

# IAHPC Annual Report 2021

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# Foreword



We are proud to present this 2021 annual report to our colleagues, funders, and the global palliative care community. The activities, initiatives, statements, and resources we implemented throughout the year all aimed to relieve serious health-related suffering and improve the quality of life of patients and families around the world.

We are also extremely grateful to our small staff of workers and officers who continue to do their job tirelessly to ensure that IAHPIC achieves its mission and delivers on its promises. And to our Board of Directors for their guidance and wisdom in helping us do our jobs better.

In 2021, we announced changes to the IAHPIC leadership and back-office team. After serving for 21 years as the “public face” of the organization, participating in public events, conferences, interviews, and other public for a, Liliana stepped back from this public role at the end of December, while continuing to guide the organization, and support the staff, board, and membership, in my role as Executive Director. This will allow her to focus on personal projects and dedicate more time to her growing family.

As part of this change, Dr. Katherine Pettus was promoted to Senior Advocacy and Partnerships Director and Ms. Genevieve Napier to Senior Operations Officer. Both Dr. Pettus and Ms. Napier, hired in 2014 and 2015 respectively, are committed to the IAHPIC vision and mission, and are well recognized by the global palliative care community. Together, they continue to act as the public face of the organization, along with the directors, advisers, and other IAHPIC officers, as appropriate.

The IAHPIC’s mission continues unchanged: to serve as a global platform that inspires, informs, and empowers individuals, governments, and organizations to increase access and optimize the practice of palliative care.

We could not have achieved all the above and much more without the generous support of our board of directors, members, donors, and the foundations and other organizations that contribute in so many ways. Your generosity also helps keep most of our content free to palliative care workers in areas with fewer resources, so please consider making a gift to IAHPIC through our website. Our ability to actualize this vision without incurring conflicts of interest largely depends on the support we receive from our members and readers.

We prepared this annual report using the framework of the Strategic Plan adopted in 2019 for the term 2020-2024. The Plan focuses on four areas of work: Advocacy, Education, Research and Dissemination/Communication. We hope that you will enjoy browsing over it as much as we enjoyed putting it together.

*Lukas Radbruch*  
*Chairperson*

*Liliana De Lima*  
*Executive Director*

# Who we are / Mission and Vision

**The International Association for Hospice and Palliative Care (IAHPC)** is a global membership organization dedicated to the advancement and development of palliative care.

IAHPC works with **UN agencies, governments, associations, and individuals** to improve access to essential medicines for palliative care, foster opportunities in palliative care education, research, and training, and increase service provision around the globe.

IAHPC works at **the international, regional, and national levels** to promote appropriate policies and regulations to ensure access to palliative care for those who need it.

The **Vision** of IAHPC is towards a world free from health-related suffering.

The **Mission** of IAHPC is to serve as a global platform to inspire, inform and empower individuals, governments, and organizations to increase access to and optimize the practice of palliative care.

# Strategic Plan 2020-2024

In 2019 the IAHP Board completed a Strategic Plan for 2020-2024 that outlines where the IAHP came from, where its heading, how it will get there, and what it means to all its stakeholders. In developing this Strategic Plan, the Board examined the organization's priorities against the current global health policy landscape and considered where the organization could have a more meaningful role. The full Strategic Plan is available in the IAHP website in the [About Us](#) section. We continued to follow this plan when we were impacted by the COVID-19 pandemic in March 2020, finding alternatives to previous routines and developing new ways to meet our goals.

## *IAHP Thematic Areas of Work*

A survey completed by IAHP stakeholders (members, directors, patients, caregivers, funders, volunteers) helped us to refine our strategy and allowed the Board to identify four thematic areas of work. We will continue working on these four areas and to achieve the goals and expected outcomes for each:

1. Advocacy
  - a. for the integration of palliative care into primary health care, within the spectrum of universal coverage, and
  - b. for improved access to essential palliative care medications.
2. Education, to increase the workforce skilled in primary health palliative care.
3. Research, to gather data and evidence to inform global development of palliative care.
4. Information dissemination to educate stakeholders and amplify impacts where change is happening, to increase demand for palliative care and inspire additional changes.

## *IAHP's Strategic Plan: Goal, Outcomes and Outputs*

### **Overview of IAHP'S Strategic Plan: Goal, Outcome and Outputs**

#### **Goal (the high-level change that IAHP is working towards)**

- A world free from health-related suffering.

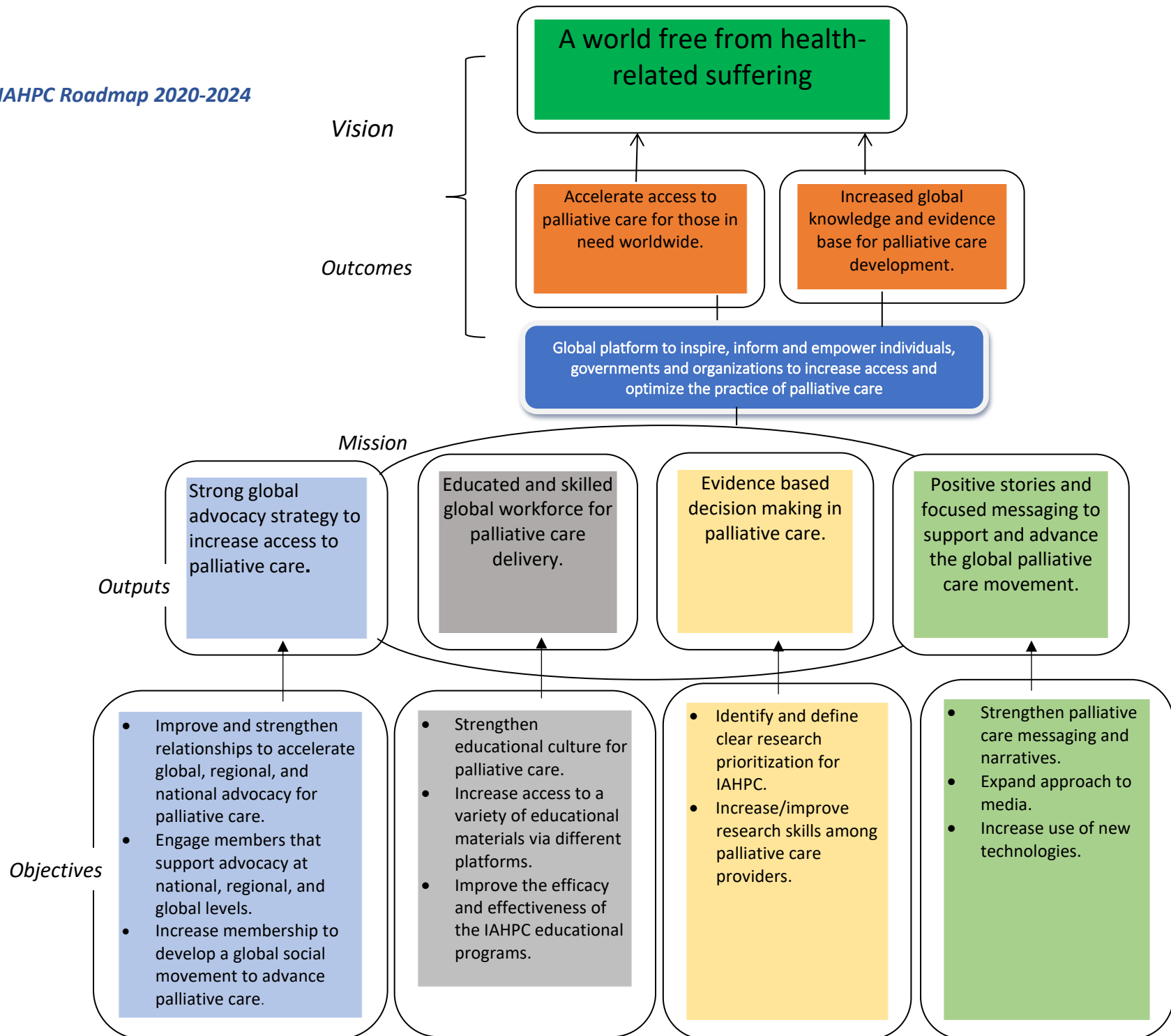
#### **Outcomes (changes IAHP is contributing to)**

- Accelerated access to palliative care for global population in need.
- Increased global knowledge and evidence base for palliative care development.

#### **Outputs (IAHP's broad areas of work)**

- **Output 1: Increased access to palliative care** – Strengthening advocacy to increase global access to palliative care.
- **Output 2: Educated and skilled global workforce for palliative care delivery** – Strengthening palliative care education and skills among providers worldwide.
- **Output 3: Evidence based decision making in palliative care** – Strengthening access to data, information, and global knowledge around palliative care to inform programming.
- **Output 4: Positive stories and focused messaging to support and advance the global palliative care movement** – Strengthening palliative care messaging, information, and communication to inspire global change.

## IAHPC Roadmap 2020-2024



# Advocacy Program

The IAHPAC Advocacy Program provides technical assistance to multilateral organizations, civil society organizations, academia, and to regional and national palliative care associations. We consult with member states upon request of our partners in the field.

*The objectives of the Advocacy Program in the 2020-2024 Strategic Plan are to:*

- *Improve and strengthen strategic relationships to accelerate global, regional, and national advocacy for palliative care;*
- *Engage members to support advocacy at national, regional, and global levels;*
- *Increase membership to develop a global social movement to advance palliative care.*

*The expected output of the Advocacy Program in the 2020-2024 Strategic Plan is a strong global advocacy strategy to increase access to palliative care.*



As **Senior Advocacy and Partnerships Director, Dr. Katherine Pettus** collaborates with civil society organizations and policymakers to achieve IAHPAC'S vision of a world free from health-related suffering. She represents IAHPAC at meetings of the United Nations organizations to ensure inclusion of language relating to palliative care and essential medicines in relevant technical documents, reports, resolutions, and political declarations, providing national palliative care organizations with information about these provisions of the global health framework. Katherine mentors IAHPAC members to foster governmental and non-governmental partnerships in their own countries that support effective service delivery for people with palliative care needs.

We will continue to strengthen palliative care advocacy at the national, regional, and international levels by empowering palliative care civil society organizations to advocate for the integration of palliative care in national policies and programs as a component of the right to health.

## **Advocacy Focal Points**

In 2021 our advocacy work consisted in capacity building in our team of Advocacy Focal Points who serve in Argentina, Australia, Bangladesh, Canada, Colombia, Costa Rica, India, the Russian Federation, the USA, and Zambia. Advocacy Focal Points are usually fully time palliative care workers who volunteer their time to advocate with their governments and participate in multilateral meetings.

As an NGO in consultative status with the UN Economic and Social Council and a non-state actor with the World Health Organization, the IAHPAC is invited to register a delegation for most intergovernmental meetings convened by the UN Organizations. As these were all virtual or hybrid, we were able to register delegations from all over the world. In January, IAHPAC Advocacy Focal Points participated in the 148<sup>th</sup> meeting of the WHO Executive Board. Our interventions on the floor, and preparatory meetings with member states focused on issues such as access to controlled medicines during the pandemic and inclusion of palliative care in national pandemic response and preparedness. In March, we participated in the 11<sup>th</sup> meeting of the United Nations Open Ended Working Group on Ageing, advocating for integration of palliative care for older persons, and holding a side event that included the Special Rapporteur for Health.



In April, our delegation participated virtually at the regular 74<sup>th</sup> meeting of the Commission on Narcotic Drugs, co-sponsoring a side event on access to controlled medicines during the pandemic with De Justicia and Harm Reduction International. Our delegation participated actively in the 74<sup>th</sup> World Health Assembly commenting on topics such as pandemic preparedness and response and access to controlled medicines.



## World Hospice Palliative Care Day

*World Hospice and Palliative Care Day*, a great campaign coordinated by the Worldwide Hospice Palliative Care Alliance with the support of the global palliative care community. Organizations throughout the world planned celebrations to increase awareness among lay people, governments, and patients that palliative care improves the quality of life of patients and families, and that appropriate policies and funding mechanisms need to be put in place to ensure access to palliative care to those in need.



We marked World Hospice Palliative Care Day 2021 by cosponsoring a webinar with the United Nations University International Institute of Global Health, featuring two panels of speakers from health ministries in Lower- and -Middle Income countries in dialogue with civil society organizations working to improve access to palliative care in those same countries.

WHO Director General Dr. Tedros gave [this very warm and supportive endorsement of palliative care](#) in his recorded welcome, reporting that he has written to all heads of state urging them to support the 2014 WHA 67/19 resolution on palliative care.

We continue to have regular meetings with WHO and other civil society partners to discuss joint strategies moving forward. In December, IAHP participated in the World Health Assembly Special Session in December, fielding a delegation of AFPS. Our statement on the floor urged member states to include palliative care as a component of care. IAHP is participating in the ongoing WHO member state working group on this topic.



## Advocacy Course

In 2021, we launched the new advocacy course, which consists of eight modules covering a range of topics around which IAHP advocates. The IAHP advocacy course is a component of the IAHP Academy, which includes educational projects leading to certificates in different fields. Advocacy for integration of palliative care into primary health care within the spectrum of universal coverage, and for improved access to essential palliative care medications is one of four thematic areas in the IAHP Strategic Plan 2020-2024. The advocacy course consists of several modules, which are released monthly.



The overall goal of the IAHPAC advocacy course is to continue building and strengthening partnerships to accelerate global, regional, and national advocacy for palliative care.

By the end of the IAHPAC advocacy course, participants will have learned:

- How advocacy can strengthen their national and regional PC organizations;
- How the global normative framework supports access to palliative care and palliative care medicines as an essential component of primary healthcare and as component of the human right to the highest attainable standard of health;
- Why it is important to build effective partnerships with other NGOs, policymakers, the media, and the secretariats of UN entities, including by drafting statements and organizing collaborative side events at UN meetings with other NGOs
- How to use evidence and stories to present a compelling case for equitable palliative care in their own settings.

The Advocacy Course is available in the [IAHPAC website](#).

Amount spent (including salaries) in **Advocacy** during 2021: **\$87,391**

# Membership



The goal of **Genevieve Napier's work as Senior Operations Officer** is to assist the Executive Director and other members of the IAHPC team in developing and implementing strategies to grow membership and membership engagement, strengthen the education and skills of our members, and support advocacy to increase access to palliative care.

Genevieve helps to design new programs and projects to meet IAHPC members' needs. This includes but is not limited to evaluating IAHPC's existing programs to ensure that they run smoothly and meet expectations. She is responsible for the Scholarship Program, Members' Recognition Awards, and the Membership benefits, among other programs. Gena collaborates with other members of the IAHPC team to develop communication strategies and newsletter content. Our

communications platform serves to educate members and the general public about IAHPC resources, tools and programs that benefit the global palliative care community.

*IAHPC members are the key to our goal to create a global social movement to advance palliative care. A complete list of the individual and institutional IAHPC Members is included in the [Members' Section on the website](#)*

## Membership Trends

*Since 2010, there has been a 71% increase in members.*



*The proportion of renewing members increased by 182%. Lifetime members have increased by 139%.*

*There was a decrease of new members of 18%.*

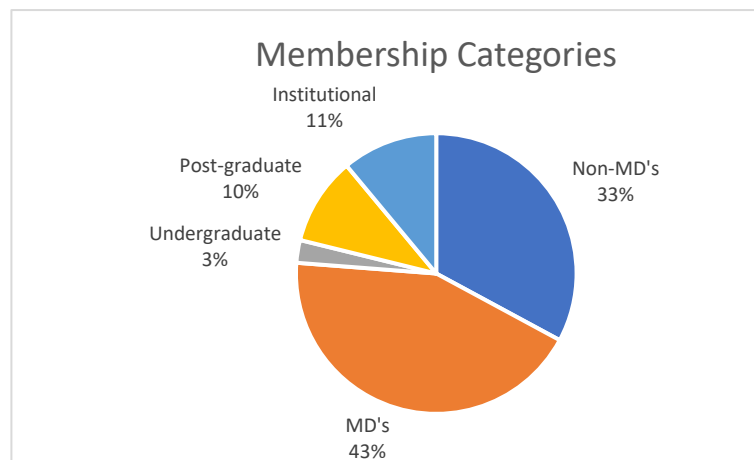
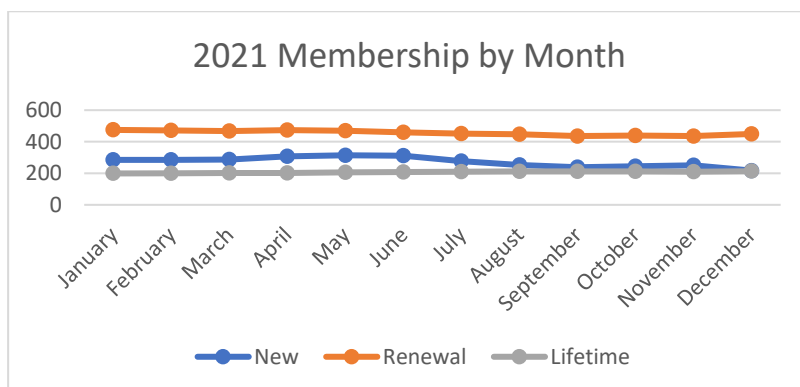
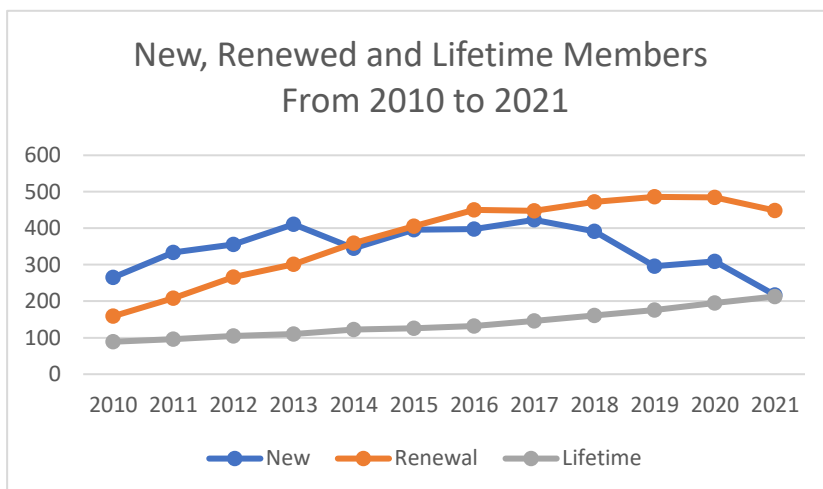
*According to Higher Logic, American associations' membership is down about 20% as a result of the pandemic. Our membership for 2021 was down 8.3% from the previous year.*

*During 2021, lifetime members grew by 9% while renewing members decrease by 7%. New members also declined by 29%.*

*The majority of our members are physicians, followed by other healthcare professionals.*

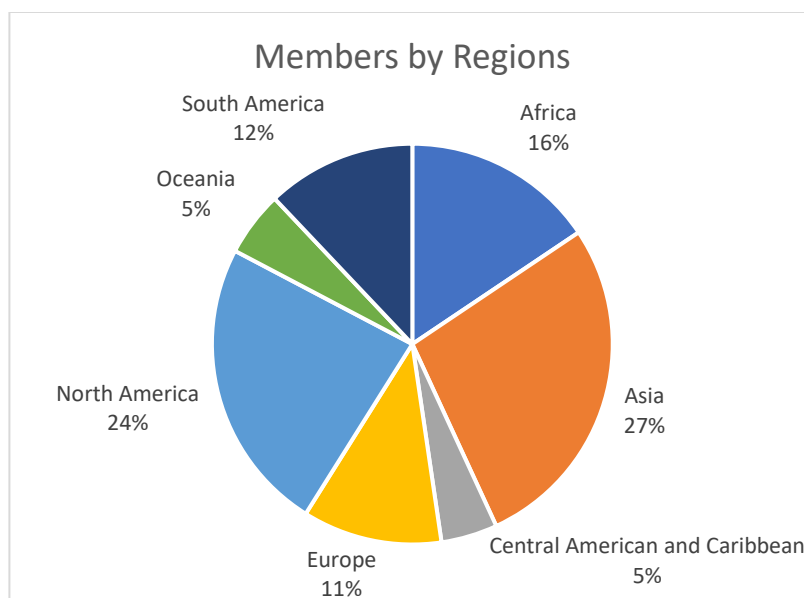
*During 2021 the proportion of institutional member grew 12.8% and post-graduate student memberships increased by 12.6%.*

*Physician members showed a decline of less than 1%, where the largest decline (22%) were other health care professionals.*



*The majority of our members live in Asia (27%), North America (24%), and Africa (16%).*

*Unfortunately, in 2021 there was decline in each region. Asia had a decline of 4% while North American had the largest decline of 14%.*



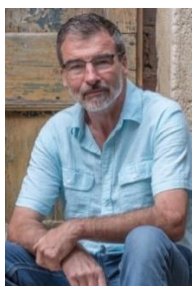
## **Membership Engagement**

### **Membership drives**

In 2021, we conducted two membership drives by reducing our membership fees by 20%. The first membership drive was conducted at the end of May through July, which resulted in 111 new or renewed members and generated \$14,290 in revenue. The second membership drive was conducted from November through the end of the year, where 65 new or renewed members joined. The revenue from that membership drive was \$8,985.

### **Loyal Members**

The IAHPH recognizes that our members are our greatest resource. To show our appreciation, at the end of 2021 we began reaching out to our members who have renewed continuously over the years to personally thank them for their continued support.



*Dr. Kim Adzich (Canada)*



*Mr. Miguel Rodriguez (USA)*



*Dr. Gayatri Palat (India)*

Dr. Kim Adzich, Mr Miguel E. Rodriguez and Dr. Gayatri Palat joined in 2008 and have consistently renewed their membership over the past 13 years. These members were highlighted in the 2022 [January](#) and [February](#) newsletter. The IAHPH team met with each one over a video call to thank them personally. We also took this opportunity to offer technical support and guidance on new projects. We will continue this practice regularly to show our appreciation and gratitude.

## Photo Contest

In 2021 we conducted a photo contest among IAHPH Members. The goal of the contest was to showcase palliative care practices and experiences around the world, inspiring and informing the global IAHPH community. There were three prizes given for winners.

- 1st Place: a 2-year membership extension and a cash prize of \$300
- 2nd Place: a 1-year membership extension and \$200 cash prize
- 3rd Place: a 6-month membership extension and \$100 cash prize

The photos submitted were reviewed in a blind selection process involving six judges.



First Place was awarded to Martin Lankoandé of Ouagadougou, Burkina Faso. Mr. Lankoandé's description of this photo is a "57-year-old patient, with pancreatic cancer, ranked his pain at a permanent 10 out of 10: he no longer ate or drank, refused to communicate with family, and asked for euthanasia. The only pain reliever prescribed was 1g of paracetamol (acetaminophen) every 12 hours. After sensitization of the family, we prescribed a morphine tablet that reduced his pain. Death in pain, and people

suffering at the end of life, are a daily occurrence in Burkina."

Second place was awarded to Tonny Mwabury of Teyateyaneng, Lesotho. Mr. Mwabury's description of the photo is a "volunteer from Najojo Better Living Mission Association assists a patient to visit the doctor. She complained about body aches and extreme tiredness after being vaccinated for COVID-19."



Third place was awarded to Farah Anil Joseph of Hyderabad, Sindh, Pakistan. Ms. Joseph's description of the photo is "Muhammed Hanif, 48, was diagnosed with Stage 4 cancer of the esophagus. He was attended by two young palliative care nurses from St. Elizabeth Hospital, Sheraz Suleman and Headley Creast, who deliver compassionate care at patients' homes with great zeal and wearing proper personal protective equipment during COVID-19.

Amount spent (including salaries) in **Membership Benefits and Membership Engagement** during 2021: **\$93,374.**

# E ducation

*The educational objectives in the IAHPC Strategic Plan for 2020-2024 are to:*

- *strengthen educational culture for palliative care;*
- *increase access to a variety of educational materials via different platforms.*
- *improve the efficacy and effectiveness of the IAHPC educational programs.*

*The expected output of the Educational component in the Strategic Plan is an educated and skilled global workforce for Palliative Care delivery.*

At IAHPC we continually strive to achieve this through our programs and projects. However, due to COVID-19, we were unable to fully execute all the programs we had originally planned and envisioned for the year. However, we managed to deliver three educational initiatives.

## IAHPC Scholarship Program

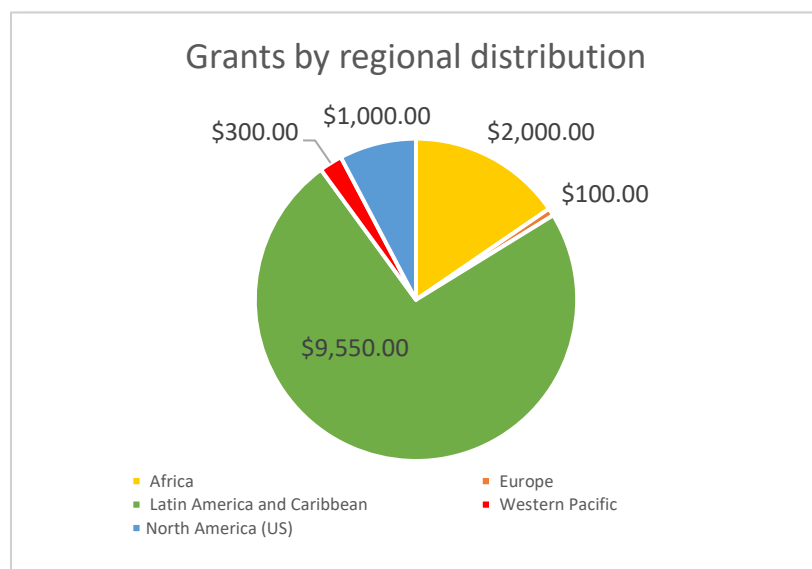
In 2021, through the IAHPC Scholarship Program, we awarded 26 scholarships to palliative care workers from 21 countries to support their participation in educational events.



Of the total amount of funds disbursed in 2021, \$4,133 were awarded to palliative care workers to enable them to participate the **14th Asia Pacific Hospice Conference (APHN) Online**, and the **Hospice Africa Uganda's Initiator Course and Placement** in Kampala, Uganda. IAHPC also supported the prizes for the winners of the **poster awards of the winners of the posters of the Latin American Association for Palliative Care online conference**.

The **17th World Congress of the European Association for Palliative Care** awarded 10 complementary registrations to the IAHPHC to support the participation of the Annual EAPC Congress held online on October 2021. With this gift from EAPC, we awarded free registrations to 10 members from Low- and Middle-income countries.

The **Latin American Virtual Conference on Palliative Care Virtual** awarded 15 complementary registrations to the IAHPHC. We awarded 15 registrations to members from South America.



**Annex 1** includes the list of grantees who received support through the different programs in 2021. The reports of the grantees are available on the [IAHPC website](#).

### ***Getting Started Guidelines (3<sup>rd</sup> Ed)***



In June we announced the publication of the third edition of **Getting Started: Guidelines and Suggestions for those Starting a Hospice/Palliative Care Service** by Dr. Derek Doyle. Thousands of people, many of whom have told us how helpful it was, have downloaded the second edition, published in 2009. The third edition is available on our website at no charge as

a service to the global palliative care community.

Amount spent (including honoraria) in **Education** pillar during 2021: **\$14,768**



# Research

The Research objectives for the 2020-2024 Strategic Plan are to:

- identify and define clear research prioritization for IAHP.
- increase/improve research skills among palliative care providers.

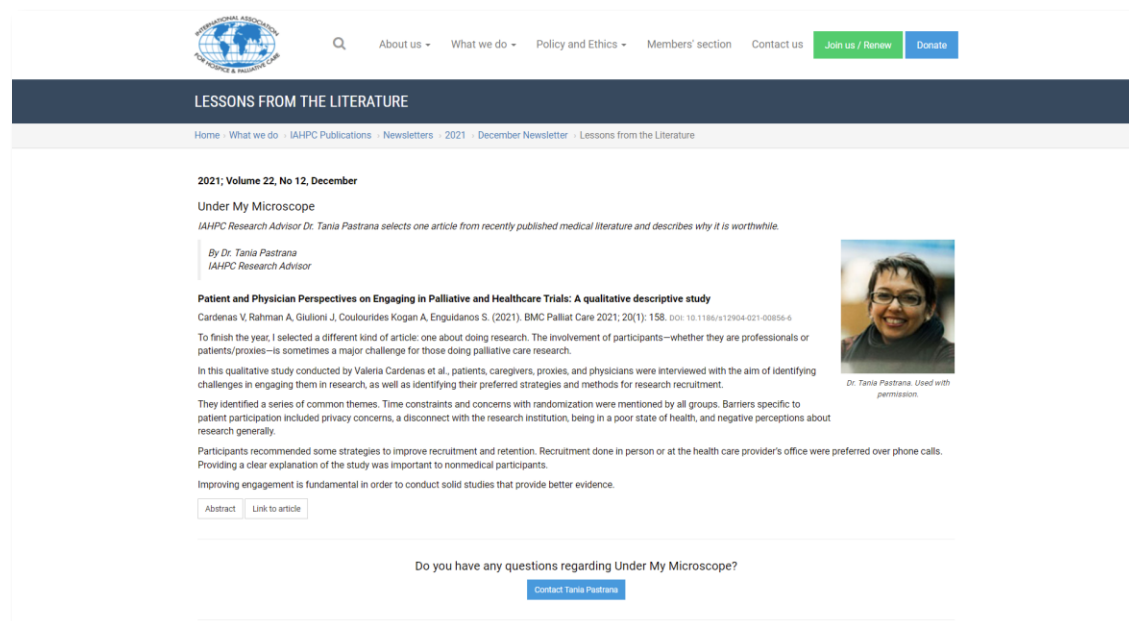
The expected output of the Research component in the Strategic Plan is evidence-based decision making in palliative care.



As the **Research and Academic adviser**, the goal of **Tania Pastrana's** work is to support IAHP's efforts in generating evidence that will lead to decision making in palliative care and strengthening palliative care education and skills among providers to achieve IAHP'S vision of a world free of health-related suffering.

In her role as Research adviser, Tania works supporting the design, implementation, analysis of data and publication of studies conducted by the IAHP and allied institutions. In her role as Academic adviser, Tania supports the design, development and teaching of courses and workshops for the IAHP. She works closely with the Senior Advocacy Director in her work with multilateral organizations and with the Executive Director in determining the research and educational priorities.

In addition, Tania writes the column "Under my microscope" in the IAHP monthly newsletter where she presents current scientific research. She also co-authors journal articles and book chapters, and represents the IAHP in collaborative research projects with academic institutions and civil society organizations.

A screenshot of the IAHP website. The top navigation bar includes the IAHP logo, a search icon, and links for 'About us', 'What we do', 'Policy and Ethics', 'Members' section', 'Contact us', 'Join us / Renew', and 'Donate'. The main content area is titled 'LESSONS FROM THE LITERATURE' and features a sub-header '2021; Volume 22, No 12, December'. The section 'Under My Microscope' by Dr. Tania Pastrana, IAHP Research Advisor, is highlighted. It discusses a qualitative study titled 'Patient and Physician Perspectives on Engaging in Palliative and Healthcare Trials: A qualitative descriptive study' by Cardenas V, Rahman A, Giullioni J, Coulourides Kogan A, Enguldanos S. (2021). The text describes the challenges of patient participation in research and the importance of engagement. A small portrait of Dr. Tania Pastrana is included on the right. At the bottom, there is a link to 'Contact Tania Pastrana'.

## Ongoing Projects/Resources

### Pallipedia (ongoing)

***Pallipedia*** is a free online palliative care dictionary produced by IAHPC. Pallipedia's goal is to facilitate access to high quality information for the global palliative care community.



At the end of 2021, Pallipedia included 1,391 terms and 1,766 definitions and registered over 366,609 users with almost 486,884 page views. The terms most frequently searched were: percentile, ethical principles, health care system, evaluation, and basic needs. The dictionary site is <https://pallipedia.org/>

Pallipedia is administered by Dr. Roberto Wenk, former Chair of the IAHPC.

## Completed Research Projects in 2021

### Impact of Covid – 19

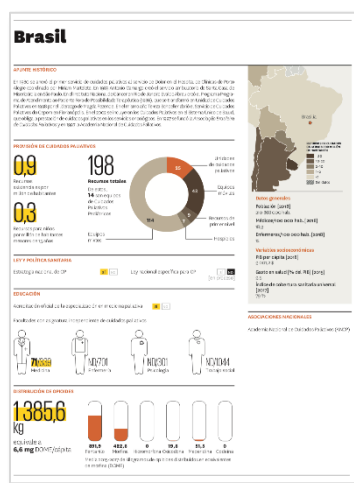
The Journal of Pain and Symptom Management published our health systems analysis on Colombia and palliative care was published titled “[How Universal is Palliative Care in Colombia? A health policy and systems analysis.](#)” As far as we know, this article, based on research by Liliana, Tania Pastrana, Felicia Knaul, Hector Arreola, and Natalia Rodriguez, is the first in-depth country health systems analysis relative to palliative care and Universal Health Coverage.

In an effort to evaluate and assess the impact of the Covid-19 pandemic on palliative care workers, the IAHPC conducted an online survey of its individual members between May and June 2020. The objective of the study was to learn how Covid-19 has impacted on the work and lives of palliative care workers around the world. The results from these surveys were published in two separate papers in 2021

and listed below: Last year, several staff and board members designed a study on the impact of COVID-19 on palliative care workers, disseminating a survey among IAHPHC members around the world. The two papers based on the results —a quantitative and a qualitative analysis— are available to download. The research design, methodology and analysis of the data were led by Tania as the research adviser for the IAHPHC.

1. Qualitative analysis: “The Impact of COVID-19 on Palliative Care Workers across the World: A qualitative analysis of responses to open-ended questions.” *Palliative and Supportive Care* 2021; 19(2): 187-192. DOI: [10.1017/S1478951521000298](https://doi.org/10.1017/S1478951521000298)
2. Quantitative analysis: “Impact of COVID-19 Pandemic on Palliative Care Workers: An international cross-sectional study.” *Indian Journal of Palliative Care* 2021; 27(2): 299-305. DOI: [10.25259/IJPC.6.21](https://doi.org/10.25259/IJPC.6.21) (open access)

## Second Edition of Palliative Care Atlas for Latin America



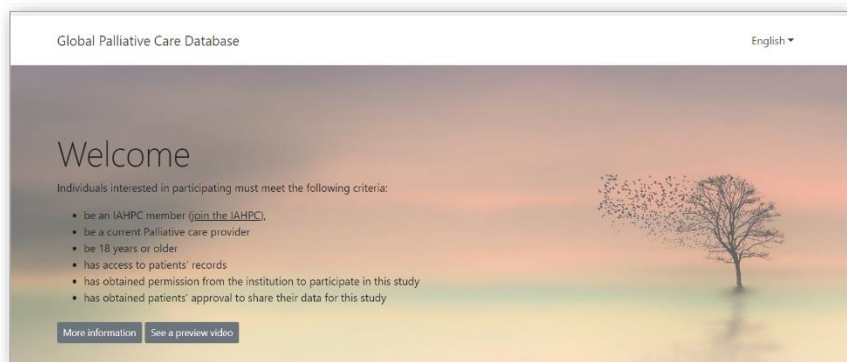
An updated edition of the Atlas of Palliative Care in Latin America was published, in collaboration with the IAHPHC, the Latin American Association for Palliative Care (ALCP) and the Global Palliative Care Observatory in ATLANTES at the University of Navarra, in Spain.

The objective of the ATLAS ALCP was to assess the degree of development of palliative care in Latin America. Secondary objectives include facilitating access to information and communication between institutions and associations dedicated to palliative care in the region, identifying key people involved in the development of palliative care in each country, and promoting the development of palliative care in the region.

The Atlas covers 17 Latin American countries whose official language is Spanish or Portuguese. This new edition of the Atlas presents a global vision of the situation of palliative care in the region as well as specific data.

## Global Palliative Care Database

This project, started in 2020 was finalized in 2021. The project was developed in collaboration with Fundacion FEMEBA in Argentina, under the coordination and leadership of Dr. Roberto Wenk.



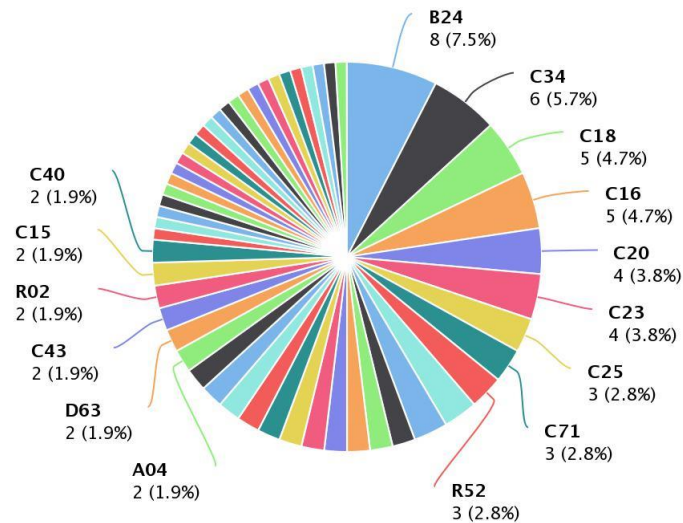
The objectives of the database were to:

- Provide demographic and epidemiological information about patients from the time when PC

was initiated (either from a PC specialist, another medical specialist, or a generalist)

- Identify the prevalent symptoms at the time of the initial palliative care consultation
- Identify the therapeutic interventions recommended for the treatment and management of the symptoms identified in the consultation
- Analyze the similarities and differences between reasons for referral and prepare a report for publication

Patient's main diagnosis (ICD-10)



Highcharts.com

Participants in the [Global Palliative Care Database](#), have access to detailed information about the first palliative care consultation. An example of interesting information is the number of days between diagnosis and initial consultation

Average: 1024.94 days

Median: 441 days

Maximum: 9676 days

Minimum: 9 days

The database shows the similarities and differences between the reasons and timing for referral to PC services, as well as the prescribed therapeutic interventions and referrals to other disciplines. The system registers items adapted from “An essential package of palliative care and pain relief health services” in The Lancet Commission on Global Access to Palliative Care and Pain Relief Report (2018). IAHPC Members were invited to participate for free and use the database for their own research and information.

## ***Published papers***

In addition to the ones listed in the Advocacy section, the following papers were also published in 2021:

1. Pastrana T, De Lima L, Pettus K, Ramsey A, Napier G, Wenk R, Radbruch L (2021). The impact of COVID-19 on palliative care workers across the world: A qualitative analysis of responses to

open-ended questions. Palliative and Supportive Care, 1–6.

<https://doi.org/10.1017/S1478951521000298>

2. Pastrana T, De Lima L, Pettus K, Ramsey A, Napier G, Wenk R, et al. Impact of COVID-19 pandemic on palliative care workers: An international cross-sectional study. *Indian J Palliat Care* 2021;27(2):299-305.
3. Tania Pastrana, Liliana De Lima, Mark Stoltenberg, Harm Peters. Palliative Medicine Specialization in Latin America: A Comparative Analysis. *Journal of Pain and Symptom Management*. Volume 62, Issue 5, 2021, Pages 960-967, ISSN 0885-3924, <https://doi.org/10.1016/j.jpainsymman.2021.04.014>.
4. Barrios C H, Werutsky G, Mohar A, Ferrigno A S, Müller B G, Bychkovsky B L, Castro E C J, Uribe C J, Villarreal-Garza C, Soto-Perez-de-Celis E, Gutiérrez-Delgado F, Kim J S, Ismael J, Delgado L, Santini L A, Teich N, Chavez P C, Liedke P E R, Exman P, Barroso-Sousa R, Stefani S D, Cáceres S A B, Rebelatto T F, Pastrana T, Chavarri-Guerra Y, Vargas Y, & Cazap E. (2021). Cancer control in Latin America and the Caribbean: recent advances and opportunities to move forward. *The Lancet Oncology*, 22(11), e474-e487. doi:[https://doi.org/10.1016/S1470-2045\(21\)00492-7](https://doi.org/10.1016/S1470-2045(21)00492-7)

Amount spent (including honoraria) in **Research** during 2021: **\$17,537**

# C ommunication and Dissemination

*The Communication and Dissemination objectives for the 2020-2024 Strategic Plan are to:*

- *Strengthen palliative care messaging and narratives.*
- *Expand approach to media.*
- *Increase use of new technologies.*

*The expected output is to create positive stories and focused messaging to support and advance the global palliative care movement.*

This section describes the tools and resources we offer to keep the global palliative care community connected and informed.

## **IAHPC Website**

The website is maintained by IAHPC webmaster Mr. **Danilo Fritzler** and housed at <https://hospicecare.com/>. As the **IAHPC Webmaster**, the goal of Danilo's work is to strengthen access to information, and global knowledge around palliative care to inform programming and strengthen palliative care messaging, information, and communication to inspire global change to achieve IAHPC'S vision of a world free of health-related suffering. As the IAHPC is an organization which relies on information technology, Danilo's role is critical to ensure the organization's performance and ability to deliver the projected outputs.

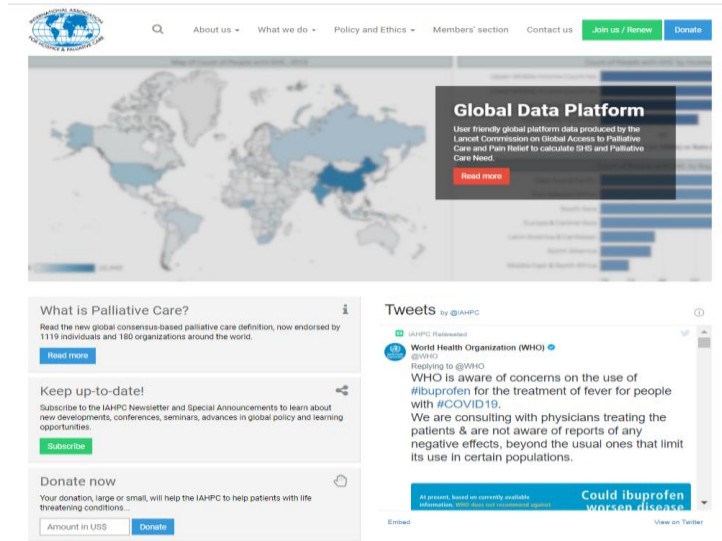


In his current role, Danilo updates the website and all the relevant forms and pages to enable users to, among others, apply for grants, provide donations, participate in research activities and join as members. In addition to the resources that are publicly available, he also develops the tools to facilitate administrative tasks, such as the membership management and engagement tool and maintaining the subscription lists for dissemination of information. He works closely with the IAHPC Newsletter Senior Editor to publishes and disseminates the IAHPC monthly newsletter and with the Senior Operations Officer to publish special announcements as well as thank you messages to donors. He also works closely with the Executive Director in setting the goals and defining the content priorities of the website to align them with the mission of the IAHPC and the strategic plan.



The IAHP website has four main sections:

- 1) **About us:** Includes information about our history, staff, and Board members; and legal and financial information.
- 2) **What we do:** Includes sections on IAHP programs, Projects, International Directories and IAHP Publications
- 3) **Policy and Ethics:** Includes information on topics related to Human Rights and Access to Medicines and Ethical issues.
- 4) **Members' section:** Provides a gateway for the members to access resources, publications as well as forms to join/renew online.



In 2021, the IAHP website welcomed 190,017 visitors and hosted 228,777 sessions, a 19% increase over the 2020 traffic.

## Newsletter

The IAHPC Newsletter is sent free of charge via email to all subscribers in the global palliative care community. The newsletter is a useful source of information about the organization, grant opportunities, partners' initiatives, events, and other news from around the world. At the end of 2021, the newsletter had over 8,200 subscribers.

April 2021 marked the 25<sup>th</sup> anniversary of the IAHPC Newsletter. After we transferred the IAHPC to Texas, we hired Ms. Anne Laidlaw from Alou Web Design in Canada as the IAHPC webmaster. She designed the organization's first website in 2000 and, in 2001, we started publishing the newsletter electronically. We increased from just over 3,000 subscribers then, to almost 9,000 in 2021.

The most-read featured story in 2021, "Is There a Protocol for Care?" written by Board Member Dr. Claudia Burla, was accessed by as astonishing 850 people during the month that it appeared.

We are grateful for the many contributors and board members who have supplied us with outstanding content each month. Special thanks to our previous senior editors Bill Farr and Avril Jackson for their service and contribution, and to the current senior editor, Alison Ramsey, who does an amazing job every month.



Figure 1 First page of the first edition of the IAHPC Newsletter, 25 years ago.





*Dr. William (Bill) Farr*  
Senior editor  
1996–2013



*Avril Jackson*  
Senior editor  
2014–2017



*Alison Ramsey*  
Senior editor  
2017–to date

## In Memoriam

**Roger Woodruff**, passed away in July 2021. He was a founder, a member of the Board of Directors of the IAHPIC since its inception and served as its chairperson for three years, 1998-2000. In 2009 he was elected, along with Drs. William Farr and Derek Doyle, as an IAHPIC Lifetime Board Member in recognition of his service and dedication to the organization.



Together with Derek Doyle, Roger coauthored three editions of the *IAHPIC Manual of Palliative Care*. He contributed regularly to the IAHPIC Newsletter, writing a monthly selection of book reviews, including the popular Palliative Care Book of the Month. More recently, Roger compiled an e-book that offers guidance to IAHPIC members on *Euthanasia and Physician-Assisted Suicide: Are they clinically necessary?*

Roger served the IAHPIC and the global palliative care community until the end. He was an amazing force and support. We will always be grateful for his guidance and leadership.

## New features in the NL

In 2021, the Newsletter added two new features: app reviews by Dr. Romaine Gallagher; and reports by, or interviews with, longtime and lifetime members. The app reviews are published four times per year; the longtime and lifetime member reports and interviews are published depending on availability. Some months, these features have been the most viewed, or garnered exceptional activity in social media; interviews with palliative care pioneers in particular (such as Dr. Robert Twycross) are clearly valued by readers.

In December 2020, we initiated a new monthly feature, Members' Impact, that publicizes our members' successes and research activity as a way to celebrate them while encouraging others in their efforts.



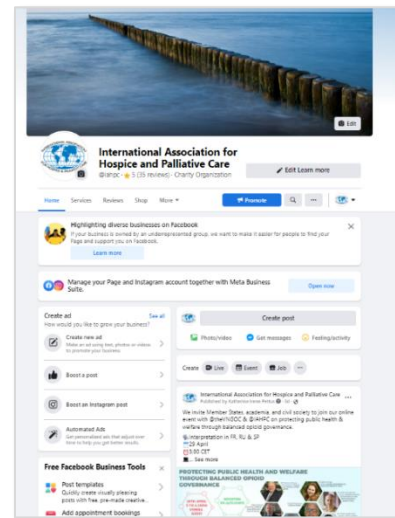
## Social Media



Social media continues to be one of the most significant ways for IAHP C to drive broader engagement and advocate for acceptable palliative care language, policies, and access to treatment as a component of Primary Health Care and Universal Health Coverage.

IAHP C engages on **Twitter**, **Facebook**, **Instagram**, **LinkedIn**, and more recently in **YouTube**, using trending hashtags to spread the palliative care message, and calling on followers to participate in a grassroots movement that can deliver results at the level of patient care.

Our followers on all platforms have been continuously increasing over the years. At the end of 2021 we had 9,873 followers on Twitter; 6,676 on Facebook; 900 in LinkedIn; and 104 in our YouTube channel.



## International Directories and Calendar of Events



The Directories and the Calendar are constantly maintained and updated by **Ms. Julia Libreros, Coordinator of the IAHP C International Directories and Resources.**

The goal of Julia's work is to help increase public access to information about palliative care educational programs and events around the world. This includes providing information about services and providers to optimize the practice of palliative care.

Julia's tasks include administering and updating the IAHP C Global Directory of Education in Palliative Care, the Global Directory of Institutions/Organizations, and the IAHP C Calendar of Events. All three resources include information about programs, services, organizations and events in all regions of the world. She also responds to direct queries about resources and providers. Julia works closely with Danilo Fritzler, the IAHP C Webmaster to ensure the accurate geolocation of the providers in the Global Directories.



- *Global Directory of Palliative Care Institutions and Organization:* This IAHPIC [directory](#) includes over 2,200 listings of hospices and institutions that provide care, support, and guidance to patients and providers. 98 palliative care services and organizations were added in 2021.
- *Global Directory of Educational Programs in Palliative Care:* This IAHPIC [directory](#) includes over 300 listings of educational programs throughout the world. The Directory of Educational Programs includes institutions offering master's degrees, fellowships, diplomas, and PhDs in palliative care. 55 listings were added in 2021.
- *Calendar of Events:* The [global online calendar](#) of events lists palliative care related seminars, congresses, and conferences. The calendar is available free of charge to the global palliative care community. At the end of the year, we had 381 registered events in the calendar of which 122 were added in 2021.

Amount spent (including salaries and honoraria) in **Communication and Dissemination** during 2021:  
**\$79,469**



The goal of **Lina Rozo's** work as **IAHPC Finance Officer** is to ensure the accuracy, transparency and timeliness of the organization's finances.

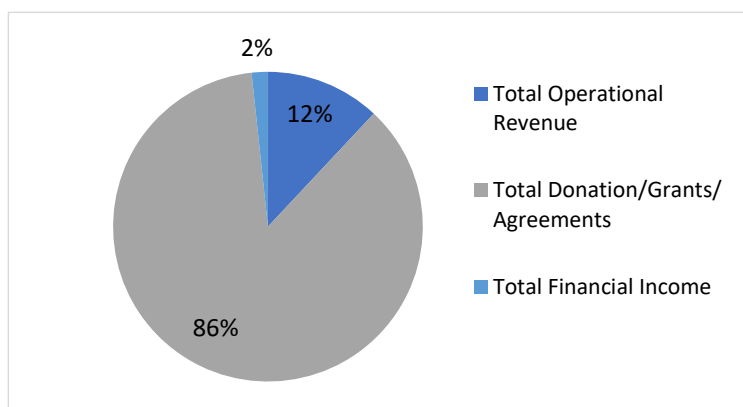
Lina works closely with the Executive Director and other team members to ensure that the organization has the funding needed to implement projects, programs and fixed expenses. She is responsible for preparing budgets, keeping the accounting books, paying grantees and vendors, supporting the payroll process, and preparing the information needed for the annual filings with US government, as required by law.

## Income and Expense statement

At the end of the year, our 2021 income was \$456,149 (42% over budget) plus \$38,992 in in-kind donations for a total of \$495,141. The main sources of revenue were individual donations and grants from foundations, including the OSF Exit Grant for 2022 that was disbursed during 2021, but will be used in 2022. In-kind donations were mostly from Google Foundation for the AdSense campaign. Individual donations were 43% over budget. Membership income was \$1,000 higher than projected. We are proud of the fact that, despite the global crisis originated in 2020 from the Pandemic, IAHPC reached its membership goal. We launched two 20% discount campaigns (in Summer and in December 2021) both of which yielded a very positive response.

Total expenses were \$307,975 (5.7% below budget). Liliana De Lima reduced her salary as the Executive Director, while other salaries were maintained at the same level.

The additional income, plus reduced expenditures resulted in a net income of \$149,347.



## Balance sheet:

At the End of the year, our cash totaled \$336,233 - this amount includes last payment of the Exit Grant from Open Society Foundations. Most IAHPC assets are in cash and money market funds. At the end of the year, our liabilities were \$650 representing payable expenses due the following month.

**Annex 2** includes the financial statements for the year.

# Fundraising

## *Grants and Donations*

We could not have achieved what is described above and much more without the generous support of our Board of Directors, members, donors, foundations, and organizations. We are especially grateful to the following organizations for their support.

IAHPC received these large grants and donations during 2021:

- *Enrique Ospina and Lilia De Lima: \$175,000 for core support*
- *Open Society Foundation: \$134,500 for core support*
- *Maria Andrea Lenis: \$50,000 for core support*
- *US Cancer Pain Relief Committee: \$50,000 for core support*
- *Pettus Foundation: \$45,000 to support the IAHPC Scholarship Program*

The IAHPC donations reflect the support of the organization's mission and the projects and programs we have implemented to change systems so that no one is left behind. The organization's ability to continue assisting others is heavily dependent on the support we receive from our donors and supporters.

**Annex 3** includes the names of the donors (foundations, institutions, and individuals) who generously supported IAHPC during 2021.



# Governance - Board of Directors 2021



[Lukas Radbruch, MD](#)

Germany  
Chair



[Roberto Wenk, MD](#)

Argentina  
Past Chair



[Liliana De Lima, MHA](#)

USA – Colombia  
Executive Director (*ex-officio*)



[Derek Doyle, OBE, Hon. DSc](#)

Scotland  
Founding member  
Lifetime board member



[William Farr, MD](#)

USA  
Founding member  
Lifetime board member



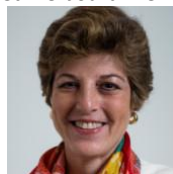
[Roger Woodruff, MD](#)

Australia  
Founding member  
Lifetime board member



[Chitra Venkateswaran, MD](#)

India



[Claudia Burlá, MD](#)

Brazil



[Dingle Spence, MD](#)

Jamaica



[Ebtesam \(Sammi\) Ahmed, PharmD](#)

Egypt, USA



[Eve Namisango MD](#)

Uganda



[Gulnara Kunirova](#)

Kazakhstan



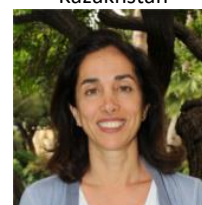
[Felicia M. Knaul, PhD](#)

Canada, USA



[Harmala Gupta](#)

India



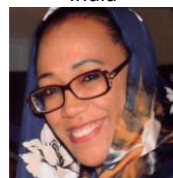
[Hibah Osman, MD](#)

Lebanon, USA



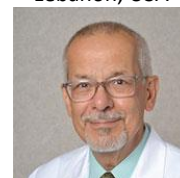
[Mary Callaway](#)

USA



[Nahla Gafer, MD](#)

Sudan



[Steven Radwany, MD](#)

USA

# Team – Officers and Staff members

The IAHP team is the backbone of the organization, and the key to achieving our mission. Each one of the staff members works together to implement the Strategic Plan, mission, and vision of the organization. Click on their names to read their bios.



[Liliana De Lima, MHA](#)

Executive Director



[Katherine Pettus, PhD](#)

Senior Advocacy and  
Partnerships Director



[Genevieve Napier](#)

Senior Operations Officer



[Lina Roza](#)

Finance Officer



[Ms. Julia Libreros](#)

International Directories



[Alison Ramsey](#)

Senior Editor Newsletter



[Tania Pastrana, MD](#)

Research Adviser



[Danilo Fritzler](#)

Webmaster



[Ana Restrepo](#)

Volunteer



## **Annex 1 – Grantees IAHPC Programs 2021**

### **Membership Engagement**

IAHPC supports, endorses, and develops poster contests, scholarship and projects aimed at improving access to palliative and hospice care at the country level, partnering with governments and palliative care organizations.

### **Posters**

*Jornada ALCP 2021*: the IAHPC sponsored the prizes for the best posters in four categories: 1) clinical, 2) management and administration, 3) COVID-19, and 4) psychosocial/spiritual aspects. The winners received a prize of \$125 each.

1. Clinical:  
*Adaptation and Validation in Chile of the SPICT-ES Instrument to Identify Palliative Care Needs.*  
Authors: Ximena Farfán Zúñiga, Melissa Zimmermann.
2. Management & Administration:  
*EDUPAL: educating future doctors about pain control and palliative care.* Authors: Gustavo De Simone, Vilma Tripodoro, Eduardo Mutto, Marcela Specos, Eduardo De Vito.
3. Category COVID-19:  
*Remote Psychological and Spiritual Accompaniment Model for hospitalized patients and their families during the COVID-19 pandemic.* Authors: Cristina Avila Ramirez, Alejandra Palma, Veronica Rojas, Fernando Ihl, Francisca Plaza Parrochia, Nivia Estuardo Agurto, Manuel D. Castillo Solis, Estefanía Acuña.
4. Psychosocial/Spiritual Aspects:  
*Perception of competencies and self-confidence of the participants in the ECHO Clinic for pediatric palliative care.* Authors: Mercedes Bernadá Scarrone, Valeria Le Pera, Martin Notejane

### **Scholarship Program**

The Scholarship program supports the registration fees for conferences, seminars, internships, university programs or other educational activities for palliative care workers in Lower – and Middle-Income countries. Grantees listed below received traveling scholarships to attend the associated educational events.

#### *Latin American Virtual Conference on Palliative Care (Virtual)*

March 27, 2021

Grantees: Alexandra Maria Aceituno Rios (Guatemala), Sofia Bunge (Argentina), Socorro Cabello (Mexico), Toshio Chiba (Brazil), Maria Del Rosario Berenguel (Peru), Diane A. Dykeman-Sabado (Dominican Republic), Martha Lucia Franco Garrido (Colombia), Mirian Gonzalez (Panama), Rut Kiman (Argentina), Guillermo Mammana (Argentina), Alba Maricela Catillo (Guatemala), Nathalie Olano Duque (Colombia), Maria Luisa Rebolledo (Costa Rica), Julio Rojas (Costa Rica) and Carolina Valdebenito (Chile).

#### *Hospice Africa Uganda Initiator Course and in Country Placement*

Kampala, Uganda

May 10 – 28, 2021

Grantees: Ruth Allotey (Ghana) and Vincent Namisi (Uganda).

*Hospice Africa Uganda Initiator Course and in Country Placement*

Kampala, Uganda

June 7-25, 2021

Grantee: Jamila Boateng (Ghana).

*2021 Oceanic Palliative Care Conference (21OPCC) Virtual*

September 7-10, 2021

Grantees: Agasha Birungi (Uganda) and Zichao Tony Xue (Australia).

*17th World Congress of the European Association for Palliative Care Virtual*

October 6-8, 2021

## ***Annex 2 - Financial Statements 2021***

### **Income and Expense 2021**

#### **Income**

Unrestricted Donations	\$ 341,524
Unrestricted Grants	\$ 8,619
Restricted Grants - Donations	\$ 89,452
Membership dues	\$ 54,581
IAHPC Sales	\$ 965
<b>Total Income</b>	<b>\$ 495,141</b>

#### **Expenses**

Unrestricted – programs/promotion	\$ 30,544
Restricted – programs/promotion	\$ 39,892
Salaries Expenses	\$ 251,356
Professional Fees	\$ 16,205
Operational Expenses	\$ 4,258
Travel & Meetings	\$ 969
Misc. Expenses	\$ 2,403
Financial Expense	\$ 7,679
<b>Total Expenses</b>	<b>\$ 353,229</b>

<b>Other Income</b>	<b>\$ 7,435</b>
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<b>Net Income</b>	<b>\$ 149,347</b>
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### **Balance Sheet 2021**

#### **ASSETS**

Total Short-term investment	\$ 306,497
Total Bank Accounts	\$ 29,736
Total Accounts Receivable	\$ 1,360
Undeposited funds	\$ 2,776
<b>Total Current Assets</b>	<b>\$ 340,370</b>
Total Fixed Assets	\$ 289
<b>Total Assets</b>	<b>\$ 340,659</b>

#### **LIABILITIES AND EQUITY**

Liabilities	
Total Accounts Payable	\$ 650
<b>Total Liabilities</b>	<b>\$ 650</b>
Total Equity	\$ 340,009
<b>TOTAL LIABILITIES AND EQUITY</b>	<b>\$ 340,659</b>

### ***Annex 3 - IAHPC Donors – 2021***

#### **Over \$100,000**

Open Society Foundation

#### **Between \$50,000 and \$99,999**

Benevity Causes

Enrique Ospina and Liliana De Lima

Pettus Foundation

#### **Between \$20,000 and \$50,000**

Google Foundation

#### **Between \$1,000-\$15,000**

Abigail Fierman

Alberto Pena

Carlos Cabarcas and Maricel Márquez

Ed Barry

Global Giving

Ingrid R. Gray

Kathleen Foley

Mary Callaway

Shannon Moore

Steven Radwany

US Cancer Pain Relief Committee

#### **Between \$100 and \$1000**

Alan Leist

Amazon Smile

Ameril Health Hospice

Bernie Casey

Cathleen Hagen

Cecilia Chan

Dan Tobin

David Wolner

Ebtesam Ahmed

Eve Namisango

Fundacion SECPAL

Juan Lozano

Julia Libreros

Kathleen Grimm

Kevin Bezanon

Maria Cigolini

Mary T White

Mathias Brian

Network for Good

Preston H. Edwards

### **Up to \$99**

Agnes Bausa	Jose Miguel Guerra de la Garza	Patricia Cury
Andi Khomeini Takdir	Judy Simpson	PayPal
Ann Powers	Karen Bate	Reena Sharma
Becky Moffett	Karen Schulz	Regina Susana Okhuysen-Cawley
Bidhu K Mohanti	Kathleen Introna	Robert Thomas Berlin
Dr. Earl L. Smith	Kent Bass	Ruth Gottfried
Francine Ruth	Leah Tech	Sebastian Von Hofacker
Gerald and Christine Wagner	Leroy H. Walz	Shanese Murdock
Glenda Moreira	Leslie Bricker	Shivam Agarwal
Grace Bricalli	Linden Chap 152 Order of Eastern Star	Simone Cernesi
Gulnara Kunirova	Marcos Lama	Sri Nivedita Ramakrishnan
Inaya Riaz	Mary Duffy	Stanley C. Macaden
Jack Kupferman	Maureen Dionysian	Stephen R Connor
Jeff NG	Mirza Jacqueline Alcalde Castro	The EY Initiatives
John Haberecht	Nancy Hinds	Tressa Bauer
John Sandlin	Natalie Greaves	Victoria Hewitt
Jorge Sanchez	Olga Dovgel	William F Hilton

### **Donors through Global Giving crowd funding campaign Between \$200 and \$499**

Anonymous  
Alison Ramsey  
Hibah Osman  
Silpa Lal

# IAHPC

5535 Memorial Dr. Suite F - 509  
Houston TX 77007 USA  
Phone +1 (346) 571-5919  
<http://hospicecare.com/home/>



**Follow IAHPC through our social media campaigns!**

