Mended Little Hearts

From Alaska to California: Searching for a Heart

by Jon Caswell

Hypoplastic Left Heart Syndrome (HLHS) — when you hear the name, right away you know that it's not a "take two aspirin and call me in the morning" situation. For Shawn Stockwell, age 9, and his family, treating this condition has been the focus of their lives since he was diagnosed at three days old. The only solutions to HLHS are surgery or transplantation.

"When we were first told of Shawn's condition," says Trista Stockwell, Shawn's mother, "our hearts were shattered. I was walking down the hall in a nightmare-like state. My legs felt as if they weighed a ton as we left the hospital to go home, pack a bag and fly to Portland, Oregon. Just a day before we were oohing and aahing over our only son, knowing that he'd follow in Daddy's footsteps and become a goalie and play football, and now I wasn't sure I'd ever hold my boy again. How would I survive the death of my son?"

The Stockwell family lives in Anchorage, Alaska, and because there is no pediatric cardiac surgery available in Alaska, they had to fly to Portland. Shawn was in a coma, the result of renal failure and pulmonary stenosis (failure of blood to flow to the lungs). "On top of that, in Oregon we were told his tricuspid valve had torn," recalls Trista. "We were also told he wasn't a candidate for surgery, so we were given the option of letting him pass there or at home in Alaska."

Open-heart Surgery

The Stockwells opted to return to Alaska but had to wait several days for flight arrangements. While they waited, Trista and husband and father George planned Shawn's funeral. But during the wait, Shawn's prognosis improved, and the doctors were willing to proceed with the first of three surgeries required to correct HLHS. After that surgery, called the 'Norwood' after the surgeon who developed it, Shawn struggled and required another surgery. A month later, the Stockwells left the hospital with their son for the first

Shawn's World

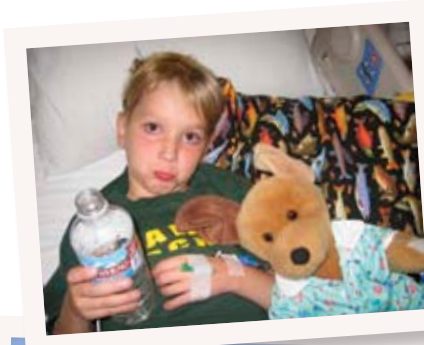
Counter-clockwise: Shawn with dad George and sister Haley; with mom Trista; clowning with Haley; with "Papa"; with sister Amanda at the Rainforest Cafe; with sisters Samantha and Haley at the RMH Prom; with Samantha at the beach; feeling blue in the hospital; making a new friend at RMH

time. "To the rest of the world, we were just a mom and dad with a tiny, somewhat blue baby boy, but to us, it was a euphoric, joyful, victorious afternoon — we were taking our son home!" says Trista.

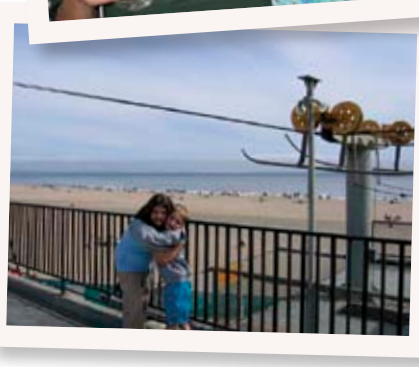
Five months later, Shawn and Trista returned to Portland for the second surgery, called a 'Glenn.' "Shawn did beautifully," says his mother. "He was off the ventilator within three hours and out of the PICU after only three days."

The next three years were fairly normal for the Stockwells. Older sisters Amanda and Samantha grew up caring for their little brother. "With Shawn's heart defect came a gift, a new awareness that life is fragile," says Trista. "Planning his birthdays is always extra sweet because it seems like it was just yesterday that we were planning his funeral."

Of course, when you have a child with a heart defect, "normal" is a relative term. There was the third surgery for the HLHS, called a 'Fontan.' There were other surgeries too, and countless doctor visits and constant fear of infection. After a story on Shawn ran in the Anchorage newspaper before the Alaska Heart Walk, Trista was contacted by Wayne and Joyce Simmons, co-presidents of the Anchorage chapter of Mended Hearts. "Wayne and Joyce had volunteered at the Heart Walk and were astonished at the number of children with heart defects," recalls Trista. "They asked if I would be part of a Mended *Little* Hearts group. I was so excited and immediately fell in love with the group, Alaska Bravehearts, and all it stands for." Soon she became the group's coordinator.



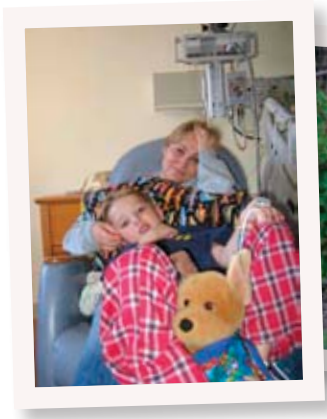
She only held that post for seven months, because it was decided that Shawn needed a heart transplant. She passed the baton to Sheila Sparks, whose own teenage son, Tye Pereira, also had HLHS and had had the three surgeries but had survived without a transplant. On April 14, 2006, Shawn was placed on the transplant list, and Trista and Shawn left home with Haley, the newest Stockwell, for the journey to Stanford University Medical Center to wait for a heart.

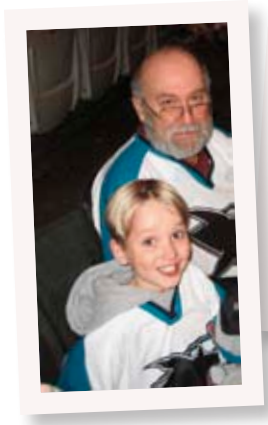


Get Pictures!

"We had only nine days to prepare for that trip, and they went by so quickly," recalls Trista. "There really wasn't time to prepare for what we would be facing. We just knew we would have to take it one day at a time and plan as we went. We just had blind faith that somehow everything would work out — it just had to!" Fifteen months later, they are still waiting, and hoping, and trusting that things will work out.

"What little advice I have for someone in this situation is to have a family portrait done before you begin the wait," says Trista. "A friend who is a photographer insisted on taking our picture, but we were too busy getting ready to leave and never got around to it. I regret that terribly now. Take the time to have a family portrait done — with your pets! To have that picture in your home-away-from-home and the hospital room brings a lot of comfort. It has been 15 months, and I can count on one hand how many days our entire family has been together." *(continued)*





What Is HLHS?

In Hypoplastic Left Heart Syndrome, the left side of the heart — including the aorta, aortic valve, left ventricle and mitral valve — is under-developed. Blood returning from the lungs must flow through an opening in the wall between the atria. The right ventricle pumps the blood into the pulmonary artery and blood reaches the aorta through an opening called a patent ductus arteriosus, which typically begins closing a few days after birth. Without a series of surgeries to rework the heart, this condition is always fatal. A heart transplant is the only permanent fix.

In Palo Alto, Calif., they moved into the Maya Immune Wing of the Ronald McDonald House (RMH), where they have a small suite with one bedroom, a small living area, a bathroom and a kitchenette — "with emphasis on the 'ette,'" says Trista. "Unlike the other parts of the house, we can have food in our rooms. It's small, but we're grateful for it."

The Good News That Wasn't

On December 6, 2006 — seven months after Shawn had been put on the transplant list — the news the Stockwells had been waiting for came at 1:30 a.m. There was heart for Shawn!

"Every emotion I had anticipated I would have I had, just amplified a hundred times," Trista remembers. "What I didn't anticipate was putting my head down and crying for the mother of the donor child. There was a family out there who had been through the trauma of losing their child, and yet they were willing to give other children a second chance at life."

That chance was snatched away when the final test revealed a defective valve. The transplant was called off when Shawn was already in the operating room.

Only about one percent of the 2.2 million deaths that occur in the United States every year qualify for organ donation. Shawn's circumstances are further complicated by the required age of the donor child — between 8–12 years of age.

So, for going on 16 months Shawn, Trista and Haley have lived at the Ronald McDonald House, unable to return to Alaska even for a visit. During the 2006–07 school year, Amanda, the Stockwell's oldest child, lived with them and attended high school in Palo Alto. She returned to Alaska at the end of the school year.

Asked what he misses most, Shawn is quick to answer: "My house, my dogs, my four-wheeler, my snowmobile, my family, my bed, my room, our kitchen, the BIG house, running down the stairs and having my own bathroom."

A Day in the Life

Everyday life in California is absorbed by Shawn's medical needs, which have become increasingly complicated as his condition has deteriorated. After she gets Amanda to school at 7:50, Trista begins preparing Shawn to go to a special school at the Lucile Packard Children's Hospital at Stanford, which starts at 9:30. "Attending public school is out of the question for him because he is physically unable to attend classes all day," says Trista, "and also because the transplant team wants to limit his exposure to colds, flu, chickenpox, things like that."

Before breakfast there are meds to take and blood pressure measurements. Trista and Haley, age 4, pick him up at the hospital at 11:30. Depending on how he's feeling, he may return for afternoon classes till 3 p.m., when Amanda gets out. Then it's back to the RMH to do laundry, fix dinner, and do housework and homework. There's a playroom where the kids can play from 4 to 8 p.m. "At 8, there's more medications, blood pressure and basic assessments. Before bed, we get Shawn's oxygen on him. On many days there are doctor's appointments, including a visit to the cardiologist once a week. Because he has protein-losing enteropathy, after the Fontan, he has to have labs done twice week. He is also required to see the transplant team psychologist every two weeks, though he's pretty tired of talking about his feelings.

"During the summer the kids swim at a neighborhood pool, something we just can't do in Alaska," continues Trista. "We love the beach and go as often as possible. But we stay close to home because Shawn gets tired so easily."

Sad News

This past March, Shawn's role model, Tye Pereira, who had shown him that having a heart defect is no excuse for not living a full life, suddenly went into cardiac arrest and died. Sheila Sparks took some of Tye's ashes to California, and Shawn put them at Pigeon Point Lighthouse.

Back in Anchorage, Alaska Bravehearts have had several fundraisers to help the Stockwells cope with the financial burden, which is substantial and which grew even bigger this spring when Trista had back surgery. As husband George says, "We now have two households and one income." George, age 36, is a foreman for a roofing contractor.

The wait and uncertainty take the heaviest toll. "You have to deal with an absurd amount of stress," says Trista. "The worst is the anticipation of this huge surgery. You worry and cry, and worry some more, and prepare the best you can. You think of little besides this surgery and wish you could take your child's place. Every single day you live with worry, fear and anxiety with no clue when it will end. That has been the hardest part — the anxiety, the wait."

KEEPING TRACK OF SHAWN

Trista Stockwell maintains a blog (Web log) on Shawn's condition at *www.thestatus.com*. At the home page, click on "Visit a Patient," then type "Stockwell" into the search window. The password is "plum-vanilla."