

~ Northwest Indiana's First Conquer Chiari Walk Across America event Raised over \$26,000 for Chiari Research ~

We arrived to set up at 7am at the site, along with many friends & family, and a gloomy wet day that was forecasted to be thunderstorms. Dressed in multiple shirts/ t-necks under our T-shirts, we worried if the 260+ people who pre-registered would come. The walkers began arriving at 9am in a steady stream of about 400 people.

At registration, the “survivors” were given colored Mardi-Gras beads to differentiate WHO were the “honorees” of the day and the colors showed if they had Chiari/ Syringomyelia &/ or shunts (since there had been many requests from people trying to get support from others with shunts—especially children). After this, people entered a building & enjoyed donuts & bagels, while being educated as to what Chiari and Syringomyelia were by our awareness table, which was staffed by one of our local support group members & my support group co-leader, Nancy. After visiting with Nancy & Kim, they walked around the building looking at (& bidding on) the over 30 Silent Auction Baskets that were donated. The baskets ranged from overnight stays, a day at the spa, & even a “picnic in the sky” package! They also looked over the “door prize” table full of gift certificates, limited-edition items, & many other donated items!



Then they went out the other door and entered the patio where they were greeted by Mark, our amazing DJ, who was the brother of Kristen, who suffers from Chiari as well. Many of the people took advantage of our face painting where some chose to have “I’m Walking for my (mom/ brother/ aunt/ etc)” painted on them. The kids enjoyed the bounce house, and the GREAT activity books that were made for them to color there & take home!

Around 11:15 I began my speech. As I took the microphone I was overwhelmed with emotion as I looked out at the sea of people, standing on their feet to hear every word. Many in groups of different colored “team” shirts, supporting their loved one who so desperately needed this day. In the words of one woman, “We had been waiting for decades for today’s event!” I saw friends of mine from elementary & high school that I hadn’t seen since I left there; the Nurse Practitioner who was there the day of my diagnosis (over 12 years ago); my former patients; my family and friends; but most of all... I saw the eyes of two teenagers who were looking at their Mom with pride for what had happened that day. The eyes of two children that several years before, after many brain surgeries & severe complications, I didn’t know if I’d be lucky enough to see them become the people that they are today. I realized then, that **every** Chiari and Syringomyelia patient there was feeling the same thing with their own stories. We’ve had to teach those around us what these conditions were, when most of the medical community didn’t even know what it was. **Together**, in this large group, we finally brought attention to this when **alone** we could not.



During the speech the crowd broke into standing ovations several times, but mostly over the energy they felt at hearing about Conquer Chiari’s news of their effect on the NIH Appropriations Bill’s focus on Chiari research! Following the speech, we explained the “Dollar Song Dedications”, I began with dedicating the song “Hero” by Mariah Carrey to all of the Chiari/ SM patients who were the real HEROES, and it was sung by a local singer, Nicole Garza & could not have been more beautifully performed... I didn’t find one dry eye in the audience. Then, as my family & I led the walk, we looked back when we were half way thru & saw HUNDREDS of people, old and young, following behind us hand in hand with tears streaming down some faces, happy that people “finally understood” what they were going thru. This is the beginning of better care for us, more Federal Funding, and nobody having to live like they were the **ONLY** person in the world with this diagnosis.

After returning, people enjoyed a lunch of hot dogs, chips and pop. Although the event was scheduled to be done by 2pm, people remained for hours talking to & supporting one another (& even dancing). Once things settled down a bit, my husband, kids & the remaining friends & family – surprised me with a birthday cake to celebrate my 40th birthday that is coming up. I stood there watching the candles on the cake thinking, & then realized that today life was perfect & at that moment, there was nothing that I could possibly wish for.





Thank you to EVERYONE who helped with any part of this Walk
You will always hold a special place in my heart!
Although there were a lot of helpers, this Walk could NEVER
have taken place without my husband, son & daughter!