

Family, friends take up fundraising to help loved ones fighting disease

May 13, 2013 |



Karen Michler holds greeting cards that she started making to help raise money for Ring14 at her home in West Lafayette.

Written by

MaryJane Slaby



Yssa DeWoody, left, and Karen Michler prepare treats for the second annual Ring14 dinner Friday at Michler's home in West Lafayette. DeWoody's daughter Marie, 8, has Ring14. / PHOTOS BY Michael Heinz/Journal & Courier

Outside Inside Cards

Karen Michler of West Lafayette creates whimsical greeting cards to raise money for and spread awareness about Ring14.

Look for cards at University Bookstore, 360 W. State St. in West Lafayette, or email outsideinsidecards@gmail.com for more information.

Learn more about Ring14 USA at www.ring14usa.org.

If you go

What: Perfect Pearl Benefit

Where: Lybolt Park

When: June 22, time TBA

The event is a co-ed softball tournament with food and raffle items. Cost is \$300 per team and includes T-shirts. Team

sign-up is due June 1 and can be made by calling Cheryl Mullin at 765-586-3817 or emailing perfect_pearl@mail.com. All proceeds go to benefit Pearl Smith of Decatur, who has cystic fibrosis.

Baking tins lined the counters. On the dining room table, cupcakes filled casserole dishes surrounded by auction items. In the living room, more auction items covered the couches, tables and floor.

It was the day before the annual Ring14 charity dinner, and the details were falling in place.

Yssa DeWoody of Lafayette, president and founder of [Ring14 USA Outreach](#), had done this once before. But Karen Michler, who had filled her West Lafayette home with the desserts and auction items, was new to Ring14 fundraising. After the first Ring14 dinner, where she learned about the disease that DeWoody's daughter Marie, 8, faces, she decided to help.

"It was fun and educational and I left thinking, 'Why didn't I know about this?' and wanting to contribute," Michler said.

So she started Outside Inside Cards to help raise money for and awareness about Ring14.

"Going to the dinner brought us together and I feel like it spoke to me," she said. "It's been an amazing year for me."

Around Greater Lafayette, community members work to raise money for loved ones battling health problems. Family and friends who never meant to be fundraisers or start companies and organizations do and learn as they go along.

"You draw people in to help, and friends go out of their way," DeWoody said.

Marie DeWoody has Ring14 syndrome, a rare anomaly of the 14th chromosome. She only speaks a few words and every few weeks has a dozen traumatic seizures, DeWoody said.

DeWoody traveled to Italy to meet other parents in her situation at a group called [Ring14 Italy](#). She remembered it was there someone first approached her about starting a Ring14 group in the U.S.

"Life was pretty scary, and I couldn't think to manage adding a layer on," she said. But as the years went on and she learned more about the research, she knew she had to help.

"I don't know what it was, but things kept happening," DeWoody said.

So a group of six moms of Ring14 children from around the U.S. started Ring14 USA in 2012, and DeWoody planned and had the first local charity dinner with the help of several Purdue University students in 2012.

“It was scary to be asking friends, family and strangers for things,” DeWoody said. “It was terrifying to ask for something so personal.”

For Kim Strong of Lafayette, raising money for her nephew Jacob Gilkey to travel to Bloomington last November to have proton therapy to stop the growth of his meningioma brain tumor was something she never thought twice about.

“I didn’t struggle with talking about it. He is my nephew,” Strong said.

She said she helped raise money for big organizations before, such as the [American Cancer Society](#), but the fundraisers for Gilkey were different.

“It’s more personal, more urgent. You think: ‘Oh my god, what if I can’t do this?’ ” Strong said.

DeWoody, who works as a research mathematician, said she never thought she’d start an organization, but it’s become her passion. She works four days a week and said she spends her day off during the week and her evenings devoted to Ring14. She also travels to research universities to hear the latest research.

Most of Ring14 USA funds go to research Ring14 and other anomalies of the 14th chromosome. The rest of the funds go to awareness and support, such as a family camp for those with a Ring14 child.

“Nobody thinks they will have a special needs child,” DeWoody said. “That’s not part of the dream.”

Cheryl Mullin of Rossville said her granddaughter Pearl Smith, who lives in Decatur, has cystic fibrosis and it’s been a struggle for the family.

“Our family has been very fortunate and it hit all of us hard,” Mullin said. “It’s a sensitive issue.”

So when Mullin’s daughter Keera George suggested organizing a softball tournament fundraiser to help raise money for Pearl’s medical bills, Mullin agreed.

Because 8-month-old Pearl needs constant care, her mom, Megan Smith, is at home with her and isn’t working, meaning her father, Justin Smith, works extra to help cover medical costs, Mullin said.

“I don’t want my brother hurting,” said George, who lives in Reynolds.

Mullin said it’s difficult to find sponsors for the event because they are not a non-profit. But the family is continuing look for volunteers and sponsors before the June 22 event.

“If I could do more I would,” George said.

Saturday was the second annual Ring14 dinner and DeWoody said more than \$40,000 was raised from community members who attended or those who sent donations.

Strong said it was also the generous community and family and friends who helped spread the word that made fundraisers for Gilkey successful and earn enough money for the extra costs during his six-and-a-half-week stay in Bloomington.

“I honestly never believed we would get all of it,” Strong said. And now, she said when she hears of other fundraisers to help with a person’s health, it hits home more.

“Before I would think, ‘That’s terrible,’ ” she said “Now, I’m digging in my purse.”