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PROJECT  
SHARE

It's time to give back

## No Place Too Far:

# Saving a Life on a Remote Island

Little Toakau Teraira, who has just turned four, can't stray far from his small home on Christmas Island in the Central Pacific without one of his parents ushering him back to relative safety. You might call Toakau's parents overly protective, but you can't blame them. Both of Toakau's brothers died of uncontrollable bleeding, and Toakau is the last remaining son.

Because Toakau has severe hemophilia A, he needs to avoid the crashing surf and watch out for sharp coral sticking out of the atoll sand. Prompt treatment is difficult on a remote island. But although Toakau must be cautious when playing, he is blessed in one respect: his father, Bangao Teraira, is the medical doctor on Christmas Island.

### Faraway Care for Chronic Disorders

The Terairas' home is in one of the most remote places on earth: 1,200 miles south of the Hawaiian Islands and 1,000 miles north of Tahiti.

Christmas Island and its two neighboring islands, Tabaorean and Teraina,

are home to more than 10,000 islanders, isolated from the rest of the world in every sense. Their country is called the Republic of Kiribati (pronounced *Ki-ri-bass*), and consists of 31 atolls strewn across the equator for more than 2,000 miles. The capital of Kiribati is Tarawa, more than 2,000 miles from Christmas Island.

Most islanders live a subsistence life, catching fish and harvesting coconuts. Supply ships don't visit Christmas Island often, but an Air Pacific flight touches down weekly. A monthly air cargo flight from Honolulu brings basic supplies, and a small cargo sailing vessel calls at the island about four times a year.

No factor, or even cryoprecipitate, is available on Christmas Island. Late last year, Toakau's uncontrollable internal bleeding was stopped only by massive infusions of whole blood, administered by his father. But Dr. Teraira knew that life couldn't continue this way for Toakau, who had already lost his two brothers: one to a large hematoma and the other to an intracranial hemorrhage. A male cousin and an uncle also died from uncontrolled bleeding.

There was no educational material about hemophilia anywhere in Kiribati, and no factor concentrate to keep Toakau alive. But thanks to the efforts of dedicated people and several organizations that rallied to help, this story has a happy ending.

### Developing a Network of Aid

Dr. Teraira, a modest and compassionate physician, was initially reluctant to ask for help for his son because—as he told us later—“There are so many in our small country who are suffering and need help,



Toakau with his parents

and I didn't want to ask for myself.” But his wife insisted he reach out to his colleagues, and that's what he did.

First, Dr. George Buchanan, a renowned hemophilia specialist, offered to help Toakau at the University of Texas Southwestern Medical Center; but he recommended that Toakau be taken instead to Kapi'olani Medical Center in Honolulu because it's closer to Christmas Island, and Toakau could be treated by one of Buchanan's former students, Dr. Desiree Medeiros.

So on February 16, Toakau arrived at Kapi'olani Medical Center with an ear bleed. After testing, he was diagnosed with severe hemophilia A and treated with factor. The next day, social worker Chanel Galario began searching for life-saving medicine for Toakau to bring home with him. Toakau had already had several bleeds in his ankle, elbows, and knees, and now his family was looking for a way to treat at home and save on the cost of travel to Honolulu.



Dr. Desiree Medeiros (left), with Toakau and his mom, Taan

“We have not had the experience of being refused ITI treatment. I can’t imagine the addition of that stress on an already stressful situation!”

—K. C., New York

happening in Puerto Rico. Will the rest of the US follow?

Almost all Puerto Rican hemophilia patients are on Medicaid and, unlike in the rest of the US, their Medicaid funds are capped. So physicians in Puerto Rico have a difficult choice to make: do they help one person with inhibitors by initiating ITI, possibly using up their entire budget? Or do they do what’s best for the largest number of people, by supplying everyone with factor and helping the person with inhibitors as much as possible? Of course, these physicians know that eliminating the inhibitor through ITI is best for patients (and for long-term cost savings), but given their funding limitations, do they really have any other option?

“At what point does an insurance company have the right to step in and say, ‘We’re not funding this any longer,’ or ‘You can continue this treatment but we will no longer cover it?’” wonders C. N., who has two sons with inhibitors.

## Help and advocacy

Even if your state or insurance company covers ITI, you may be concerned about cuts in insurance coverage: could this affect the decision to place a patient on ITI? You may also be confused about what will happen as healthcare policies change. Your local hemophilia organization can help inhibitor families like yours sort out insurance and treatment issues. You can keep up-to-date on the latest research on ITI and future possible treatments for inhibitors through meetings or Internet research. You can join others to help lobby to keep all treatment options available for everyone.

“We were never refused ITI,” says Rachel G., “but I know that I would be in a panic and totally overwhelmed. It is stressful enough to deal with hemophilia itself and all that comes with it. I think we as a country need to start looking at what is best for people’s health.” Most families would agree with her. ☺

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## *Project SHARE... from p. 6*

A few days later, after the Terairas had returned home, Project SHARE received a call from Carlton Smith, president of Pacific Islands Medical Aid, Inc., a small humanitarian charity that brings doctors, medicines, medical supplies, communications equipment, and other aid to Kiribati. He works closely with Toakau’s father, he told us, and would be traveling to Christmas Island in a week. Could he act as courier to bring medicine to the family?

So on March 13, the Teraira family received a donation of factor from Project SHARE. And since then, we have been able to donate factor to Toakau twice, with the help of Carlton Smith and the many others who worked together to help a small boy on a remote island. Today, Toakau is doing well. ☺

# in memoriam

## *Carlos Fuentes*

### Latin American author whose son had hemophilia

Influential author Carlos Fuentes died May 15, 2012, at age 83. Born in Panama, Fuentes wrote fiction and nonfiction, plays, short stories, essays, and newspaper and journal articles. He was politically active in the causes of justice and human rights, and also served briefly as Mexico’s ambassador to France. In its recent obituary, the *New York Times* called Fuentes “Mexico’s elegant public intellectual and grand man of letters.”

Like many writers, Fuentes was influenced by personal and family tragedy. His collection of essays, *This I Believe: An A to Z of a Life* (2005), is dedicated to the memory of his son Carlos Fuentes Lemus, born in 1973. Young Carlos, who had hemophilia, was a promising writer, photographer, painter, and director. He died May 5, 1999, from a blood clot in the lung during a transfusion.

—Richard Atwood



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