My Mom Has Chiari

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June 30, 2011 - I am writing about my mom who is my hero. Her name is Angela. Some of you don’t know but she has Chiari Malformation. You can’t tell by looking at her but she has it. She has had it for 3 years now. Chiari is a disorder that deals with your brain. Your skull bone pinches on your brain and it causes a bunch of problems. Some of them are headaches which can be worse when straining or coughing, muscles weakness, balance problems, dizziness, trouble swallowing and sometimes trouble with vision.

Chiari can be treated with medicine but if it gets worse you have to have surgery. To get tested you have to have tests done like MRIs, CT scans and doctor appointments. My mom has been doing all of that for a long time. I have went with my mom to a lot of her appointments and it is not fun. Not just for me but for her.

My mom is my hero because I watch her live with it every day and no matter how she feels she always makes time to play with us even though she feels bad or has a headache. My mom deals with Chiari every day and still stays strong for me and my brothers. There are days where I see her cry because she has a bad headache or she hurts really bad. She tries hard to not let us see her but I know she hurts and it makes me sad but she still keeps going and spends time with me and my brothers.

My mom has met other people who has Chiari just like her and she goes to see them sometimes when they meet and I am happy for her that she has people she can talk to.

One thing that some people don’t know is that my mom has Chiari because no matter how my mom feels she always has a smile on her face. She never wants me and my brothers to feel sad when she is hurting.

Me and my brothers help my mom when she is having a bad day. We help her by doing our chores and not giving her a hard time. When my mom is having a good day we read books, we color, we play in the yard. I love it when we play board games. Our favorite is SpongeBob Square Pants Monopoly, another board game we play and I always win is Scene it Nickelodeon. I win all the time. I love doing my homework with my mom.

My big brother Casey helped my mom and her support group in July sit at tables in front of Wal-Mart to pass out brochures and talk to people about Chiari and what it is. Not too long after that in September we did a walk for Chiari Malformation. It was so much fun even though it rained. We still showed up and did the walk. They had bounce houses, food, music, drinks, face painting, cake, ice cream and so much more. A lot of my family showed up for my mom. My nana, papa, aunt Beth, uncle Tony, Bma, Big uncle Tony, aunt heather, mommy’s friend Becca, my cousins Isabella, Laila, my dad and brothers. We all were there to show my mom we love her. We had t-shirts made for my mom’s team. There was so many people who showed up for their own families. I can not wait to do it for the year 2011.

My mom has showed me that no matter what you get or have you can keep walking forward. I am so proud of my mom. I know sometimes she can not make some things at my school or she forgets, but it is okay. I know it isn’t her fault. I know she tries. That is why I love her with all my heart and she is my hero. I love you mom

-- Christian, 7 years old, written for a school project

Would you like to share your perspective? Submit to: director@conquerchiari.org Type “Perspectives” in the subject line.