

# Know Me

NAME

Zaren

PASSION

Basketball

## My Story

Meet 2 ½ year old Zaren Berry. While mom Brittany was still pregnant, Zaren was diagnosed with Spina Bifida, Hydrocephalus, and Chiari Malformation Type II. Born on June 20th, 2017 and just 17 hours old, Zaren had his first surgery to close and repair the lesion on his back caused by these conditions. Since then, Zaren has had 8 additional surgeries, but that hasn't stopped him from being one of the happiest babies ever.

In June of 2019, the Massillon Family YMCA hosted the 5K Run for A Reason, as a combined fundraising effort to benefit the Massillon Family YMCA and one of their own Massillon All-Stars...Zaren. Funds raised were to help offset some of Zaren's medical expenses.

Here is the story written and published in June 2019 by the West Stark YMCA:

*Zaren Berry is one smiley boy with an All-Star Attitude!*

*Halfway into her pregnancy, the doctors began to monitor Brittany Berry's baby very closely. Zaren was diagnosed with Spina Bifida, a birth defect where the spinal cord fails to develop properly. He was also diagnosed with Hydrocephalus, or fluid build-up within the brain, and Chiari Malformation Type II, where certain parts of the brain's tissue extend down into the spinal canal.*



YouTube

Born on June 20th, 2017 and just 17 hours old, Zaren had his first surgery to close and repair the lesion on his back caused by these conditions. After his first 8 days in the hospital, he received his first VP shunt to help drain the excess fluid from his brain. Then, after falling ill with stridor in August, his 13 year old brother, Zahni, noticed that he had stopped breathing completely. Their grandmother, whom they call Nana, began CPR and he was taken to Akron Children's Hospital where he would stay for 21 very difficult days. The doctors' findings: Zaren was breathing only 10 breaths per minute.



Taking action, he went into surgery to remove bone from the back of his skull and spine in a Chiari decompression procedure to make room for his brain. It was during this that doctors noticed "a thick band over the respiratory nerve that was causing the slow breathing." Zaren's breathing rate began to increase following its removal, preventing him from needing a trache to help him breathe. "We were preparing to sign the papers for his tracheotomy," says Brittany, "It's a miracle that his breathing improved."



Finally, Zaren was sent home after his 21-day stay with a feeding tube that he remained on for 9 months and continuous oxygen for 5 months. Just four days following his first extended hospital stay, he developed breath-holding tendencies where he would cry, stop breathing, go unconscious, and turn blue. A long-time family friend, Cindy Miller, describes the scene as it unfolded upon her deck one afternoon.

"All of her kids are there and they come up and circle Brittany and Zaren and just stand there very quietly and patiently until he's breathing again." All five of Zaren's siblings are more than willing to participate in his well-being, always knowing when to run for the oxygen tank or the suction and the rest of his family, as well as family friends, provide support to them in countless other ways.



In November, Zaren went into the Akron Children's Neurology department for a two-day observation for his breath holding. What was supposed to be just two days became a startling 25 days filled with five separate surgeries. The first being a de-tethering of his spinal

cord and the release of the fluid weighing down his brain stem. This then was infected, causing a need to repair the shunt in his brain. The following three surgeries were caused by multiple shunt infections and malfunctions causing several replacements to ensue. At the end of the day, the breath holding went unexplained and the Berry's learned that Zaren's heart was stopping during his periods of unconsciousness.

In total, Zaren has had 9 surgeries, but that hasn't stopped him from being one of the happiest babies ever. Having developmental delays in nearly every area, he is unable to stand or walk on his own, but his family has faith that he will get better with time. Their ultimate goal: to keep him always progressing and happy in his life, so that someday, he will be able to be more independent.

Supporting Zaren and his family throughout his journey has been Stark DD Early Intervention Service Provider Jennifer Masssar.

"Jenn Masssar has been a God send. She has been with us since Zaren has been 10 weeks old. She has been my "go to" person for so many things. She has helped me go through all of the processes of getting things that Zaren needs ie. Wheelchair, walker, braces, special seating, stander, hand splints, parallel bars," said Brittany. "Jen always answers any questions I have medically and developmentally. She always helps prepare me for the next step of his wants and needs.

"Early Intervention services for Zaren have focused on monitoring his overall development and working with mom to note changes in his neurologic status, providing short term equipment to maximize Zaren's comfort motor skills and participation with his family, and working with the family on how to incorporated Zaren's 'therapy' into their daily routine," said Jenn. He has had physical therapy as his primary service since he entered the program at 10 weeks old. He has also had consultations with our occupational therapist regarding his left wrist and feeding and swallowing. Our speech therapists have helped monitor his progress through quarterly updates and provided coaching to me so I can support progress in this area."



But the support from Stark DD also goes beyond the one-on-one work. Members of Zaren's Early Intervention team participated in the Massillon YMCA walk. They have also helped coordinate holiday assistance for the family, assisted with signing up for Children with Medical Handicaps (CMH) program and coordinated Family Support Service (FSS) funds offered by Stark DD. Jenn has also written medical justification for Zaren's orthotics, walker and wheelchair that are allowing him to be more independent.

*With his family and friends supporting him along the way as he accomplishes the little things step-by-step, Brittany states, "He's had some rough times and some really touch and go moments and I just try to remind myself that things are always gonna get better – he'll get there."*

*A special thanks to the Massillon Community YMCA-West Stark YMCA for sharing Zaren's story with us.*



# Know Stark DD



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