## heart

nun, Sr. Jacintha Silva of the Sisters of Charity, Jesus and Mary, from a nearby convent by their side, they were not alone. For the two benefactors stood with them.

Not only did one promise that he would provide whatever Asitha required for his education such as books, bags, clothes, uniforms and tuition fees until he finished his school career but also sent them dry rations, boxes of goodies and toys regularly.

The other one bought this literally homeless family which was under the roof of a kind relative a nice, cozy home at Katukurunda, Moratuwa, where they are living today. She too often replenishes the family's meagre larder.

Currently, Ashani looks after her sister, brother and her own two little boys, who are eight and two, with whatever her husband, Tharanga, can bring home from a timber depot close-by, helping to unload massive logs from 10-wheelers and herself stitching sets of shorts.

The day we visited them, there had been no money for Ashani to buy a few provisions and cook as they had nothing in the house. As soon as the husband got some money, he had rushed to a boutique nearby in the late afternoon and bought three lunch packets for the six of them to share, before going back to his back-breaking work of log-unloading.

Asitha is looking for a job. "I would like to start a small lee (timber) business," he says, explaining that if he had some capital he and his brother-in-law could buy logs from afar, bring them back to Moratuwa and sell them. Otherwise, he would like to get into the "electrical busi-



Happy family: Damayanthi and Neil with their beloved baby Sanjana Praveen Shivanka now almost two years old.

Pix by M.A. Pushpa Kumara



As we are about to leave, the conversation turns to his dead mother. Emotion overwhelms and Asitha makes a "manly effort" to hold back the tears. It is futile. Against his will, and he tries very hard, the tears flow.

"Yes," he murmurs, even eight vears later, he misses his mother, who used to hug him, her beloved son, and let him sleep in her tender embrace, secure in the comfort that she was around.

We leave with heavy hearts. Asitha, on the threshold of manhood, is still a boy, longing, as the poet so effectively said ".....for the touch of a tender hand and the sound of a voice that is still".

## The 'Bubble Baby' of Sri Lanka

He talks, he walks and he scribbles on the walls. To most of our readers, the 'Bubble Baby' needs no introduction, for it is because of their overwhelming support nearly two years ago on appeals by the Sunday Times that Sanjana Praveen Shivanka is alive

The moment the appeal hit the news, even before Shivanka's birth on July 12, 2010, the monies flowed into the fund set up by the Sunday

The campaign began with a heartrending request from the doctors of the Human Genetics Unit of the Faculty of Medicine, University of Colombo that a humble young couple from Dippitigala, Lellopitiya in

Ratnapura, was on the verge of being swallowed up by despair and hopelessness, with their hearts being crushed

for the third time.

Two of their baby sons already lay buried in their backyard and the third baby that K.B.N. Damayanthi was carrying was also a victim of the rare genetic disease, Severe Combined Immunodeficiency Syndrome (SCID).

The only answer was for Damayanthi and husband K.W. Neil Anura Shantha to take their baby, soon after birth to Chennai's Apollo Speciality Hospital in India for bonemarrow transplantation. This life-saying procedure is not available in Sri Lanka.

With the Sunday Times article, 'Give them the joy of parenthood' on July 4, 2010, bringing to our readers' notice the couple's need, there was no turning back. Men, women and children not only from the far corners of Sri Lanka but also all over the world, dug deep into their pockets and the collection swelled. With some taking the trouble to drop their mite ranging from 50-100 rupees and others lakhs of rupees, the final count by the time

the Bubble Baby had to have a lengthy stint in India was a huge Rs. 5.3 million.

Back home from India last month, with his counts improving (SCID is a disorder in which the immune system's cells, especially T-cells are affected, making him vulnerable to life-threatening infectious diseases), he is still on a daily medication regimen of eight pills and three syrups.

"I crush the pills and mix them with the syrup," says Damayanthi, explaining smilingly that when Shiyanka sees her doing that he wobble-walks to the corner of the bed and attempts to keep his lips tightly sealed. He also grumbles to be taken out into the garden to avoid his medication.

> Looking at the colourful books he has been gifted by other patients at Apollo or playing with the colour pencils given by ConsultantHaematologist Dr. Revathie Raj under whose care he was, when Shivanka sees the picture of a hen he says, "Ba...ba," according to Damavanthi, and when he sees a dog

through his room window says "Buk, buk", making the sound of barking.

While the local doctors will take good care of him, Damayanthi will have to take him back to India for a check-up in six months and the couple is still struggling to pay back the arrears amounting to Rs. 2.3 million of the hospital bill there.

Neil works long and hard, going into remote villages to sell mattresses, after hiring a lorry at great cost. "We not only had to sell the lorry we owned to meet the baby's medical bills but also everything we had," says Damavanthi, explaining that they may also have to sell their home.

Amidst the hardship, bills and worries, as she lights the tiny oil lamp before the statue of Lord Buddha at the shrine in their garden and says the gathas, with Shivanka repeating them in baby language. Damayanthi not only gives thanks for saving her little one but also remembers all those, you our readers, who are instrumental in keeping him alive.

"How can I ever, ever, thank them," asks Damayanthi.

