

Conquering Chiari in Iraq!



September 21st, 2013 (Baghdad, Iraq) - Approximately 5 years ago, I met a woman and as I became friends with her she informed me that she had Chiari. Now just like most of the rest of the world, I had no idea what Chiari was and had never even heard of it. She explained very briefly what it was and in non-technical terms I translated it to a brain disease that there was no real cure for and she was going to only get worse with time. Now in the beginning the thought of this woman suffering to a point of losing her life was very frightening for me and I did not know how to react to it. I had never met anyone with a disease like this before.

Well as the years went by I grew to call this woman my best friend. She became the person I could turn to for anything and would always bring me up and to a better place. I still had not done any research on Chiari and other than hearing her explain what it was, the symptoms and that brain surgery was something that she might have to consider, I still knew very little of CM. I began to see the symptoms affect her and how she had to deal with them. I saw how one day she would appear completely normal and unaffected and then the next be laid up in bed. I would watch as she had to limit her physical activities with her son and the pain on her face. I observed this and began to think, why this woman who is so amazing and beautiful inside and out have to go through this pain and alter her life around this Chiari whatever that really is.

I then watched what most of the Chiari Patients have to deal with all the time, Depression, Friends distancing themselves, relationships failing or faulting due to this illness. I kept wondering why this woman has to go through this. She has an amazing son, a heart like no other woman that I have ever met before and she is just so strong. I had no idea how strong she actually was and is. She made two statements to me that have stuck with me. The first "No man ever makes it through a hospital stay" and the second "People just don't care cause it is not like Cancer or something well known, no one is going to support this". Well right then and there I decided that no matter what I was going to prove her wrong. I vowed to always be there for her and that if I was near her when a hospital stay happened to come about I would be there and do it on my head with a smile on my face.

The second was to not only educate myself but to help in any way I could to educate and build awareness for Chiari. I started looking at web sites, ordered books and read them cover to cover. Patient guides, etc. When I actually learned what Chiari was and how it affects each and every Chiari patient broke my heart, but what I realized was that this woman who I already knew was this amazing, strong, smart, beautiful woman was now a super hero to me. To deal with this every day and still be able to do the things she does and support her friends, family, and community the way she does was absolutely amazing. She was so much stronger than I had ever imagined. I absolutely hate that she has Chiari and that she has to deal with this on a daily basis but I also love that she has it, because it makes her who she is and the woman that she is today. This is when I realized the true meaning of the phrase Chiari Warrior because she and all Chiari patients are warriors in my book.

My job takes me out of the United States for months at a time and therefore I cannot be by her side at all times and physically there to support her. I know she has a great passion for supporting Chiari and I knew that if the rest of the world was like me they would not understand what Chiari truly was. I work at the Embassy in Baghdad, Iraq. I decided with the Conquer Chiari Walk Across America coming up on September 21, 2013 that I would try to conduct a fund raiser on the embassy for Chiari and on behalf of my best friend.

This is where I really began to see how much a simple thing as a 5K run can mean to a Chiari Warrior. So the planning stages began, I contacted the running organization here and asked for their sponsorship and support. I sat down with the head point of contact Kerry and explained what Chiari was and that I wanted to do this for Chiari Research and on behalf of my best friend. Kerry immediately put things into motion getting Scott to help out and the ball rolling within a few days we had authorization to conduct the event, fliers out, and items organized for the date and time of the run. Over the next 3 to 4 weeks we continued to advertise on social media networks and pushing the fliers out. Other departments on the embassy started sending out mass emails to everyone in their areas of responsibility.

I had set a goal of a thousand dollars to raise to put the team name on the Research Center wall for a year. So here we are September 21 the day of the event. I show up and everything is set to go, we had very few people actually register online for the run under the walk anywhere section so had no clue as to the turnout or support that this event would get. We had a dry erase board that said Conquer Chiari 5K on it and some speakers and coolers full of water. As I am sitting there with a few of the volunteers that Kerry had gotten on board for me before she went back to the States, I watch as people come up stop and ask what Chiari is. Now I am figuring that I am going to have to do all the talking because these other people only know what was on the flier. I was mistaken, big time. Dave had volunteered to DJ and do all the announcements for me. As people are coming up and asking about Chiari he is rattling off facts, explaining symptoms and procedures, talking about my best friend and her fight. I was baffled this guy had actually done some research on this and said that he had no clue what Chiari was before two weeks ago. The other volunteers were grabbing people walking buy asking for support etc. An older gentleman just walking buy stops looks down at the sign and asks, "What is Chiari"? As Dave gives him the short brief description, the guy



reaches into his wallet and pulls out a \$50.00 bill and puts it in the donations jar and walks off. Other people stopped and were talking to me about the disease and said well we can't run or walk because we have to be someplace but we want to support this do you mind if we stick around till you start. We ended up with about 40 runners and about 10 to 15 extra people that were just there to support and hear about Chiari and to support the effort that we were putting forward for Chiari Research.

I had spoken to Melissa prior to the run date and she asked me why are you doing this. After explaining to her that my driving force was my best friend and that I wanted to give her the hope and courage that people do care and do support her and this cause, she explained to me that not only had I done something wonderful for my friend but had given others hope also. She said that when other Chiari Warriors found out that there was a group of people in Baghdad, Iraq conducting a 5K run to raise awareness and funds for Chiari Research they were amazed. Some site locations made honorable mention of our efforts here in Baghdad. I got numerous messages from other Chiari warriors thanking me and what I was doing. I had no idea the response that a simple thing like this would get and how touched I am to give this hope and support to complete strangers.

I know that every year I will make an effort to educate other people about Chiari and to assist in raising money for Chiari Research. I know that I will always try to be there for my best friend as much as humanly possible to show her that there are people that care and are willing to fight the fight alongside her.

So as this little journey of meeting this woman and 4 years later deciding to go the little extra effort to learn about Chiari Malformation has ignited a passion inside of me that I am going to keep going every year. I will wear my Chiari necklace and bracelet with pride and honor of all of you Chiari Warriors and don't ever give up hope. People do care and people will support the cause sometimes the unknown is scary for people but if you can break that wall down and show them that even though Chiari is a very serious thing it is not something to be afraid of, instead embrace that courage and strength that Chiari Warriors have and thrive off of it. HOPE, COURAGE, STRENGTH

-- *B.M.*

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