

10<sup>th</sup> Year Milestone – Founder’s Notes (Samiksha Foundation)

### **Education for Children with cancer and Long-term non-infectious illnesses**

The 3 Cs Concept of Samiksha Foundation,( Continuous care with Commitment and Compassion) conceived and pursued over 10 years at one of the largest State Cancer centres in the country, has been proven steadfast and necessary when the WHO announced the Global Initiative for Childhood Cancer in Sept 2018 with an aim to help countries reach at least 60% survival rate by 2030.

As we have heard before from the Doctors at Kidwai Cancer Institute, the survival rate of a child with cancer can reach 76% if detected early and given quality medical care. This calls for thought on Transition Guidelines and Methods to empower the child for a better quality of life. The Samiksha endeavour focusses on this need for positive and smooth transitions of children and their caregivers confronted with the challenges of cancer Diagnosis and treatment. By engaging ourselves with the children providing essential Non-Medical Care and allied care, mainly that of facilitating Integrated Educational Support to the child with cancer during treatment. We have positively impacted over 5000 little lives since inception, by enabling them to bridge the Gap in their education during illness. Over 2500 of them have been able to go back to mainstream life and School with Pride, Hope and Dignity, perhaps far more confident and empowered after leaving the rich experience at the Samiksha Learning Centre.

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Some 12 years ago, when I studied the need, the International Children’s cancer Patients Organisation ( ICCPO) guidelines were followed. We set up a Module of Care or a Therapeutic Alliance , as defined by them;

what we call the “Triangle of Care” wherein the Team at Samiksha occupies the core of the Triangle, the Doctors, Parents and Family and Children form the 3 vertices of this Triangle. This Concept developed 12 years ago has proven to be our most powerful tool to date for Pediatric Oncology Care in (Non-Medical) ancillary support. Volunteers and Core Team at Samiksha are oriented to this Concept of Care with clarity and commitment. This closed “Triangle of Care” is a strong bond that boosts the child’s confidence as powerfully as good medical treatment and nutrition boosts a sick child’s health towards recovery.

More recently, The International Society of Paediatric Oncology The SIOP (US) on the psychosocial issues in Paediatric Oncology in 1993 suggested a mandatory program to have a well defined and planned hospital/school program. There are clear instructions about the Management of the children with cancer treatment requiring a Multidisciplinary approach. Its amazing that we at Samiksha had already set in motion 10 years ago, a personalised education program for every child here, and provided additional resources if the child requires extra help. It starts during the period of diagnosis, continues during

the period of treatment, and is extended after the completion of treatment. Only co-operation among the family, care team, and educators, in addition to a well-structured program, can help in achieving this goal and preventing serious negative outcomes such as these kids being out there with nothing post cancer.

To that extent I am proud to say that we at Samiksha have been hugely successful. Thanks to this wonderful and dedicated team, who all believe that fighting any serious illness is often more than just the medical treatment, the physical, mental and psychological and social support that the patient gets from his family, medical and social circle is especially true for paediatric cancer where the patient is young, the disease is scary, the symptoms often painful and the treatment itself long drawn and draining. It is **here** that the subsidiary care organisations such as Samiksha have a very important role to play.

We are convinced about School being an essential ANCHOR for these children, the Role of Yoga, Creative Visualizations and Art therapy as necessary and are also being studied and evaluated by our very competent teachers and resource persons here. The work and studies are being systematically documented too. We work toward assisting these children deal with the challenges of serious diseases like cancer by;

Helping children understand and deal with physical limitations during their illness

Emotional issues like fear of abandonment or phobias

Improve cognitive abilities

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In addition to these challenges, art therapy can help children relieve stress, increase awareness of self, and develop healthy and effective coping skills.

The reintegration of the child with cancer into school is an essential part of the total treatment program. It is with this Goal that the Samiksha Scholarships Program was launched in March 2018, where children who were discharged post cancer treatment and clearly interested in pursuing higher studies, are given financial aid in the form of scholarships paid directly into their personal accounts for school or college purposes. To date 55 scholarships of Rs.20,000/- each have been awarded and another 25 are expected to be added to this list in this year.

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As an observation, we also understand the hurdles and challenges that we are facing in this work in India over the last 10 years.

These Barriers to Education of a sick child, as identified to continuity in education; and retrieved from the article on 'Education of children and adolescents with medical needs at hospital and home', Hope Survey 2008, retrieved from <https://www.hospitalteachers.eu/> ; and I list out :

- There are no regulations for education at home or unclear policies of responsibility for the education of the absent student

- Clear stipulations relating to length of time that a child needs to be out of school before any educational intervention can start, causes unnecessary delays and anxieties
- Consent forms (parents/medical team/school) cause delay in the education process.
- There is No communication between mainstream school and the hospital school
- Hospitals do not always offer a proper learning environment as there is no legislations prescribing this.
- no specialised education training for hospital teachers

Samiksha's education initiative has shown that the need for such programs is imperative with all childcare hospitals treating long term illnesses. The children respond well to the programs and are happier with their hospital stay with it. Further surveys are needed to test the immune-response of such children but it is a general given fact that their psycho-social well-being affects their response to treatment. Ideally all paediatric cancer hospitals should have a multidisciplinary team (physicians, psychiatrist and/or psychologist, nurses, social worker, teachers, recreation specialists).

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Notwithstanding this, I am proud to also note that we have earned a good reputation in this work albeit done quietly, and many a hospital have called us to discuss a possible synergy at their pediatric departments.

In April this year, we have started work at the new Samiksha Learning Center at Narayana Health City at Mazumdar Shaw Cancer Center, and have a happy team working there too! 2 other hospitals are in active discussion with us at this time. It is my prayer today that All hospitals have an auxiliary space for children's education and other activities, a children's library and therapeutic exercise sessions. These spaces need to be near enough for easy access from the paediatric wards and yet separated to have access to outside volunteers. The content of teaching may need to encompass more than formal curriculum to include special needs arising from the illness and its treatment.

A further need is for professional training of teachers and volunteers to deal with these special needs. As of now there are no formal play and art , Music and Dance Therapist education in India.

In Conclusion, I would like to say, that in 10 years, we at Samiksha Foundation have been able to set up and successfully run the Samiksha Learning Center at Kidwai Cancer Institute , much along the lines of these observations and references of study by International Paediatric Oncology Societies. And Yes, we wouldn't have been able to do

any of this without the steadfast support of the Doctors and Social Workers at Kidwai Cancer Institute. I personally extend my sincere gratitude to All the Directors since Dr.Ashok Shenoy , who gave us the first permissions, Dr. Vijayakumar, Dr.L.Appaji,Dr.Lingegowda and Now Director Dr.C.Ramachandra, who graces the occasion today, Dr. Janet Parmeshwar, the retd.Head of Social Work Deaprtment at Kidwai who was most encouraging an dynamic, Oncologists, Dr. Avinash, Dr. Arunkumar, Dr. Padma and Dr. Nuthan and others at Kidwai, Dr, Mahantesh, Dr.Aruna, Dr.Prabha, who have been encouraging, especially for the unstinting support and Love at Kapur Ward form the children all through these years.

I hope that we will continue to learn from the wisdom of others who work in this space. It is our endeavour to take a multidisciplinary approach to Learning and Education at our Learning Centres and study the child's success of not only coping with her cancer condition and also reintegrate into Mainstream Life with Pride, Confidence and Dignity, for we know that "Dignity is Priceless!"

What started as a Vision and Understanding of a Need, has become a Happiness Project for many people involved. As I always say , Samiksha Happiness Project is not just for the Children, It is our Happiness Project!

We firmly believe that "Knowledge Empowers and Happiness Heals and hence our Motto that constantly inspires and grounds us:

"The Pursuit of Knowledge is Key to their Pursuit of Happiness!" Thank you!

Ar.Sandhya Sharad

## TRUSTEE VIJAYA'S NOTE:

Care involves a lifetime commitment, requiring a change in work, social and domestic patterns, income and domestic responsibilities and expanding decision making capabilities.

Care is not static.

An important step in future care for childhood cancer is transition guidelines for both medical and non-medical support to shift physically, mentally and emotionally from disease to disease-free state, from treatment to post treatment phase, from child-care to adult selfcare, from trauma of disease discovery to acceptance, to plan for the future to re-embrace life, employment, love, family and society.

As such comprehensive non-medical support is also a tool to improve the quality of care continuously, enhancing comfort and value to patients and their families for survivorship, positive outcomes and experiences especially in children with distress and life threatening diseases.

Samiksha's 3C (Caring for Children with Cancer) model is an investment in comprehensive care, enhancing happiness, encouragement and confidence to be equals, and joyful experiences by providing supportive education and learning in a friendly and caring environment living the adage "Education Empowers and Happiness Heals."

The dream of Samiksha required moving out of comfort zones, focusing on significance rather than goals, embracing constraints, small steps to providing opportunities and celebrating little victories.

As Samiksha completes 10 years, in this journey of happiness and faith, courage, learning, and enthusiasm, we thank all Volunteers, Donors, Doctors, Well Wishers, Support Groups and Beneficiaries to help make a difference.

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