



# ANNUAL REPORT 2017-18

## PALLIUM INDIA TRUST

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**Pallium India** was established in 2003 as a registered national charitable trust. With the aim to provide and promote quality palliative care in India. Since its inception, Pallium India has worked to improve access to palliative care through training, education, advocacy, and delivery of services.

## Vision

An India in which palliative care is integrated in all health care services so that every person has access to effective pain relief and quality palliative care along with disease-specific treatment and across the continuum of care

## Mission

To catalyze the development of effective pain relief and quality palliative care services and their integration in health care services across India through delivery of services, education, information, strengthening capacity, policy, research and advocacy.

## Core Values

The patient is the most important consideration. Commitment to Pallium India will be secondary to commitment to the patient and family.

- ‘Care’ is the right of the patient and family and we stand committed to giving it to them. ‘Care’ is not a charity that we give them. By giving us the opportunity to care for them, they are enriching our lives.
- Compassionate and competent care valuing human dignity is at the very heart of what we do and why we exist. We shall endeavor to do the right thing for the right reason as best as we can.



- We recognize the strength of the social capital and shall engage in a partnership with the community enlisting the support of volunteers and other community entities, creating the capacity to meet community needs.
- Each one of us shall treat everyone else with respect, remembering that every individual is superior to each one of us in some way.
- We shall embrace the ethical principles of autonomy, beneficence, non-maleficence and justice, exercising them to the best interest of those we care for.

## Main focus areas:

- Initiation of palliative care facilities, expand facilities where they exist and maintain the services for the benefit of the patient and families.
- Provide palliative care services to the needy as far as possible at their homes.
- Undertake activities at the national level to ensure availability of opioids and other low-cost drugs.
- Develop and ensure provision of minimum standard and quality of palliative care services.
- Generate awareness about palliative care among health care professionals and the general public.
- Support research in palliative care and all aspects of pain and pain relief.
- Provide palliative care training programs for Doctors, Nurses and allied medical professionals.
- Act as an information center to assist patients in identifying palliative care services near to them and also to guide doctors and nurses for palliative care training purposes.
- Help the central and state governments to develop policies related to integration of pain and palliative care services in health care and in the implementation of such policies at the central and state levels.



# I. Pallium India Trust – National Level

## i. *Development of palliative care centres.*

- Catalyzed the development of 8 new palliative care centres in 7 states with the help of TATA Trust by providing expertise and financial support.
- Initiated state-wide projects in Andhra Pradesh, Mizoram, Uttarakhand and Himachal Pradesh with the support of grant from Pallium India Inc., USA. Submitted draft palliative care policies for Andhra Pradesh and Himachal Pradesh.
- Initiated the project under the Pain Free Hospital Initiative in Cancer Research Institute, Dehradun. A research paper will be published soon. Pallium India is preparing modules for training professionals under this initiative.
- Financial support provided to 9 social workers for operating palliative care kiosks based in Thakurpukur, West Bengal with the support of Jiv Daya Foundation extended for one more year.
- Extended salary support to palliative care centres at Jaipur, Jodhpur, Cuttack, Indore and Vadodhara under Jiv Daya Foundation.
- Continued work with the newly-formed education centre in Regional Cancer Centre in Ahmedabad, Gujarat and extended financial support for the same for one more year.
- Provided scholarship for attending 6 weeks training program to 35 Doctors and 35 Nurses through TIPS Trivandrum, MNJIO Hyderabad, GCRI Ahmedabad, BMCHRC Jaipur and CAN SUPPORT Delhi, with funding support from Indo American Cancer Association.

## ii. *Opioid Availability Workshops and Advocacy on Pain Management Drugs*

- Conducted opioid availability workshops in 7 regions – Himachal Pradesh, Madhya Pradesh, Uttar Pradesh, Maharashtra, Andhra Pradesh, Pondicherry and Delhi involving government officials, medical professionals, medicine suppliers and palliative care activists. The meeting clarified the objectives of the amendment and possible ways of implementing. These workshops



were attended by the Drug controller, representatives from the Excise department, Principals of Medical colleges, Pharmaceutical suppliers and health care professionals from the respective states.

- Based on the opioid availability workshop conducted in Pondicherry in March 2017, we have submitted guidelines to the state government for implementation of the amended NDPS act. The government is taking necessary steps to implement the amended NDPS act and had published the guidelines in the gazette of Pondicherry. This was made possible through the combined efforts of a group of palliative care professionals – both from government and private sector.
- Approached Pondicherry Lieutenant Governor to brief her about the situation of palliative care in Pondicherry and the difficulties in implementing the amended narcotic policy. As per the directions received from the Lieutenant Governor, the matter is being followed up with the government officials for implementation.
- Our efforts have contributed significantly to the availability of methadone as a low-cost opioid alternative for pain management. We initiated the formation of a working group (includes national and international experts) which prepared detailed instructions and information on the use of methadone as an analgesic. This was published as a special supplement of the Indian Journal of palliative care which is available for free access for anyone in the region. Ref: Indian J Palliative Care 2018; Vol: 24

*iii. Collaboration with the Department of Health and Family Welfare*

- Working with the Ministry of Health, Pallium India was represented in the ASHA mentoring group annual meeting.



- The chairman of Pallium India is chairing a working group established by Ministry of Health of Government of India for implementation of the palliative care component of the National Health Policy.
- Dr MR Rajagopal chaired a taskforce by National Health System Research Centre to draft palliative care guidelines under Comprehensive Primary Health Care. Sumitha TS, project officer of Pallium India Trust was also a member in the taskforce.
- Pallium India, as one of the founding members is actively involved in the “Healthy India Alliance” which is the Indian arm of the Global “NCD Alliance”.

iv. ***Development of Medical and Nursing curricula:***

- Follow up is made to the submission to the Medical Council of India and Indian Nursing Council in 2013 to integrate palliative care curriculum in undergraduate courses.
- Pallium India entered into a MoU with Sri Balaji Vidyapeeth, Pondicherry for integration of palliative care in the medical and nursing curricula. The training of one doctor is completed. Nursing curriculum with palliative care has been submitted for copyrights. Students groups are actively involved in palliative care related activities.
- Working with KUHS (Kerala University of Health Sciences) in the implementation of inclusion of palliative care in under graduate medical curriculum.

v. ***MOU with the Catholic Health Association of India (CHAI)***

- Pallium India has a MoU with the Catholic Health Association of India (CHAI) to make palliative care accessible to more patients across India through CHAI’s vast network of over 3,500 member institutions. In collaboration with CHAI, Pallium India is training of 21 doctors from CHAI through TIPS-ECHO. They received hands-on training from MNJIO RCC, Hyderabad. We foresee more palliative care centers being run through CHAI hospitals.



## II. National Level Advocacy

- Sought information from 29 regions to check on the current status of the NDPS Law and Palliative Care Services. We received encouraging response from 20 of them and established network for advocacy in 12 of them.
- Met government officials involved in implementing the NDPS law or the NPPC in 14 regions which includes State Health Minister/Governor of a UT , State Principal Secretary Health, State Drug Controller, State National Health Mission (NHM) – Mission Director (MD), State Nodal Officer (SNO), DHS, DME, Director of Regional Cancer Centers, State Medical Colleges, State Excise or Revenue Officer
- In 29 states and UTs, we established links with champions for palliative care and strengthened our advocacy efforts in 20 states.
- Reached out to National Health Missions of Himachal Pradesh, Tripura, Meghalaya, Uttar Pradesh, Gujarat, Tamil Nadu, Mizoram, Madhya Pradesh, Uttarakhand, Assam and Haryana to collaborate in the implementation of NPPC in all district hospitals in these states. Started discussions with Dr NTR Vaidya Seva Trust to integrate palliative care into all its empanelled hospitals across the state.
- Conducted sensitization sessions for the medical fraternity and government officials in the following states through different networks: (1) Through NHMs – Himachal Pradesh, Haryana and Tripura (2) Through NGOs: Mizoram, Uttarakhand, Andhra Pradesh, Gujarat, Tamil Nadu, Assam (3) Through individuals/medical colleges: Madhya Pradesh, Pondicherry, Maharashtra, Goa, Bihar, Nagaland, Uttar Pradesh, Meghalaya and Punjab.
- Developed a core team at national level to provide training to Palliative care and health care professionals to improve the quality of care through continuous online training





program. Most of the discussions and training are based on case presentations by the participants.

### *Advocacy in Kerala*

- State Bank of India contributed a Wheelchair Friendly Vehicle along with 5 motorized wheelchairs during the bank day and it was handed over by the Hon'ble Governor of Kerala.
- Conducted rehabilitation product exhibition in KINFRA Park with the help of Ernst & Young, and at Technopark in collaboration with Social organization Prathidhwani.
- Conducted Sahayathra cycle ride from Palakkad to Trivandrum - Cycle club (College of Engineering, TVM) conducted Cycle rally in collaboration with IAPC, Kerala Chapter for spreading palliative care awareness. It was a 4-day ride across Kerala and it received a good response and support from local NGOs and the general public. Pallium India's volunteers and staff members arranged a food festival at KINFRA park, Kazhakuttom and Technopark for raising fund for children's Summer camp.
- Manjuthulli – Exhibition and sales of painting by group of volunteers and well-wishers for fundraising Palliative care awareness campaign – Wall art at Sreemoolam club, Trivandrum. Pallium India members, students and teachers of Thanal unit of Mar Baselios college, Nalanchira jointly associated for the program



### III. Launching of “HIPPOCRATIC” Film

Hippocratic is a feature-length film (90 min) exploring the life story of Pallium India’s Chairman Dr.M.R.Rajagopal, produced by ‘Moonshine Agency’, Australia. The project was funded by International Association for Hospice & Palliative Care (IAHPC), Lien Foundation, TPI Enterprises, Open Society Foundations, Australasian Palliative Link International (APLI) and Moonshine Agency. The story uses Dr. Rajagopal’s narrative to encourage the audience to rediscover the first principles of medicine. The film was first screened in Australia at University of Adelaide and subsequently in around 21 venues. In India the premier in Bangalore happened on the 20th of January 2018. The movie was screened in Malaysia, Bhutan, Europe, Australia, Canada, USA, and New Zealand. The screenings have contributed to fundraising for Pallium India.

### IV. International Collaboration

Partnering with WHOCC at Madison-Wisconsin to overcome regulatory barriers to opioid access. Dr Rajagopal, Director of WHOCC TIPS, Trivandrum continues to function as a member of the international experts committee of WHOCC at Madison-Wisconsin.

- *University of IOWA, USA*

Pallium India in alliance with University of IOWA, USA conducts a cultural immersion program every year. The program is for a period of 4 weeks, which includes class room sessions, home care, clinical services etc. This year we had 19 students from IOWA University along with two faculty members.



- *Collaboration with Child Health and Family International (CFHI)*

Since 2012, Pallium India in alliance with Child Family Health International runs a cultural immersion program of 4 weeks duration. This year we had 3 students visiting us, as part of the program.



## V. Conferences and Trainings

### International level

- Dr. M. R. Rajagopal participated in meeting for development of guidelines for the management of cancer pain– WHO Geneva.
- Dr. M. R. Rajagopal presented on palliative care in neurology at the World Congress of Neurology in Japan.
- Dr. M. R. Rajagopal conducted classes at Palliative care workshop in Bhutan.
- Ms. Smriti Rana, Programme Director -Children's Palliative care and Ms. Shalini, Sr. Project Officer attended a workshop on Making Change Happen: Strategic Advocacy and Communication for Palliative Care" hosted by The Salzburg Medical Seminars International at Salzburg.

### National level

- ***IAPC Conference, Delhi, India:*** This year, 12 members from Pallium India participated in the IAPC conference held at Delhi. Among them our project officer Ms. Anjali Krishnan gave an oral presentation on “Development and Implementation of Palliative care in Kerala – Health policy analysis”, Palliative care physician, Dr. Sreedevi Warriar presented a paper on “Swallowing difficulties in head and neck cancer patients presenting for palliative care in Trivandrum, India”. Eight other members presented posters on the topics “Impact of Psychosocial support to improve the quality of life among geriatric patients” by Reshma , “ A model to integrate mental health in palliative care in improving quality of life” by Mr. Sherin Wilfred, “Study of quality improvement initiative for home care – services of TIPS” by Dr. Sudhamani Amma, “Antibiotic prescription pattern for Foleys catheterized patients in palliative care centers by Dr. Sunil,



it was a retrospective analysis ; Anjali Krishnan and Sr.Dejitha on “Palliative care programme development in a low middle income country; Babu Abraham on delivery of care by a NGO in India” and “SANS-PAIN – Students Against Needless Suffering and Pain

- Dr. M R Rajagopal attended End of Life Care in India Task Force – Workshop in Chennai & Bangalore
- Dr. M. R. Rajagopal attended National Cancer Grid (NCG) Meeting at Mumbai.
- Dr. M. R. Rajagopal attended Neuro Palliative care workshop in Bangalore
- Ms Sumitha, Project Officer and Mr.Sarath Mohan, Sr. Social worker presented papers on “Pallium “I’s (Insight, Innovation and Integration) Through Psycho-Oncology” and “Enhanced quality of life in oncology patients through early palliative care intervention” during Indian Cancer Congress in Bangalore.
- Dr. Sunil Kumar, Sr. Sheeba and Ms. Sumitha, attended ECHO immersion training program at New Delhi which was supported by ECHO India.



## VI. Trivandrum Institute of Palliative Sciences (TIPS).

Pallium India has developed a successful model for the provision of palliative care through its Trivandrum Institute of Palliative Sciences (TIPS). TIPS is a WHO Collaborating Centre for Training and Policy on Access to Pain Relief and an approved centre for Prime Minister's National Relief Fund. The following are the activities undertaken by TIPS

### *Clinical Services*

Trivandrum Institute of palliative Sciences' provides free care including medicines. More the 90% of our patient population belong to poor socioeconomic background.

### *Palliative Home Visits*

Patients who are bedridden, or who cannot travel long distances either due to their physical problems or due to financial constraints, are seen at home. Five home care teams, comprising of volunteers, palliative care assistants, nurse, social workers and doctors conduct visits. Fourteen Link centres have been set up in rural and urban areas of Trivandrum district that bring local community volunteers to assist the home care teams.

### *Inpatient services*

Patients who need continuous observation and monitoring avail the inpatient services, usually for a period of a few days to three weeks, mainly for symptom control or terminal care and occasionally for respite care. We have our inpatient facility to Arumana Hospital, West Fort, Trivandrum and have an inpatient capacity of 18 beds.



### *Outpatient Clinics*

Outpatient services were provided at Arumana Hospital on all days, Trivandrum Medical College on all days except Sundays. It was also provided at Sree Avittom Tirunal Hospital (on Thursdays), General Hospital (Trivandrum), CHC Vizhinjam, CHC Poovar, Arumana Hospital and at link centres.

### *Adult rehabilitation unit for Paraplegic patients*

A halfway home for rehabilitation of Paraplegic patients was started in the leased premises of Arumana hospital, under Pallium India with the support of Social justice department, Govt. of Kerala. The objective of the project is to identify physical, psycho-spiritual and social issues of people with spinal injury or stroke and to rehabilitate them physically, psycho-spiritually and socially, as useful members of the community. It is a facility to accommodate three patients with family at a time.

Emergency services are provided on a case to case basis and as per the recommendation of our palliative care physician.

Telephone consultations are encouraged for review – and we find this particularly valuable because our home visit program reaches patients only once a week. One staff member keeps a mobile phone, whose number is made available to all patients and families.



**In 2017-2018, Pallium India provided care to 2032 new patients and families.**

Table1: Number of new patients seen by Pallium India at Trivandrum during 2017-2018

<b>Link Centres</b>	<b>No of new cases</b>
Trivandrum Medical College	741
TIPS	688
Muttacaud	72
Palode	92
SAT	45
Kulasekharam	65
Poovar	67
Murukumpuzha	72
Uzhamalakkal	41
Karakulam	18
Jagathy	42
General Hospital	64
Azhoor	7
Pallithura	18
<b>Grand Total</b>	<b>2032</b>





### **Psychosocial Care and Rehabilitation**

Pallium India believes and practices active total care. We cater to not just the medical needs of the patients, but also the psycho-social-spiritual concerns of the patient and the family. We provide the following services in this regard.

***Bereavement Support ‘Unarv’*** Group is made available to the families who need psychological support to address and work through their grief following the death of their loved ones.

Physical rehabilitation particularly for the patients who are paralyzed including provision for devices like wheel chairs and walking aids.

***Vocational rehabilitation*** for the patient and/or the family where they are encouraged to undertake creative activities which also provide an income.

*Food kits* are provided to those patients and families who are extremely poor

***Educational Support*** for children who would have been forced to drop out of school, because of the illness and poverty. This is continued till the student finishes his/her education. Support group for children receiving educational support endeavors to develop their self - confidence, aptitude and skills. Three days summer camp was conducted for all children supported by Pallium India Trust.

### **Specialist care services**

Specialist Consultations- Based on the need of the patient and the caregiver, the services of specialist consultants is made available based on the need of the patient. The team consists of specialists/ consultant doctors who have volunteered their time and services.



*Physiotherapy* is provided to patients suffering from varying degrees of paralysis because of accidents, stroke or other neurological problems, and cancer with the objective to improve their quality of life. A consultant physiatrist and a physiotherapist leads this program through home visits and in in-patient and out-patient settings of TIPS.

*Mental health in Palliative care:* A new initiative addresses the mental health issues of the patients who are enrolled in Palliative care by a team consisting of a psychiatrist and a social worker. .Dr Chitra Venketesh of Mehac Foundation is voluntarily supporting Pallium India Trust.

*Lymphedema care and Colostomy care-* Apart from providing lymphedema care and colostomy care to those patients in need, we also train their caregiver in its management.

## VII. Education, Training and Capacity Building

To increase awareness of palliative care among the general public and the health care professionals, we conduct awareness programs and training programs.

In Trivandrum, the Pallium India is running six weeks' Certificate Course in Pain and Palliative Medicine (CCPPM) for doctors, Certificate Course in Palliative Nursing (CCPN) for nurses and Certificate Course in Palliative Care (CCPC) for other healthcare workers respectively. Pallium India conducts 10 days' Foundation course in Pain and Palliative Medicine (FCPPM) for doctors and nurses.

In addition to TIPS, Certificate Course in Pain and Palliative care is carried out by other three centres catalysed by Pallium India. These are MNJ Institute of Oncology, Hyderabad, Gujarat Cancer Research Institute and BMCHRC, Jaipur. Pallium India coordinates the fellowship program in palliative care offered by Indo-American Cancer Association (IACA).



**Virtual Learning Program:** As part of providing continuing education on palliative care, we conduct ECHO (Extension for Community Health Outcomes) sessions through virtual learning platform called “Zoom”. We have conducted six TIPS-ECHO sessions, attended by medical professionals from various parts of India as well as from Bhutan, Bangladesh and Nepal. Conducted 4 ECHO clinics - Treat that Pain, Multi-modal approach to pain management, Opioid availability, Foundation course on palliative medicine with 13, 23, 8 and 12 persons respectively attended the clinic. TIPS-ECHO session was also conducted on “Enhancing Dignity in Palliative Care through Integration of Social Work values” by Medical social workers team of Pallium India. MNJIO (Hyderabad) and TIPS started using “methadone” after TIPS-ECHO course on methadone which was taken by experts in USA. Our opioid sessions were useful for our spokes who received permission to stock and dispense essential narcotic drugs based on amended narcotic policy in India.

**National Information Center:** The primary objective of the Information Centre run in Trivandrum is to provide information on palliative care and establishments that provide palliative care India. A trained medical professional responds to the calls and provide relevant information. We also disseminate information through email and our website.

### **Awareness Campaign and Volunteers Training**

To empower the community and to ensure their continuous participation in this area, we provide volunteer training programs and awareness campaigns at different levels. With the support of Director of Public Instruction, started conducting awareness programs in Government and Aided Schools. Awareness class was given at 22 Schools in Trivandrum. This has resulted in a tremendous increase in the number of participants. This has also helped us in forming student’s initiative in palliative care in schools.



**Initiated Students against Needless Suffering and Pain (SANS Pain)** – The main objective of this project is to involve students in the palliative care activities. The Education Department (Kerala) has authorized Pallium India for conducting awareness program on Palliative care in schools. Started SANS Pain units in 7 schools in Trivandrum. SANS Pain unit at College of Engineering, Trivandrum launched “DeCARE”; a student’s startup to support patients by developing low cost assistive devices.

Table 2: Data on clinical and non-clinical services rendered at TIPS

<b>Clinical Services</b>		
	<b>Patient Care</b>	<b>No. of beneficiaries</b>
1	Number of new patients	2032
2	Number of patient contacts	23833
3	No. of patients admitted in Adult Rehab centre	14
4	Total no of unique patients	4244
5	Total patients seen in Physiatrist	303
6	Total patients seen in Psychiatry	29
<b>Psychosocial Care and Rehabilitation</b>		
	<b>Programs</b>	<b>No. of beneficiaries</b>
1	Food kit	61 families
2	Physical aid	199 patients
3	Vocational training and rehabilitation	13 families
4	Education And Mentoring Program	292 children
5	“Kuttikkoottam” Summer Camp	47 children
6	Unarv- Support group for bereaved families	74 family members
<b>Information Centre Statistics</b>		
1	No of enquiries attended	1062 603- via phone 459- e-mail



Table 3: Data on training programs

<b>Training Programs</b>	<b>No. of participants</b>	<b>No. of programs</b>
Foundation Course in Pain & Palliative Medicine (FCPPM)	52	5
Certificate Course in Pain & Palliative Medicine (CCPPM)	28	5
Certificate Course in Palliative Nursing (CCPN)	28	5
Foundation Course in Palliative Nursing (FCPN)	18	2
Certificate course in Palliative Auxiliary Nursing (CCPAN)	7	1
Geriatrics care observation and training	5	1
Number of Nurses attended Lymphedema Training	60	4
Number of Asha Workers attended Lymphedema Training	16	2
Volunteer Training Program	75	5
Awareness Program	1200	33
Observation visit 2 <sup>nd</sup> year mbbs students mch tvpm	19	1
University of IOWA cultural immersion program	19	1



## VIII. Awards and Recognitions:

- The Government of India honored Dr. M. R. Rajagopal with “Padma Shri”
- Kerala State Youth Icon Award received by Ashla Rani (Executive Assistant to Chairman).
- Ms.Ashla Rani, (Executive Assistant to Chairman) received state award from Kerala Social Justice Department.
- Honorable Kerala Governor Justice (Retd) Sadasivam honored Dr.M.R Rajagopal during the Republic day function.
- Department of Health & Family Welfare, Government of Kerala declared TIPS as a nodal agency for the implementation palliative care projects for achieving Sustainable Development Goals (SDG). Received a Government Order (GO) to provide palliative care training for government service doctors

## IX. Major events organized

- Opening of the Elizabeth Kubler Ross – Pallium India Library by former Chief secretary of Kerala - Shri.S.M.Vijayanand

