There's no place Like home!

PALCARE

There's no place like home

ANNUAL REPORT 2019-20

THE JIMMY S BILIMORIA FOUNDATION

Our Vision

We aspire to provide palliative care to those suffering from life-limiting and serious medical conditions, particularly cancer patients, so that they may live a pain-free, symptom-free, comfortable and peaceful life, in the familiarity of their own homes, surrounded by loved ones.

Our Mission

To deliver an exceptionally high quality, all-encompassing, home-based palliative care service for patients with serious, life-limiting conditions delivered by a well-trained, accomplished, compassionate and interdisciplinary medical team comprising doctors, nurses, psychologists, social workers and other professionals who also provide full support to caregivers and loved ones in order that the patient may live in dignity till the very end.

Our Ethos

Our values originate in the belief that honesty and trust are the corner stones of living a life of integrity, and that every individual, irrespective of income, gender, religion, caste or creed, has the right to have a dignified existence – not only in health but in sickness as well.

Our Inspiration

The Jimmy S Bilimoria Foundation has been inspired by the gentleman of the same name, who passed away in May 2013 after a prolonged battle with cancer. While Jimmy fought the good fight in a spirited way, it became obvious to him and his family that patients like him were in dire need of palliative care and preferably at home.

The Bilimoria family came to realise that often when patients run out of curative options, treating doctors will ask them to go home and continue as best they can, because there is nothing more they can clinically provide. But patients with serious and life-limiting conditions, such as advance stage cancer patients, have a gamut of symptoms to deal with, including pain and emotional distress. Such patients normally like to spend their last months in the comfort of their own homes surrounded by family and friends - not being tied down to tubes and hospital beds. And above all they would like to die in dignity.

And that is when the Bilimoria family decided to launch a charitable organisation to help such patients.

Our mentors

Board of Trustees


DEEPAK PAREKH


ISHAAT HUSSAIN


RUSTOM B. MEHTA


PHEROZA BILIMORIA


RISHAAD BILIMORIA


LEILA BILIMORIA

Medical Advisory Board


Dr. MARY ANN MUCKADEN


MS. HARMALA GUPTA


Dr. R. AKHILESWARAN


DR. NAVEEN SALINS

Clinical Consultative Committee


Dr. R. AKHILESWARAN


DR. JENIFER JEBA


Dr. SEEMA RAO


MS. ANN SAVIO THELLY

About PALCARE

When **PALCARE** began its operations on 1 December 2015, palliative care was almost unheard of. People would raise their eyebrows and say "What is that?" But today, as we reach our 1300th patient enrolment, we are happy to know that palliative care is now much more widely understood and appreciated for the benefits it brings to patients with life-limiting conditions. In fact, as one of the first private, home-based palliative care services in the city of Mumbai, PALCARE led the way for other organisations to follow.

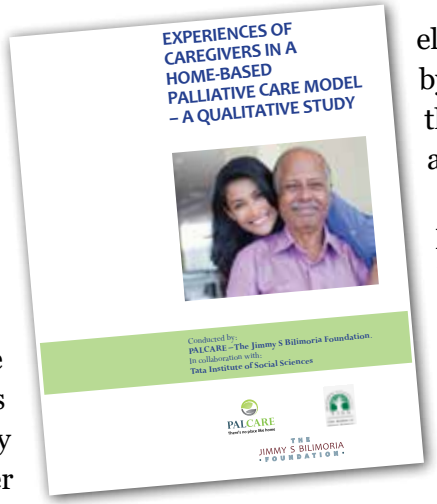
PALCARE now has 4 interdisciplinary teams and they cover practically all of the Mumbai Metropolitan Region (MMR), which is spread over 4,355 sq. km, from Colaba at the southern tip of the island city to Vasai, Thane, Kalyan and Navi Mumbai. Each team comprises one doctor, two nurses, one counsellor. They are supported by a social worker and back end support staff. The teams visit their patients weekly, fortnightly or monthly, depending on the patient's condition being categorized as high, medium or low priority. Each team member plays his/her role in harmony with the rest of the team.

The doctor will assess the physical condition of the patient and prepare the medical plan. The nurse will follow up with the plan and ensure it is being complied with by patient and family. He/she will also take care of nursing issues, diligently teaching the main caregiver how to manage the patient in-between PALCARE's visits. The psychologist is a key element of the service. H/she looks after the patient's emotional and psychosocial needs, both for the patient and family members as well, as the trauma that patients and families go through at this point in time is immeasurable.

COMPASSION
is a key element in palliative care - compassion sends a signal to patients that they do indeed matter and are not just a registration number on a chart.

The year that was

Enrollments: The Financial Year 2019-20 was a very satisfying one at many levels. It was in August 2019 that PALCARE reached a new milestone when it enrolled its 1000th patient. By 31 March 2020, the number of patient enrollments stood at 1262 and at any given point of time, PALCARE's 4 clinical teams served anywhere between 120 to 130 patients concurrently. More than sheer numbers, what is important is that the patients and families are extremely happy with the service – one family member recently called PALCARE a "God-send". Others call the service "exceptional" , "beyond words", "I don't know how we would have managed without you".



New Projects: Happily, two of the organisation's ambitious projects were completed in the period of this Report. These were (1) The Caregiver Study in collaboration with the Tata Institute of Social Sciences (TISS) in July 2019 and (2) The launch of 39 thoroughly researched and elaborately discussed guidelines developed by a committee of palliative care experts for the use of the team – so that the service is of a uniformly high standard across the board.

Hospital Associations: When PALCARE began operations, 90% of its patients were referred by Tata Memorial Hospital. Today as the number of patients have exponentially increased, the percentage of patients from Tata Memorial has dropped to 45% as many other oncologists, leading physicians and other hospitals refer their patients to PALCARE. An encouraging development during this period was productive discussions with two leading hospitals - Jaslok Hospital and Research Centre and the P. D. Hinduja National Hospital & Medical Research Centre- both of which have large and highly respected oncology departments. Both meetings saw a genuine desire by the specialists to use PALCARE's services for their stage 3 and stage 4 cancer patients.

Advocacy and Promoting PALCARE: Members of the PALCARE team participated as speakers, panellists and faculty members at several conferences and seminars.

18-19th May 2019 - Pheroza Bilimoria and Head Nurse Dirk Dlima were panellists on the Tata Memorial organised Continuing Medical Education (CME) on End of Life & Hospice Care.

24th June 2019 - PALCARE participated in an ***Awareness programme on Palliative Care*** in Ghatkopar for the volunteers of the NGO, Sahyog Mumbai and the local community. Sahyog is an NGO which is "committed to a community-based model of social change, responsive to the expressed and felt needs of women and children".

6th June 2018 - Pheroza Bilimoria addressed about 50 to 75 members of the Bombay Gymkhana in their library explaining what palliative care is all about and how PALCARE functions.

28 February to 1 March 2020 - Each year, Tata Memorial Hospital organizes a conference on Evidence Based Management of Cancers in India. For the first time since inception of this conference, the **XVIII EBM Conference**, included a module on **Palliative Medicine**. Our Founder Trustee Mrs. Pheroza Bilimoria was invited to be on the National Faculty for the Palliative Medicine track and co-Chair the session on Early Palliative Care.

In January 2020, PALCARE participated for the first time in the **Tata Mumbai Marathon (TMM) 2020**. PALCARE was fortunate to come across some willing runners who were supporters of PALCARE. Apart from the required minimum donation for the bibs, these marathoners enthusiastically agreed to be individual fund-raisers and raise further funds. In addition, five PALCARE staff jumped on board to participate in the Dream Run, Half Marathon and Open 10 K.

The year that was

Staff Training Sessions: PALCARE has always placed the greatest of emphasis on professional development. We believe that the organisation is only as good as the people who deliver the care. So they must constantly upgrade their skills and enhance their knowledge. Staff attended the following programmes in FY 2019-20:

External Programmes:

April - Oct 2019: ***Palliative Care Always*** - an online course for Indian professionals by Stanford University, Palo Alto, California, USA attended by 1 doctor

May 2019 : ***Re-exploring Spirituality in Palliative Care***- Tata Memorial Hospital Mumbai attended by 2 doctors, 1 nurse, 1 psychologist, 1 social worker and 1 medical coordinator

August 2019: ***Palliative Care Training for Social Workers and Volunteers*** – a 2-week training programme at Tata Memorial Hospital Mumbai attended by 1 psychologist and 1 social worker

August 2019: ***One-year National Fellowship Programme in Palliative Medicine*** - organised by Institute of Palliative Medicine (IPM) in Kozhikode enroled by 2 Senior PALCARE doctors

Sept-Oct 20019: ***Six-Week Intensive Diploma Course in Palliative Care*** - Tata Memorial Hospital Mumbai attended by 2 doctors and 2 nurses

November 2019: ***Advanced Therapeutics Course for Palliative Medicine*** - Bangalore Hospice Trust attended by 1 doctor

January 2020: ***Communications Workshop*** - Centre for Advancement of Philosophy attended by 1 social worker and 1 medical coordinator

February 2020: ***Shadows and Light (Gestalt Therapy Workshop)*** - Classic Club Andheri West attended by 2 psychologists and 1 social worker

February 2020: ***World Palliative Care Congress IAPCON 2020*** - "Entrust, Engage, Empower" Guwahati - Indian Association of Palliative Care, attended by 2 doctors and 1 social worker

February 2020: ***Social workers and counsellors working in palliative care settings (children and adult)*** - Cipla Foundation, Mumbai, attended by 2 psychologists

February 2020: ***Let's talk - Conversations with families of children with serious illnesses*** - BJ Wadia Hospital for Children, attended by 2 doctors and 1 psychologist

Feb-March 2020: ***XVIII Annual Conference on Evidence-Based Management of Cancer in India*** - attended by 4 doctors

Internal Workshops:

There was a total of 15 Internal training programmes during the year and 3 Guest Lectures. The internal programmes were conducted by PALCARE's Head of Clinical Services, Head Psychologist, Head Nurse and Senior Nurse on subjects such as symptom assessment, managing lymphoedema, bladder care, enteral feeding, breathlessness; and on the psycho-social side, depression, spiritual issues, breaking bad news and conversations with families on serious illnesses.

During the lockdown period, some of these workshops were conducted through ZOOM.

The year that was

The guest lectures were conducted by (1) ***Dr. R Akhileswaran***, Palliative Care expert, Singapore, on ***Terminal Delirium & Signs of a Dying Patient and (2) Dr. Roop Gursahani***, Senior Neurologist and ***Dr. Jayarajan***, Palliative Care specialist at the ***Hinduja Hospital***, ***Mumbai*** on basic care in cases of Motor Neuron Disease.

Challenges: This is not to say there weren't any challenges in this period. May 2019 was a difficult month as our two senior doctors had personal commitments and had to go on leave. In August - September 2019, the heavy rains disrupted home visits. Also, in September 2019, two nurses were on leave for a few days during the Ganapati festival and one counsellor was away for a family emergency. In the months of October, November and December 2019, a number of nurses fell ill and had to call in sick.

These events sometimes led to the teams having to re-organize the day's visits on relatively short notice. Moreover, burnout is a challenge as the team faces misery and death, day in and day out. PALCARE attempts to address this with regular relaxation therapies.

In February 2020, there was a spate of conferences and so doctors and nurses had to cut down on home visits while on these conferences. But PALCARE lays great importance on learning and expanding its staff's knowledge, so that they keep abreast of the latest ideas and approaches in palliation – so essential to provide a cutting-edge service. And hence encourages the team to participate in worthwhile conferences and seminars.

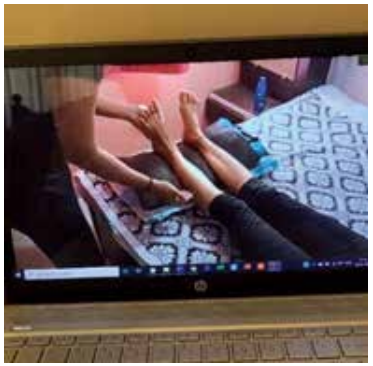
COVID-19 and Telemedicine: Of course, the greatest challenge came in March 2020 when WHO declared COVID-19 as a pandemic. At the local level, the Government of Maharashtra passed a Work-From-Home (WFH)

directive on 17th March 2020 and on 25th March 2020, the Government of India followed with a total lockdown across the nation. This posed challenges not only in terms of looking after patients, but equally protecting PALCARE's own staff – keeping them safe from possible contraction of the virus.

During the short Work-From-Home period, PALCARE's front line team of doctors, nurses and psychologists carried out home visits to all High Priority patients, maintaining all the necessary protocols to keep safe. All other patients were managed by phone visits and video calls.

However, from 25th March, even High Priority patients were treated over the phone. Fortunately, telemedicine is working well. Often the doctor, nurse or counsellor will talk on facetime with the patient or caregiver or both. At other times, the caregiver will take a video to show the team what the patient's condition is, thereby allowing the doctor to hear the patient's breathing or show the extent of a swollen leg, a bloated tummy, a pressure sore, etc. Many a times, the nurse will explain, step by step, to the caregiver how to handle the issue on hand. Sometimes, a video of the procedure is pre-recorded by the nurse in her own home - using a family member as the mock patient - and then the video is sent across by WhatsApp; and the nurse checks how well the caregiver has understood the procedure. Often the nurse will be at the other end of the phone while a family member facetimes the procedure being carried out by the caregiver, often telling him/her how to proceed.

An advantage of tele-medicine is that since travel time is saved, our teams can make many more calls a day than they can with physical visits. Sometimes they speak with the patient or caregiver twice or more a day, multiple times a week, if the situation warrants this. And, since weekends have lost their significance in a lockdown, if a patient needs help on a Saturday or Sunday, calls are made on those days as well. On occasion, the help of a nearby GP has been sought (as GPs until very recently were also staying at home, hence this was not always an option). Very occasionally, patients have had to visit the closest hospital and our team has had to coordinate with the hospital doctors.

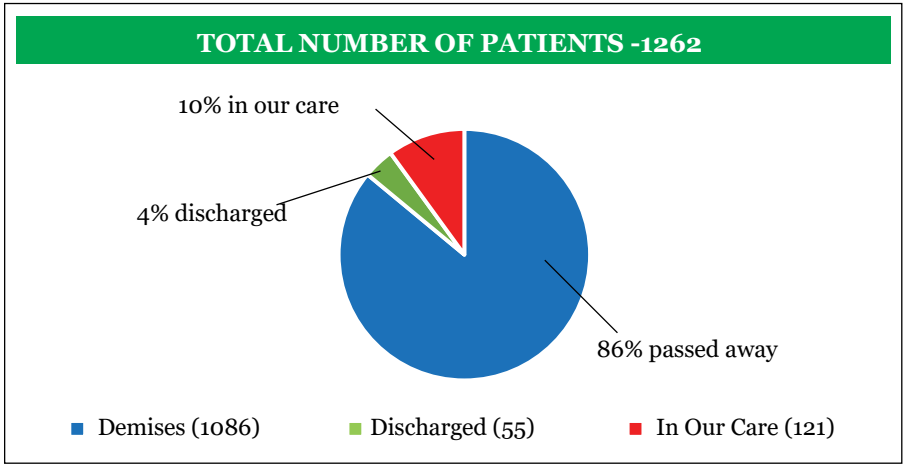


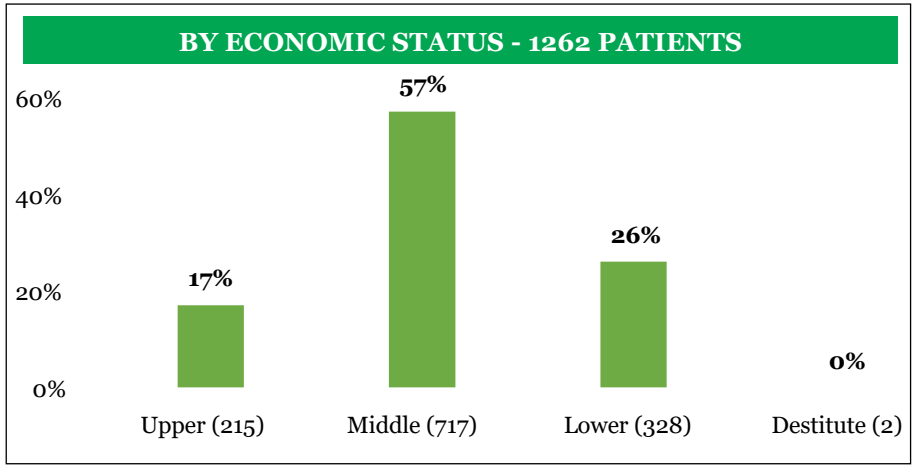
Our Raison D'etre: OUR PATIENTS

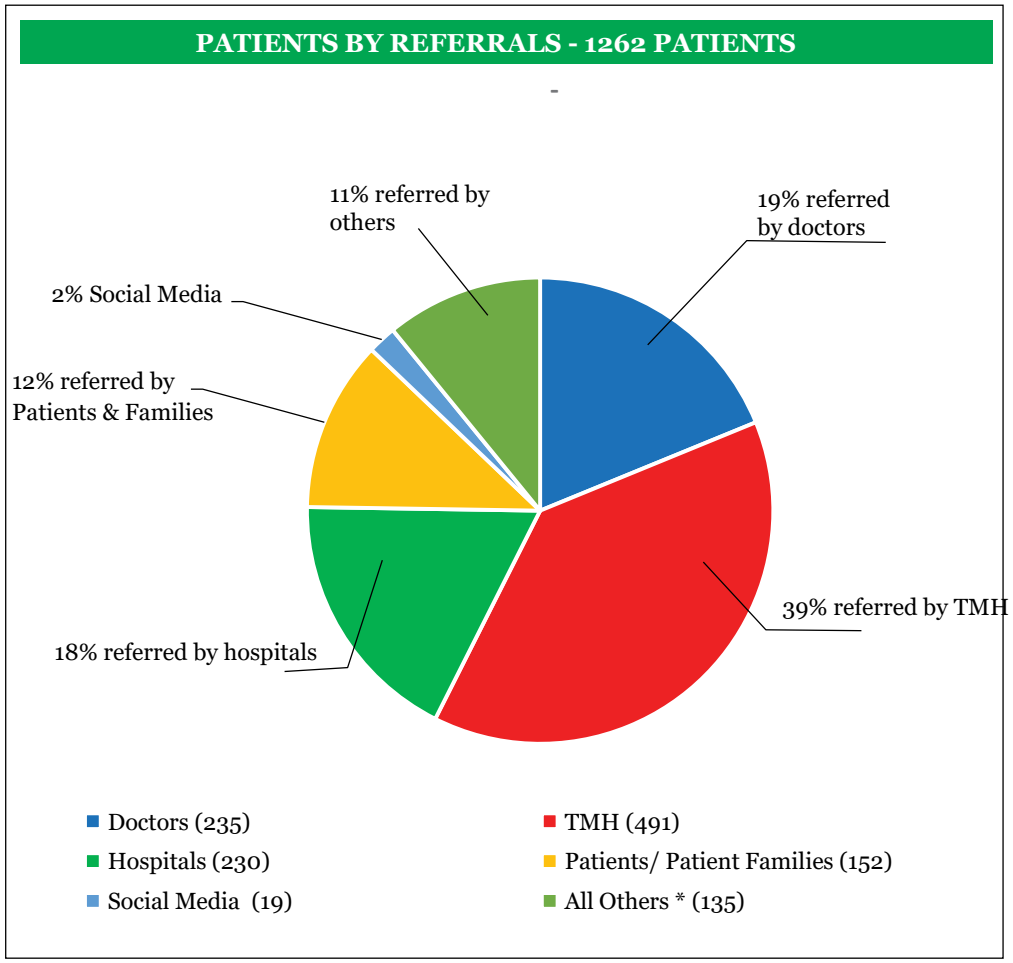
Because every person deserves a dignified end

Patient Data

Details of patients since inception – 01 December 2015 to 31 March 2020







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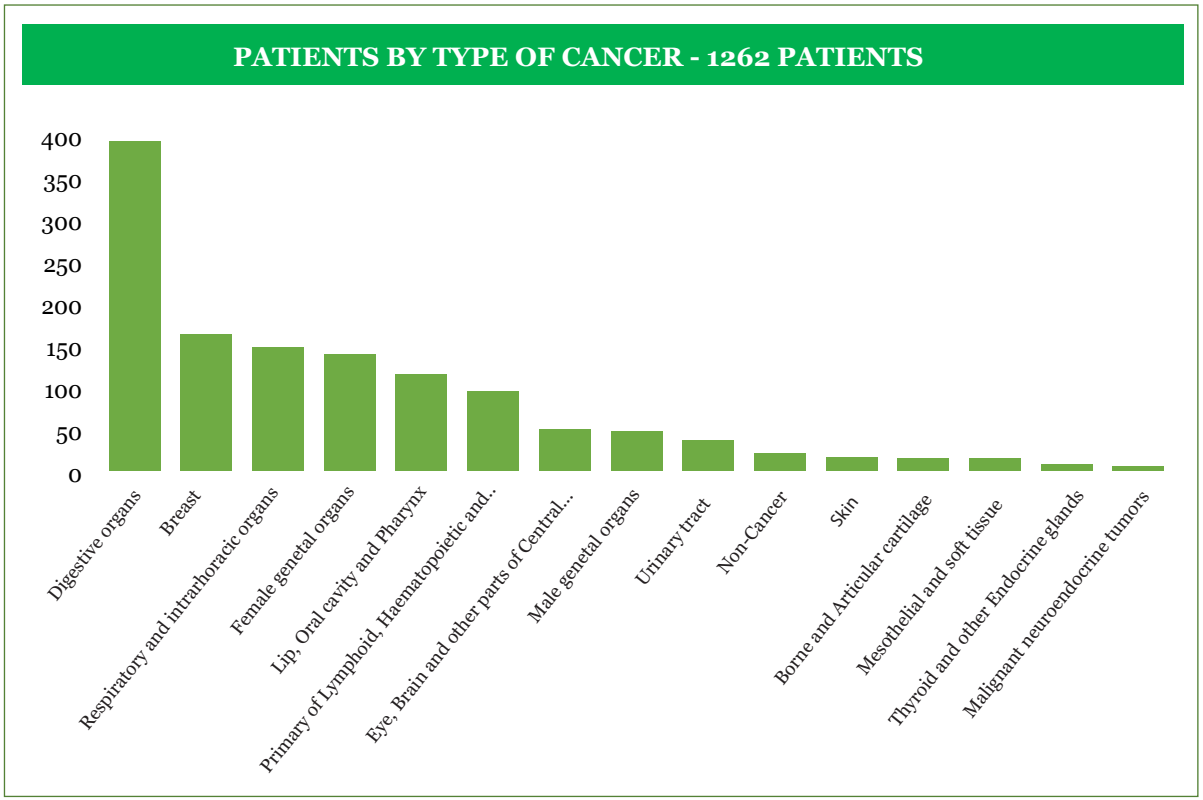

NO. OF DAYS WITH PALCARE	
1 - 7 Days	16%
8 - 14 days	11%
15 - 1 month	22%
1 - 2 months	19%
2 - 3 months	9%
3 - 6 months	13%
6 - 9 months	5%
9 - 12 months	2%
12 - 18 months	3%
18 months Plus	1%

Don't the count days.
Make the days count.

Our Visits			
	2017-18	2018-19	2019-20
# of patients 	293	463	517
Number of Home teams 	3	3.5	4
Number of Home visits 	2,574	3,754	4,513
Average visits per patient 	8.8	8.1	8.7

Our service is 100% free because our patients cannot afford to pay and many have been financially wiped out with curative treatments. Most of those who can afford to pay, make a donation

Our Expenses			
	2017-18	2018-19	2019-20
Salaries - Medical Team	87,89,921	1,08,04,401	1,05,00,899
Salaries - Administration and Accounts	20,86,222	23,46,000	29,56,241
Provision for Gratuity	2,33,742	1,26,181	2,18,967
Total Salaries	1,11,09,885	1,32,76,582	1,36,76,107
% of total costs	75%	75%	77%
Total Capital Costs	3,45,221	8,56,052	5,14,078
% of total costs	2%	5%	3%
Total Program Cost	10,73,587	12,88,006	13,38,391
% of total costs	7%	7%	7%
Total Admin Cost	23,41,502	22,57,055	23,33,371
% of total costs	16%	13%	13%
Grand Total Costs	**1,48,70,316**	**1,76,77,695**	**1,78,61,947**

How People die
remains in the
memory of those
who line on

Dame Cicely Saunders,
(1918 - 2005), founder of the modern hospice movement

PALCARE

There's no place like home

THE JIMMY S BILIMORIA FOUNDATION

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Email: contact.palcareindia@gmail.com | Website: www.palcareindia.com

Registered under the Maharashtra Public Trust Act 1950—registration no: E - 31101 dated 30.03.2015

Income Tax Registration U/s 12-AA - Registration no: 47760 dated 13.10.2015

Income Tax Exemption U/s 80 G (50% tax exemption to donor) – Registration no: CIT(E)/80G/1192/2015-16 dated 18.12.2015

Permanent Account Number: AACTT 5523 F

Bank: HDFC Bank

HDFC Bank Ltd. Manekji Wadia Bldg, Ground Floor, Fort, Mumbai – 400001

Bank Account No.: 50100147954161 (savings) | IFSC Code: HDFC0000060