






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Originally published February 5, 2007

When heart disease afflicts children Local moms band together for support

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By Mary Leslie

DEMOCRAT STAFF WRITER



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When doctors told Kim Rooks that her unborn daughter's little heart wasn't functioning properly, the Tallahassee mother-to-be had nowhere to turn.

Devastated, she had no one to tell her how this would affect her daughter's life, what questions she would need to ask or how to cope with the fact that her daughter's heart might kill her.


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"We were completely in shock," said Rooks.

Taylor Rooks was born with congenital heart disease, a birth defect that causes more fatalities in children every year than cancer. Three days after Taylor was born, she had her first pacemaker surgery.

One in 125 babies are born each year with a congenital heart disease, according to

the Congenital Heart Information Network, and of the estimated 40,000 children

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who will be affected in 2007, 4,000 of them won't see their first birthday.

Broken Hearts of the Big Bend, an organization co-founded by Rooks, meets this week to spread awareness about congenital heart disease, North America's most common birth defect, and to promote national Congenital Heart Defect Awareness Week, beginning Wednesday, and A Day for Hearts (Feb. 14).

The support group was the idea of Karen Thurston Chavez, whose son William was born with blood draining into his right atrium.

"When I found out he had a heart defect, he was 11 months old," said Chavez, "and it was 7 o'clock at night. It was going to be at least three months until our next cardiology appointment at Shands (Gainesville hospital), and I had so many questions."

Chavez was dismayed that there were no support groups for families coping with congenital heart disease in Tallahassee, so she took matters into her own hands, taking out an ad in the *Tallahassee Democrat* looking for parents dealing with what she was going through with William. She received only one response.

"I met Karen and thought what she was trying to do was great," said Rooks, "and I was willing to do whatever I could do to get it started."

The pair has since drawn in more than 25 families, meeting regularly to hold question-and-answer sessions, inviting local pediatric cardiologist Louis St. Petery to forums and spreading the word in the medical community of the group's existence.

There are 35 known congenital heart defects, and it is still unknown why they occur.

Looking at the children, it's difficult to imagine that they had severe heart complications that required invasive surgeries.

Taylor Rooks, now 4, has blond hair and blue eyes and appears as rambunctious as any other child. However, she has a pacemaker and must take medications daily to regulate her blood pressure.

"My heart gets surgery," said Taylor, who said she knows her heart is different from her classmates' hearts. "I tell (my doctors) when my heart starts bothering me."

William Chavez, now a healthy 2-year-old, carries a green plastic harmonica with him everywhere. Blowing air through the harp helps to strengthen his heart and lungs. Both run and jump around Winthrop Park's playground with no signs of

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fatigue or illness.

The mothers, who provide constant support for one another, chat about the upcoming surgery of another child, William McBride.

Jennifer McBride, William's mother, was pregnant with fraternal twins but lost one child early in her pregnancy.

Chavez gave William a small wooden statue of a boy holding a sign that reads "hope."

"It's just perfect," Jennifer McBride said.

Chavez spoke with one mother who, upon discovering that her her 3-day-old baby had Tetralogy of Fallot, or "Blue Baby" disease, felt emotionally abandoned by doctors.

"The physician who told her," she recalls, "basically said 'well, your daughter has Tetralogy of Fallot. Here's a booklet. Let me know if you have any questions.' "

Chavez said that she doesn't think physicians are heartless, but families who are living with the disease are more empathetic.

"That's what we're here for," she said, "to step in and say, 'It's going to be hard. It's going to be sad, but in the end things are going to be OK.' "

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