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Making A Difference: A mother's courage

SOMA BASU



A heart shattered by a child's death can never be put back together. Yet, G. Renganayaki is determined to give meaning to the lives of children with muscular dystrophy

It's two and a half years since Adhiban surrendered to death. He was only 17 years, 5 months and 13 days old when he passed away, in a room full of friends and well-wishers. For one last time – his eyes told his mother – he wanted to embrace and kiss her. But muscular dystrophy had rendered him so weak that he was unable to lift himself.

G. Renganayaki masks her sadness behind a smile, but nothing can take away the pain of a 13-year battle against this progressive degenerative muscular disorder. She takes me from the first doctor's appointment that held bad news to the unrelenting patience of her baby, who believed his parents could save him from any calamity.

This isn't a story about death. It is the story of how Adhiban lived and was guided with his parents' unconditional love and persistence despite all odds. It is about a complex relationship between family members, the emotional impact on them all, the effect on finances, the resigning of jobs, despair and denial, and acceptance of tolerable pain. And after it all, the conversion of grief into energy to work for children with MD. "All the good things that I was able to provide my son and those I wanted but could not, I am trying to give to as many children who are fighting a losing battle with MD," says Renganayaki.

In 1996, Renganayaki and her husband M. Louis Stanislas thought it abnormal that their four-year-old boy found it hard to climb steps or run around, but their paediatrician dismissed Adhiban's problems as calcium and vitamin deficiency. It was only two years later that a homoeopath felt there was something wrong in the little boy's calf muscles and advised them to meet a neurologist.

Recalls Renganayaki, "After a few expensive tests and results, the doctor just told me your son will be in a wheelchair by the time he is nine years old, won't live beyond 17, it's better you go for a second child."

The young couple diverted all their time, energy and resources to their son. "We started researching and compiling all information from the net and books. We were shocked by the paediatrician's failure to diagnose even though without our knowledge we had described the exact symptoms of MD in our child."

The other decision they took, albeit unknowingly, was to focus on Adhiban. "It was later when we were scouting information, that we found that once the genetic mutation enters the family, it is inherited by siblings too either as a patient or carrier," says Renganayaki.

While taking care of her child, Renganayaki realized there must be so many families in a dilemma and lacking in information. "Adhiban was a topper in academics, extremely sensitive to nature and skilled in art. We treated him as a normal child and the Jeevana School staff was extremely understanding and helpful when he slowly started losing mobility."

Says Renganayaki, "I always built a positive world around him. Whenever he asked me why he was unable to run and play like other children, I would tell him other children were not able to score more than him in exams. That motivated him to do better in what he was good at."

While preparing herself for the inevitable, she silently initiated a movement for MD patients and their parents. Within two years of Adhiban's diagnosis, she registered the Muscular Dystrophy Foundation India (MDFI) in 2000 and committed herself to it.

A decade on, the MDFI has grown into the single largest organization of and for MD patients and parents across the country, offering reliable information, medical advice, appropriate guidance and support, and, most important, confidence and hope to over 3,500 families with one or more MD-affected child.

"I have seen families with five MD children. It is difficult to imagine the trauma. I attend two-three funerals every month and identify with each of them," she says.

As a mother who suffered the loss of a son, Renganayaki has spoken on how MD can be prevented. It is a sensitive matter in our society, she feels, but restricting the inheritance of the disorder is the only way to prevent it.

She also brings out a quarterly newsletter on MD in India and distributes 3,500 copies free. But for her efforts, MD would not have been listed as one of the types of disabilities in the Rights of Persons with Disabilities Bill, 2011.

She has painstakingly simplified the cost factor of high-end research initiatives like stem cell therapy to make it accessible to ordinary families. On an average, stem cell therapy costs Rs.15 lakhs, but through her persistent talks and meetings with Bangalore-based research institute, the International Stem Cell Private Services Ltd., she has brought it down to Rs.1.75 lakhs for those registered with MDFI. Even the waiting period has been reduced from three years to four months.

“There can not be a better mother than her for any MD child,” says her husband, who stands rock-like behind her every thought, idea, proposal, and programme. “She has given so many parents the courage to smile in such an extraordinary battle.”

Renganayaki networks with doctors, hospitals, clinics, schools, organizations, friends, well-wishers and neighbours across the country to be able to deliver help to an MD child in times of emergency or otherwise. She personally interacts with 1,000 families and with the rest shares a unique bond over the phone or through e-mails. Much of her time now goes in travel and meetings. “I am available for them 24X7 for any emergency arrangements or help, in all weathers, through any mode of communication,” she adds.

It is Renganayaki's dream now to set up a multi-speciality hospital exclusively for people with genetic disorders and a hospice for MD children. This school and college topper, once a civil service aspirant, always wanted to do “something useful in life.” Having channelled her emotions and come so far, Renganayaki will surely accomplish her mission.