

Link : [www.palliativecare.in/iapc-newsletter-july-2021](http://www.palliativecare.in/iapc-newsletter-july-2021)

## Stories from our COVID Heroes!

### Holistic care at Home:

Golden Butterflies' efforts to help child-patients and families cope during COVID-19  
– Aneka Paul, Stella Matthew, Ramalakshmi V. Chennai



The novel coronavirus (SARS CoV-2) spread worldwide, lakhs of people succumbed to COVID-19 (COroNa Virus Disease), and healthcare systems across the globe crumbled under the patient load. Chronically ill or terminally ill child-patients tend to most often slip under the radar of care in most developing countries, even during the best of times. Golden Butterflies Children's Palliative Care Foundation (GB) was therefore determined to provide the extra and much needed care and focus to our cohort of child-patients, whose compromised immune systems made them more vulnerable to the virus.

**GB Hear For You:** Post imposition of the nationwide lockdown, GB was quick to switch to telephonic counselling. We assigned each of our counsellors and trained volunteers with a limited number of child-patients and their families to be in regular contact with. We witnessed a spike in both the number and duration of calls. Caregivers were either in need of material help or information, or wished to express their emotions.

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**Material Support:** GB stretched itself to provide financial support to child-patients towards their medical treatment like chemotherapy, immunotherapy, surgery, scans, assistive devices, etc. We procured donations for smart phones and internet connection so that our child-patients could attend online classes uninterrupted.

**GB Nutri-Bowl:** Families of many of our child-patients, being daily-wage earners or from out-of-city/state, could not go out to work during the lockdown, and consequently could not afford living expenses. Child-patients' growing bodies require additional nutrients to cope with the medications, as the absence of basic nutrition and hygiene threatens the safety of the already immuno-compromised child. We provided nutritional support in the form of monthly groceries and hygiene kits to impoverished child-patients and their families.

**GB Shuttle:** The strict lockdown's made access to scheduled treatment difficult for our child-patients, as transportation options to get there (in absence of public transport) were also scarce and expensive. We provided the families of our child-patients' with transportation costs to and from their treating hospital, to avoid delays which could potentially cause the cancer cells to regrow and advance making the disease incurable and render further treatment ineffective or worse endanger their lives.

**GB Magic Envelope:** We missed the opportunity to conduct the 'GB Bandwagon' – our hospital-based group art and recreation sessions, where kids walk in, participate and enjoy themselves till it's time for their consultation. Instead, we started 'GB Magic Envelope' – an edu-tainment kit couriered every month to a small group of child-patients. This A4-size treasure includes a theme-based craft activity (along with all the required raw materials and color pictorial instruction sheet), coloring sheets, and a tiny gift. This Magic Envelope kept our child-patients creatively engaged and even enhanced sibling bonding.

**GB Caregivers Connect:** Our intense counseling sessions with parents/ caregivers of our child-patients revealed the depth of support they too required to be able to cope healthily. Once the state imposed restrictions eased, our 'Caregivers Connect' program was born. 'Caregivers Connect' adhered to all the public health safety guidelines and created a safe space for caregivers dealing with children with a chronic/incurable illness or bereaved families, to grieve, de-stress, relate with others, and receive appropriate information and support from GB.

**Bereavement Support:** Families (particularly siblings) were supported and guided to rebuild their lives after the child-patient had passed on.

**About Us:** Aneka Paul is a Trustee, Stella Matthew is the Managing Trustee and Ramalakshmi V is the Project Manager at Golden Butterflies Children's Palliative Care Foundation. GB is a not-for-profit, public charitable trust registered in February 2018 in Chennai, dedicated to serving the needs of underprivileged children suffering from chronic, advanced or incurable diseases, and their families. Please visit [www.goldenbutterflies.in](http://www.goldenbutterflies.in) to know more about us.

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## Cancer Survivors Day, 6 June, 2021



June 6, is commemorated globally as the Cancer Survivors day. It is a day dedicated exclusively to raise awareness about cancer, to celebrate those who have survived, and to inspire those who have been recently diagnosed by providing the needed support to the affected families and their communities.

We celebrate this day by bringing to you two very motivating and inspiring reads. The first story, '**One step at time: The story of a Cancer Survivor**' features how the timely support from an organization assisted Sarita and her family to maneuver the challenging path that lay ahead of them. The second article '**A story of Resilience**' is a story that is straight from the heart, in which Mr. Param shares his personal story of survival and his victory against his battle with cancer.

### One step at a time: The story of a cancer survivor

– Ramalakshmi V, Stella Matthew, Aneka Paul. Chennai

Sarita (name changed) is a very smart and young girl, who lives with her mother and older sister. Her mother became the sole breadwinner of the family after she was deserted by her husband. One fine day Sarita noticed rashes on her skin. Her mother decided to take her to a doctor and get her treated for the same. During their visit to the hospital they learnt of a free health check camp that was being organized at the hospital the very same day. Sarita and her mother registered themselves for the general health check up. The report which followed proved to be a nightmare as it frightened her whole family. A lump was detected in Sarita's ovary. She was immediately hospitalized for further investigations and was finally diagnosed with ovarian cancer at the age of 12.



Sarita standing proud with a crown of flowers adorning her thick re-growing hair

The first few weeks of hospitalization were a blur painted with fear and confusion for the family. Young Sarita began to lose her hair as the treatment progressed. Her pain now needed to be managed with medication. Her mother and sister were given diagnostic and therapeutic counseling by the counselors at Golden Butterflies Children's Palliative Care Foundation (GB). These sessions helped her mother to gather courage and gain confidence to continue supporting Sarita in any way that she needed during the course of her therapy. As unfortunate as it may be, Sarita and her family had to wade through and fend for themselves during these turbulent times, as their extended family offered no support.

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The loss of hair and changes in her body image dented Sarita's self esteem to such an extent that she began isolating herself and avoided interacting and socializing with people. The GB Counselor involved Sarita in Cognitive Behavioral Therapy, to reinforce positive thoughts, challenge unfounded beliefs that she had conjured up about herself and to guide her towards developing a healthier body image. The GB counsellor also engaged Sarita in Art therapy to minimize the negative impact of the illness and hospitalization that had eclipsed her. Gradually, Sarita began to express her emotions and got actively involved in her art and play activities.

The early detection of cancer allowed Sarita to receive timely and appropriate treatment: surgery, chemotherapy and radiation. Sarita's resilience manifested in her being free of cancer for the past year, and now at the age of 14, enjoys the prospect of a full and exciting life ahead of her. Sarita is also elated that her thick, black curly hair is growing back day by day. Bearing witness to Sarita's emotional turmoil when she lost her hair, motivated Sarita's mother to donate her own hair to make wigs for other cancer patients.



A Magic Envelope art activity completed by Sarita

The nation wide lockdown's imposed due to the COVID 19 pandemic restricted Sarita's mother's earning capacity and therefore added another layer of challenges for Sarita's mother to maneuver. GB extended support to the family by providing monthly groceries, hygiene kits, arranging for and covering their transportation from their home to the hospital and back.

Despite the limitations that the pandemic created for us, we continued to uplift her spirits and assured her mother that Sarita would continue to smile. We understand that her face lit up each month when she received the 'GB Magic Envelope' that was couriered to 'her name'. The edu-tainment kit or the A4 sized treasure that she received was aimed to engage her creatively as it consisted of a theme-based craft activity (along with all the required raw materials and color pictorial instruction sheet), colouring sheets, and a tiny gift.

**About the authors:** Ramalakshmi V is the Project Manager, Stella Matthew is the Managing Trustee and Aneka Paul is a Trustee at Golden Butterflies Children's Palliative Care Foundation. GB is a not-for-profit, public charitable trust registered in February 2018 in Chennai, dedicated to serving the needs of underprivileged children suffering from chronic, advanced or incurable diseases, and their families. Please visit [www.goldenbutterflies.in](http://www.goldenbutterflies.in) to know more about us.