

## With healing arts, a mended heart

**A surgical procedure, rare in the U.S., has Bethlehem girl back in pink of health.**



Arden Ashford, 12, (center) with parents Sarina and Rob, in the music room of the family's home in Bethlehem. Arden was born with a rare heart defect, known as Ebstein's Anomaly. Last year, she underwent a new procedure to correct it. Her father started the Ebstein's Anomaly Foundation to raise money for research into the defect and other heart ailments. (Harry Fisher/The Morning Call / July 2, 2008)

**By Steve Esack, Of The Morning Call**



Arden Ashford, feeling oddly fresh from a warm-up jog around the tennis courts, gripped her racket in both hands and waited.

Instructor Eric Pecuch lobbed the ball over the net toward Arden's backhand. She took the racket back with both hands...Pop! The ball sailed sideways and bounced over the 12-foot high fence.

"Here's another, Arden," Pecuch called before hitting another ball.

This time the 12-year-old hit it back over the net to him. Then she jogged a few yards to get back in line with the other players as her proud father watched the 60-minute clinic at Saucon Valley Country Club.

"It makes me feel good to see her out there," Robert Ashford said as he stood under a shade tree, "but to be honest...I'm still super-worried."

A year ago, Arden -- born with the rare heart defect known as Ebstein's anomaly -- could not have played tennis without getting angry and winded. She couldn't even walk up the steps of her parents' Bethlehem home without losing her breath. And she couldn't walk to class at Moravian Academy

without feeling sad at always being last.

"It was very frustrating," Arden said.

Now she's an active child again, thanks to a relatively new heart procedure her parents learned was being done by doctors in Boston. On May, 29, 2007, when Arden underwent a so-called "cone procedure" to repair the deformed valve between the heart chambers that pump blood to her lungs, she became just the sixth person in the country to have the surgery.

"I'm happy," Arden said after tennis practice. "I ran two laps and I felt perfectly fine."

Like all parents who confront a serious medical condition with a child, Arden's mother and father devoted themselves to finding a treatment for her, and they have used the same entrepreneurial spirit and technological acumen the family used to forge its wealth.

Now they want to commemorate their daughter's new life and make sure other families have the same opportunities she did.

Robert and Sarina Ashford have started a nonprofit organization, Ebstein's Anomaly Foundation, in conjunction with the national Children's Heart Foundation, to raise money for research into congenital heart defects.

The fledgling organization, which features Arden as a young spokeswoman, will hold its first fundraiser, a dinner and car show, Thursday night.

"It's a chance for us to help other kids, but also a chance for Arden to help, as well," Robert Ashford said. "People don't realize it, but the No. 1 birth defect is of the heart...and we want to raise money for that."

### **Something wasn't right**

Arden was born Jan. 8, 1996, at St. Luke's Hospital-Fountain Hill in the middle of a blizzard. But something wasn't right; she wasn't turning pink. Hospital staff rushed the newborn from her mother's arms to the neonatal intensive care unit and then told her parents that their baby needed to be flown 87 miles to Penn State Milton S. Hershey Medical Center.

"I felt completely helpless," said Sarina Ashford. "I was just overwhelmed by all the emotions of being a new mom and then I was thrown into this bizarre situation."

The next day Robert Ashford and his wife drove along Interstate 78, a seemingly endless canyon of white snow, to Hershey to be with their first-born child, not knowing whether she would survive. When they arrived, Louis W. Hansrote, a pediatric cardiologist with the Children's Heart Center of Northeastern PA, diagnosed the baby with Ebstein's anomaly.

The heart is so complex that heart defects are frequent in babies. Congenital heart disease is the most common form of birth defect, affecting about one out of every 100 babies, according to the the Web site of the Mayo Clinic in Minnesota. Ebstein's anomaly is caused by a deformed tricuspid valve, which connects the heart's right atrium to its right ventricle. It is one of the rarest defects, affecting one in 10,000 babies, according to MayoClinic.com.

In Ebstein's anomaly, the tricuspid valve grows lower than normal, causing blood to leak back through the valve and into the right atrium. As a result, breathing can be affected because blood flow to the lungs can be reduced and the right side of the heart can grow larger than the left.

Ebstein's anomaly varies and can stabilize or get worse with age, according to Hansrote.

Arden was in the hospital in Hershey for 10 days and then she came home. "But we always knew she would need open-heart surgery," Robert Ashford said.

The Ashfords immersed themselves in the known science and medicine of the problem. Although she was born with a heart defect, Arden and her parents were lucky in an sense. Arden was growing up at the same time the Internet was becoming commonplace. The technology became a powerful tool in the family's quest to help their daughter.

"Before the Internet, it wasn't as easy to get the information," Sarina Ashford said. "But then with the Internet...you find out you're not the only one out there."

Most times, however, Sarina Ashford, was left alone to raise Arden and her siblings, Elise, now 10, and Wade, now 8. Robert Ashford, a Penn State-educated economist-turned-entrepreneur, was almost never home.

"I traveled for 200 days a year," he said.

In the 1980s, he and his father George, a retired dentist, started a chemical company, Osmegen, after George Ashford invented an odorless deodorizer they called Nature's Magic. In 1997, Robert Ashford bought out his father's shares, the company invented a new product and the company took off.

In November 2004, Ashford sold Osmegen, giving him the wherewithal to catch up on lost time with his family, research Ebstein's anomaly and organize his daughter's medical history and X-rays on computer files.

## **Complications**

The Ashford's didn't know it, but his organizational skills soon would come in handy. In December 2006, one month before Arden's 11th birthday, the Ashford's noticed their daughter was laboring to walk up steps and could not keep up with Elise and Wade. Then one day she nearly blacked out from what they learned was an arrhythmia, caused by a disruption of the heart's electrical impulses.

The Ashford's took their daughter to see Hansrote, who said Arden's growth rate was causing the right side of Arden's heart to grow too large. He recommended an operation and gave the Ashford's a list of hospitals the family should consider.

The Ashford's then either drove or rented planes so Robert Ashford could tell their daughter's medical story, using multimedia presentations, to doctors.

"I kind of looked at the doctor's visits as I did my business," Robert Ashford said. "I tried to make it as simple as possible, like I wanted them to buy my product."

Every doctor recommended the same thing: Arden needed to have her damaged valve replaced with a pig's valve, the decades-long standard procedure to correct the worst cases of Ebstein's anomaly, even though the pig valve wears out in about a decade and needs to be replaced.

But then, a doctor at Children's Hospital in Boston said Arden did not need a pig's valve. The doctor, Pedro del Nido, said he had learned a new technique from a Brazilian doctor, Jose Pedro da Silva, who had pioneered a new way to treat Ebstein's anomaly. In da Silva's "cone procedure," the extra tissues on the overgrown right side of the heart are folded up and the defective valve is then reshaped into a cone.

"We anguished," Robert Ashford said. "We didn't know what to do."

So on May 5, 2007, he e-mailed one of the Mayo clinic doctors, Joseph Dearani, who had recommended the pig replacement, to ask his opinion. Coincidentally, when Ashford sent the e-mail, Dearani was sitting next to del Nido at a medical conference in Washington, D.C.

"Ironically, I received your e-mail last night...and [after] having a long discussion with Pedro del Nido...I think your daughter should have the surgery in Boston," Dearani wrote in an e-mail to Ashford.

Robert Ashford cried as he printed out the e-mail to show his wife. She cried, too. The parents then sat down with their three children to talk.

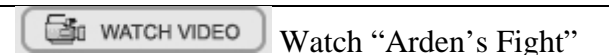
To ease her older sister's fears, Elise, then 9, volunteered to sleep in the Boston hospital room with Arden. Arden asked for a laptop computer to keep up with her friends and to post a picture narrative of her hospital stay.

"She was the bravest little girl," Robert Ashford said.

The long-term effects of the cone procedure are unknown because it is so new. But Dearani, the Mayo Clinic doctor, said that after meeting the Ashfords he traveled to Brazil in June 2007 to learn the cone procedure, and he thinks it will offer more lasting benefits than the pig-valve procedure.

"I have performed it now in many patients since last summer and have been happy thus far," Dearani wrote in a recent e-mail to the Ashford's. "I really believe in this repair."

So do the Ashford's. Without it, they wouldn't have started Ebstein's Anomaly Foundation to help others.



[www.mcall.com/news/local/all-4arden-061808,0,7838854.story](http://www.mcall.com/news/local/all-4arden-061808,0,7838854.story)

**ONLINE:** [ebsteinsanomaly.org](http://ebsteinsanomaly.org)

[steve.esack@mcall.com](mailto:steve.esack@mcall.com) 610-861-3619 Copyright © 2008, [The Morning Call](http://TheMorningCall.com)