

Foundation bringing back the smiles of children



Volunteers of the Smile Shop in Ubud and Yayasan Senyum (from left) Smile Shop volunteer manager Carrie Johnson, Eva Kortkamp, Yayasan Senyum voluntary head, Mary Northmore-Aziz, Peter and Marliese Knoppfen and Nicola Seiler.



Toddlers with cleft lips are held by their mothers at a Jakarta medical center in this file photo.

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Contributor/Guest

In a world where appearance is a passport to jobs, marriages, first dates and social acceptance, having severe facial deformities can bar people from ever entering the life most of us take for granted.

Add poverty and little access to health services on top of disabilities such as cleft and lip palates or severe deformities, such as the Elephant Man Syndrome or Goldenhar Syndrome, and the chance for sufferers from remote regions in Bali and Lombok to receive medical treatment was, until a

couple of years ago, almost nil.

Today these are the people Yayasan Senyum or the Smile Foundation seeks to help across Bali and Lombok. People who, if born in another country, would have had these disabilities treated as babies; others caused through infection would never have occurred.

"The simple act of eating and drinking can be denied to these people; looking in the mirror, putting on makeup, feelings of being punished for unknown sins, being disadvantaged in everything.

The ideal of beauty operates all over the world and aberrations (like these) are

not well received," said long time Bali resident Mary Northmore-Aziz, who two years ago, with an ever-growing band of volunteers and supporters, established Yayasan Senyum. The foundation helps arrange reconstructive surgery for sufferers of severe facial disfigurement and cleft and lip palate across Bali and Lombok.

"Yayasan Senyum began two years ago when Dr David David of the Australian Craniofacial Unit, asked me to set up a foundation to track down patients in need of facial reconstruction," Northmore-Aziz said. "Senyum then guides people through the

process of pre- and post-operative assistance, getting some to the Adelaide Women's and Children's Hospital in South Australia and others into Sanglah or Dharma Yadnya hospitals in Denpasar."

Patients and a family member are housed at the foundation's Smile House in Denpasar during trips to the city for medical treatment. Rental for the Smile House was donated by local Balinese Sanford Chase and opened in January 2007. The house acts as a halfway home for patients with the family atmosphere helping to reduce the stress and fear of the hospital process.

And that process can be terrifying for patients and their families from remote villages who may never have left their homes and are already socially isolated and traumatized by their facial disfigurements.

"These people are often without information. Many can not read or may not speak Bahasa Indonesia. Poverty is a lack of any resources. Not just money, but including the information we need to cushion the hard times. Because of that lack of information when these people decide to have surgery they only know that decision will be the forerunner of a very frightening and painful experience," said Northmore-Aziz.

Walking hand-in-hand with patients through the chaos of hospital registrations, pass-

port applications, visas, blood tests and more is one of the many ways Yayasan Senyum cushions the fear and confusion faced by patients at the foundation's Smile House.

"Smile House has a coordinator, Oki Made Widawati. She walks people through the process, the reading of admissions forms, how to go for blood tests, where and when to go to X-Ray. These things are all very frightening and confusing. Having the coordinator journey through this with patients eases those fears," Northmore-Aziz said.

She adds that patients who arrive in Denpasar face not only the fear of surgery and possibly travel to a hospital in a foreign country, but also the fear of being far from home, possibly with language barriers, different religious practices and genuine culture shock, all these fears are calmed by Smile House's coordinator.

"There are also the irrational fears felt by not only patients, but also by family and community. We had one young girl who was in hospital in Adelaide for so long a rumor went around her village that we had sold her. Having a family member so far from home can be very frightening. Trusting people they do not know; setting out from a village into the unknown," said Northmore-Aziz of the trauma faced by patient's communities.

But for the dozens of people helped by Yayasan Senyum, once the rounds of operations and hospital stays are over, life never looked so good.

"Rusmini had lost much of her cheek bone and jaw to infection when she was a child. Today she works at the (Smile House) center and wears lipstick. She never wore

lipstick until she was 32 years old. She did not want to draw attention to herself and always covered her face. Surgery gives these people a new life. They can't stop smiling and they chatter nonstop, they are so delighted with their lives. They are filled with confidence, pride and courage," Northmore-Aziz explains.

World craniofacial leader working with Indonesia

The Australian Craniofacial Unit is a world leader in facial reconstruction and works throughout much of Asia from its base at the Adelaide Women's and Children's Hospital.

The Bali-based Yayasan Senyum has to date sent nine people from Lombok and Bali to the Adelaide Women's and Children's Hospital for highly intricate faciocranial surgery and more than 30 others to Sanglah and Dharma Yadnya hospitals in Denpasar for lip and cleft palate reconstructions. Bali operations are carried out by Dr Asmarajaya and his team, trained under Dr David David, head of the Australian Craniofacial Unit.

Operations carried out in Adelaide address the most severe forms of faciocranial disabilities, such as Goldenhar Syndrome. One sufferer of this rare disability and deaf mute, 3-year-old Ketut Wira of Bali, had her eyes moved closer together, her jaw straightened and a tongue tie released, as well as the implanting of a bone-conducting hearing aid during two months of operations in Adelaide.

The team of medical experts included a craniofacial surgeon, orthodontist, speech pathologist, eye surgeon and audiologist. "Ketut has now spoken for the first time, heard her father's voice for the first time and smiled for the first time," said Northmore-Aziz.

Closer to home, the foundation last year ran the Lombok 70 Project that aimed to treat 70 patients from Lombok needing cleft palate surgery at Denpasar's Sanglah Hospital. Out of that project 51 patients, mainly babies, were treated with funding from Rotary Nuss Dua, the British Community Committee and the Australian Consulate-General's Direct Aid Program.

Those needing treatment in South Australia's Adelaide Women's and Children's Hospital are funded under an agreement with the government of that state to cover all medical expenses for up to 10 Indonesians annually. Australia's QANTAS airlines assists with travel for Adelaide-bound patients, a role Garuda Airlines filled when the national carrier had direct flights to that city.

You can help

Yayasan Senyum raises funds through its Smile Shop on Jl. Sriwedari, Ubud, which receives donated goods such as clothing and bra-a-brae for sale. To date the Smile Shop has raised more than Rp 100 million to continue the foundation's work. Yayasan Senyum has also launched its Smile House Fund to raise money to build a new Smile House in Denpasar. People wanting to donate to the Smile Shop, volunteer their time or donate to the Smile House Fund can contact Yayasan Senyum on 0361 233 758 or email.yayasanenyum@yahoo.co.id