



## ***Carli's Speech to Congress September 18, 2014***



Good afternoon, I'd like to thank you for the opportunity to share my story. My name is Carli Clement. I'm 16 years old and I live in Yorktown Heights, NY. **I HAVE HYDROCEPHALUS.** I am the founder of a community called Carli's Angels. I started Carli's Angels to be a loud positive voice for Hydrocephalus patients and families everywhere. I want to lend my voice, as someone living with Hydrocephalus, to help raise awareness for Hydrocephalus and to help fund a cure.

Hydrocephalus is a terrible condition and there are a lot of horrible facts that I could share. I could tell you how many people in the US have Hydrocephalus, **A LOT.** I could tell you how much Hydrocephalus treatment cost this country, **A LOT.** I could even tell you how much funding is provided for research into a cure or better treatments, **SADLY, NOT A LOT.** One fact I do want to share is this: **THERE IS NO CURE FOR HYDROCEPHALUS.** Unless we act and a cure is developed, I will have Hydrocephalus all my life.



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But, instead of boring you with a bunch of facts, I am going to tell you my story. I want to give you a sense of what it's like to live with Hydrocephalus. What it's like for my family and loved ones to live with Hydrocephalus. Hydrocephalus not only affects the patient, it affects the whole family and all their loved ones.

I was diagnosed at approximately 5 months with Hydrocephalus caused by aqueductal stenosis. I had my first brain surgery at just 5 months old. This surgery was to insert a mechanical medical device called a shunt, through my brain and into my ventricles. Yes, I said, through my brain. I had my second brain surgery just days later due to a shunt malfunction. 2 months later in July, I had two more surgeries to revise my shunt, again due to malfunctions.

For those of you that are parents or want to be parents, I want you to close your eyes, and imagine, God forbid, your child is having brain surgery. Think for a second about carrying your 5 month old child into an operating room filled with doctors, nurses, wires, lights and medical equipment. Having to leave your child on the operating table knowing they are going to have brain surgery. Knowing all too well how risky this type of surgery can be. Well, my father has had to do this many times. Imagine you and your family sitting in the hospital just waiting to



hear from the operating room or from the Doctor. Scary to imagine this happening to you or one of your loved ones. Now you can open your eyes.

My shunt keeps me alive and functioning. Without my shunt, I would likely die in a matter of months, weeks, maybe days. My shunt system includes several pieces.

1. A catheter that goes through my brain, and rests in my ventricles.
2. Tubing connects this catheter to a valve system. This valve system helps to regulate the Cerebral Spinal Fluid in my brain. This helps to regulate the pressure on and inside my brain.
3. This valve system is connected to another tube that drains the fluid to my heart where it can be absorbed.

My shunt used to drain into my stomach cavity, like most shunts, but I had complications with that location so the Doctors moved it to my heart. Please take a minute and think about this. I have a catheter that goes through my brain and I have a tube that drains into my heart. My hydrocephalus treatment touches my two most vital organs.



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Did you know, the shunt has the highest failure rate of any medical device? Over 50% will fail in the first two years. And a shunt is the primary treatment option for Hydrocephalus. We need your help to change the course of Hydrocephalus treatment, which is brain surgery!

The most dangerous part of the surgery is placing a catheter into my ventricles. This catheter has to be passed through my brain in order to get to my ventricles. As you might imagine, placing a catheter through the brain tissue is very risky. I have had this catheter replaced many times. In total, I have had over **60 (SIX ZERO)** surgeries related to my hydrocephalus, and I consider myself one of the fortunate ones. It is important to note that my surgeries were all because something was wrong and I was in a great deal of pain. Thankfully most of my surgeries have been without complications. But not all.

How does Hydrocephalus affect my day to day life?

I have spent weeks at a time, in a hospital bed fighting off shunt infections. Not even being allowed to leave the hospital area I was in for risk of additional infections. After a week of being inside, I had to beg the doctors and staff to allow me to leave the floor and visit the gardens on the first floor, for 10 minutes.



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I have spent weeks at home with a PCIC line, hanging bags of Antibiotics to fight off further shunt infections. Not allowed to go outside and play for risk of infection or damaging the PICC line. Keep in mind the risk of infection is not like other surgeries. If I get a post op infection, there is a good chance it goes directly to my brain if it is not caught in time. I have seen what a shunt infection that goes to the brain can do to a child and it is tragic.

I suffer from routine headaches. Some are very severe. Doctors have determined my headaches are likely caused by the repeated trauma from brain surgeries. I have tried a number of medications with no luck.

One related surgery left me unable to walk properly. I had to endure months of therapy to re-learn how to walk correctly.

Just a few years back, I had one surgery that left a large air bubble in my ventricles. This blocked the flow of fluid from my brain and within hours I was in a coma, being rushed for a CT scan and ultimately having a procedure in the ICU to remove the air bubble. I don't remember much of this event but my parents and doctors were terrified by what they witnessed. My surgeon at my post op



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appointment even said to me, "Can I hug you? You scared me; I didn't think you were going to make it". Imagine that!

Over the course of my 16 years and 60 plus surgeries, I have missed countless days of school. I have had to work harder than my peers just to keep up with my studies. I have spent many weekends and vacations, making up work. Last year alone, I missed over 45 days of school due to Hydrocephalus and related surgeries. I missed so much school; I had to complete two classes during this past summer. My family and I had to cancel our routine summer vacation because I had school work to make up. I can tell you, my little brother was not happy with me.

Speaking of vacations, do you know how we plan vacations in my family? We pick a location and before any plans are made, we speak to my Neurosurgeons. Why do we speak to them? To find out where the nearest qualified hospital is. We ask them for recommendations regarding doctors as well. In other words, what do we do if I have a shunt malfunction while on vacation? Once we have the name of a good hospital and surgeons, then we book our trip. This planning was very helpful in July of 1998. We were driving from Florida to meet family for a



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vacation in New Jersey. Our routine, summer vacation on the beach. Crossing the Delaware Memorial Bridge, I started to show signs of a shunt malfunction. I was vomiting and nearly in a coma. My parents, using the information my doctors had given us, headed to NYU in Manhattan where I was operated on for the 4 time in less than 2 months. Needless to say, that vacation was not too fun for my family.

Missing so much school brings a number of social challenges. I am often times isolated from my classmates and friends for weeks at a time. I lose many opportunities to bond with friends at football games and other social activities. When I go back to school, I am usually missing some of my hair where it is shaved during surgery. Thankfully my main neurosurgeon has a daughter my age and does his best to limit the hair that is shaved. I often times will still have bandages over my incisions when I go back to school. When trying to explain why I missed school, I often get blank stares and am asked if it is contagious. For the record, Hydrocephalus is **NOT** contagious.

I miss out on a great deal because of my hydrocephalus. In elementary school I played volleyball and was hoping to play in high school. A few days before tryouts



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I was in the hospital having brain surgery, again. Needless to say, I did not get a chance to try out for the team.

Birthdays. Ever celebrate a birthday in the hospital? I have. It's not fun. Last year I was in the hospital on my brother's birthday having another surgery. My father stayed in the hospital with me and was not able to celebrate his birthday with him.

I have had to miss class trips because I was in the hospital or home recovering from surgeries. Trips that my friends and I were looking forward to.

My parents have missed countless days of work sitting by my bed side, keeping me company. My mother even lost one of her jobs because she could not be at her desk on a regular basis.



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Why am I here and why am I so passionate about advocating for Hydrocephalus?

I choose to be an active voice because of people like Mason Ocasio. Do you know his name? You should. He was a handsome 2 year old boy from Staten Island, NY who was loved by many. Sadly he died in July due to complications from Hydrocephalus. He is no longer with us and all because of a condition that too many people have never heard of. Children die from this condition. Children in the US, the greatest country on Earth, die from Hydrocephalus.

I am here to help put an end to Hydrocephalus.

I am here so that, someday, we can live without fear of a headache, headaches are not just headaches when you have Hydrocephalus, they are a potential life threatening shunt malfunction.

I am here so that, someday, we can live without the need for brain surgery.

I am here so that someday, we can live without the fear of dying.

I am here so that, someday, my Hydro friends and I won't have to miss out on birthdays, holidays, volleyball games and just being a kid.

I am here, most of all for friends and fellow Hydro Heroes like:



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Cole

Brayden

Ally

Isaiah

Adrienne

Jeffrey

Maddie

Madalyn

Carly

And the list goes on and on and on...

I am here for all the parents and loved ones who give tirelessly to care for hydro heroes everywhere. Who routinely sleep in hospital chairs, routinely miss work and routinely sacrifice vacations and free time. Who routinely love, unconditionally.



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I am here to ask this group, to lend their voices to help further advances towards a better treatment and one day a CURE.

I believe there will be a CURE

I know this group CAN help.

I am honored to be here and I thank you for your time today.