Madrid Conference Global Palliative Care Slide Captions – English
Katherine Pettus, Supporting Palliative Care in the International Organizations.

Slide One
Good afternoon everyone. Many thanks to Dr. Centeno for inviting me to speak at this important event. I am so sorry I cannot be with you in person. I am Katherine Pettus, Senior Advocacy and Partnerships Director for the International Association for Hospice and Palliative Care. It is a great honour to be with you at this global conference, albeit from a distance. The title of my presentation is Supporting Palliative Care in International Organisations.

Slide Two - Contents
This presentation attempts to answer the following questions: Why and how do international organisations support PC? There is a short answer to both questions: "Words" -- after all, we have it on the highest authority that "in the beginning was the Word". We advocate for the inclusion of words and with words, which now form the pallium of authority for palliative care professionals worldwide. I will identify the main issues we work on, the fundamental concepts we share with international bodies, the achievements we have made together, and the challenges we still face.

Slide Three - IAHPC vision
A few words about IAHPC, the organisation I work for. The word "world" in our vision: a "world" free from health-related suffering aligns us with international organisations, formed by all the world's governments and based on international law. We are working to build a global palliative care movement in which all people with palliative care needs have access, not just the fortunate few who live in a health system that provides it privately or through charitable organizations. Now, only a minority (about 20% of our world) benefit from palliative services. Our goal is to have coverage for 100% of those in need.

Slide Four - IAHPC role
The IAHPC is a civil society - non-state - non-governmental sector organisation. The UN explicitly provides for civil society participation in governance and has accredited us to represent our members in over 100 countries. We participate in Member State meetings, which means we can speak out and identify the unmet global need for palliative care and its benefits to all health systems. We also have the title "Non-State Actor" in official relations with the World Health Organisation and in this capacity, we can participate in commissions and technical consultations - but not vote - at the World Health Assembly.

Slide Five - Relevant issues
The UN member states themselves have authorised the construction of the global palliative care house. ATLANTES has worked hard to build this model with the WHO in a consensus process with palliative care workers from around the world. Relevant themes from our work with international bodies, reflected in this model, are Improving the availability and affordability of controlled medicines, Integrating PC into primary care and universal health coverage through policy and education, and ensuring that older adults have access to PC.

Slide 6 - United Nations
UN organisations are governed by member states. There are functional and specialised agencies with executive boards and their secretariats. Secretariats perform technical and normative functions at the request of member states. Civil society representatives - bodies such as the IAHPC - are allowed to participate on the margins, with limited discourse and a circumscribed role, not as protagonists, but as experts on a specific issue and in this capacity, advise member states to make decisions that are favourable to patients.

Slide 7 - Right to health
The cornerstone for us as advocates for PC at the UN is the Covenant on Economic, Social and Cultural Rights, which stipulates the right to health. Although well-intentioned, many people mistakenly say that palliative care is a right, but this is not entirely accurate. Palliative care is not a right per se, but it is a component of the right to health, as this general comment published in 2020 makes clear.

Slide 8 - Global House
UN member states authorised the plans and construction of the house because over the years some have heeded the words of civil society organisations persistently advocating for integration of palliative care into health systems. We saw what had worked at the micro level in private and charitable services in various countries, and believed that these should be universally available as a public good. Member States, in collaboration with the secretariats and civil society, including the European Commission, should be encouraged to develop a new approach to the integration of palliative care. Member states, in collaboration with secretariats and civil society, including human rights organisations, drafted resolutions calling on secretariats, such as that of the WHO, to assist member states in integrating palliative care. This is a new discourse at the global level - at the "macro" level.

Slide 9 - WHA 67/19
Through such resolutions, reports, documents and technical guidelines, they have put together the blueprints for the house, and invited us to work with them in disseminating and developing the design. The first key resolution was that of the World Health Assembly in 2014, Strengthening palliative care as part of comprehensive care across the lifespan, initiated in principle by Panama, and endorsed by all WHO Member States. Eight years later, we are still in the process of global implementation, but lack budgets at the national level for both advocacy and education - to spread the words from macro to mezzo and micro levels....

Slide 10 -- Secretariats
These are some of the organisations in which we participate and the Secretariats with which we collaborate closely to advance the development of palliative care. These international organisations support palliative care organisations by providing what is called "agreed language" - consensus words - through official documents that authorise and legitimise the work of palliative care services on the ground. The secretaries implement resolutions and produce the

reports and technical work required by member states. If they do not approve budgets, they are demands and empty words, without resonance and flesh.

Slide 11 - Agency endorsements and recent achievements
Before we had the world house plan there were indeed hospice and PC services in various countries, mostly in the UK and Europe, but they were private or run by faith communities. They were not a UN issue because access was not yet seen as a human rights issue, a public health issue or an equity issue. as palliative care became more widespread, it became part of the global human rights narrative.

Slide 12 - Fruits of collaboration
These fruits emerge from our official status and relationships with international organisations built on years of partnership and trust. It starts with the publication, dissemination and review of official drafts with expert teams - generally, these draft resolutions and drafts omit palliative care and controlled medicines, reproducing old narratives. We have to remind secretariats and member states to include them in the agreed language of the text, advocating for them as part of the right to health and the subject of a WHA resolution. It is a slow process to build a new narrative, one that depends on diplomacy and personal relationships. Here are some highlights of how international organisations are now supporting professionals delivering services on the ground.

Slide 13 – WHO Model List of Essential Medicines
In 2012, the WHO asked the IAHPC to prepare a list of essential medicines for palliative care, which was approved by the expert committee and incorporated into the EML in 2013 as a separate chapter. It is now available in electronic format and all countries in the world are obliged to ensure that the medicines are affordable in the public system. There is a long way to go to achieve this end.

Slide 14 -- UNGASS –
The special session on 'drugs' took 2 years of intensive preparation in Vienna and took place between 19-21 April 2016 in New York, bringing together member states, UN agencies and civil society representatives. I was privileged to participate in these 2 years of preparation. The Session critically reviewed global drug control approaches, gave far more significant visibility to the issue of controlled medicines than any other high-level drug policy document adopted by UN member states before. It included an extensive stand-alone section on the issue, providing both a detailed analysis of the situation and specific guidance to UN Member States. Thanks to UN endorsement, all member states are now obliged to report on their consumption levels, although most still do not. It is another tool for building the house!

Slide 15 – Astana Declaration on Primary Health Care 2018
Integration of PC into Astana Declaration on Primary Health Care 2018 was a major achievement. The Astana Declaration outlines a way forward to achieve universal health coverage, 40 years after the of the declaration on primary health care in Alma-Ata. As it now

includes PC, we always refer to Astana as a guiding document for the integration of palliative care in PHC. It is a key tool!

Slide 16 – Human Rights of Older People 2021
The inclusion of PC in this resolution was the fruit of years of work with the Special Procedures of the Human Rights Council in Geneva, as well as with the Open Working Group on Ageing at the United Nations in New York. As a result of this work, palliative care will now be included in any global convention on the rights of older persons, just as it is included in the Inter-American Convention on the Rights of Older Persons. The other day, the High Commissioner for Human Rights, Michelle Bachelet, mentioned the urgent need to improve access to essential medicines for palliative care in a speech at the Brandenburg Forum.

Slide 17 -- Challenges
There are many - first and foremost is the
1) ignorance from most sectors of society, health systems and governance about the benefits of palliative care for all health-related suffering, not just cancer, and not just at the end of life. The second is
2) the traditional ideology and narrative of global health and public health, which focus on saving and prolonging lives - preventing avoidable mortality.
3) The Northamerican opioid epidemic driven by the global pharmaceutical industry.
3) Lack of understanding of the importance of advocacy/advocacy at national, sub-national, and regional levels - and the lack of a "we" - a defined constituency that demands PC. These are compounded by
- Public sector disinvestment
- Lack of sustainable funding for civil society organisations
- Polarised societies
- Popular movements in favour of euthanasia

What is at stake in losing funding is nothing less than perpetuation of the appalling inequality in global PC services. We will return to a global landscape in which PC is potentially only available to a fortunate few in areas where there are privately or charitably funded services. Most people will die without care, with avoidable suffering, while a fortunate minority will receive adequate care and pain relief. A human rights-based approach is essential to ensure dignity and equity for all.