

Psoriasis-afflicted community sees ray of hope

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Tiny Putu Malini is home from Denpasar's Sanglah Hospital for the major *Galungan* and *Kuningan* Balinese-Hindu celebrations, which took place in late November.

In cloud-covered Sukawana, a village perched on the upper slopes of Mount Batur, the 6-year-old had more reason than most to pray.

Throughout her short life, she has never experienced a moment without pain. Extreme physical discomfort is her everyday understanding of life, as she suffers from a rare skin disease found in several villages in Bangli regency, central Bali.

It is perhaps merciful that Putu has no comprehension of a pain-free body. Born with an horrific case of psoriasis, Putu is almost crippled by the disease and unable to close her eyes because her eyelids have fused to the skin on her face.

The disease does not shock Sukawana villagers who say it has occurred for generations. Putu's father also suffered the disease.

Until 2006, the only treatment was the application of medicinal leaves found in the surrounding jungles or a mixture of fresh cow dung and vinegar, boiled and applied for two-week stretches.

According to Putu's mother, Luh Sari Manis, the traditional dung-and-vinegar paste worked: her younger daughter, also born with the skin disease, has traces of psoriasis only on her neck. She was treated with the remedy along with honey soon after birth.

But the disease shocked Gede Mangun from nearby Songan when, earlier in the year, he discovered Putu Malini and at least nine other sufferers in the surrounding district.

"A friend of mine from Kintamani, Kadek Arminingsih, and myself were contacted about these people. Friends there know I try and help others when I can, so they contacted me," said Gede. "When I went to the villages and saw them, I was scared, they looked so sad and the disease is horrific. It's like it is eating through the skin and into their bones, killing the skin and exposing raw flesh. I cannot imagine how painful it must be."

According to Gede, several families had taken their psoriasis-stricken members to hospitals for treatment, but the cost of medical treatment and drugs, combined with the doctors' general lack of knowledge about the disease, had forced them to return to traditional healing methods.

"These people are from small farming communities in the mountains. I don't think the government was aware of their situation, so (it) has not helped. They are poor and cannot afford long hospital stays and the regular medication a disease like this requires. After Kadek and I met these people we decided to get them to a hospital for free medical and

drug treatment," said Gede, who went to Wayan Sudirta, a Balinese representative in the central government, for help.

"Wayan Sudirta helped a lot. He knows a lot of people in medicine and medical research, along with the national health minister, and organized a medical team from Jakarta to come to Sanglah Hospital to research the disease in hopes of finding a cure. At the time, no one knew what the disease was or why it occurred," he said.

The study established that the disease was genetic, he continued, due to intermarriages between first and second cousins over several generations in the remote Batur regions.

Due to its genetic imprint, the disease affects either all males born in a family or all females, latching on to the Y or X chromosomes.

"In a single family you might find six boys with the disease, but the girls are disease free. Or all the girls will have the disease and the boys are unscathed. I know of two cases in Klatkat, two in Sukawana and six in Songan and they all follow that male/female pattern," Gede said.

Due to the intervention and assistance of Gede and Kadek, and advanced disease research out of Jakarta, combined with medical treatment at Sanglah Hospital, the Bangli sufferers of this utterly debilitating disease are improving day by day.

A couple of youngsters with the disease have started school, wearing hats and sunglasses -- an essential factor in holding off a recurrence of the disease according to Gede -- while others have had skin grafts to address years of ravages caused by psoriasis.

The youngest villager undergoing medical treatment is just 7 months old, and given the success already achieved thus far, this toddler will not suffer as Putu does, who is still undergoing treatment.

Urgently needed to prevent Putu from going blind is sophisticated plastic surgery to restore her eyelids. Because she cannot close her eyes, they are at risk of sunlight radiation burns. In addition, her tear ducts continually produce moisture, attracting flies and making her vulnerable to the highly infectious trachoma -- the leading cause of preventable blindness around the world, according to Helen Keller International (www.hki.org).

Also needed desperately is a physiotherapist that can teach Putu to walk again. Her feet, due to extreme psoriasis, are so painful that she hobbles from point to point. And at 6 years of age, her feet are deformed due to her compromised mobility.

Putu has recently returned from treatment in Denpasar, this time for the upcoming *Nyepi* Day of Silence, which opens the Balinese New Year on March 19.

Perhaps this year, Putu Malini will get her wish -- to be healthy enough to go to school -- and that she will emerge a healthy and happy child who can finally close her eyes to sleep at night.