

SENYUM UPDATE

Newsletter of Yayasan Senyum

A Bali based foundation bringing health care to people with craniofacial disabilities

Editor: Sue Frost

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A lot has happened...

Since our last *Update* we have had the happy return of Ketut Wira from Adelaide – read her story below.

We have also opened The Smile Shop which is proving to be a good money earner for Yayasan Senyum.

Our website – www.senyumbali.org – is now up and running.

AND The Smile House has been found! In mid-Jan we rented a house near Sanglah Hospital to accommodate patients and our office. More next issue!

Sue Frost, ed.



Ketut Wira – home from Adelaide

In the last *Update* we reported on our quest to get Ketut Wira to Adelaide at short notice. Ketut Wira was in urgent need of treatment for Goldenhar Syndrome as she was ready for school but could not speak, hear or even smile.

Professor David David of the Australian Craniofacial Unit first met Ketut Wira as a baby when he repaired her cleft lip in Bali in 2001. The rest of her surgery, however, had to be delayed until she was 5 years old.

So, in October 2006, Ketut Wira went to Adelaide. She arrived home in Bali on the 22nd December, after almost two months treatment in Adelaide's Australian Craniofacial Unit.

Courtesy of the Government of South Australia, she had a team of experts consisting of radiology, social worker, dentist, geneticist, craniofacial fellow, photography, speech pathologist, craniofacial surgeon, orthodontist, neurosurgeon, eye surgeon, ENT surgeon, paediatrician, anaesthetist and audiologist!

Her treatment included: moving her eyes closer together, straightening her jaw, removal of ear tags, and release of her tongue tie. She has also been given a bone-conducting hearing aid.

She has now spoken for the first time, heard her father's voice for the first time, and smiled for the first time. Her family and all of us at Yayasan Senyum would like to thank all those donors who rallied to her cause at such short notice.



Ketut Wira arriving home in December (above) and at home with her twin sister, older sisters and parents in January

Our Patients



Aussie Consulate Hosts Party

On the 1st of December, Consul General Bruce Cowled and Vice Consul Adelaide Worcester hosted a gathering attended by some of our *Lombok 70 Project* patients.

The Consulate's *Direct Aid Program* contributed Rp36.6 million towards the cost of bringing patients from Lombok.

Also attending were representatives from Yayasan Senyum, Yayasan Kita Peduli, Sanglah Hospital and the Rotary Club of Nusa Dua who are covering medical expenses for the operations.



Yayasan Senyum
Ubud, Bali, Indonesia

The Smile Shop Raising Funds for Yayasan Senyum

Located in Banjar Taman
just up from Seniwati Gallery of Art by Women, Ubud

Become a 'donor' while having fun shopping!
help us to help others have life-changing operations

Bali's first op-shop!

All goods sold are donations – new or pre-loved

Open 10am to 4pm Tue, Thur & Sat

To donate items for sale, or to volunteer to staff shop
kindly phone Peta on 0361 785 7366
or email us at info@senyumbali.org



Smiles all round on opening day of The Smile Shop in Ubud. Staff and volunteers outside the shop. Our shopper-donors came out in force and a good time was had by all!

Thanks to our generous donors who have contributed since the last Update

☞ Eko Designs
☞ Sanford Chee
☞ Prof Astri Wright
☞ Bernard Northmore

AND

Everyone who has donated goods to the Smile Shop and made it such a success!

How You Can Help - Donating or Volunteering - contact Mary Northmore

Ketua Yayasan Senyum, Ubud, Bali 0361 975568 or hp 0811 395 963

Email: info@senyumbali.org

In Bali: dedicated Rupiah bank account: BCA Ubud, A/C No 1350249555 a/n Mary Northmore

US\$ transfer by Paypal – to send:

1. Go to www.paypal.com.
2. Select the 'send money' option.
3. Recipients e-mail: marynorthmore@yahoo.co.uk

Goldenhar Syndrome

This congenital birth defect involves deformities of the face, usually affecting one side of the face only. Underdeveloped jaw and facial muscles cause the affected side to be smaller than the other; the ears are small or misshapen with skin tags or pits to the front of the ear. Problems in the shape of the tongue may occur. There may also be abnormalities of the vertebrae and a narrowing of the eye opening. Cleft lip and palate may be present. Sufferers, such as Ketut Wira, have hearing and speech problems.



The cause of this syndrome is thought to be a vascular accident, cutting off the blood supply and damaging the developing tissue of the fetus. The condition is also referred to as Oculo-Auriculo-Vertebral or OAV Spectrum and if the spine and eyes are not involved, Hemifacial Microsomia. It was named in 1952 when described by Dr Goldenhar.

Visiting Lombok

Yayasan Senyum volunteers Mary Northmore, Sue Frost, Manawar, Ayu and Raditya took time in December to visit Lombok. As well as meetings with Pak Sugiarto of Yayasan Kita Peduli, we were able to catch up with some of the *Lombok 70 Project* patients.

The visit has confirmed our firm belief that it is not enough just to provide money for operations. Poor patients, many living in remote villages, cannot afford to get to the hospital. They need assistance with transport and accommodation as well as help in negotiating the health system.

The *Lombok 70 Project*, which provides this assistance is continuing – the first group for 2007 arrived in Bali on 10 January.



Abdul Aziz lives in this remote fishing village in eastern Lombok. Without help it is difficult, if not impossible, for his family to reach a hospital where the operation can be done.

