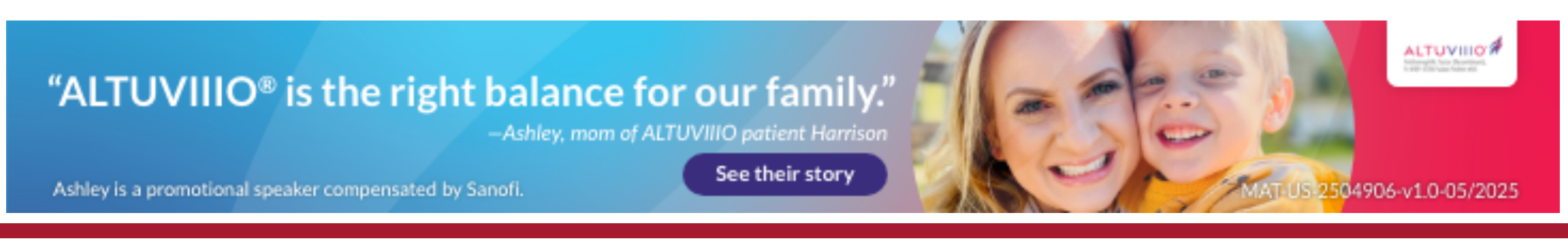

# International Adoption of Children with Bleeding Disorders

## Working together, a committed group of advocates has made it possible for many children to find their forever families

**Author**: Rita Colorito
**Posted:** February 28, 2019
**Updated:** March 1, 2019

Family Matters

*Since 2010, more than 40 international children with bleeding disorders have been adopted by families in the United States. Below, you'll meet three of these families and get to know their inspiring stories.*

In her role as advocacy and outreach coordinator for the Hemophilia Foundation of Michigan (HFM), Shari Luckey helps find forever homes for international orphans with bleeding disorders. The story of how Luckey came to that role—and how she adopted her youngest child with hemophilia, Luke, from China—can best be described as a series of fortunate events.

It started in 2009, when Pamela Thomas, then the China program director for the international adoption agency Across the World Adoptions, was in China checking on a donation of beds to an orphanage in Nanjing. Thomas spotted a lump under one of the covers. It turned out to be an 8-year-old boy who looked over at Thomas, grinned and flashed her a peace sign.

Orphanage caregivers told Thomas that the boy, then named LuFeng, couldn't be placed for adoption. The reason? He had hemophilia, a condition that orphanages in China considered untreatable. Thomas didn't know much about hemophilia at the time, but the image of that smiling boy stuck with her.

## Advocacy in action

The story could've ended there, but serendipity intervened. At the same time Thomas met Luke, she was helping a family in New York adopt a little girl from China. That family had a biological son with hemophilia.

Thomas told the mom of the New York family, Melissa Penn, about Luke. Penn said that Luke could have a bright future with proper care. They both got to work advocating on his behalf. While Thomas urged the orphanage to allow Luke to be adopted, Penn reached out to her network. Penn contacted Laurie Kelley, founder of the bleeding disorders media company LA Kelley Communications and the international bleeding disorders nonprofit group Save One Life.

Kelley turned to her contacts, including Dave and Shari Luckey in Michigan. In 2009, Shari Luckey was a well-known bleeding disorders community advocate. Hemophilia B runs in Luckey's family: She, her brother, her biological son and her twin daughters all have bleeding disorders.

There was an urgency to Kelley's message. In China, children who aren't adopted by the time they turn 14 are ineligible for international adoption. They age out of the system and either must work to care for themselves or are placed in senior homes, according to The Borgen Project, a Seattle-based antipoverty nonprofit. "By that time, those with severe hemophilia, because of complications from lack of treatment, often end up being institutionalized for the rest of their lives," Luckey says.

Moved by Luke's story, Luckey and her family reflected, talked it over and increasingly felt they were being led to adopt him. And so, in 2010, they brought Luke, then 9, home to Michigan.

## The need for forever families

In the US, great strides have been made in the treatment of bleeding disorders. High-dose prophylactic factor replacement therapy is the standard today, and life expectancy for people with hemophilia is roughly the same as the general population's. Around the world, however, about 75% of people with bleeding disorders receive inadequate or no treatment, according to the World Federation of Hemophilia. Without proper treatment, many people with bleeding disorders die before adulthood. In Luke's case, he received treatment only when he had a bleed, spending weeks at a time getting blood transfusions in the hospital adjacent to the orphanage—an antiquated level of care that's unfortunately common throughout the orphanage system.

Luckey recalls the first time Luke, now 18, received a dose of factor after stubbing his toe. "The next morning I was doing laundry, and he came up behind me, tapped me and said, 'Momma.' I turned around, and his eyes were really wide," Luckey says. "He pointed down to his big toe and said, 'All better.' And then he put his thumb up and said, 'Medicine good.'"

## A coalition is born

Once connected, Luckey, Thomas and Penn vowed to do all they could to help children with bleeding disorders living in orphanages. Luckey calls Thomas—who now works for the adoption agency Hand in Hand Adoptions—the "fairy godmother of children with hemophilia" for her tenacity in convincing orphanages to allow families to adopt these children.

"Between the three of us, and as other families adopted children, a growing number of people were advocating. But it was, 'Gosh, here's a child who needs a home,' and we would quickly try to find them a family," Luckey says. In some cases, it was a mad scramble for children about to turn 14.

That informal network went on for several years, until Susan Fenters Lerch, executive director of HFM, hired Luckey in 2015 to establish the Hemophilia Adoption Program (HAP). The program, supported by HFM, serves as a resource for families across the country looking to adopt, or who have adopted, children with hemophilia or other bleeding disorders.

HAP isn't an adoption agency. Rather, Luckey works with international adoption agencies to identify and advocate for children in countries with whom the United States has adoption agreements, known as Hague Adoption Convention partners after the international treaty that establishes safeguards for children, birth parents and adoptive parents in international adoptions.

Since 2010, US families have adopted more than 40 children from abroad who have bleeding disorders. Most have come from China, but children from Bulgaria and Honduras have also been adopted. Luckey is now working to build relationships with agencies that work in India in the hopes of identifying children in need there. The average age of children with hemophilia waiting to be adopted in China is also going down, Luckey says, an indication that the outlook for these kids is changing for the better.

## Learning on the fly

Katrina and Russel Kelly of Indianapolis adopted their son, Gosho, from Bulgaria. Katrina has spinal muscular atrophy, or SMA, a genetic neuromuscular disease that leads to weakness of voluntary muscles. She's wheelchair-bound.

Concerned her condition would prevent them from adopting domestically, the Kellys turned to RainbowKids.com, an adoption advocacy website that maintains an online database of children in the US and abroad awaiting adoption. Many of the children have special needs, including bleeding disorders. As the Kellys searched, once again serendipity intervened.

Gosho's photo on RainbowKids.com said he had hemophilia, and the profile of the then-4-year-old said he also had SMA. "So it hit me, like, 'Wow, this might be meant to be.' Stars were aligning and all of that," Katrina says.

Luckey had been advocating for Gosho's adoption on social media groups and adoption sites for a few years when the Kellys saw his profile. "We reached out to Shari, and that's when she connected us with some of the hemophilia resources that were around us," Katrina says. "We knew nothing about hemophilia and bleeding disorders. Talk about learning on the fly. And we're still learning, but we're getting there."

After a yearlong adoption process, the Kellys brought Gosho home in 2017. He's now 6 and enjoys being a regular kid, Katrina says.

## Help for happy endings

Families who've adopted children with bleeding disorders internationally are evenly split between those who have a family history or experience with bleeding disorders and those who don't, Luckey says. As a result, education about both the adoption process and hemophilia is a big chunk of HAP's focus.

Another focus is helping families overcome the financial hurdles to international adoption, which can be significant.

In November, HAP launched Luke and Jack's Together Forever Adoption Grant, which provides up to a $1,000 grant to US families adopting a child with a bleeding disorder. The grant was made possible by a donation from Robin and Phil Monin of Virginia. In December 2017, the Monins adopted their second child, Luke, from China. Luke has hemophilia.

The Monins were previously involved in the bleeding disorders community. Their biological son, Jack, has hemophilia, and Robin is a carrier. Initially they decided to adopt to protect Robin from the dangers of bleeding during childbirth (she'd had a difficult delivery with Jack). Through their ties to the bleeding disorders community, they learned about the needs of international orphans. Inspired, they began their search for a child to join their family. Luke and Jack, now 3, were born just two months apart. "We thought, 'How cool would that be if they could grow up together?'" Phil says.

The idea for the grant came from the couple's own search for financial aid. "We wanted to start a nonprofit foundation but quickly realized how much work would be involved. That's when we reached out to Shari," Robin says. "We hope that with this grant, we can raise awareness so maybe families looking to adopt will consider adopting a child with hemophilia," Phil says.

For anyone considering adopting a child with hemophilia, "go for it," Katrina Kelly says. "It's very manageable with what's out there, and there are new things on the horizon that are just amazing," she says. "Additionally, seek out allies. Find people you are comfortable talking to who have already been there. There's plenty of them around."

***Learn more about the Hemophilia Foundation of Michigan's Hemophilia Adoption Program and Luke and Jack's Together Forever Adoption Grant.***

---

## The International Adoption Process

International adoption is governed by the laws of the country where a child resides (and by US and state laws), so the process varies. However, general steps to adopt include the following.

### Determining eligibility

Requirements differ by country and may include age, marital status, the number of children in the home and the education level of the parent(s).

### Home study

The home study is a multipage document typically prepared by a social worker. It details the background of the adoptive parent(s), including finances and health, and their home life.

US Citizenship and Immigration Services must approve the home study to proceed with an adoption. To adopt a special needs child, such as a child with a bleeding disorder, the home study must include details on the family's ability to care for the child's special needs.

### Selecting an agency

Parents must work with an accredited or approved adoption service provider that meets standards set forth in the Hague Convention on Protection of Children and Co-operation in Respect of Intercountry Adoption. The Intercountry Adoption Accreditation and Maintenance Entity lists such providers in the US on its website.

### Medical information about the child

The level of detail and accuracy of a child's medical records that parents receive differs by country (and sometimes by orphanage). Parents should share any records they receive with doctors in the US (including a hematologist) so medical experts can provide their interpretation and advice.

### Assessing the cost

There is a wide range, again depending on the country. A survey by *Adoptive Families* magazine covering adoptions completed in 2016–2017 found that the average cost of an international adoption was $44,000. Adoption service providers should disclose in advance a schedule of all expected fees associated with an adoption. Along with Luke and Jack's Together Forever Adoption Grant, other resources available to help offset adoption costs are listed on RainbowKids.com.

### Timing

Generally, international adoptions take one to four years to complete.

- For more details on intercountry adoption: US Department of State
- View a listing of US accredited and approved adoption service providers: iaame.net
- View waiting children and adoption resources: rainbowkids.com

**Audience**
Parents

## Related Stories

What Parents Should Know About Telehealth Appointments
Fun Activities to Do with Your Kids at Home
Nurturing Your Parent Partnership
How to Help Your Child with a Bleeding Disorder Cope with Anxiety and Stress in the Pandemic
Promoting Body Positivity in Teens

Need Information about Bleeding Disorders?

Contact The Neil Frick Resource Center (NFRC)

Contact NFRC