

FACES HHEPE

Project New Life helps children inside and out. By Xiyun Yang





ZHAO HAOXIANG, two-and-a-half months old with long eyelashes and chubby cheeks, is oblivious to the fate that almost befell him. From the minute he was born, took his first deep breath and screamed to the high heavens, his family knew something was wrong.

"He just didn't cry the same. You could hear sounds of escaping air," said Zhang Dehe, 54, his grandfather. The baby was diagnosed with a cleft palate and suddenly his place in the family became uncertain.

"His mother wanted to give him away," said Chen Zhanfang, 56, his grandmother. "She cried for days. Where can we find money to cure him," she said. "How can he find a wife later on?"

Haoxiang is one of an estimated tens of thousands of babies in China who are born each year with cleft lips or palates, conditions in which the two sides of the lip, palate, or sometimes the soft inner cartilage of the nose, is not joined. Almost all of them will require corrective surgery in order to assimilate fully into society, but with the operations costing between

"This programme is primarily for children who are stricken with this disease and their families. These children suffer emotional pain sometimes beyond any physical pain they experience, even though it is not a life-threatening illness. The greater purpose of this programme is to help patients regain dignity and confidence, and be able to live happily and contribute to society. Care is the most important social perspective. To me, the significance of promoting a culture of giving is to help society recognise that even a small star shines in the darkness. If everyone pitches in and invests a little of ourselves and our resources, the multiplying effect will be great. More government policy support and better implementation will also contribute to more satisfactory results. By working together, we can bring about positive change."

HWL Chairman Li Ka-shing

RMB6,000 and RMB7,000 for the simplest procedures, to tens of thousands of RMB for multiple, long-term treatment, many of China's poor do not have the financial means to care for their children. As a result, some families will abandon these babies.

Haoxiang was luckier. His grandparents stood by their only grandson, but they knew that life with a cleft lip would be difficult. There is one man with a cleft lip in their Hebei village and many of the villagers don't know his real name; they only refer to him as huaide, broken. "From now on we have to work hard, save money, we thought. Even if it takes us four or five years," Ms Chen said.

Then, a few months ago, the family couldn't believe their luck. Haoxiang's father heard about Project New Life, a charity that offered completely free cleft lip treatment for the needy. The family qualified. Mr Zhang and his son work as welders in Beijing, while the women tend the small piece of land they received after being relocated as the result of a local dam project. The four working adults of the family made about RMB10,000 a year, Mr Zhang estimated.

Project New Life brought baby Haoxiang and his grandparents to Capital Medical University's Beijing Stomatological Hospital and paid for their round trip transportation, accommodation and food costs. Now, crying as his grandmother rocked him in her arms while a nurse administered an IV in his ankle, baby Haoxiang is waiting for his surgery.

Another of the project's many heart-warming stories belongs to Zhang Shengyong, who back in 1998 was found abandoned under a bridge in a remote village in Henan province. He was just a few months old and his face was badly deformed, but his foster parents, themselves suffering from poor health, de-



Thank you, Project New Life

Project New Life receives many letters from grateful parents. Here, we publish one of the most moving.

In March 2007, I gave birth to a daughter. I named her Zhang Mingyue. The first time I laid eyes on my darling daughter and saw her severe cleft lip and palate, my mind went suddenly blank; my tears overflowed. I didn't know whether it was that my daughter was unfortunate or I was cursed with a bitter life. I had given birth to a still-born baby during my first pregnancy, and now this. At the time, I really thought I no longer wanted to live.

We took my daughter to the hospital and the doctors said she could be completely cured for over RMB200,000. This is an astronomical sum for our family! Just as we were approaching the depths of despair, we heard about Project New Life. With renewed hope, we thought we'd give it a try and took our daughter to The Second Affiliated Hospital of Shantou University's centre for cleft lip and palate patients. To poor families like us, only our hot tears can express the gratitude we have for the excellent and caring work of the doctors and nurses and Mr Li Ka-shing. We must raise my daughter and educate her to repay our country and our society in order to express our gratitude.

> Zhang Huilian and Cai Juhua, parents Lishu Village, Guangdong 21 January 2009

fied their hardships to give Shengyong an education. One day, a doctor visited the village and brought the little

boy in for surgery. He hasn't stopped smiling since.

Founded by the PRC's Ministry of Civil Affairs and the Hong Kong-based Li Ka Shing Foundation, Project New Life is a unique private/public partnership which is a new model for standardising surgical procedures, professional project management that meets international standards and stringent quality control.

The project has already changed the lives of over 5,000 children since its inception in April 2008. Project New Life has links with 20 top university-supported hospitals across the country selected specifically for their leading expertise in oral surgery and cleft lip and palate treatment. The project plans to expand the network of hospitals to cover all provinces.

The Ministry of Civil Affairs and the Li Ka Shing Foundation have formed a task force to supervise the project office that is responsible for implementing sponsorship plans, promotional work and assisting eligible poor patients indentified by Civil Affairs Departments throughout the country in a transparent and accountable way. The Beijing-based project office also evaluates the results of the project's work and maintains an online patient database and financial system.

The project is an offshoot of the Li Ka Shing Foundation's work to provide care to the poor and is the only cleft lip charity that offers not only free surgery but also transportation, housing, food, speech rehabilitation guidance and comprehensive assistance to the patient and family.

In addition, Shantou University Medical College is investigating the genetic basis of cleft lips and palates and is building a comprehensive database on China's cleft lip population to gain better insight into the causes of the disease and explore more effective prevention and treatment solutions.

While medical science points to a variety of factors that contribute to the occurrence of cleft lips and palates, the exact cause is not known. Orofacial clefting is, to an extent, a hereditary condition: if a parent was born with a cleft the chances that his or her child will also have a cleft rise to one in 14, given no other factors.

On the other hand, genetics only answers some of the questions. Environmental factors like exposure to pesticides or lead, extra stress, the mother's vitamin deficiency, and the use of drugs, alcohol and cigarettes can interact with a genetic predisposition.

The condition manifests itself within the first two months of pregnancy, when the two plates of an embryo's skull are not joined during fetal development. This results in a gap in the lips, palate, gums and nose cavity, ranging from a small gap to something much more severe.

Occurrence rates are about 1.65 to 1.8 births per 1,000 in China, a number that is consistent with worldwide rates, although it may be rising due to as yet unknown reasons, according to Dr Chen Renji, the head of surgery at Beijing Stomatological Hospital, Capital Medical University.

Surgery for cleft lips can be simple, lasting as little as 45 minutes. However, babies with more severe deformities may require years of surgery, dental work, speech therapy and even counselling. Most hospitals in China only provide the surgery, and only a few specialist hospitals in the country have the resources to treat the patient using a holistic approach.

At the Beijing Stomatological Hospital, Dr Chen has personally treated over 3,000 cleft lip and palate patients during his 20 years in the field. "When there isn't a charity helping with the cost of the treatment, the notes some families bring are dirty and wrinkled. You can tell that they haven't lived well for years, that they have been saving forever."

Dr Chen said that before surgery, his patients have trouble at school and are made fun of by other students. Even teachers may

avoid communicating with the student because of their speech difficulties.

"Often, even if society accepts the child, he or she won't have the confidence to enter society," said Dr Chen, who not only performs surgery but also does research into speech therapy and other cleft lip and palate treatments. "They feel the pressure in their hearts and some, though definitely not all, may develop psychological problems."



HOW THE TROUBLE STARTS

Here are three main types of cleft lip and palate conditions



Unilateral incomplete

In the case of cleft lips, there is an indentation or gap in the lip that does not extend to the nasal cavity. In the case of cleft palates, there is a hole or fissure in the palate. Simple surgery is required to sew the

two sides of the fissure together. Babies with cleft lips and palates can also have hearing problems and constant ear infections.

Unilateral complete

The fissure in the lips and palate extends, in the case of the cleft palate through the gums, to the nasal cavity, linking the oral and the nasal cavity. Depending on the severity of the clefting, the patient may require multiple sur-

geries of the lip, palate, gums, and nasal cavity. Years of orthodontic work and speech therapy may follow.



Bilateral complete

The most severe category of the birth defect. The fissure splits off in two directions and extends through the lip and gums on two sides to both nostrils, the lip tissue in between the two fissures flip

upwards. The deformity may extend to the jaw and require bone grafting.

Some students, like Liu Yingying, 18, and her twin sister Liu Jiawei, both recipients of the free treatment from Project New Life, began school late as a result of their cleft palates. They are now in their third year of junior high (ninth grade).

Yingying, who was waiting alone for her surgery in the sunny hospital room she shared with six other younger patients and their parents, speaks in a fast, self-conscious clip, often shrugging to make her point. Her speech is devoid of

> the guttural stops and H sounds, like the one at the beginning of her native province, Hebei.

> Her parents are originally farmers, but have worked in Beijing for years. She and her sister live with their grandmother. Their surgeries have been delayed until now because the family lacked the funds to treat them. When asked about her upcoming surgery, Yingying smiled nervously but widely. "I'm happy. Really happy."