

CHIARI BRIDGES

BEYOND WHAT WE THOUGHT POSSIBLE



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Worth The Fight (WTF!)

By Michelle Cole

Few know this, but Worth The Fight (WTF!) is the origins of Chiari Bridges, not the other way around.

WTF! began in June 2016 with a small group of women who believed that we could use all that we've been through as Chiari patients and make a difference in each other's lives. We had no idea how far it would go or even how far we were willing to take it.

The Chiari Bridges vision developed as we were helping so many people and having to type the same things again and again, that we decided it would be beneficial to have a site with links to the information making it easier to share in and outside of our group. It has ultimately enabled us to help thousands of suffering people looking for answers. In 2021, we decided that it was time to merge the two visions together!

When I look back at how we evolved and all we have been able to accomplish, I have to stop and smile. In my wildest dreams, I never thought that we would be able to help all the people that we have!

[\[Find out more about what WTF! offers!\]](#)

WHAT'S NEW

INTRODUCING WTF!

What is WTF! and why we merged.

BEYOND FACEBOOK

Why moving beyond Facebook became important!

BEATING THE ODDS

Getting back all that we can!

REDEFINING THIS FIGHT TOGETHER!

Chiari Action Network (C.A.N.)

COMING UP

We have so much more in store.

HELP US MAKE A DIFFERENCE!

We need your financial support.

Beyond Facebook

By Michelle Cole

The decision was made when Facebook blocked us from sharing a story about a sars-cov-2 nasal swab test that resulted in a woman getting a CSF leak. Apparently, it was picked up by their algorithm which mistook it for causing a break between the blood-brain barrier. They removed the post from all of our pages and groups on their platform and added to our accounts that we were "sharing false information." They gave us no means of recourse to debate its accuracy and relevancy to our community.

As advocates for patients having access to all information pertaining to our health, this put us in a precarious situation. If we stopped and just simply complied, it could make patients like us worse. If we refused and continued to share the information and Facebook shut us down, we could lose all means of reaching members as we have for so many years now. So, the decision was made to merge Chiari Bridges and Worth The Fight (WTF!) and create a social platform on our site where we were free to talk about all things pertaining to us.



Beating The Odds!



The odds are heavily stacked against us, but we can defy some of those odds! While we can't control everything going on with our bodies, we can learn to control that which is still within our control in order to change where we're at! We cannot leave it all to our doctors, far too many of them don't understand what we're facing anyway (they think it's all psychosomatic).

Most of us have spent years (or decades) complaining about symptoms only to have it fall on deaf ears by those we love and trust. Overtime, that can wear out even the strongest and most confident amongst us. We tend to stop believing what we feel to be real, and it ultimately changes the way we see ourselves and our attitude towards everything pertaining to us. We need to turn our perspectives, so that we see ourselves as worthy and capable of more.

We don't have to ignore our reality or turn a blind eye to the negative aspects of our conditions to have a positive and healthy perspective. We can choose to frame things in a positive light. For example, if I am no longer able to walk as far as I could this time last year, I can look upon that situation with an air of defeat... or I can remind myself that I was also unable to walk that far three years ago, but with determination, with time I made progress! It may be unfair that I must start over again, but I am worth every ounce of effort that it takes to do so. I can acknowledge the unfairness, and then choose to focus on making progress towards my goal. A positive attitude is not going to will Chiari or EDS away, but it can improve our experience of living with these conditions.

Learn what other patients have found to reduce pain and improve their quality of life through diet, exercise, and stress control.

This year we are pushing the bar again to try and help us do just that!

[\[Find out more!\]](#)

Redefining this Fight, Together!

By Michelle Cole



I have always been amazed how Chiari patients have learned to be what we need for each other, despite the lack of governmental funding for Chiari and its comorbidities. Chiari isn't rare and neither are its comorbid cofactors (last statistics were cited as 1 in 100), yet when you compare funding with any of the other top conditions, you can see that we are definitely lacking research development. No wonder there is so much confusion surrounding its definition, proper testing, and treatment options available to patients. That has to change, and together, we CAN change it! The Chiari Action Network (C.A.N.) was designed to blaze the trails for us legislatively.

With what most of us have faced with our doctors, we have every reason to be apathetic, but the truth is, we don't have time for apathy! With the genetic component of Ehlers-Danlos Syndrome, what we fight to change today, will directly influence what our kids have to face tomorrow, and failure is not an option! Please roll up your sleeves and find a way to get involved today and let's redefine this fight together!

[\[List of volunteer positions we need to fill!\]](#)

Help Us Make A Difference!

Many of the Chiari/Comorbid non-profits bring in close to a million dollars a year in donations. During the early years, my husband and I paid for everything. We've done a lot with a little, but our expenses have grown beyond that now (with new things like the social media platform and app). We currently have a handful of people who donate every month through PayPal, but if we're going to grow this and keep things free for those that need it, we are going to need help.

[\[For more information on how you can help support us!\]](#)

Coming Up...



CHANGING THE FIGHT!

We are organizing online support groups to help patients take control of what is within our control in regard to:

- Eating wiser to help control pain & symptoms
- Moving wiser to help control pain & symptoms
- Reducing stress to help control pain & symptoms

CHIARI BRIDGES/WORTH THE FIGHT APP COMING SOON!

Most of our members use mobile devices and therefore are more accustomed to using apps (as opposed to websites), so we are working on rolling out an app for the site to make it easier for everyone to get the help they need! These apps will be available for both Apple and Android.

ONLINE SUPPORT GROUP MEETINGS ARE BACK!

We have resumed our online support group meetings. We are now meeting on the 2nd and 4th Tuesday evening of each month.

[\[Times and reminders.\]](#)