

EXPERIENCE—CHRISTINA ASHFORD, BURBANK, CALIF. FOR THE EYES OF A CHILD

Christina and Matt Ashford save their daughter Emma’s eyesight and establish the Retinoblastoma Institute.

I am a professional sing-er/dancer. I met my husband, Matt, in 1985 at an SGI-USA culture festival in Hawaii; we were married two years later. Our lives were unfolding like a fairy tale. Matt got hired to work on the TV show “Days of Our Lives,” we bought a beautiful home and had our first child, Grace, in 1992. Unfortunately, like most fairy tales, sooner or later, great loss and frightening challenges appear to test the mettle, faith and conviction of the “good guys.”

Ours began with two devastating miscarriages. My heart became gripped with fear that I’d made some terrible cause to deserve this. But I kept that to myself, and we tried again. This time I miscarried one of the twins I was carrying. The other I was able to hold on to life and on July 23, 1997, we had a healthy baby girl. We chose the name Emma Cecily, which means “absolute faith illuminated” or “of the eyes.”

At Emma’s four-month well baby checkup, I expressed concern that one of her eyes was turning in. The doctor referred us to a pediatric ophthalmologist. My visiting sister, a nurse, was going to come with me to the appointment.

The ophthalmologist told us that Emma had malignant tumors in one and possibly both eyes, a condition called retinoblastoma. Most children worldwide die from this disease because at the point it’s symptoms are noticed, the fatal cancer has already spread to their brain. The first step in treatment is eye removal, followed with chemotherapy and radiation.

I couldn’t move or speak. I just sat there, paralyzed with silent tears.

My sister called Matt. By the time we got home, Matt was chanting Nam-myoho-renge-kyo in between contacting our SGI-USA leaders and friends in faith to ask for their prayers.

Our oldest daughter, Grace, who was 5, made a sign for the altar, which read: “Emma’s left and right eye will totally heal (with a smiley face).”

Emotionally, I was in a dark place. I spoke with a senior in faith that night. With her encouragement, a deep resolve rose in my life: I would not accept this. I would not let my daughter die! I put that spirit into my prayer.

At the follow-up exam, the doctors discovered Emma had six tumors in each eye. They would attempt shrinking them with chemotherapy and simultaneous laser treatment. All I could think was, “She’s just 4 months old!” In my prayers for her life, I tried to infuse her body with Nam-myoho-renge-kyo and send her my strength, health and love.

Many members encouraged us with their individual faith experiences of making the impossible possible. We recognized it was our turn. And the outcome would be entirely up to my and Matt’s Buddhist practice.

Daily, Matt and I took Emma in for brain scans, tests and other treatments. While we waited, we saw bald, terrified, screaming children in pain being restrained to get medication, accompanied by parents sitting silently in their own pain and hopeless resignation. This was a world that we never knew existed. Living in it was our foreseeable

future. Nichiren Daishonin, the founder of this Buddhism, wrote that Hell exists in our own bodies in this life. Seeing this place, I now knew what he meant.

Consumed with hospital appointments and specialists, days could go by that we wouldn't see our precious oldest daughter, Grace. But she seldom complained.

We were isolated by illness. Because Emma's immune system was weakened, we were confined to the hospital, so we found it hard to participate in faith activities. Most of our chanting took place in hospital rooms and into Emma's ears as they took her from us for another test or surgery.

The head of pediatric surgery performed Emma's first operation. Then a doctor who was one of eight ocular oncologists in the world trained in state-of-the-art procedures for this disease performed her next surgery. The doctor's expertise, combined with the early diagnosis, made them hopeful Emma's eyes could be saved—but there was still a long road ahead.

SGI-USA members began arranging to visit us and chant in our home. I began to study this Buddhism more deeply, including the writings of SGI President Ikeda. I developed a new perspective about his life. I read once again about the health, poverty and societal struggles he had overcome. But this time, because I was seeking from a deeper level, my life responded differently. I began to feel a deeper bond with him. Not starry-eyed hero worship, but as my living example of a true human being of incredible conviction, compassion and strength that has consistently applied this practice to achieving victory.

Not long after, we received a message from President Ikeda: "I am chanting every day for the health of your daughter." I was deeply touched by his consideration. I realized that each SGI member is precious to him. I felt he understood the fears and struggles we all go through and is trying to give us all courage.

My oldest daughter, fighting so hard to be strong for us, was having nightmares. As for me, I wish I could say that I was this strong iron maiden—filled with the determination of faith that my family would definitely win and Emma would be fine. The truth is, every day was a battle between having faith and feeling overwhelmed by fear and doubt. Some nights, screaming, I would wake up in cold-sweat panic attacks. Matt and I had to chant deeply not to allow our fears, or differences in handling crisis, let us lose each other.

After completing chemotherapy, 11 of the 12 tumors were flat scars. The 12th had shrunk by 50 percent. The doctor felt it was in a regressive state. She warned if it grew again, her eye would have to be removed. That's why she wanted us to consider one more cycle of a different chemotherapy. The possible side effects were hearing loss, sterility and leukemia with no guarantee that it would save either of her eyes. She asked us to choose between those possibilities and the possibility of blindness. Based on prayer, we decided to try one last chemotherapy cycle.

Emma had stopped eating. She only nursed. With no immune system left, Emma contracted a virus and even stopped nursing. She became completely lethargic; we thought she was dying. I contacted my fellow SGI members to chant for us. Matt and I raced to the hospital with Emma. Holding her on my shoulder, chanting in her ear, I was locked in the biggest battle yet between my faith and doubt.

Then, in an instant, my hope overcame my fears. I knew, unconditionally, Emma was coming home. Within three hours, her condition reversed and she started to nurse again.

It has been 32 months since the last cycle of chemo. The tumor continues to diminish. In total, Emma has had more than 30 surgeries. She's had two clean MRI's and is the only child at the hospital with both of her eyes. Most important, she has just turned 3. At age

3, the retina stops developing 99 percent of the time, and so does the possibility of this cancer. She still could contract other forms of cancer, but there's a strong possibility that she will go on to have a normal life. Our doctors call Emma their "poster baby."

The veracity of this disease compelled Matt and I to take some action so we formed Retinoblastoma International. In the past two years, RBI has produced three black tie dinners, two golf tournaments and three theatrical benefits raising more than \$500,000. Along with this, a generous donor from Children's Hospital has just contributed another \$500,000 specifically earmarked for genetic research. We've started the first Website on this disease, www.eyecareforkids.com, that is reaching out to families in six different languages.

Recently, with the help of local Assemblyman Martin Gallegos, our non-profit organization sponsored state legislation that insures mandatory pupil dilation for infants at the eight-week well baby visit. Because of this, retinoblastoma, infant cataracts and many other ocular diseases leading to blindness will be diagnosed much sooner—hopefully saving vision and lives. This inexpensive procedure, costing \$.02 per child, will also save the State of California millions of dollars. I am pleased to share with you this bill was recently signed into law by Governor Gray Davis.

I first confronted this challenge thinking I was receiving punishment and there was something deeply wrong with me that created this suffering. I now realize how significant this experience was to fulfilling my purpose in life. I now embrace every moment of my struggle as a graduation ceremony in faith.

When I began practicing Buddhism, I frequently heard that each person has a mission that only he or she can fulfill. At that time, I was convinced my mission was singing and dancing to give people joy. Now I understand fulfilling your mission may not be that obvious, but it will naturally unfold in the course of life. On behalf of my family, I want to thank the everyday, yet extraordinary people who make up this beautiful SGI organization for all their support.