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## Donor Spotlight

### To make a difference

by Marc Whitney

Chip Nickolett did not set out to become an advocate for children's health. His daughter, Heather, turned him into one. Heather's health challenges introduced Nickolett to a world completely foreign to him, but one he is fully committed to today. One need look no further than the Nickolett Family Fund for Childhood Rheumatic Diseases at Children's Hospital of Wisconsin.

From the start of her life in 1999, Heather's health was a cause of great concern. She was diagnosed with a coarctation (narrowing) of the aorta at 5 weeks old and needed heart surgery.

"We met with Dr. Bert Litwin, who told us that some doctors only see a handful of similar cases in a career, but he sees a dozen each year at Children's Hospital," Nickolett said. Litwin is a cardiothoracic surgeon at Children's Hospital. "I was very impressed with him and the entire staff."

Heather had successful surgery and was back home four days later.

In just two months she was pain-free and problem-free. Nickolett and his wife, Jackie, figured the worst was behind them.

"I never had any health problems while growing up so I had no contact with Children's Hospital," Nickolett added. "But that first exposure was so positive that I wanted to do something."

The following year, the success of Nickolett's consulting company gave him the opportunity to do something substantive through a gift to the Children's Hospital and Health System Foundation. His focus, at first, was on cardiology.

But within a week of his decision to do this, Heather had developed new medical issues and was back at the hospital. She soon was diagnosed with Juvenile Rheumatoid Arthritis (JRA).

"Heather was at Children's Hospital for nearly a month when she was 15 months old. It was tough because she was so helpless," Nickolett said. "I never knew children could get arthritis."

Like any concerned parent, Nickolett was full of questions about his daughter's care.

"At night I would research and learn as much as I could and the next morning come



**The Nickolett Family -- Heather, Chip, Paige, Jackie and Jacob -- became avid supporters of Children's Hospital as a result of Heather's medical issues.**

in and ask the doctors questions. That interaction was key to me, and the staff was so receptive to it. There are so many wonderful people on the staff at Children's Hospital. We even named our second daughter after one of the nurses. We are so glad to have such a hospital nearby."

The focus of Nickolett's charitable efforts turned toward JRA. As Heather fought through the challenges of the disease for the first year and a half, Nickolett's business continued to grow. He now was in a position to make a positive financial impact on the hospital's rheumatology program.

"There are 30,000 children in the United States with JRA," Nickolett said. "I wanted to work as an advocate for them to generate awareness and raise funds. We can help Heather, but we also can easily help so many others."

Arthritis is just one of more than 100 rheumatic diseases. Besides the well-known pain, stiffness and swelling of joints, rheumatic diseases can affect other areas of the body, including internal organs.

The Nickolett Family Fund is helping staff at Children's Hospital in their fight to combat the effects of JRA. For Nickolett, the endowed fund is about more than giving money.

"It has been helpful in training doctors and nurses, but it also has helped to create a research profile on arthritis. At the early onset of the disease they are taking steps to control and fight it," he commented.

"I watch the work of Dr. Bob Kliegman and Dr. Cal Williams and what they are doing at the Children's Research Institute. Direct funding can help in finding a cure for JRA."

Kliegman is executive vice president of Children's Research Institute, pediatrician-in-chief and Muma Family Chair in Pediatrics at Children's Hospital, and chair of the Department of Pediatrics at the Medical College of Wisconsin.

Williams is a rheumatologist and D.B. and Marjorie Reinhart Chair in Rheumatology at Children's Hospital, and an associate professor at the Medical College of Wisconsin.

Heather still comes to Children's Hospital on a regular basis. She visits the clinic for her arthritis every two to three months and has an annual electrocardiogram on her heart. And once again, a father is able to look to his daughter's future in the long term.

"When Heather looks back in 20 years, I want her to know that we tried to make a difference."

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