

Dear Friends,

How would you respond if, because of a disease, your family no longer wanted you to live at home ?

How would you feel if, because of a disease, your husband or wife wanted a divorce ?

What would you say if you lost your job because of an illness that had no impact on your ability to carry out your work, or cannot send your children to school because you contracted a disease ?

These situations may sound remarkable, unbelievable even, and yet these are real situations, faced by real people every day in India. They happen just because the person has leprosy. This situation could easily change with the cure found for leprosy, but it still continues to be haunting the lives of the people.

As you know, ODP has been reaching out to the children of leprosy patients for the last 7 years from three leprosy colonies. In fact there are many more leprosy colonies existing in the region and many of these children, instead of going to school, get on the streets, begging. We have been evaluating the possibility of extending our support to more colonies in the near future as these children are in need of moral and economic support. As we all know, the need is so much and we are like a drop in the ocean. Our earnest effort is that we do the best possible within our capacity, with each of your support, so that what we do bring a better change in the lives of the individuals, families, communities and to the societies at large !



Les anciens lépreux espèrent un avenir meilleur pour leurs enfants.

## Leprosy in India

When Gandhi was once invited to inaugurate a Leprosy Home, he wrote back saying; I regret I cannot come to open a leprosy home, but I shall be very glad if you call me to close it down. This was in 1944 and 66 years later, the disease still cripples one in 10 thousand Indians and the plight of the patients in search of an asylum continues. Every year there are more than hundred thousands new leprosy cases in the country and those curable in 6 months of treatment and not contagious in 90 percent cases, the stigma still runs deep. The Times of India, New Delhi edition, on February 9th 2010, publishes the following information from WHO. « India continues to record the highest number of new leprosy cases in the world followed by Brazil and Indonesia. While globally in 2008, two hundred and fifty thousand new cases of leprosy were re-

corded, India accounts for one hundred and thirty seven thousand new cases. India also records the highest number of children newly detected with leprosy in 2008 – 13,610. »

In the year 2005, Government of India declared that Leprosy is Eliminated from India and NGOs working in the field of leprosy were forced not to report the cases. Fr. Borgia, the Director of Œuvres Des Pains in India has been also working for the Leprosy eradication Program for the last 2 decades in North India.



Here is what he says : *«In the field of Leprosy Elimination, our Society has worked for 18 long years in the peak period of the Leprosy Elimination driven by World Health Organisation (WHO) and the Government of India (1988-2006). Our team detected an average 8 to 11 cases of leprosy in a population of one thousand. We were carrying out Survey Education and Treatment (SET) method and in the course of implementing the scheme, we detected over fifty thousand leprosy cases and over forty thousand patients were released from treatment (RFT). When we were asked or forced to stop detection, reporting and treating patients in the year 2005- 2006, the Prevalence Rate and new case detection remained almost the same as before and implementation of Elimination of Leprosy programme was not evenly carried out, including the period of elimination of leprosy drive.»*

It is, as well, remarkable to note the facts that: A 2003 Supreme Court ruling states that leprosy patient cannot contest election or hold any civil post : The Hindu Marriage Act 1956 has provisions for divorce on the ground of the spouse suffering from leprosy. The Juvenile Justice and Care Act 2000 says the leper child has to be dealt with separately, aloof from society. The real challenge therefore is not only the treatment but also a change into the legal system.

Gandhian Dream of Equality of a Society which is not disfigured or disabled by disease is so far away from the present reality.

### **A home away from home**

Though it is a Good News that the medicine for leprosy was found in 1982 and leprosy is curable, the medical science could not have much impact on the belief of the illiterate population, super powered by superstitions. Deep into the villages where there are hardly any hospitals, people don't have access to the medicine and the medical practitioners in the villages still treat these cases with their traditional herbal medicines. Without proper medication on time, many of them get deformities and end up being excommunicated from their communities.

The Leprosy Colonies are home to thousands of former leprosy patients, who other-

wise will end up on the streets. They build a new home in these colonies and bring up their children, they feel secure in this community. There are many families living happily in there, however, some of them cannot come in terms with the bitter reality they had to face. To cover up their pain, they turn to drinking and get addicted to alcohol and drugs. Many patients burn their hands and feet to get them disfigured, so that they can evoke sympathy in the people and get a better living or come back to the leprosy hospital where they can stay longer time.

### **Support from Œuvres des Pains**

The sponsorship program in the leprosy colonies are going on without much difficulties. Jena and Giri, our social workers regularly visit these children, their teachers and family and evaluate their performance. Most of the children are growing well, they get moral support from their parents and school. However some parents who are addicted to alcohol make problems in the colonies and a few of them were sent out by the Pradhan (leader) of the colony last year. We had to interact with the leaders to get back a few of them. We are following up those families having more trouble, and doing our level best to help them live a better life.



Our social workers meet the sponsored children regularly to check the evolution of their studies.

## Gopal from the Leprosy Colony, Delhi

Gopal was born in a middle class family and lived his childhood with his parents, brother and sister. He went to the school until he was diagnosed of leprosy, at the age of 14, in the year 1984. When he was 11 years old he noticed weakness in his hand and he could not hold a pen in his hand. The parents of Gopal took him to a local hospital where he took medicine for 3 months, however, there was no sign of improvement. Gradually his both hands and feet got affected and the fingers and toes of both hands and feet became claw. At this stage his parents took him to the hospital run by Sisters of Charity, where his disease was diagnosed and treated. He spent 3 years in this hospital, got cured of leprosy, however the deformities caused by leprosy remained. His family and community didn't want him back. He stayed back in the hospital since he had nowhere else to go, the Sisters employed him as a sweeper. There in the hospital, he met Sabita, who was also in the same condition as Gopal. With the help of the Sisters they got married and settled down in the Leprosy Colony in Delhi.

For the last 23 years they live in this colony and they have two beautiful children. Gopal has a cycle rickshaw and when his physical condition permits him he goes to work and earns a little money, however it is not enough to sustain his family. When *Œuvres des pains*



Gopal is very proud of his family !



met them they were struggling to educate their children. *Œuvre des pains* has been supporting this family and the education of his children since last 3 years ! Gopal's dream is to educate his children and make them have a better life ! *Oeuvre des Pains* is there to help their dreams come true !

\* Gopal & Sabita are not the real names, we replaced the real names for privacy sake.

## Mobile telephones more common than toilets in India ! U.N. Report

«It is a tragic irony to think that in India, a country now wealthy enough that roughly half of the people own phones, about half cannot afford the basic necessity and dignity of a toilet.» It is a report released by United Nations University. The report also says that 45 percent have access to cell phones where as only 36 percent have access to the toilets in India.

I was on the terrace of the Teacher's residents around 6.00 am, enjoying the beautiful nature and the rising sun, in the month of March. It took my attention as I saw people going into the open field to defecate, with a bottle of water in one hand, talking over the mobile phone. The outside world looking at these people may think it is strange, but as I understand, for them going to the open field has become part of their lives. The entry of mobiles into the lives of these people is from the last three years and since then there is a crazy run for the mobile phones. I remember, back in 2005, when we wanted to install the telephone line with ISD (International calls) in St. Anthony School, the Telephone Exchange asked us to pay a huge amount and we had to refuse it. Instead we set up an internet connection. Now with this prepaid mobile phones anybody can reach anywhere in the world !

Of course it is good to have mobile phones when one can afford it, but the case is not exactly the same in the villages. I know many people getting addicted to it and struggling with the expenses they have to bear. I wonder how far it will continue like this. Will the new generation seeing their parents on the mobile and forced to go to defecate in the open field think the other way ? We are trying to make a change ! The Social workers are trying their level best to conscientise the villagers about



the dangers of defecating in the open. Our Self Help Group is giving loans to build toilets and we are happy to see many women profiting this loan and making toilets.



Le programme de micro-crédit dont nous vous avons déjà parlé précédemment permet au villageois dans la région de l'école Saint-Antoine de construire des toilettes.

Œuvre des pains asbl, rue A. Delzenne 9, 7800 Ath.  
Site internet : <http://www.OeuvreDesPains.org>  
CCP 000-3000291-81 (Attestations fiscales, 30€ min.)

France : Œuvre des pains asbl, c/o Adom sarl, 5 impasse de l'Ourcq, 78310 Maurepas. CCP Paris 25.984.20.A.