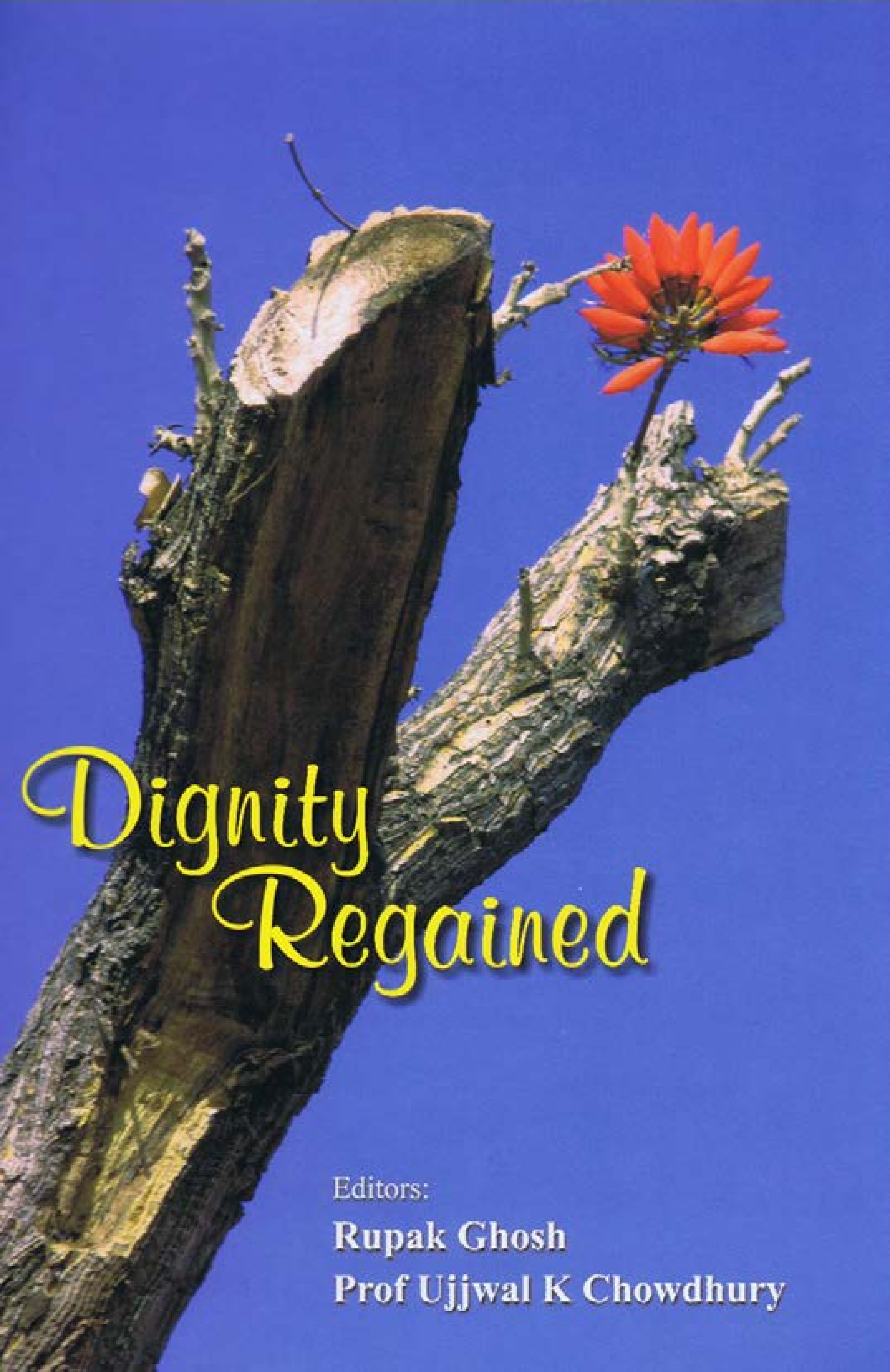

Dignity Regained

Editors:

Rupak Ghosh

Prof Ujjwal K Chowdhury

This book is dedicated to
the Father of the Nation,
Mahatma Gandhi,
who was the first to dream of
a Leprosy-free India;
and to the
Eleven Million Indians
who are today affected by Leprosy
and struggling
to lead a dignified life.

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REGAINED

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An **ICONS Media** Publication
(In collaboration with ILU, IDEA India, TNF and SMHF)

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Let them speak up!

Since the widespread introduction of Multi Drug Therapy (MDT) in the mid-1980s, enormous progress has been made to reduce the leprosy caseload. Since then, around 14 million people have been cured of the disease; 10 million of them in India alone. India has taken giant strides in tackling leprosy, and I have nothing but praise for its efforts. Undoubtedly, without the progress made by this nation, the world picture would not be as positive as it is today.

The success in eliminating leprosy as a public health problem has been a worldwide phenomenon. As of today, only nine countries are yet to achieve the target set by the WHO, that of less than 1 case per 10,000 people at the national level. These countries are India, Brazil, Nepal, Madagascar, Mozambique, Tanzania, the Democratic Republic of Congo, Central African Republic and Angola.

Most of these nations, India included, are expected to reach this goal by the end of 2005. Eradicating (permanent reduction to zero-incidence) the disease, however, is a much more difficult medical challenge, given the long incubation period and is unlikely to happen in the near future. But major emphasis needs to be laid on the fact that leprosy is a curable disease, treatment is available free of charge to all who require it, and that there is no place for any irrational inhuman discrimination against leprosy-affected people.

As a disease, leprosy has two aspects: medical and social. Thanks to the efforts of the WHO and its partners in the fight against it, the medical aspects of the disease have now been addressed. The time has come for attention to be focused on the social aspects, particularly the stigma and discrimination associated with leprosy. In August 2005, it seems likely that the UN Sub Commission on the Promotion and Protection of Human Rights will pass a resolution highlighting leprosy as a human rights issue. Once it happens, it will pave the way for the full Commission to pass a resolution, which I believe will have a significant impact on the circumstances of people affected by the disease.

Leprosy is one of the oldest ailments known to mankind. Over the centuries, many misconceptions about the disease have taken root, for instance that it is God's curse or a result of sins from an earlier birth. The main reason that stigma remains is that the population at large is not fully conversant with the correct information about the disease, including the fact that around 95% of people have a natural immunity to leprosy, it is completely curable within six to twelve months of starting treatment and it is not contagious.

The role of the media is vital in disseminating correct details about leprosy. Media must also set for itself a high standard and avoid the use of unacceptable terms, such as 'leper' or 'kodhi', which unfairly define a person affected by the disease. It is also very important to have people who have recovered from leprosy speak out about their experiences, via different media vehicles and in various public gatherings, to show that it is possible for someone who once had the disease to lead a perfectly normal and productive life. Happily, we are seeing more and more people coming forward to set examples, which I find extremely encouraging.

This book with several first person testimonials by affected and cured individuals from different parts of India is a powerful illustration of the new and inspiring trend in the battle against the disease and the stigma associated with leprosy world-over. It can prove to be a landmark in the history of this battle in recent times. My best wishes to the persons who have narrated their experiences, the writers, the editors and the publishers of this book.

We must hear them now. Let them speak up!

Yohei Sasakawa

WHO Goodwill Ambassador for the Elimination of Leprosy
Chairman, The Nippon Foundation, Tokyo

Contents


SINGER

AFSANA BEGUM

> *“I am no longer afraid of the question, 'What are those scars, Afsana?'”*

Name: Afsana Begum

Age: 21 years

Location: Tiljala, West Bengal

Profile: Displaying determination that belies her age, she has defied fate in emerging victorious over her battle with leprosy to be where she is today, living a contented life with her little daughter and learning her way towards self-employment.

With a pounding heart full of hopes trying to anticipate what the future held in store, I had stepped onto the Bihar-bound train. I was only 14 and married to a man twice my age. He lived in a small town in Bihar. That was where I was headed to.

Leaving behind my loved ones, parents, siblings, the surroundings I was born and brought up in, was not an easy task. It was akin to the feeling of being uprooted from the soil one had learnt to cling to for warmth, tenderness and love. But my trepidations proved to be unfounded, at least initially.

My mother-in-law loved me dearly and so did my husband. Towards the end of the second year of my marriage I was gifted with a small bundle of joy, a baby boy, whose arrival into this world brought with much jubilation to the entire household.

Little did I know then that my days of happiness will be short-lived. I had no inkling whatsoever that I was about to encounter an episode in my life that was so dreadful and painful that it would change my life into a living nightmare.

It was the sixth year of my marriage. Suddenly patches started appearing on my forehead, cheeks and hands. I had no idea what they were and so, I dismissed them as some temporary ailment that will go away as abruptly as they had appeared. But they were not so easily written off by others, mainly my in-laws and our neighbors.

Gradually, the patches started spreading all over my body like an oil spill on a clear pond. There came a time when I was treated as a pariah, with people refusing to come near me. My in-laws, even my husband, began treating me like a recluse, an untouchable. Being a poor illiterate girl I did not possess adequate knowledge to realize that I was being afflicted by a disease. The only thing I understood that like a pack of cards, my life and along with it the world around me was falling apart .

To add to my woes, I gave birth to a frail little girl child at that point of time. My mother- in-law intended to kill her upon birth. Till then I had been silently enduring all the pain being inflicted on me but motherhood aroused the human being in me. I wanted to protect my daughter and vowed never to give her up under any circumstance.

Thus began my trial by fire. My newborn and I were locked up and deprived of food for days on end. My pleadings to spare my innocent child fell on deaf ears. I prayed day and night to Almighty Allah asking him to save my child's life.

Hidden from the rest of the world and cooped inside a locked room like a shame that needed to be forgotten, I was not even allowed to get in touch with my parents who stayed in Kolkata. Finally, like a godsend, my brother came to visit me one day. Appalled at my condition, he decided to take me back with him. But the act did not turn out to be as simple as it sounds. It took a Herculean effort on my brother's part to persuade my husband to let me return to Kolkata. He agreed, but on one condition. I had to leave behind my four-year old son with them. Their argument was that my son should not contract the disease I was suffering from. I knew no amount of pleading will help, so I had no other option but to agree. I slipped away quietly, under the dark cover of the night, because I was afraid that my son might cry, watching me go. My heart would not have been able to bear the sight.

When I stepped onto the platform at Howrah station in Kolkata, my sole possessions were a diseased scarred face and a frail child. I started living with my parents. The household comprised of my sister, my brother, his wife and their two-year old son. It did not take me long to understand that I was not welcome. But looking at my daughter's face, I knew that I had no choice but to silently endure the caustic remarks, veiled disgust and open discrimination.

Meanwhile my scars were getting worse. I desisted from going to a doctor. I was afraid of my malaise coming out into the open. Additionally, I did not want to increase the monetary burden on my father who was a tailor by profession.

My father was the only person in my family who really cared for me, the only soul who was happy to have me around. Even my mother's attitude towards me was that of indifference. My aunt even tried to make my mother understand that it was wrong for her to allow me to stay with my own parents.

That proved to be the last straw. With tears of humiliation stinging my eyes, I made up my mind to leave my parents home as soon as I could arrange a means of livelihood for myself. I knew I had to, there was no other choice. But the big question that hounded me day in and day out, circling my mind like vultures atop a carcass was where would I seek shelter, considering my state and moreover, with my little daughter in tow. I felt helpless, forlorn and resigned to fate.

There is a saying which mentions that the darkest hour of the night comes just before dawn. One morning I took my nephew, who was running a mild fever for a few days to the nearby Tiljala dispensary. While waiting in queue to visit the doctor, I suddenly felt someone patting me on my back. I turned to see the smiling face of Dilruba Begum, an employee of the medical facility, who had earned the epithet Mamata Didi ('Mamata' means love and compassion) from the people of the locality. As I looked at her, she asked me to wait until all the other patients went away. The sudden touch, her soothing voice and her pleasant disposition were aspects long missing from my life. I waited. When there were no more patients to tend to, she called me into her room and took a good look at the scars on my face and hands. When she held my arms in hers, I knew that a ray of light had shown through the dark life of mine.

It was from Mamata Didi that I learnt those ugly scars on my body were the result of a deadly skin disease called leprosy. She warned me that if left untreated, it could affect my eyes and mouth and deform me permanently.

Later on, I learnt that she worked at the dispensary on behalf of an NGO called GRECALTES which treated people afflicted with diseases like leprosy and tuberculosis. The organization first identifies patients after conducting surveys. Then, all those afflicted with those diseases are provided free treatment. Finally, the cured individuals are rehabilitated, thereby helping them to lead a normal life once again.

Mamata Didi gave me medicines, painstakingly explaining the procedure of taking them. Initially I was very scared to go to the dispensary every week to get myself examined and bring back the medicines prescribed, for fear of my neighbors coming to know the truth. The constant worry of being spotted, singled out and subjugated to discrimination even stopped me from visiting the dispensary at times. But trust Mamata Didi! Whenever I failed to go to the dispensary, she would turn up at our doorstep with my medication.

My body reacted adversely as I began the dosage. When I first started to take the medicines, the scars on my face got worse. They swelled up and looked horrible. Even my family members grimaced at the sight. I was so scared that I rushed to show them to Mamata Didi. She laid my fears to rest. She told me that the pain I was going through was the sign of the medicines starting to work. Her words proved prophetic and within six months after I began taking the medicines, my scars were almost gone.

Now it feels like I have been reborn. I have no qualms in going out during the day time without covering my face and hands. I hold my head proudly and without being mortally afraid that somebody will point an accusing finger at my scars and ask with mock sympathy, 'What are those scars, Afsana?'

Mamata Didi not only gave me a new life she also became my psychological mentor. It came naturally to me to confide everything to her, be it monetary difficulties or problems regarding my family. What was there to hold back from someone who had seen me through my darkest hours and stayed by my side when the rest of the world had turned its back towards me?

It was Mamata Didi who took me to GRECALTES' office where cured individuals are trained in sewing. I go there every weekend. I am confident that by the time the training gets over I will be able to get myself a job in a tailoring shop and earn enough to feed both myself and my nine-month old daughter. Did I tell you, I have named her 'Raunak"? It means light or shine. Every time I look at her bright face, I silently pray to Allah that he give me the strength to bring up my daughter in a way that she never has to undergo the ordeals I have been through. She is my whole world now.

***Interviewer's note:* Sreemoyee Mukherjee**

21-year old Afsana had to endure immense hardships and pain at an age in which an average young girl would still be enjoying her childhood. In spite of her worries for the future, ever-smiling Afsana till date carries her husband's photograph with her and never fails to shed a tear whenever she thinks of the son she left behind in Bihar. From a girl in her teens fighting against all odds she has carved a place for herself as an ideal portrayal of a woman who fought for her self-respect and won it. My salute to her.

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ANJAN DEY

> *"I have taken back the dignity which the society had once seized from me"*

Name: Anjan Dey

Age: 53 years

Location: Pune, Maharashtra

Profile: A successful physiotherapist who dreams of a society where cured individuals will be able to shrug off every vestige of the disease that society imposes on them.

I am a Bengalee from Orissa. The sole son in a family of five daughters, I was the apple of everyone's eyes. I excelled both in academics and extra-curricular activities, with volleyball and cricket being my favorites. I also enjoyed acting, being an 'A' grade artist at the Cuttack Television Centre. It was natural for my parents to harbor a lot of expectations for me. And I tried not to let them down. After clearing my High School exams, I enrolled myself in an engineering college. My dream was to become one of the best engineers of the country.

It was around this time that my mother noticed me hurting and sometimes burning my right hand without even realizing it. She took me to the local hospital; the doctor there doubted leprosy and refused to touch me further for any treatment. The diagnosis left both my mother and myself speechless and stunned.

As reality sunk in, glimpses of past incidents flashed across my mind. I remembered how as a child if a beggar afflicted with leprosy came to our house, my mother would tell me to give the alms but to be careful not to touch him. I recalled the times when I went to the temple with my grandmother, and there would be rows of people sitting on the steps, with bodies scarred by leprosy and how immediately my granny would pull me away from them.

The truth caught me in a stranglehold, a similar fate was awaiting me in the not-so-distant future.

I was devastated. 'Why me?' I kept asking myself. The next thought that came to my mind was whether the life henceforth was worth living. I could not see myself seated at those temple stairs asking for alms. Ending my life was an option that I was considering and giving it quite a thought.

Meanwhile, I faced discrimination from the most unexpected quarters. The doctor in my town refused to touch me, forget offering me any treatment. This delay in treatment was slowly leading to a deformity in my hand.

By now, my relatives, friends and neighbors had come to know about my situation. They either openly or diplomatically started maintaining a safe distance. I could see the sorrow in my parents' faces, their entire world had crumbled with me, their only son. All my dreams disappeared in a second... But the worst was yet to come. My sister's wedding was called off when the prospective groom's family came to know of my condition.

I realized that soon the time will come when my entire family will be ostracized for no fault of their own. The only option left before me was to leave. So, one day, I left my town without telling anyone at home.

Certain harsh truths had dawned on me by then. I knew it was a hard battle that I had to fight on my own. I did not know the outcome, but this much was certain, I would not give up without a fight.

I reached Bombay (now Mumbai) where I came to know that this disease can be cured. I learnt of a hospital in Sattra district of Maharastra, where they treat leprosy afflicted individuals. I immediately went there. The doctor there kept me in a cowshed for seven days. He did not touch me even once. My food was thrown at me. Dejected, I left the place.

But something told me there was still hope. I reached Pune and visited Dr. Bandorwala Leprosy Hospital at Kondhwa. It was there for the first time that a doctor actually touched me.

I stayed in the hospital for treatment and at the same time I used to clean the floor of the ward to earn a living. Slowly, but gradually, I was recovering. But all this while, the desire to get back my dignity, to live the life I had dreamt of, kept burning somewhere within me. I kept on telling myself, I still had a life to live and I wasn't going to let it go just because of an unfortunate disease.

During my stay at the hospital I had developed an interest in physiotherapy. I told the hospital authorities about my desire to study further and obtain qualifications to get myself a decent job. Dr. Mehta suggested me The Christian Medical College, Vellore. I applied for a course in Physiotherapy where I got selected after an interview. Meanwhile every three months, I sent a letter back home, telling my parents that they need not worry about me.

By 1980 I was fully cured and had become a qualified Physiotherapist. My first choice was Dr. Bandorwala Leprosy Hospital. The reason behind my choice was possibly the fact that it was here for the first time doctors had touched my deformed hand.

Meanwhile, I got married to a Maharashtrian girl, Urmila. I call her 'Uma'. She used to work in the hospital itself and no, she has never been afflicted with the disease. Three years after becoming a physiotherapist, I went back to my home in Orissa.

My parents were over whelmed on seeing me. Many relatives and friends who had moved away from me initially, came to meet me at home, maybe it was because I had carved out a position for myself in society. I had left home a lost man, clueless of my dignity and destiny. Today I can proudly state that I have regained both of them .

I am a very proud man today. And why shouldn't I be? I have a beautiful wife, two healthy children, who are good-looking and intelligent. I own a house and a vehicle. My children study in renowned colleges. And I have no qualms in proclaiming that all these have been made possible, only through my will and sheer hard work. I have worked and earned for everything I have today. You can imagine how proud I feel to say that, I head the department of the same hospital where I used to clean the floor once.

Besides working full-time at Dr. Bandorwala Leprosy Hospital, I am also a visiting physiotherapist for various other hospitals and clinics in Pune. Though, technically speaking I am not a 'doctor', but people refer to me as 'Dr. Anjan Dey'. My heart swells with pride.

One of the highlights of my career occurred when I got the opportunity of working in a research project which was conducted by the Department of Podiatry, Queen Margaret College, U.K. on the concept of healing ulcers. One of my main areas of work is providing preventive and corrective treatment of the planter ulcer and imparting health education to the patient about hand and foot care. Presently, I am conducting a study under the Science and Technology Department (Ministry of Welfare), Government of India, on prevention of planter ulcers through the usage of therapeutic pads with footwear.

But there comes a time when I find myself getting caught in an endless strand of thought about what my life could have been had I not contracted the disease; how my life could have turned out to be different if the doctors hadn't initially refused to touch me. This much is for sure, I would have had ten fingers instead of five.

During my battle with the disease and interaction with all I have come across, I have understood one basic fact, people do not fear the disease, they fear the deformity. MDT cures the ailment, but not the abnormalities.

It is true that society has progressed as far as its outlook on leprosy is concerned than where it was, say, 20 years back. But, even today, in spite of all that I have achieved there are instances when many of my colleagues introduce me as, 'Meet Mr. Anjan Dey, a very successful physiotherapist, doing lot of work in his field and you know, he is an ex- leprosy patient'.

That one term 'ex-leprosy', I feel drowns all my achievements! It is as if a new identity has been created for me. It is curious, how we never say an 'ex-malaria patient', 'ex-TB patient' or, for that matter, 'an ex-cancer patient' Then why an 'ex-leprosy patient'. I think it is one of those mysteries which I can never fathom.

The society needs to learn first. It needs to accept leprosy as just another disease, treat it and let the cured individuals get on with life. One move that can really help the cause is to get rid of the rehabilitation centers. I feel such centers do not assimilate or integrate the affected. They just segregate them further. All these pockets of leprosy colonies, homes, and vocational centers … I find them very regressive. They are, in a way, responsible for creating a world of 'ex leprosy' patients. Thus, branding them forever. Rehabilitation can only become meaningful when an afflicted person can go back to his village, his home and resume his life from the point he had left it.

Interviewer's note: **Pallavi Baruah**

In spite of efforts at disseminating knowledge about leprosy, the truth is that even today, half of our society is either disinterested or oblivious of the fact that a section of people are still being ostracized just on the basis of deformity or fear of contracting the disease. The 'stigma' has to turn into a natural process of social acceptance. It is true that no one can force an idea upon a society, the society itself has to grow and mature to accommodate the idea. And for that, awareness has to start at a very basic and primary level of social education.

Society needs to look away from the deformity and accept 'the person' beyond that irregularity.

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Md. Salahuddin

> *"What sets a leprosy affected individual apart from others is not his deformity, but being branded for life by society"*

Name: Md. Salahuddin

Age: 74 Years

Location: Hyderabad

Profile: The scion of one of the most affluent families of Hyderabad, he has made a name for himself as a visionary who has made the seemingly impossible possible - a colony where individuals cured of leprosy reside side by side with their 'normal' counterpart.

Born in one of the richest families of Hyderabad, I was showered with endless love and affection throughout my childhood. Maybe it was this love that made me empathize with the poor and needy during the later stages of my life .

One of my cherished dreams during my childhood was to become a doctor when I grew up. I even practiced scribbling 'Dr Md. Salahuddin' in my notebooks! Besides studies, I engaged myself in a lot of extra-curricular activities, especially sports like football and cricket. But what I enjoyed most was body building. To keep my body fit, every morning I made it a point to run ten miles.

It was all going pretty well with my life until everything changed within a span of a few days. During one of my visits to our neighborhood doctor, Dr Najmul Hussain, he noticed some red patches on my cheeks. He insisted on meeting my father immediately. When both of them met, I was given no indication whatsoever regarding the conversation.

However, this much I was sure of that it was because of the doctor's advice that my father took me for medical check ups to a number of medical practitioners. Finally, he settled on Dr Christian, who was a well-known specialist on leprosy during those times.

I was still kept in the dark regarding my ailment. However, one day while collecting my medicines, my eyes fell on the envelope that contained my medications. Two words caught my eye 'Leprosy

Specialist'. A shudder ran through my body, my heart skipped a few beats and a deep breath escaped my lungs. I could not restrain myself and asked Dr Christian if I had contracted the dreaded disease.

He did not keep the fact secret from me. Realizing fully the anxiety I was going through, he tried to put me at ease by stating that the disease was in its earliest stages and I would soon be completely cured. I had full faith in his words and I regularly took my medicines without fail for two months.

But at the end of that period, instead of an improvement in my condition, I began feeling a loss of sensation in my right toe, which gradually spread to my foot. This time the doctor himself was not really sure about what was happening with me. All my fear, anger and frustration, I vented on the doctor. After severely reprimanding me for my immature behavior, my parents requested me to continue with the treatment. But by then, I was determined never to be treated for leprosy for the rest of my life.

The reality of an incurable disease in me had shattered my dreams, but I was determined to overcome all hurdles. So I began focusing all my attention on my studies. But once more, fate thwarted my endeavors when I was refused admission to a Medical College. The authorities demanded a medical certificate from me specifying that I did not have leprosy, before they could grant me admission. I was outraged, but helpless.

There is a saying that I had heard when I was a child. It mentioned that when all doors close, one of them opens somewhere. During those exasperating times, I kept on reminding myself of this saying. I began visiting the recruitment office with a heart filled with hope.

Finally, the day came when I found my name on the list of candidates selected for the Navy. On the very next day we had to leave to Dehradun for training. Just when I thought that my days of despair were over, fate caught me off guard yet again. The authorities used a euphemistic excuse to throw me out. Supposedly, after conducting a number of medical tests they had come to the conclusion that my skin was unsuitable for the salty waters of the sea. Hence, they suggested me to join the land forces. But in my heart of hearts I knew that there, too, I would be declared leprosy affected. I could not and did not want to face the humiliation again. I returned home.

Life had turned into a dead end. The road ahead seemed to be dark and difficult. But my mind was made up. I wanted to start a fresh chapter of my life. I wished to completely eradicate from my mind that I ever suffered from leprosy.

I took the first step towards fulfilling my urge to earn a respectable livelihood all on my own when I moved out of my parents' house. I then went from door to door with a hand-written application in search of a job. But from everywhere, I received the same response a curt 'no'.

By then I had reached a conclusion that the only way out for me was to add to my educational qualifications. To this end, I joined a part-time college. I spent the mornings doing typing work to earn some extra money. Apart from being a typist I also worked as a second hand car dealer. Sometimes I also participated in some construction site jobs. Life seemed at last to be looking up when suddenly a setback in my health changed everything all over again.

For some time, I was running a fever and quite a few extremely painful ulcers had developed on my feet. I was in so much pain that my friends thought it best to take me to one of the most famous hospitals in the city Victoria Hospital at Dichpally (Hyderabad). I had tried my level best to prevent this from happening, but my condition had worsened to such an extent that I had no other option but to accede to their requests.

My initial reaction was that I shall be alienated once I find myself inside the hospital. But my fears were proved to be unfounded by three individuals - Mr Sagar who first met me in the out patient department and took me to the O.P Examination room where I met two doctors, Dr Samuel, the hospital superintendent and Dr Davey, the Director.

I was disappointed at the state of the room I was in. It made me feel even more depressed. I requested Dr Davey to do something to improve its state of utter disrepair before beginning my treatment. The kind soul that he is, he offered to shift me to his house instead, an offer that warmed my heart, but was politely refused.

The very next day Dr Davey arranged for a new bed with new bedding for me. Moreover, he assured me that if I ever needed anything, all that I needed to do was send a word to him. I have never met a kinder, gentler and more compassionate human being in my entire life.

Within a fortnight of beginning my treatment the ulcers on my feet began drying up. I was ecstatic but I knew that what was really helping me was not the medical treatment, but Dr. Davey's kind behaviour and his daily visits along with his wife. When I felt healthy enough, I requested the doctor to allow me to resume normal work. He told me that I was free to leave but added that he would be really happy if I stayed back and took charge of the administrative work of the hospital. I could not have asked for more! I agreed immediately, but on the condition that the only person superior to me in the hospital would be Dr.Davey and that I should be allowed to go whenever Dr.Davey left the hospital. He agreed to my condition with tears of joy in his eyes.

Thus, the same individual who had entered the hospital as a patient became the administrator.

During my days at the hospital, Dr Davey became my idol. I remember one particular incident which exemplifies the man's greatness and commitment towards those affected with leprosy. Once the District Collector had come to visit our hospital. While he was escorting the Collector in his tour of the rooms, Dr Davey noticed him holding a handkerchief over his face. I still remember the look on his face when he took a stand and refused to accompany the Collector any more. He categorically stated that he found covering the face with a handkerchief to be a disgraceful behavior which was nothing short of disheartening for all the patients. Another person in the hospital who has left behind an indelible impression in my life is Sister Elizabeth Wright. I consider her to be kindness and caring personified.

One of my first assignments as the administrator of the hospital was to register the out patients and prepare registration cards for them. I was told to collect a consolidated fee of Rs.25 for the entire three-year long treatment. However, I was instructed not to deprive anyone of treatment on account of paucity of money. Since this was the only source of contribution to the hospital funds, I tried my best to collect as much money as possible.

Meanwhile I was getting more and more involved in my work. I started visiting patients who lived in a colony just outside the hospital. All of them were fully cured, though the disfigurements had remained. However, they could not lead a normal life because society had declined to accept them back into its folds.

Their plight tugged at my heartstrings. I asked Dr Davey if something could be done to rehabilitate these individuals. A joint decision was taken to employ them in our own hospital. They began working as laboratory technicians, assistants, physiotherapists, non-medical assistants and chemists among others.

The Government of Andhra Pradesh took notice of our activities and asked Dr Davey to take over the functioning of a rehabilitation centre located at Moulali (in Hydearbad). He sent me to visit the center with the objective of returning with a report.

I went to Moulali expecting a clean, green, rehabilitation area. What I saw shook me to the core of my heart. It was, arguably, the most dirty, unhygienic and malodorous place I have ever been. I could not imagine how human beings could survive in such utterly deplorable conditions. On returning, I asked Dr Davey if it was feasible for us to take over the rehabilitation centre at Moulali and run it on our own. Somehow, the matter was taking time to get resolved and in the meantime, in 1973, Dr Davey had to leave for England. In accordance with our agreement, as soon as he left I also returned to live with my brother in the city.

However the thoughts of rescuing the cured individuals from the misery of the rehabilitation centre kept on circling in my mind. Towards this aim, I began visiting the center twice a week to see what could be done for them. I was determined to turn the situation around in favor of the inmates, change it completely so that they could once again lead a normal, healthy life. It was during this time that I decided to dedicate my life to the services of those people who are neglected in the name of poverty, disease and disability.

I knew that the biggest hindrance to those affected with leprosy is the burden of the term 'leprosy patient'. Hence, I decided to fight the social stigma first. Bringing back the cured to the society plays an important role in achieving the goal of eradication of leprosy. But it was something that the unfortunate inhabitants of the Moulali rehabilitation center could never hope for.

Initially, to convince them that they were like any other normal human being, I encouraged them to participate in several sports events organized for those who are physically challenged. The response I received fueled my enthusiasm. I proposed that they should go looking for employment in government offices.

However, to apply for governmental jobs one has to get registered at the employment exchange, which at the very outset denied these individuals registration on account of the fact that they were once affected with leprosy. Accompanied by sixteen such persons, I paid a visit to the employment exchange. Faced with the same barrier, I asked the people over there to let me take a look at the eligibility criteria for registration in the exchange. Surely enough, one of the by-laws clearly mentioned not to exclude people who had any form of skin disease. Nothing could stop us now from getting registered. It was through similar efforts that we managed to get employment for nearly four hundred cured individuals in different capacities at the Municipal Corporation of Hyderabad.

While we were busy trying to erase the social stigma associated with leprosy, we also came across those who after being discharged from rehabilitation homes had nowhere to go to .Most of them were forced to beg on the streets, thereby leading a life of destitution and debasement. I took up their cause and after a lot of hard work managed to settle them in a camp set up exclusively for them. Furthermore, I tried to imbibe in them the desire to earn a decent livelihood.

However in spite of these achievements, my real objective of bringing back those who are fully cured of the disease to the mainstream of society was still very much unfulfilled. At all stages I was ridiculed by the government and private departments. After considerable efforts, all of which proved to be futile at the end, I realized that the best way to solve the problem would be set up a constitutional body and get it registered by the government.

Thus, in the year 1978, was born 'Council of Hansen's Social Welfare' (after Dr Hansen who discovered the bacillus of leprosy. Hence, leprosy is also called Hansen's disease.) I deliberately chose this name because it was little known and hence would lead to lesser stigma being attached to those who got associated in our activities. One of the first things the Council did was to get the leprosy patients enlisted in the Municipal Corporation as citizens of the community. The day when for the first time in the history of the Government of Andhra Pradesh, a leprosy afflicted individual stood in the same queue as a normal human being to exercise his right to vote was indeed a day of pride and joy for our organization.

Eventually, our camp was transformed into a colony, which we named Gandhinagar Colony. This point onwards my long cherished dream began to gain fruition.

Later that year, while addressing a gathering, during the celebrations of World Health Day, I requested the Government of Andhra Pradesh to come forward and extend their cooperation to our Council. What we wanted was to build a colony where normal healthy people and cured individuals would live side by side, leaving aside any fear of disease and differences of caste and creed. To our pleasant surprise, the Government agreed to allot nearly 56 acres of land for this dream project.

I realized that the first step to take would be to counsel the people living in the surrounding areas about our objective. We began by speaking to them, and trying to make them understand that leprosy was not a punishment for one's sins; neither was it a contagious disease. We tried to emphasize the point that those who were fully cured of the ailment had every right to lead a normal, healthy life with other normal, healthy people.

The next major problem was finding employment opportunities for those who would reside in the colony. Initially no solution seemed at sight because the area was quite remote and deserted. But I have always been a firm believer that good intentions and sincere efforts always payoff. And this case proved to be no exception.

I appealed to the building contractors to utilize the services of our people as laborers on their construction sites. To our surprise, they readily agreed to our suggestion and our people started working with full dedication and honesty. Additionally, I took a bank loan with which I bought ten rickshaws. Some of the cured individuals engaged themselves as rickshaw pullers.

During this time, at the insistence of the inhabitants of the place, I decided to name our colony 'Rockland Colony' or 'Parvathnagar'. Parvathnagar became synonymous with refuge for those who for long had been shunned and ostracized by the society.

Ever since then, activities like child and health care, adult education programs, mahila mandalis (women's organizations) and others have been launched for the betterment of the inhabitants. The concern for their future generations have prompted these people to send their children to good hostels and today the next generation is emerging with high academic qualifications, ready to take up the challenges which life may pose for them.

Today, nearly three hundred families live in Rockland Colony which, I believe, is a true example of 'Social Integration' of the cured and normal people. I dream of a society when many more such colonies will become a reality; a world where there will be no more stigma and no fear of contempt and humiliation for those affected by leprosy.

This autobiographical story has been written by Mr. Salahuddin himself.

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M GURUAPPA

> *“No deformity, no patches and no fissures on my skin... surely I didn't have leprosy!”*

Name: M Guruappa

Age: 55 years

Location: Faridabad, Haryana

Profile: His story is an exemplary case of triumph over misfortune. Even when relegated to a life of destitution and beggary, never did he abandon his self-respect. He played an important role in swaying the government to initiate a system of daily meal and monthly ration for those who earn their livelihood by asking for alms.

I was born and brought up in Karnataka, in a district called Gulbarga. Our source of livelihood was through agriculture. When I was just four years old, I lost my father. My mother raised all four of us, two brothers and two sisters by toiling hard on a small piece of land. She also passed away when I was barely 12.

Though I was quite keen on continuing studying, there was no one to support the cost of my education. Being an orphan with no one to look after me, the village Panchayat decided to hand over the reins of my upbringing to my elder step brother.

Even though my dream of completing my school education was nipped at the bud, I did not abandon my thirst for knowledge. I approached our family guru an Ayurvedic doctor by profession,to allow me to assist him in his work. I was fortunate enough to be granted my wish. I stayed with him at his place where I, under his tutelage, prepared medicines which were then distributed among his patients. For about five to six years, I continued to be his apprentice, until one day, on a very short notice I was called back to the village to help my brothers in agricultural activities.

I was reluctant to return, but once I did, I found myself gradually getting involved in the village life. There came a time when my younger brother was at the right age to begin his schooling. To my dismay, I found that there was no initiative from my elders to help his cause. Knowing the importance of education, I decided to fund him myself, and towards this end, started a milk supply business in our small village.

It was around this time that I noticed a strange numbness in my feet and hands. I had no idea whatsoever about the reason behind the total lack of sensation. I remember one day I was chasing a bull on an Arhar (a type of pulse) field. When I returned home everyone was aghast seeing the sole of my feet dripping blood. Immediately some home-made remedy was administered, but no one could fathom how I had been totally unaware of such a deep wound on my body. On another occasion, my white dhoti was found drenched with blood that had dripped from my left thumb. In this case, too, the extent of the wound and my lack of sensation dumbfounded everybody.

This much I could understand that whatever was happening to me was no ordinary ailment. I paid a visit to our family guru, Dr M S Nawari and sought his advice. He heard me out patiently and then offered his diagnosis - a minor sugar problem. The treatment prescribed was a mix of desi ghee and some local medicines. The notion, borne out of the little knowledge of Ayurveda that I had gained from him, that the prescribed medication was of little or no help kept gnawing me at the back of my mind. Tell me, how could desi ghee cure a sugar problem?

But the real truth ultimately did come out in the open. One day, unknown to him, I noticed that the medicine he was administering on me was not meant for patients with a sugar problem, but for those who had contracted leprosy.

I was appalled, angry and apprehensive. I confronted him, demanding to know why he had hidden the truth about my condition. His explanation was that he was unsure about how I would react if he had told me the reality of my condition. My young age and aggressive nature made him question whether I was mentally mature enough to handle the shock that such a revelation usually leads to.

I did not believe there was an iota of truth in his diagnosis. My face and my body were not disfigured; neither did I have patches or fissures on my skin. The only noticeable change in me was an unnatural shine on my face and numbness on certain parts of my body. Surely, I did not have leprosy!

To get a second opinion, I was taken to another doctor in the village. My family members and neighbors all started advising me to take care of my health. I had no idea why, all of a sudden, the whole world had begun to care for my well-being!

The doctor checked my neck, feet, etc. before commenting on my condition. However, I was left in the dark regarding what exactly I was suffering from. Instead, he informed the person I had gone with that I had contracted leprosy. Within a few days, almost everyone knew about my ailment, except myself. Things took a turn for the worse when my younger brother, disturbed by what I was suffering from, failed in his class X exams. Consequently, he gave up studying and left for Bombay (now Mumbai).

I started visiting various private doctors in the hope of finding an end to my misery. But everywhere I was offered free treatment and a parting advice never to return to that clinic. My only solace was my brother, who by that time had managed to obtain a job in Mumbai. He wrote to me saying that he was ready to bear the cost of my treatment, come what may. He wanted to see me cured. That letter brought tears to my eyes.

As time went by I began facing discrimination from my near and dear ones. I felt shattered, confused and helpless. I knew I could not bear such ill-treatment for long. Hence, I began gathering information about where and how leprosy was treated. In course of my findings, I learnt that at Dichpali in Andhra Pradesh leprosy was being treated by German aid with German medicines (since then this initiative has been taken over by the Govt. of India). With a month's ration and clothes in tow, I visited the hospital and met a doctor from my home state with whom I shared my anxieties.

All my life I had despised the disease. My disgust was so deep-rooted that I just could not make myself believe that fate had turned me into something that I had learnt to hate. I left the hospital within a day.

Next day I met the same doctor from the hospital. He advised me to regularly take Dixon (a German medicine) and asked me to pay him a visit after three months.

Returning home, I decided to carry on with my life while taking the medicine as prescribed. One day I found myself discussing my experiences at Dichpali with one of my distant relatives. She, herself, was undergoing treatment for leprosy and when she heard the name 'Dixon', she acted quite surprised. When I asked her to explain her concern, she told me about the adverse reaction that the medication had caused. I believed in her and thinking it would have the same effect on me, I threw all the medicines away. The fool I was!

The sole reason I kept on living and did not end my life was my younger brother. He took the entire responsibility of my treatment in a manner that belied his age. Once, instead of writing to me, he wrote to my step-brother. It was so uncharacteristic of him, that my suspicions were aroused. I literally had to fight for that letter and when I read it, I realized the reason behind my younger brother's action. The letter revealed that he was suffering from typhoid. Having read that, I could not stop tears welling into my eyes because I knew that he had no one to look after him. I went to the money lender and mortgaged one portion of the land for Rs 500 and bought a ticket for Victoria Terminus.

Thankfully, all my fears turned out to be unfounded. My brother survived the typhoid attack and when I met him he offered me to stay with him so that together we could find some job in 'the city of opportunities'. I agreed.

However, my weakness started taking a toll on me. Once I returned to my village, I realized that I was not in a condition to do physical labor on a regular basis. However, instead of being a haven, my very own village turned out to be a place where my presence was unwelcome. Hence, I returned to my younger brother once again.

When I got to learn that he was literally starving himself to pay for my treatment, I could not bear it any longer and left his home without informing him.

I attempted to live on my own else where in Bombay and also took up a job. Less than two months into it I hurt myself while working. This time I had no other option but to discontinue any manual labor. My wounds were refusing to heal and my fingers were gradually becoming disfigured. Once these caught any prospective employer's eye, my chances of getting a job vanished then and there.

Destiny had trapped me. I refused to return to my younger brother and my village did not want me back. When I was gradually losing all hope, I came across some more people like myself. To my utter surprise they lend me a helping hand. I began staying with them and thus became a part of the beggar community. I started begging on the streets and would spend my nights sleeping on platform no. 3 of Khar station.

My condition was deplorable no doubt, but never did I give up hope. Eventually I got married to a woman who herself was afflicted with the same disease. Our common desire was to be cured of our malady and lead a normal life. In course of time, I came to know of a charity hospital run by Mother Teresa at New Delhi. Immediately, I left Bombay to visit the hospital. There again I was denied admission. I was told that it was a facility meant only for those whose conditions were serious. I received some basic treatment after which I was relieved.

Now Delhi became my new address. During the Emergency of 1974, while beggars were being arrested from various places in large numbers, some of us fled to the nearby state of Haryana and took shelter at Faridabad station. One day while Babu Jagjiwan Ram was traveling on a train which was scheduled to stop at Faridabad, the Railway police began a massive cleaning operation. It was conducted during the morning hours when beggars were busy cooking their only meal of the day and commuters were waiting for their trains to go to work.

A huge crowd had gathered witnessing the ruckus that was created by clanging utensils and screaming individuals. Suddenly, a middle-aged man emerged from the crowd and tried to explain the helplessness of the beggars to the police officers. When he was rudely cut short by them, I saw something I had never seen before. He took out his residential address and asked us to meet him in the evening. Additionally, he requested some locals to help us see the day through. His name was Dr Brahma Dutt.

We met in the evening and he worked out a contingency plan along with a few of his friends. After a lot of efforts he managed to get us a vast piece of land close to the station. It was our new heaven, a place where we could live in peace. During the long summer days, he and his friends collected some money and got us some bamboo and mats to build hutments.

During those days we often visited Dr Nelson, fondly called Mataji (mother), for our medicines and bandage. It was a place where we were treated like normal human beings, a place where we could freely talk about our pain and aspirations. It was during one of those days while a few of us from our settlement were narrating our stories that she showed interest in visiting our settlement.

Her visit turned out to be a major turning point in our lives. It was followed by regular visits by a number of social activists who took up the cause of alleviating our misery.

Often gatherings were held which were attended by all the inmates of our shelter. However, such occasions were marked by a perceptible demarcation along provincial lines, 'with groups hailing from a particular province being represented by their own person. It was Dr Brahma Dutt who called upon us to unite, making it clear to us that unless we stand together as one, our chances of living a dignified life was next to impossible.

Realizing the truth behind the suggestion, the small groups began coming together and with the inspiration of Doctor saab we formed a Samiti (a unified body). To gain recognition, we applied for registration at Chandigarh which was finally given to us in 1982.

Gradually, support and financial aid started trickling in with which we installed two hand pumps in our settlement.

It was a rainy day. Most of us could not brave the showers and go out to beg. While seated underneath a shade, some of us noticed a few of our children were playing with our begging trolleys and pans. They were enacting us. It was a scene that I shall never forget.

I was agitated, disturbed and crestfallen. I told my companions that if we did not do anything about our situation soon, our children will be doomed to lead the same miserable lives like us.

That very day we went to Doctor Dutt and requested him to show us the way out. As always he offered to help us fight for our rights. What followed was a series of representation and demonstrations. During the middle of 1983 a benevolent individual, Father Thomas, agreed to admit 36 of our children in his school at Kota, Rajasthan.

In 1984, the then Deputy Commissioner of Faridabad, Bhaskar Chatterjee, an IAS officer who was an able administrator and a true gentle man, forwarded our request for monthly ration to the Governmental Department with a favorable note. This was the same year when MDT (Multi Drug Therapy) began in India and our settlement was one of the pilot cases. We were administered MDT for two weeks at a stretch. The symptoms were closely monitored and health workers visited our settlement on a regular basis.

It was almost two years after our treatment and monitoring had begun that a group of doctors visited our settlement and were satisfied at what they saw. That day was the happiest one in our lives.

In spite of governmental support and efforts by a number of voluntary organizations, it was still proving difficult for us to manage a square meal a day. Thus, many of us, even though we intended to, could not give up begging. During one of our group interactions with the then Social Welfare Minister, Mrs Sakuntala, I proposed, on behalf of my compatriots, that if we are given even one meal a day we would stop begging for ever. Many others present at the scene seconded my proposal. But the government officials did not seem too enthusiastic at the idea. They recounted that similar initiatives at Ambala and else where had not yielded favorable results as people had again resorted to easy money through begging. I contended that in our case the situation was different. This was because we, ourselves, were putting forward the proposal. I tried to persuade them to sway the decision in our favor by telling them that the request was a call from the deepest recesses of our hearts, a call, if answered, might change the course of our lives forever. My efforts bore fruit. During October 1984, we were allowed a monthly ration worth Rs120 by the government. Today, it amounts to Rs 400.

Two decades have passed since then and I am happy to say that I am no longer a beggar. Granted, life is not a bed of roses, but I am happy because of the love and affection we get from people around. Today I live with my wife and our 12 year old adopted daughter. While working on my poultry farms I often thank God for engaging me meaningfully in life to earn my livelihood.

Interviewer's note: **Sudeepta K Pal**

The most admiring aspect of M Guruappa's life is his self-respect. Even though he had to beg for a living, never did he harbor a thought of being dependent on his relatives, including his beloved younger brother. It was this characteristic that inspired him to persuade his fellow inmates to be self reliant and discard beggary.

The observations he made about life and the simplicity with which he adapted these truths are awe-inspiring.

The lesson to be learnt from his life is that one of the chief reasons many leprosy afflicted people take to beggary is the absence of hospitals where they can be admitted and treated so as to gainfully employ themselves.

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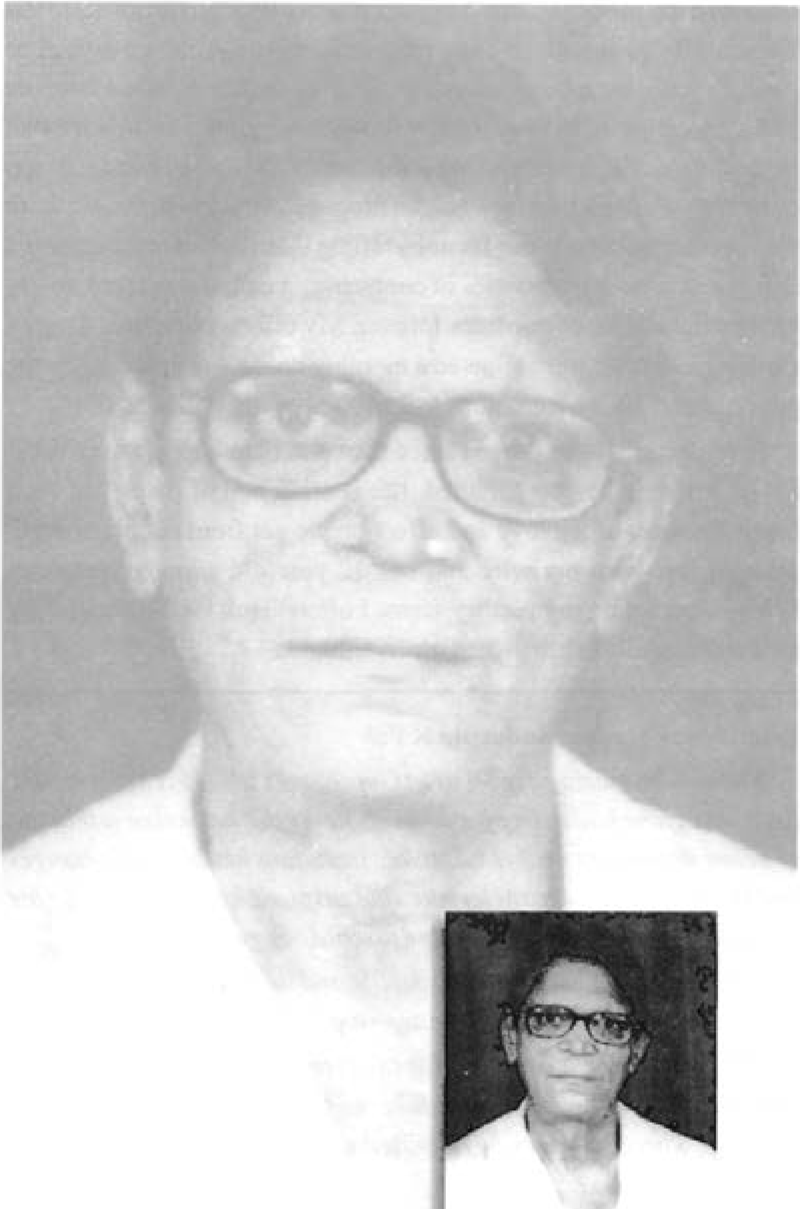

JOGEN DAS

> *"Leprosy is*
> *God's own way of*
> *testing our*
> *inner strength"*

Name: Jogen Das

Age: 50 years

Location: Bishnupur Leprosy Colony, West Bengal

Profile: A cured individual who, with his family by his side, has devoted his life towards garnering support regarding the availability of basic rights to all those afflicted by leprosy.

I hail from a tiny village called Bagmari, situated in the Dhanbad district of what is now known as Jharkhand. My father was employed with the Hazaribagh Registrant and my mother, like most womenfolk in villages, was a housewife. This small family of three lived a contented life, until tragedy struck, and struck hard. My father passed away when I was a wide-eyed teenager, all of thirteen. It was like losing the roof over my head. Confused, bewildered and heartbroken, I had to muster all my inner strength to come face to face with the harsh realities that life presents to a fatherless teenager. I was just about beginning to cope when another setback pushed me further into the darkest recesses of misery and helplessness.

A year had passed since my personal loss. As the dark clouds of grief slowly began to disperse from my heart, white blotches of wretchedness started appearing on my body. It was the early symptoms of the dreaded leprosy, a term which evokes an aversion matched only by the shunning of the people it afflicts.

At that point in time, Bagmari was a small and remote village, lacking adequate treatment facilities for the disease. The only option available was Ayurvedic medicine, which proved to be of little help. As time elapsed, the malady started to spread to other parts of my body, leading to acute physical pain. The agony was excruciating, no doubt, but what was unbearable was the discrimination I faced from my near and dear ones. I was baffled, depressed, angry and frustrated.

The same people who had stood by my side, consoling me, providing solace when my father died; were balking at my sight, recoiling at my presence and ignoring my existence.

Life had caught me off-guard and off-balance. I was desperately looking for a hand to hold and a shoulder to lean on. In those darkest hours of my life, the only person who supported me was my mother. Her resources were limited, but caring boundless.

But when she realized that mere love will not relieve the malaise I was suffering from, she sought help from Shri Kalipada Banerjee, a friend of my late father's. He proved to be a guardian angel in my life. It was he who took me to Dhanbad Chandmari Hospital, where I started receiving proper treatment. But the odds against my recovery began stacking up. My body refused to respond to the treatment. There was no discernible improvement in my condition. As my body grew weaker, my determination became stronger. I decided to fight back.

But fate still had a few aces up its sleeves. This time it took my mother away from me. My pillar of strength, my sole reason of existence was gone forever. Now I was alone, truly alone. To add to my woes, the treatment I was receiving at the hospital in Dhanbad was having no effect at all. My hands and face were becoming more and more deformed with every passing day.

The doors of society were gradually swinging shut for me. I was on the verge of an emotional breakdown.

I had lost everything in life, my parents, my friends and my place in society. But I was determined not to lose heart. Some unknown force, which arose from within, kept me going and I finally managed to get myself admitted to Gouripur Leprosy Hospital.

I spent two long years within those premises. Those years have left an indelible mark in my memory. Marked by caring, and compassion, it was during these times that I began to see a ray of hope for myself a life ahead that was not characterized by loneliness, loathing and languish. At the end of those two years I was a cured individual. The only remnants of the disease were the physical deformities that were a constant reminder of the darkest period of my life.

I had won the battle against the disease, but my biggest challenge was waiting in the wings, the stigma that a leprosy patient is branded with. It is a scar that is indelible because it is deep-rooted within the social psyche. No matter how much I wanted not to believe it, in my heart of hearts I knew that nobody would be able to accept me back, and not because of my disfigurements alone. I had no idea where to go and how to get my life back.

There's an age-old saying, which states that God is there for those who have no one to turn to. I have always been a firm believer in that statement. This time, too, God led my path and I decided to take shelter at Kalyanpur, an after cure colony. Thus began the second phase of my life, when I decided to leave my worries behind and look forward with hope.

In 1978 when the 'Paschim Bangal Kustha Kalyan Parishad' (The West Bengal State Leprosy Sufferers' Welfare Association) was formed, I decided to join as an active member. It was a decision that came naturally to me. I had been one of them. I felt at one with them. I could feel their suffering. I could relate to their struggle. It was quite amazing how the same disease which took so much away from me gave a meaning to my life. In the next few years, I shifted to Bishnupur Leprosy colony at the behest of the then secretary of the Welfare Association, Shri Priyaranjan Burman.

I found a partner in my endeavors, my wife, who herself was a leprosy patient at one point of time. Life was so much easier, now that I had somebody else who was concerned about me and was ready to face life by my side. My joy knew no bounds when she gifted me with a healthy son.

Starting a family and its associated responsibilities led to my earning a meager livelihood through rearing cattle, goats, hens and pigs. Simultaneously I carried on the work of a social worker one who lends a listening ear to leprosy patients and relates to them with compassion, not pity.

My interaction with multitudes and my own struggle against the disease has reinforced my belief that leprosy is neither a curse nor a result of sin committed in a previous life. It is just God's own way of realizing our inner strength. The only disadvantage that an individual suffering from the disease has over others is the physical deformities. Otherwise, in no way is he or she a lesser mortal than his or her 'normal' fellowmen.

I have been in the fore front of several movements against discrimination and social ill-treatment of leprosy patients. Among our many achievements, the most notable ones are acquiring the rights to vote, drinking water and ration cards. I dream of a time, which, I am sure, is not too distant, when all those suffering from this curable malaise will be able to enjoy all the rights and facilities enjoyed by other citizens.

Interviewer's note: **Sudeepta K Pal**

The pain of being discriminated against is one of the biggest impediments that a leprosy patient faces. Denunciation by one's own friends and family can be extremely agonizing. While talking to Jogen Das about his life I have often heard him repeat that the pain he experienced when he was shunned by his friends and relatives was much more than that he feels seeing his deformed face and hands. In his words, 'I can live happily with what leprosy has left behind on my body, but I cannot think of surviving a single day, the way the world still wants us to live'.

Recounting the past 50 years of his sufferance, he states with optimism that the world around us is changing. The dark clouds of prejudice are clearing and it is becoming easier to survive in this otherwise suffocating, self-centric world of ignorance. According to Jogen das, this change has been brought about by the courage that the new generation has shown in endeavoring to bring to an end the trials and tribulations faced by individuals like him.

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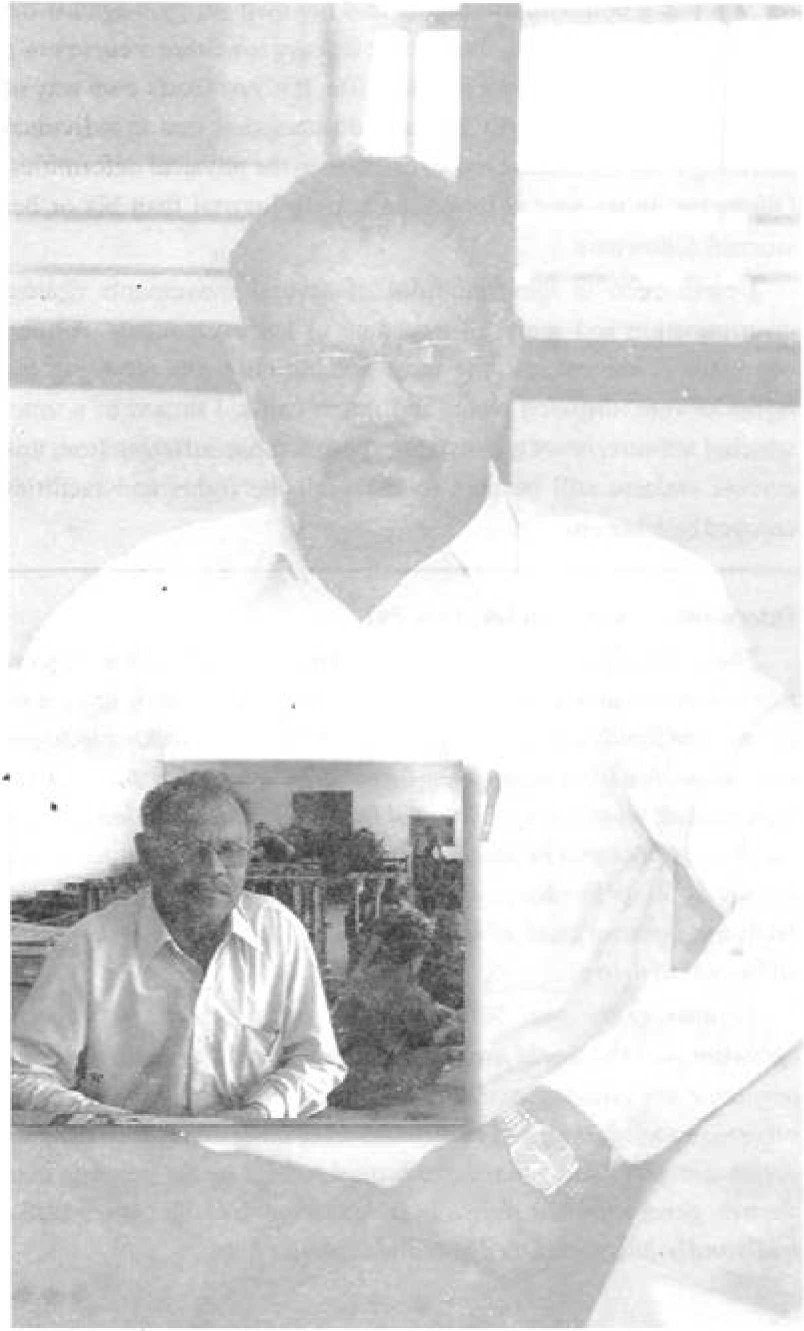

PRAKASH PATIL

"I am still scared of being abandoned by society"

Name: Prakash Patil

Age: 56 Years

Location: Kondhawa (Pune), Maharashtra

Profile: A completely cured individual, Prakash Patil has risen in the ranks from being a trainee to the post of the Chairman in the same organization which acts as a supplier to automotive giants, such as Tata Motors

I was born in Dhulia, a district in western Maharashtra. Even though I was the eldest son in my family, I grew up at my maternal aunt's home, since she did not have any children of her own.

I was nearly 13 years old, studying in seventh standard, when one of those regular medical check-up camps was organized at our school. Once the doctors had completed the check-up, out of fifty students, six or seven of us were asked to stand aside. Another set of doctors were brought in for us. Later, we came to know that initially the doctors had suspected that the few of us were suffering from leprosy. However, the results of the second check-up revealed that their diagnosis was wrong. Eventually, the entire incident slipped from everyone's minds.

Three years later, after passing my Board Exams, I obtained a diploma as an electrician. Two years after leaving school, I had successfully started my very own 'motor rewinding business'. The very next year, I had five people working under me.

Those were happy times, which gave me no indication whatsoever of the torment that I was about to face.

It was around that time; one day while shaving, I noticed some patches on my face where hair was not growing back. I did not pay much attention to it, but for some reason it continued nagging me at the back of my mind. Once during a casual conversation, I mentioned this fact to one of my close friends. When he noticed the patches, he told me with an edge in his voice that he feared those were symptoms of leprosy. He further instructed me to immediately go to Pune for treatment. I didn't take him seriously nor did I pay any heed to his advice…..but I guess I should have, especially because he was a cured individual himself.

A couple of years passed by and the patches persisted, showing no sign of disappearing. In fact, they proliferated spreading over my body. A niggling doubt and fear began growing inside me. What if my friend's words were true?

One morning I noticed a big pinkish patch near my eyebrow. It was at that precise moment, I realized matters have come to a point where they could not be ignored any more. At the same time, I did not want to create a situation of panic amongst my family members. Before breaking the news to them, I had to be sure myself. Hence without telling anyone at home, I left for Pune with the address my friend had given me. It was the address of Dr. Bandorwala Leprosy Hospital, Kondhwa. There the doctor confirmed what my friend had suspected. The patches on my face were caused by the presence of '*bacillus leprae*' in my body. Dr Joglekar, the attending doctor, told me that they I could be treated if I stayed back for a fortnight. However, all around me I saw scarred faces and deformed bodies. I was scared beyond my senses. I was horrified thinking that if I stayed here, one day I would resemble those ghastly faces. I fled.

I returned to my village, clueless of what to do. I felt frustrated, irate at everything and at everyone around me. Most of all, I was annoyed at my fate and at God for inflicting such a bane on me.

My father had been afflicted with the disease himself; hence I was aware of the stigma that an individual goes through once he contracts leprosy. Through one cruel gesture life had suddenly taken away from me the will to see tomorrow. The gravity of the situation made me feel as if I was snared in an eternal today, scarred by a dreaded disease with no reason to look forward to spending the rest of whatever was left of my life, even after I get treated and the bacillus is removed from my body. I lost interest in everything.

The first thing I did after I learnt of my malady was shut down my business. I knew I did not have to do it immediately, but I knew it for certain that I would eventually have to take that step. People around me were quite perplexed at my decision. It was quite a profitable venture and they just could not see the point of closing it down. I could not muster enough courage to confide in anybody, not even my own family. The fear of being ostracized terrified me.

Meanwhile, I could feel the illness growing inside me. I increasingly felt helpless. Confused, I moved around like a kitten in a room full of mirrors.

Three more years passed by without any improvement in my condition. The raging anger inside me, the pent-up emotions gradually subsided into a perpetual sense of disorientation. I knew I was no longer in charge of my life. I lacked the inner strength to face the life that I would be compelled to live once my ailment became known to the society at large.

At the same time, I was slowly crumbling at the pressure of hiding my dark secret within my heart. Finally, I confided in my mother, pleading her not to disclose the matter to anyone else.

It was she who advised me to immediately return to the hospital in Pune and resume my treatment. It took a lot of contemplation on my part, but ultimately I gave in to her suggestion. I thought to myself, why not at least give myself a chance to be cured and lead a normal life? When I went back, I found that Dr Joglekar remembered me as the person who had run away from the place. He was happy to have me back.

My treatment started but the faces in the hospital ward still filled me with terror. I could not help grimacing at their sight. I could not even look straight at any one of them. During the first few days, I could not even eat the food that was being served to me at the hospital.

Soon I got my first dose of MDT (Multi Drug Therapy) and my treatment began. I was aware that no matter what medicines I take, they would not be able to cure me of my inhibitions. I knew that I could not live with the ailment gone from my body, but still affecting my mind. Hence, I started interacting with the people around me. Each one of them had a story to tell that was more painful than the last one. The more I talked with them, the more I realized that there were people who were more ill-fated than I was. Hence, the same people from whom I had run away at one point of time provided me with a ray of hope.

One of the afflicted individuals, Sher Khan, with whom I had developed a friendship, was undergoing the last stage of his treatment. Like me, his body, too, had not developed any deformity. I noticed that he stayed in the hospital for his treatment but went out every day to earn a livelihood. Seeing him, it struck me that even I could lead a normal life after I underwent the full course of my treatment. This was the second positive thought in almost three years after I had come to know about my condition.

There occurred a noticeable change in me within a few weeks of beginning treatment. A month or so had elapsed when the doctor informed me about some better medicines that were now available. Dr Joglekar advised me to stay back some more time to get myself fully cured. By then I had learnt to trust him implicitly. I agreed, but requested him if I could leave the hospital and stay amongst the so-called 'normal' people. To my surprise he accepted and arranged for a rented room for me, at a distance of five kilometers from the hospital.

Meanwhile, two years had passed by. Not a single member of my family, except my mother had any idea about where I was or what I was doing. Unable to hide the matter any longer, my mother confided to my brother, who had become a professor by then. He paid me a visit at Pune and offered me to go back home with him. But I refused. It is not that I did not desire to live with my family again, but the same fear came over me, the fear of being ostracized and the shame that followed once the truth about my condition got revealed.

But then the question of my brother's marriage came up. He wanted to get married but could not because of the inevitable barrage of questions that society asks on occasions when a younger sibling is married while the elder one is still a bachelor. I decided to marry Kamal, one of the cured girls from the Leprosy Hospital itself. However, I thought it best not to reveal her condition to my family members, fearing that they might not accept her. Till date, not a single family member of mine knows about Kamal's past.

The next problem was to find a way to support my family. Being a qualified electrician myself, I asked for a job at the *Dr. Minoo Mehta Apangoddhar Auddyogik Sahakari Utpadak Sanstha Maryadit* (a factory run by the cured individuals on a co-operative basis). I joined there as a trainee. Next year, thanks to a lady doctor, who had visited the hospital to take up the issue of absorbing cured female individuals in the factory, Kamal also started working beside me.

Meanwhile, we had our first child, a healthy baby boy. At this juncture of our lives, we decided not to have any more children. Instead, we focused our efforts on providing the best possible upbringing for our only son.

Three years passed by. By then I was working full-time in the factory. But the desire to go out of the rehabilitation net and prove myself in the competitive world was still very strong within me. My superior in the factory liked my work and did not want to let me go. But finally seeing my insistence to compete with the world outside, he told me of an opportunity at Aurangabad.

Bajaj Auto's Aurangabad division offered me a job at a salary more than three times of what I was drawing from the factory. But as fate would have it, I had to leave the job within a week or so of my joining because of a clause in the appointment letter. It specified I would be made a permanent employee only after nine months of my working there. I could not take the chance of being left in the lurch in case my job was not confirmed at the end of the stipulated time period. At that point of my life I could not take a gamble because I had a wife and a child to support.

I returned to my previous workplace which at least gave me job-security. Ever since that time I have been completely dedicated to the factory which has provided both me and my family financial security and a social identity. We saved most of what we earned and within a few years we were able to build a small house. The day I built my house, I realized that economic prosperity and attaining a social position leads to a lot of difference in a person's life. Some years ago I had come to Pune without a penny to my name. Today, I am the Chairman in the same factory where I had started off as a trainee.

The factory is now a co-operative enterprise, run by cured individuals, where each employee shares the profit that accrues. Every one is a part of the decision-making process. Products and automobile accessories manufactured in our factory are accepted by some of the leading automobile companies of the country like Tata Motors and KINETIC.

Currently we have an annual turnover of around Rs. 70 lakh and we aim to raise it to Rs. 80 lakhs by the next financial year.

Besides, I have also begun a new venture on my own. It is a small 'chemical plant' run by my son. I am a satisfied man today. I feel I have achieved more than what I dreamt of twenty years back.

I think the biggest mistake an afflicted individual or his family can make is hiding the malady and not going for a proper treatment. Leprosy is very much curable and this is what everybody should be made aware of. It is the refusal to accept it that causes the stigma in it. I am glad I did not give up so easily.

To tell you the truth, I, myself have not got rid of my fears as yet. I want to go and speak on a public platform or in a leprosy rehabilitation drive about how I overcame my adversities, but I still do not have the courage to let others know that I once had leprosy. This is because I am still scared of being abandoned by society.

It was only recently that a journalist wrote an article about me in one of the local newspapers. My life was treated as a success story of someone who had been affected by a dreaded disease but has overcome all challenges to lead a 'normal' life. Hence, my secret is now out in the open. Soon after the article was published I got many calls from my business associates and suppliers, congratulating me on my strength and struggle. I was pleased but I wonder how these people would have reacted if somebody in their own family contracted the disease!

My son, who is also planning for higher studies, recently got married. My daughter-in-law is still unaware of the fact that I and my wife are cured individuals. I never felt the need to tell her or her family about this. My cured father who is deformed because of the disease lives with us, but my daughter-in-law has never asked any question. Maybe with time she will come to know the truth and I am sure that she will judge the situation in terms of our present and future, and not by an unfortunate chapter of the past.

Interviewer's notes: Pallavi Baruah

Prakash Patil, a fully cured individual, acknowledges that even though the germs of the disease have been wiped out from his body, it has left its traces on his mind. The fear of denunciation by the society still resides somewhere deep within him.

There are many more such Prakash Patils who might have successfully fought the disease in their bodies, but still have not been able to overcome the stigma associated with this ailment. It is this stigma, this humiliation, which is so deep rooted in the psyche of afflicted persons as well as that of the society, which should be eliminated forever.

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DR. JAL MEHTA'S
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SHALINIBAI BANSODE

> *"However humble, I am happy with my new life, my new world"*

Name: Shalinibai Bansode

Age: 50 years

Location: Ahmednagar, Maharashtra.

Profile: Abandoned by her in-laws, forsaken by her own children and neglected by the society at large, Shalinibai, with a steely resolve has fought them all to become a self-reliant individual.

With five brothers and four sisters, I considered myself blessed to be born in a large family, until the day my father walked me home from school, never to send me back again. I was a keen learner and studied till Class II. In fact it is because of whatever little I grasped at school, that I can sign important papers instead of using a thumb impression.

My father was a tailor and my mother a housewife. With such a large family to look after, it was difficult for them to make ends meet. And a girl child, invariably, adds to the burden. So, when I was fifteen, I was married off to a mason from Aurangabad.

At Aurangabad, we lived behind a dispensary; paying a monthly rent of Rs 150 for a single-room house. My husband was the eldest son among four brothers and two sisters. I had moved from one big family to another, but was happy being the wife of the eldest son. Soon, the birth of our first child, a son, made my husband proud and brought happiness in the family. With my new role as a mother came a lot of respect & responsibility. I believed that the warmth & happiness would last forever.

My son was a year and half, when I gave birth to a girl-child. That was when I noticed the first signs of disapproval in my mother-in-law's behavior. Gradually, I was made to feel that I had betrayed the family and it was insinuated that my daughter was a burden. To add to my misery, the third child I gave birth to also turned out to be a girl.

This time, my in-laws did not even pay a visit to bless the newborn. Neither was there any indication from their side that they were keen to bring me back from Jalna, where I had gone for the delivery. Finally, after days of waiting to hear from my husband; my father accompanied me to Aurangabad. The cold welcome that both of us received the moment we stepped inside the household made me apprehensive about what was in store for me and my child.

One day, soon after I was back from Jalna, I was taken ill with high fever. Moreover, some parts of my body began to show signs of swelling. When my swollen fingers rendered me incapable of helping in household work, my mother-in-law took me to the near by dispensary.

Samples of my blood and urine were taken and a skin test done on me. No one agreed to accompany me to collect my reports. For four days at a stretch with fever raging through my body, I went to the dispensary all on my own. I had no inkling whatsoever about what was written in those reports, but my mother-in-law categorically instructed me to stay away from all the cooking utensils in the house. I was not allowed to touch anyone. I was barred even from touching my newborn daughter. I thought I could confide in my husband, but he shied away from me.

Unable to bear the alienation, I requested my in-laws to inform my parents, but my pleas fell on deaf ears. For four days that seemed more like eons, I was treated like an untouchable. Then, I was packed off to Jalna with my children in tow. My husband did not come to see me off at the station. Instead, my youngest brother-in-law, who was then studying in class VII was sent with us to Jalna. He was given strict instructions to handover the doctor's reports to my parents and return without accepting any food or water at my place.

My parents were shocked when I arrived at their doorstep. In those days it was common for men to dump their wives and remarry after they sired two or three offspring. My brother-in-law made a quick exit after handing over my reports. My parents were illiterate and they gave my reports to the village schoolmaster who showed it to a doctor. He came back with the news that I had the 'Maharog' (the 'big' disease). At that time, in the late 1970s there was hardly any public awareness about leprosy. We had no idea about its cause, symptoms, nature or cure.

I was afraid. I knew I had a disease which none of my brothers or sisters had. I also had three children to take care of and no support from my husband's family. However, my parents stood by my side and took as much care as was financially possible for them of both me and my children. After my father spoke to the village doctor, I was sent to Jalna Mission Hospital.

From there, I was shifted to Jamkhed under the care of Dr Rajnikant Arole. Since the preliminary medication had little or no effect, I was shifted to the Wadala Mission Hospital. There again, the doctors decided to move me to the Ahmednagar Kusthdhaam (leprosy home).

Eventually the financial burden proved to be a little too much for my parents. They had no other option but to admit my children in a remand home at Paithan. Surprisingly, one day my husband came to take my youngest daughter back to Aurangabad. On his arrival, I was hoping against hope that he would agree to accept me back into his family after I got cured. Neither my daughter nor I turned out to be fortunate. After she finished Class II, she was sent back to my parents and my in-laws decided to wash their hands off any responsibility in this matter whatsoever.

My children spent their childhood in a remand institution while their mother was admitted in a leprosy home. Can a mother's fate get any worse?

As my condition improved at Kushthadhaam, I began assisting a trained nurse and helped her wash & dress the wounds of those affected with leprosy. When the last traces of the disease left my body, the older patients and staff of the place encouraged me to start a new life.

They even found a suitable match for me! He was Damodar Bansode, who had spent ten years at Kushtdhaam and was himself a cured individual. Haunted by loneliness and with no other family than the hospital staff to guide me, I decided to accede to the proposition. We were married at Kushthdhaam and a number of officials blessed us on our wedding day. Intentionally I kept my family in the dark regarding this matter.

After the wedding we stayed for six months at the quarters provided to us by Kushthdhaam. Me and my husband then shifted to a construction site where he took up the job of a watchman while I worked as a maid in the nearby buildings. Since 1989 both of us have been employed at *Dr. Jal Mehta's Firodiya Punarvasan Audhyogik Shakari Sanstha Maryadit* (Firodiya Rehabilitation Centre) at Ahmednagar. As assembly line workers we are happy with our limited but fixed income.

I have been blessed with an understanding husband, but nothing can fill the void in my heart created by not having my children by my side. I visited them twice at the remand home.

Occasionally I got news about them from my brother when he came to pay me a visit. It was from him that I learnt that my son had studied till class X and was married. He also informed me that my daughter is married as well and living at Aurangabad with my two grandchildren, both boys.

My husband, Damodar, and I shifted to Renuka Nagar five years back and we now have a house there. I work at the nearby factory nine hours a day. Since I have not seen my grandchildren, often I wonder what they look like. It hurts me when my own children do not bother to maintain contact.

Though I find it humiliating to be treated as a money machine, especially by my son, I have resolved not to be exploited by anyone again. I am happy with my family at the workplace and a husband who has been through similar hardships. However humble, I am happy with my new life, my new world.

***Interviewer's note:* Sneha Walke**

It takes a heart of stone for a mother to stay away from her offspring. A self-reliant Shalinibai misses her children and the joy of playing with her grandchildren. Though she is a mother of three, none of them wants to acknowledge her existence even after her successful battle against leprosy. Despite this, Shalinibai's love for them has not lessened a bit. She wishes all of them well and hopes that some day they will understand their mother and the harsh realities of her past.

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TARANI PATHAK

> “*I believe people need time to come to terms with who I am*”

Name: Tarani Pathak

Age: 56 years

Location: Hengrabari (Guwahati), Assam

Profile: A *paan* (Betel leaves) and cigarette shop owner, who has taken the reins of life in his once leprosy-afflicted hands, and with dignity & succcss.

I was born and brought up at Bhawanipur in Barpeta District, where I completed my education. My father was a farmer who did not have any land of his own. My brothers and I used to help him out in the fields when we were young.

After I expressed interest that I would not be pursuing studies any further (I had reached Higher Secondary level in a school near our village), my father helped me set up a shop with about twelve thousand rupees. Back in those days, it was a substantial sum. Moreover, it was a loan.

The shop turned out to be a success and I slowly built up a steady clientele. By the time I was 30, I got married to a woman who bore me four sons and a daughter. Life was a smooth ride for me. It was then that I decided to come to Guwahati. It was the place to be with the political climate heating up and future looking rosy.

I gave my shop in Bhawanipur to my brother and with a capital of Rs.50,000 bought a grocery shop in Hengrabari. My sons were studying in schools at Guwahati and I considered myself well- settled in life. It seemed as if nothing could go wrong. But it did. Everything went wrong.

About three years ago I began to realize that something was wrong with my left foot. I have always been used to walking bare feet. Increasingly, I could feel a loss of sensation in the foot. Never did I suspect, even for a single moment that what I was going through was nothing more than a mere toughening of the sole of the feet that is the usual precursor to the appearance of corns.

My condition worsened as time passed. Sores began to appear on the skin. I began noticing gashes on my skin, whose presence had gone undetected because of the gradual loss of sensation. My biggest fear turned real the day my eldest son took me to a health check up camp in Shantipur. The doctor there diagnosed me with leprosy.

It comes as a rude awakening for many, that word 'leprosy'. I was anticipating to be shocked, outraged, even dismissive. But to my utter dismay, I did not feel anything. It was as if the doctor had diagnosed me with nothing more than a common cold.

I looked around me in the health camp. There were others like me, branded with the same dreaded ailment. I noticed that their faces, too, like mine were devoid of any emotion, be it grief or despair. But I could sense underneath that casual demeanor lay a heart that was not ready to give up. I could relate to them. I felt at one with them. The doctor prescribed me some medicines, which I took home. But what I gained from that visit was courage to fight back, no matter what the odds.

For quite sometime my clients were suspecting that something was amiss. When I broke the news to them, it was greeted by expressions that varied from the nonchalant 'I thought so', to the false 'Don't worry, we are with you' promise.

Rumors spread as fast as the disease on my body. I was shunned by all and sundry. One by one people began avoiding my acquaintance and sales in the shop got reduced to a trickle.

The distance from Hengrabari to Shantipur was about 12 kilometers and it was not always possible for me to travel and get my medicines. Doses were skipped and my condition deteriorated to such an extent that my left hand was now curled up and I could not do much with it. My joints ached constantly and my legs began giving up on me. Quite often, especially at night, I stumbled over stones and other objects.

By then my face was scarred with lesions and rashes. I feared the worst and rushed to the Guwahati Medical College and Hospital for help. The nurse I met scolded me for not coming in earlier. She did not believe me when I told her that I had been diagnosed a year back and had been under medication. Out of sheer frustration, I showed her the wrappers and the empty medicine cases that I had brought along with me.

She directed me to Dr. Bhabesh Das, who headed the Hansen's Disease Cell. Dr Das told me that my condition was aggravated by the irregularities in the intake of medicines. I was asked to come in every fortnight for check up.

The Public Health Directorate is located very near to my residence. There I was introduced to Dr. Sheelananda Barua, a senior leprologist who was dedicated to the cause of amelioration of the disease. In him I found a constant source of faith and encouragement.

Since I could not find new customers, I had no other option but to sell my grocery shop. I was embittered at life. After about three months of being constantly cared for by my wife and sons, I knew the time had come for me to take a tough decision. I asked all four of my sons, three of whom were now working, to look for their own accommodations. They agreed. I persuaded my wife to agree to take my two younger kids to our village and stay there till I felt better. I blamed myself for separating my close-knit family. But did I really have a choice?

What was really disheartening was the attitude of the society. The very people who I felt would understand my ordeal and lend a helping hand left me in the lurch. A few of my so-called 'friends' openly discouraged my clients to buy my business from me. 'Why buy from a leper?' they would urge. In times like those, my mind went back to my childhood when my father asked us not to come in contact with those who were afflicted with the same disease as I am, people who sometimes used to come to our doorstep asking for alms. 'God is angry with them and has inflicted them with the Bor-Bemar (leprosy)', he would tell us. I often wondered what had made God angry with me. I was now taking medicine regularly and fast recovering. My wife and my sons would often come to visit me and wish to stay back. I am glad that all my offspring are doing well for themselves.

The rashes on the skin have disappeared but some lesion marks around my face still remain. I have been told by the doctor that the cramp in my hand and the curling would take a long time to recover. However, there is a chance that they might not return to their normal state ever again. I blame nobody else but myself for this situation. I should have taken the medicines as directed.

I continued meeting Dr. Sheelananda Barua. It was he who advised me to restart my business. From what I had left, I started my paan (betel nuts & leaves) and cigarette shop. To tell you the truth, my business has not really picked up very well. This is primarily because people are interested more in how well I am recovering. They need to be assured that I am free of the last remnants of the disease before they come and start buying from my shop. I do not mind. But I do have some regular customers who are fully aware of my condition.

People are still repelled when they see my hand. I believe I, too, have to give them time to come to terms with my situation. I know in my heart of hearts that things will be normal once again.

The Guwahati Medical College and Hospital gave me a pair of comfortable black canvas shoes that I wear regularly. They have a good grip. In a way they have helped me stand back on my feet.

If you ask me what is hindering the total eradication of the disease from this country, it is not lack of medicine, but the paucity of public education. The other day there was a program on All India Radio on Leprosy that dispelled a lot of myths about the disease. We need more initiatives like these. That's the least we can ask for.

I am happy that I did not waste any more time with the disease and took medicines regularly. The doctors have confirmed that there are no more germs in my body though some of the deformities will persist. I guess I can live with that.

Interviewer's note **: Ashutosh Sharma**

I have a confession to make. Though I consider myself an educated person, I did exhibit skepticism at some point during my interaction with Tarani. After my interview was over, when he emphasized, 'One thing is for sure, that the days of Bor-Bemar are limited in our state', I felt ashamed that I still harbored such reservations.

I learnt from him that many individuals who could not be rehabilitated into the society have been absorbed by the hospitals which cured them. They now lead a quiet, normal life.

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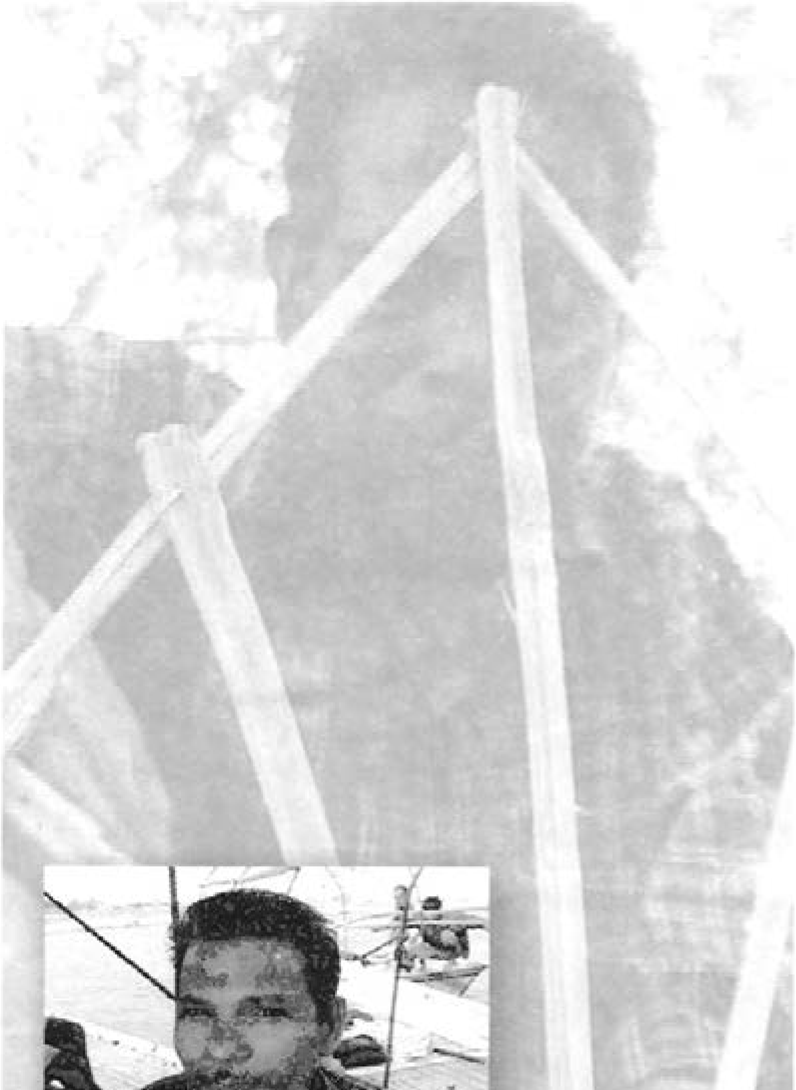

DHRUV KUMAR

> *It was a terrifying thought to be in a film that might be seen by people I know*

Name: Dhruv Kumar

Age: 45 years

Location: Allahabad, Uttar Pradesh

Profile: A craftsman of cane furniture. Dhruv is still unsure as to how the society will react to the fact that he was once afflicted with leprosy.

I still remember the day I came to know I had contracted this dreaded disease. Three years have passed since then, but the memory is still etched in my mind, as if it was yesterday. I began developing a deformity in both my forelimbs. As I watched my own arms turning alien to me, I was haunted in my dreams by the thought of being ostracized by the society. I was so deeply concerned that I decided to keep it the matter a secret from my own parents.

My primary concern was not going for treatment but finding out a way to cover up the gaping wounds on my fingers. I was worried about my family members. My two daughters, Richa (20 years) and Meeta (17) were both of marriageable age. My son, Pawan, was 15 years old and studying in a school. I knew that deep down my children felt that their father's ailment was God's curse. I noticed that their patience was wearing thin. But someone has rightly said that blood relations are seldom severed. Life's events meander sometimes on a normal or an abnormal course...

Bringing up my family was not an easy task, especially when this disease in the guise of a social malaise took over me. For the last twenty odd years, I had earned a living by pounding nail on the anvil and sewing bamboo sticks together to etch out ethnic cane furniture. One fine day, I realized that my chances of carrying on with my business had come to a sudden halt. I had turned jobless.

I desperately looked around me to seek out an anchor to my life, a solace. I found it in the calm waters of the Ganga. For four months at a stretch, everyday before sunrise I visited the banks of the holy river in the hope of deriving energy and inspiration.

The conditions of my forelimbs deteriorated with the passage of time. However, during those dark hours there appeared an unexpected source of hope. Financial assistance poured in from some unknown sources which kept the wheel of my household chores moving. I have no explanation to this apart from being God's magnanimity. The only question was for how long it would suffice as the expenses kept on mounting day by day. The lines of worry on my forehead grew deeper.

I felt like a vegetable, and hated myself for what I was going through. I detached myself from everything around me. I had no idea about proper diagnosis or treatment. The only remedy I knew was to dab the wound with tincture and wrap it with a clean white cloth. At times I applied my grandmother's medication of desi ghee mixed with vermillion and lemon.

Every night I dragged myself to bed, writhing in pain and agony. Many a time I noticed my daughters inadvertently grimacing at my sight. When they caught me looking at them, they would immediately come around to lend a helping hand. Those were the moments when I wished I could put an end to my misery.

I remember waking up one morning and finding my bed sheet soaked in blood. When I was asleep, unknowingly my bandage had come undone. My wound looked like the fissures of a rock.

I could not bear it anymore. Several times I tried to end my life by slitting my wrists. But every time my wife came to my rescue. Panna, that's my wife, has been my savior. She was the one who made my children understand that what I was suffering from was an ailment and not a curse. She, through her soothing words revived the love that my children once felt for their father. She even took a stand against society while tending after me and put up a bold visage before our relatives, neighbors and friends.

Then came the day when my life changed for the better. I still remember basking in the winter sun, when my children alongside my wife brought a doctor from the Leprosy Mission Hospital, Dr Lorretta Das. She turned out to be my guardian angel, the panacea for my pain. She gauged the condition I was in and advised me to immediately visit the hospital. She warned me that if I continued being so careless about my situation then a time might come when there would be no other alternative but to amputate my arms.

I could not sleep the entire night. The only thought circling my mind was contemplating what might happen if somebody I knew saw me entering the leprosy Mission Hospital. It was hard to reach a decision. I vacillated like the pendulum of the clock I was staring at, my panic growing with every passing minute. Ultimately I decided to leave for the hospital before sunrise, under the cover of night. I had to wait for three hours before I met Dr Das.

My life turned over a new leaf at the Leprosy Mission. It was more a voyage of self-discovery. It was on a chilly winter day that the doctor advised me to undergo my first reconstructive surgery. It was painful, but what I felt was nothing compared to my torment when I came to learn my wife and children had to concoct a number of excuses when people started asking questions about what was happening to me.

The operations required money and I did not have enough funds. So, I took a loan of Rs 50,000, an amount I had no idea if I would ever be able to repay. Even here, I had to resort to lying. The reason cited for taking the money was that the entire family was going out of town.

Post-operation, I anxiously waited for the day when the bandages would be removed from my fingers. When the moment arrived at last, I felt the first taste of victory. My fingers were numb because of the infection but I noticed a marked improvement in the way they looked.

Gradually the doctors allowed me to participate in a number of extra-curricular activity sessions. Initially I learnt how to separate thin bamboo sticks from the rest and lay them in a linear fashion.

Apart from this I practiced holding a ball in my palm everyday, so that the groove formed inside could open out further.

With each passing day my disfigurements decreased but the infection was not completely removed. I was informed that it would take another two years for me to termed 'normal'. Eventually, I got discharged but with standing instructions that I had to pay a daily visit to the hospital. To tell you the truth, I was not emotionally prepared to handle the situation. In fact, I remember when the Leprosy Mission ambulance took me back home, I requested the driver to drop me when there were at least three more kilometers to go.

I grew extra conscious of my hands and fingers whenever I sat amidst friends and neighbors. I was thrilled the day I went to my shop for the first time and touched my bamboo stock. It felt like touching the soil of one's home after a long time spent in a different country.

My biggest concern was the repayment of the loan I had taken. Creditors started making bee-lines at my doorstep, armed with demands that I did not have the capacity to fulfill. Marriage proposals for my elder daughter also started trickling in, thereby doubling my financial responsibilities. What suffered most were my visits to the hospital.

I started going back to the banks of the Ganga. But this time I went as a vendor of frilly bamboo items persuading those who came to the river for a holy dip to buy them. My sole objective was to bring back a minimum of hundred to hundred fifty rupees daily.

Dr Das visited me one day enquiring about my health. She expressed deep concern over my worsening physical condition. I tried hard to conceal the truth about my working as a vendor, but eventually broke down in front of her. I sobbed like a little missing child who had found its parents after a long gap. She hugged me with tears in her eyes. Before she left that day, she promised me financial assistance. In return, she had only one small demand, that I pay regular visits to the hospital because I had to undergo my second reconstructive surgery.

As I resumed treatment, my business began to flourish and my work picked speed. I started thinking in terms of expanding my business with my son's assistance. My elder daughter's marriage was fixed and now the challenge was to make arrangements for the occasion without letting her future in-laws know about my ailment.

One day while returning from work, I noticed a camera crew near my house. It was a four-member team asking my neighbors the question that had been the source of innumerable nightmares 'Where does Dhruv stay? He makes cane furniture and he has leprosy on his fingers...' I felt as if at that precise moment whatever I had built for myself and my family over the years would fall apart, with that one single question. Fortunately, my neighbors unanimously agreed that though an individual with the same name and job description did stay in the area, they were sure that he was not afflicted with leprosy.

When the initial confusion died down, I sent my son Pawan to talk to the camera crew and learn what they wanted from me. It was a team of documentary filmmakers who had come to Allahabad to pick up a case study on leprosy and film his trials and tribulations. On one hand, I felt a sense of heightened excitement to be part of a film, at the same time I developed cold feet contemplating the adverse effect it could have on my daughter's impending marriage.

Initially I declined their offer, but then they told me that they have been sent by Dr Loretta Das. This bit of information put me in a quandary. I asked for some time from them. That night at around 1 am as I was pacing up and down trying to reach a decision, I noticed the entire crew waiting for me outside my house. I knew then that I could no longer decline their offer. I agreed, but on one condition. I refused to be interviewed at home. It was mutually decided that the shooting would occur on the banks of the Ganges just before sunrise.

It was a new dawn for me in every sense of the term. When I saw the team walking towards me, I left everything to destiny. The camera team assured me that the film would not be shown to the Indian audience and therefore it would not make any difference. That was the assurance I wanted.

The crew took me to the Leprosy Mission Hospital where I posed with my bamboo sticks for the camera team. I tried to pound nail on the anvil, etch out cane artifacts and gifted a bouquet case made of bamboo for the documentary team.

Maybe once the film is made and shown, members of the foreign audience would exult, clap or sympathize with me. But my greatest reward would come the day afflicted individuals like myself would be able to arrange for their daughters' marriage without losing sleep over the effect of their condition on their daughter's marriage.

Interviewer's note: **Neelu Vyas**

As I completed the shoot and left the city of Ganges, Dhruv had managed to leave an indelible mark on our minds. Every ending, I feel, sets the stage for a new beginning. And this one, too, is no exception.

Dhruv's journey is one of treading a territory unchartered by someone like myself. Maybe my documentary will earn laurels. But what would matter more to me is if it influences even a single individual to take some concrete steps towards wiping off the social stigma that people like Dhruv face on a daily basis.

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NAJMA BEGUM

> *"Why cannot the world just let me be myself? Why can't I say*
> *-Yes I had leprosy*
> *- So what?"*

Name: Najma Begum

Age: 51 years

Location: Kolkata, West Bengal

Profile: Leprosy alienated her from her own family. Left to fend for herself and her children, she now leads a life of lies, forever afraid that the truth behind her deformities will not set her free but result in even more discrimination.

Leprosy, the curse of God for sins committed during my previous birth, has left me devastated and helpless.

I am a fifty-one year old woman. Having spent five decades of immense physical and mental agony, today I feel exhausted. Reflecting on my past, all I can recollect are memories of humiliation, shame, disgrace and struggle, beginning right from my childhood to this very day. It is not that I have not seen good times or that I have never been loved and cared for, but those instances are so few and far between that they seem lost somewhere amidst the innumerable trials and tribulations that I have encountered.

Apart from the scars on my psyche, the disease has left its ugly marks on my hands and feet as well. When these deformities attract piercing gazes from the people around me, I feel a deep fury welling up. I feel hurt to an extent beyond anyone's imagination. The worst part is that I cannot explain it to anyone the conflicting emotions that I feel deep within.

I was born in 1956 in a lower middle class Muslim family. Our father, a driver, left us when I was a kid. I hardly have any of his memories in my mind. I grew up with my mother, my two brothers and four sisters in a respectable locality. Life was normal until the day some patches started developing on my body.

Ignorant and illiterate that I was, I hardly understood what those blemishes stood for. At the insistence of some friends I decided to show them to the sisters at the Missionaries of Charity Hospital. There needles were pricked on these patches, which were found to be devoid of sensation. It was at that precise moment that I was diagnosed with leprosy.

That word, 'leprosy', meant nothing to me at that time. I hardly understood its implications, but as I grew up, the discrimination I started facing at the hands of my own friends and relatives convinced me that I was 'cursed'.

My own siblings refused to eat the food which I handed over to them, children in our neighborhood refused to play with me. Even my mother did not let me meet the guests who visited us for fear of them coming to know of my condition. Before I could realize it the world as I knew it was fast changing. I began hating my existence.

The sisters at the Charity Hospital gave me some medicines which I used to take very irregularly. Hence, due to lack of proper treatment the patches began to grow into wounds and wounds gave rise to deformities.

The team of GRECALTES (an NGO which treats and rehabilitates people affected with leprosy and tuberculosis) were carrying out surveys in our locality to identify those affected by the disease. At that time I was around 20-22 years old.

I avoided them at all cost. But one day one of the social workers got hold of me. By then, the scars on my hands had become quite visible. However, quite contrary to my belief, the people at GRECALTES were very helpful. They tried their best to counsel me. They made me understand that I would become handicapped if I did not take my medicines regularly. Although I did realize that they did not mean me any harm, however, whenever I saw their jeep outside my home I would go into hiding until they went away. I was scared that if my neighbors saw me talking to these people; they would come to know that I had leprosy and subject me to further discrimination. I was afraid of being excluded from the society.

In spite of all my protests and unwillingness, they did manage to make me take the medicines and miraculously my wounds started healing. There came a time when I was completely cured except for the deformities of my limbs.

But even then my own family members continued discriminating against me. Neither of my brothers and sisters wanted to stay with me. The situation worsened to such an extent that I was forced to look for an alternative by which I could sustain myself.

But getting a job seemed next to impossible. Finally I decided to black movie tickets at cinema theatres. However, with the advent of satellite television in the beginning of the 1990s, I suffered a crisis. People preferred to stay at home and watch television rather than buy cinema tickets at double and triple prices. The halls closed down and I was out of work once more.

Life seemed to have come to a standstill. By that time I was married with two small daughters and earning money was an absolute necessity for me.

It was GRECALTES who came to my rescue again. They came up with a plan for rehabilitation of those who have been cured of leprosy. Various kinds of aids were being provided including vocational training and financial help. I applied for a loan and with the money I received; I set up a fruit shop opposite the Calcutta Medical Research Institute.

Though the earnings from the fruit shop are very meager, I have found a job as a sweeper at the Corporation School in my locality as well as at the neighborhood club house (Khidirpur School of Physical Culture). The club members have been kind enough to allow me take shelter in the club building during the nights on the condition that I keep the premises clean. My daughters too have been married off into good families.

Sometimes when I ponder as to how my life could have been if I had not contracted leprosy, I realize that I have been forced to miss out on a lot of things that life could have offered me. Leprosy has not only affected me physically, it has left me mentally wounded and scarred for life. I have never been able to be a part of the mainstream society where I belong- only because of this disease. I have been deprived of the love of my own brothers and sisters, my in-laws, even my own mother because of leprosy. I have to carefully cover my deformed hands while walking on the roads so that they do not attract inquisitive stares. In case, someone notices them I have no other option but to tell lies. My daughters hesitate when I wish to meet their in-laws. Whenever the workers from GRECALTES come to enquire about my condition at the club house, I have to lie to the people around me telling them that they have come to collect money for the loan I had once taken.

I am tired of pretending and lying to the world. Why cannot the world just let me be myself? Why can't I say-Yes I had leprosy- So what? Why doesn't God give me the strength to face the world?

Interviewer's note: **Sreemoyee Mukherjee**

The exasperation and weariness in Najma's voice is evident. She is tired of carrying the burden of being branded 'A leprosy patient'. Rehabilitation centers do provide treatment and later on help individuals affected with leprosy rebuild their lives by providing them financial aid. But more importantly, a way needs to be found out to cure them of the stigma that they face at every stage of their lives.

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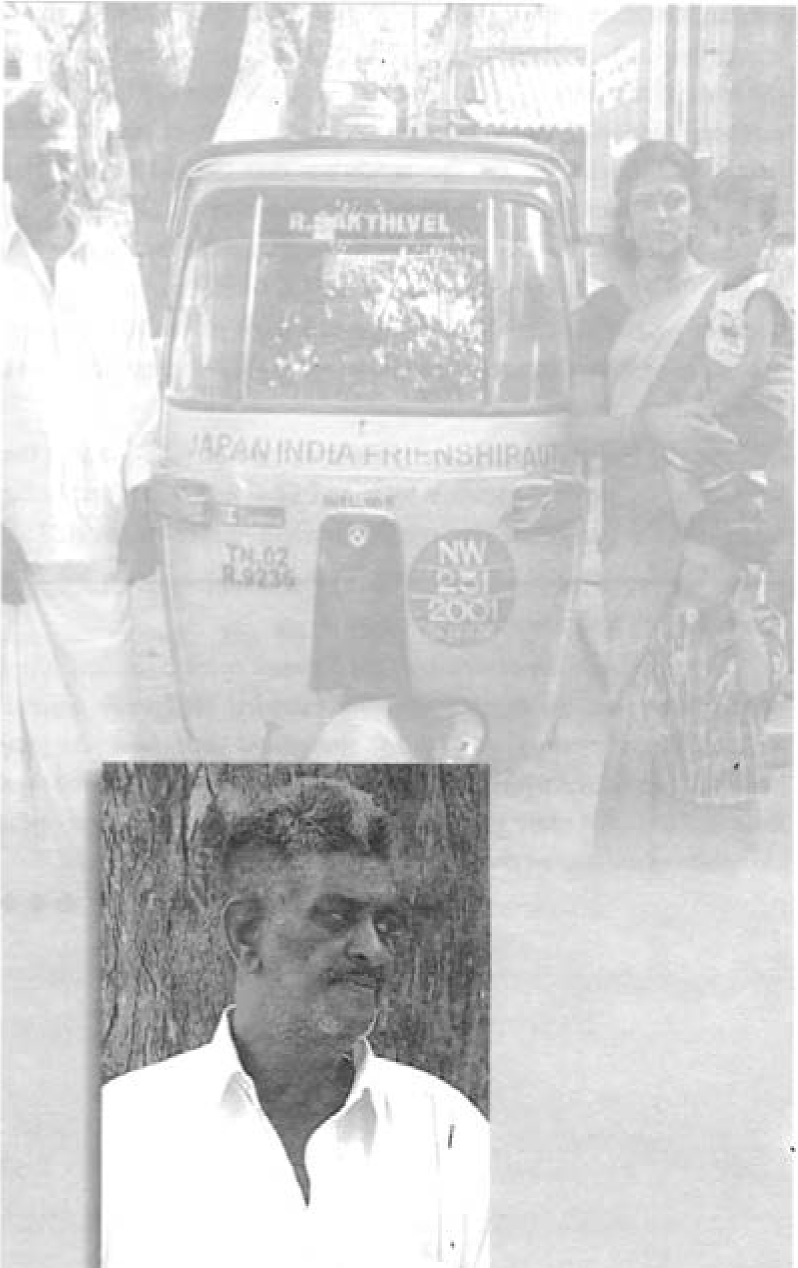
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PRAKASHAM

"I will pursue the Mission of my Life till my death"

Name: Prakasham

Age: 65 Years

Location: Balarampur Leprosy Colony, Chennai

Profile: President, Tamil Nadu Leprosy Colonies Federation, Chennai. From smuggling rice to leading the battle against leprosy, his life teaches us about the symbiotic relationship between an ailing society and a strong individual: both need each other for their self-actualization.

I have been surrounded and affected by leprosy all my life and it has given my life a unique character. However, I have never allowed the disease to determine the course of my life .

I am Prakasam, born in the village Rampakkam of Tamil Nadu to Adhimoolam Raja and his second wife, Singarammal. My mother died when I was only five years old. Immediately after that my father contracted leprosy and typhoid at the same time.

Later, within a couple of years, patches appeared on my body. But, as we were poor and ignorant, we did not know that these were the early signs of leprosy.

Later, when the villagers found out about our disease, both of us were sent out of the village to seek medical help. We went to a government leprosy hospital in Thirukoilur. After three months of medication, we were shifted to Chengalput Leprosy Hospital.

Even after being treated for several months at Chengalput and Kumbakonam, there was no perceptible difference in our health. In fact, our condition deteriorated. Finally, my father took me to a leprosy hospital at Tuticorin, in the southern part of Tamil Nadu, where we stayed for ten years.

After almost twelve years we returned to our village, Rampakkam, after the results of all our tests turned out to be negative, only to encounter rejection by the villagers and our immediate family.

During those days western India was going through an acute rice shortage. In desperation both my father and I began smuggling rice from Chennai and Mumbai by train. We did not have money to buy tickets and in this case, our deformities turned out to be a boon. Nobody arrested us because we had leprosy-generated deformities.

Within a year of hard work, my father, who was by then above 60, passed away in a distant land, unsung and unheard. I wept a lot, but carried on with life, involving myself in small business endeavors.

By then, I was a young man in my late 20s. I fell in love with a girl named Lakshmi and we got married within a year. We were soon blessed with a daughter, whom we named Rajeshwari, and our little family was filled with laughter and joy.

I found that I could support my small family by starting a scrap iron business. I collected scrap from several small industries and sold them to specific customers. Life seemed to have begun to smile on me, when suddenly my daughter contracted leprosy. She was five years old. Thereafter began another struggle to get her treated.

We settled ourselves in the Balarampur area of Chennai in Tamil Nadu. Today, there are 110 families staying here. The colony was started by a number of families like ours, who, even after being completely cured, were refused to be accepted by their near and dear ones. Some of us took to a number of illegal trades when there were no other alternatives available to sustain our families. Even the policemen, for fear of contracting the disease, stayed clear of us. But one day a high-ranking officer visited our colony and explained how the things we were trading in (mainly, drugs) spoiled the lives of many young people. It was then that we realized that we should refrain ourselves from such activities.

And, I got the mission of my life.

All drugs and opium were collected and burnt in the colony itself marking a new beginning in that abode of discarded people who once had leprosy.

We started small-scale work like selling vegetables, goat rearing, selling milk and a cycle shop.

Soon I was elected the President of our Balarampuram Leprosy

Colony. Since then, for more than 15 years, I have taken care of all activities here and have tried leading my community in all possible ways.

I was later elected President of the Tamil Nadu Leprosy Patients' Rehabilitation Guild which represents 42 major leprosy colonies of the state, and I have been serving in this capacity for many years now.

In 1997, when IDEA India was started, they approached me to help them conduct a study of the leprosy colonies of Tamil Nadu, and I came in touch with Dr P K Gopal, the President of IDEA India. We were later invited to participate in a workshop, which motivated us to regain the dignity that was lost from our lives.

Since then, we have worked with IDEA India in programs for the development of the people in rehabilitation colonies, and today many have taken up small businesses. Our children are now pursuing their higher education with courses in computer science, nursing, engineering, medicine, among others. Since 2000, IDEA India, Danida and German Leprosy Relief Association have been assisting us for the education of our children and in setting up some of our small businesses.

Finally, in recognition of my work over the last two decades, I have received two great honours. The first was when Mother Teresa herself blessed me. It was the most memorable moment of my life. Second, the Tamil Nadu government gave me an award for public service.

One lesson I have learnt during my long association with the disease and the people it affects, is that, if we want to integrate the afflicted with the community for them to lead a normal life, an alternative source of income needs to be generated. If the state government can increase the current pension level from Rs. 200/- to Rs. 600/- then many of us will be able to lead a comfortable life. Additionally, there are laws that bar the leprosy affected individuals even after they are cured from living like 'normal' citizens. These laws have to be looked into.

Today, I feel I have lived my life to the fullest. My son is married with a child. My wife and daughter are with me, helping me in my life's mission, helping people affected with leprosy as well as rehabilitating cured individuals of the state of Tamil Nadu.

Interviewer's note: **Prof Ujjwal K Chowdhury**

Leadership is a trait which has to be evolved in a historic context and with self-realization: Prakasham's life is a clear proof of this. Amidst the worst of challenges due to the disease afflicting several persons in his family, Prakasham was almost rudderless in life. With focus and direction, he stand strong and tall among his peers and is today a role-model for many others.

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Saraswati & Manohar Harke

> *Leprosy was the bond that sealed our relationship.*
> *We felt reborn after we were remarried*

Names: Saraswati & Manohar Harke

Age: 50 years & 58 years

Location: Ahmednagar, Mahrashtra

Profile: With similar histories, this leprosy cured couple came together because of loneliness and societal obligations. Today, with three children & after two grandchildren they still work and live together as each others biggest support.

We met at the Ahmednagar Kushthadhaam. Cured of leprosy, I was in my third year of stay at the institution and was slowly beginning to pick up the pieces of my lonely life. To make use of my time constructively, I assisted in the kitchen and helped in dressing the wounds of the other leprosy patients. I got to know Manohar through the hospital staff. I learnt that his wife had deserted him and abandoned their three little children out of the fear of contracting the disease. I understood his plight as I was also deserted by my in-laws. The hospital staff was keen that we get married so that we have each others support for our lives ahead.

I had seen Saraswati cleaning the wounds of leprosy patients at Kushthadhaam. I did not know much about her before the wedding but I wanted her to know the truth. I was very forth right when I told her the prospect of having a mother for my three children after years of having to bring them up alone, was more important than just getting married for a second time. I told her that I had spent ten years of my life at Kushthadhaam while my children had spent their childhood in a remand home. I had already lost my youth; I did not want their youth to suffer without the warmth and care of a mother. If she was interested in marrying me she would have to promise to take care of my children.

When I contacted my brother, he readily agreed that I marry Manohar as it would be difficult for me to find anyone in the 'outside world'. After having a temporary childhood, a temporary marriage and temporary motherhood, the prospect of becoming a wife and a mother again, were equally important. I wished for something long lasting and I found that trust in Manohar. But before we were married, I wanted Manohar to know my story.

I was born in a small village called Wadoni in Beed Taluka, Maharastra. When I was only a year old my parents died leaving behind two sons and four daughters. My maternal uncle took up the huge task of raising all of us. I never went to school; instead, I spent the early years of my life assisting my uncle on our small handloom set up.

It was my uncle who first contracted leprosy. I was twelve at that time and my uncle was in a rush to get me married. Looking back, I think he wanted to rid himself of all responsibility before the disease took him completely. Surprisingly my groom and his family agreed to accept me believing my uncle when he said the disease would never come to me.

Finally, as was common with most girls my age, I was married off when I should have been spending care-free years at school. After marriage I had a son who died of some medical complications. I was too young and thankfully I do not have too many memories related with his death. After a few years of marriage I started to show the first signs of leprosy with swelling and reactions on the skin. The death of the family's first grandchild was understandable as nature would bless me with another, but with leprosy my life had no second chance.

The arguments presented by my uncle at my marriage were proven wrong. My family was called names for 'hiding dark secrets' and slowly each of the twelve members at my in-laws home left, fearing for their lives. My husband was the last to leave, but in the end, he left me too.

I was in my late teens and could not bear the shock. I was informed that a few persons who had the disease had traveled to a small village in Andhra Pradesh for treatment. I had never traveled out of my village, and the idea of traveling all by my self was unimaginable. But the hope for a cure dragged me to Andhra Pradesh. Those were difficult times. There was a new sense of independence, of having beaten the odds by hopping buses, carrying one's own luggage and asking unknown people for the right directions. On the other hand, there was a gripping fear that if my swelling became worse, people traveling with me would get to know of the disease and I would never reach my destination. At many stations, I asked police men to guide me as I was afraid of talking to the locals in case I was misunderstood.

With a hope that I could get my life back and that the disease would disappear I stayed at Dichpalli village in Andhra Pradesh for eleven months. But even after initial treatment my stomach and knees did not stop hurting. Finally I returned to Wadoni where a few supportive elders suggested that I leave the village and get my self admitted at the Ahmednagar Kushthadhaam. Following their advice I traveled alone once again, this time to Ahmednagar.

Manohar was a very kind hearted man. Though he had put the condition that I take care of his children after marriage, when he heard my story, he was sure I would never desert him or his children. There was so much love within me, so many things that never got expression, that with each others support and in each others company we could rebuild our lost lives.

I was very disheartened by Saraswati's story. Kushthadhaam was a different world. There were so many like us, with troubled pasts and unhappy events that made their lives. Yet the struggle to re-establish oneself in the outside world made it one big family with everyone fighting the same battle.

I had little to tell Saraswati about myself. My plight was nothing compared to what she had gone through. I was born in Mohol Taluka of Solapur district in Maharashtra. We were a small family. My parents were handloom workers and they could afford my education till Class VII. When I was 13 years old, I quit school and took up working at bi-cycle shop in the neighborhood. I worked there for about 5 years before I got married.

My wife was from Bhingara. With three loving children, ours was a happy marriage. After a few years of marriage I began developing patches on my stomach. For quite some time they went ignored. I thought they were just a reaction. At first I ignored them, but at the insistence of my wife, I went to the doctor for a test. The doctor told me that I had leprosy for quite some time. I was in complete shock. I told my wife and parents. At first my wife cooperated, but one day she said she's going away to stay with her parents and she wanted nothing to do with me or my children. For the first time 'our' children became 'my' children.

My condition got worse with wounds on my feet and so I admitted myself at Ahmednagar Kushthadhaam. I understood that it would be difficult for my old parents and newly married brother to take care of my children, so I admitted them in a remand home.

Like many other couples, Saraswati and I we were married at Kushthadhaam in the presence of staff, patients and government officials. Leprosy was the bond that sealed our relationship. I felt reborn after I was remarried.

While at Kushthadhaam we read about the Firodia Rehabilitation Centre in the newspapers. They employed disabled and leprosy affected persons. We applied for a job and for over fifteen years now, both of us are employed as assembly line workers at the factory. About seven years ago, we borrowed a loan of twenty-two thousand rupees from the management and built ourselves a one room home. Before this we lived with our children in the quarters provided to us, close to our factory.

When Manohar got out of Kushthadhaam and started earning again, his first wife asked him for a share in his income. Till date, out of the little we earn, my husband gives Rupees 500 to her each month and I do not object to it. She even visits us at times and it is nice that my children interact with their birth mother. Though she has caused a lot of misery to my husband and our children, I know she must be lonely and is completely dependent on the money we give her.

Many a time, I have questioned my self whether she deserves our attention, our empathy and our money? But then again, are five hundred rupees anything compared to the love I get from my children and my husband; a love, that she had, a love that she abandoned?

When our eldest daughter got married, we told her future in-laws about the harsh realities of our past. Times have changed so much. Before we could get into an apologetic tone, and promise for a dowry larger than we could afford, they told us that they knew everything about us and about the disease. Before we could tell them, they told us there was nothing to fear because leprosy is not hereditary. There is a certain awareness today. And because of awareness there is happiness today.

***Interviewer's note*: Sneha Walke**

Saraswati's visible deformities speak nothing of her beautiful heart. Having adopted three children from her husband's first marriage, she is now a proud wife, mother and grand mother.

Re-marriages among cured leprosy persons are common and believed to be long lasting. Though these marriages are based more on each others support than anything else, there is an underlined respect for each others past struggles and a protectiveness that stems from years of societal rejection & isolation, which make them stronger than many ordinary relationships in the world around us.

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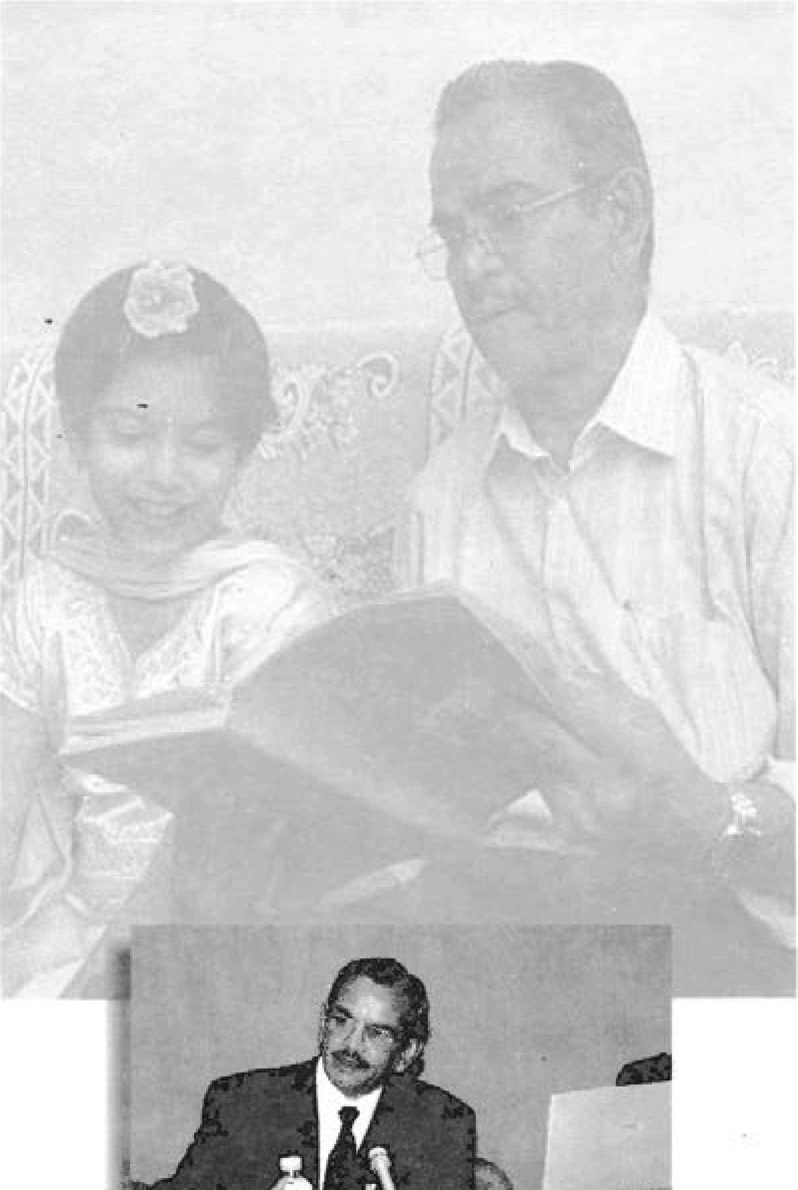

DR. P K GOPAL

Where the mind is without fear and the head is held high
Where knowledge is free
Where the world has not been broken up into fragments
By narrow domestic walls…
Where the clear stream of reason has not lost its way…
Into that heaven of freedom, my Father,
Let my country awake

-- Rabindranath Tagore (Gitanjali)

Name: Dr. P. K. Gopal
Age: 64 years
Place: Erode, Tamil Nadu
Profile: Ph.D. in Social Rehabilitation, winner of the President's Award as a Rehabilitation Officer;
he is currently the President of IDEA-India.

> *Unlike medical treatment, wherein the same medication is given to every individual, in the socio-economic approach, each person is treated differently.*

Dr P K Gopal: The Man & His Mission

Born into a weavers' family in 1941, Dr Gopal shared his childhood with his four sisters and one brother. It was while he was studying in High School, the first patch on his skin, the harbinger of the dreaded leprosy began appearing on his body.

Without any delay, he, along with his father visited the nearest government-run hospital. However, the doctors did not diagnose him with leprosy at that point of time. Moreover, as the patch did not itch or cause pain, not much attention was given to it and the incident soon got relegated to the back of everyone's mind.

Around seven years later, more patches began to appear on his body. Dr Gopal was in his final year before graduation when during a routine medical check up in his college it was revealed that he had contracted leprosy. Referred to a government hospital for treatment, he continued his studies (in Economics) while being treated at the nearby Leprosy Control Unit.

However, the high dosage of Dapsone, which was one of the prescribed medications, had an adverse effect on him leading to frequent complications. Having no other option, he was compelled to leave his studies for an entire year. He had to discontinue his studies for a year. Confined within the four walls of his house, he spent his days being cared for by his friends and family.

In 1967, at the age of 26, he was admitted to a leprosy hospital at Chengalputt (Tamil Nadu). During his two-year long stay at the hospital he completed his graduation by privately appearing for the examinations. Discharged from the hospital in 1969, he joined the Sacred Heart Leprosy Centre at Kumbakonam, Tamil Nadu, as a social worker.

While working with those afflicted with the same disease as he once was, Dr Gopal carried on his pursuit of knowledge. The very next year he enrolled himself with Loyola College, Madras (now Chennai) and obtained a Post Graduation Degree in Medical and Psychiatric Social Work.

On completion of his course, he resumed his work with the Sacred Heart Leprosy Centre. In 1972 he initiated the first Social Welfare and Rehabilitation Department at the hospital itself, which provided Socio-Economic Rehabilitation services to many individuals affected with the malaise.

His undying dedication towards the cause led him to conduct numerous research studies as well as presenting his findings at a number of national and international fora. In 1993 he obtained a Ph.D. Degree in Rehabilitation from the Ranchi University.

With grace and dignity, he spoke to the media, both in India and abroad about his views on the need for social and economic empowerment of people affected by leprosy. The fact that he himself is a cured individual added that extra edge to his enterprising efforts.

IDEA (Integration, Dignity and Economic Advancement), founded in 1994, is a Brazil-based international organization and a brainchild of Dr P K Gopal. It aims at promoting a positive image of leprosy through disseminating education and eradicating prejudice. Dr Gopal is one of the Presidents of IDEA and is in charge of International Relations. His wisdom, empathy and proactive attitude while dealing with individuals affected by leprosy, health professionals, government officials or service organizations have played a pivotal role in the success of IDEA. Moreover, it was he who first suggested that an international network be formed to support individuals affected by leprosy and promote opportunities for social and economic empowerment. Knowing fully well that the purpose will not be served by establishing a 'patients' organization' that would continue to define individuals on the basis of their ailment, rather than achievements, he suggested that the organizational constituent be divided equally between those afflicted by the malady and those who have not been touched by leprosy.

Dr. Gopal has directly influenced the lives of thousands of individuals affected by leprosy in India and worldwide through his efforts to promote social and economic justice. He has traveled extensively to participate in meetings where he gave voice to their rights to lead productive lives with dignity. The difference between Dr Gopal and others who have taken up the cause of making people aware about the rights of leprosy-affected individuals is that he knows how to implement programs that break the cycle of poverty and social exclusion so often associated with the disease.

The contributions of this illustrious individual have not gone unnoticed. Dr P K Gopal was felicitated by the Honorable President of India in 1986, when he received the award for being an outstanding Rehabilitation Officer. In 2001, he received the Wellesley Bailey Award in London for his exceptional contribution in the field of rehabilitation towards improving the quality of those affected by leprosy.

> *Even after an individual is totally cured, he or she is still termed a 'treated leprosy patient'. Now, isn't that a misnomer?*

Prof. Chowdhury: One of the major concerns for those cured of leprosy are the abuses and discriminations they face at the hands of society. Based on your experiences in the past two-and-a-half decades, what sort of abuses and discrimination have you witnessed?

Dr. P.K. Gopal: As you know, I, myself am a person who had contracted the disease. I got treated, completed my studies in social work and found employment in a hospital as a Rehabilitation Officer. That job provided me with an opportunity not only to interact with those afflicted with the disease, but also to understand their status of living, sufferings and the discriminations they faced. The discriminations exist at various levels. First they exist within the family. In many cases the family does not accept the individual once he or she gets affected. Forsaken by their families, these individuals are unable to go for treatment. Having exhausted all options, many of them leave their families and get admitted to a leprosy hospital. That explains the large number of people who stay in leprosy asylums even today.

Then there are the leprosy colonies, which are nothing but settlements located far away from the main cities. There are about five hundred such colonies in India where those afflicted with the ailment live a segregated, discriminated and isolated life. Most of the inhabitants of these colonies earn their livelihood by begging. We, at IDEA, have requested the Non-Government Organizations as well as the governments and the public at large to treat these people with dignity and avoid discrimination thereby helping them lead a normal life in the society.

Some milestones in Dr P K Gopal's Life

1972 : Became the first professionally-qualified social worker in the field of leprosy in India.

1988 : Presented a paper on Rehabilitation at the XIII International Leprosy Congress held in The Netherlands.

1993 : Invited to visit Korea as a member of an international team to observe the achievements of those affected by leprosy in that country.

1993 : Presented a paper on rehabilitation at the XIV International Leprosy Congress at Orlando, U.S.A.

1996 : Elected as a member of Medico-Social Commission of ILEP (International Federation of Anti-Leprosy Associations).

1997 : IDEA INDIA was initiated under his able guidance.

1998 : Elected as a Council Member of the ILA (International Leprosy Association).

1998 : Presented two papers at the XV International Leprosy Congress held in China.

2000 : Invited and Chaired the WHOAIFO Workshop on Rehabilitation at WHO, Geneva.

2000 : Received the International Raoul Follereau Award from AIFO in Italy on behalf of IDEA.

2001 : Participated as a temporary technical expert of WHO in the 'Rethinking Care Conference' held in Norway.

2004 : Received the FESCO Award in Japan presented by His Imperial Highness, Prince Hitachi.

Prof Chowdhury: Do you think there has occurred a shift in emphasis as far as the cause of leprosy is concerned?

Dr P K Gopal: Nowadays the emphasis is more on elimination of leprosy. Elimination is reducing the number of cases to one per ten thousand of the population. But terms like these, I believe, conveys a wrong message to the people. Many of us draw an inference that elimination implies eradication; that there are no more incidence of leprosy. At the same time, it is also true. Of course from the medical point of view, we have seen tremendous advancement. A large number of people have been cured but a similar war has to be waged against discrimination, to enable the people affected by leprosy to lead a dignified life in the society.

Prof Chowdhury: How do you think this can be achieved… this victory in the war against discrimination?

Dr P K Gopal: First of all a change in attitude is needed. Consider the derogatory terms that are associated with this disease. Even after an individual is totally cured, he or she is still termed a 'treated leprosy patient'. Now, isn't that a misnomer? How can a person who is 'treated' also be a 'patient'? At IDEA, one of our foremost initiatives was developing what we called 'dignified terminology'. We coined a term 'people affected by leprosy'. Over the years, this term has gained universal acceptance.

Secondly, we requested the NGOs and national governments to involve those afflicted with the disease as partners in the programs aimed at alleviating their condition. We firmly believe that a successful program is that which is of the leprosy affected people, for them and by them. Unfortunately, a concerted effort in this direction is yet to take place.

You know, in India, there has been a lot of misinformation about the disease, loads of wrong notions. This is the reason we call it a stigma. This stigma is responsible for the segregation and exclusion of people affected with the malady. It has turned them dependent on others' mercies. So, if the same people are given an opportunity to work, thereby earning enough money to support themselves, I am sure they will not resort to options like asking for alms.

There are two ways of fighting this stigma. One of them is educating the public by conducting mass education campaigns utilizing various media. We have been doing this for the last fifty years with little or no effect. The second and more effective way is to invest on the people affected by leprosy. See to it that their status is elevated, through employment and earnings. As soon as we achieve this, their family, friends and the society at large will once again accept them.

Prof Chowdhury: I would like to know if there were areas, like education, family, work, etc. where you faced discrimination? If yes, how did you cope with it?

Dr. P.K. Gopal: My family stood by me when I contracted the disease. However, I suffered a lot during my graduation and final year. I could not write my exams because of the complications of the disease. I wasted two years, one in school and another one in college because of the physical problems caused by my ailment. When I joined college for post graduation studies my treatment had begun and there were no more problems on the physical side. Mainly because my family stood by me that I did not face much discrimination in the community. However, this is not the case with most of those affected with leprosy. When I was working as a Rehabilitation Officer, I had to deal with many individuals who were forced out of their homes, segregated from their families; many more had lost their jobs because of the disease. They all came for treatment and requested for asylum in the hospitals. For all these people, socio-economic rehabilitation aims at improving their economic condition. Keeping this in mind, we have begun a number of self employment initiatives which enable people to start their own business based on their physical capacity and aptitude, as well as the demand for the products manufacture. Unlike medical treatment, wherein the same medication is given to every individual, in the socio-economic approach, each person is treated differently.

Prof. Chowdhury: Now that the United Nations has joined this movement against leprosy, what are your expectations as the one leading the movement of dignity for the affected people?

Dr. P.K. Gopal: As I have mentioned before, a major impediment is the stigma attached with the disease that leads to segregation and discrimination. This phenomenon is not typical of India but is evident in other countries as well. This particular aspect had been brought to the notice of the U.N. Human Rights Commission two years ago by Mr. Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination, who is also the Chairman of 'The Nippon Foundation', Japan. The U.N. Human Rights Commission took up the matter and started discussions on the issue. I was invited to present two papers on the level of discrimination which presently exists in the community. Now the U.N. Human Rights Sub Commission has passed a resolution to study the issue in different parts of the world and submit a report this year so that preventive measures can be taken. I wish that the U.N. Human Rights Commission issues some guidelines similar to the ones they have passed concerning HIV infected people. Considering the inviolability of such a guideline, it will act as a helpful tool to fight discrimination.

Interviewer's Note: **Prof. Ujjwal K Chowdhury**

The lines by the famous poet Rabindranath Tagore at the outset of this chapter beautifully summarize what Dr P Karuppannan Gopal has aspired to achieve and succeeded in doing to a great extent.

His is the most well-known of all successfully treated individuals in India. A Doctorate in Rehabilitation and a winner of the President's Award as a Rehabilitation Officer, he is now in charge of the India operations of the international organization Integration, Dignity and Economic Advancement (IDEA). He is emerging as the leader of national federation of leprosy colonies in India, and represents the cause of rehabilitation in the UN and the Indian governmental bodies.

His life serves as an inspiration to any leprosy afflicted individual, irrespective of caste, creed or country. An international icon in his own right, he has, over the years, nurtured a happy family comprising his wife, daughter, and grand-daughter.

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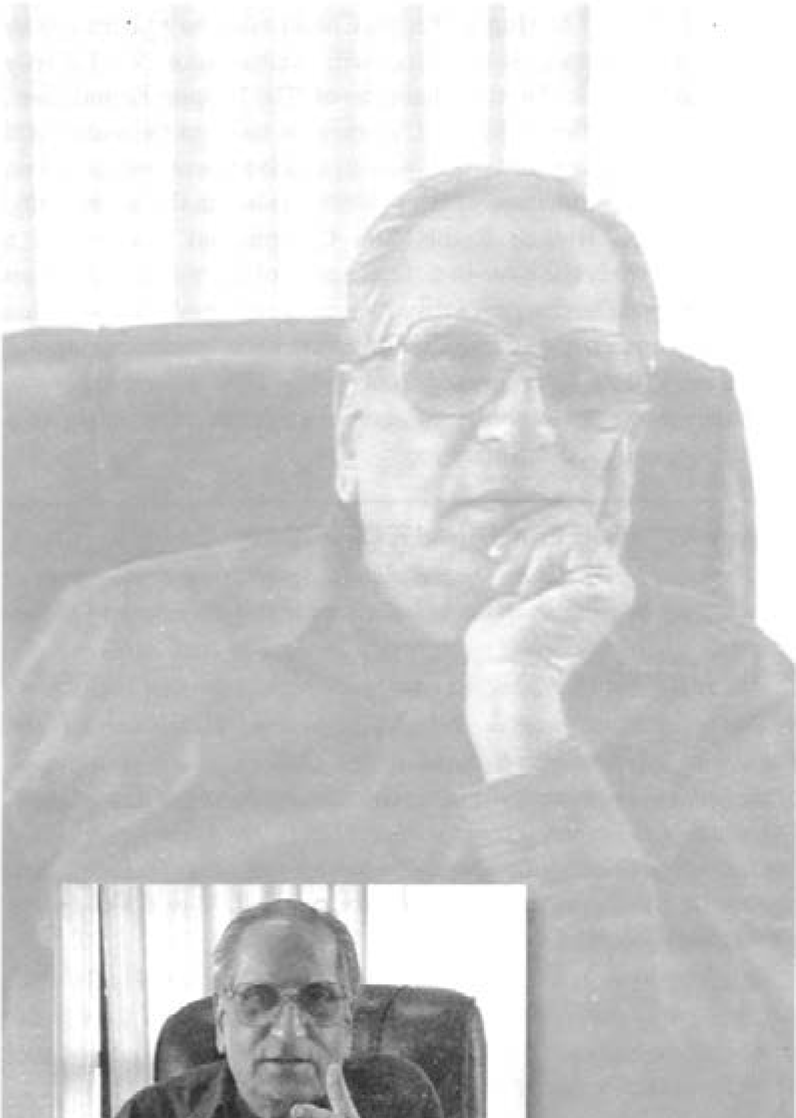

DR. SHARATCHANDRA D. GOKHALE

“Evolving a Life Beautiful”

Dr. Sharatchandra D. Gokhale, Chairman, International Leprosy Union, who loves to call himself “a worker in the field of leprosy for almost 50 years”, explains to **Prof Ujjwal K Chowdhury**, the evolution of his beautiful life in the service of leprosy affected people and there by his learning through the lives of many such beautiful persons.

The Initiation into the Life Beautiful

I was employed with the Government of Maharashtra. The Government of Bombay (the erstwhile name of Government of Maharashtra) decided to apply an Act by which it could establish leprosy institutes across the state. The first such institute, the Receiving Centre, was started at Chembur in Bombay. I was promoted to be the Director of that Centre. Till that time I had no experience of working with those affected with the disease.

I started the institute with 2000 leprosy afflicted individuals. The only medicine available was the chalmogra oil which had to be injected painfully. It was only later that Dapsone began to be used and it turned out to be a much better medicine.

The first thing I realized when I entered the establishment at Chembur was that all those affected by leprosy had a feeling of rejection towards our society. They felt totally isolated. Surrounded by tall, prison-like walls they had resigned themselves to a fate from which they could not escape from. For them, only death could take them into the world beyond their prison.

When they met me, the first thing they wanted was to come forward and shake hands with me. For them this simple gesture was a test. Probably they thought if I could perform such a simple act without any discomfort, I would pass the test of being the affectionate Director they were looking for. I could understand what was going on in their minds. I shook hands with a patient and picked up the little child from his arms. I began interacting with the person by asking him his child's name, the place he was born and his plans of educating him. Slowly, I saw that the people around me were letting their guard down. This whole process of acceptance was itself my first lesson.

The Challenge Compounded: Not Merely a Medical Problem

Though I had a Doctorate in leprosy rehabilitation, I knew what lay ahead of me was much bigger and more difficult an issue than what the text books had taught me. Winning their trust and acceptance was my first practical lesson. Then I realized that these individuals suffered from various problems, especially, rejection from their families which had resulted in their losing their identity. Many of them had changed their names; some got married within their leprosy colonies, thereby creating second families, and an alternate world.

The situation was such that even when I used to invite high ranking government officials such as the Chief Magistrate to visit the Centre, they would just take a peep from the outside and comment that within those walls was a world which might be beautiful, but was entirely different from the 'normal' world they came from. That was also the attitude of the community at large and surprisingly of the doctors, too. Lady Doctors would refuse to go into the institute in case of a delivery.

But I realized that these people had their own personality, their own intuitions and interests, their own lives. Only if we helped them rebuild that life could they return to society.

A very simple example was an old lady at the institution. When a Collector of Bombay came to us on a visit, the lady told me, "Sir, please do not call me out of the ward. I do not want to meet him." I had no problem with that. But after the visit was over in the afternoon, I went over to her ward and asked her why she had refused to see him. She first asked me to promise that I would keep the matter to myself. She revealed to me that the Collector was her son. Her family had told him that his mother was dead. She did not want to embarrass or shock him with her presence.

The Journey Forward

That was a typical example of the stigma associated with the disease which is very difficult to conquer. But I had a great advantage in my friends. Dr. Wardekar who was the Chairman of the Gandhi Memorial Leprosy Foundation (GMLF) had altered the scenario of leprosy work in India through education and treatment. Caring after leprosy affected individuals in their own homes was a concept initiated by Dr Wardekar. I learnt a lot under his guidance. I was so very involved with the GMLF that after Baba Amte, they made me the Chairman.

The Cure and The Nippon Foundation

After Dapsone, which was introduced by Dr. Cockerne in India, WHO has been very active in trying to find out more on the medicine that could cure leprosy. They found what they were looking for in a combination of three drugs and called it Multi Drug therapy, or M.D.T.

My colleagues at WHO informed me that it is so powerful that even one dose is enough. But, I feel to avoid any complications we would like to persuade the individual to take the medicine for at least 18 months.

But even if the cure is available, the person needs to regularly visit the hospital for treatment. The society needs to know that leprosy can be cured and should be ready to accept such individuals back into its folds. Once M.D.T was discovered, the next issue to be addressed by WHO was seeking out sources for funds and a funding organization that could look after all the leprosy affected individuals worldwide. No country had enough money for this; not even India.

At that stage, Yohei Sasakawa's father, Ryoichi Sasakawa, was himself involved in leprosy work. He used to run boatyards to earn a living. He obtained some funds from the municipal corporations of Japan and decided to utilize it to buy medicines for leprosy affected individuals. We are most grateful to The Nippon Foundation as well as Sasakawa Memorial Health Foundation which supplied free medicines across the world, until others like Novartis Foundation took over. This Drug Security from Nippon has been singularly important in bringing leprosy under control in India.

The Needs of the Leprosy Affected People

Once leprosy is contracted, feet, hand and eye-care are of utmost importance. Unfortunately, at times, some of those affected with the disease cannot shut their eye-lids and need to put a towel or an eye-mask as they cannot sleep with open eyes. We should provide them with important support aids that protect their eyes and feet among others.

Apart from physical aid, the affected person needs psychological help. We need to tell his family that there is nothing wrong with him. There has to be no fear after the person is cured. Today, there are thousands in this country who are back with their families, happily occupying respectable positions at work and within their community.

Fighting the Stigma: The Role of Media

The next significant question that arises in this battle is how do we change the society and use the media in this process. We have started a fellowship programme for media people to visit the leprosy affected, talk to him and his family and write about their experiences. With awareness generated on the issue, it will be easier for the community to accept them. In our battle against the stigma attached with leprosy, we are also going to organize Media Partnership Workshops in eight cities of India in late 2005 reaching out to around 250 development and health journalists across all major media houses.

Apart from the media fellowship programme, our aim is also to counsel families living under the shadow of leprosy. Rehabilitation for us is making a leprosy affected person economically self sufficient, socially accepted and psychologically confident.

Partners in this Battle

Apart from WHO, The Nippon Foundation and Novartis, it is important to note that without the involvement and commitment of the government machinery in India, both at the centre and in several endemic states, controlling leprosy would not have been possible. However, I must also note that the Government has usually considered this as a health issue only. To my mind, this is a wrong approach. It is a problem that has different aspects health (medical cure), economic (rehabilitation and livelihood), social (discrimination and stigma), and psychological (loss of self-dignity).

The NGOs from Germany, Belgium, France, USA, U.K. and local

NGOs like the G.M.L.F. are working in this particular field. But their activities are mainly concerned with providing medication, running hospitals, etc. Most of the Indian NGOs have traditionally avoided issues such as a change in the attitude of the affected and cured individuals, altering the attitude of society and the Government, or modifying the laws and legal practices associated with the disease. The focus has been more on teaching the afflicted individuals to take care of their hands, feet and eyes and rehabilitating them. Hence, what evolved was a kind of an understanding that two different NGO-segments would handle the two faces of this problem.

Stigma & the Law

Certain laws in India actually fuel the creation of this stigma. For example, the Indian Lepers Act prevented leprosy affected individuals from traveling on trains, going to public places, etc. A long and arduous battle that lasted 15 to 20 years has helped us get this law off the statuette book. Even then, dozens of other pieces of legislation exists which attempt to segregate those affected from the mainstream society. Consider, for instance, the Juvenile Justice Act which states that if the child is suffering from leprosy one must immediately segregate him and put him into a leprosy home. This is grossly wrong and unnecessary. Leprosy is like malaria, it is like any other common disease, and one can get oneself treated at home itself. There is a dire need to change these laws and modify the Government policies because they are effectively taking away the basic human rights of these patients. The Prevention of Begging Act in Bombay mentions that a leprosy afflicted person has to be remanded to a leprosy institution till he dies. The point is, do we really have the right to infringe upon the liberty of a person in such a manner? Also, the Hindu Marriage Act and the Muslim Marriage Act allow divorce on grounds of leprosy, which I think should immediately be taken off.

From Rejection to Self-care

So far as patients are concerned, people who are being treated or even those who have been cured are not accepted back into the society. They are abandoned by their families and rejected by their village folks. Our task is to change the psyche of the community and that of the media which reaches this community at large.

So, we started developing a program which begins with self-care. Self-care implies us teaching a patient how to take care of his feet. This is because the germ causing the disease affects the nervous system, which in turn leads to the affected losing any sensation on his fingers and skin. It is usually the exposed ends of the body, such as fingers or the nose which are the first to be affected. For example, if such a person is holding a cigarette, he will not get to know when it has burnt his fingers because the lack of sensation will not make him feel the pain. Therefore, through physio-therapy, we need to find out what are the supports of daily living we can provide to these patients. A lady with hands which are devoid of any sensation can lift anything. She can lift a very hot pot from the stove, she can burn her hands and not feel a thing. A patient whose feet are totally affected can walk on fire and will not feel it. In my institute there was an instance where a patient got up at about two o' clock screaming that there was something wrong. When we rushed to find out, we saw a huge rat running out of the room. The rat had bitten off a part of his feet but the patient did not realize it until some blood trickled to other parts of his body and he felt something cold touching him. To avoid situations such as these, it is important to help patients understand the fundamentals of self-care.

Lokdoots & Madhyam doots: The Historic Concepts

To achieve this objective, it is vital that apart from the mainstream media, we need to get these cured individuals on a public platform so that they can tell their stories. This first person experience sharing is certainly more credible. A man who has suffered can tell his tale with great confidence. When he says, "Look, I had leprosy, but I am happy, I am working, I am married and have my family", it is more believable. So, we are now using cured individuals we call them Lokdoots (peoples' messengers), to spread awareness about leprosy elimination and prevention of stigma. In all the endemic states of India we are tying up with volunteers. There are nearly hundred thousand girls who are working as volunteers in this field. A large number of media persons, both from electronic, print and online media have agreed to become Madhyamdoots (media messengers) for generating awareness on leprosy, working towards eradication of stigma and aiding in the rehabilitation of these individuals into the society.

We have been following this pattern which started only this year when a number of cured individuals were publicly felicitated by the former President of India, Sri R Venkataraman and the WHO Goodwill Ambassador, Yohei Sasakawa. This recognition provided them confidence and supported them in their journey back to the society they once belonged to. As a part of his speech during the felicitation ceremony, one of the Lokdoots said, "My friends, if society does not come to you, let us to go the society and tell them that there is nothing wrong with us."

I believe the struggles of these cured individuals and adequate coverage by the media will help reduce the stigma that has been accumulating for ages. Society will have to listen. Stigma is society's reaction; it is to me a continuum from total rejection to total acceptance. As a social scientist I do feel that it is quite possible for us to see to it that the continuum moves actively from rejection towards acceptance.

The Social Stigma & the Lokdoots

We were talking about the stigma, which is really the root cause of the alienation of these leprosy affected persons. This is based on the disabilities, the disfigurements of the patients, the attitude of their families, the understanding of the community about the disease and its cure. To do away with stigma, the best possible way is to present the brave survivors.

We started our meeting on 27th January, 2005 by congratulating people who are cured of leprosy. We put up posters and photographs of individuals from various fields of work - one was a manager, the other a nurse and another, a doctor. The title of the poster read 'There is one thing common amongst us' and in a very fine print below was the line 'we were all leprosy patients'. The point is when we felicitated these people, one of them got up and said, "We have heard enough of this, now let us go, walk up to the society and tell them that we are going to be there, we are a part of the society and you have no right to deny that right to us".

The New Attitude: the New Movement

This is a new attitude that has come about, a shift that has taken place and we believe this whole movement is a revolutionary change in the outlook towards leprosy. We are not looking at distribution of MDT as the only program we have. We are more concerned about stigma, acceptance of these people into society, their rights, their self-care and finally, their rehabilitation. To achieve this, they have to be economically independent, socially accepted and confident in their own personality, with their own identity. I am sure that it may not take more than a year for leprosy to be eliminated from India.

Elimination & the Mahatma

I am not saying that leprosy will totally disappear from this country, even if you have any absence of a case at a point of time, there can be some future incidence. You see, when we say eliminated, it implies less than one patient in every 10,000 people in the country. If we can go below that we have achieved elimination. We will not have any more disabilities, further instances of disfigured people thrown out of their families, their villages and their homes into isolated leprosy settlements. If we can achieve this end, we would have achieved a lot in this country.

I would want to add here that Mahatma Gandhi was once requested to come to Duttapur to inaugurate a leprosy home by one of his great colleagues, Manohar Dewan. In reply to that invitation, Gandhiji wrote, "I am sorry I cannot come to this inauguration but I shall be glad to be there when it closes down". This was the attitude of the Father of our Nation who looked at the root of the problem to be rejection and stigma, while WHO took about twenty years and Indian society has taken about forty years to understand this. I think we are now on the right path and we shall reach our objective soon.

My Personal Battle

Let me narrate to you my experience. When I joined as the Director, my father in- law came to me and said, "You are mad to leave Tata Institute of Social Sciences and to become a Director of a leprosy home. You may play with your life but I am not going to allow my grandchildren to be with you." That was a very angry moment for him. That night when I asked my wife regarding what she had to say about my decision, she asked me to present her the pros and cons of the case. I said, "If we work with these patients there is one in a million chance that we may get leprosy. Nobody has ever contracted leprosy by working with them. But we will surely have the opportunity to wipe their tears and bring a smile on their face. So you decide and you choose what you want to do." My wife is still with me, so she has answered the question. But the point is that the stigma was so deep-rooted that almost every medical doctor appointed in my institute would leave saying that no man wanted to give his girl in marriage to him as he was working in a leprosy home. So the stigma was not only attached to patients but also to those who worked with them.

PDLC, Dr Bandorwala & Dr Jal Mehta

The PDLC or Pune District Leprosy Committee has a very long history. Originally it was an institute and one of the missionaries who ran it was killed by the patients. But his son, who was equally devoted, got into office the next day and declared that he would continue to devote his life to his father's mission. Later on, when the missionaries withdrew, the Government was keen to know who could take over the institute. They requested Dr. Bandorwala who was the President of the Indian Red Cross Society, Pune Branch, to take it take over and he organized a group of people called Pune District Leprosy Committee. The committee started running the Kondhwa Leprosy Home.

Dr. Bandorwala's son-in-law, Dr. Jal Mehta, was a renowned surgeon. He succeeded Dr Bandorwala, as the President of PDLC. His wife Neeru, an equally well known surgeon, stood by him. Jal not only developed the institution but made a major contribution to the field of leprosy by developing a new technique of hand surgery which was internationally recognized and awarded. At a later stage he was joined by Bharat Kothadiya, who quit the corporate world to join the movement led by Jal.

For the first time a novel idea of starting a factory workshop attached with a few homes was considered. This meant bringing work for cured persons. It would give them a means of livelihood and a shelter over their heads. This is what real rehabilitation is all about.

True Rehabilitation: Cured Persons' Factory in Pune

The next thought was about the kind of work they could do. People like Cyrus Poonawala pledged his support by providing equipments and machinery. The cured individuals started making automobile parts for TELCO. The TELCO trucks have a locking system that is quite complicated. It is made by such cured individuals. Similarly, Mr. Kothadia used to get work from other agencies in Srinagar, Solapur etc.

For the first time patients who were living alone in separate colonies started mixing with the general society in Pune around Kondhwa. They bought houses in Kondhwa village and now have an elected Panchayat also. At a later period, when Jal thought that he must leave and find somebody else to work at the PDLC, he requested me to take over as the President. It is unfortunate that at that point of time, I had to accept a New York posting that was offered to me by the UN.

I passed on the mission to some of my other colleagues who are running the institute quite efficiently. But I have been associated with the factory and keep visiting to enquire about it progress. I am very happy that the factory is unique in the sense it is a co-operative and run by cured individuals. They take all the decisions, whether it is regarding production, financial policies, employment, or sharing profits among themselves. This initiative has been internationally recognized and has received the ILU award.

Leprosy, Human Rights and the UN

Recently an issue has come up for discussion on human rights abuses of the leprosy affected people. The U.N. Human Rights Commission has established a sub commission on this subject which made a trip to Pune. We were requested to conduct a survey and collate data on the subject of stigma and human rights. The Indian Human Rights Commission had also requested for the same data. Towards this end, the International Leprosy Union selected six endemic states. A team was appointed in each state which worked in tandem with major research institutes of that state, (like the Lucknow University in Uttar Pradesh), and collected data on 200 patients per state. The survey asked questions on the breach of human rights, segregation, and differential treatment. The report is now complete and the major findings reveal that the real concern is about the laws and social practices that create discrimination. Secondly, we have been able to put forward certain recommendation to the National Human Rights Commission (NHRC) and now the report is being submitted to the U.N. Sub commission on Human Rights as well.

Preventive Vaccine & Research

One may always question us as to why we are emphasizing so much on cure and M.D.T and not trying to prevent the disease by developing a vaccine. Leprosy develops in the body through M Lepre a bacillus. M.D.T. kills the bacillus and prevents it from reappearing. The main problem behind finding a vaccine for the disease is the curious fact that leprosy incidence of leprosy has not been found in any other animals like mice, rats etc. The only animal which has been found to develop some traits is the armadillo, which is a Latin American animal. When scientists brought this animal into the laboratory they found that it does not breed in captivity. This revelation complicated the research. It was only at a much later date that they could get the leprosy bacillus in a test tube & started some work at two institutes in Mumbai and Delhi.

The effort was to take the bacillus and cultivate it into a vaccine. Dr Chandrakant Bapat from Pune was the pioneer in this field. I also know that Dr Talwar, Director General of the Institution of Immunology, Delhi, has been working on this vaccine. Dr. Dev from the Hopkins Institute has also contributed to this research.

There are many issues that need to be solved. There are certain tribal communities who do not have leprosy at all. We do not find any incidence. Why, we do not know. Vaccine trials are still going on at the WHO and at present there are three vaccines which are being tried on human beings in different countries. One of the trials is being done in Maharashtra. The point is, all this will take time because WHO cannot come to a conclusion that the vaccine is effective unless a certain number of people have been experimented upon. Experimenting with human beings is a complicated, process. There are many ethical issues involved in it. But a lot of hope is pinned on these vaccines. May be about ten years from now we will find a vaccine that prevents the disease altogether.

That will be the real victory. But I am not a medical scientist, or a researcher, what I am saying is based on my reading and my discussion with my scientist colleagues. What I am now focused on is battling the stigma against the people affected but cured and ensuring their integrated rehabilitation in the society to which they rightfully belong.

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MISSION 2005: INDIA REVISITED

With the Prime Minister of India, Dr. Manmohan Singh

It was Ryoichi Sasakawa who opened his son's eyes to the unconscionable and multifaceted plight- physical, emotional and social- confronted by the leprosy sufferers worldwide. Since then, for nearly four decades now, Yohei Sasakawa, Chairman of the Nippon Foundation, one of the world's largest conglomerations of philanthropic organizations, and the WHO Goodwill Ambassador for Elimination of Leprosy, has been intensely and wholeheartedly involved in the global battle against leprosy.

In early 2005, Mr. Sasakawa met with Dr Manmohan Singh, the Prime Minister of India. While appreciating Mr Sasakawa's contributions in the battle aginst leprosy, Dr Singh expressed the commitment of his government in ensuring socio-economic integration of the treated persons in the social mainstream.

A high level delegation from The Nippon Foundation and the WHO headed by Mr Sasakawa and Dr Salim J. Habayeb, WHO India Representative, met the Union Minister for Health, Dr Anbumani Ramadoss at Nirman Bhavan, Delhi. Dr Ramadoss acknowledged that the dream of eliminating leprosy from India is going to be realized by the end of this year, but the end of discrimination would need persistence & social understanding.

Mr. Sasakawa also met Mr. Rajiv Kumar, Chief Economist of the Confederation of Indian Industry (CII) who assured him that efforts will be made to replicate the good work done by Tata Motors in buying automobile spare-parts from a factory at Pune purely managed by the leprosy cured persons.

In May 2005, Mr. Sasakawa met Mr. Thalavai Sundaram, Minister for Health & Family Welfare, Government of Tamil Nadu. While expressing happiness on account of leprosy being eliminated in the state of Tamil Nadu, the Health Minister added that in future his Ministry would also look into the 'social elimination' of leprosy.

Mr. Sasakawa also met Mr. Buddhadev Bhattacharya, Chief Minister of West Bengal, and Dr Suryakanta Mishra, Minister for Health, Government of West Bengal, in mid-2005. While applauding Mr. Sasakawa's relentless efforts, the Chief Minister expressed his solidarity with his mission and assured that the state would achieve the WHO target of less than one leprosy patient in every 10,000 people in West Bengal, a state which now has the second highest prevalence rate in India, next only to Bihar.

Rupak Ghosh, a student of Economics from Presidency College, Calcutta, has completed his Masters from the Pune-based Symbiosis Institute of Mass Communication.

He has worked across industries, such as advertising (McCann-Erickson), newspapers (The Statesman) and event management (Encompass ESP and Shobiz Stage Management Pvt. Ltd.), while freelancing as a copy editor for publication houses like Sage.

In his spare time he teaches Advertising Management at EMPI (New Delhi). Currently, he is the Manager (Marketing) at Career Launcher, India's leading edu-corporate.

Prof Ujjwal K Chowdhury, currently Media Advisor to the Government of India (Textiles Ministry), is actively associated with the anti-leprosy stigma movement within the Indian media-space. He is a communication consultant with several media and management institutes, apart from being the founder Director of India's fore-ranking media school, the Pune-based Symbiosis Institute of Mass Communication. A former Ford Foundation Research Scholar, Prof Chowdhury, was also a journalist with well known television news channels such as Zee News & TVI and publications such as The Times of India, Observer & Blitz. He is also the Managing Trustee of the Generation Next Trust, of which ICONS Media is an initiative.

'Rise and go your way;
your faith has made you well'
Luke 17:19

It's not just a disease....

For centuries, leprosy has been considered not only as the affliction of the body but of the soul itself; the very embodiment of an immoral life.

For an equal length of time, it has also been untreatable, and those affected by the disease have been forced to live and die in pain, at the boundaries of society, watching their family, friends and limbs fall away. The stigma of contagion and depravity has stuck to it (and to those affected by it) even when the cure has been found and made available across countries rich and poor.

This collection of personal narratives provides an evocative account of the trials and public malignment, faced by the victims of the disease; who overcame their stigma to reach a new evaluation of their own worth, and of others similarly affected and the prevailing attitudes in wider society. The support from a few friends and their faith in life saw them through it all.

This collection of real life stories of people who have successfully battled against a disease and stigma called leprosy, is a representation of both genders from across the vast Indian nation and from its different religious and linguistic communities. And, while we have been talking to them and penning down their stories, there has been an unmistakable impact on our lives. We have actually seen, felt and understood what it is to lose one's self-dignity and then fight to bring it back.

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