



AN ODE TO  
ARUN SHAH

against  
all  
odds

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YASHWANT R SHAH

# **Against all Odds**

**Arun Shah**

**This is a story about Arun...**

**a courageous soul with a never-say-die attitude, a winning personality  
and yes, many severe physical infirmities.....**

**It is also a story about his parents,  
who persevered even when doctors gave up hope,  
overcoming their own ignorance and despair,  
learning through trial and error,  
struggling to gift their son  
a feeling of inclusion, self-esteem and emotional well-being.**

**It is about inspiring a specially-abled person to focus  
more on his abilities and less on his limitations,  
about creating for him a loving, normal, fun-filled world  
a world he enjoyed waking up to,  
about giving him a zest for living, sharing and caring  
with healthy relationships to cherish;  
all the while nurturing the delicate network  
of immediate family, relatives, friends and associates.**

**As it turned out, Arun was destined  
to experience life  
in many more fulfilling ways than one would imagine,  
given his constraints.  
Perhaps the secret lay in the positive environment provided for him,  
which paid richer dividends than any other investment in life could have.**

**This amazing and wonderful little hero,  
boldly soldiered on, unstoppable for 39 years...doing everybody proud!**



**Our Valiant Soldier**

## **Acknowledgements**

Our dad, Yeshwant R Shah wrote this book with the intention of inspiring readers and helping them take solace in knowing that they are not alone. It is not intended for commercial purposes. I have co-authored this book and sincerely hope that the readers find the courage and motivation to lead fulfilling lives.

This book is very dear to us and would have not been possible without support from many quarters.

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But most of all, the invaluable support from Neelu, my sister, Jivan my brother-in-law and their daughter Alisha; Shailendra, my husband, Krishi and Karan my sons.

Raj Shah for his valuable feedback.

To conclude this thought, this book was an endeavour by my dear dad to reach out and perhaps inspire families with a journey similar to ours. I, on my part hope to make it a reality and fulfill his wishes.

***Versha Bhuta***



# 1

To begin Arun's story, we need to visit a time well before his birth.

My roots go back to Mombasa, Africa, where my parents, Ravilal Makanji Shah and Rambha ba were settled. As the Second World War shook the world, our family of 10 was forced to flee Africa and set sail for India on a small steamer along with other Indian families. We landed in Mandvi, Kutch, via Bombay after 10 days of seaborne adventure, tired, uncertain and unaware of what was in store for us.

In Mandvi, we tried to rebuild our lives, which had changed so suddenly. My adolescent days were spent trying to find my bearings, all the while adding friends, attending school and acquiring a growing reputation as a prankster! But Mandvi was not the right place for a progressive-minded, energetic family like ours and we decided to relocate once again. My father set up home in Ghatkopar - a suburb in Mumbai, the erstwhile Bombay, in search of better prospects. As for me, after a few small-time jobs, I found myself working with Sumati bhai, a respected person in the crockery business.

We bonded instantly, built mutual respect and soon he saw in me a prospective groom for his younger sister, Rama. Our families were known to each other; both parents were highly respected members of the Gujarati community, and my father was widely acclaimed for his contribution to social reforms. This fortunately left no grey areas to scrutinize as far as family lineage was concerned, on either side.

Sumati bhai's plans moved swiftly, and when Rama came to our shop to, "sight the tiger" on some pretext, we were instantly attracted to each other. We tied the knot on April 30, 1955, and wedding celebrations soon eased into togetherness, children, travel and the normal dreams that every young couple looks forward to fulfill. In the interim, as a matter of principle, I quit my job at my in-laws' place much to everyone's dismay, and signed up for a job in Nagpur.

This new job meant I had to travel constantly, moving back and forth, struggling to divide my time between work and my ever-growing family. I must give credit to Rama for interacting well with my 11- member family of self-expressed strong personalities. Our kitchen was transformed into a makeshift bedroom when I was in town and she coped well under these restrictive circumstances. Our daughter, Neelu was born on June 20, 1956 and then Versha came along on July 23, 1957.

A couple of years later we were expecting our third child.

Life was shaping up fine except for the fact that this time Rama's pregnancy seemed different. She was distinctly disturbed, uneasy with a deep sense of foreboding that she could not understand. Several times, quite late into the pregnancy, she complained about the baby's lack of movement. Though she did have medical check-ups, medicine had not advanced enough to investigate her concerns fully.

On December 11, 1959 while I was travelling, the family set about the routine of yet another normal day in Mumbai, and whilst our two small daughters were busy in their carefree world playing with their dolls, our little son entered this world.



### **Our Star is Born**

But the eager anticipation for a newborn's arrival was soon replaced by shock! Our baby was born with obvious multiple problems of varying severity; so unusual were his problems that they baffled both doctors and family elders. Confusion and inexperience compounded by firm conviction from doctors, about our son's survival beyond a few hours, left us totally shattered.

Helplessness, panic and disbelief all converged on us like an avalanche and the mere thought of losing our little baby boy was unbearable! In retrospect, Rama's earlier apprehensions of things not being right were validated. Neither our adverse circumstances nor any other prior difficult experience came even close to preparing us for the challenges that awaited us. Nothing!

The more we saw our son, the more confused and helpless we felt. What we saw was a tiny newborn with an extraordinarily large-sized head because of the water collecting in his brain. The skull was not fully formed and there were gaps between the skull bones, which we could feel. On his spinal cord just above the waist was a large open wound. Both his feet were crooked and bent inwards. His eyes did not close and remained open 24 hours, even when he was sound asleep, due to the acute water pressure on his brain. To avoid dangerous injuries or infections like meningitis, the doctors had to frequently drain the water from his brain with a syringe. Arun was kept under observation as the doctors grappled with the best course of treatment for his condition. However, three renowned child specialists and our family doctor were skeptical about his survival.

Well, Arun clearly had other plans! Our prayers were answered and he navigated each day, strengthening our resolve to help him to the best of our ability.



**She is Mine**

Arun, adorable and cute, followed his destiny and proved the doctors wrong, living for nearly four decades absorbing the pain, limitations and dark moments, with dignity and resilience. Subsequently, we learnt that the maximum span of life recorded for such children throughout the world was 38 to 40 years, and we are deeply grateful that he lived his full life. Arun enriched our lives, captivating all who came in touch with him. Despite all the serious challenges we faced, his very presence gripped us with a feeling impossible to express. He became the axis around which all our lives would revolve.



**A Different Perspective**

In time, we learnt that Arun's affliction had a name. Spina Bifida literally means "split spine" that occurs when the child is still in the womb and the spinal column does not close all the way. It is a congenital defect of the spine in which, part of the spinal cord and its meninges are exposed through a gap in the backbone, often causing paralysis of the lower limbs. Nowadays, surgery to close a newborn's back is generally performed within 24 hours after birth to minimize the risk of infection and to preserve existing function in the spinal cord.

Hydrocephaly or hydrocephalus, a common companion of Spina Bifida, is an abnormal build-up of cerebrospinal fluid (CSF) in the ventricles of the brain. "Hydrocephalus" translates to water in the brain and can be damaging. We know that today the treatment of hydrocephalus involves the insertion of a shunt to let the excess fluid drain, relieving pressure on the brain. In some countries, like the US it is the most common permanently disabling birth defect, and about eight babies a day are born with similar conditions. The causes are unknown but one theory is that it is a genetic disorder.



**Knotted up a Bit**

We are wiser today, but back then, had we the comfort of this knowledge or support of sensitive doctors, we could have escaped the ensuing fear and demoralization that could have defeated us and proved dangerous to the well-being of the baby. It is fortunate that did not happen.

This book is prompted by a deeply felt desire to inspire other families that might experience such an event in their lives, and instill a sense of confidence that with the right mindset and a positive environment, anything is possible.



## 2



**Love the View from this Seat!**

We were a lower middle class family of 11 that lived in one big room and a small kitchen. With Arun's arrival home, everyone in the family realised that adjustments had to be made. My family, all positive-thinking individuals, made me proud; they stood unflinchingly by our side. We all accomplished this seemingly stupendous feat of nursing Arun by mere observation, commonsense and application of our minds individually and as a family.



**My Father, Arun and I**

My father, a strong personality with great insight and a practical, encouraging outlook on life, suggested we try alternative therapies, which have evolved over thousands of years and been traditionally followed in our country. We experimented with ayurvedic, homeopathic and herbal alternatives. An ayurvedic doctor suggested that we apply a special type of mud on the head to drain the water, which was fast accumulating in the brain, a therapy that proved partially successful.

However, the list of complications remained long. He had high fevers; frequent wound infections and no control over his bowels or bladder. The final challenge came when we discovered that there was no nerve sensation below his hips, starting from the thighs right to the feet. In the absence of medical help, the only thing left for us to do was to apply commonsense to comfort our child.

We experimented with untested methods coupled with healthy doses of positivity to help alleviate Arun's unusual problems. We made heart-wrenching and tough decisions, as untried medication might prove risky. In an odd way, what made it bearable was the fact that we didn't have the luxury of any other options!



**Grandma's Pet**

One significant fact that bears repetition was that while the medical world forecast the worst, Arun continued to live on, week after week, month after month. His sweet and innocent gaze stole our hearts. Rama, young, inexperienced and just 21 years old, was deeply disturbed—it was a very traumatic time for her. I was at a loss and confused, but unwilling to give up on our child.

Due to Rama's depression and shock, her parents took her to their own home in Calicut for a few weeks. This turned out to be a blessing in disguise because it was here that Rama's elder brother and my mother-in-law who were believers in Bio-chemic medicines, decided to try some formulations. By then Arun was 4-5 months of age. He would lie down in one place, unable to turn his heavy head with his eyes open all the time.

After some weeks, the bio-chemic medicine showed results, which encouraged them to further pursue the line of treatment. Their efforts paid off! Soon, to everybody's delight, Arun was turning his head from side-to-side on his own, and there was a marked improvement in his eyes, which he could move. Now upbeat, my in-laws persisted with the treatment and within a few days, a major development occurred. The water collection in his brain stopped increasing - a fact medically confirmed later. The progress of the Hydrocephalous was arrested, which according to the medical world was a miracle.

Faith begins where reason ends. Magic was happening. Arun began to open and shut his eyes normally and he was actually smiling. We were elated! When we returned to Bombay, Arun was definitely in a better condition. We decided to pursue homeopathic and Bio-chemic treatments more professionally. This was certainly a wise decision given our financial constraints. We couldn't afford to spend on experimental cures by allopathic doctors, especially since their advice and opinion was negative and held out no hope. From then on, we resorted completely to home remedies and alternative therapies.





**Always the Centre of Attraction**

My job provided a woefully inadequate salary and involved a great deal of travelling; I could not stay at home and help constructively in the situation. The family managed as well as they could—there was no other option at the time. Arun completed one year and everyone was very attached to him. He had an endearing smile and a magnetism that drew everyone towards him.

Rama, to her credit, came to terms with Arun's condition and immersed herself completely in his care with a positive outlook. Arun's many physical challenges were demanding and she was left little time to brood. Mothers have unimaginable reserves of strength and Rama rose to the occasion with incredible spirit. She set aside her own feelings of helplessness and approached the immediate need to look after our son with quiet determination and will.

It was under such conditions that fate intervened and brought about a welcome change in our lives.



**The Shah Team**



# 3

Our life took a turn for the better when my company transferred me to Calcutta. I went ahead to my new place of work while my family stayed back in Bombay for the first six months and then I took my wife, two daughters and son to Calcutta with me.

This move brought about many beneficial changes in our life; we were able to do a lot more for Arun. By then, he was a year and a half and I was no longer required to travel. The Company provided me with a big house, a garden and pleasant surroundings, a welcome change from our crowded one-room residence in Bombay.



**Special Friends – the Heroes  
who made a difference**

Arun and our daughters, Neelu and Versha, spent an idyllic childhood here in Agarpara, a place close to our hearts. Into our lives entered the Hose family from England - Julie, Jeffrey, Colin, and Mr and Mrs Hose; Kariappa and Prema. Life became a little less tough and much more enjoyable as they supported and befriended us in invaluable ways at every step.

As I could not take my daughters out frequently, the Hoses and Kariappas often took the responsibility of taking them for movies and other outings ensuring that they led normal lives whilst Arun had other homes to visit and enjoy comfortably. Arun turned out to be our little hero who, with his antics, his charming smile and frailty, endeared himself to all.

My new employers, The National Tobacco Co, supported me in every way possible. Lady luck had accompanied Arun into our lives and there was all around progress. We were able to get live-in help, who Rama handled compassionately while training them on the job.

In the absence of guidance from doctors, the only way forward was for us to tirelessly monitor all of Arun's problems. It is from here that new directions opened up for us towards a better understanding of Arun's debilities and the best ways we could contribute to alleviating them. Homeopathy became our magic wand and we were blessed by knowing a competent doctor who also taught us the art, much later down the line. Every member of the house, including our young daughters and the help, were instructed to closely watch and report anything unusual and were trained to help Arun become as comfortable as possible. Choices had to be made frequently and at every juncture.



We never spent on usual luxuries but rather made sure there were two full-time attendants for Arun. Rama was always conscious of the fact that the help had left their families to look after her son, and treated them well with generosity and kindness, never allowing them to feel any lack in their lives.

The pressure of looking after a specially-abled child did undoubtedly affect our life, particularly in the absence of knowledge about this affliction. Additionally, Arun developed a serious problem of epilepsy and we were at a total loss but were compelled to move forward all the time and deal with each new crisis as it came along. The lack of any professional medical guidance created a situation fraught with continuous anxiety and stress – we acquired additional know-how reading books and magazines.

An early but hugely significant triumph was of a more personal and delicate nature. When Arun was around two years old, our willingness to try unorthodox remedies successfully solved a key issue. His one serious problem was constipation. He had no control over his bowels or bladder. Frequently, either he would wet himself or he would soil his clothes without realising it. This was a daily and deeply troublesome problem, and yet again medical advice failed to help us.

Again, a chance observation came to our aid. One day as Arun was laughing loudly at a joke we noticed that such forceful laughing led to him soiling his clothes! Realizing that this was something that could be used to his advantage, we started an experiment; at a fixed time we would tickle him and the laughter that ensued helped toilet train him. By consistent timed application of this action, just once or twice a day, we won over one more challenge and another serious issue was solved using unorthodox methods. A folding wooden lightweight commode-chair was made for him specially, which was carried wherever we went, being particularly useful during train travel.

At two and a half years of age, a significant event changed Arun's daily life forever. We were on the other side of the house discussing something loudly. My son was far away in his bedroom, lying on the floor playing with some toys, and must have got very curious about the loud conversation. We were utterly shocked when he pulled himself into the room where we were sitting. It was unimaginable that he had dragged himself on his belly, a virtually unattainable feat in our minds since he could not even lift his heavy and enlarged head a few inches above the ground. Yet he had lifted his head above shoulder level while lying on his belly, and had travelled the entire distance of 100 feet, which was impossible to believe. He could not use his feet, which had no sensation at all, and had moved with the help of his hands only. The very first thing we checked was whether any injuries had occurred. But we found nothing and he seemed delighted and laughed loudly at our incredulity. While we realised this was a progressive development, we were aware we could not allow him to drag his body over a great distance, as the possibility of injury was high.



Necessity became the mother of invention! I narrated this incident to one of our factory engineers who came to the house to understand exactly what had happened. In a couple of days, the engineer designed a small wooden cart with castor wheels, proper protection on two sides, and a wooden paddle with handles to propel the cart forward. We were very amused and certainly overjoyed to see the little fellow zipping all over the bungalow in this cart. Since then Arun became totally mobile within the house.

### **My Racing Car**

This made a tremendous difference to his daily life; not only in terms of physical movement but also the amount of emotional pleasure he derived from this. We then realised that there was a great deal we could do for the child by adding simple homemade inventions to enhance his day-to-day comforts.

Sometimes, he used the cart as a vehicle to charge into battle when he was annoyed or angry about things and a sobering realization crept in that here was a boy stepping into teenage mode!

Arun defied known concepts; he unknowingly challenged us to achieve the impossible. The cart was just a beginning—but an important one that freed him from many limitations and also allowed us to imagine greater possibilities for him.

Another significant incident occurred. One afternoon as Arun was lying down in the verandah of our house and playing, Rama suddenly noticed there were thousands of red ants on both his feet, which were covered with very tiny drops of blood, a horrible and disturbing sight to witness! We realised that since Arun had no sensation in his feet he felt no pain and was blissfully unaware of the ants. Fortunately, this did not do any serious damage, but it did create havoc in our minds and since then we were more watchful.

Another incident, which was a constant reminder to not leave Arun alone, was the time when he was sitting in a chair near a small fishpond with other children playing around him. Suddenly, we heard a terrible sound and realised that Arun had fallen into the pond. He had leaned forward to watch the fish and his head being heavy, he lost his balance and fell when Sarmeshwar bhai was away for a few minutes. Luckily we managed to rescue him in a couple of minutes, but not before he had swallowed some water! That evening, sure enough was followed by shock and seizures, and one can never blot out that scary incident, which highlighted the fact that we could not let our guard down with him for even a minute! With Arun, every day was different, and we alternated between agony and ecstasy, with no letting up.

Arun was naturally left-handed but whenever he lifted his left hand, the right hand would also involuntarily repeat the same action. Even while eating or handling any material, both hands would behave identically. We were wondering how to generate normal separate hand movements when it occurred to me that we could give him some kind of exercise or game that would induce movement of both hands. Music entered our lives. We hired a tutor to teach him the tabla, playing of drums, where automatically both hands had to act separately. This also triggered our joyful family musical evenings that were held frequently, as we were music lovers, which continues till this day.

A few months down the line, his movements started becoming free and independent. The next project was to encourage him to type on an old typewriter where both the hands moved separately, initially with a single finger, but in time both the hands acted normally and independent of each other. This process continued till he turned six and by then he had already achieved success in many other minor problems of day-to-day life, boosting our morale tremendously!



# 4

When Arun was still young, many of his daily limitations were solved or reduced in effect. Increased mobility due to the cart really expanded his interests. Then we found a tremendous change in him. He was very curious to know more about everything around him. He would browse through magazines, would read the newspapers, go through children's books and started developing an in-depth interest in many subjects.

During this period we came across some articles on Spinal Bifida Hydrocephalic children, where we learnt that such children are either precocious or dull. Fortunately, it turned out that my son was precocious and his grasping power was excellent.

One of the factors that we had to immediately consider was his basic education. It was clear by now that Arun was gifted with a sharp intellect and good memory.

Since he could not attend school we engaged a private tutor to teach him the primary subjects for a couple of hours daily. We decided he needed to learn only language, Arithmetic, basic Literature, History and Geography. His knowledge base expanded with greater interactions with the tutor, and he started taking an interest in many other subjects like poetry, music and history, which totally changed him.

During this time, he developed an interest in drawing and painting. He constantly questioned us about animals, birds, airplanes and automobiles, among others.

I noticed that he was fascinated with colourful birds and animals. My hobby was stamp-collecting and I prepared one small album for him that included pictorial stamps of different animals. This led Arun to the idea of collecting stamps.

Within a couple of years Arun became a keen collector of animal themed stamps. He also developed a tremendous interest in airplanes and aviation and had many questions on aviation history. We did our best to provide him with all kinds of literature, books and pictures. Arun then went on to become a recognised collector on aviation and even won several medals at national and international exhibitions for his aviation themed stamp collection. This hobby enhanced his general knowledge and insight and led to him dealing with stamps in his 20s.

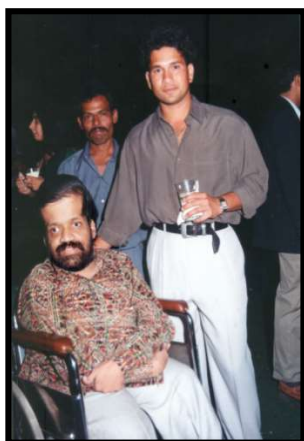
While he was a natural learner, the other factor that made him learn, talk and communicate faster was the cosmopolitan nature of our neighbourhood. We were staying at the Company-owned accommodation commonly known as Agarpara - where the other occupants were foreigners or from other parts of India.

The children around us came from dissimilar backgrounds and Arun enjoyed playing and spending time with them. He was in good spirits and eager to take part in all celebrations during festivals and gradually began to enjoy hosting small parties at our home. This free and diverse interaction aided in developing wide-ranging interests such as indoor games like Carom, Ludo, Chess and Cards. He also enjoyed drawing, painting and poetry. He looked forward to meeting people and making friends.

Arun came as close as possible to being like normal boys his age! In spite of his physical challenges he was mischievous and light-hearted, with a prankster's impish sense of humour. Together, he and Jeffrey proved to be a lethal duo and were constantly up to all kinds of mischief! One day when we returned after a trip to town, having left them together, the boys decided to give the neighbourhood parrot a bald look and had stripped the feathers off the poor bird. Another time, Arun and his cousin Vipul placed two puffed rice flakes on their unsuspecting grandmother's nostrils when she was sound asleep. They had a hilarious time watching the flakes swing around with each inhalation and exhalation! We guess there must have been many more pranks, but thankfully, they remain hidden from us!

Cats and other rescued stray animals always surrounded Arun. Lulu was a crab that Jeffrey kept in his pocket, and every so often he would call "Lulu" and the crab would climb out and look at all of us, as if saying hello. Rama kept small tortoises in a little pond in our garden and Arun, Jeff, Julie, Neelu and Versha, would spend hours frolicking there. These were very uncomplicated, simple joys, without gadgets like mobiles or televisions; but for Arun, these moments were what made him who he was--a positive, creative, secure and loving young boy, towards whom every one gravitated! He was everyone's darling, to be loved, pampered and protected.

Unexpectedly, he developed an interest in cricket and started listening to cricket commentaries on the radio. This passion for a game, which he would never be able to play, continued for many years



**Rubbing Shoulders with Celebrities!**

He also developed a keen interest in Hindi film music and loved the work of singers like Mohammed Rafi, Mukesh, Kishore Kumar, Lata Mangeshkar and Asha Bhonsle, I bought him a gramophone with records of his favourite songs and he spent many hours listening to their wonderful melodies.

Arun's repertoire of interests was truly remarkable.



# 5

While there was tremendous all-round progress in his daily life, there were other serious developments concerning his health. When Arun was two and a half years old, he had a severe and entirely unexpected attack of epilepsy. This new development was both alarming and unsettling. We tried some home remedies to no avail. Our company provided for a resident Doctor who treated Arun but seeing no improvement recommended immediate hospitalization.

Our staff quarters were located on the outskirts of Calcutta. The best hospital for neurological problems was about 15 kms away and going through the notoriously congested streets of Calcutta, could take at least two hours.

This seemed like an impossible situation, as Arun's fits were incessant. We went through a nerve-racking time fearing for Arun for the next 45 minutes but managed to reach the hospital.

The seizures continued for the next 72 hours and we were given very little information. The hospital management was strict and we were not allowed to be with Arun. We gleaned bits of information from the nurses and ward boys.

Finally, after 72 hours of anxiety and anguish we were informed that he was out of danger, the seizures had stopped and he had regained consciousness. The torment of those moments ceased instantly the moment we saw Arun's face and had him back with us.

After 12 hours, we could finally take Arun home. We were advised that Arun would have to take some special medication regularly to prevent further attacks.

It was during this time that an in-depth health examination was completed and the open tumor on his back was reassessed. We were advised surgery to resolve this issue. However, the top-ranking doctors had different opinions. One neurosurgeon told us that it would be dangerous and ruled out surgery completely. Subsequently, within a few weeks, another famous neurosurgeon examined him and suggested we should go ahead with the surgery since it would help him immensely.

As parents, we were in a dilemma. My wife was reluctant to go ahead with surgery but I was positively inclined towards surgery.

The tumor was definitely a serious problem for Arun. It was a live open wound on his back, extremely sensitive to even the lightest of touch. There was also always the danger of infection leading to an attack of meningitis. Due to these reasons, Rama finally relented and Arun aged seven, successfully completed the required surgery in Madras (now Chennai).

Thereafter, we observed rapid progress in his daily routine. He was far more comfortable when lying down or seated.

The next challenge was to correct his feet, which were malformed and crooked. After the orthopedic surgery on both feet, we were advised to help Arun stand and eventually walk.



**Standing Tall**



**Amazing Efforts**

Towards this, we created a double bar stand for him to hold on to in an attempt to walk. This required custom-made calipers that were made under expert supervision. We helped him use the bars to stand and over a period of time he was able to for 10-15 minutes. That gave us great hope that he would be able to walk some day. But in this hope we were disappointed.





After many months of trying, we consulted another orthopedic surgeon from Vellore and were shocked to hear from him that it was not possible for our son to walk unless a series of orthopedic surgeries were performed, since his hipbones were dislocated from birth and there were problems with his kneecaps. Given Arun's current neurological concerns, the doctor advised against further surgeries.

### **Unending Trials Spanning a Lifetime**

So we reluctantly abandoned Arun's standing and walking rehabilitation programme. This was a bitter reality and we had to accept the harsh and painful truth that Arun would never ever walk. Thereafter, for the rest of his life, he remained dependent on wheelchairs for his mobility. Though he was bound physically, at heart, Arun always remained a free spirit!



# 6

Help came to us from many unexpected sources. It was during this period when our son was around 8-9 years old that we came across a magazine from the UK named “Link”. It was published in London and was specifically for Hydrocephalous bifida patients in England.

We were astonished to find there was a specific magazine in England dedicated to such patients. Almost every other town in England housed a number of such patients of different ages, both male and female. Some had partial problems of only Hydrocephalous, while others had only bifida and other imbalances in the body caused by those particular conditions. We felt a sense of kinship and derived great comfort from being a part of a larger community facing similar challenges. Of course, we subscribed for the magazine!

What was truly enlightening was the knowledge that such patients could do many routine things, which we had not thought possible. We now understood how far we could push the boundaries of such patients; help train them to overcome their natural limitations, while applying the required safeguards. This encouraged us to remove many natural restrictions on Arun and enabled us to enlarge his world through hobbies and travel. We were able to guide our son and he became more aware of, and responsive to, his own problems.

Arun simply loved to socialize.

It gave him immense happiness to invite people home. He enjoyed picnics and parties, and freely expressed his opinions on varied subjects. Fortunately, my company had a riverside bungalow with a swimming pool where we organized parties. We invited our relatives, friends and their children. The party included different types of games, songs, quizzes and anything of interest for children aged 12-15 years.

During these get-togethers we realised that Arun was interested in writing his own poems. We were pleasantly surprised that a boy who never had a formal school education, showed interest in many subjects.

It was very clear that while he had all kinds of disabilities, he was brilliant and had above average intelligence. Our life in Agarpara helped Arun flourish and realise his true potential. His quality of life saw many positive changes that contributed to his independence in many small ways.

During this time my company went through many changes too. The original owners left in 1973 and the company was taken over by an industrialist from Calcutta. Through my career of 20 years, I had progressed and prospered in the company from a junior officer to a top-level executive and the owners were very good to me. The thought of retiring from this company never occurred to me. The new owners wanted me to continue in my position considering my experience and knowledge of the company.

Through these changing times, my wife and I often thought about Arun's future and wondered what would happen if circumstances changed—perhaps a new place of residence or a new job. While Arun was well settled in a secure and comfortable environment with round-the-clock amenities and attendants, he hardly had any exposure to the outside world.

It occurred to me that unless I left the comforts of Calcutta, my son might never gain the kind of exposure that would enable him to manage himself in future. We had to ensure that he was self-reliant and gained enough confidence to be able to make independent decisions as he stepped into adulthood.

These thoughts prompted my decision to leave the company and move to Bangalore permanently. This was a milestone in my life too, and it was not a decision that many endorsed; as a matter of fact my own elders were disapproving. They did not appreciate my leaving a great job and moving to a new place, without an idea of what I was going to do next.

Their fears were not without reason. It was true that I did not have any job offers, nor did I have substantial savings. I had worked very hard from the age of 15, and by the time I left Calcutta at the age of 44 I had already worked for 27-28 years. I had two daughters to educate and my son needed two attendants permanently, which meant that unless I had a substantial income, I could not possibly take a step forward.

I discussed this with my wife and daughters and they supported my decision to start life afresh in a new city. This encouraged me and gave me strength to make this bold move.

One of the main reasons to choose Bangalore was its proximity to Vellore, which was a world-renowned medical center for many disciplines including neurological treatments.

My first order of business after moving to Bangalore was to take a break for the first three months. A once-in-a-lifetime opportunity to truly enjoy my time with my family. All we did during this blissful period was visit restaurants, watch movies and explore the city. After my hiatus, I decided to try my hand at an export-import business instead of a job.

I did not have the financial power but I had practical experience and this self-confidence enabled me to begin a new venture in the granite stone business after a period of 6-8 months in Bangalore. I chose this line of work because it required very low capital. I learnt everything through experience and over the next three years I achieved a lot through the granite business - name, fame and comforts.



# 7

The move to Bangalore seemed to have been blessed by the divine.

It was there that Arun's future took concrete shape; his exposure to the outside world grew in leaps and bounds. I decided to have my home and workplace in proximity so that my son could come to the office too. While Arun was completely sheltered in Calcutta, in Bangalore he never hesitated to tell the attendants that he wanted to visit the garden, the shops or even nearby restaurants. Thus over a period of time, he gained immense self-confidence to do things independently.

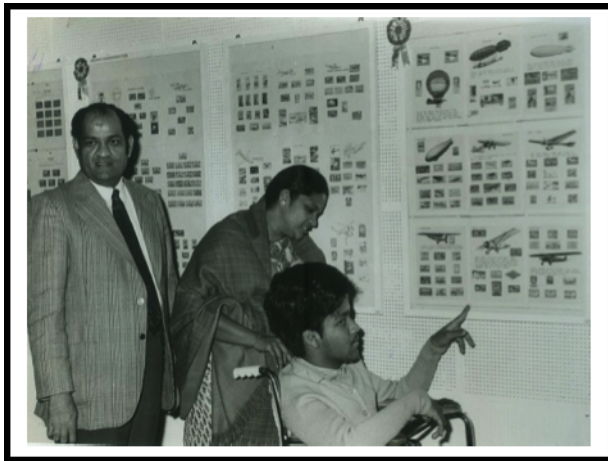
His hobbies of stamp collecting, listening to cricket commentaries and music developed further because by then we had a television at home and he was able to watch everything live.



**At his Desk**

As Arun grew more comfortable with his new life in Bangalore, so did his hobby on stamp collecting. He developed his own stamp collection on aviation and airplanes. He won several prizes including one silver medal in an international stamp exhibition, the INDIPEX 73. He became a member of the well-known philatelic federation on airmails in the USA. His knowledge was so vast that he was able to easily identify the airplane and corresponding engine. I was proud of what Arun had achieved in this field. His quest could have won him many more accolades but he could not participate in many of the contests, as I was a member of the international and national philatelic jury panels.

Arun's keen interest in cricket continued to grow and he understood the technicalities and had an insight of the game. It was ironical that I who did play cricket as a student did not know the technical terms of the game, whereas my son could explain every move in great detail. It was an unforgettable occasion when he personally met the renowned Indian cricketers, including the iconic Sachin Tendulkar.



**Stamped with Joy**

By the time Arun was 20 years old, the traumatic early-life experiences and doubts about his very survival were completely forgotten. His cheerful nature wouldn't let anyone, himself or those around him dwell on his shortcomings. Despite his limitations, he was eager to pursue his different hobbies and interests whether it was music, stamp collecting, painting, bird watching or travelling.



# 8

Arun was blessed in so many ways. He was never depressed; his mind was active, optimistic and intensely curious. He was willing to try anything and his sense of humour and smile never ceased to amaze us.

Travel was his doorway to the outside world. He wanted to visit and learn about different places from a young age and we readily agreed. We had to be mindful of the preparation required since his needs were unique. We had custom-made a folding lightweight wooden commode, folding wheel chair and a small folding table and chair that we could carry with us. We needed a modified vehicle to ensure comfortable access. Arun's two attendants accompanied us on our travels. We prepared an extensive travel kit to protect him from fever, injuries and insect bites.

With everything in place we planned our first holiday to Ranchi and Hazaribag in Bihar. We spent four idyllic days and Arun enjoyed many new experiences. This trip was a huge success and it gave us the courage to continue taking him to other places, including Puri, Delhi and Agra.

It was during these excursions that we discovered Arun's keen interest in bird watching. We gifted him a professional pair of binoculars to help identify birds that he had only seen in books and in his collection of pictorial stamps.

After our move to Bangalore, Arun expressed a desire to see elephants, deer, birds and other animals in their natural habitat. Our first trip to Nagarhole was beautiful and Arun's wishes became an exciting reality. Over the next few years we visited many national parks like Kabini, Mudumalai and Bandipur. Arun's love and curiosity of the wilderness knew no bounds.

During one of our trips, the Manager of the forest lodge informed us that there was a herd of 35-40 elephants nearby. Two jeeps were placed at our disposal with armed forest guards assigned to protect us. As we drew closer to the elephants we were asked to maintain silence. The forest guards proceeded to make a peculiar sound and to our utter horror started honking. This alerted the elephants to our presence. We soon witnessed an amazing sight.

A group of 8-10 young elephant tuskiers moved to the front of the herd and it was clear that they were rounding up the young ones and pushing them to the centre, followed by the older and bigger elephants. This almost military maneuver was a once-in-a-lifetime experience. Gradually the elephants started moving towards us trumpeting all the while, ready to charge and we had to rush away.

Another unforgettable moment was when we saw three tigers crossing the road in the moonlight at Mudumalai. We were thrilled that Arun had seen a big cat in the wilderness.

Though forests and nature held a special place in Arun's heart, we decided to show Arun other cities like Bombay and Madras. Owing to his adventurous spirit, Arun expressed a desire to travel by train, something that he had not experienced previously.

An ideal opportunity arose when an international stamp exhibition was scheduled in Delhi. Both Arun and I were exhibiting participants. After a great deal of effort we managed to reserve a coupe compartment in First Class for the two-day journey. Our only worry was any medical emergency, which thankfully did not arise. The railway staff were mindful and accommodating of Arun's condition and ensured that we were comfortable through the trip.

Our friends in Delhi helped make arrangements to facilitate our visits to the Red Fort, Kutub Minar and other tourist attractions. Arun enjoyed this lesson in history and his ability to make friends easily went a long way in enriching each of his trips.

We also visited the Taj Mahal. To view the upper level, Arun was fortunate enough to be carried up in his wheelchair and continue exploring this great wonder of the world.

Over 10 days, Arun and I visited the stamp exhibition daily. Since Arun was a stamp collector himself and had won a silver medal in this international exhibition, we were able to meet many philatelists from India and overseas and Arun made many friends.

The success of these trips rested largely on our ability to plan and make arrangements in advance. Lady luck was frequently on Arun's side and we were able to procure special permissions and had our backup plans ready in case of an emergency. We were so happy that we could provide Arun with these amazing experiences, which helped build his confidence and allowed him to make new friends.



# 9

Arun's cheerful nature was one of his most attractive traits. Yet there were times when he, like any other normal person, succumbed to the relentless frustrations of life. The side effects of his seizure medication compounded this. It was not easy for him or for us. His constant forays to the hospital would often disrupt our lives, and when he got back things would eventually return to normal.

It was also heart-rending for us, as parents, to quietly witness the dreams of a teenage boy, destined to remain forever unfulfilled. He would innocently talk of getting married and did not understand or accept, till much later in life, that it would not become a reality for him. It was a reflection of the fact that he grew up so normally that he dreamt the same dreams as everybody else!

The family's dependence on help was another reality. We always had to have well-trained staff, accessible to us 24/7 as he was too heavy to be carried thrice a day for his basic routines once he grew up. Special mention must be made of Sarmeshwar bhai and Jatti bhai his attendants who were with Arun till the very end and were very much a part of our daily life, tending tirelessly to his needs.

The move to Bangalore brought about a significant change in Arun's outlook. He tasted freedom from several restrictions he endured in Calcutta.

One fine morning at about 11:00 a.m. we received a phone call that shocked us! Arun had convinced Sarmeshwar bhai to take him to my sister Pramila's house, which was 3 kms away in his wheelchair, traversing over uneven roads! This unusual and risky incident shed light on Arun's emerging need for independence, and our need to safeguard him whilst facilitating his desire to venture out on his own.

Since our home and my workplace were nearby, Arun often visited my office where he pursued his philatelic activities. He continued to play the tabla and made many new friends in the neighbourhood and at the park he visited. We were able to take Arun to movies, theatre, poetry gatherings and even the drive-in theatre. These activities along with more independence enabled him to thrive and boost his self-confidence.

Communication was one of Arun's winning abilities; he was able to convey his own feelings and win friends easily. When he turned 20 years of age, Arun expressed an interest in learning more about differently-abled people. He reached out to various organisations and connected with people from similar situations and eventually founded an organisation called 'SPHOORTI' wherein Arun was made the treasurer. Arun also facilitated the use of wheelchairs for the members.



Every other month, our spacious home with its sizable garden became a meeting place where several brave souls wheeled in on their wheelchairs. They were open-minded, positive and carried a great sense of humour and discussed their issues frankly whilst helping each other find solutions that worked.

We realised that such gatherings provided an invaluable support group imparting a sense of not being alone in their problems.



# 10

Frequently, circumstances compelled us to resort to experimenting.

When Arun was a little child, in addition to his medical problems he developed an abscess that measured around 3-4 inches in diameter behind his left thigh, which required surgical intervention.

Unfortunately, the surgery created a wound that was almost three inches deep. What we all failed to realise was that that part of Arun's thigh did not have any nerve sensation.

For nearly two months the surgeon tried to heal the wound using antibiotics and ointments. None of the treatments worked and using ointments only heightened the infection. We were told that there was nothing more to be done and we would need to dress the wound every day to keep it clean.

Since allopathic treatments had failed us completely, we decided to try an alternative therapy. Having read about the use of papaya to heal cuts and wounds, we experimented with this and the biochemic powder Ferrum Phos. We were able to control the infection and keep the wound healthy though not cure it completely. Hunting for papayas in the market everyday became the norm, and we continued this treatment for the next 25 years.

Caring for a special needs child teaches you many aspects of caregiving that others are not aware of. The family plays the role of day-to-day caregivers and this places us in a unique position when it comes to the practical knowledge of dealing with routine challenges.

Arun's frequent hospitalisations demanded new ways of relating to hospital staff and doctors. We had to intervene with the use of alternative therapies when doctors were unable to resolve issues with their line of treatment. I refused to get intimidated and stood my ground; the doctors relented as they watched with amazement the incredible effects of papaya and biochemic application on the wound even whilst Arun was in ICU.

Medical science has made tremendous progress in the last 50-60 years. Arun was born in 1959. The medical opinions we received soon after Arun's birth reflect the level of medical knowledge available at the time.

Back in the day, the negative opinions of learned specialists troubled us most of the time. We found it difficult to take many decisions and were keenly aware that these decisions might prove wrong and perhaps cause Arun more suffering. But the need of the hour always dictated our actions as each day threw open a new challenge. Good instinct, courage, perseverance and above all, our love for our son kept us going strong.

Arun lived a happy and comfortable life and all our efforts in improving his daily routine were a huge success, as we never stopped using creative ways to keep him happy.

One such event was when we decided to keep a simple gift under his pillow to be discovered each morning, and told him that the ‘Pari” (fairy) had brought it for him because she liked him very much. His thrill and excitement for that small gift was so heartfelt that we continued to leave little treasures like a pen, a bar of chocolate or a comic book, which he woke up to with undisguised innocent pleasure. The entire family gathered each morning as Arun awoke to join in his happiness making it a wonderful family ritual!

Thus many years went past; our connection with Arun and providing him with the best that we could helped create a very deep and special bond between the five of us. Arun passed away at the age of 39 when his body succumbed to its weaknesses. But we as a family felt richer for having him amongst us for what seemed like a lifetime. We were no longer an ordinary family; the divine had touched our lives and psyche. We are forever blessed that we were the chosen ones to be the family of such a special human being.



## Epilogue



**Arun Shah**

Being parents of a specially-abled child, especially with severe multi infirmities, is certainly a very difficult and traumatic experience at many junctures. The fact that he is our child gives rise to immeasurable reserves of strength and courage.

If one is faced with a similar situation, reading about our experiences is not going to make it any easier. But what we can promise is that a positive mindset, common sense, professional guidance and a quiet determination can replace the initial shock and sadness leading to a deep sense of acceptance that can enable your child to become a winner.


Albeit, most importantly, extra care, comfort and special attention are crucial in developing self-esteem, inclusion and independence in the adult years of the child's life, which parents can provide sensitively.



# Arun's Passion for Philately

Arun's tryst with Philately started early and continued to grow leaps and bounds. His collections were greatly appreciated and he won several national and international competitions. His collection of aviation themed stamps was renown and he hosted several auctions. This hobby enabled Arun to meet new people and make friends. Arun's sad demise was a huge loss to the world of philately as is witnessed by the following letters from associated societies expressing their grief.

### ARUN Y. SHAH IS NO MORE



Arun Y. Shah, a well known and familiar face to all Philatelists of Bangalore and many in the country and abroad, passed away on 2nd September after a prolonged illness. He was the son of Shri Y.R. Shah, International July 1984 and was born on 11th December 1954. A Philatelist to the core, at the age of 5, he started collecting thematic stamps of Aircrafts, Ships, Trains, Airplanes and specialised on Aircrafts from the age of 11. He participated in great local exhibitions at Calcutta and won prizes and finally he received a Silver Award in India's 73 International Exhibition. His record of exhibitions is commendable for a physically handicapped person who had severe disabilities but a very good mind and tremendous enthusiasm for stamps, music, sports and many other things in life. For Air cards on Stamp he won the following awards:

- India 73 - Silver
- Espana 75 - Bronze
- Mysore 75 - Bronze
- Karnataka 75 - Bronze
- Karnataka 80 - Large Vase

He would have participated in many more, but his later falling in National and International Exhibition July 1984, he was barred from participating in our National and International Exhibitions.

He developed enormous interest in this hobby, which helped him a lot to overcome his problems of dismemberment. He was a member of many national and international Philatelic Societies.

He was founder Director of Philatelic Publications Pvt. Ltd. since September 1984, later known as Philatelic Trade and Publications Pvt. Ltd. Bangalore. He has donated his entire personal library of Magazines, Stamp catalogues and reference books to the Company and it is always available for any philatelist to refer without any payment. His main intention was to spread the knowledge of Philately amongst more people and help philately to survive. The company under his leadership started conducting auctions from May 1986 and so far held 10 auctions. He was trying his best to serve the philatelists through this company.

All those who knew him or came in contact with him took instant liking to his dynamic, affable, social person.

Our National Philately has lost a most promising star who was aggressively proceeding to build up his Philately and in the process helping and guiding many new young philatelists.

May his soul rest in peace.

160
INDO DAS / September 1988

### K

10 B. Das Road  
Calcutta 700 001

September 15, 1988

My dear Shah and Mrs. Shah,

I find it extremely difficult to write you this letter as my own emotions and thoughts are disturbed. Though over years we drifted apart, sentimentally I will always be as much a part of your family as I used to be two decades ago. Losing Arun has been a very severe blow to me too.

Both of you will be emotionally devastated now. Words of sympathy, sorrow and sharing from others, gives a limited comfort of knowing that others too grieve with you but this in no way will lessen your sense of loss. They are palliatives at best and it will be a long walk through sadness by yourself for you both. I know this from my own personal experience.

Arun's passing away, even while leaving a tremendous void in your lives, brings to me and the physical suffering and awareness of deprivations that were constant companions all his life. He bore it all stoically. Despite of all this, he rarely showed any distress or pain; it was always a shy smile and impishness that played on his face. His will to be normal inside of me was astounding and the spirit within as bright. If God has His own ways of giving salvation, possibly this was the way he blessed Arun now. He freed him from all suffering.

Both of you must take consolation from the fact that you made bearing, caring and bringing up Arun with such courage and determination your mission in life. What God cruelly denied him at birth, you tried to make up for it in every possible way. It was a rare act of love, dedication and compassion. Watching it from close was a moving experience for me and my admiration for you both is boundless. You can take pride in the fact that you came through the trial that God put you through for years, never once accepting defeat. The example you set is exemplary. While Arun's life was one of many deprivations, the one blessing he had - you both as parents - made it up for all of them. I feel privileged that I was close enough to you to perceive and partly experience this unique phenomenon. It taught me (and many others too) what love and duty in life is all about.

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160
INDO DAS / September 1988

### K

Sanju tells me that both of you are bearing up to this tragedy with tremendous strength and courage. May God help you, Nilu and Varsha in passing through this experience with minimal scarring. I am really sorry that I am unable to be with you till now but I will come as soon as possible.

I pray for dear Arun's soul; may it rest in peace. I remember you always in my prayers. May He lead you to acceptance of fate and tranquility soon.

Ravi

160

**The Philatelic Society of India**  
Estd. 6th March, 1897  
100 Years of Philately



19th Sept. '98.

Dear Mr. Shah,

I am sorry to learn of the sad and untimely demise of your dear Son Arun on 2nd September '98. Please accept my heart-felt condolences on the sad bereavement and may God give you enough strength to bear the irreparable loss.

Yours sincerely,

*Shree*  
(Dhirubhai M. Shah)

Mr. Y.R. Shah,  
123 Swathi, 6th Main Rd,  
Malleswaram,  
Bangalore 560 003.

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JULY-SEPT '98  
WHOLE NO. 141

**OBITUARY.**



ARUN Y. SHAH is no more.  
An ardent philatelist, full of ideas for philately and for expansion of 'Philatelic Trade & Publications Pvt. Ltd.' activities passed away on 02.09.1998 after a prolonged illness for last several months.  
The loss is irreparable for the above mentioned enterprise as well as the Indian Philatelic World. Even though disabled physically, most able in mind, budding young life, an inspirer, dynamic and smiling personality has left this world.  
We offer our heartfelt sympathies to his parents and office bearers of the above enterprise.  
MAY HIS SOUL REST IN PEACE.

JAMSHEDPUR PHILATELIC SOCIETY  
P. O. BOX - 86  
JAMSHEDPUR-831001



V.V. BALAKRISHNAN  
1-3-183/40/46/5, Gandhinagar, Hyderabad - 500080. Ph: 7530598/818036.

Dear Yashwant Shah:

Mama & Mami have given us the opportunity to host them at our place during the pilgrimage, along with Kumud's Mother. From them, I come to know about the sudden passing away of your DEAR ARUN.

All these 38 years, he has been valiantly fighting cheerfully till the final exhalation. Fortunately in you both, he has had the best parental affection shown in such magnitude, which can be only seen in story books.

To an ordinary man, it may be the most sorrowful moment, when some one so dear passes away from the scene. But for an enlightened person like you, this moment is the most appropriate time for introspection.

Every day the SUN rises and by the evening, it dips down for the day. It does not mean that the all pervading darkness is going to remain permanent. For, when the next morning comes, the ARUNODAYAM, brings in brightness in every one's life.

The concept of the 'Day' may be a relative term. But the presence of him everyday in your life is as certain as the morning SUN. Right from the rays of the morning in every such other things, you can feel the presence of him. For others it may be a different story. But you will continue to live with him, even though he is not visible to our physical eyes.

I, along with Kumud and Manoj, pray for him, wherever he is and this turning point in your life is certainly going to add a new facet of your purposeful living style. May God be with you all during this testing period and I am sure to see you smiling during my next visit to Bangalore.

With warm regards.

Sincerely Yours,  
*V.V. Balakrishnan*  
(V.V. BALAKRISHNAN)

CHIRAN 1-3-183/40/46/5, GANDHINAGAR, HYDERABAD-500080. PDA PHONE: 0402-011131

P. GUPTA  
Director

16 September 1998

Mr Y R Shah  
Oriental Select Granites (P) Ltd.  
32/60, 2nd Main Road, Vyalikaval  
Bangalore 560 003

Dear Mr Shah,

I was indeed shocked to learn about the untimely passing away of your son Arun few days back. Words fail me to console you at this tragic hour. May God give you and other members of your family courage and fortitude to face this calamity.

Do let me know if I can be of any service to you at this juncture.

With kind regards,

Yours sincerely,

*P. Gupta*  
(P. Gupta)

cc: Mr A Mahalingeswar  
Director  
Philatelic Trade & Publications Pvt. Ltd.  
Bangalore.

cc: Mr Mani M. Krishnan  
Director  
Philatelic Trade & Publications Pvt. Ltd.  
Bangalore

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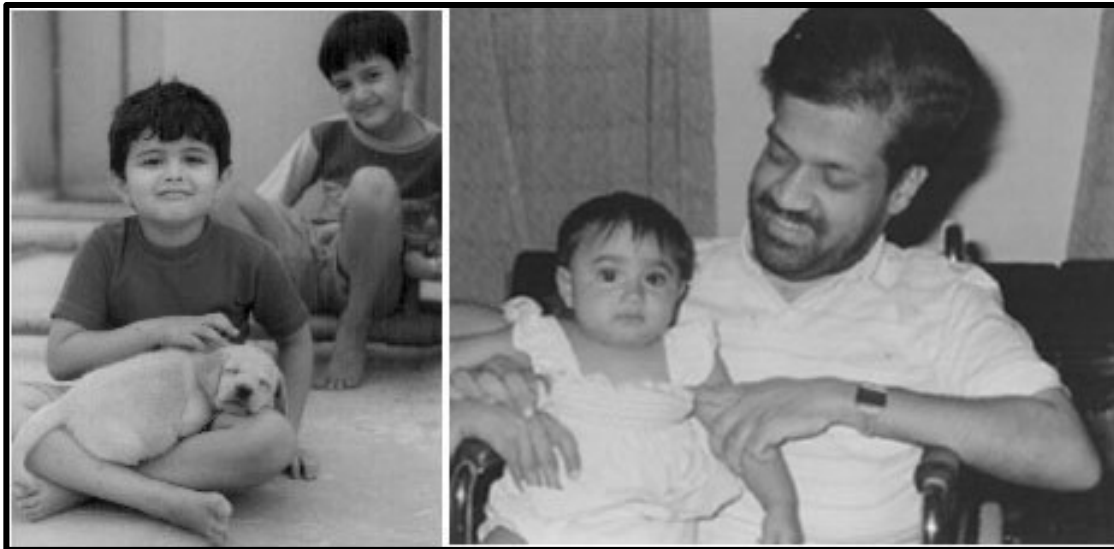
## **Our Family and Friends**

There's a very famous saying, "When life gives you lemons make lemonade." Our Dad and Mom made our lemonade with every possible flavour of life blended beautifully and joyfully into it! Most significantly they ensured that whilst Arun's needs demanded total attention, they gave equal time and attention to our needs and wants.

We were always a part of important decisions, and our home was encouraged to become a hub of activities, hobbies, music, arts, games and family visits, which enabled the creation of a community where Arun was always included and nurtured.

Dad would come home and narrate every important incident that happened at work and his travel, so whilst we lived a sheltered life in Agarpara, he became the window to the outside world. I can only say we are indebted with life for blessing us with such an amazing, compassionate, fun and happy family.

Another important role that Arun played was that of being a fun loving and caring maama to his beloved niece Alisha and nephews Karan and Krishi. The little ones enjoyed spending time in our garden with Arun maama amidst laughter and learning. This special time with Arun instilled a deep sense of compassion and acceptance, which is reflected in their everyday life.



**Arun with Alisha, Karan and Krishi**



We have a deep sense of gratitude and love to those who touched our lives and were a part of our journey with Arun. Dad's sisters, Jayaben and Gunwantiben and their families stood by us every step of the way. The Hoses and Kariappas provided invaluable support when we lived in Calcutta. Our family and friends close to home and around the world were always just a phone call away. Colleagues from NTC, the OSG staff members, PPTL members, Hema of Sphoorthi and its members continue to be dear friends. The staff at home deserves a big shout out especially, Sarmeshwar bhai and Jatti bhai.



## **Memoirs**

Arun with his endearing smile, sharp intellect and great sense of humour left an indelible mark on so many lives. He brought many people together and created a small little world of wonder around him. Here are a few personal snippets from people that interacted closely with him.

### ***Bela Patil***

Our friendship started when I was about 11 and our family used to visit your family in Vyalikaval on Sundays at tea-time, or on our return from *derasar* in the morning. Arun bhai was usually at the table sorting stamps. In my school there was a stamp club (that's what we amateurs used to call it). Arun bhai encouraged me to join the club and participate in the exhibitions. With his guidance and generosity I won several school-level awards.

As I grew older and joined college, he was a constant friend and a reminder (verbally and just by being himself) of not letting anything drag one down. I had a scooter and used to visit him on and off and was definitely reprimanded if the gap between visits was too long. We would sit by the garden and chat; he was always cheerful.

Then I moved to Bombay for 10 years but I always visited with him when I came to Bangalore. He also wrote me the occasional letter. I moved back to Bangalore after my wedding and that was the time I had a chance to not just have a friend, but also to be a friend. I used to visit Arun bhai would be treated to musmusiya and methambo and Gujarati lunch when I came, and we would chat. If there had been some hiccups in the health situation, they would be mentioned but never in a way as if it was taking over his being. The highlight for me was when Arun bhai came home to my apartment (after several tries as the elevator in my old apartment was not very reliable), and I had a chance to cook a meal as per his request. It was a wonderful afternoon with simple friendship, listening to each other and no expectations.

Arun bhai was a strong, determined person with a positive outlook. The way he was raised made him the person he was; when I think of him, I think of him as unstoppable. I know he was differently-abled physically but I don't think that ever stopped him.

I remain inspired by his life and the love and care that were showered on him by the family. You will always be in my heart Arun bhai.

## *Ila Fai*

There was excitement in the air; their bhabhi had gone to the hospital to deliver a baby. We faibas kept a baby outfit and blanket, whilst we waited for news of the birth. Tiny, innocent sisters Neelu and Versha were confused with a mix of emotions--joy, curiosity and the bewildering notion that a baby was going to come out from mummy's big tummy.

After waiting for a few hours we received news of the birth of a specially-abled baby with a big head, which, we learnt later, was termed as hydrocephalus. Our feeling of joyful anticipation turned into anxiety. I was confused was tormented with troubling thoughts for a long time. Is this the result of bad karma or bad luck or God's mistake? Who knows?

The devastated old grandfather, a very wise soul committed to simple and honest living answered, this child is a guest in our home and will be treated with care and compassion. None of us was ready to give this news to the child's father; we feared that he would be very disturbed, and couldn't even imagine what his state of mind would be!

Time passed and Arun started to smile. But for bhabhi it was a very difficult time and she suffered intensely. Many times I noticed her quietly wiping her tearful eyes with her sari. The traditional celebrations for a newborn birth and the naming ceremony were not held, and we two faibas named the baby Arun.

All the time while staying with Arun, I learnt much about life - that one should live a life with care and compassion. Arun's determined parents became perfect models of humanity, love, care, compassion and performed their exceedingly difficult roles to the best of ability. Without any apparent disappointment they loved Arun unconditionally and did everything to give him a happy and fulfilling life.

I see in my memory pictures of a smiling Arun, enjoying with his two sisters, at times a little naughty with his Ila faiba. Arun accomplishing great progress in his hobbies despite his many challenges. I heard that Arun received the presidential award for coin collection! Even though he could not move freely, he blazed a path for himself. The question is, who made this impossible situation into a potential one? This unusual and captivating story of caring and courageous parents teaches us how it is possible to achieve personal excellence and successful living in a gravely difficult situation. It is indeed a lesson in our current turbulent times.

Arun's life is an inspiring tale, which provides a step-by-step approach on how to live with love and compassion. It is a guiding light for all parents of similar children. It inspires one to cultivate self-discipline and act courageously when God himself appears not to be favouring the child.

Arun's life had a great impact on my mind. I developed a renewed sense of compassion and guided me to devote some part of my life to those who are less fortunate and to give back to society in a meaningful way. I feel blessed to have shared Arun's journey with him.

### ***Sarita***

Yes I can recall Uncle's love, care and dedication to Arun. He was always patient, compassionate and so proud to share Arun's achievements. You all were one steadfast family; yes, I do remember vividly that we would come to your place and always be engulfed with arts and craft. Such beautiful and artistic people! I do remember the smell of achar and the taste of wonderful Gujarati snacks. In spite of all the challenges your parents faced there was cheerfulness in your family. I remember Arun always wanting to show his stamp collection and Uncle Shah ever obliging to go and fetch it for all to view.

### ***Tarak***

Walking down memory lane, I remember the mischievous face of Arun Bhai. Though we did not come often to Bangalore, I have a few clear memories.

We would watch movies at the drive-in theatre. I don't know if the drive-in theatre exists in today's times but it was a novel and exciting experience to drive your car into the theatre and watch a movie sitting in your car or besides the car in the open air. Once the car was positioned, Sarmeshwar and Sunil would remove the wheelchair. Arun Bhai would then be shifted to the wheelchair and we watched the movie along with delicious food. It was an outdoor picnic-cum-movie experience; a unique one. Arun Bhai was a big fan of renowned singer Mukesh.

Another incident I remember is when we had all visited Banarghatta for the lion safari. We took two Ambassador cars; one with adults and one with the youngsters and Arun Bhai and it so happened that the elders' car broke down during the safari. The safari staff ordered us not to venture out due to the nearby lions. As we waited for the bus we got into a heated argument. Sunil driver got out of the car to speak to the staff followed by Yashwant kaka, papa and Sarmeshwar. I remember Arun Bhai's worried face and he was screaming at Sarmeshwar to get inside the car.

Finally some of us moved into other car and some were allowed on the bus. This incident left a permanent impression on my young mind.

### ***Ajay***

I have so many fond memories about the times I shared with Arun. Being part of his many birthday parties; playing with the various toys; going to movies/shows with him; playing burako together with other family members; watching his growing interest in philately... The last time we were together was in 1997 (which turned out to be his last full calendar year in this world), when he showed me his office where we worked with stamps - his keen intellect and love of

### ***Leela Masi***

The one thing that has always stayed with me is how Yeshwant bhai and Rama Bhabhi ensured that the lives of Versha and Neelu were never disturbed because of Arun's problems. They were able to compartmentalise the issues and ensured that the two girls were encouraged in everything that they wanted to do. And I was always impressed with this method.

I will always have fond memories of your family, especially Arun.

### ***Pramila Fai***

One incident I remember vividly, after your moved to Bangalore. One fine day, Arun and Sarmeshwar landed up at our doorstep in Kumara Park, which is a good 3 kms from Vyalikaval and with a lot of inclined roads. I was shocked at this wheelchair marathon, which Arun attempted and all the while everyone was wondering where they had disappeared to. That was the spirit of this boy I can't forget!

Of course my role in those tough days that your mum went through, was to raise you two girls, whilst Rama bhabhi grappled with Arun's challenges. And that is why I am so attached to both of you. Rama bhabhi never complained but just molded her life, and immersed it in creative hobbies to keep her spirits up and create a comfortable and lovely atmosphere at home.

### ***Mani Muthukrishnan***

Although Arun Bhai had many challenges since birth, his alertness and knowledge of subjects were phenomenal and his memory was absolutely unbeatable. Even today I only recall his interest in stamp collecting and his memory of various people, philatelic dealers, prices of stamps, country names and other data.

I remember seeing Arun Bhai first at the Diwali Pooja in the office in 1980. I was invited to visit his house to view his stamp collection.

Soon my sister and I visited Arun at his Vyalikaval residence, usually on Sundays, and we started learning about the various aspects of stamp collecting.

In 1987, one more important person entered our group of philatelists – Mr Athani Mahalingeswar – Retd from the civil aviation department and he attended our sessions on stamp sorting.

In 1991, I had started working for AIGSA and my interest in philately continued. As part of my work, I visited the OSG office and often interacted with Arun Bhai. During this time I taught Arun Bhai how to use computers. Mr Shah let Arun bhai do some stamp transactions as a commercial activity. At this stage, Mr Mahalingeswar and I became directors of the Company PTPPL.

We established an excellent philatelic library with all the literature, auction catalogues, exhibition souvenirs and so on collected by Mr Y R Shah over the years. Even Col Shenoï contributed to the library. Since the library did not generate revenue, we decided to start spot auctions.

The first spot auction was planned in 1995. Arun bhai came to office daily to identify, sort and value the stamps that we received. Mr. Shah, Arun bhai and I spent a lot of time reviewing the collections. We held more than 10 successful auctions from 1995 to 1998. Arun bhai truly enjoyed all the hard work and our success.

Losing Arun bhai left a huge void in many hearts. His cheerful personality, warm smile, sense of humour and intellect is how I will always remember Arun bhai.

### ***Jivan Bhatt***

My association with Arun began in 1983 and became Virtual after 1998.

I have only heard about the various physical, social and physiological challenges Arun and the Shah family faced and how they managed to transform the impossible to the possible. Collectively the family beat all odds.

"Arun Nu Jivan", is real life and not a story. It is far from the imagination or characterisation capability of any renowned author. It may remain unique though one would wish for it to be an inspiration to parents who face such challenges in the present or future.

My image of Arun is a smartly dressed, neatly groomed man, sporting an impressive watch and pen, attending office in the most disciplined way. Arun was always friendly, easy to converse with on a variety of subjects and always curious to catch up on new gadgets or computer developments. All you needed in order to connect with Arun was a nice joke and he would burst into purest laughter. Laughter was a tonic for Arun.

Arun was passionate about cricket, birds, wildlife, jungle safaris, music, poetry and philately. He was God's own child, an evolved human being. He was an exceptional soul who brought strong purpose, enormous love and a special joy to the Shah family.

He remains ever present in spirit and thoughts of his family and friends.

### ***Shailendra Bhuta***

I remember Arun as an intelligent and jovial boy and credit for this goes to the parents, despite having to deal with pressures of ordinary living. 'Encouragement' at all times and in any way, was the name of the game.

Neither Arun nor the family ever subconsciously or consciously asked for or expected help from outside – as they were so self-sufficient within themselves, and what they had to give Arun was much more than he should ever require.

I would like to give a special mention to Dad – as head of the family who steered the family ship in crisis or otherwise, with such a positive and uplifting attitude.

### ***Solomon***

Arun was a kind and loving person. He had tremendous memory power. He would store all-important events in his mind and give you a surprise on your birthday, anniversary day etc. The best thing about him was that he was very candid in his views. He would criticize you for your faults and praise you for your achievements. Even when the computer was in vogue, he preferred to use my handwriting for his philately work. He was an astute person blessed with enormous wisdom. He would update you on current matters-- be it cricket, politics or cinema and any other topic that interested you. A great human being, I surely miss him very much.

### ***NS Hema***

A smile is the light in your window that tells others there is a caring, sharing person inside, said Denis Waitley.

For me, the memory of Arun is of a person who as a child and adult always welcomed you with a beaming smile! I met him as a child, along with his parents, in Malleswaram where I live. He was severely affected by spina bifida but he never let this come in the way of his positive attitude towards life.

His parents too, provided him with all the comforts he required to live a life with dignity. Their total and selfless care made him feel wanted and instilled a sense of being the most precious part of their family. His parents were extraordinary people and loving caregivers. As in the words of John Joseph Powell, “It is an absolute human certainty that no one can know his own beauty or perceive a sense of his own worth until it has been reflected back to him in the mirror of another loving, caring human being”.

(For those who are not aware, Hema a dear friend of Arun and who is physically challenged herself, went through similar trials in life, which like Arun, she overcame with great courage and positivity. She runs a centre for the physically challenged in Bangalore and does an admirable job, which was supported by Arun and now by us.)

### ***Manu***

[manurikamsi@gmail.com](mailto:manurikamsi@gmail.com)

I was 14 years old when we received the news of Aun's birth and that he would need special care. For the next 18 months I have memories of his special and loving needs - provided by everyone in the large family to their best of their ability. It was clear everyone in the family from his grandparents to his two sisters, his mother and father, were trying to cope up with this gift from God and make sure Arun was comfortable at all times. As Aun grew our priorities changed and all the normal stuff we take for granted changed forever.

Soon my brother and his wife moved to Calcutta with his two daughters and Arun. Few years later I moved to America but stayed in constant touch with our family and visited often over the next 40 years.

I learned many years later that Arun was born with a condition known as Spina Bifida. There is no cure for this condition. The courage and acceptance of Arun and his special needs shown by his mother Rama and father Yashvant is etched in our memory. Both of them remain a role model for how to accept what is and adapt to every new challenge with the goal of overcoming it each time. Arun lived almost 40 years with SB and that is only because his parents sacrificed everything for his care.

My wife, Rika and I have learnt many lessons in life from the Shahs and will always remember how to keep going even if there are no answers to problems we face.

### ***Kishori***

In my life I have not come across anyone as intelligent, positive, updated with everything as Arun was. I guess credit goes to him for making an effort and not giving up, as well as to maasa, for sharing his experience with him and to maasi for giving him a lot of space.

I also observed that neither Versha nor Neelu sympathized with him or made him feel that he had restrictions.

In totality I think it's the family support that helps the most. I truly think that maasa, being the head of the family was a man way ahead of his time.

### ***Madhuri***

Every time I start thinking about our beloved Arun, it brings back the fondest memories of my childhood. He was just special. Arun was such an integral part of the happy times of our childhood. I just cannot forget his smiley handsome face, his naughty smiles and the times when he would laugh whole-heartedly without making a sound. He was so precious to all of us, especially to Mama-Mami.

We often accompanied Arun to the movies, zoos and funfairs and we enjoyed receiving all the attention and special treats too. Arun was very intelligent and smart.



One incident that I recall when he was young, Mama-Mami would leave small gifts under his pillow to encourage him to learn. He was told that a fairy godmother keeps it for good boys. Arun used to love these gifts. Once he must have caught them leaving the gift under his pillow. He was so smart, he enjoyed the gifts for a few days, and then he told everyone that he knew that there was no fairy godmother but it was mama-mami.

Whenever Arun would come to stay over with us, he would call my mom, his Jayafaiba to put salt in the rice, as we never use to put salt in the rice.

### *Ashmi*

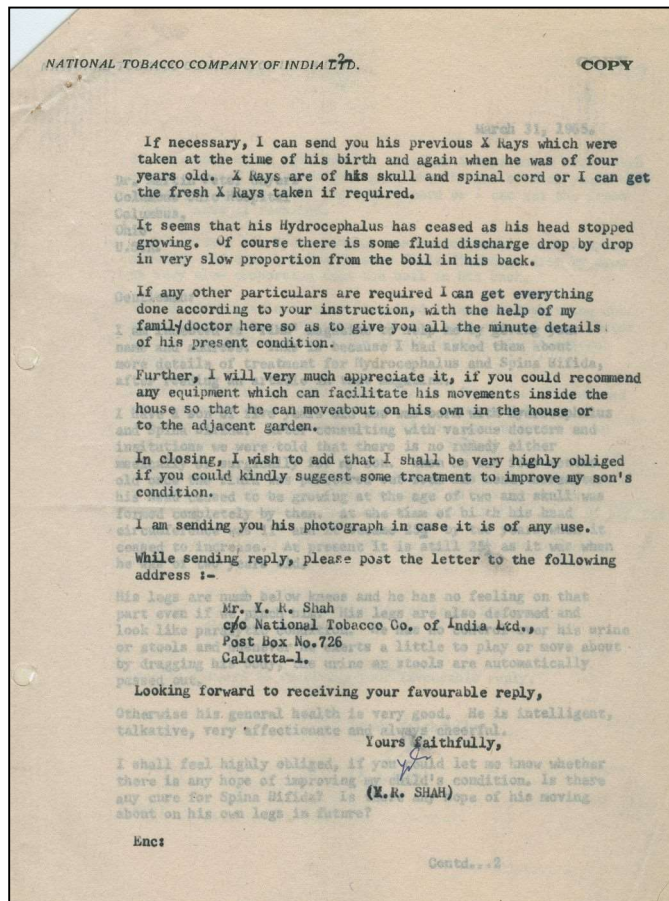
Though I don't recall too much, I do remember that Yashwant bhai and Remaben's lesson to us- "How to take care of a physically challenged child, in the best possible way! "



## Dad's Perseverance

Where there is a will There is a Way!

In the absence of medical knowledge during Arun's time with us, the following reveals the keen and cohesive correspondence with the medical fraternity to find solutions.



March 29, 1965.

If necessary, I can send you his previous X rays which were taken at the time of his birth and again when he was of four years of age. I can also send you his skull and spinal cord or I can get Mr. J. Lawrence Poole of his skull and spinal cord or I can get Neurological Institute of New York 710 West 168th Street New York U.S.A. Of course there is some fluid discharge drop by drop in very slow proportion from the hole in his back.

Gentleman : Particulars are required I can get everything done according to your instruction, with the help of my I am indebted to 'TIME' magazine to help me by giving your name and address. This is because I had asked them about more details of treatment for Hydrocephalus and Spina Bifida, after reading an article in that magazine. I have a son of five years old who was born with Hydrocephalus and Spina Bifida. After consulting with various Doctors and institutions we were told that there is no remedy either medically or surgically for my son. When he was four months old once the fluid was punctured out from his head thereafter his head ceased to be growing at the age of two years and skull was formed completely by then. At the time of birth his head circumference was 11" and it became 25" by two years age when it ceased to increase. At present it is still 25" as it was when he was of two years old.

His legs are numb below knees and he has no feeling on that part even if we pinch him. His legs are also deformed and look like paralytic condition. He has no control over his urine or stools and whenever he exerts a little to play or move about by dragging his body, the urine or stools are automatically passed out.

Otherwise his general health is very good. He is intelligent, talkative, very affectionate and always cheerful.

I shall feel highly obliged, if you could let me know whether there is any hope of improving my child's condition. Is there any cure for Spina Bifida? Is there any hope of his moving about on his own legs in future?

Contd...2

Dr. JOHN REES ROBERTS

Telephone Numbers  
ROYAL 2422

ARROWEBROOK 1193

72 RODNEY STREET,  
LIVERPOOL, 1

5th November, 1963.

Mr. Y. R. Shah,  
c/o National Tobacco Co. of India Ltd.,  
1 & 2 Old Court House Corner,  
Calcutta - 1,  
India.

Dear Mr. Shah,

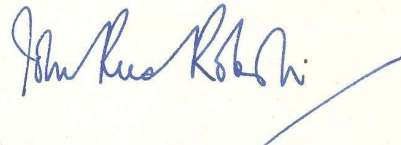
Thank you for your letter of the 16th October, 1963. I must point out that you did not enclose photographs although you stated that you would do so in your letter.

I am quite sure from your story that there is little we can hope to do for this little boy - I think it would have been easier to come to some conclusions if you had enclosed some photographs. If I felt that Mr. Rickham and myself could help in any way I would not hesitate to tell you to bring him to see us, as I am sure this would be your wish also, but under the particular circumstances which you relate there is obviously little hope, after four years of hydrocephalus, that any operation would improve the boy at this stage. There is, of course, the added complication of spina bifida which is virtually irremediable.

I am sure your Neuro-Surgeon in Calcutta was right otherwise he would have tackled the problem himself.

I need hardly add that I am very sorry that I cannot be of any further help.

Yours sincerely,





Page 2

Dr. Ramamurti.

If the nerves are adjusted back properly, will there be any improvement in his lower extremities of bladder and bowels and also the legs, or they will remain as they are at present.

In conclusion, I beg to be excused for asking so many questions but I very much hope you will understand and appreciate my anxiety.

Will you be kind enough to forward your reply to the following address :

Y.R. Shah  
c/o National Tobacco Co. of India Ltd.,  
1 & 2 Old Court House Corner  
Calcutta - 1.

Awaiting your early reply and with best regards,

I remain,  
Yours sincerely,

  
(Y.R. SHAH)

Encl:

Dr. B. Ramamurthi, M.S., F.R.C.S.(E), F.I.C.S., F.A.C.S.,  
Neuro Surgeon  
11 Main Road  
C.I.T. Colony  
MADRAS - 4.

May 11, 1965.

Dear Dr. Ramamurti:

There has been a lot of new hope for improvement in my son, Arun's case after I met you on the 27th April at Mr. Gupta's place, and it was indeed a great pleasure meeting you.

On your advice to start with Orthopedic matters first, I have consulted Dr. Ashoke Sengupta M.B.B.S., F.R.C.S., over here. He has taken keen interest and has suggested to start with correction of hip bones and thereafter an operation for correction of foot and ankle during September/October this year.

Before we start anything he has asked me to send his report and plan of action to you so as to get your O.K. on it. I am sending herewith the detailed sheet he gave me, and would await your advice. Only after I hear from you, we intend to start the treatment. Kindly advise me at your earliest convenience.

Apart from the above, I am sending a true copy of letter received from another well known Neuro-Surgeon from New York who too has suggested to consult you, alongwith the names of Dr. Chandy and Dr. Ginde.

As I had written in my letter to him that there is still some kind of fluid discharge from the meningocele, Dr. Lawrence Pool has mentioned that there is the possibility of Hydrocephalus not being fully arrested and hence the operation to set right the spine deformities might cause a severe flare up or worsening of the Hydrocephalus.

This is a cause of worry for me and I look forward for your guidance, as to :-

1. If really there is leakage of fluid from the brain and meningocele operation is performed, what is the worst that can happen ?
2. What are the remedial measures for that ?
3. Are there any definite means to check whether Hydrocephalus is fully arrested or not ?

Further, with the removal of Meningocele, will the nerves which are now in it, be set back under the spinal bones or that portion of nerves will be removed with Meningocele ?

-/2

Master ARUN SHAH, 5 years.

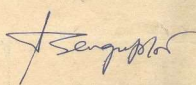
1. Hydrocephalus :- Mental development is fair, he can talk in three languages including English. Power and co-ordination in upper limbs fair. Both suggests arrested hydrocephalus.
2. Spina bifida aperta with Myelomeningocele and Myelodysplasia:- Incomplete paralysis of the lower limbs, paralysis is suggested to be below the 4th. Lumbar roots on both sides by the following deformities on both sides ;
  - a. Hips - Held in flexion, adduction and external rotation. Both are dislocated.
  - b. Knees - Held in extension permitting about  $10^{\circ}$  of passive flexion. Tendency of lateral dislocation of patellae. The bones forming the joints are within normal limits though the ossification, as expected, is delayed.
  - c. Ankle and foot - severe degree of calcaneo-varus deformity.
3. Testicles on both sides are undescended.

Proposed line of orthopaedic management ;

Will consist of

- a. Correction of the flexion deformity of hips,
- b. Correction of foot and ankle ,
- c To make the child ambulant with help of walking machines followed by calipers incorporated with body corsets and crutches.

Dated. Calcutta 10th May 1965.

  
Ashoke Sengupta  
M.B., B.S. (Cal.),  
F.R.C.S. (Eng.)

Lecturer in Orthopaedic Surgery,  
Institute of Child Health, Calcutta.  
Visiting Orthopaedic Surgeon to  
Asaram Bhawanwalla Hospital, Calcutta.

NEW YORK UNIVERSITY MEDICAL CENTER  
NEW YORK UNIVERSITY SCHOOL OF MEDICINE  
550 FIRST AVENUE, NEW YORK 16, N.Y.

DEPARTMENT OF NEUROSURGERY

AREA CODE 212 OR 9-3200  
CABLE ADDRESS: NYUMEDIC

April 7, 1965

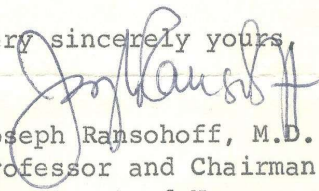
Mr. Y.R. Shah  
N.T.C. Bungalow No. 3  
B.T. Road  
Kamarhati 24, Parganas

Dear Sir:

Unfortunately, I do not believe that there is any active therapy which would be correct for your young son at the present time. His hydrocephalus, as you so well indicated is now arrested and any interference with this would certainly produce a great danger. The neurological deficit in his lower extremities and bowel and bladder control is permanent, and here again, surgical intervention is not indicated.

It certainly might be possible for him to undergo a period of rehabilitation therapy with bracing for his lower extremities if such is available to him; however, I do not think we can offer very much in terms of a permanent or significant improvement.

Very sincerely yours,

  
Joseph Ransohoff, M.D.  
Professor and Chairman  
Department of Neurosurgery  
New York University Medical  
Center

JR/m



Hon. Visiting Surgeon  
Calcutta Medical Research Institute  
Sri Sri Lakshmi Narayan Hospital  
Rehmatul Vaidnagarwala Hospital  
Gujrati Relief Society.

DR. VIJAY MEHTA.  
M.D. (Bom), F.C.P.S. (Bom),  
F.R.C.S. (Ed).

Phone (Residence : 24-1202  
(Chamber : 24-5533)  
67, PARK STREET,  
CALCUTTA-16  
Consulting Time—  
6 p.m. to 8 p.m.

Date 29th April 74

Master Arun Shah

Age: Yrs.

Born with congenital Meningo myelocoele of Lumber region, paralysis of both lower limbs with deformities and no pain sensation in the limbs. Also hydrocephalus.

He was operated for the meningo myelocoele in child hood and hydrocephalus is now stable. He also had some corrective surgery of limbs.

Two years ago he developed abscess of his left buttock, which had started as a boil. Incision and drainage was done, suitable antibiotics were given after culture and slowly pus disappeared. There was no formation of granulation tissue, hence there was no healing. This has continued up till today despite repeated and varied attempts to stimulate formation of granulation tissue.

Correction of anemia, high protein diet, high doses of vitamins and specially VitC. Scraping of the wound, application of known granulation stimulating agents and secondary suturing has been done twice but of no avail. Wound is clean with hardly any discharge. Some irregular attempts at healing is seen at the base of the wound in growth of a few processes of fat. Blood supply is all right but no nerves are there.

He is now on Hematinics, vitamins, and Epilan for control of epileptiform fits.

His problem has been discussed in many clinical meetings and all suggestions have been tried

Further advice is solicited

*Vijay C Mehta*

Page 2  
Mr. Y. R. Shah  
April 7, 1965

I would think that your son's problem now would revolve around corrective procedures for the deformity of the feet, physical therapy and training with appropriate bracing for ambulation using crutches and braces and the operative repair of the meningocele.

He will remain, however, a crippled child as far as this is concerned and ultimately the bladder operation might be necessary.

I am not too familiar with your local situation but I do know that Dr. Jacob Chandy is an eminently qualified neurological surgeon in Madras, India, and also Dr. B. Rama Murthi of Madras, is eminently qualified and could give you advice concerning your son if you have not already contacted them.

In the event you should bring your child to this birth defects center, we would be glad to give you every consideration and advice as far as we can foresee.

With best wishes, I remain

Yours most sincerely,

A handwritten signature in blue ink, appearing to read 'W. F. Meacham', with a stylized flourish at the end.

William F. Meacham, M.D.

WFM:er



DRS. MEACHAM, COBB AND CAPPS

NEUROLOGICAL SURGERY

WILLIAM F. MEACHAM, M.D.  
CULLY A. COBB, JR., M.D.  
JOE M. CAPPS, M.D.

April 7, 1965

VANDERBILT HOSPITAL  
NASHVILLE, TENN. 37203

Mr. Y. R. Shah  
National Tobacco Company of India, Ltd.  
P. O. Box 726  
Calcutta 1, India

Dear Mr. Shah:

I have your letter of March 31, concerning your son.

Obviously your son has an arrested hydrocephalus and paralysis of the bladder and lower extremities from the spina bifida with myelomeningocele.

It is fortunate that the hydrocephalus is arrested since his intellectual functions may remain normal.

The meningocele can be repaired and a good cosmetic result over the back obtained. However there is no known way now to make the paralyzed nerves to the bladder and lower extremities perform with anything like normal function.

We have been able to get such children to walk with the aid of crutches and braces by various stabilizing operative procedures on the clubbed feet and many such children with normal intellect, can get about quite well on the crutches and braces.

As far as the bladder problem is concerned, it is often necessary to bypass the bladder and to make an artificial opening in the abdomen so that the urine will drain into a pouch. This is much more preferable than to allow gradual infection of the bladder and kidneys to take place with resultant deterioration in kidney function.



Modern X-Ray Clinic

PATEL CHAMBERS

OPERA HOUSE

Bombay-7.

TELEPHONE  
CLINIC 71513  
RESID: 72549

December 11, 1959

Name of the patient: Baby Shah

Referred by: Dr. M. D. Adatia, M.D., F.C.P.S., F.I.C.S., D.C.

Roentgenogram of skull and spine:

SKULL:

A.P. and lateral views of the skull reveal that the frontal, parietal and occipital bones are well developed. The fontanelle are normal. There is no abnormal calcification in the skull. Base of the skull is well developed.

Impression:

No abnormality is seen in the plain x-rays of the skull.

SPINE:

A.P. and lateral views of the entire spine reveal that the bodies of the vertebrae are sharply outlined. Intervertebral spaces present normal width. Pedicles are well developed on both sides. Spinous processes show spina bifida in 3rd, 4th and 5th lumbar vertebrae. Remaining spinous processes are normal. Transverse processes are normal. There is inadequate development of the left ala of the sacrum and left ilium

Impression:

Spina bifida of 3rd, 4th and 5th lumbar vertebrae with inadequate development of the left ala of the sacrum and the left ilium.

*Mukund S. Warawdekar*

Mukund S. Warawdekar

D.M.R.E.(BOM) M.A.C.R.(U.S.A.)

THE PRACTITIONER  
5 Bentinck Street, London, W.1, England.

February 19, 1965.

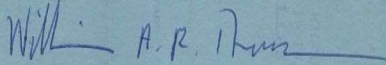
Dear Mr. Hose,

Thank you for your letter of February 16.  
Unfortunately, Dr. Paul H. Sandifer, the physician  
on the staff of The Hospital for Sick Children, who  
was the authority on this subject, died recently.

In view of your colleague's close interest in  
this subject, I would suggest that the best pro-  
cedure now would be to write to the Honorary Secre-  
tary of the National Association for Spina Bifida  
and Hydrocephalus, which has recently been set up  
in this country. His name and address is:-

Mr. T. L. Williams,  
174 Beech Road,  
ST. ALBANS, Herts.

Yours sincerely,



William A. R. Thomson, M.D.  
Editor

Mr. F. J. Hose,  
National Tobacco Company of India Ltd.,  
National Tobacco Building,  
1 & 2, Old Court House Corner,  
CALCUTTA-1,  
India

WT/w.

J. LAWRENCE POOL, M.D.  
NEUROLOGICAL INSTITUTE  
710 WEST 168TH STREET  
NEW YORK, N.Y. 10032

BY APPOINTMENT

WADSWORTH 7-2158

April 23, 1965

Mr. Y.R. Shah  
c/o National Tobacco Co. of  
India Ltd.  
Post Box No. 726  
Calcutta-1, India

Dear Mr. Shah:

I have read, with interest, your excellent, descriptive letter concerning your young son.

I must state at the out-set that it is wrong to feel that there will be regaining of useful function of bowel, bladder or the lower extremities inasmuch as the neural pathways involved in this difficulty are congenitally malformed and cannot be repaired nor do they usually improve.

In this regard, however, it would be of importance to have him seen by an orthopedic consultant inasmuch as some corrective or stabilizing procedures are, at times, possible which with the aid of braces or crutches enables such patients to ambulate.

With regards to the underlying condition if, as you describe, there is still a periodic leakage of fluid from the sac in the back there may be a suggestion that condition of hydrocephalus is not fully arrested. In these cases if the spine deformity is treated surgically it almost always produces a severe flare-up or worsening of the hydrocephalus. In these cases sometimes we consider a shunting operation for the hydrocephalus following which there is drying-up and healing of the lesion in the spine. This is something which might be considered.

DR. VIJAY MEHTA.

M.D. (Bom). F.C.P.S. (Bom).  
F.R.C.S. (Ed).

Phones : 47-5286  
47-9655

Chamber & Residence :  
508, HARISH MUKHERJEE ROAD,  
CALCUTTA-25.  
Consulting Time - 5 p. m. to 8 p. m.

Date, 2nd, July, '71

Arun Shah

Age 11 yr. 6 months.

On 15th. Oct. '70 he got fit which lasted for three hours. At first Inj. Cardinal was given up to 800 mgm. but it did not relieve the status epilepticus hence 20 ml of Inj. Paraldehyde was given which stopped the fits.

All the investigations were done, which are sent herewith

He got fits again on 29th. March, 17th. May, & 23rd. June. These were relieved by giving Inj. Paraldehyde 20 to 30 ml with Inj. Cardinal 600 to 1000 mgm.

He was started on Tab. Epilan (100mgm.) 1/2 tablet three times a day in Oct. '70 which is now increased to one tablet three times a day.

He had little sore throat and the bacteria were cultured and is being given vaccine now.

It is felt that he has got an independent epileptic focus which is causing the fits and now full dose of Epilan should control it. No cause of aggravation was found during the episodes of fits.

*Vijay Mehta*  
( Dr. Vijay Mehta. )



B. RAMAMURTHI,  
M.B., F.R.C.S. (ED.), F.I.C.S., F.A.C.S., F.A.M.S.,  
NEUROSURGEON - GENERAL HOSPITAL, MADRAS,  
PROFESSOR OF NEUROSURGERY - MADRAS MEDICAL COLLEGE.

PHONE: 71475  
2ND MAIN ROAD, C.I.T. COLONY,  
MOWBRAY'S ROAD, MADRAS-4.

Dated 14th August 1966

Ref:27.4.1965.

Dear Mr. Shah,

Thank you for your letter dated 10th August.

It is better for you to continue the Gardinal 30 mms tablets twice a day for at least one or two more years so that the child may completely rid of the trouble. You can let me know his progress after three months.

Kindly send Rs.25/- as further consultation fees.

With best wishes,

Yours sincerely,

B. RAMAMURTHI.

Mr. Y. R. Shah,  
C/ O. National Tobacco Company of India Ltd.,  
National Tobacco Building,  
land 2, Old Court House Corner, Post Box.726,  
Calcutta-1.

Y. R. SHAH

CALCUTTA

- 2 -

Under these circumstances, there is nothing that we can do over here. Dr. Bagchi also informed us that not only here, but nowhere in the world my child could be helped, as his is a back case and any surgery would be fatal to him.

With all these, I still wish to write to Dr. J.R. Roberts, M.D., whose name you have very kindly suggested, as I have no alternative but to keep on trying.

In conclusion, I once again thank you very much,

Yours faithfully,

(Y.R. SHAH)

Y. R. SHAH

NATIONAL TOBACCO CO OF I. LTD.,  
NATIONAL TOBACCO BUILDING,  
1 & 2, OLD COURT HOUSE CORNER,  
CALCUTTA-1  
(INDIA)

National Association of Round  
Tables of Great Britain and  
Ireland,  
Area No. 8,  
105, Childwall Park Avenue,  
Childwall,  
Liverpool 16,  
ENGLAND.

16th Oct '63.

Dear Sirs,

My friend, Mr. F.J. Hose, showed me your letter AGH/IC of 25.9.63, and I do not know how to express as to how grateful I am to all of your members, who took keen interest in my child's case. Indeed, I am very much thankful to you all, and the same may be conveyed to all the persons who have spared their time in research of my child's case.

Since you had taken all these pains to point out that this can be treated over here, I must also let you know the results. I and Mr. Hose had contacted Dr. A. Bagchi, who, after seeing the child and the X-Rays, advised us that there is no treatment nor the surgery, which can help my child, and that the condition will remain same for ever.

contd....

Y. R. SHAH

CALCUTTA

-2-

Similarly, there is no control over his bowels and the urine.

I have consulted a neuro-surgeon over here very recently and was told nothing could be done in my son's case. With a ray of hope that you might be able to advise me into the matter, as I have been given to understand that you have been an authority on this, I write this letter to you. I enclose herewith two photographs of my child. I can also send the X-Rays of skull and spinal chord, if they are required.

I know it must be extremely difficult for you to spare even few minutes, but having no other alternative, I have to write to you.

Hope you will understand my feelings and bear with me.

I now look forward to your early advice.

Thanking you,

Yours sincerely,

(Y.R. SHAH)

Dr. J.R. Roberts, M.D., M.R.C.P.,  
Alder Hey Childrens Hospital,  
West Derby,  
Liverpool.



Y. R. SHAH

NATIONAL TOBACCO CO OF I. LTD  
NATIONAL TOBACCO BUILDING,  
1 & 2, OLD COURT HOUSE CORNER,  
CALCUTTA -1  
(INDIA).

16th October '63.

My dear Dr. Roberts,

A letter from an unknown person from India, I know, will be a surprise to you. I am indebted to a friend and colleague, Mr. F.J. Hoss, who happens to be a resident of Liverpool, who is here at present, and National Association of Round Tables of Great Britain and Ireland, through whom I got your address.

The purpose of writing this letter is that my son is suffering from Hydrocephalus with Spina Bifidia. He is now four years of age. The circumference of his head was 11" when he was born in December, 1959, which went on increasing and came to 25 1/2" by December 1960. Thereafter, the circumference has remained same and there is no increase at all. There is a tendency of discharge of the fluid one drop at a time from the boil in the back, which has gradually slowed down in the last one year, i.e. the discharge is comparatively lesser than what it used to be a year back. His general health is very good. He takes normal diet. He is cheerful all the time. He is intelligent. However, his legs are deformed, and below the knees there is numbness.

Dr. J.R. Roberts, 23, M.B. Road,  
Rider Bay Childrens Hospital,  
West Derby,  
Liverpool.

contd....

NATIONAL TOBACCO COMPANY OF INDIA LTD.

COPY

March 31, 1965

If necessary, I can send you his previous X Rays which were taken at the time of his birth and again when he was of four years old. X Rays are of his skull and spinal cor or I can get the fresh X Rays taken if required.

It seems that his Hydrocephalus has ceased as his head stopped growing. Of course there is some fluid discharge drop by drop in very slow proportion from the boil in his back.

If any other particulars are required I can get everything done according to your instructions with the help of my famli doctor here so as to give you all the minute details of his present condition.

Further I will very much appreciate it if you could recommend any equipment which can facilitate his movements inside the house so that he can moveabout on his own in the house or to the adjacent garden.

In closing I wish to add that I shall be very highly abliged if you could kindly suggest some treatment to improve my son's condition.

I am sending you his photograph in case it is of any use. While sending reply, please post the letter to the following address :-

Mr. Y. R. Shah legs are also deformed and look like paraly. c/o National Tobacco Co. of India Ltd., his urine or stools and a little to play or move about by dragging the urine or stools are automatically

Looking forward to receiving your favourable reply,

Otherwise his general health is very good. He is intelligent, talkative, very affectionate and always cheerful.

Yours faithfully,

I shall feel highly obliged if you could let me know whether there is any hope of improving my son's condition, is there any cure for Spina Bifidia are any hope of his moving about on his own legs in future?

Enc:

Contd...2

March 31, 1965.

If necessary, I can send you his previous X-rays which were taken at the time of his birth and again when he was of four years of age. I can also send you a photograph of his skull and spinal cord or I can send you a photograph of his head and neck.

Dr. Joseph Ransohoff  
New York University Medical Center  
550 1st Avenue  
New York, N.Y.  
U.S.A.

His hydrocephalus has ceased as his head stopped growing. Of course there is some fluid discharge drop by drop in proportion from the bolt in his back.

Gentleman : If any other particulars are required I can get everything done according to your instructions with the help of my famil doctor

I am indebted to 'TIME' magazine to help me by giving your name and address. This is because I had asked them about more details of treatment for Hydrocephalus and Spina Bifida, after reading an article in that magazine.

I have a son of five years old who was born with Hydrocephalus and Spina Bifida. After consulting with various doctors and institutions we were told that there is no remedy either medically or surgically for my son. When he was four months old the fluid was punctured out from his head thereafter his head ceased to be growing at the age of two years and skull was formed completely by then. At the time of birth his head circumference was 11" and it became 25" by two years when it ceased to increase. At present it is still 25" as it was when he was of two years old.

His legs are numb below knees and he has no feeling on that part even if we pinch him. His legs are also deformed and look like paralytic condition. He has no control over his urine or stools and whenever he exerts a little to play or move about by dragging his body, the urine or stools are automatically passed out.

Otherwise his general health is very good. He is intelligent, talkative, very affectionate and always cheerful.

I shall feel highly obliged, if you could let me know whether there is any hope of improving my child's condition. Is there any cure for Spina Bifida? Is there any hope of his moving about on his own legs in future?

Contd... 2

(2)

May 27, 1966

There has been no improvement in his Bladder or Bowel control. The condition is same as it was before the operation. So is the case with his legs below knees. This is for your information.

Profuse sweating takes place right where the Meningocele closure is done. Is there any significance in this symptom?

Kindly write to me at the earliest and oblige.

Thanking you.

With best regards,

Yours sincerely,

(Y.R. SHAH)

YRS:KA

Dr. B. Rammurthi M.S. F.R.C.S. (E) F.I.C.S. F.A.C.S.,  
Neuro Surgeon,

11, Main Road, C.I.T. Colony,  
MADRAS - 4. This generally happens once in three to four weeks only and he gets the cramps for a day or two. He is being treated by our family doctor during this trouble and visiting steps in day or two.



May 27, 1966

Dear Dr. Rammurti, I am happy to hear of his improvement in his hands after the operation. It is the case with his legs and knees. This is for your information.

Re: Arunkumar # 27.4.65.

After we came back from Madras after Meningocele closure operation for my son Arun, he has been keeping well in general.

We are now trying to make him stand with help of calipers etc.

Recently, we have found that at times he is having jerks in both his hands which looks like some kind of twitching. Generally this happens immediately after he goes to sleep in the evening. Two minutes after he sleeps jerking in both the hands starts and stops after a second or two, and again it reoccurs every few minutes and finally after 30 to 45 minutes it stops. This happens only for both the hands upto shoulders. These jerks are mild. In between he had these continuously for 6 days and all the time only in the evening after he had gone to sleep and the jerks stopped within half an hour to 45 minutes. Presently in last few days it has not happened.

We have been regularly giving him Cardinal 30 Mg tablets twice a day ever since we have come back from Madras.

As he has twice in past had Epileptic attacks, I am afraid this may be some kind of Epileptic trouble.

Kindly advise me suitably as to what treatment should be done to prevent this in future if it reoccurs. We are continuing with Cardinal two tablets a day, right now.

Apart from this, once in three to four weeks he gets vomiting sensation and also vomits few times during the day when it happens. But this generally happens once in three to four weeks only and he gets the trouble for a day or two. He is being treated by our family doctor during this trouble and vomiting stops in day or two.

Otherwise he is normal.

*The End*

