



GOLDEN BUTTERFLIES
CHILDREN'S PALLIATIVE CARE FOUNDATION

Regd No. 18/2018

On Golden Wings *Annual Report* *April 2018 – March 2019*



6, Ashwin Flats, Prof. Subramanian Street, Kilpauk, Chennai - 600 010



Contents



Managing Trustee's remarks	03
Messages by well-wishers	05
Our Journey	09
Launch of Services	11
Affiliations & Memoranda of Understanding	13
Our Beneficiaries	14
Capacity Building	15
Creating Compassionate Communities	16
Audited Financials for FY 2018-19	17
Sneak Peek into GB Bandwagon's Regular Activities	19
Donation Options	25

Message from the Managing Trustee

Stella Matthew

Managing Trustee

Dear Well Wishers & Stake holders,

“Alone we can do so little, together we can do so much” - Helen Keller

Within this **Annual Report** you will find the story of our Foundation with a humble beginning, great expectations and some of the most heartwarming pictures that will speak for itself, of our objectives. It is my privilege to present the **1st Annual Report 2019-2020 of our Foundation.**

Golden Butterflies Children's Palliative Care Foundation's Mission is to provide counselling, medical aid, palliative care and financial assistance to families of underprivileged children suffering from any Chronic, Advanced or Incurable diseases, in Chennai city and its surrounding districts of Tamilnadu.

I thank the Trustees for reposing in me their confidence by nominating me as the Managing Trustee. I promise the Trustees in particular that I would carry out my responsibilities as the leader of the foundation with the highest degree of integrity, commitment and diligence.

I am humbled and honored to work alongside this group of hard working & devoted Trustees. **Hemal, Lavanya, Aneka & Nandhini** are thoughtful & successful professionals who bring both competence and character to the deliberative process, to advance the **GOLDEN BUTTERFLIES VISION**. Their unique insights and perspectives strengthen our Trust's growth.

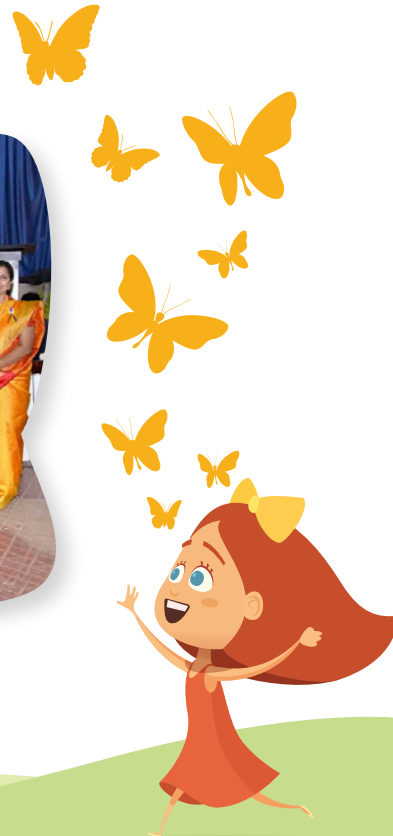
We have an extremely dedicated team of Medical Advisors in **Dr. Julius Scott, Dr. Rejiv, Dr. Rajkumar, Dr. Kathiresan & Dr. Aarthi** who guide, mentor and counsel us continuously to bring out the best in us. This helps us to be focused in our cause towards Palliative Care.

We have an exceptional, determined and energetic team of **GB - WINGS** (Volunteers). Their leadership and management skills help us take our projects forward in an equally impressive way. Their willingness to step up and meet the ever-demanding requirements without batting an eyelid makes our continuous projects - **GB Bandwagon, Counselling and Capacity Building** move forward confidently. **Golden Butterflies** provides them a platform to evolve and grow as an Individual.

Finally, without the support of our Stake Holders we would not have been able to reach this toddler stage. Their continued hand holding will help us to start taking our first steps and move forward to help more children and their families lead a life with less **PAIN & SUFFERING!!**

To make a difference in someone's life, you don't have to be brilliant, rich, beautiful or perfect. You just have to CARE - Mandy Hale

Team Golden Butterflies



Messages by well-wishers

The genuine support given by Golden Butterflies and their team for serving the children suffering from chronic incurable disease like cancer is commendable. That's what made me choose Golden Butterflies. Very happy and satisfied that the money is going for a good cause. Their innocence and being unaware of what is going to happen next. Makes me realise that in this world of suffering there are angels to help the sick children

With regards

Dr. Gowri Swarna

President 2019-20

IWCM Esplanade



Golden Butterflies an organisation devoting time to take care of little children with their illness has a special place in my heart. It is such a gratifying feeling when I hear from the members about their visits and work they do to help the innocent children to feel happy. Helping GB has left me with a sense of well-being. God Bless every member who is a part of this noble cause.

- Mythili Shankar



16 Hour Palliative Training



Abhirami: A Cancer Survivor





Cherian Foundation



I came to know about Golden Butterflies from a friend. Being at WINGS has exposed me to a lot of new experiences and has made me a better person. Children need love more than anything and especially when they are sick they need more love. It has helped me to be a better person and has improved my personality.



- Aruna Srinivasan

Being a WING (Volunteer)

I believe the best form of devotion is lending a helping hand and being there for the people that need us and recently I have been fortunate enough to do this.

It was on a Tuesday that I met Stella mam from Golden Butterflies at RMD pain and Palliative Care. I was introduced to Golden Butterflies and about what they did and this intrigued me. Being a Genetic counseling student I too was looking for an organization that did non-profit activities for the betterment of mankind that I could Volunteer with. As I shared my interests and passions about my life with mam, she told me about the counseling that is being carried out by "The WINGS" from Golden Butterflies at Kanchi Kamakoti Child Trust Hospital for children affected with cancer. I immediately said a yes and went for my first counseling the very next Tuesday. That day changed my life and I realized that this was something that made me happy. Being next to children and talking to them might just be a mere volunteer work for us but it makes the world of difference for the children. The fact that there is someone out there, looking out for them and to support and listen to what they have to say makes their stay at a hospital a little more bearable. Being heard is all that they want and I have been lucky enough to be able to do it. The smile on their face when they receive a toy, the smiles on their parent's face when they see their child happy is all that you want at the end of the day. We might not be able to help them with the treatment but we sure can help them forget about the disease at least for a fraction of a second and that is great.

I cannot put into words the sheer joy that falls upon me to have met Stella mam and become a part of Golden Butterflies. I look forward for working with The WINGS in the future as well.

-Sreelakshmi Pradeep



Our Journey

The Trust Deed for Golden Butterflies Children's Palliative Care Foundation was signed on February 8, 2018, and registered with the Sub-Registrar's Office, Chennai. Subsequently, the 12AA and 80G certificates were received on 19-06-2018 and 16-08-2018 respectively.

The Trustees and Volunteers (WINGS) took care to prepare ourselves for the task that lay ahead by participating in several training programs and capacity building workshops, organized by reputed institutions. A week-long training workshop from 25th to 29th September 2018 at Lakshmi Pain and Palliative Care Trust exposed the group to the nuances of caring for palliative care patients, taught by the eminent and compassionate faculty. This was followed up with a day-long Master class on soft skills, organized by M.O.H.A.N Foundation on 27th October 2018. To properly understand the challenges of child-patients, the group attended a CME (Continuing Medical Education) program on Paediatric Palliative Care, organized by Department of Paediatrics, Mahatma Gandhi Medical College and Research Institute on 10th November 2018, at Puducherry. We also attended a Workshop on Palliative Care for Volunteers, organized by Ark Hospital on November 17, 2018 at Chennai.



Christmas Cheer



On the WINGS of the Butterfly

By: Christine McClimans

Counselling & GB Capacity Building

Your friendship is special,
Like the flowers that bloom,
Or when a butterfly emerges
From within its Cocoon....

You remind me of that butterfly,
Loving and free,
Bright and colourful,
For the world to see....

We shall share
Sunshine and rainbows;
Sometimes, the rain
And the snow;
We'll stand together through it,
While the cold winds blow...

When the time is right,
We won't stop to ask "why?"
Our friendship will take flight
On the wings of a butterfly...



Launch of Services

In honour of the child-patients we strive to care for, Golden Butterflies officially launched its services on the evening of Children's Day, 14th November 2018. Our stated aim is to provide access to palliative care and counselling to children suffering from advanced, irreversible, incurable diseases like cancer, HIV/AIDS, end stage organ failure, etc, while also focusing on the well-being of the family as a whole.

The function, held at Parmadevi Goyal Auditorium of Anna Adarsh College for Women, Anna Nagar, Chennai, was attended by approximately 200 well-wishers. Senior doctors from the field of cancer care and palliative care were also in attendance to give their blessings.

The Guest of Honour, Dr. Mallika Tiruvadanan, Managing Trustee, Lakshmi Pain and Palliative Care Trust, Chennai, highlighted the need for palliative care alongside curative treatments right from the point of diagnosis, thereby busting the myth that palliative care is limited to end of life. She also released the first video on Golden Butterflies, prepared by Wanderers Media Works, Chennai.



Our Special Advisor, Prof. Dr. Julius Scott, Head, Department of Paediatric Oncology, Sri Ramachandra Medical Centre, Chennai, gave an insight on the lack of knowledge about palliative care in the undergraduate and post-graduate medical curriculum, based on his own experiences.

Ms. Rohini, Actress and Social Activist, as well as Golden Butterflies Ambassador, spoke about the need to extend palliative care to child patients with various ailments, and pledged her full support to the cause. A souvenir titled “On Golden Wings” – an eclectic collection of original articles about children’s palliative care – was released by Ms. Rohini at the event.

During the launch, Golden Butterflies announced its partnerships with Y.R. Gaitonde Centre for AIDS Research and Education (YRG CARE), Sri Ramachandra Medical Centre, Integrated Cancer Care Group and Lakshmi Pain and Palliative Care Trust in Chennai, for referral of underprivileged, terminally-ill children and their families, requiring counselling and financial support. Financial donations were made to the first three child beneficiaries of Golden Butterflies, and the programme ended with a performance of Holistic Music by Sound Wellness Gong Bath.



Affiliations & Memoranda of Understanding

“If you want to go fast, go alone. If you want to go far, go together.” —African Proverb

We at Golden Butterflies know that we need to join hands with several like-minded institutions and organizations in order to take forward our vision of helping terminally-ill children and their families. Accordingly, we are affiliated to the International Children's Palliative Care Network and the Tamil Nadu Palliative Care Society. Further, all trustees are individual members of the Indian Association of Palliative Care.

To further our work in Chennai city, Golden Butterflies signed Memoranda of Understanding with the following:

1. Y. R. Gaitonde Centre for AIDS Research and Education (YRG CARE) – signed on 8th November 2018. Golden Butterflies provides financial support to 2-4 HIV+ child-patients per annum for medication and routine tests, referrals to paediatric centres or hospices as required, and counselling of HIV+ child-patients and their parents at review camps. Golden Butterflies undertook a 1-day training at Y. R. G. CARE on 17-09-18, for Camp Rainbow
2. Sri Ramachandra Medical Centre – signed on 21st November 2018. Golden Butterflies provides counselling of child-patients and their family/caregivers, provision of finances for medications and tests, conduct of awareness programs, and workshops for training in counselling. Counsellors are available once a month, from 9:30am to 12:30pm, in Paediatric Oncology ward.
3. Kanchi Kamakoti Childs Trust Hospital – signed on 27th February 2019. Golden Butterflies provides counselling of child-patients and their family/caregivers twice a week at the hospital and as required at their homes, provision of finances for medications and tests, art and play therapy group activities for child-patients, conduct of awareness programs and workshops for training in counselling. Room No. 126 at KKCTH is allocated for 'Golden Butterflies' counsellors from 4pm to 6pm every Tuesday and Thursday. Rounds of the Paediatric Oncology ward on the 6th floor of the hospital are also done.

The trustees of Golden Butterflies participated in the Indian Association of Palliative Care's IAPCON 2019 at Kochi, Kerala from 8th to 10th February 2019. We took the opportunity to introduce our work to the larger palliative care community by screening a short video about one of our beneficiaries, titled **"Indomitable Spirit – Golden Girl: Heroes of Children's Palliative Care"**.

Our Beneficiaries

All aboard the Golden Butterflies Bandwagon!!

– A fun-filled endeavour to engage child-patients in Art and Play Therapy, in groups.

Golden Butterflies teamed up with the Ark Society of India, a Home for destitute HIV+ children, to spread a bit of Christmas cheer on 15th December 2018.

We bid farewell to 2018 and welcomed the New Year 2019 by distributing gifts to children in the paediatric oncology ward of SRMC & KKTCH on 31st December 2018.

The child-patients at Kanchi Kamakoti Childs Trust Hospital and their parents joined us to celebrate Pongal in traditional style on 12th January 2019.

We also extended support to individual patients in the form of finances for medication and routine tests, monthly groceries for impoverished families, hygiene products, and/or art and play therapy articles. These included:

1. Ongoing support to 3 child-patients suffering from rheumatoid arthritis (12y), paraplegia following spinal surgery for tumour excision (13y), and mixed leukaemia (7y).
2. Past support to 2 (deceased) child-patients suffering from Primitive Neuro Ectodermal Tumor - PNET (18y), and Rosai Dorfman disease (16y).



Capacity Building

Golden Butterflies aims to equip students and practitioners of medicine, nursing and social work with the essential skills of palliative care and counselling, in order to make their work with child-patients more effective. Our first venture, a Workshop on “Capacity Building in Palliative Care and Bereavement Counselling”, was held on 2 February 2019. About 60 participants including students of Masters in Social Work (MSW), doctors and nurses from various departments of SRMC, and representatives of organisations dealing with cancer care from Madurai and Coimbatore attended. Eminent faculty included Prof. Dr. Julius Scott, Head, Department of Paediatric Oncology, SRMC; Dr. Mallika Tiruvadanam, Founder & Managing Trustee, Lakshmi Pain and Palliative Care Trust; and Dr. Subathra Muthukumaran, Trustee, Lakshmi Pain and Palliative Care Trust. The need to understand what palliative care is, and the special communication skills required to handle children was the focus of the workshop. A caregiver also shared her personal experiences on what was expected of volunteers and counsellors.



Creating Compassionate Communities

WINGS:

The most prominent feature of a butterfly are its colourful wings – so also are the volunteers to support us, and take Golden Butterflies to newer heights. After the first ‘WINGS’ meeting on 1st September 2018, introducing our enthusiastic volunteer group to our cause, the committed lot got busy in participating in various training programs to enhance their competencies in paediatric palliative care. Subsequent meetings focused on “Volunteerism” and “Training in Art and Creative Therapy”. Needless to add, systematic trainings have successively professionalized our approach to counselling.

Strengthening our ties:

Trustees and Wings alike, used networks to spread the message to more people in the surrounding community. Awareness Generation programs were conducted at Rotary Club of Madras Esplanade (dist 3230) and Inner Wheel Club of Madras Esplanade (dist. 323). The Dandiya function organized by GujRaj Cultural Committee, was a platform to inform the public about paediatric palliative care as well as raise funds for the fledgling organization.

Golden Butterflies participated in an online poster campaign on the occasion of International Childhood Cancer Day on 15th February 2019. We also partnered with like-minded NGO CanKids in their walkathon, on 17th March 2019.

Audited Financials for FY 2018-19

GOLDEN BUTTERFLIES CHILDREN'S PALLIATIVE CARE FOUNDATION
No.2, III Floor, Manchester Court, 21 Club Road,
Chetpet, Chennai- 600031

INCOME & EXPENDITURE ACCOUNT FOR THE YEAR ENDED MARCH 31,2019

INCOME

Donation Received	475251
Capacity building workshop	29600
FD Interest	279
	<u>505130</u>

EXPENDITURE

Project expenses	150303
Event Expenses	154450
Rent	20750
Office expenses	23659
Patient Expenses	85850
Printing & Stationery	18110
Advertisement Expenses	10170
Travel expenses	11450
Training Expenses	27840
Repairs and Maintenance	1440
Depreciation	14205
Bank Charges	775

519002

Excess of Application

13872

For Golden Butterflies

Trustee



As per books of accounts produced
and Information furnished herewith
For S.K.MURTHY & ASSOCIATES
Chartered Accountants

VIGNES.D

Partner

M.No. 236804



GOLDEN BUTTERFLIES CHILDREN'S PALLIATIVE CARE FOUNDATION

**No.2, III Floor, Manchester Court, 21 Club Road,
Chetpet, Chennai- 600031**

BALANCE SHEET AS AT MARCH 31,2019

₹

SOURCES OF FUNDS

PERMANENT FUND :

Corpus Fund		596001
General Fund		
Opening Balance	Nil	
Add: Excess of Application	-13872	-13872
		<u>582130</u>

APPLICATION OF FUNDS

Fixed assets	67756
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CURRENT ASSETS

Advances & Deposits	400000
Cash at Bank	114374
	<u>582130</u>

For Golden Butterflies

Stella
Trustee



As per books of accounts produced
and Information furnished herewith
For S.K.MURTHY & ASSOCIATES
Chartered Accountants

[Signature]
VIGNES.D
Partner
M.No. 236804



Sneak peek into GB Bandwagon's regular activities

Counselling:

1. Individual and Group counselling at KKCTH twice a week, including rounds of the Paediatric Oncology ward.
2. Individual counselling at the Paediatric Oncology ward of SRMC once a month.

Butterflies Bandwagon – Art and Play Therapy in Groups:

1. At KKCTH on the first Saturday of every month.
2. At SRMC on the second Wednesday of every month.

– feel free to join us!!!





Love to Live & Live to Love

Being in the hospital service sector for more than 2 decades as a patient relation officer in various administrative departments, I joined GB as a WING to continue my service to the sick even after my retirement from my office.



I have seen the value of this precious life and how people struggle to retrieve that life when they fall critically ill..

Being in GB Children's palliative care as a Wing, I have to support not only the sick child but also their whole family. My experience can provide support to a sick child and the family mentally as well as physically.

I can support the health care team to provide optimum best quality of life to every child with a life limiting condition and their family.

I have improved my listening skills, understanding and accepting others feelings regarding their anxiety and fear over their life. I have improved a strong comfort level with people approaching death.

Children, are real worriers. We adults surrender to failures very easily but children, they fight back till their last breath is taken.

As an individual, I have now more respect and love for one's life and I am more strong in my vision "Love to Live & Live to Love "

Thank you GB for taking me as a part of this family, believing in me and given me a chance to love our fellow beings....

- Lata Babu



I take joy doing your Will God, for your instructions are written on my heart'

I joined Golden Butterflies to be a flyer.

Being WINGS makes me feel Very Responsible and caring in a daring way.

The best part I cherish, when being with the Sick Children are, when they give me a SMILE with a SHY, and when their eyes go wide on receiving toys from GB. Gives me an entirely new meaning to my life.

Joining GB has made me a person with a Vision to fulfill a Mission for a Worthy Cause.

- Sunitha Solomon



Hi I'm Jyothi,

I had not much of idea about palliative care, when one my friend from Robinhood army told me about Golden Butterflies I just join

I feel great of being a part of Golden Butterflies. It have me wings to fly and kiss little cute flowers

I love to interact with the kids, so innocent unaware of their battle with life.

The Bandwagon activities brings smile on the kids faces. Now a days they are awaiting for Bandwagon

Palliative care is another way of serving humanity. Thanks to Golden Butterflies for giving me an opportunity to attend seminars and learn more and more also a platform to serve practically

I thank Golden Butterflies from the bottom of my heart.



I always believed we can make difference in people's life who are emotionally /physically down by lending our hand & supporting them. Personally I had strong emotional support from people around me made me to fight negative turmoil inside me as care giver, in turn helped my mother (she was patient) to be positive, recover. I joined GB, believing my small contribution can make difference.

Met like minded people through wings. Feeling great working with them. Looking forward to meet lot more members.

Kids even when they are going through so much pain physically, when you spend time with them they are happy. We can see Smile & excitement in them

Personally given me opportunity to learn & develop my skill through like minded people Who are working for cause. I can feel difference in myself more positive, calmer & stress, anxiety has reduced.



Thank you,

Jeevitha



I was over whelmed when I joined "Golden Butterflies" as a volunteer since that gave me the opportunity to enhance my skills as a counselor and story teller, through various sessions and seminars under the guidance of experts in the respective fields!!It was an eye opener for me in Palliative Care!!I enjoy the sessions with children during story telling ,crafts and other activities as well!!I feel blessed to be a part of these "GoldenWings"!



Chandini Sampath

It directly supports the beneficiaries and hence feeling satisfied to work for it.

Proud to say a WING, because I have enough freedom to implement my thoughts and work as a WING, Times are flexible so whenever I find freetime can give my time and do my service.



Feeling satisfied when I see the smile on their face and pray god to keep it permanent on their faces

Grateful for the knowledge and skills that I have gained working for this, its a blessing for me.

With Love

Lakshmi

Donation Options:

- Transportation to Homes / Hospital for counseling per day = **Rs. 1,000/-**
- Counseling Workshop = **Rs. 5,000/-**
- Training camps for Volunteers = **Rs. 5,000/-**
- One Child's Medications / Supplements per month = **Rs. 5,000/-**
- Celebrate Birthdays / Anniversary with our Children's = **Rs. 5,000/- – Rs. 10,000/-**
- One child's Palliative Chemo / Radiation = **Rs. 25,000/- – 50,000/-**
- Donate Toys or Play Items in Good Condition
- Contribute to GBCPC Foundation's Corpus Fund – ANY AMOUNT

Bank Account Details:

Name : **Golden Butterflies**

Bank Name : **Indian Bank**

A/c No. : **6678025465**

Branch : **Chetpet**

IFSC Code : **IDIB000C017**

Join **WINGS** – Volunteer with us at events to spread awareness about Palliative Care and its availability.

Contact Us:

Golden Butterflies

6, Ashwin Flats, Prof. Subramanian Street,
Kilpauk (Ground Floor), Chennai – 600 010

Website: **www.gbpcpfoundation.org**

E-mail: **letschat@gbpcpfoundation.org**

Mobile: **0091-8754448845**

IAPCON Conference



MoU SRMC



New Year



DISCLAIMER: All photographs of paediatric patients in this Annual Report are used with the assent of the child and consent of his/her parent/guardian.

