



Issue 38

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THE 13th ASIA PACIFIC HOSPICE CONFERENCE

Surabaya - Indonesia, August 1st - 4th, 2019

EPEC
Pediatrics

Education in Palliative & End-of-Life Care

18 - 19 May 2018
Kuala Lumpur, Malaysia

[Click here for more info!](#)

Special run of programme from the USA

Only 40 places available!

Dear members

Sunday, 4th February was World Cancer Day, when organisations and individuals around the world unite to raise awareness about cancer. According to the [article](#) on American Cancer Society website, it is estimated that 8 million people worldwide will die from cancer this year.

It makes me wonder, how many of those 8 million people do not have access to palliative care or pain medications that can help them achieve a better quality of life in their last days? What are we doing about it? What has been done?

There are so many meaningful projects carried out in the region by organisations and individuals. Yet, the stories never got to the APHN editorial team. We strongly encourage you to connect to us, or refer your contacts to us. We need to get our collective voices heard in the world!

If you or your organisation has organised activities on World Cancer Day, do write an article and send it to us or tag us on social media!

Warm regards

Joyce Chee

APHN Executive

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Japan Hospice Palliative Care Foundation

Recent medical developments in Japan have been astonishing. Especially in diagnosis and treatment technology Japan ranks top-level in the world. Nevertheless, for such incurable conditions as "progressive cancer" and "terminal cancer", even with the highest possible level of medicine, care which is really adequate is not easily available.

Patients with no prospects of recovery are often forced to stay alive as long as possible without receiving pain relief and adequate psychological care, and many end up dying a painful and lonely death.

Anxious to improve this situation, not only medical and nursing staff but also the general public have become increasingly interested in hospice/palliative care during the past three decades. Japan's first hospice unit was set up in 1981. As of July 2017, there were 386 official hospice units across Japan.

At present about 300,000 Japanese people die of cancer each year, so it is clear that more hospice units are necessary for meeting the needs in Japan.

These developments have revealed how important it is to improve the quality of hospice/palliative care, and thus to enhance the quality of life (QOL) of patients and their families.

In response to these concerns, the Japan Hospice/Palliative Care Foundation, after receiving official authorization, was established on December 28, 2000. This organization is placing a major emphasis on the development of a more satisfactory hospice/palliative care system through the following objectives:

1. Conducting investigation and research for the purpose of improving the quality of hospice/palliative care.
2. Providing technical support to the staff involved, including doctors, nurses, pharmacists, co-medical staff and social workers.
3. Sponsoring PR activities
4. International exchange related to hospice/palliative care.

Areas where the organisation hopes to contribute regionally

JHPF continues its activities with the aim of contributing to the improvement of hospice and palliative care by conducting high quality research with APHN countries. We are currently conducting joint research projects with Japan, Korea and Taiwan. As a cohort study for patients hospitalized in palliative care units, the aim is to clarify the changes in symptoms and the effects of treatment on the death process of terminal cancer patients.

We hope to have the joint high-quality collaborative research with APHN countries.

The 14th APHC will be held in 2021 at Kobe City, Japan .
We hope many participants gather and have good fellowship.

President:
Tetsuo Kashiwagi



APHN Annual Report Highlights

REVIEW OF YEAR 2017 (1 January to 31 December)

Activities

Member's newsletter

Lien Collaborative for Palliative Care (LCPC)

APHN Dialog

APHN Social Media Discussion Groups (Facebook, WeChat)

Calendar of events

**LCPC events are marked with an asterisk*

January	<ul style="list-style-type: none"> • "Dialog" #5 – Hydration at end of life • *LCPC CTC Training Programme Phase 1 - India
February	<ul style="list-style-type: none"> • *LCPC Follow up visit – Myanmar • APHN – Hospis Malaysia Palliative Care Workshop: Palliative Care Nursing
March	<ul style="list-style-type: none"> • *LCPC 6th Training Module – Sri Lanka
April	<ul style="list-style-type: none"> • APHN – Hospis Malaysia Palliative Care Workshop: Clinical Ethics in Palliative Care
May	<ul style="list-style-type: none"> • *LCPC CTC Training Programme Phase 1 – India • APHN-Hospis Malaysia Palliative Care Workshop: Communication Skills
June	<ul style="list-style-type: none"> • "Dialog" #1 –Holistic treatment of late stage cancer (Chinese) • Meeting of the 16th Council
July	<ul style="list-style-type: none"> • 12th Asia Pacific Hospice Conference 2017, Singapore • Meeting of the 16th Council • Annual General Meeting • Meeting of the 17th Council • *LCPC Clinical Mentorship Programme – Myanmar • *LCPC Clinical Attachment Programme in Singapore for Myanmar and Sri Lanka Train-the-Trainers participants • *LCPC CTC Training Programme Phase 1 - India
August	<ul style="list-style-type: none"> • "Dialog" #6 – Management of Total Pain • APHN-Hospis Malaysia Workshop: Suffering and Hope
September	<ul style="list-style-type: none"> • APHN Mini Interview Series – Dr Ong Wah Ying, Singapore • *LCPC 5th Training Module – Bangladesh • *LCPC CTC Training Programme Phase 2 - India
October	<ul style="list-style-type: none"> • "Dialog" #7 – Sharing Experiences in Asia (In conjunction with World Hospice Day) • Facebook "Change your profile frame" Campaign • APHN-Hospis Malaysia Workshop: Paediatric Palliative Care
November	<ul style="list-style-type: none"> • APHN Mini Interview Series – Dr Masanori Mori, Japan • *LCPC Follow up visit – Myanmar • *LCPC CTC Training Programme Phase 1 Audit – India • Meeting of the 17th Council • APHN-Hospis Malaysia Workshop: Pain & Symptom Management
December	<ul style="list-style-type: none"> • "Dialog" #2 – Hospice Palliative Care Models - Taiwan (Chinese) • APHN Mini Interview Series – Prof Myo Nyunt, Myanmar • *LCPC CTC Training Programme – India • *LCPC Follow up visit – Sri Lanka • APHN-Hospis Malaysia Workshop: Grief & Bereavement Care

APHN ANNUAL REPORT HIGHLIGHTS CONTINUED

Other Activities

The research collaboration project, Asian Patient Perspectives Regarding Oncology Awareness, Care and Health, also known as the “APPROACH” study, in cooperation with Duke-NUS Graduate Medical School of Singapore started in 2016 and continued in 2017.

The Journal of Palliative Medicine became APHN’s first affiliated journal in March 2017.

Fundraising Event and Activity

There was no fundraising event or activity held in 2017.

Membership

Report on Membership figures for 2017

The total membership subscription for the year ended 31 December 2017 comprises of organizational and individual membership.

Table 1: Membership figures by sector as at financial year end

Sector	Ordinary Organizational members	Affiliated organizational members	Individual members	Total by sector
Australia	4	0	23	27
Bangladesh	4	0	44	48
Bhutan	0	0	15	15
Cambodia	0	0	5	5
Canada	0	1	0	1
China	1	0	10	11
Hong Kong	6	0	18	24
India	3	0	34	37
Indonesia	1	0	23	24
Iran	0	0	1	1
Japan	5	0	10	15
Jordan	0	0	1	1
Korea	16	0	13	29
Malaysia	10	0	41	51
Mongolia	1	0	4	5
Myanmar	1	0	17	18
Nepal	0	0	4	4
New Zealand	1	0	3	4
Pakistan	0	0	3	3
Philippines	8	0	28	36
Rwanda	0	0	1	1
Samoa	0	0	1	1
Singapore	12	0	44	56
Sri Lanka	1	0	20	21
Taiwan	15	0	12	27
Thailand	2	1	13	16
UK	0	0	3	3
USA	0	0	1	1
Vietnam	3	0	13	16
Grand Total	94	2	405	501

APHN ANNUAL REPORT HIGHLIGHTS CONTINUED

APHN has 169 new individual membership subscriptions and 9 new organisational membership subscriptions for the year 2017.

REVIEW OF FINANCIAL STATE AND EXPLANATION OF MAJOR FINANCIAL TRANSACTIONS

The Charity has a balance of 218,980 SGD in unrestricted funds, and a balance of 725,171 SGD in the Lien Collaborative for Palliative Care Project fund (restricted funds) as at 31 December 2017.

— End of Annual Report Highlights—

If you will like a copy of the APHN annual report and audited financial statements for the year ended 31 December 2017, please email Joyce at aphn@aphn.org, stating your membership number.

Global Launch Symposium of The Lancet Commission Report: Alleviating the access abyss in palliative care and pain relief— an imperative of universal health coverage



THE LANCET



From: IAHPC Newsletter

The Global Launch Symposium at the University of Miami, co-hosted with The Lancet and the International Association for Hospice and Palliative Care (IAHPC), marks the print release of the Report of the Lancet Commission on Global Access to Palliative Care and Pain Relief, titled "Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage." The online release of the Report received wide media coverage among outlets like The New York Times, The Guardian, Washington Post, BBC, CNN en español, and Voices of America.

In his accompanying editorial, "A Milestone for Palliative Care and Pain Relief," Dr. Richard Horton, Editor-in-Chief of The Lancet, issued a call to action for the global health community to remedy the appalling global inequities in access to palliative care and pain relief. The Symposium will serve as a response to this call and offer the opportunity to design projects and programs for national, regional, and global implementation of the key recommendations outlined in the Report. The event will focus on projecting the research contained in the Report, and defining an implementation agenda, led by IAHPC, to assist countries and global health institutions in moving forward efforts to improve access to palliative care and pain relief.

Background resources including factsheets, data appendix, and a recorded presentation on the key findings and recommendations of the report are available at www.miami.edu/lancet

This symposium will be attended by representatives of Regional Palliative Care Organizations including the International Association for Hospice and Palliative Care, World Hospice Palliative Care Association, the International Children's Palliative Care Network, African Palliative Care Association, Asia Pacific Hospice Palliative Care Network, Asociación Latinoamericana de Cuidados Paliativos, Caribbean Palliative Care Association, European Association for Palliative Care, and others.

On World Cancer Day: Improve access to internationally controlled essential medicines

In the article, she talks about how World Cancer Day asks us to reflect on how we can play our part, as a collective or as individuals, in reducing the global burden of cancer.

“The “global burden of cancer” is actually an aggregate of the very real burden that falls on individual people: on cancer patients, their family members and their caregivers. In the vast majority of cases, people face severe untreated pain, financial worries, often bankruptcy, and psycho-spiritual distress.’

She also shared the a personal story of her mother’s severe unrelieved cancer pain and how she could do nothing to help her at that time, and she found out decades later that her pain could be easily relieved if the doctors and nurses had been properly taught how to manage it.

Universal health coverage, one target of the Sustainable Development Goals, could stop this tragedy in its tracks. **Bridging the global abyss in access to internationally controlled essential medicines for the relief of severe pain, including cancer pain, for instance would cost around USD145 million per year, according to the [Lancet Commission](#), a fraction of the USD100 billion the world spends every year on drug control.**

Read the full article written by Katherine Pettus, Advocacy Officer of the International Association of Hospice and Palliative Care [here](#).

No one said he was dying: families’ experiences of end-of-life care in an acute setting

ABSTRACT

Objective To explore the family’s experience of end-of-life care for their dying family member during the last few days of life in an acute rural hospital.

Design Interpretive design using qualitative methods, including 1:1 semi- structured interviews.

Setting The study was undertaken in a large regional health service in Victoria. **Subjects** Twelve relatives who were next of kin of people who died between 1 January 2012 and 30 June 2013 in an acute ward at the health service agreed to participate in the study.

Main outcome measure Families’ perceptions of end-of-life care for their dying family member.

Results Data analysis identified five themes that were grouped into two general dimensions – communication (guidance for family member’s role in end of life care, the family’s preparation for death, the dying experience) and care and support (the hospital care experience, follow-up after death).

Conclusion A lack of open and candid communication hindered family members’ engagement in decision-making and involvement in their loved ones’ last days of life. The absence of formal processes for end of life (EOL) care planning resulted in families being unprepared for what they perceived as their family member’s ‘sudden death’.

Read the open access article at AUSTRALIAN JOURNAL OF ADVANCED NURSING [here](#).

生前预嘱推广协会会长陈小鲁先生辞世

资料提供：王娜宁，北京生前预嘱协会会员

资料整理：崔媛媛，APHN 志工（北京）

生前预嘱推广协会会长陈小鲁先生因急性大面积心肌梗死，在海南三亚301医院抢救无效，于2018年2月28日不幸辞世。

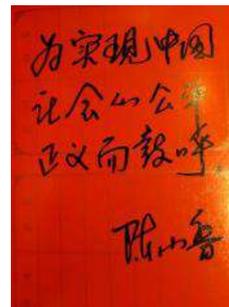
2006年3月，由罗点点“选择与尊严”团队创办的“选择与尊严”公益网站投入运行，这是中国首个提倡“尊严死”的网络信息平台，建立起供中国大陆居民使用的“生前预嘱”注册中心。

2013年6月，北京生前预嘱推广协会成立后，为加大“生前预嘱”的推广力度，加固提升网络信息应用基础，小鲁会长、点点总干事决心对公益网站进行大规模升级、改造、扩容，小鲁会长为此身体力行、广为动用人脉，反复进行调研、咨询、论证、筹资，竭尽全力筹备项目启动事宜。

2014年9月，小鲁会长决定与中国电信签约合作，并亲自主持启动网站升级改造项目，组成技术团队投入开发，并与中国电信领导保持沟通，协调疏导开发进程。翌年3月项目圆满完工。新网站运行首日，小鲁会长在新系统上率先填写“我的五个愿望”，并发微信告知：“我填好了，一次成功！”

2017年6月，随着移动网络应用技术的突进，开发“选择与尊严”公益网站的手机端应用已迫在眉睫，小鲁会长再次亲自主持启动微信应用项目：“掌上我的五个愿望”。软件设计中途，他看了试运行样板后说：“设计要更精巧、更漂亮些，让这种教育积极而不沉重。”对微信应用寄以厚望。

2018年1月5日二期项目杀青，试运行大获成功，项目收官终验签字之际，陈小鲁离世。陈小鲁会长是中国大力推广尊严死的公益人士。愿陈小鲁会长安息！



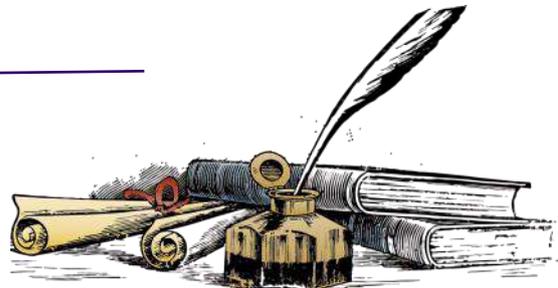
Call for content contributors!

Dear members,

If there is an important event or development in your country that you will like to share with other colleagues in the region but you have no time to write, fret not! The APHN volunteer support team is here to help you!

You may submit content and pictures in your local language and English to aphn@aphn.org. Our editorial team and administrative support volunteers will help to craft and edit the article for our newsletter.

So wait no longer! Send in updates and stories on palliative care in your region TODAY!



Demise of Mr Xiaolu Chen, President of the Beijing Living Will Promotion Association

Content provided by: Ms Naning Wang, Beijing Living Will Promotion Association member

Writing and translation by: Ms Yuan Yuan Cui, APHN Volunteer (Beijing)

Edited by: Ms Djin Lai, APHN Editorial Team

Mr Chen Xiaolu, President of the Beijing Living Will Promotion Association passed away on February 28, 2018 in the 301 Hospital in Sanya, Hainan. The "Choice and Dignity" public service website, founded by Diandian Luo's team, was launched in March 2006 as China's "dignified death" network information platform to establish a "living will" registry for mainland Chinese residents.



In November 2011, Mr. Chen and his team went to Taiwan for a visit.

In June 2013, after the establishment of the Beijing Living Will Promotion Association, Mr Chen Xiaolu and his team resolved to upgrade the site in order to increase the promotion of living wills and strengthen the foundation of network information. Their work included establishing large-scale upgrades, and transforming and expanding the service through widely used contacts, conducting repeated research, and engaging in consultation, demonstrations, fund raising, and active facilitation of start-up matters on projects.

In September 2014, Mr. Chen Xiaolu and his team decided to partner with China Telecom, forming a site development technical team, and personally presided over the site's upgrade project. Their team communicated with China Telecom's leadership, to coordinate the development process. The project was successfully completed in March of the following year. On the first day of the new website, Mr. Chen was the first to fill out "My Five Wishes" on the new system.

In June 2017, with the breakthrough of mobile network application technology, and the development of "Choice and Dignity" public welfare website mobile terminal applications imminent, Mr. Chen personally presided over the WeChat application project: "The Palm of My Five Desires". He had high expectations, even for the for WeChat application design.



In 2013, founding of the Association

On 5 January 2018, the second phase of the project was completed. The trial operation was successful, and the final part of the project was signed. Not long after, Mr. Chen passed away. Mr. Chen was a public welfare person who vigorously promoted dignity of death in China. We will like to express our condolences at Mr Chen's passing.



At the end of 2014, Mr. Chen and his team visit to inspect Japan's palliative care



On June 1, 2017, Mr. Chen attended in the signing ceremony of the second phase of the website

EPEC-Paediatrics Train-the-trainers' programme

EPEC
Pediatrics

Education in Palliative & End-of-Life Care

18 - 19 May 2018
Kuala Lumpur, Malaysia

[Click here for more info!](#)

Special run of programme from the USA



Who Should Attend

Healthcare professionals who support children with life-limiting illness and their families

Register Before
31 March 2018

Esteemed International Faculty

Dr Ross Drake - Coordinator

Consultant and Clinical Lead, Paediatric Palliative Care and Complex Pain Services, Starship Children's Hospital, Auckland, New Zealand

Stacy Remke - Co-Coordinator

Clinical Social Worker and Teaching Specialist, University of Minnesota School of Social Work, Minnesota, USA

Dr Mary Ann Muckaden

Professor, Department of Palliative Medicine, Tata Memorial Centre, Mumbai, India

Jody Chrastek

Coordinator, Pediatric Advanced Complex Care Team, Fairview Home Care and Hospice, Minnesota, USA

Karyn Bycroft

Nurse Practitioner, Paediatric Palliative Care Service, Starship Children's Hospital, Auckland, New Zealand

Lee-Anne Pedersen

Nurse Practitioner, Paediatric Palliative Care, Lady Cilento Children's Hospital and Hummingbird Children's Hospice, Brisbane, Queensland, Australia

The programme consists of the online curriculum and a two-day workshop. The online modules will have to be completed before attending the in person workshop. Find out more at <http://aphn.org/epec-paediatrics-workshop-2018-2/>

Read more about the EPEC curriculum at <http://bioethics.northwestern.edu/programs/epec/curricula/pediatrics.html>

This programme is jointly organised by APHN and Hospis Malaysia.

APHN-Hospis Malaysia Workshop: Communication Skills



Dear Doctors, Nurses and fellow healthcare professionals,

PALLIATIVE CARE WORKSHOP ON COMMUNICATION SKILLS **(14 – 15 April 2018)**

We would like to invite interested participants to our 2-day Palliative Care Workshop on Communication Skills which will be conducted from 14 – 15 April 2018.

Effective communication skills are an absolute necessity towards providing well planned palliative care which is delivered through the collaborative efforts of many people including the patient, their care givers (family and friends) and healthcare providers.

This workshop deals with the mechanics of communication that ranges from issues, techniques and practical sessions when dealing with patients with life-limiting illness and their families.

This workshop will be facilitated by Dr Rebecca Coles-Gale, Clinical & Health Psychologist from the United Kingdom together with Dr Sylvia McCarthy from Hospis Malaysia. This workshop will focus on highly interactive role plays, problem-based learning and case studies in small group settings.

It is conducted in English, all participants will be expected to communicate and interact during the workshop. Doctors and nurses will benefit most as the most difficult areas are encountered during clinical consultations.

Registration for workshop can be made online at our website: www.hospismalaysia.org For further enquiries, kindly contact Communication Department via telephone: 03 9133 3936.

Thank You.

Yours sincerely

Dr Ednin Hamzah
Chief Executive Officer, Hospis Malaysia

4th Maruzza Congress on Paediatric Palliative Care

Click <http://www.childrenpalliativecarecongress.org/congress-2018/> to go to the conference website.

The APHN is proud to be a supporting partner of this conference.



Paediatric Palliative Care: a medical approach, a cultural approach

The 4th Global Gathering will be held in Rome from the 24th to the 27th of October 2018

The Maruzza Congress on Paediatric Palliative Care, now in its fourth edition, brings together many of the world's leading authorities on children's palliative care. Drawing an eclectic audience of healthcare professionals from over 40 countries across 5 continents, it is considered one of the most important global meetings of the sector.

The goal of this event is to transfer experiences and encourage knowledge sharing, to divulge fresh perspectives and innovative solutions, to foster new synergies across disciplines and geographical regions aimed at improved palliative care delivery to children with serious illness worldwide.

The scientific program, devised by a team of international palliative care experts lead by the pioneer of child-specific palliative care in Italy, Franca Benini, provides many opportunities for professional development and networking: pre-congress workshops, keynote lectures, plenary sessions, abstract presentations.

To access the scientific programme, register, submit an abstracts and for all other information, please consult the congress website: www.childrenpalliativecarecongress.org/congress-2018/



TOGETHER, FOR A BETTER TODAY.

Asia Pacific Hospice Palliative Care Network (APHN)

Being the regional association for hospice and palliative care in the Asia Pacific, we are dedicated to promoting hospice and palliative care in the region.

We aim to empower and support organizations and individuals committed to alleviating suffering from life threatening illness through the establishment of programmes and services.

We promote education and skills development as well as awareness and communication, along with research and collaboration.



[DONATE TO US](#)

THANK YOU



We will like to thank the following members who joined the APHN or renewed their membership:

**Arranged by sector in alphabetical order, then by receipt no. till no.12247

Australia

Sydney Institute of Palliative Medicine
Palliative Care Victoria Inc
Mrs Jan Phillips
Ms Robyn McIntosh
Mrs Carol Quayle
Dr Cyril Latt
Dr Yamin Myat Aye
Dr Anthony Herbert

China

Dr Joyce Hill
Dr Jianmin Wang

India

Dr Sanjay Dhirraaj

Indonesia

Dr Wayan Sudarsa

Japan

Sasakawa Memorial Health Foundation
Dr Yasuo Shima
Mr Masami Otani

Korea

Ulsan University Hospital

Malaysia

Malaysian Association for the Study of Pain
Dato' Seri Dr Devaraj Thamboo Pragasam
Ms Aspeir Wong
Dr Mei Ling Look
Ms Aidah Abdul Hassan Chin
Dr Choo Yoke Ling
Dr Cindy Teoh

Nepal

Assoc Prof Sunita Panta

New Zealand

Mrs Liese Groot-Alberts

Philippines

Dr Evangeline Barbara Go
Ms Jenelyn Rualo - Pring

Singapore

Dover Park Hospice
Ms Soh-Mun Chin
Dr Poh-Heng Chong

Sri Lanka

Dr Ranjan Mallawaarachchi

Thailand

Dr Tharin Phenwan

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