

# The Bhopal Medical Appeal

Charity registered in England & Wales, No 1117526

Dear Supporter,

My name is Tabish and, though I wasn't born here, I live in Bhopal. My studies were in biotechnology and business but I've chosen a different path and now work as an Information Officer for Sambhavna and Chingari, the clinics whom you support. I don't ever regret my choice of career.

Over the four years I've worked at Chingari I've seen a lot of children grow and develop, often in ways that couldn't have been imagined when they first came to us. I hope you don't mind if, with the help of their mothers, I share a few of their stories of struggle and progress with you.

While I was trying to decide which of the children's stories to share I found something I'd written shortly after joining Chingari, at what was at a testing time for me. I'd just visited the house of a boy named Imtiaz who suffered from cerebral palsy. Thanks to careful therapy Imtiaz's condition was improving and he was beginning to respond to sights and sounds but one day, after his parents stopped being able to bring him to Chingari, he had suddenly passed away. I went to talk with his mother. Her voice was filled with grief - it is impossible for me to write her pain in words. The following day I sent this email:

*I was really sad after yesterday's experience and was not feeling good. Whilst walking through the main corridor on my way to collect information about Rahil I was stopped by Zehra, another child who comes to Chingari. She held my fingers and, with her unusual voice (she has issues with speech, as well as leg deformities), she asked me to make her walk - or, I felt she was asking for that, as it is really difficult to understand her words. So, I held her fingers and helped her walk through the corridor. I don't know how, but in that small walk that small girl managed to bring a lightness back to my heart. It helped me return my mind to my work.*



## Zehra & Nusrat's story

Nusrat says that her daughter Zehra used to walk like a crab, moving painfully on hands and feet, crouched close to the floor, her knees bending the opposite way to normal. The syndrome is known as *genu recurvatum* and can be caused by cerebral palsy and wasted muscles in the lower limbs, from both of which Zehra suffered. To add to her misery Zehra had *anklyoglossia*, or a tied tongue that thickened her first sounds and prevented her from learning to speak at the same rate as other children.

Lengthening the list of debilitating afflictions were *hygrophobia*, a fear of moisture (Zehra couldn't bear to be touched by anything wet), *eremikophobia* or a fear of sand, and a *strabismus* or violent squint.

This complex little girl came to Chingari when she was three years old. Despite her problems, Zehra is good-natured and willing to work hard to get better. When first with us she spent a great deal of time in our physiotherapy room doing compression and muscle-strengthening exercises, practising carrying and lifting techniques, and learning to balance on the beam and equilibrium board. Regular ocular exercises have helped reduce her squint. There's a lot to be done so we have taught her mother Nusrat some simple exercises for Zehra to carry out at home.

Because Zehra is so affectionate she makes friends easily. She carries about a much-loved doll to which she is a perfect mum, feeding it, tenderly putting it to bed. Recently she has discovered music and asks her mum for the radio as soon as she wakes up. She likes helping in Chingari's garden, playing with her friends Rishikesh, Sana and Subhana and loves to be sent soaring on the playground swing.

Six years after she first came to us, Zehra is eight and grown tall. Wetness and sand no longer bother her and other sensory problems have become negligible. Her squint is barely noticeable and she now wears glasses so she sees well. With the aid of modified shoes, Zehra is now able to stand and walk on her own. Whereas earlier she could only say 'papa' with clarity, she's now able to use sentences such as '*Papa Ghar aa jao* (Papa come in the house)' or '*Papa Mandi gaye hain* (Papa's gone to the market)' and make herself understood. Though she doesn't yet much care for writing, Zehra has learned the alphabet from A to Z and is showing good progress in the school nursery she now attends alongside Chingari.

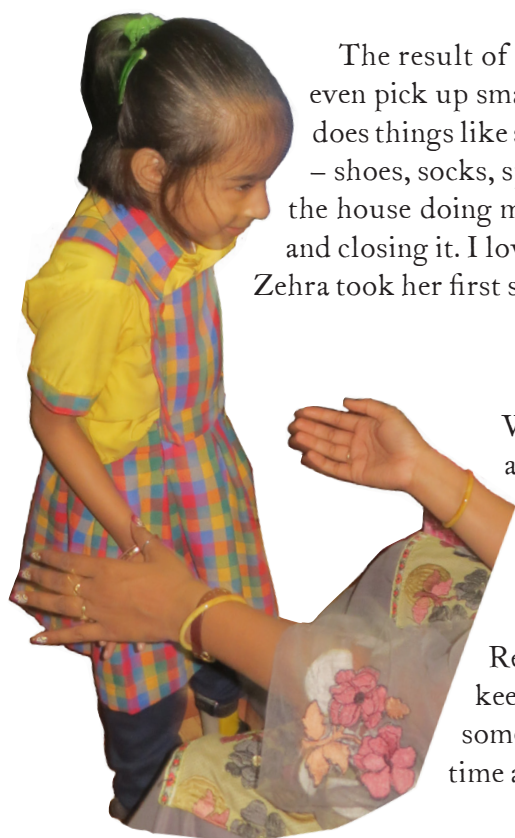
The result of all this? 'She used just to sit still and do nothing and couldn't even pick up small objects,' says Nusrat. 'Now she wants to help me cook and does things like sorting vegetables. She has learned to look after her own things – shoes, socks, spectacles. She has also become much naughtier! She flits about the house doing mischief – she broke the dresser drawer by constantly opening and closing it. I love it! But the best moment of all for me came at Chingari when Zehra took her first steps.'

### One tiny triumph at a time

When Rehanna first brought her son Sohaib to Chingari he was a small crumpled heap, unable to lift himself from the ground. Born with cerebral palsy he could not sit up for long, nor chew his food or swallow properly.

'Life was very difficult. He was crying 24 hours a day,' says Rehanna. 'He slept neither night nor day. I got no sleep as I had to keep him in my lap at all times. When I cooked I had to give him to someone else to hold. Sometimes lunch would get cooked at dinner time and vice versa.'

'The stiffness in his body made it difficult to hold him properly and his body became even tighter when he cried. He would only take a little milk, at most one bottle a day. I



Zehra, practising her steps

was at my wit's end but then my husband's aunt told us about Chingari.'

Rehanna has been bringing Sohaib, now five, to Chingari for over three years. When he arrived, we found that the musculature of his mouth and throat was severely constricted. It was hard for Sohaib to open his mouth and to chew and swallow, let alone form words. We started him on special exercises to relax his jaw and initiate teething. He started to drink milk and chew his food. To Rehanna's huge relief, he was able to sleep normally through the night.



Chingari occupational therapist Poonam working with Sohaib

Physiotherapy has helped by loosening his limbs and improving his mobility. Our occupational therapist Poonam patiently taught him to crawl and sit unaided for increasing periods of time.

In his social education classes Sohaib learned to tell the difference between sweet and spicy flavours and discovered the joys of *kheer* (creamy rice pudding) and of spiced *daal*.

'After only a few visits to Chingari Sohaib stopped crying so much and began to understand things,' Rehanna explains. 'He started recognising his father and smiled at him whenever he came into the house. He loves his father the most. Sometimes he refuses to drink from my hand and we have to call his father home from the middle of work so that Sohaib can drink his milk.'

'Because of stiffness, Sohaib wasn't even able to lie down properly before coming to Chingari. Now he not only lies comfortably, he has also started rolling and can sit on a chair with support.'

Sohaib also began making real efforts to stand, painful yet hopeful to witness. Today, with the use of supports, he has achieved this. In time he may be able to stand unaided and Rehanna hopes that one day she will see her boy walking.

'If today Sohaib can stand, tomorrow he might walk. We have a lot of trust in Chingari. The therapists take care of my child as though he was their own.'



Sohaib, aged three



## Anju & Krishna

When Anju's son Krishna arrived at Chingari, his legs were rigidly crossed, impossible to ease apart. He looked as if he were attempting some yogic exercise, yet yoga, supremely flexible, is the very opposite of what this poor child was suffering.

Krishna's spasticity had pulled all his muscles taut. His fists were tightly clenched and his fingernails dug into his palms as they grew. To cut those nails, one by one uncurling his tiny fingers, was difficult and nervewracking.

With his balled fists Krishna was unable to use his fingers, he couldn't eat, couldn't point, couldn't reach out and touch or do any of the hundred things that children, and all of us, take for granted. Can you imagine what your own everyday life would be like if you had no fingers?

Krishna was a baby when he came to us. Born, like Sohaib, with cerebral palsy, his neck muscles were too weak to support his head, he lolled forward looking down at his crossed legs. He could not lift his head to see the green parakeets in Chingari's garden, a kite flying, or a starry night. How cruelly ironic to be forced instead to stare day and night at the legs that denied him the power to walk, run, and play.

In most ways other than physical Krishna is a normal little boy who loves singing and whose favourite treat is a bar of chocolate. He listens keenly to the voices and laughter of other children as they run around the corridors and playground.

It has taken seven years of careful physiotherapy to loosen Krishna's frozen limbs. He can now hold up his head, unclench his fists and has begun sitting up using the support of his knees.



His speech is slowly improving and he can say simple words like papa, mummy, hello, come. He recognises and can name the colour yellow. When watching cricket, he will clap keenly if a batsman is given out.

In addition to speech therapy, Krishna's treatment focuses on strengthening exercises, stretching Achilles tendons and hamstrings. Following this steady preparation with Sanjay, his therapist, Krishna was able to begin standing using support. Unfortunately Krishna suffered a small seizure, setting back his progress by several months. The work of preparation has therefore begun once more.

Krishna's mother Anju says that she is ready to spend the rest of her life trying to help her son.

### Krishna's speech therapy

'There's tragedy enough in our family,' she says. 'My husband used to be a driver, but since the gas he has had breathing difficulties, and even though it's over thirty years ago now, he is still getting worse. I believe Krishna would have been highly disabled without Chingari: he has shown so much improvement after coming here. I live for the day when I will see my son stand on his own two feet and – who knows – maybe even kick a ball.'



## Learning to dance

‘In our family we are all damaged to a greater or lesser extent,’ says Bushra’s father Altaf. ‘Myself, all my family. Sufiya my wife. All her family.’

Both Altaf and Sufiya breathed Carbide’s gases on the terrible night of December 3rd 1984. Altaf thinks his own injuries were not particularly serious. ‘True,’ he says, ‘I am often forgetful. Walking leaves me a little breathless. There are times when I feel there’s nothing wrong with me, but then if I have to run breath’s gone, lungs are burning, heart’s banging in my chest and it feels like my blood pressure’s rocketing. The truth is that we are all affected and our lives are not what they were. There’s all the difference in the world between our lives before the gas and how we are today. Our worst fear is that the gas has also affected our children.’

In the months after their second daughter Bushra was born, Altaf and Sufiya had to face the fact that she was not behaving like other children of her age. ‘She couldn’t sit up or crawl, nor could she say a word, and it was soon obvious that she did not understand anything we said to her.’

Bushra was eighteen months old when her parents first brought her to Chingari. Within the first year she made great strides. ‘Earlier she could not sit,’ said Sufiya at the time, ‘now she can sit on her own, without help. When we call her name she responds and it’s clear that she understands. What’s more she has started to talk and can say *amma* (mother), *abba* (father) and *bhai* (brother).’

‘Plus,’ Bushra’s father reminded her, ‘she’s learned to tell us when she’s hungry by smacking her lips. Like this – muh, muh, muh. It means, “I’d like some milk please.”’

It’s clear that Bushra’s parents are delighted with the progress she has been making over the last three years. She can now stand and walk independently, perform squats and climb stairs under supervision. She greets her friends in class, and says goodbye when she leaves.

‘I feel that if she continues to improve at the same rate then she might be talking properly within the year’ says Sufiya. ‘She’s become very attached to her aunt and so tries to copy her. When her aunt is doing her exercises, for example, Bushra will start exercising next to her. Not only is she walking, she has started running and jumping, too. And whenever she hears music, - any music - she will break into dancing! Bushra can even play by herself now. Sometimes, when playing with her doll, she gives therapy to it.’



Bushra

Bushra and her family live a fair way from Chingari and used to find it difficult to get to the clinic. ‘It took a lot of time every day, which affected the time I spent earning’ says Altaf. ‘Though it caused difficulties we decided it was worth the sacrifice to get here. But then, Chingari was able to begin sending a minibus to our area and we no longer had to struggle.’

‘This clinic is a very special place. It’s doing outstanding work and it is run by a good group of people. The staff give the children lots of love and affection. The children here know that they are loved. And we know it too.’

## Our greatest gift

Chingari Rehabilitation Centre was founded to give first-class care and social support to Bhopali children born disabled, and to their families. We provide physiotherapy, occupational & speech therapy, and social and educational training, all of it entirely free.

Chingari's founders, Champadevi Shukla and Rashida Bee, are both survivors of the 1984 gas disaster, and both have disabled children within their own families. In 2004 they were named joint-winners of the Goldman Award in recognition of their long and selfless service to survivors of the 1984 gas disaster. They gave all of their \$125,000 prize money to set up Chingari.

Thousands of babies are born damaged in Bhopal, most in the *bastis* (poor neighbourhoods) near Union Carbide's now-derelict factory, source not only of the lethal gases of 1984 but also of toxic wastes that continue to leak from the site, contaminating the drinking water of thousands, causing sickness and birth defects.

A community health survey by the Sambhavna Clinic, due to be published in 2016, identifies at least 2,500 children born damaged in these areas. However, the authorities do not recognise disabled children born to gas-affected people or families whose water is poisoned as victims of Union Carbide and there is no official programme to help them. Parents who cannot afford to pay hospital charges or exorbitant doctors' fees must watch helplessly as their child struggles to survive.

Chingari's care is therefore a real blessing to poor families and there is a long waiting list of those wanting our help. Sadly, we do not have the facilities or funding to look after them all. There are over seven hundred special children on our books, of whom some two hundred visit the clinic every day. The daily journey can be difficult for parents and children, and without help many would not be able to come, so we provide five minibuses which tour the *bastis* each morning to bring mothers and their children in for treatment and take them home again afterwards.

Because so many children who come to us are undernourished we also make sure they have a good lunch; the sweet rice porridge is especially popular. All of these services are free. I hope you feel proud to support this work.

If you have received a copy of the *Chingari Bazooka*, the newspaper the children themselves draw and write, you will know how important the clinic is to their lives. As Sachin, a Chingari teenager, wrote in a poem about his life at the clinic, 'the love shown by Apa and Didi and all the folk at Chingari, has taught me to love my life.'

Chingari's greatest gift is in showing parents and children that they are loved, that they matter and that they are not alone. This is your gift, too. Wishing you very happy festivities.

*Tabish*

Tabish Ali



Zehra and me at a Chingari picnic