

# EXTENDING A HAND

PHILANTHROPY AT RGCIRC



Extending  
A Hand





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**Contact:**  
CEO, RGCIRC; Email: [ceo@rgcirc.org](mailto:ceo@rgcirc.org)

Head, Department of Philanthropic Services;  
Email: [philanthropy@rgcirc.org](mailto:philanthropy@rgcirc.org)

Telephone: 011 47022619  
Website: [www.rgcirc.org](http://www.rgcirc.org)

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**Text and interviews:** Bhavana Pankaj  
**Photographs:** Vivek Sharma  
**Design and Production:** Designations

#### OUR VISION

To provide affordable oncological care of international standards and help to eliminate cancer from India through research, education, prevention and patient care.

#### OUR MISSION

To be the premier cancer care provider in India and the preferred choice of patients, caregivers, faculty and students.

#### OUR VALUES

We hold our patients in high esteem and stand for ethical practices and compassion.

We care and function in mutual respect, trust and transparency.

We deliver accurate diagnosis, correct advice and effective treatment.

*This publication attempts to recapitulate the humanitarian work that is being done by RGCIRC as part of its vision to extend oncological care to all those who need it, regardless of their resources. While this work has been going on uninterruptedly for nearly a quarter of a century, we now seek the benevolence of friends, partners and patrons to take it forward.*

**RAJIV GANDHI CANCER INSTITUTE AND RESEARCH CENTRE**



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# OVERVIEW

Nearly 10 million people die globally of cancer every year. The disease kills every sixth man on the planet. In India it takes more than 1300 people every day, adding more than a million new cases to world numbers annually. More people are falling prey to a riddle called cancer as populations across the world grow and age.

But someone has very aptly said that every riddle has one perfect answer: for life, it is love.

It is this sentiment that inspired the inception of the Rajiv Gandhi Cancer Institute and Research Centre (RGCIRC) in 1996 as the first of its kind multispecialty cancer facility in North India. Two and a half decades later, the vision of our founders continues to guide us in our endeavour to provide comprehensive, affordable care rooted in ethics, empathy and excellence.

We have the unique advantage of putting cutting-edge technology in the service of our patients through the hands of some of the best oncologists in the domain. The problem is: at cancer turnstiles, many a prince has become pauper. The affluent can ill-afford the emperor of all maladies, the poor even less. In India, the average cost of cancer treatment is about five to six lakh rupees, including radiation and surgical interventions. A patient advised radiation may be down by more than a couple of lakhs in a matter of few weeks. A bone marrow transplant or a few cycles of targeted chemotherapy alone may run into several lakhs. Given that it is a tiny fraction of our population that can even afford and has medical insurance, a large percentage of healthcare expenses is met with personal funds. Treating cancer is more than a heart-breaking story: it is a bank-breaking one.

Even if the break is inevitable, we, at RGCIRC, have been trying to minimise the cracks, and the pain.

Statistics are soulless. But they too have a story to tell. In fact, many stories if only we care to listen with our heart: story of a Kamala Devi who was found positive for cervical cancer at one of our community camps, or a 16-year-old son of lower middle income family Tushar who came to us with blood cancer, little money and about a month to live, or little Prateek, son of a small farmer and teacher mother, who came from Haryana with T-lymphoma. There are many such stories: of people in flesh and blood, of names that eventually become numbers, and remote. Some stories end happily, some others unfortunately not.



Whatever the end, our founders had pledged to bring these numbers closer home and to not give up before giving our best fight to the disease. So each time we read our vision statement, we read into that pledge “no patient is denied treatment because of lack of funds.” But for this, of the thousands who come to RGCIRC every year, there is a large number that is probably denied treatment elsewhere.

The point of having the twin advantage of talent and technology is to take the two beyond the confines of the hospital to those who will find it nearly impossible to access a cancer facility. Oncology centres are rarely interested in devoting resources to prevent a projected tragedy for obvious reasons. But at RGCIRC, the definition of profit goes beyond the financial. We see prevention as a critical part of cure. We have adopted 50 clusters in the community so we can screen around 90 lakh people in the next five years. But with current teams, we have been able to reach only one-tenth of the screen-worthy population in three years. With populations growing, there is much work to be done to translate this vision into reality. And that needs man and money.

We are a not-for-profit society, without any aid except that which comes from a shared feeling. Last year, we ploughed back 10 crore rupees towards supporting patients in-house through free beds – something we have done since the founding of RGCIRC; welfare schemes, discounts, special OPDs, preventive and palliative services, including matching contributions to those made by some individuals and partner organisations.

It is a drop in the ocean, we know. But we also know that if we dive deep, we are bound to find more drops that carry whole oceans within them. Cancer, unsparing in its incidence and potency, transcends boundaries and distinctions of social segments, economy, race, caste and gender. That, and the grief of loss unites us all. It tells us we may be different but not separate.

It is this unity we call upon in our mission to raise a corpus fund of 100 crore rupees in the next five to ten years to restore hope and dignity to the underserved sections of our people.

The fund will be divided broadly over childhood cancers, cancers of the blood and general cancers. As part of this initiative, our endeavour is also to add to direct patient treatment – through research. Our world-class bio-repository, a not-for-profit activity, offers a resource to in-house investigators and to those from across the world to work towards understanding cancer and keep pace with its march so that prevention, and better, lesser expensive treatments may be made available to patients.

Cancer can be a lonely country, often with quarantined citizens. Goodwill, the willingness to give, and to invest in a better world – where profits transcend accruals of money into social responsibility – is the way to reach them. As RGCIRC commits to bringing the benefits of innovation to all its patients, it has begun knocking at hearts so people may have a chance to live outside of themselves, and live truly.



*Everything that exists is in a manner the seed of that which will be.*

– Marcus Aurelius

PHILANTHROPY AT RGCIRC:

# AN OCEAN IN THE DROP

“I had only 50 thousand rupees in my account and 24 hours when I brought Tushar here,” mother Kiran breaks down as she relives the agonising last few months when she was on the verge of losing her 16-year-old son.

Tushar had been diagnosed with Acute Lymphoblastic Leukemia (ALL) at a government hospital in Delhi. Premier government institutes in the city either did not have a bed or the necessary expertise to treat the disease. The parents had been warned that their child needed immediate treatment failing which his condition could go from bad to worse. The mother, who runs a small beauty parlour in a lower-middle income Delhi locality, and father, an auto-rickshaw driver, had by this time already spent about a lakh of rupees on investigations and treatment.

“Tushar was very sick when he came to us,” says Dr Dinesh Bhurani, Director, Haemato-Oncology and Bone Marrow Transplant. “It was not feasible to start with chemotherapy then. He had fever and a lot of infection. The parents had virtually no money. We had to take care of both.”

As if cancer isn’t overwhelming enough, lack of money to treat it may be devastating. In the absence of insurance or ready resources, a family is often driven to sell an heirloom or scour its meagre savings. Tushar’s parents had little victuals for a journey that would last three years and possible complications on the road to their son’s recovery.



“Dr Narendra Agrawal, Tushar’s treating doctor and one of Dr Bhurani’s associates, recommended his case to the hospital,” says Swarnima Jaitley, Head, Department of Philanthropic Services, “and the child was given a free bed. Barring medicines and consumables, this included free-of-cost facilities such as doctors’ consultation and visits, conventional surgery and associated charges and several free or largely discounted lab and radiology investigations.”

Tushar was in the hospital for about a month. He got the free bed facility for 20 days during which he was started on antibiotics and chemo in small doses. Tushar still had a long way to go. But the weary family got a breather, and some shade under which to rest before moving on.



### Genesis

“The very seeds of our hospital are sowed in philanthropy,” says Chairman Rakesh Chopra. “It comes from the vision of a man – KK Mehta – and some others like him who wanted to reach out to the needy and to those who had to go to Bombay for treatment. Whether it was the land, the building that came up on it, the equipment to get it started – all of it came from institutional benefactors and thousands of ordinary people. Whatever we are doing now is partly a repayment of our debt to our founders and partly from our DNA to not only treat to charge, but, most importantly, to take care of the needy.”

Mr Mehta had no money. There were loans, salaries and heavy debts to be repaid. But starting day one of RGCIRC in 1996, five of every 100 patients were to be treated free, the home care programme was to be free of cost and concessions were the order of the day. The general OPD was highly subsidized with a 5 rupee

card on Tuesday and Friday every week for people who couldn’t afford to pay for opinions and consultations.

“Do not ever turn away empty-handed anyone who comes to you for help, was the one-line policy laid out by Mr and Mrs Mehta,” remembers Dr AK Dewan; Director, Surgical Oncology and former Medical Director of RGCIRC. “He never had a standard for who was poor and who wasn’t. Doctors would recommend to him cases and barring the occasional time, I do not remember him saying no. All of us embraced these unwritten rules then. Two and half decades later, we continue to largely maintain this tradition even today.”

### Beyond the Mandate

A tradition must move and flow with the times to stay alive and healthy. The Department of Philanthropic Services was formally established in 2019 to make some assessments as to the financial status of a patient. Unlike in the past





where a patient's letter stating he was jobless or had only a little *rehri* was enough, the department has some norms that must be fulfilled and documents such as the BPL card, an affidavit or other similar documents presented, that meet some standards of 'need'.

That said, RGCIRC has in these years strived towards an aesthetic to perform some important rituals – not

of magnanimity, but basic humanity – with as much dignity as possible. "Time is of the essence in cancer: there is the physical disease and also, mental trauma. If our surgeon, for instance, recommends immediate surgery to an early stage patient of head and neck cancer, we cannot wait for the PM or CM Relief Fund that takes four to six weeks to materialise," says Jaitley. "The In-house Patient Support Scheme that we started in 2014 provides immediate relief. The patient gets registered with us today – and the surgery happens tomorrow."

This and other similar schemes provide for aid up to 5 lakh rupees, including several free of cost tests, bedside procedures, free bed and no doctor's charge. It could be a businessman like Moradabad's Musharraf Ali who had to transition from a private room to the general ward within a year and received the much needed help with chemotherapy expenses post a colon cancer surgery. Or 28-year-old Chandan Saha with germ-cell tumour who was given a free bed facility and a lakh of rupees for chemo drugs from an NGO partner, the Ramakrishna Seva Sansthan – the hospital has held true to its vision of not denying treatment to a patient for lack of funds. Or young Sonu, grandson of a small farmer from Pataudi, Haryana, whose osteo-sarcoma needed both surgery and chemotherapy for which they may have had to sell their couple of acres but for the equal contribution of five lakh rupees made by both the Indian Cancer Society and RGCIRC.

In fact, the hospital has gone far beyond the mandate of its founders of providing free beds to at least five patients a month. Any one registered with the hospital and under treatment for 3-4 months is eligible. There are exceptions like Tushar, or Saha where the rule is bent. If a patient needs support mid-way through the treatment, it is procedurally difficult to ask a partner like the Indian





Cancer Society for help. So, the facility is extended three to four times during the course of treatment, for five days each time, consecutively or intermittently depending on the need, to as many patients as possible. That said, each case has to be duly recommended and assessed by the treating doctor and other personnel concerned.

“We have tried to encourage a continuum of empathy in RGCIRC, starting from the top,” says CEO DS Negi. “Our vision statement says no patient will be denied treatment because of lack of funds. Our mission is to raise a corpus of Rs 100 crore for blood, paediatric and general cancers in the next five to 10 years. I do not think we can bridge the gap between the two without our donors and their trust. These and more such partnerships are of utmost value to us so that we can make some headway in this direction.”

The RGCIRC has, in the past, received for haematological and paediatric cancers as

well as research funds from individuals and institutions who have had a close brush with cancer, says Jaitley. Some of them have chosen to give anonymously to the corpus that the hospital wants to build. Apart from the in-house welfare schemes, the hospital also implements some programs in tandem with its NGO partners such as the Indian Cancer Society-Cancer Cure Fund, Shri Ramakrishna Sewa Sansthan and Yuvraj Singh Foundation and makes matching contributions towards giving its patients a fighting chance.

“It’s been some years that we first came to RGCIRC when one of the members of our Sansthan came from Tata Memorial Hospital to RGCIRC to continue treatment. We saw how expensive and difficult it is to treat cancer. The experience of our colleague with the doctors here, and the way administration works has been the reason for us to affiliate with them,” says Ramakrishna Sewa Sansthan President OP Bagla.



### Invisible Giving

Forty-year-old Mohammad Yaseen was treated at the hospital for CA Rectum a few years ago. He was a self-employed man from Saharanpur, fortunately from a joint family with strong filial ties. “At the behest of the CEO, we wrote to Shri Ramakrishna Sewa Sansthan as well as the Indian Cancer Society to seek funds for his treatment,” says Sushma Kaushal, Patient Welfare Officer with the Department of Philanthropic Services.

“The family had also applied for the PM Relief Fund which came later. But money from the Society also took a while coming. The family had pooled in all their resources to start him on treatment. When he finally got the 5 lakh from the Society, I called the elder brother who accompanied Yaseen on his trips to the hospital. He broke down and thanked me profusely: ‘Aapne mera ghar bacha liya.’ He was just about to take an advance towards the sale of his house. That’s when I truly felt the ramifications of philanthropy...”



Coming to a private trust-run hospital, patients know they would have to dip into their own resources. Many of them come to RGCIRC after being turned away from institutes like AIIMS because of the sheer waiting time of three to four months. “But there are so many in-house welfare schemes and partnership plans that the patients can benefit from. My work here for the last 11 years has been of a bridge that connects each of them to the schemes best suited to them,” says Kaushal.

Money is, perhaps, the most visible manifestation of philanthropic intent. But there are some unseen – but real – needs of a cancer patient that may be fulfilled only through fine understanding. An amputee of a post-osteosarcoma surgery could lose his willpower or go into depression. A teenager’s treatment may demand long spells of absence from school. A husband accompanying his ailing wife may need to leave behind an old parent or a young child at home. “We try and take care of the emotional and social aspects of this disease. We speak to the school so that the child doesn’t have to drop a year. Or ask the family how children or elderly parents back home are doing and if we can facilitate their getting in touch. And sometimes, just simply checking in with them and listening is all it takes.”

Sometimes even well-to-do people come here to seek a second opinion – and they may want it gratis. Given that 25-30 doctors may sit in the Tumour Board to discuss a case for 10 minutes, it amounts to 300 minutes of their time. And the





of infrastructure that houses some of the finest men and their machines. “The hospital pays for and maintains some of its state of the art equipment – robots, cath lab machines, PET CT, radiation therapy and MRI equipment, pulse oximeters... in dollars and earns in rupees,” says Dr Sudhir K Rawal, Medical Director and Chief of Uro-Oncology. “We have to keep that in mind as much as the poor man who comes to us for treatment. It just doesn’t feel right to charge that man who is already struggling with what feels like a death sentence to him. A surgeon may forfeit his fees. But the hospital charges for drugs and disposables. And the treatment doesn’t stop with surgery either. Chemo and radiation may follow. If someone could donate those expensive medicines or just adopt patients, we could treat many more BPL patients.”

RGCIRC does not charge anything extra. “I don’t know of many consultants here who would refuse a second opinion. Besides, money isn’t all. I believe we have earned a lot of goodwill and experience over these years. And there is no financial yardstick that can measure either. Unlike many of our peers, we have been protected from upheavals, grown and never looked back even once in 24 years,” reiterates Dr Dewan.

The Rajiv Gandhi Cancer Institute and Research Centre has expanded in terms



“We do this work from choice, not from any compulsion of law. We want to keep it like that. Our top priority still is treating the poor free of cost. But we have cast our net wider: even a reasonably well-to-do patient may need financial support at some point, such is the nature of this disease. While our charges allow us to have the best resources and cross-subsidise our philanthropic work, we want to augment our services in Preventive Oncology, Research and Home Care services that we offer virtually free of charge. We are stepping them up but we also need a corpus fund that will enable a lot more work in these areas,” explains Mr Chopra.

A lot more work indeed: for there is still a Tushar – now out of the woods but still plodding along the arduous path of unexpected exigencies before he recovers fully. There is also Sonu, Chandan, Musharraf Ali – and many more like them. But as a saying goes, if we can keep a green tree in our heart, perhaps a song bird will make its way to it.





PREVENTIVE OUTREACH:

# NIPPED IN THE BUD

When the Preventive Oncology team in April 2019 went to the doorstep of Kamala Devi, 42, in one of the JJ clusters adopted by the RGCIRC for a screening camp, neither, perhaps, knew Anne Frank or what her words may have meant. Having made several other checks-ups, the team simply returned with her Pap-smear sample to find that she had screened positive for CA Cervix.

It essentially meant that she had HSIL, a high-grade lesion which could have been asymptomatic or led to cervical cancer, rampant at over 16 per cent in India. It would take more sophisticated tests and, at the last, biopsy to confirm she had cancer of the cervix. The Head of Department, Gynaecology and Urology, Dr Rupinder Sekhon recommended a hysterectomy. Kamala went through the surgery which alone took care of the disease without any need for chemotherapy. The single most important reason was: the disease had been diagnosed in the very initial stages.

*Look at how a single candle can both defy and define the darkness.*

– Anne Frank



*“Agar yah camp nahin hota, to mera ilaaj nahin hota,”* says the 42-year-old wife of a car mechanic, and mother of two. *“Aur agar main jaanch nahin karvati to aaj theek nahin hoti. Ab main apne ghar ka kaam karti hun, har teen maheene par hospital aati hun,”* she says with a smile.

Behind that smile is a story of difficulty and determination which began in March 2018 when the hospital decided to shift from doing opportunistic screening to an organised, population-based screening in under-served localities. That meant conducting screening camps on the basis of demographic contours, and adopting certain localities.

## Screening: From Testing to Treating

Prevention was going beyond the four walls of the hospital. It would incorporate 90 lakh poor and high-risk people in 50 communities living in urban slums, semi-rural areas and unauthorised or relocated JJ clusters, in the 10km-radius of RGCIRC.

But long before, in 2008, a dedicated Department of Preventive Oncology formally started screening people who came to the hospital for a routine health check. “We started with preventive OPDs where we screened people and also offered them health packages. Walk-in patients included attendants of patients or citizens from neighbouring RWAs, faculty from schools and colleges etc. These were spots where we went out to conduct awareness and screening camps at the behest of an RWA or an organisation such as the Rotary Club, corporates and whoever cared to call us,” recalls Head of the Department Dr Indu Aggarwal. Women who made up for nearly half the screenable population were tested for three common cancers – breast, cervix and oral cavity. This involved clinical examination, Pap-smear and visual examination respectively for the three cancers.

“This was followed up by calling people, who screened positive in the first round, for further investigation to the hospital. Those who presented themselves were recommended tests like mammography and colposcopy (for a close examination of the cervix) totally free of charge if







they fulfilled the BPL criteria. In either case, we had some satisfaction in the knowledge that we were able to sensitise people towards the disease, irrespective of whether they chose us or any other hospital for treatment,” quips Dr Aggarwal.

The hospital gave – and continues to give – close to 50 per cent discounts on Pap-smear, mammography and low-dose CT scans (for lung cancer) to promote screening through preventive OPD. The numbers have increased over time as has the quality of screening. It also runs a free tobacco cessation clinic as part of its preventive work. The clinic counsels on cessation and offers advice on nicotine replacement therapy.

In the last 10 years, more than 80,000 people have been screened – close to one-third through OPDs and the rest through community camps. “An ounce of prevention is worth a pound of cure. About 500 or 600 of the 10,000 people we screen annually are pre-cancerous. What this means in effect is – these lives have been saved either by preventing cancer or through early detection. We can cure nearly 80 per cent if they are at stages one or two. But allow the cancer to grow to stages three or four, and we can help cure only 20 per cent. It’s great for the patient, and for the country. That

is why we want to step up our prevention work,” adds Chairman Rakesh Chopra.

The downside of opportunistic screening was that early detection couldn’t be taken to its logical end – treatment. People were lost to follow-up. That’s when, a decade later, the RGCIRC decided to screen not only to test but screen to treat. In line with their vision of not letting resources decide treatment-worthiness, they began with the under-served populations around the hospital.

### **Screening, Positively!**

Intent brought its energy and the Department of Preventive Oncology found able partners in ASHA workers, and later NGOs, who knew the community well and were able to pave the way for prevention work. “The big question that hung over us was – what do we do when people screened positive. If we really wanted to save them from this disease, we couldn’t have forsaken them after the camp,” says Dr AK Chaturvedi, Chair, Department of Radiology.

Some deliberations on the question yielded the answer. Data had little meaning if it wasn’t translated into doctoring. The hospital would screen to save, not merely to test. Screening camps for the adopted communities would be 100 per cent free.

Women and men who screened positive would only make a one-time registration of 150 rupees when they presented at the hospital. Thereafter, on the approval of the consultant in charge, the hospital would adopt the patient and take care of everything – investigations, treatment and follow-up. “The hospital committed to expending 5 lakh rupees per patient and more for the same patient if the need arose,” adds Dr Chaturvedi.

“Preventive oncology is not merely a health check-up which is often meant to cater to the well-heeled. It also means going out to the masses who may not be able to afford a cancer hospital,” says Dr AK Dewan, Director, Surgical Oncology. “The complications of cancer can be minimised and survival rate increased if we are able to detect early and treat well. Arresting the disease at a pre-cancerous stage is still prevention, even though secondary. But primary prevention is about creating awareness, whether in an RWA or a slum, on hygiene, diet, smoking, lifestyle and other such issues.”

### **The Awareness Trial**

Creating awareness, not surprisingly, was a challenge. It was also the only way in which people would willingly submit to the screening process. It took – and still takes – much learning and doing by the RGCIRC



team to familiarize and sensitise its population to the menace of cancer and the importance of early detection.

There is a phobia associated with cancer, reminds Dr Aggarwal. Of those that the RGCIRC serves, even the reasonably well-educated present late. But awareness levels in the under-served sections is dismal. They are more likely to present at an advanced stage that puts them at far greater risk.

“Nearly 90 per cent know what a Pap-smear is in an urban cluster but only 1 or 2 get themselves screened periodically,” Dr Aggarwal says. “But practically no one knows about Pap-smear in a JJ cluster, or a rural area, and only a couple of them may have heard of cervical cancer. It is important to know that while breast cancer largely affects urban women, the incidence of cervical cancer is higher in the under-served populations because of known risk factors such as poor hygiene practices and early marriage. Most of them are very diffident even talking about it, let alone coming to a screening camp. In fact, it is difficult to convince a 50 or 60 year-old woman – the high-risk category – to enlist because she thinks menopause and becoming a grandmother naturally protects her against cancer.”

And then there are cancer myths and psycho-social problems to contend with. A woman may believe a Pap-smear test will make her infertile. Or that a biopsy can actually cause her cancer, or a cut during a procedure could cause it to spread. Confirmation of the disease itself may mean that she could stand to lose her marriage and home – the twin blades of stigma and abandonment hanging over her head. A male patient with oral cancer may much rather refuse treatment than being refused at work.

The promise of free treatment is attractive but...

“The work of awareness and partly and fully subsidized preventive treatment are also a cost,” says CEO DS Negi. “And cancer doesn’t come alone. It brings an extended family of challenges. While long-term vision of screening and treating increasing number of patients is important, shorter-term plans of supporting them are equally critical. Can a patient who has lost his job during treatment be supported for a length of time? Can expenses of medicine that a patient has to incur from her own pocket be borne by someone? Can someone support intensive awareness drives which require transport, personnel and

materials? This too is a cost – human cost. We need to augment for more than meets the eye.”

### Patience and Plans

Changing entrenched behaviours demands consistent work and unending patience, as the sole team comprising two doctors, two nurses, a counsellor and a manager testify. “We have learnt from experience that speaking to the patient with caution is very important in awareness work and we cannot present through our language any mental obstacle should a patient be even half-inclined to go ahead with treatment,” says Gagandeep, Assistant Manager, Preventive Oncology.

The team conducts 11-12 camps a month in the identified localities for oral, cervix and breast cancers, which is in line with the national policy on cancer. The department is unmanned when the team is out for screening in the community. “Between April 2018 and August 2019, we screened close to 5000 eligible people in 18 of the 50 localities. Around 85 screened positive, 50 refused and only 35 presented themselves at the hospital. Nine of these were positive for malignancy.”

Kamala Devi was one of the nine who had been adopted and are now being treated at the hospital.

“I was told very clearly that I would not have to pay even a rupee whatever the expense of investigations and treatment. I did not, except for some money on antibiotics and vitamins after the surgery. They were good to me – the doctor and everyone else,” says Kamala who is still in follow up and doesn’t know the cost of the process which was over Rs8 lakh.

True, a small percentage is walking the mile from screening to treatment. But with success stories such as Kamala’s and similar people, the RGCIRC looks to having many more sign up for the programme. “She came to us with a very positive outlook. We took her husband and children into confidence and they were very cooperative. Clearly the success of our programme depends as much on



external resources as the cooperation of the patient,” reflects Gagandeep.

“The brief to the Preventive Oncology team is to cover all the 90 lakh people in the next five years. This translates as more teams, resources and allocations so that 60 per cent of the eligible population can be screened in the next three years. Till 2018 we did not have a policy for screen-positive cases. Now, we do and hope to add at least two more teams towards this work. With our facility in South Delhi, we look to adopting clusters in Govindpuri and contiguous under-served areas and have one of the new teams cover this population. It’s a tall order but we also know the urgency of doing this as quickly as we can,” says Mr Negi.

Disease is often thought to represent darkness, a peculiar set of pathogens manifested by it. But the essential infection almost always lies in ignorance and indifference. And light – even of a lone candle – almost always comes from awareness and empathy.







PAEDIATRIC ONCOLOGY:

# TOWARDS THE GROWTH OF THE SMALL

*Grace is given not because we have done good works,  
but in order that we may be able to do them.*

– Saint Augustine of Hippo

Thirteen-year-old Prateek eagerly awaits his return to his village in Jhajjar, Haryana. It's been seven months since he has been living away from all that he has known and loved, at Grace, a residential facility offered by the RGCIRC. In August 2019, his parents brought him to Delhi when they found that his fortnight-plus long cough was more than just that. When a CT showed the child had a tumour, doctors at PGI, Rohtak directed them to RGCIRC. Further tests confirmed Prateek had T-cell lymphoma, a fast-growing, acute cancer that responds well to chemotherapy.

Asked to come for periodic follow-up visits, the family is winding up to return home which his mother Meenu, a teacher in the village, says wistfully they have all missed. "The hospital helped us secure the PM Relief Fund and we spent a few lakhs from our pocket for treatment. But staying at Grace, however, has been a comfort! Even though we maintain a fair quality of hygiene in our house, here I learnt how critical it is when you have a child with this disease. The hospital is very close from here. There have been times when we have had to rush Prateek to the hospital during his chemotherapy – he sometimes came down with fever or diarrhoea... and sometimes he would throw up," she wells up, recalling the difficult times. "That helped us very much because we could reach the hospital in a few minutes in an e-rickshaw that is available here all the time. But the best thing about being here is that Prateek was able to play with other children. We had our anxious moments – but we also had the company of so many other parents in the same boat as us. They understood us and gave us the emotional support which wouldn't have been easy to get had we been by ourselves."

The facility, which is part of the hospital's endeavour to reach out to its paediatric population is a home away from home where children like Prateek and their families can stay for the duration of therapy. "Barring a small token that barely covers the running expenses such as electricity, water, gas and other services, the accommodation itself is

free of cost. Only those who can afford it are charged for even the former, so that the parents feel more involved and accountable for the upkeep of the home. No income certificates are needed either; but we talk to a family and get a fair sense of the need, and that helps us decide which way to go. When in doubt, we waive it all," says Dr Gauri Kapoor, Director, Paediatric Haematology and Oncology. "The treatment lasts anything between a few weeks and some months. And the costs can be forbidding even for a middle income family," she says. "Then there are hidden costs too. Transport, accommodation, wage cut or loss of employment of a parent who accompanies her sick child, expenses of daily living are all invisible costs when one is at home. Sometimes, the parents have to shoulder the burden of running two households – one back home, the other at the place of their child's treatment. Families from Delhi prefer to commute to the hospital. But it is tough and expensive to find clean and proximate board and lodging for those who come from other states and cities – we have them coming from Rajasthan, Gujarat, Madhya Pradesh, Uttar Pradesh, Bihar, Kashmir, Sikkim and some other north-eastern states."

It is an accepted concept worldwide to have a home away from home as part of cancer care. But here in Delhi, finding a place that the hospital could rent was fraught with difficulties primarily for the reason that it would house people with cancer. After seven long years of making do with sub-optimal infrastructure in terms of light and sanitation and with short-term funding, says Dr Kapoor, Grace happened.

When the Krishnans, whose child completed treatment at RGCIRC, wanted to do more than routine gift-making for those who weren't as blessed as them, Dr Kapoor responded to their commitment. She explored with them the renting of a residential facility for patients. A new, four-floor apartment building was taken on a long-term lease. The home answered the need for privacy. Two people – mother and any of her male relatives could stay in a clean,



self-sufficient room with the child. Shared kitchen and staff for enabling educational and play activity with children, security and maintenance were made available to the families. Institutionalized as part of the CSR work of the family's company, Grace has for the last seven years been part of some other funders that work with the department for treating childhood cancers.

Philanthropic outreach in paediatric cancer cure began with the inception of RGCIRC. Patient welfare at all costs being the touchstone of its work, the endeavour is to arrange for funds based on their ability to cure the disease, not on the patient's ability to pay for it, says the doctor.

"The treatment is complex – the family has to virtually set aside their life during this period. We apprise the parents of the possible prognosis and do whatever is in our power to support them if they can comply with some rules and are motivated to undertake this journey. Sometimes we get a very poor patient who needs treatment for just six months, like this child with Hodgkin's Lymphoma who came to us with her uncle – a daily wage. She had lost both her parents. We arranged the funds for her, treated her when the uncle brought her at all the odd hours, and also got his own small child along against hospital rules. Had we refused permission for this child, the uncle would have in all likelihood stopped bringing our patient to us. We occasionally allow these small



5. Further develop the Survivors' Clinic that supports life post cancer-treatment of children.

As of today, more than 100 children have been helped through partnering with the Indian Cancer Society that mandates free treatment from the hospital to avail of their funds. The department also works with the American Indian Associated Charities, another US-based umbrella Trust, members of which contribute from their own salaries to fund the treatment of five children every year.



irregularities in the interest of our patient alone."

"A child stricken with cancer can be heart breaking. And if the child is poor, she becomes even more vulnerable. We have, at RGCIRC, instituted a corpus fund for paediatric cancers just so that we can reach out in a focussed manner to economically vulnerable children," says CEO DS Negi. "Childhood cancers form 3 per cent of all known cancers and 90 per cent of these are curable if treated properly in time," says Dr Kapoor, "and we want to cure as many children as we can." More funding in this domain could mean:

1. Treatment for more paediatric cancer patients
2. Hiring of highly trained nurse managers and specialist nurses with expertise in Pediatric Oncology, and more resources to train staff
3. Investigator-initiated clinical trials in childhood cancers to address problems unique to India
4. Making available new drugs currently not available in India, for instance Blincyto and CAR-T-cell therapy, both immune therapies regarded as having ushered in a new era in haematological cancers.





# ABIDING GRACE

A DONOR STORY



"I do not know if we can, or even want to, call it philanthropy. We've been able to touch so many lives and received tremendous satisfaction in turn.

For all of us who are devoted to Grace, it is simply a response driven by fellow-feeling," says Mr Ganesh Krishnan, the man who refuses to take any personal credit or applause for instituting Grace six years ago.

**Grace** – a four-floor building, not too far from RGCIRC, that children with cancer and their parents call home for the duration of treatment at the hospital. The home has 16 clean, self-sufficient rooms, common kitchens with piped gas on each floor and play area-cum-office space on the ground floor. Located in a somewhat busy neighbourhood, it could pass off as yet another brick and mortar place if one were to see it only from the outside.

Going in, as always, reveals more.

In 2013, the Krishnans found their 6-year-old son had lymphoma. They

came to Dr Gauri Kapoor, now heading the Department of Paediatric Oncology at RGCIRC, and never looked back. When the treatment was over, they wanted to do more than making a one-time gift as closure, little knowing that this finish would start a whole new chain of events. "Dr Kapoor suggested to us an idea that was much larger than we could have thought. She proposed a more permanent gift – a home that could be added to the infrastructural facilities of the hospital. The home would house children with cancer and their care-givers. The idea was noble. Could we make it sustainable and accessible to a larger population? We simply did not know how and where to start," he recalls.

In that unknowing were sown the first seeds of Grace. Mr Krishnan believes emotions alone are not enough to manifest visions. But they do spur movement in that direction. Financial and functional support followed their emotion and after a period of haze, there was light.

Together with Dr Kapoor and Dr Shalini Misra, Consultant, Paediatric Surgical Oncology, and Dr Sandeep Jain, coordinator at the department, the Krishnans scouted for similar facilities both in India and abroad. From the pool of ideas, they picked a stream best suited to flow directly to the patients of RGCIRC. "After initial hiccups, we decided to make the project a part of the CSR of our company. We found a building that would meet Dr Kapoor's approval and rented it on a long-term basis. Our lawyers apprised the landlord as to its purpose and assured him of a company lease. The last seven years have been trouble-free and he has received the rent without fail. Finally, our corporate team joined hands with the hospital administration. While the doctors brought in the medical intelligence, we contributed with management experience," Mr Krishnan pieces together the making of Grace.



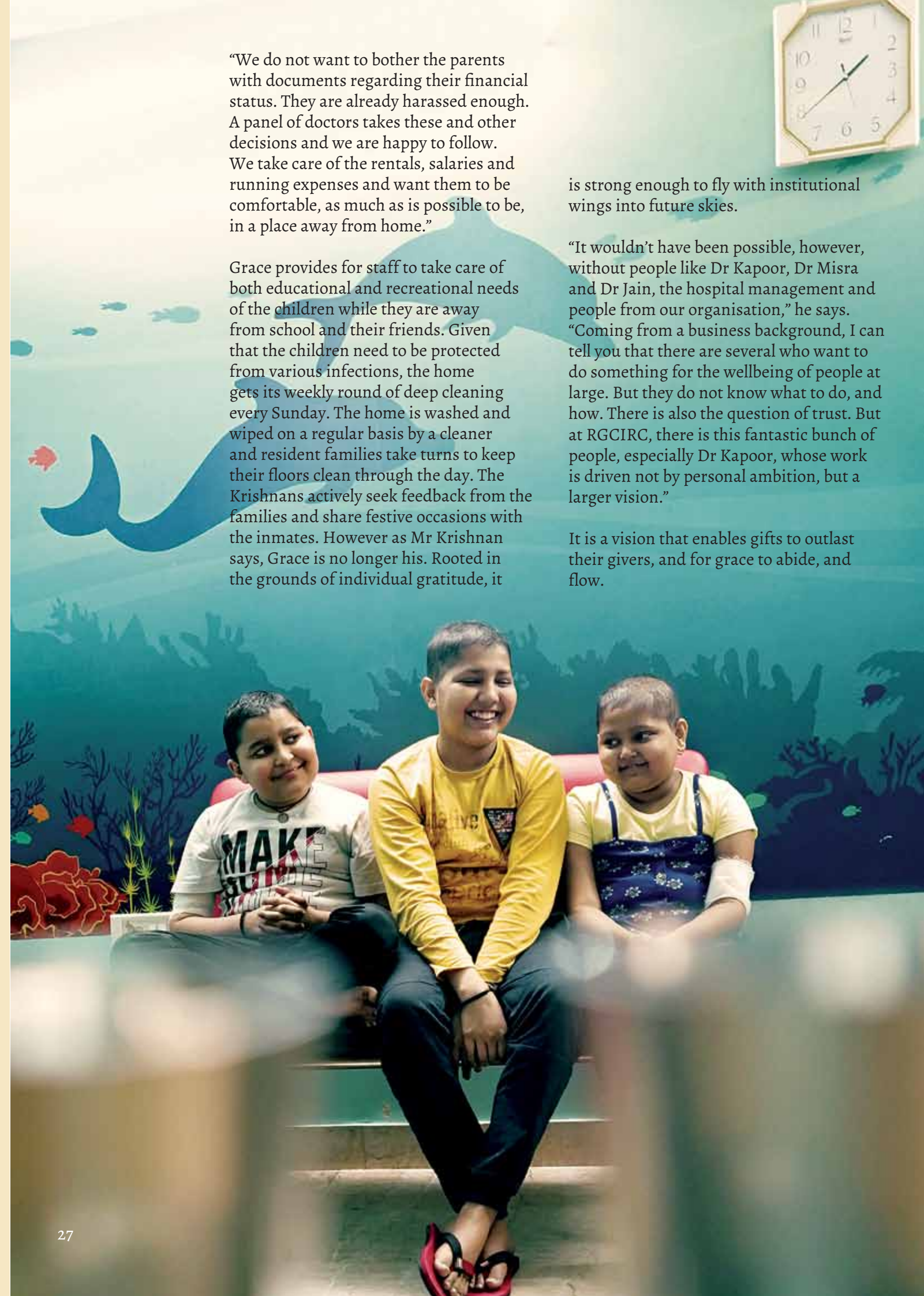
"We do not want to bother the parents with documents regarding their financial status. They are already harassed enough. A panel of doctors takes these and other decisions and we are happy to follow. We take care of the rentals, salaries and running expenses and want them to be comfortable, as much as is possible to be, in a place away from home."

Grace provides for staff to take care of both educational and recreational needs of the children while they are away from school and their friends. Given that the children need to be protected from various infections, the home gets its weekly round of deep cleaning every Sunday. The home is washed and wiped on a regular basis by a cleaner and resident families take turns to keep their floors clean through the day. The Krishnans actively seek feedback from the families and share festive occasions with the inmates. However as Mr Krishnan says, Grace is no longer his. Rooted in the grounds of individual gratitude, it

is strong enough to fly with institutional wings into future skies.

"It wouldn't have been possible, however, without people like Dr Kapoor, Dr Misra and Dr Jain, the hospital management and people from our organisation," he says. "Coming from a business background, I can tell you that there are several who want to do something for the wellbeing of people at large. But they do not know what to do, and how. There is also the question of trust. But at RGCIRC, there is this fantastic bunch of people, especially Dr Kapoor, whose work is driven not by personal ambition, but a larger vision."

It is a vision that enables gifts to outlast their givers, and for grace to abide, and flow.





## Prologue

*Mid-19th century: German researcher Rudolf Virchow first gave the world words such as leukemia and neoplasia, a term even today used to describe cancer.*

*Today in early 21st century: About 1000 scientists. Thirty-seven countries. Two thousand six hundred and fifty-eight cancer samples. And 10 years. It has taken global collaboration and several years for science to tell us that cancer is like a 100,000-piece jigsaw puzzle and until this study – Pan-Cancer Analysis of Whole Genomes – 99 per cent of the pieces were missing. The study reveals common patterns of mutations that drive the growth of cancers and can be ‘targeted’ with treatment. Yet, all the king’s horses and all the king’s men, have not been*

RESEARCH & BIO-REPOSITORY

# TRANSLATING RESEARCH INTO REMEDY

*What is research but  
a blind date with knowledge!*

– Will Harvey



*able to find out why 5 per cent of the cancers appear to have no reason to mutate and require even further research to treat them better.*

*In the middle of these time spans, lies the long, arduous story of cancer research. Countless people have devoted their time and lives to years of hard, often wearisome work, faced failures and whispered hurrahs, and discovered a thousand ways, as Edison may have said, of how not to make the light bulb. Whether it was radiation therapy that was sourced in Marie Curie’s invention of radium, invention of the very critical Pap-smear test by George Papanikolaou, mining knowledge of opiates and anti-nausea drugs in palliative care, or making major advances in learning details about how to prevent, diagnose, treat and survive cancer, ground-breaking discoveries on the nature of shape-shifting cancer cells that cause metastasis and big strides in looking for more convenient, less expensive and invasive combination therapies – research has been the distance, as someone said, between an idea and its realisation. One tortuous step at a time.*

“We need a very elaborate system to get research work going in a lab, even though research need not be the sole preserve of a laboratory. Given that patient care is the final goal of all research, one may work to find how disease is caused, how it may be prevented and how to rehabilitate a patient post treatment. However, a lab is that vital space where one can look for biomarkers, or make molecular discoveries that help in developing new drugs, finding new ways to test, diagnose, monitor and prognosticate for the disease. And it takes a number of years and intensive investing before it can translate into real benefits for the patient,” says Dr Anurag Mehta, Director, Laboratory Services and Research.

When researchers at IIT, Roorkee found certain proteins in saliva samples sourced from healthy, breast and ovarian cancer patients, and also from those who had undergone chemotherapy, they were not just staring at some laboratory findings. They were, in fact, looking to ascertain an easy, non-invasive alternative to screen patients



for metastatic cancers of the breast and ovary. And the salivary proteins could be possible indicators of metastasis in the two cancers that comprise more than one-third of all cancers afflicting Indian women and leading to one-fifth of all cancer deaths.

It was only right that the samples were sourced from the RGCIRC bio-repository, the largest and world-class institution-based bio-bank in India and a fount of about 36,000 consented bio-samples across various cancer indications since 2013.

A bio-repository is a storage area where left-over samples of an individual may be retained once the diagnostic work on samples – blood, urine, tumour etc – is over. This tissue that is discarded in the normal course is retained for research in a bio-repository following due permissions from a patient who chooses to contribute.

“A bio-repository is an excellent source to accelerate research by providing relevant samples. We can make available, for instance, to a researcher a sample of urine of a patient of gall bladder tumour,” informs Dr Mehta. “These samples are preserved at temperatures such as minus





180-195 degrees Celsius so that the integrity of the tissue and the molecules of life are not vitiated for research. We collect and keep each sample annotated with information about the patient-donor, maintain an inventory of tissues; issue them and post them out to be delivered at requested destinations. A difficult, resource-intensive task, to say the least! But a bio-repository is a community resource. We believe our work exists only because the community itself exists. Therefore, we run the project as a global outreach programme, on a no-profit, no-loss basis through which several organisations are able to further their research.”

The bio-repository was founded with Shri RKP Shankardass, a senior Supreme Court lawyer expressing his wish to donate for research. “We requested that the endowment be given towards establishing a bio-repository which would eventually help in research. He gave 50 lakh rupees towards the fund with RGCIRC contributing the other 50 lakh,” says Ms Swarnima Jaitley, formerly Principal Research Officer with the Department of Research. His bequest included 5 lakh rupees each for funding two research projects on breast cancer which were later published.



The bio-repository at RGCIRC caters to the needs of the scientific community focused on cancer and allied research. Apart from its own investigators and academic institutes such as IIT Roorkee, the RGCIRC offers bio-specimens to the Delhi Technical University, University of Delhi, and Jamia Millia Islamia University etc. The specimens are also shared with other international institutes like Cureline, a global human bio-specimens biotech company, and Reprocell.

“We know our tissue samples are being used for diagnostic tests or drug discovery, thereby contributing immensely to state-of-the-art research across the world, including in the USA and Australia. With this, we manage to generate just enough revenue to sustain ourselves,” says Dr Mehta.

But the lab is a different story. “This work amounts to only investing – investing for a long, long time. And it is like a shot in the dark. You may hit the bull’s eye or several years of hard work may come to nought. We may be able to market or commercialise translational research, or new knowledge generated in the process, but the possibilities are remote. We have all that it takes to do cutting-edge research work – we are a comprehensive cancer care centre, have immense clinical material and follow-up data and capacity. Our limitation? Funds.”

Some families who have lost their loved ones to the disease have sought to give towards research so that work may be carried out in a specific, identifiable area. Dr Mehta, who has

put the institute on the leader board of molecular diagnostics, underscores the need for philanthropy the field. “No single organisation not funded by the government or the taxpayer is capable of undertaking this work in India. We need philanthropic organisations and individuals to invest in meaningful research and enable it to become self-sustaining, and then generate revenue. That takes more than a few years.”

The institute has several completed and ongoing research projects. Many more are in line awaiting the currency of a long-term vision that is unhurried by the need for short-term accruals. Bio-repositories – as Dr Mehta says – are for, by and of the community. They are instruments for future explorations in the vast field of human wellness. The community, therefore, would do well to sow the seeds in spring and, like a fond optimistic farmer, hope to reap a good harvest in autumn – even if it may take several seasons to arrive.







SUPPORTIVE AND  
HOME CARE SERVICES

# CARE WITHOUT END

*Our most cruel failure in how we treat the sick... is the failure to recognise that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives.*

– Dr Atul Gawande  
*Being Mortal: Medicine and  
What Matters in the End*

“I remember the last time when we went to their house,” says Sister Hema Clara Singh about Mr Munshi Ram Bhasin who passed away not too long ago after battling with advanced prostate cancer. “He was very active for his 80 plus years. And his wife, who told me she had had the happiest years being his partner, was distraught to see him frail, and powerless. His son told us that Mr Bhasin wasn’t eating much. That day, I just sat with his hand in mine, invited myself to a meal with him and told him he needed to eat if he wanted to be like me. It was nice to see him laugh,” the portly nurse recalls, allowing herself also to laugh a little.

Mr Bhasin, his son would later report, had, in fact, started to eat a little. And then, of course, life turned the inevitable corner. Dr Savera, the Senior Palliative Care Physician at the Department of Supportive and Home Care Services sent the family a condolence letter which was to be followed by a personal visit should they accept.

Cancer – metastatic or otherwise – spreads beyond one person and has many casualties. It takes a doctor all his ability to break it to the family that it’s time to take the patient home so she can live with dignity, doing things that matter to her surrounded by people who are dear. It takes every ounce of fortitude for the family to accept the sentence – one with many blanks, and no one to help fill them.

“It was part of our vision-mission that we provide comprehensive cancer care – from prevention to palliation – to our patients,” says Dr AK Dewan, Director, Surgical Oncology and former Medical Director. “From day one, our founder KK Mehta wanted the hospital to extend free home care service to terminally ill patients. He named it ‘home care’. While he meant it to be part of the palliative programme, we have held on to that name even today.”

Since then, the RGCIRC has been taking the hospital to patients when the latter can no longer benefit from cure, but still need care – and lots of it. The sole

home care team comprising a doctor, a nurse and a counsellor have for all these years visited patients referred to the Department of Supportive and Home Care Services, either by the consultant or on request from caregivers. “We see a patient twice a month, two or three patients every day if they are on the same route and have averaged 50 to 60 homes in a month. Barring the last few years during which our visiting areas has shrunk, we have covered Delhi, Faridabad, Noida, Ghaziabad and Sonapat since we started,” says Sister Hema, who was part of the first home care team.

“A terminally ill patient needs symptomatic treatment. Intense pain, constipation, fever, diarrhoea, nausea, gastritis, poor appetite, fading memory, failing bladder control... these symptoms may change every day, posing new challenges both to the patient and the caregiver,” says Dr Savera. “Depending on the need, we give them anti-inflammatory and anti-emetic medicines for nausea, mild pain-killers like paracetamol and even opiates. The medicines are not very expensive and we provide these for free. But the nutritional supplements, an important component of patient care, are beyond the reach of a poor patient. That’s what poses a limitation to us.”

Once home, the team does virtually everything that it would do at the hospital. The nurse monitors the vitals, dresses a wound, gives dietary instructions, mobilises the patient, teaching him the necessary exercises, and trains the attendants in catheter care and keeping the PICC line free of infection. The doctors and nurse become confidante and clinician, friend and counsellor, all at once to the patient as well as the caregivers.





whether the hospital had the money or not. It was his dream project. Lack of funds may have terminated the dream. But RGCIRC is committed to remedying and rehabilitating this service.

That said, palliative care is an expensive programme; home care being only one aspect of the service. “I am of the view that a robust palliative programme stands on a tripod – hospital, home care and hospice,” Dr Dewan delineates a vision for a cancer hospital.

“As far as home care is concerned, an end-of-life patient may need care every other day, which given the resources at our disposal, is not possible. Nor is servicing two or three patients every day enough. We need multiple teams, ambulances, more medicines to cover more patients, and make more frequent home visits.

“I have also heard doctors in corporate hospitals say that palliative care is a lost opportunity, a no-return-on-investment service. A patient with modest means, who needs neither chemotherapy and surgery nor even antibiotics, may come to the hospital and is likely to ask for a free bed. He may end up occupying that bed from anything between a few months and a few years till the very last. That would mean the hospital denying a bed to a patient who is undergoing active treatment and has better chances of survival. That is why a dedicated palliative ward and pain clinic within the hospital is necessary to make this service sustainable.

“Adopting a hospice and engaging capable doctors for the job can be an alternative. Hospice services often engage ill-paid doctors and ANMs (auxiliary nurse midwife) who replace trained nurses. The nature of this service is such that it demands empathy, and a passion that cannot be measured in terms of wages. In such an event, a cancer hospital can even send its own doctors and trained nurses by rotation there. But that means loss of manpower at the hospital. Maintenance of infrastructure and people is a huge recurring cost as well. The question,

however, is: are the terminally ill not deserving of quality life because they are dying? Do they not need our care and comfort, psychological and spiritual support? Running such a service may be a burden, but it is a precious one. And a hospital like ours, committed to expanding these services, needs partners in carrying it.”

Currently, the Department of Supportive and Home Care Services offers pain management and counselling services to caregivers and bereaved families. They would like to start the patient on palliative care before she becomes terminally ill. That would clearly need more resources, human and other. “I encourage patients to call me any time for their slightest need. If they don’t, we do. We would like to fulfil our basic objective of offering our patients a holistic support system to live well till the very last,” Dr Savera echoes the vision of the hospital.

“I have many plants in my house. Watering them makes me happy. When I do that, I think of how I can take care of my patients,” says Sister Hema, who perhaps knows something of their pain as she administers to a cancer patient closer home: her mother.

“Some patients look forward to seeing us. Sometimes, the family knows how it is all going to end because the doctors have told them but the patient does not. The latter may not understand why he isn’t going to the hospital any more. But he feels comforted when his family tells him that an entire team from the hospital is coming to see him. He feels confident that a doctor is still there with him. The attendant also finds it easier to cite us – the doctor or nurse – in case the patient gets difficult in our absence,” Sister Hema says, thoughtfully.

Isolation, anxiety, sadness and a range of emotional and mental upheavals come with the disease. There is no escaping them and the only way out is going through them, as many attendants will vouch. The home care team is a partner on this journey, extending care to the patient and the family to the very end. The founders of the RGCIRC were acutely aware of this, the reason why it is the rare cancer hospital with free home care service even today.

Old-timers recall Mr Mehta insisting that the home care programme should go on and the patient must receive the medicines at home irrespective of





## Corpus Funds

One of the ways of ensuring annual support to needy patients is through contribution to our Corpus Funds. You may donate to any of our three corpus funds:

1. Haematological Malignancies
2. Paediatric Malignancies
3. Other Cancers

Donations shall be maintained as part of the Corpus Fund and invested in Fixed Deposit Receipts (FDRs). Interest accrued (at the end of a financial year) from the fund invested in the FDR shall be utilized for treatment of patients, the base amount of funds remaining intact.

## Support to weaker sections of the society

A large part of the population is unable to access necessary and timely medical attention because it is unable to afford the treatment. You may:

1. Adopt a patient (Rs.5 lakh)
2. Extend support for partial treatment, or any one or two of the three modalities of the treatment: Radiation, Surgery or Chemotherapy (Rs.2-4 lakh per patient)

## Preventive Care

Prevention is the first most important step towards cancer care. You may contribute to spreading awareness of cancer and educating/supporting community initiatives through the following programs:

1. Early detection and screening programs
2. Organising awareness camps
3. Capacity Building – Training of manpower
4. Developing educational materials and conducting workshops for the local population

## Home and Supportive Care

We have been striving hard to keep the home and palliative care services going. You may donate in favour of the following to give a fillip to the programme:

1. Nutritional supplements
2. Analgesics for pain management
3. Manpower training and resources such as vans and ambulances.

## Defined Research Projects

Research, a resource-intensive activity, as critical as treatment, is an area of significance at RGCIRC. We invite you to donate to any one or more of the several research projects on and around breast, head and neck and lung cancers.

## Miscellaneous

There are some other areas you may contribute towards:

1. Board and lodging for outstation patients and/or families during treatment.
2. Wage replacement for the primary wage earner undergoing treatment.
3. Education of children of a person undergoing treatment.
4. Household expenses for outstation patients who have to run a parallel household when with RGCIRC for treatment.







## TAX INFORMATION

RGCIRC is exempted under Section 80G and Section 35 (i) (ii). Hence, the donation made will be eligible for tax deduction as:

- i. Under section 80G of the Income Tax Act, 50% of your donation amount will be eligible for tax exemption. We are registered under 12AA of the Income Tax Act.
- ii. Under section 35 (i) (ii) of the Income Tax Act, 175% of your donation amount will be eligible of tax exemption. We are a notified institute to carry out scientific research activity.

The cheque may be made in favour of:  
The Indraprastha Cancer Society and  
Research Centre

### **Name of Hospital**

Rajiv Gandhi Cancer Institute  
and Research Centre  
(A unit of the Indraprastha Cancer Society  
and Research Centre)

### **Beneficiary Bank**

Axis Bank Ltd., Rohini, Sector-10,  
New Delhi-110085

### **Beneficiary Name**

Indraprastha Cancer Society and Research Centre

### **Beneficiary A/C No.**

431010100077622

### **Beneficiary IFSC Code**

UTIB0000431

### **Beneficiary MICR Code**

110211045

### **Beneficiary PAN**

AAATI0440C

### **Contact Details:**

CEO, RGCIRC; Email: [ceo@rgcirc.org](mailto:ceo@rgcirc.org)

Head, Department of Philanthropic Services;  
Email: [philanthropy@rgcirc.org](mailto:philanthropy@rgcirc.org)

Telephone: 011 47022619  
Website: [www.rgcirc.org](http://www.rgcirc.org)

Rajiv Gandhi Cancer Institute and Research Centre  
D-18, Sector-V, Rohini, Delhi – 110085



