

Extending Her Family

by Jon Caswell



When she was in first grade, Jana Stewart was diagnosed with two life-threatening heart defects. Nearly five decades later, her accomplishments as mother, grandmother and MHI volunteer continue to inspire.

“I am a grandmother, and that thrills me to no end,” said Jana Stewart, age 53, of Evansville, Indiana and Central RD. Many grandmothers would make the same claim, but for Jana, it’s doubly sweet because it was not supposed to work out that way. When she was in first grade, she was diagnosed with an aortic coarctation, a narrowing of the aorta between its first two branches, as well as an atrial septal defect and pulmonary stenosis. In 1962, when Jana was 8, fixing those problems required serious surgery. In her case, that meant 9½ hours’ worth, in a New York hospital a long way from her Miami home. Her parents weren’t allowed to see her after the surgery; they had to wait till the next morning. “Sometime later a nurse told me that because I’d had heart issues as a child, I’d never have children of my own,” remembered Jana.

In 1974, she married her husband Rick. “My cardiologist insisted that I have a cardiac catheterization to make sure the repair was still in good shape before he would give me the go-ahead to get pregnant. It showed that everything was fine.” She gave birth to son Neal in 1978 and daughter Amanda in 1982. In 2006, Neal and his wife Angie had twin daughters, Alivea and Kaytlin.

In 1985, Jana contacted a brother-in-law who worked at Deaconess Hospital in Evansville and asked if the hospital had a support group for parents of children with congenital heart defects. “My thinking was that I could relate to parents whose children were going through surgery and recovery. I was 31 with two small children of my own, and I wanted to comfort those parents that things can turn out all right,” Jana said. “Deaconess didn’t have a support group like that, but I was referred to Mended Hearts. I joined Chapter 107 that year, and the rest, as they say, is history.”

And what a history it’s been! Jana’s been her chapter’s program director, vice president and president twice — she’s just finishing her second term. “I’ve written our chapter newsletter for 18 years, been an ARD for six and I’m now serving my second term as Central RD,” she said.

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“I’ve been an accredited visitor since 1986, but I don’t visit the hospital anymore because my surgery and recovery were so different. There have been so many changes since 1962, it’s hard for patients to relate to me.”

She does Internet visiting and follow-up phone calls. “My one wish is one day to get a Mended *Little* Hearts group started here in Evansville. That way I could visit with parents and relate to them more on the same level.”

From the start, MHI has been about the connection to an extended family. “My life is richer because of the people I’ve met in MHI at home and across the country,” she said. “There’s a group of ladies that I email almost every day. We’ve formed such a close bond that I don’t know what I would do without them. It’s a support group within a support group. We met at the Boston Convention in 2002 and have been very good friends ever since.”

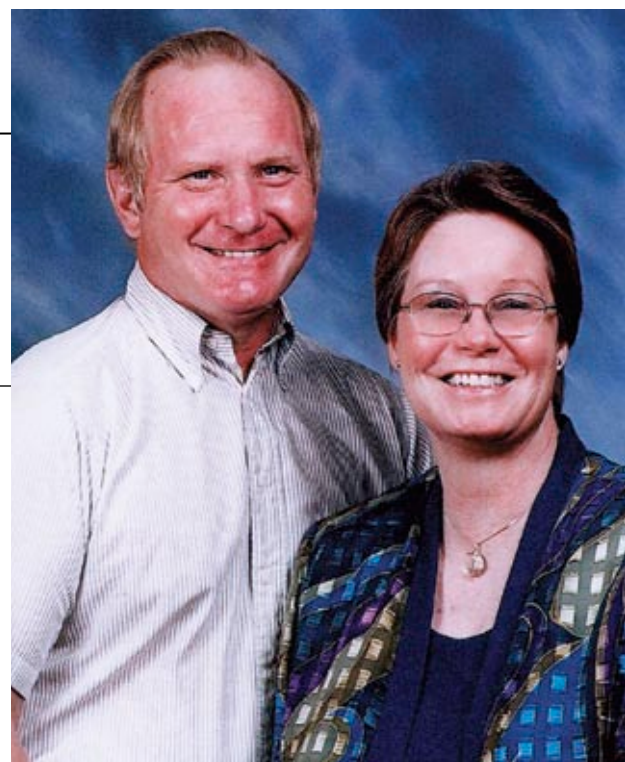
There are other rewards: “About a year ago I had a call from a lady whose husband was facing a very serious heart surgery in another state. The husband was in his 40s. He had about a 50-50 chance of survival. I spoke to her several times on the phone. Just before they left for Louisville, Kentucky, I went to where she worked and brought her a Huggy Pillow for her husband to use during his return trip. We had never met face-to-face, but I wanted her to know that I truly believed that he would be coming home. Her face went from terrified to hopeful in a matter of seconds. And he did come home.”

As any volunteer who’s ever had to manage others knows, there are plenty of lessons to be learned. “I’ve learned that I can’t do it all by myself, that I have to delegate. I’ve also learned to be open-minded and to listen to what people have to say before I form an opinion.”

Although Jana works full time, she spends plenty of time with the twins, who were born 10 weeks early. Their mother has had health challenges, and Jana has stepped in, along with Carolyn Baugh, the other grandmother, to help with the babies’ care.

“The girls bring me so much joy,” she said. “It’s difficult to explain, but their being here is all the more special to me since without surgery I wouldn’t have lived to see my 13th birthday. I am now 53 years old; Rick and I have been married for 33 years. My children are 28 and 25. Life couldn’t get much better than this.

“I really liked President Elbert’s theme for the 2006 Convention when she talked about being like a turtle, that in order to get anywhere, we have to stick our necks out. Being in MHI has taught me to step outside my box. In all levels of MHI we see possibilities in others around us. What we need to learn is to dream of the possibilities within ourselves. And then be a turtle and stick your neck out!” 🐢



Top to bottom: Rick and Jana Stewart today; the Stewart family in 1989, with daughter Amanda and son Neal; twin granddaughters Alivea (l) and Kaytlin (r)