



**ANNUAL REPORT**

**APRIL 2016- MARCH 2017**



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**M R Rajagopal, MD**

**Chairman**

**Poonam Bagai**

**Vice Chairman**

(Registered Charitable Trust No. 693/IV/2003)

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**Pallium India** is a registered national charitable trust formed in 2003 to provide and promote quality palliative care programs to reach the millions of Indians who are in need of pain relief and palliative care. Since its inception, Pallium India has worked to improve access by strengthening expertise in palliative care through education, advocacy, and delivery of services.

Pallium India developed a successful model – **Trivandrum Institute of Palliative Sciences (TIPS)** - to deliver palliative care in Trivandrum. 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**.

**Pallium India has catalysed the development of palliative care centres in 16 states and two Union territories** - Jharkhand, Tripura, Uttar Pradesh, Manipur, Mizoram, Bihar, Orissa, Gujarat, Meghalaya, Tamil Nadu, Utharakhand, Maharashtra, Chattisgad, Himachal Pradesh, Madhya Pradesh, Rajasthan, Pondicherry and Lakshwadeep.



## **Vision**

An India in which palliative care is integrated in all health care 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 across India through delivery of services, education, building capacities, policy, research, advocacy and information.

## **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 endeavour to do the right thing for the right reason as best as we can.
- We recognise 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:**

- Start 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 a minimum standard and quality of palliative care services provided.
- Generate awareness of the possibilities of palliative care to health care professionals and the general public.
- Support research in palliative care and all aspects of pain and pain relief.
- Providing palliative care training program for Doctors, Nurses and allied medical professionals.
- Act as an information Centre to assist patients in identifying palliative care services near to them and also to guide doctors and nurses for palliative training purposes.



## **NATIONAL WORK**

### **I. Development of palliative care centres outside Kerala.**

- a) Financial support provided to 6 social workers for operating palliative care kiosk in Thakkurpukkur with the support of Jiv Daya Foundation extended for one more year.
- b) Extended salary support to palliative care centres at Jaipur, Jodhpur and Vadodhara under Jiv Daya Foundation.
- c) With the support of Jamsetji Tata Trust, started palliative care centres at Tanda (HP), Anand (Gujarat), Indore and Wardha in addition to 4 centres started in 2015-16.

### **II. Development of Palliative Care Training Centres.**

- a) Developed Palliative care training centers in MNJ institute of Oncology Regional Cancer Centre, Hyderabad, Bhagvan Mahaveer Cancer Hospital & Research Centre (BMCHRC), Jaipur and Gujarat Cancer Research Institute (GCRI), Ahmedabad. Extended support for another one year to palliative medicine department of Regional Cancer Center in Ahmedabad, Gujarat to continue their palliative training centre there.
- b) With the support of Indo American Cancer Association, given scholarship for attending 6 weeks training program to 14 Doctors and 14 Nurses through 4 training centers.

### **III. Opioid Availability Workshop**

- a) Conducted opioid availability workshop in Nagpur, Dehradun, Pondicherry and Mizoram. These entire workshop are been attended by Drug controller, representatives from Excise department, Principals of Medical colleges, Pharmaceutical representatives and health care professionals locally.



b) Based on the opioid availability workshop at Pondicherry in March 2017, we have submitted a guideline to them so as to implement the amended NDPS act. We are privileged to say that the government is taking necessary steps to implement the amended NDPS act and had published the guidelines in the gazette of Pondicherry with some modifications. This might not have happened without the help and unity of a group of palliative care professionals – both from government and private sector there. We were also instrumental to start an essential course by IAPC in one of the hospitals at Pondicherry

**IV. Department of Health and Family Welfare** for the implementation of the National Program for Palliative Care (NPPC) in India's 5 year plan, by holding several meetings with Ministry of Health. Working with the Ministry of Health, we also took part in the ASHA mentoring group, appointed by the Government of India. Chairman Dr. M R Rajagopal attended a meeting of ASHA mentoring group.

**V. WHO Collaborating Centre at TIPS engaged in the following activities**

**1. Partners with WHOCC at Madison-Wisconsin to overcome regulatory barriers to opioid access**

a. Dr Rajagopal, Director of WHOCC TIPS, Trivandrum is a member of the international experts committee of WHOCC at Madison-Wisconsin.

b. Dr. Rajagopal, Director of WHOCC TIPS, Trivandrum is one of the mentors at International Pain Policy Fellowship (IPPF) organized by WHOCC Madison-Wisconsin.



## **2. Opioid Availability Survey**

Our aim being a WHO Collaborating Center includes understanding the barriers in obtaining oral morphine and carrying out educational programs for professionals. We had conducted a survey among all our contacts in various states. Even after repeated efforts, we had received a very few responses. Analysis of this response itself was more than enough to make us understand that the barriers are still persisting and we have to do a lot of work to figure it out. As a continuation of this survey, we are trying a big scale survey with the help of a researcher who is already trying to dig out the facts about the barriers in opioid access

### **VI. Developed Medical and Nursing curricula :**

The final UG curricula created by the team of experts under the initiative of Pallium India were submitted to the Medical Council of India and Indian Nursing Council in November 2013. Follow up efforts are continue to integrate submitted palliative care curriculum in UG.

**VII. National Information center:** The primary objective of the Information Centre is to provide all possible information related to palliative care and about establishments where such facilities are available in India. A well trained medical professional is attending the calls and provide needful information's. We also provide the information services through our website and on email.

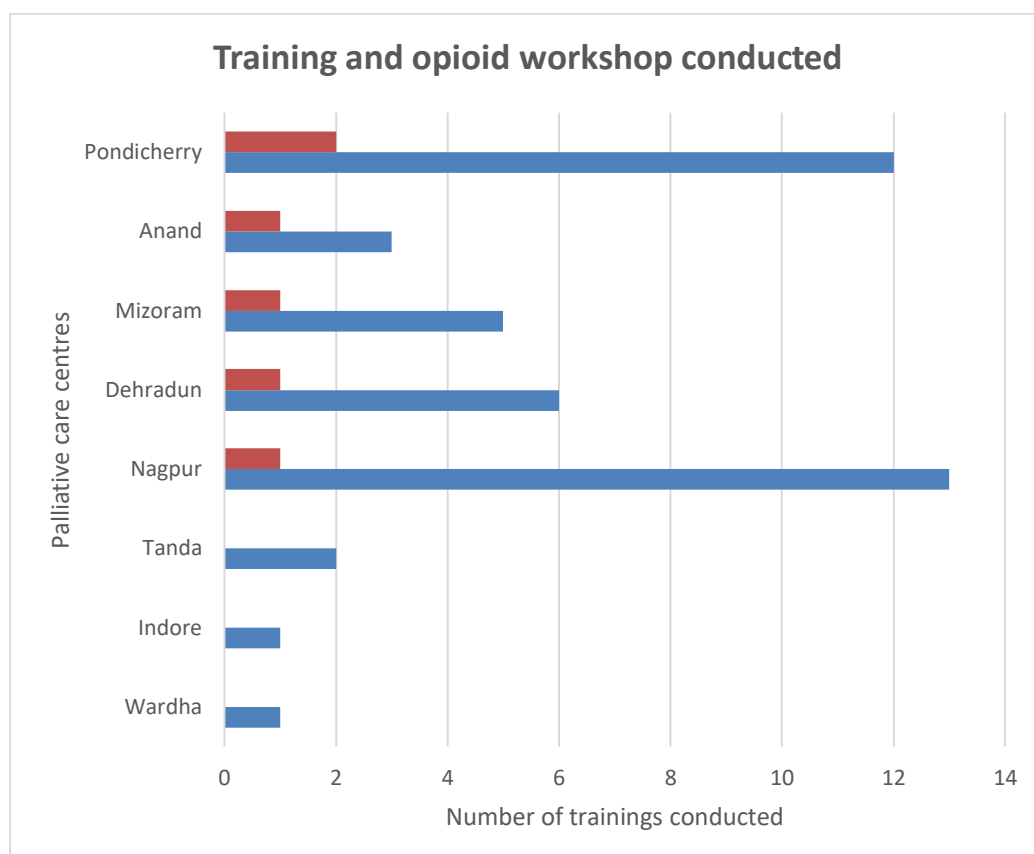
**VIII. Virtual Learning Program:** As part of continuing palliative care education, we have been conducting ECHO (Extension for Community Health Outcomes) sessions through virtual learning platform called “zoom” since January 20, 2017. Till March 31<sup>st</sup>, we had conducted six ECHO sessions on various topics and the experience was amazing as we strongly believe that “sharing of knowledge is the first step of







humanity”. ECHO sessions were attended by medical professionals from various parts of India as well as from countries like Bhutan, Bangladesh and Nepal.

**IX. Graph 1: Distribution of training programmes and opioid workshops conducted**



 **Number of training programmes conducted**  
 **Number of opioid workshops conducted**



## **X. Conferences and Trainings**

### *International level*

#### **i. Indian Association of Palliative Care Conference, Coimbatore, India:**

This year, 18 members were participated in the IAPC conference. Among them our palliative care physician, Dr. Sreedevi Warriar presented a paper on “professional oral care services in a specialist palliative care setting in South India”. Three other members were presented posters on the topics “Education support- social rehabilitation for patient’s children at Pallium India” by Sherin Wilfred ; “Palliative care coverage- Role of Pallium India” by Sheeba R.S and “Impact of public awareness programme in palliative care by Babu Abraam- A model project by Pallium India”. In addition to this, Ashla Krishnan did a presentation on “User and provider of palliative”.

- ii. Dr. M. R. Rajagopal attended a meeting on guidelines for the management of cancer pain in adults – WHO Geneva.
- iii. Dr. M. R. Rajagopal attended lancet commission on global access to palliative care and pain control in Mexico City.
- iv. Dr. M. R. Rajagopal attended care conference in Uganda.
- v. Dr. M. R. Rajagopal attended palliative care conference in Montreal, Canada and Muscot.
- vi. Dr. M. R. Rajagopal lectureship in Queens University, Kingston, Canada.
- vii. Dr. M. R. Rajagopal attended Vatican pontifical academy meeting.

### *National level*

- Dr. M. R. Rajagopal attended national conference on NCD in Delhi.
- Dr. M. R. Rajagopal along with 3 other team members attended a TOT held in Delhi.



- Dr. M. R. Rajagopal participated in an orientation programme on food preservation conducted by Food and Nutrition Board, Government of India.
- Dr.Nandini attended a meeting on law covering end of life care organised by Indian Society of Critical Care Medicine and Indian Association of Palliative care held in New Delhi.
- Dr. M. R. Rajagopal attended a meeting on removing ban on Ddextroprpoxyphene in New Delhi.
- Dr. M. R. Rajagopal attended a workshop on essentials in palliative care held at Seth G.S. Medical College & KEM hospital.
- Dr. M. R. Rajagopal attended a workshop at Indian cancer society.
- Dr. M. R. Rajagopal attended cancare foundation conference at Chennai.
- Dr. M. R. Rajagopal, Dr.Nandini, Dr.Sreedevi and Manoj had attended ECHO immersion training program at New Delhi.

#### *District level*

- Seminar on life with dignity to the end was organised by Pallium India in collaboration with IAPC.
- Painting competition for school student was organised in connection with barrier free Trivandrum project.



### **Activities related to advocacy**

- Conducted opioid availability workshop in Nagpur, Dehradun, Pondicherry and Mizoram. Director of Medical Services (DMS) and the Food and Drug Administrator, principals of medical colleges and local health professionals were participated. The meeting clarified the objectives of the amendment and possible ways of implementation.
- 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.



## TRIVANDRUM INSTITUTE FOR PALLIATIVE SCIENCE (TIPS) – ACTIVITY

### Clinical Services

The clinical services, medicines and disposables provided from Pallium India through Trivandrum Institute of palliative Sciences are free for all patients. More the 90% of our patient population belong to poor socioeconomic background.

- a. 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 go out each day for patient visits and they operate through the link centres which include rural and urban areas of Trivandrum district. With support from local enthusiasts, we provide palliative care services at 14 link centres, covering more than 30 panchayats (local self-government institution at the village).
  
- b. 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.
  
- c. Outpatient Clinic:** Outpatient services is being provided at Arumana Hospital on all days, Trivandrum Medical College on all days except Sunday,



Sree Avittom Tirunal Hospital(Trivandrum) , General Hospital (Trivandrum),  
CHC Vizhinjam, CHC Poovar, Arumana Hospital and at link centres.

- d. 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.
  
- e. Emergency services** are provided on a case to case basis and as per the recommendation of our palliative care physician.
  
- f. 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.
  
- g. Information center:** The primary objective of the Information Centre is to provide all possible information related to palliative care and about establishments where such facilities are available in India.



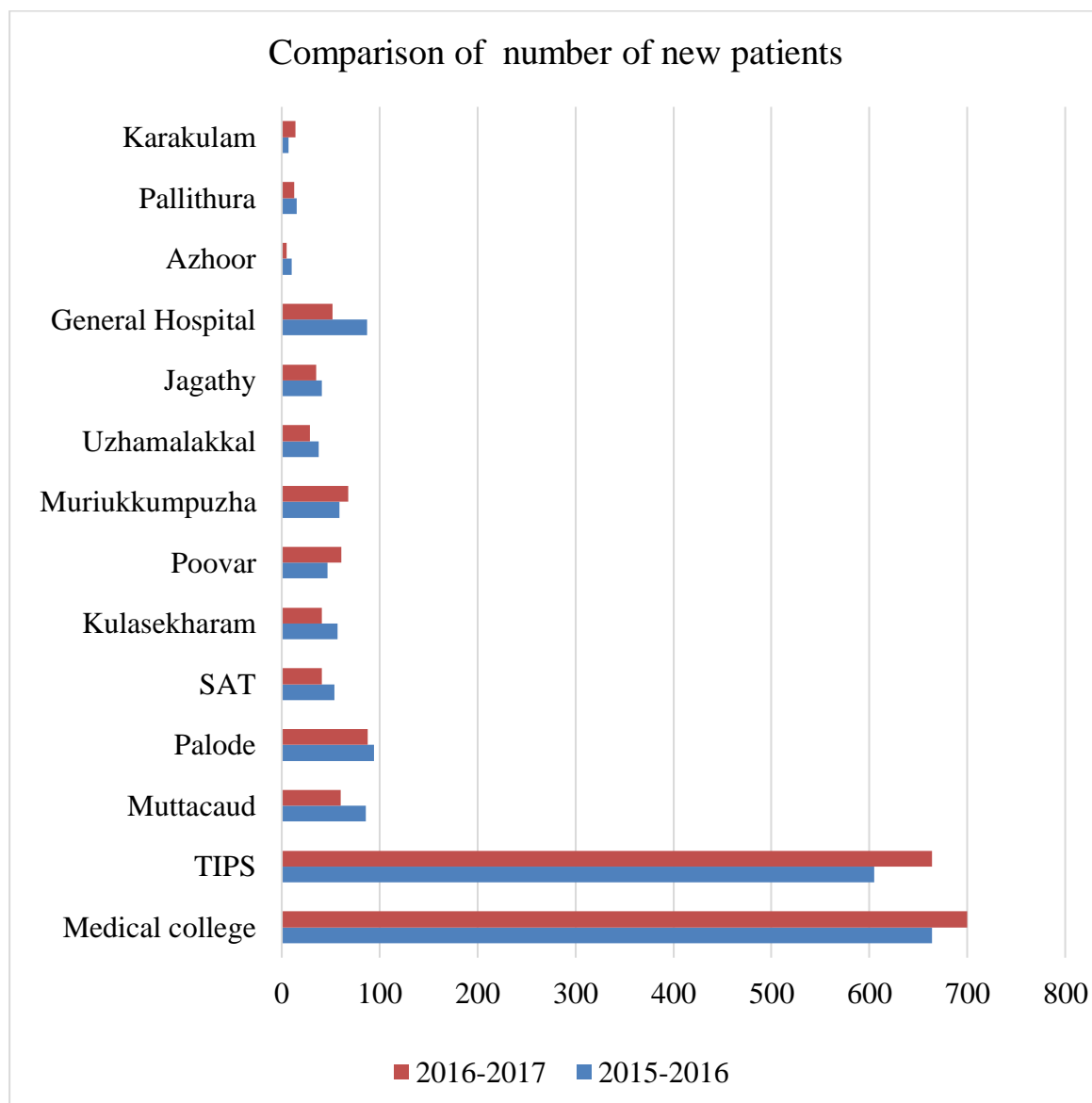
In 2016-2017, Pallium India provided care to 1871 new patient and families (table: 1)

**Table1: Number of new patients seen by Pallium India during 2016-2017**

<b>Financial Year</b>	<b>2016-17</b>
<b>Link Centres</b>	<b>No of new cases</b>
Medical College	700
TIPS	664
Muttacaud	60
Palode	88
SAT	41
Kulasekharam	41
Poovar	61
Murukumpuzha	68
Uzhamalakkal	29
Karakulam	14
Jagathy	35
General Hospital	52
Azhoor	5
Pallithura	13
<b>Grand Total</b>	<b>1871</b>



**Graph 2: Comparison of new patients seen by Pallium India during the years 2015-2016 and 2016-2017**



**XI. 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 psychosocial-spiritual concerns of the patient and the family. We provide the following services in this regard.





- a. **Bereavement Support Group** is made available to the families who need psychological support to address and work through their grief following the death of the patients.
- b. **Physical rehabilitation** particularly for the patients who are paralyzed including provision for devices like wheel chairs and walking aids.
- c. **Vocational rehabilitation** for the patient and/or the family where they are encouraged on creative activities which also provide an income.
- d. **Food kits** are being provided to those patients and families who are extremely poor.
- e. **Educational Support for children** who would have been forced to drop out of school as a consequence of the illness and poverty. This is continued till the student finishes his/her education.
- f. **Support group for children receiving educational support** endeavors to develop their self - confidence, aptitude and skills.

## **XII. Specialist care services**

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



- b. Physiotherapy-** It is provided to patients suffering from varying degrees of paralysis because of accidents, stroke or many other neurological problems, and cancer with the objective to improve their quality of life.
- c. Lymphedema care and Colostomy care-** Not only we do provide lymphedema care and colostomy care to those patients in need, we also train their caregiver in its management.

**Table 2: Details about the clinical and non-clinical services rendered**

<b>Clinical Services</b>		
	<b>Patient Care</b>	<b>No. of beneficiaries</b>
1	Number of new patients	1871
2	Number of patient contacts	12580
3	No. of patients admitted in Adult Rehab centre	22
<b>Psychosocial Care and Rehabilitation</b>		
	<b>Programs</b>	<b>No. of beneficiaries</b>
1	Food kit	54 families
2	Physical aid	177 patients
3	Vocational training and rehabilitation	13 families
4	Education And Mentoring Program	280 children
5	“Kuttikkoottam” Summer Camp	48 children
6	Unarv- Support group for bereaved families	74 family members
<b>Information Centre Statistics</b>		
1	No of enquiries attended	918 441- via phone 477- e-mail



### **XIII. Education, Training and Capacity Building (Table 3)**

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

#### **a. Trivandrum Institute of Palliative Sciences (TIPS):**

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.

In addition to TIPS, Certificate Course in Pain and Palliative care is carried out by other three centres including,

#### **b. Awareness Campaign and Volunteer 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 in Trivandrum, this has resulted in a tremendous increase in the number of participants attended. This has also helped us in forming the student's initiative in palliative care in schools.



**c. Child Health and Family International (CFHI):**

Pallium India in alliance with Child Family Health International is running a cultural immersion program since 2012 the program is for a period of 4 weeks and this year, we had 4 students from around the world for the program.

**d. University of IOWA, USA:**

Pallium India in alliance with University of IOWA, USA is running a cultural immersion program. The program is for a period of 4 weeks, which includes class room sessions, home care, clinical services etc. This year we had 15 students from IOWA University along with two faculties.

**Table 3: Details about the training programme**

<b>Training Programs</b>	<b>No. of participants</b>	<b>No. of programs</b>
Foundation Course in Pain & Palliative Medicine (FCPPM)	13	5
Certificate Course in Pain & Palliative Medicine (CCPPM)	30	5
Certificate Course in Palliative Nursing (CCPN)	36	5
Certificate Course in Palliative Care (CCPC)	9	3
Three days workshop for homeopathic doctors	32	2
Volunteer Training Program	85	6
Awareness Program	9000	78
Observation visit of nurses	75	3
University of IOWA cultural immersion program	15	1



### **Awards and Recognitions:**

Dr. M R Rajagopal – Chairman, Pallium India and Director, Trivandrum Institute of Palliative Sciences received the following awards and recognitions:

- Dr. M. R. Rajagopal received “Human Excellency award” from Sathya sai trust, Bangalore.
- First TNG Award for human Excellency was awarded to Dr. M R Rajagopal by Asianet News

Pallium India / TIPS received the following recognitions during this year:

- Pallium India got NGO accreditation from Social Justice Department, Government of Kerala. Only 12 NGO in Kerala received the government accreditation.
- 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).

### **XIV. Major events organized.**

- Conducted a food festival to raise funds for patient care with the help of our well wishers and volunteers. The entire food product which was sold there was prepared by volunteers and well wishers at their home and was successful.
- Organised an art exhibition in connection with barrier free Trivandrum project at saphalyam complex, Palayam, Trivandrum. It was inaugurated by Shri.K.T.Jaleel, minister for local administration.
- Organised a major fund raising event “Musical Night” at cochin in connection with World Palliative Care day celebrations. Famous music director Mr.Jayachandran and his team of play back singers performed the musical night at free of cost.



## **XV. New Initiatives**

- **Extension for community Health Outcomes (ECHO):** It is an educational programme which mainly aims to democratize medical knowledge and get best practice care to underserved people all over the world. It connect a multidisciplinary team of experts located at the hub.
- **Lymphedema training programme:** Lymphedema is a common consequence of breast cancer. Post treatment lymphedema continues to be a significant problem following breast cancer therapy. There is a huge need to educate lymphedema care (skin care, massaging, bandaging and exercise) to patients, family members, care givers and community and to ensure active participation in patient care and follow up. Pallium India started training programmes in ten identified panchayats for community volunteers, ASHA workers, panchayat nurses and medical officers. The next phase of the project will be done in collaboration with health department and local self-government.



## FUNDING SOURCES

The funding of Pallium India comes from a variety of sources but is primarily based on philanthropic donations.

- Unsolicited donations from families of patients who have been treated by TIPS
- Regular donations by several doctors of Kerala origin working in Western countries or in the Gulf countries.
- The organisation's fleet of eight vehicles that are used for home visits and other patient care, have all come from nationalized banks
- Donations/ Grants received via projects in 2016-17
  - ✓ Tata Trust – Improving access to pain relief and palliative care in India
  - ✓ Savitry Waney Foundation Trust – Lymphedema & Physiotherapy Project
  - ✓ Jiv Daya Foundation (JDF) – Capacity building project in cancer and supportive care
  - ✓ Pallium India incorporated (inc.)- Advocacy for scaling of palliative care and implemented NDPS act.
  - ✓ Department of Social Justice,  
Government of Kerala - “Half way home” for paraplegic patients
  - ✓ Indo American Cancer Association – Scholarship for palliative care training programs for doctors and nurses.
  - ✓ CanKidsKidsCan - Support on Advocacy work at North and North East.
  - ✓ Bank of India- Donated a home care vehicle valuing 4.5L



## PALLIUM INDIA

CARE BEYOND CURE

### PAIN FREE HOSPITALS

- CCHRC, Silchar, Assam
- SGCCRC, Kolkata, West Bengal

### PALLIATIVE CARE CENTERS (ONGOING PROJECTS)

- MPMC, Jamnagar, Gujarat
- RBH, Jaipur, Rajasthan
- RCC, Agartala, Tripura
- SVMCH & RC, Puducherry
- NKPSIMS, Nagpur, Maharashtra
- SGRRIMHS, Dehradun, Uttarakhand
- Dr. SNMC, Jodhpur, Rajasthan
- Synod Hospital, Aizawl, Mizoram
- Dr. RPGMC, Tanda, Himachal Pradesh
- PMC, Anand, Gujarat
- JNMC, Wardha, Maharashtra
- GCH, Indore, Madhya Pradesh
- SSGH, Vadodara, Gujarat
- TIPS, Trivandrum, Kerala
- SKHMC, Kulashekharan, Tamilnadu

### PALLIATIVE CARE CENTERS (COMPLETED PROJECTS)

- KGMU, Lucknow, Uttar Pradesh
- RCC, Aizawl, Mizoram
- RIMS, Imphal, Manipur
- SGPGI, Lucknow, Uttar Pradesh
- MTMH, Jamshedpur, Jharkhand
- TCO, Kavarati, Lakshadweep
- IGIMS, Patna, Bihar
- NEIGRIHMS, Shillong, Meghalaya

### PALLIATIVE CARE TRAINING CENTERS

- TIPS Kerala (WHO Collaborating Centre)
- MNJIO (RCC) Hyderabad, Telangana
- GCRI (RCC) Ahmedabad, Gujarat
- BMCC, Jaipur, Rajasthan



### ADVOCACY

1. International
2. National
3. State

### PAIN PREVALENCE STUDY

1. CNCI (RCC) Kolkata, West Bengal
2. AHRCC (RCC) Cuttack, Odisha
3. MNJIO (RCC) Hyderabad, Telangana
4. GCRI (RCC) Ahmedabad, Gujarat

### INFORMATION CENTRE

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