure palliative care for all in Uganda. They have 25 member organizations and 1,300+ individual members. PCAU works hand-in-hand with the Ministry of Health which is a driving factor in their success. Our partnership engagements are guided by and work toward PCAU's strategic plan and objectives.



PCAU and CHC/HF team meeting with the Palliative Care Division and other members of the Ugandan Ministry of Health



68%
of palliative care
services are
provided at
public hospitals

77
private hospices
or palliative care
services in
private hospitals

226
accredited health
facilities offer
palliative care
across 107 districts
in Uganda

94%
of palliative care
funding comes
from external
donors

Partnership Milestones



Start of partnership under FHSSA

2008



First staff exchange visits

2009



CHC launches sponsorships for clinicians to train in palliative care

2010



Students begin interning with PCAU



Okuyamba documentary produced

2011



PCAU building/secretariat opens



Road to Hope (RTH) program launched

2012



First engagement in PCAU's Biennial conference

2013



Partnership wins FHSSA Global Partnership Award

2014



Hollywood fundraiser for RTH program



First RTH child graduates from the program

2015



Road to Hope documentary produced

mHealth data project piloted



PCAU/CHC present at NHPCO's Management and Leadership Conference

2016



10 years of partnership celebrated at Okuyamba Fest

2017



PCAU/CHC presentation on partnership at the APCA conference

2018



ADPCN program launched at Mulago School of Nursing and Midwifery

Rose Kiwanuka, founding director, retires and is succeeded by Mark Mwesiga

2019



COVID-19 lockdowns and extra support to ensure care provision

2020



PCAU/CHC presentation on partnership at the APCA conference

2021



Integration of palliative care data at Ministry of Health

2022



15 YEARS!

2023



PCAU vehicle fundraiser



Advanced Diploma in Palliative Care Nursing Program in Partnership with Mulago School of Nursing and Midwifery

The Importance of Building Palliative Care Capacity

PCAU works with the Ministry of Health (MoH) to strengthen health services provision – and having trained palliative care health workers is crucial for that to succeed. Our partnership has focused on capacity building – education, training and mentorship for health and non-health palliative care workers. From 2010 to 2018, CHC/HF supported 62 nursing students through the diploma in clinical palliative care course offered at the Institute of Hospice and Palliative Care in Africa. PCAU continued to lobby the government to integrate a similar course into its public nursing schools to help increase the country’s training capacity. In 2019, due to the tireless efforts of PCAU, the advanced diploma in palliative care nursing (ADPCN) course was launched at the government’s largest nursing school, Mulago School of Nursing and Midwifery

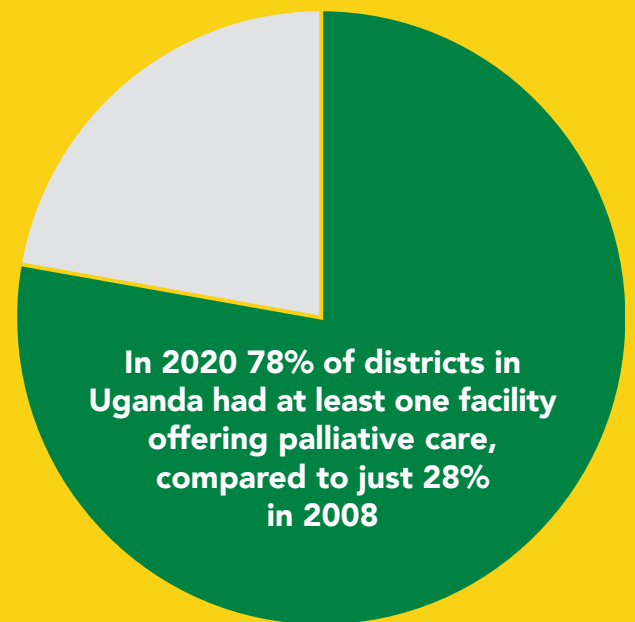
(MSNM). In the inaugural year of the program, CHC/HF supported 25 students. The COVID-19 pandemic lockdowns impacted recruiting and retention in the first few years of the program. The 2023 ADPCN cohort, which started in February, includes 21 students from 18 districts of Uganda that have limited or no palliative care services. Healthcare providers supported by the partnership and trained in specialized palliative care total 111, including the 2023 ADPCN cohort. Uganda’s Ministry of Health recently introduced recognized positions for palliative care nurses within the health system. The government creation of these key positions affirms the significance of the ADPCN program and that the need for qualified palliative care nurses is greater than ever.

Recheal K. Namara

Mpigi Health Centre IV attracts patients from neighboring districts and receives an average of 800 patients per month. As the nurse in-charge of the outpatient department, Recheal saw many sickle cell patients; “I wanted to do something extraordinary that could bring an impact and leave a legacy... and to follow up even after they are discharged.” To start a special clinic where she could administer morphine to help alleviate the pain sickle cell patients experience, she needed further training in palliative care. Recheal received the CHC/HF and PCAU scholarship and enrolled in the ADPCN course in 2019. She is back at Mpigi Health Centre IV and providing better support to sickle cell patients. Now the assistant nursing officer and a palliative care champion, she is working with administrators to establish a palliative care unit within the health center.



“I wanted to do something extraordinary that could bring an impact and leave a legacy... and to follow up even after they are discharged.”
–Rechael Namara



Road to Hope Program

Individual and Community Empowerment

The Road to Hope (RTH) program supports child caregivers from impoverished backgrounds so they can continue their education and access basic needs while caring for their chronically ill parents. Many are already orphans. The children are identified in collaboration with palliative care practitioners in the community, enrolled in appropriate schools and supported by the program with:

- school tuition, uniforms and other scholastic materials
- basic medical care
- psychosocial support tailored to each individual's needs
- support for issues regarding individual rights, legal issues and child protection
- the opportunity to socialize and interact with their peers during the annual children's camp and empowerment retreat.

The goal of the program is to improve these children's quality of living and provide opportunities for them by supporting their education and their physical, emotional and personal growth. In doing so, the positive impact of this intervention extends to their families and communities.

The RTH program is a catalyst for PCAU's advocacy and programming activities at the community level. This strategy of empowering people and communities for palliative care is a key part of the World Health Organization's (WHO) conceptual model for delivery of palliative care.

Program Impact

Since 2012, the program has supported close to 80 children in their individual growth and education. Currently there are:

- 22 children enrolled in primary school
- 22 children enrolled in secondary school
- 23 children in vocational school
- 7 students have graduated from their courses in medicine, development studies, motor mechanics, electrical installation and maintenance, hair styling, tailoring/seamstress and accounting

Thank you to the many selfless individuals who commit to sponsor children on the RTH program. Our unique sponsorship program, focused on meeting the individual needs of the child, is only possible with your generous support. Thank you for believing in the future of Uganda!





Connecting Resources, Creating Impact

Collaborators and Community Engagement

As the partnership has grown, it has involved numerous stakeholders in our respective communities. These relationships support partnership activities and enrich the work of both organizations. Universities have been key partners. We also engage individuals, churches, government and community organizations to increase the visibility of the mission and outstanding work of PCAU.

Friends of Uganda Network (FUN)

Friends of Uganda Network (FUN) is a group of individuals and organizations in and around South Bend, Indiana who

engage in work with non-governmental organizations, religious or educational initiatives throughout Uganda. Since 2015, the group has met to share information, best practices, ideas and lessons learned about the work they are doing in Uganda. Members bring valuable insight to each other's work. The collective knowledge of the group in working with partners in Uganda is significant. The group strives to be aware of others who are working in Uganda so that we can be a resource for those who are beginning their own engagement with partners in Uganda.

University Student Internships

Student interns significantly contribute to PCAU's research goals. Guided by PCAU and faculty from their institution, interns bring energy, knowledge and human resources for advancing research projects. Students may also engage in project-based or experiential internships. PCAU has hosted 32 student interns since the start of the partnership.

These students come from a variety of disciplines: public health, theology, business and a broad range of sciences. Student projects are established to meet the needs and focus of PCAU. These internships not only provide valuable support to the work of PCAU but also benefit the student's learning.

Intern Projects



In 2011, **Ben and Mary Ann Wilson** did a spiritual care internship with PCAU as part of their Master of Divinity degree at the University of Notre Dame.

In 2015, students from the Executive MBA program at Notre Dame

conducted a national morphine supply chain analysis with PCAU. The resulting report was used to identify gaps in the process and improve morphine access across Uganda.



In 2019, Notre Dame undergraduate **Kat Kostolansky** supported the Road to Hope (RTH) Program and researched best practices for child sponsorship programs which improved PCAU RTH programming and informed the current RTH policy.

In 2020, Notre Dame master's student **Ainur Kagarmanova** led a descriptive study of the current state of palliative care in Uganda with PCAU. Her work resulted in a peer-reviewed publication in 2022, "Palliative care in Uganda: quantitative descriptive study of key palliative care indicators 2018-2020."



In 2022, Notre Dame undergraduate **Mariah Horvath** researched the effects of the COVID-19 pandemic on the mental health of palliative care workers in collaboration with Makerere University and PCAU. The research resulted in a workshop and joint planning with palliative care and mental health leaders in the country.



Advancing Palliative Care Research

PCAU aims to be a hub of palliative care research and information in Uganda. They carry out research, host relevant research projects and collaborate with numerous national and international institutions to advance palliative care research. The goal is to not only ensure that research takes place, but to also assure that information is regularly disseminated so it can improve palliative care services. CHC/HF staff, interns and university partners engage in research with PCAU. Students and faculty from the University of Notre Dame, in particular, have worked with PCAU since 2010 on various research projects.



Palliative Care Data Project

PCAU is leading the effort, in collaboration with the Ministry of Health, to ensure harmonized palliative care data collection and management nationwide. To better support palliative care services, quality data is needed to help leaders understand the current state of palliative care, identify gaps and provide evidence for making decisions to enhance the availability and use of these services. Their efforts were recognized by the World Health Organization as a model for implementing data collection on palliative care (WHO, Assessing the development of palliative care worldwide: a set of actionable indicators, 2021).

In 2015, PCAU launched this project in collaboration with CHC/HF, University of Notre Dame and Uganda Martyrs University, with the following objectives:

- collect regular, accurate and timely data on palliative care
- provide capacity to health care workers on how to collect and use this data

- provide evidence for advocacy and lobbying policymakers
- ensure sustainable scale up of palliative care data collection countrywide

The project grew from a pilot at four health facilities in 2015 to 20 facilities in 2017. PCAU focused on collaborating with the government to ensure the project's sustainability, and in 2019, the Ministry of Health developed data collection tools for palliative care that are now integrated within the national Health Management Information System (HMIS). The tools are:

1. the HMIS OPD 008 unit palliative care register
2. HMIS 105c health unit palliative care monthly report

PCAU supports the training of the developed tools and works with the Division of Health Information to ensure the quality of the data collected. In 2023, a palliative care data report was fully integrated into the DHIS2, the electronic health reporting system that will eventually be rolled out across the country.



Sharing Our Experiences

Staff Exchange Visits

Exchange visits are vital to the strong relationship between CHC/HF and PCAU. In 2009, CHC sent two staff to Uganda for an initial visit to listen, learn and offer assistance. The visit fostered an overwhelming appreciation for PCAU's work as well as for the dedication of PCAU's members who provide care to patients in their homes.

CHC/HF staff have continued to visit PCAU every other year, and in the off years, PCAU staff visit Indiana (although COVID impacted these visits in 2020-21). This investment of time and resources provides an opportunity for staff to deepen relationships, fosters learning opportunities and gives enhanced insight into program initiatives.

Our exchange visits often happen in conjunction with other events and conferences. CHC/HF holds a signature Uganda event, *Okuyamba Fest*, when PCAU staff are in Indiana. PCAU teams have joined CHC/HF staff at the national NHPCO conference in the US and the CHC/HF team often participates in the PCAU national conference on cancer and palliative care which is co-sponsored by the Uganda Cancer Institute.



PCAU Conference

PCAU has been holding biennial national palliative care conferences since 2003. The conferences bring together people from around the world to share palliative care research, education and best practices in service provision. In 2011, CHC/HF began co-sponsoring the conference, and in 2017, PCAU partnered with the Uganda Cancer Institute to hold a joint UCI – PCAU Uganda Conference on Cancer and Palliative Care.

Over 10 CHC/HF staff have participated and presented at the conference since 2013. In addition to conference attendance and participation, CHC/HF staff also spend time working alongside PCAU colleagues during the week following the conference.

Okuyamba Fest

Celebrating community collaborations and partnerships is the focus of *Okuyamba Fest*. "Okuyamba" is the Lugandan word meaning "to help." The event began in 2012 to help raise funds for PCAU's work. It coincides with PCAU's exchange visit to the U.S. It features international foods and beverages as well as a silent auction of Ugandan arts and crafts. Proceeds from the event benefit the work of PCAU.

15 Years of Learning from One Another

Best Practices and Lessons Learned

1. CHC/HF and PCAU agree on partnership goals and objectives and track these annually.
2. The significant involvement of staff, administration and the boards of both organizations has ensured deep commitment and an active partnership, not just one on paper.
3. The engagement of other community partners and organizations significantly contributes to the partnership goals and raises the profile of the partnership.
4. As much as the partnership is between two organizations, individual people and relationships are what keeps the motivation strong. Spending time together in person has been crucial to this success.



ROBERTA SPENCER
Former CHC Staff
and PCAU Partnership
Committee Member

“There have been many tangible success stories, but it never would have occurred without the strong leadership, friendships and relationships between the staffs of PCAU and CHC. 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.’”



PCAU Partnership Support

A New Vehicle for PCAU

A sturdy, reliable vehicle is one of the most valuable tools PCAU must have to help realize their vision of reaching all. It allows PCAU staff to move across the country to raise awareness and advocate for hospice and palliative care services, visit the Road to Hope children, establish new palliative care teams, conduct mentorship activities and streamline access to pain relief medicines at health facilities.

PCAU's 13-year-old vehicle needed to be retired this year, and CHC/HF committed to help in fundraising. With the contribution of many generous donors, PCAU purchased a new Toyota Land Cruiser in July 2023. It is a steady and reliable vehicle and PCAU is confident it will do the job!

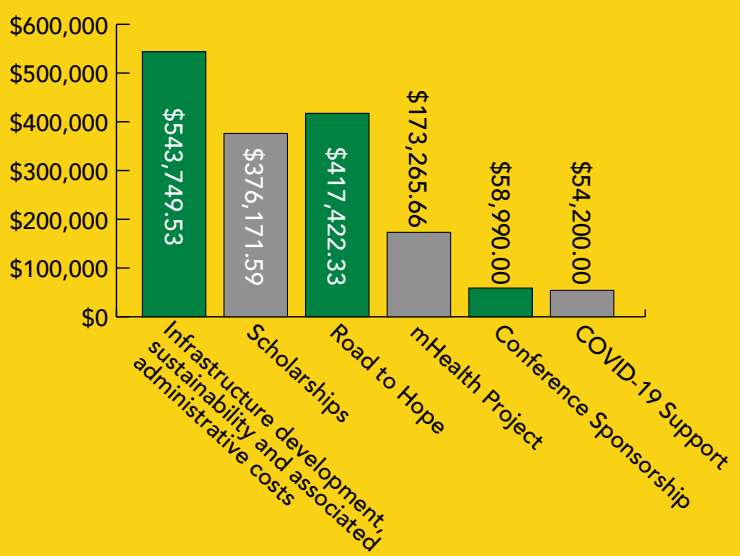
COVID-19 Support

With the March 2020 pandemic lockdowns, PCAU had to find ways to continue their work – and most importantly, their national leadership role to ensure their members across the country could still provide necessary palliative care services. PCAU continued their advocacy

work with the country's Prime Minister and the Coronavirus National Taskforce on COVID-19 Response. They also joined the national COVID-19 Case Management Committee tasked to plan for the potential surge in cases and helped train ICU nurses in basic palliative care to manage and support COVID-19 patients and their families.

The partnership generated extra support for PCAU including:

- support for Road to Hope children and their families while schools were closed
- resources to enable virtual work, including: Zoom license, internet and cell phone data and laptops
- general funding to support PCAU's COVID-19 emergency response efforts which included public health messaging and PPE for palliative care providers



CHC/HF Employee Giving

CHC/HF employees can support PCAU's success and sustainability via payroll deductions. Employee support helps PCAU hold quarterly update meetings which bring together individual and organizational members and other stakeholders for learning, knowledge sharing and networking. These are also opportunities for PCAU to coordinate and generate advocacy support, celebrate successes and address challenges.

Over the past 15 years, 178 employees have donated to support the PCAU partnership. Through the end of 2022, employees have given over \$260,000, more than half of that via payroll deduction.

Staff members have also sponsored children in the Road to Hope (RTH) program as well as providing financial support for RTH program services.

Heidi Payton and her husband Rich support a young girl on the RTH program.

“When we first heard about the Road to Hope program, we were so intrigued and saddened to learn that these young children are pulled from school and expected to be the caregivers or breadwinners for their dying parents.”

That awareness, coupled with the knowledge of the strong partnership between PCAU and CHC/HF, motivated them to support Patience.

“We have full confidence that our sponsorship is going towards her education and are pleased that PCAU also provides a camp experience where the children receive counseling, lessons in life skills and fun activities.”



HEIDI PAYTON
Hospice Foundation

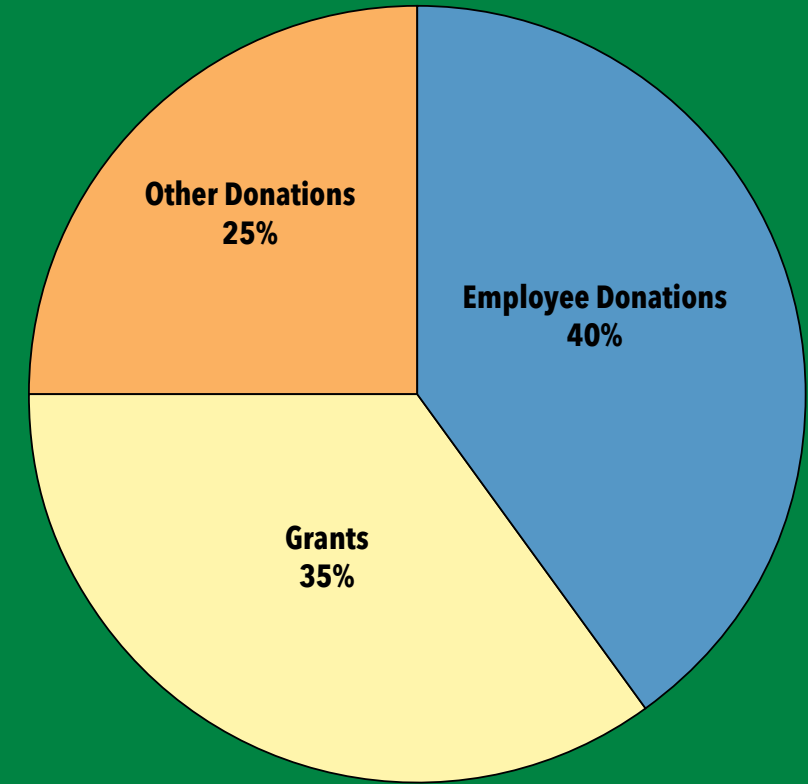


PATIENCE
Road to Hope Student



Fundraising & Support

Over the past 15 years, the partnership between CHC/HF and PCAU has generated \$1.6 million to support palliative care in Uganda. In addition to the generosity of CHC/HF employees, we have received several substantial grants and collected donations from individuals across the US.



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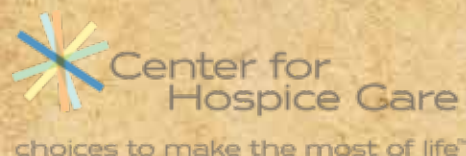
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