# **IAPCONKochi 2019 Proceedings**

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# INTRODUCTION

The state of Kerala, the 'God's own country' as it is fondly called, harbours 90% of the country's palliative care programmes though it has only 3% of the country's population. This is characterized by a large number of home care services, which have wider coverage. Ernakulam district alone has about 38 palliative care units serving a population of 32 lakhs. The 26th International Conference of Indian Association of Palliative Care was held from 7th to 10th February 2019 (including a day of Preconference workshops) at AELI Hills, Keezhmadu, Aluva, Kerala, India. This was organised jointly by the Consortium of Pain and Palliative care units of Ernakulam district along with IAPC. The Consortium delegates attended IAPCON 2018 at Delhi and set the ball rolling. The Conference theme was "Voices in Palliative Care, Ensuring Quality, Creating Solutions". Mr. Anwar Sadath, MLA, formally inaugurated the conference activities on 10th March 2018 at the conference venue. A free eye camp supported by Dr. Tony's Eye Hospital and Research Centre, Aluva, was held on the same day providing care for 210 patients. This was followed by a gynecology camp on 18th November 2018 attended by 160 patients and a multi-speciality medical camp on 20th January 2019 for 170 patients. As part of the campaign to reach out the message of palliative care to the rural population, the team encouraged individuals and institutions to establish palliative care centres across the country. The three days conference covered a wide range of topics in palliative care; selected on each day giving importance to the three aspects of the theme. We had about 1100 participants from 16 countries who interacted with each other and shared their expertise.



It was our aim to make this conference accessible to not just doctors and nurses but also to volunteers and other health care professionals who have lot to contribute to improving Palliative Care in India and especially in Kerala.

Several new national and international speakers were invited with diversity and excellence in mind.

# KOCHI DECLARATION

Astana declaration of October 2018 was taken as the basis of this declaration, which calls on health care systems to include palliative care as part of primary health care and to ensure partnership and control by the community.

As a prelude to the preparation of the draft declaration, a workshop was organised by Government Medical College, Thiruvananthapuram and Pallium India Trust on 11th December 2018 at Government Medical College, Thiruvananthapuram. A detailed version of the declaration was published in VOICES – the commemorative souvenir -brought out in connection with IAPCONKochi 2019.

# **Preconference workshops**

The conference went on to a great start with 7 Preconference Workshops on 7th February 2019 at the Conference Venue for a total of 110 delegates. These included; Navigating the Unknown – Tools for the Psychological Care Giver, Epidemiologic statistics for beginners – hands on workshop using Epi Info and Open Epi, Communication Skills in Palliative Care, Neurology in Palliative Care, Volunteering in Palliative Care and Paediatric Palliative Care. A closed workshop "Understanding Quality Improvement Methods to implement change to the Indian Palliative Care Experience" was held outside the venue and supported by TATA Trust.

An experience with the unique home care programmes in Ernakulam were another important option provided to interested delegates as a part of preconference workshops, enabling them to have a hands on experience with the Kerala model of Palliative care. The expert faculty for the various workshops were varied from National and International organisations. For instance, from Columbia University USA, Pallium India, Apollo Cancer Speciality, Achutha Menon Centre for Health Science Studies, Tata Memorial Hospital Mumbai, Kasturba Medical College and Manipal Hospital Manipal, University of Colorado School of Medicine USA, P.D.Hinduja National Hospital Mumbai, World Child Cancer programme and ICPCN.

# **Conference (8th to 10th Feb 2019)** *Venue*

AELI International in Aluva, Kerala acceded to a request from the Organising Committee to associate with the conference as one of the major Conference Partners. They provided the whole of the 20 acres of AELI Hills, a 'hillock on a hill', including all the structures and amenities free of any charges, accommodation for 140 delegates and two grounds for the conference along with the manpower. A total facelift had also been made exclusively for making the structures and the surroundings comfortable and disabled friendly to the delegates. Three sound proof air-conditioned tents (in view of the humid climate in Kerala) were installed days before the conference and had capacity to seat the required delegates.

# HIGHLIGHTS OF DAY 1

# Meet the experts

An early morning session on the first two days of the conference titled "Meet the experts" which was an hourly session on specific topics were planned, to have informal discussion with experts in the respective topics. The first day the discussion was around "Narratives, Education and training, and Humanitarian issues". The sessions were led by Dr Jayita Deodhar, Prof David Oliviere, Dr Fiona Rawlinson, Dr Lulu Mathews, Dr Mhoira Leng, Dr Savita Butola, Dr Megan Doherty, and Ms. Joan Marston.

# **Plenary sessions**

In the first plenary on "Voices of the Frontline" Ms Ashla Rani, Dr Stephen Connor and Ms Bhavana Issar brought extremely relevant narratives, Dr Stephen brought along with a prerecorded video message from Ms Lucy Watts MBE, a global palliative care advocate.

The second plenary on the first day on 'voice for the voiceless' theme with focus on information sharing with media and public led by Mr Sashi Kumar, a media doyenne of India followed by stimulating panel discussion led by Dr MR Rajagopal, with Mr Sashi Kumar, Dr Sushma Bhatnagar and Ms Harmala Gupta.

## **Parallel sessions**

Case based discussions on various important clinical topics relating to conference theme was a new initiative in this conference and were presented as parallel sessions on all the 3 days. Each session was led by experts in the field and coordinated by Dr Shoba Nair (member of Scientific Committee). The topics covered on Day 1 included Head and Neck Cancer, Parkinson's disease and Dementia. The other theme based parallel sessions of the morning covered Children and their voices, Mental health needs and their voices, Community based palliative care and its relevance- Voices from models. The post lunch session highlighted Voices from various settings in Progress in Palliative Care, Pathways for care in different palliative care settings and Vulnerable population and their voices where the voices of transgenders, tribals and those living in the slums were outlined.

Dr Mary Ann Muckaden, Prof Julia Downing, Dr Spandana Rayala, Dr Anjum Joad, Ms Poonam Baghai, Dr Aditi Chaturvedi, Ms Priya Kumari, Dr Lalchhanhima Ralte, Dr Devi Vijay,Dr Dan Munday,Dr Carol Douglas, Mr KV Hamza, Dr Sameera M J, Dr Ashita Singh, Dr Anuja Damani, Dr Bindu Menon, Dr Sunitha Daniel, Dr Reena Sharma and Dr Athul Joseph Manuel were the main speakers on the first day parallel sessions.

## Inauguration of the conference

The Conference was formally inaugurated by Mr.Ramachandran Kadannappally, Honourable Minister for Ports, Museums, Archaeology and Archives, Kerala, at a solemn function organized on 8th February 2019, which was presided over by Dr. Mary Ann Muckadan, President, Indian Association of Palliative Care. Dr. Sushma Bhatnagar, Incoming President who then addressed the gathering. Mr. Ramachandran Kadannappally, Hon'ble Minister gave away the International Award for Excellence and Leadership in Palliative Care for the SAARC Countries 2018-19 instituted by Cancer Care Society to Dr. Savita Butola, Commandant, Border Security Force, Gwalior. The Award carries a cash prize of INR 100000 and a citation. Mr. Anwar Sadath, MLA, gave away the prestigious Bruce Davis Gold Medal to Dr. Anish Das Gupta, MD Student, Medical College, Kolkata, instituted by the Institute of Palliative Medicine, Kozhikode. VOICES - the souvenir brought out by the Organising Committee to commemorate the occasion - was formally released by Mr. K A Ramesh, President, Keezhmadu Grama Panchayath.





# **Highlights of Day 2**

On Day 2, the morning started again with the 'Meet the Experts' session which included topics like "Setting up a palliative care unit, Research and Integrating into Oncology and PC PAICE (a workshop on Quality improvement). The sessions were led by experts in the field including Ms Harmala Gupta, Dr Mohanasundaram Thiagarajan, Dr Dan Munday, Dr Eva Brun, Dr Mary Ann, Dr Sushmita Pathy, Dr Lukas Radbruch, Dr Karl Lorenz, Dr Sushma Bhatnagar, and Dr Nandini Vallath.

#### **Plenary sessions**

The plenary theme of "Ensuring quality" was emphasized by talks from experts like Dr Raman Kumar talking about Integration to generalist and Dr Craig Blinderman on Ensuring Quality- In relevance to Death and Dying in Palliative care; in the morning session.

In our post lunch plenary with a theme of "Ensuring quality by empowerment" the talks focused on outcome measures in palliative care by Prof Richard Harding, the wider definition of PC as proposed by the International Association of Hospice and Palliative Care (IAHPC) was presented by Prof Lukas Radbruch and a senior nurse Ms Alice Stella inspired her colleagues to develop education in leadership skills and reinforced the vital role of nurses in the palliative care team.

#### **Parallel sessions**

Case based discussions on "bedridden patient with cancer was an interactive and well attended session with Dr U.Nandakumar Nair and Dr Tarey acting as experts. A highly relevant 2 hour sessions were entirely on "Serious illness conversations "How to do it? led by Dr Megan Doherty and Dr Gayatri Palat. The other parallel sessions touched on Education and curriculum development, Volunteer delivered interventions, Humanitarian issues, Role of IT in delivery and data management in Palliative care, and Spiritual care-New methods to ensure quality. Delegates were reminded of the recent floods affecting people of Kerala in 2018 and how palliative care contributed to relief and rehabilitation. Dr Spandana Rayala, Dr Shrikant Atreya, Ms Rowsan Ara, Mr K M Noordeen, Dr Mhoira Leng, Ms Vicky Opia, Dr Jeremy Johnson, Dr Biji MS, Ms Vineela Raepelli, Dr Athul Joseph Manuel, Dr Priyadarshini Kulkarni,



Ms Joan Marsten, Mr Ken Ross and Dr Seema Rao were some of the speakers for the parallel sessions.

The day concluded with the screening of "HIPPOCRATIC 18 -Experiments in Gently Shaking the World", the film about Padmashri Dr M R Rajagopal produced by Moonshine Agency followed by dinner and banquet. The General Body Meeting of IAPC was held in a parallel hall during the telecast of the movie in which pertinent issues and de cisions of IAPC were taken.

#### **Entertainment**

The evening of the second day of the conference saw the delegates entertained by a variety of music and dance programs. Indian folk dances by Elsy Pettah, Viswadeepthi Vidyalaya Public School, Chirayam, group dance forms coordinated by Suvarnalekha, Nursing staff, Anwar Memorial Pain and Palliative Care Society and more from Yohans Vimukthi International Yilaga Students, Thrikkakara. There were contemporary classical dance forms like Bharatanatyam by Dr. Sreedevi Warrier, Pallium India, Thiruvananthapuram, excellent performance of traditional Kerala dance form "Thiruvathira kkali" by staff and nurses of General Hospital, Ernakulam; coordinated by Dr. Geetha Vijay, Kolkali by Viswa Deepthi Vidyalayam Public School, Chirayam, Magic show and Music by Rewind Music stories. Delicious Kerala cuisine for dinner was enjpyed by everyone.

# **HIGHLIGHTS OF DAY 3**

# **Plenary session**

The concluding day began with the plenary talks of the conference bringing in discussions highlighting the ongoing difficulties of patients on life support with Dr Roop Gursahani pointing out Supreme Court verdict and challenges in India in End of Life followed by Dr Naveen Salins talking about Task force on End of Life (IAPC) and recent developments.

Dr Odette Spruyt, who was unable to be at the conference presented via a video link on "The healing relationship in palliative care"- introduced and summarised by Dr Chitra Venkateswaran.

#### **Parallel sessions**

Our last day's Case based discussion was on Carcinoma Cervix with Dr Anjum Joad, Mr Swarup I playing their roles well as experts on the subject. The parallel sessions were on "Needs





**General Body Meeting of IAPC** 

Assessment, Tools and Standard Guidelines in Palliative Care, Interventions for Older Persons, Family and Care givers and a panel focusing on Universal Health Coverage facilitated by Dr Savita Butola. One of the sessions enabled a group "Thanal-Freedom on Wheels" led by paraplegics conduct a music session highlighting the importance of music therapy in palliative care. This session was introduced by Dr Satheesh Kumar C.

Dr Ravinder Mohan,Dr Peace Bagasha, Dr Lakshmi K, Ms Gilly Burn, Reverend Abraham Varghese, Dr Shaji KS, Dr Vidya Viswanath, Ms Chandralekha KP and Mr Ganapathy KV were the main speakers for the sessions.

## **Oral presentations**

The top scoring abstracts, four of them chosen by the Abstract Review Committee were given opportunity to present during one of the parallel sessions.

- 1. Palliative Care: Part Of Integrated Management For Non-Communicable Diseases - A Model For Low Income Communities by Dr Vandana Kanth
- 2. Experiences And Attitudes Towards Disclosure Versus Nondisclosure Of A Poor Prognosis To Advanced Cancer Patients: Indian Oncologists Perspectives by Ms Sravannthi Maya
- 3. Palliative Care For Dementia: A Social Work Model by Ms Priya Thomas
- Surviving The 2015 Earthquakes In Nepal: The Experiences Of People With Life- Limiting Conditions In Two Rural Districts by Dr Dan Munday

## **Oral and poster presentations**

A total of 198 abstracts were approved and the presentations were made on 8th and 9th February 2019 in the following manner. We also had a new category of "Narratives"- presented as photos, posters or video presentations.

1.	Free Oral presentations	- 46
2.	Poster Presentations	- 127
3.	Narrative Posters/Photo Presentations	- 8
4.	Video Presentations	-17
Total		- 198

46 presentations were chosen from a whole lot of abstracts submitted by students, volunteers, doctors, nurses and other health care professionals.

Presentations were scored by respective chairs and the top three were awarded during the Valedictory function.

#### **Oral presentations**

First Prize of INR 10000 sponsored by Mr. K Radhakrishna Menon in memory of his mother Chempolli Lekshmikutty Amma.

Creating Solutions through developing leaders in palliative care:

Evaluation of two cohorts of leadership training in Uganda by Dr Julia Downing.

## Second prize

Assessment of coping of hematological childhood cancer patients (curative and palliative) by Mallika Narayan.

#### Third prize (2 in number)

- 1. Development, implementation and evaluation of palliative care education for health care workers, village health teams and family caregivers providing healthcare for South Sudanese Refugees in Adjumani District, Uganda by Vicky Opia
- 2. Do we need Step 2 of the WHO Pain Ladder; an EAPC Research Network Study by Mhoira E F Leng

Our gratitude and Thanks to all our chairs and our abstract reviewers who had the difficult task of judging the presentations which included Dr Linge Gowda KB, Dr Vidya Viswanath Dr Priyadarshini Kulkarni, Dr Seema Misra, Dr Vidya Kumaraswamy, Dr Sairu Philip, Dr Chitra Venkateswaran, Dr Shoba Nair, Dr Sumita Mohanty, Dr Subathra Muthukumaran, Dr Punita Lal, Dr Aditi Chaturvedi, Dr Sushmita Pathy, Dr Sarita Singh, Dr Preeya Desh, Dr Sunil Kumar,Dr Satheesh Kumar, Dr Geetha Vijay, Dr Raghavendra, Mr Swaroop I.

#### **Poster presentations**

127 chosen posters were displayed over two days. Judges gave a feedback that the quality of posters had improved and it was quite a close challenge in choosing the best three of the lot.

The Judges for the posters did a commendable job and the Scientific Committee extend their gratitude to Dr Liz Minton, Dr Micheal Minton, Dr Jayita Deodhar,

Dr Preeya Desh, Dr Fiona Rawlinson. Dr Jo Hayes, Dr Anjum Joad, Dr Ruth Powys, Dr Liz Grant, Dr Dan Munday, and Dr Tarey.

#### **First prize**

Collaborative Approach: Combined clinics and joint ICU consultations for comprehensive and seamless care of older people approaching End of Life by Dr Stanley C Macaden.

# Second prize (3 in number)

- 1. An audit on implementing End of Life Care Policy in medical intensive care unit of a quaternary care centre in India by Dr Chinthu S Kumar
- 2. Creating a compassionate community to support care for children with chronic diseases in an Urban Informal Settlement in Bangladesh by Ms Maryan Bezzahou
- 3. Evaluation of a project echo on paediatric palliative care targeting health professionals in South Asia by Ms Emily Evans.

#### Third prize (2 in number)

- 1. Comfort at End of Life: Can bispectral index monitoring add to our understanding? by Dr Greg Barclay
- 2. Illness perception in a paediatric cancer population at a tertiary cancer centre by Dr Biji M S.

#### **Meetings Facilitated during the Conference**

- Project India Meeting, led by Dr Stanley Macaden.
- Central Council meetings of Indian Association of Palliative Care were held on 7th February 2019 and 10th February 2019.
- The Annual General Meeting of Indian Association of Palliative Care was held on 9th February 2019.



**Scientific Committee** 

# CONCLUSION

The IAPCONKochi 2019 with record -breaking number of attendees, high-ranking speakers from across the globe and in depth discussions on pressing challenges facing Palliative Care in India, was well received by the delegates despite some challenges due to the humid climate and logistics of transport to the venue.

The event was successful in achieving all the objectives that was set out for. The event also had unprecedent social media coverage well before the conference with an active Facebook profile, twitter handle and linked-in profile.

The conference committee wishes to acknowledge with deep gratitude all the support extended from the IAPC, CIPLA Palliative Care & Training Centre, Anwar Memorial Pain and Palliative Care Society, Rajagiri Hospital sponsors, faculty, delegates and all supporters who made this happen.

The success of this conference was an outcome of 12 months of thorough planning and hard work by a team of efficient and dedicated members, with a vision to promote and improve access to Palliative Care locally and nationally. The conference committee would like to thank all the members below for their outstanding commitment to the success of IAPCONKochi 2019.

The Chief Advisor of the programme was Padmashri Dr M R Rajagopal.

# **Scientific committee**

Dr Chitra Venkateswaran, Dr. Mhoira E F Leng, Dr. Sunitha Daniel, Dr. Shoba Nair, Dr. Rajith Ramachandran, Dr. Biju Raghavan, Dr. Athul Joseph Manuel

Dr. M M Sunil Kumar and Ms. Pallavi Naidu

#### **Organizing committee**

Dr CM Hyder Ali, Mr Radhakrishna Menon, Mr Mujeeb Kuttamassery, Mr K J Joseph, Mr K K Basheer and Volunteers in Palliative Care Units of Consortium.

# Volunteers in Palliative Care Units of the Consortium

We like to extend our best wishes to Dr Dinesh Goswami and his team for a successful IAPCON 2020.

**Financial support and sponsorship** Nil.

#### **Conflicts of interest**

There are no conflicts of interest.