



# ***ONE FAMILY'S***

# ***PUSH FOR A CURE***



Chip Nickolett's daughter, Heather, was diagnosed with juvenile rheumatoid arthritis (JRA, now referred to as juvenile idiopathic arthritis (JIA) to highlight that its cause is unknown) in October 1999. At the time, Chip never would have realized that children get arthritis, but once he learned about the potential effects of this disease he realized how terrible it could be. Chip soon realized just how much work was needed in order to gain and share knowledge on the disease, and to improve the quality of life for children with arthritis. Little did he know at the time how much of a focus this would become in his life.

Chip recalled Heather's diagnosis, calling it a process of exclusion that involved more than a week of tests and even some minor surgery. Chip and his wife, Jackie, spent days at the hospital with Heather. Chip spent the nights in the hospital trying to learn as much as he could about JRA, finding some information in books and on the Internet and getting some assistance from one of the nurses caring for Heather. It was then he decided that he had to do something to raise awareness of juvenile arthritis (JA) and work towards finding a cure.

This was an especially difficult time for Chip because earlier that year he had started an information technology consulting company (Comprehensive Solutions) and was in the middle of a large project. He was lucky that one of his first hires, and now a co-owner, was willing and able to run the business for almost a month. As the business grew and prospered, he used it to support his interests in JA.

Chip and Jackie created funds and later sponsored research efforts at both the Children's Hospital of Philadelphia (CHOP) and the Children's Hospital of Wisconsin. The funds focus on issues relating to JA. Chip became a member of the President's Council at the Children's Hospital of Wisconsin where he advocates

research and education for JA. Chip has also provided funding for Arthritis Foundation programs and research projects.

When asked about research, Chip replied, "I wanted to make an immediate impact. Pilot projects seemed like a great way to get involved, to generate data to support or refine a scientific hypothesis, and leverage those findings to gain increased support, funding and awareness." Chip commented, "I do not have a medical background but this was an excellent way to support those who were in a position to make a difference."

The Nickoletts seek proposals for research projects that could not occur without additional funding. Through the hospitals, they funded two projects in 2004 at CHOP and are funding more in 2005. One of the 2004 projects was a bone fracture study that found kids with JA were more than twice as likely to have bone fractures due to decreased bone density related to their JA. The other project identified a unique and very effective treatment for TMJ Arthritis that treats the problem before bone growth problems occur.

"I am willing to talk to anyone doing research," Chip said. "I am looking to get involved with anyone with good ideas who's doing good work." Over the summer, Chip met with John H. Klippel, M.D., President and CEO of the Arthritis Foundation. They discussed the Arthritis Foundation's emphasis of JA as a core area and the various programs and efforts supported by the Arthritis Foundation.

"It made me feel very good that an organization as large and influential as the Arthritis Foundation took juvenile arthritis so seriously," stated Chip.

Heather has received primary care in Wisconsin, but has also been seen several times in Philadelphia.

Chip stated, "Both the Children's Hospital of Wisconsin and the Children's Hospital of Philadelphia are world-class facilities and Heather has received excellent care. But, unfortunately for children in more rural areas or in cities without specialty hospitals for children, the understanding of this disease may not be as great and they might not be this lucky." This is just one key area where Chip feels that the Arthritis Foundation can make a significant impact moving forward. "Getting information on diagnosis, treatment, and the effects of JA to physicians who might otherwise be unaware could possibly lead to better care for their patients."

Approximately 300,000 children in the United States live with some form of Juvenile Arthritis. Chip realized that not much attention was being paid to JA and he set out to raise awareness.

"I needed to make others aware and get them involved," said Chip. He feels he is starting to "make a dent," but there is still so much more to be done.

Chip has also just joined the National Arthritis Foundation's Medical and Scientific Advisory Council. He views this as the perfect "next step" where he can continue to learn about JA and add perspective as a parent of a child with JA.

"I am honored to have this opportunity and will make the most of it over the next two years. You feel completely helpless as a parent. You are told what can happen and the life-long impact this could have on your child," said Chip. "You just know that you have to get involved and do whatever you can to make a difference."

Heather used to say, "Daddy, make my arthritis go away," and today Chip is doing what he can to try and make that happen.



Chip and Heather Nickoletts are working to increase awareness and research for juvenile arthritis (JA). Together they traveled to Washington, D.C. to speak to our legislators about this children's health issue.

**Wisconsin Arthritis Advocates** are a growing network of people who respond to legislative concerns that affect people with arthritis. Efforts include sending letters and E-mails, making phone calls and visiting legislators.

**Wisconsin's American Juvenile Arthritis Organization (AJAO)** Advisory Committee is a volunteer advisory committee that oversees all juvenile arthritis (JA) programs and activities, promotes awareness of JA and works to help children with JA and their families.

**Programs for children with arthritis include Family Day, Camp M.A.S.H. and Mini-Camp**