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## Cover Art

### Artist's Statement: Champei's Petals

When I met Champei,\* her body looked like it had been scorched with fire; her skin was a landscape of white, pink, and brown patches scattered with hillocks of crusted scabs. Her mother told me that Champei's skin began to blister shortly after birth and had never healed since. Champei's beauty existed beneath her skin, held captive by the harsh marks caused by poverty and disease. She was an infant fighting to survive but failing to thrive. She would have been hospitalized for intensive nutritional therapy in the United States, but she was born in a remote Cambodian village and slept on a dirt floor.

At 11 months, Champei was severely malnourished and was the size of many newborn babies. She weighed 4 kg (7.7 kg = 5th percentile) and had a mid-upper arm circumference of 6 cm (16 cm = 50th percentile at 12 months). Her poor weight gain was likely secondary to her chronic skin disease coupled with poor nutrition due to inadequate resources. Champei's exam findings seemed most consistent with epidermolysis bullosa (EB), a rare, inherited, connective tissue disease of the skin and mucosal membranes causing easy blistering from minor mechanical friction. Since her parents were both without skin problems, I presumed she had the recessive dystrophic form of EB. With this diagnosis, Champei could be at risk for internal problems like an esophageal stricture, as well as invasive squamous cell carcinoma when she got older. Since modalities to visualize her esophagus (e.g., endoscopy) were not available, we counseled her mother and the local health care worker to watch for



Champei's Petals

feeding intolerance or emesis as signs of a stricture.

We obtained a supply of infant formula with iron from Phnom Penh and instructed her mother how to make up 22 kcal/oz formula. As an inexpensive method to help minimize skin infections, we showed the mother how to make a modified "Dakin's" solution at a concentration of 0.025% using clean water and a teaspoon of bleach in our 1.6-liter water bottles. We then trained Champei's mother and the health worker to clean Champei's skin and to make dressings using gauze completely saturated with plain petroleum jelly. We provided her with a stack of clean towels and a small foam mattress for Champei to sleep on. I knew that we could not cure

Champei, but I was hopeful that we could improve her quality of living.

Six months later, I found out that Champei had died. I was distraught over her death and the image of her weak, scarred frame motionless on a foam mattress in a hut with a dirt floor and no clean water. Subsequently, I received some good news that Champei's mother was pregnant again. Four months later, I was notified that she had a baby girl. Tragically, the baby had the same skin lesions as Champei had. And, like Champei, the baby died.

What more can be done to help little children like Champei? Obtaining a skin biopsy and performing immunofluorescent electron microscopy to verify the diagnosis of EB was not an option and would not have saved Champei. So how do we help these innocent children, fragile like rose petals, thrive in low-income countries when the sharp thorns of poverty, malnutrition, unclean water, and inadequate health education surround them? Do we just accept their suffering and death as reality? Or does global awareness mandate global action by you and me?

The painting *Champei's Petals* honors Champei and all the infants who suffer and die globally for lack of reasonable medical care. Only through acknowledging the problems these individuals face can we begin to address these critical questions.

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\* Name has been changed to protect the patient's confidentiality.