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- WELCOME TO -

# CAMP Gizmo!

Welcome to Camp Gizmo in Romney, West Va.! We are in a large school auditorium with a panoramic view of lush green mountains. We are surrounded by seating systems, standers, gait trainers, and any other mobility, positioning or seating device we could ever want. All of our friends are here: suppliers, manufacturer's reps, educators, physical therapists, vision specialists, speech therapists, occupational therapists, families and, of course, the children we will get to meet. Imagine you are there with me and the state has funded five magical days to meet all the children's needs for mobility, education, communication, vision, sensory, feeding, recreation, and more. Teachers and early intervention providers across the state have come to learn together and to make recommendations for 25 children. At the same time we are evaluating the children, sibling and parent workshops which are offered. There are also tons of fun camp activities that are fully inclusive. Three families have left their children with a counselor and group of campers for the very first time. In seven years these moms and dads haven't been alone together! We'd like to share one child's journey during this amazing gathering.



Ethan is 5 years old and has no diagnosis. He has bilateral club feet, hip dysplasia and some joints that are similar to children who have arthrogryposis. He has had hip reconstructions, heel cord lengthenings, club foot correction and surgery on his diaphragm and lungs. Ethan has a significant torticollis and some visual field loss. He also has a g-tube, trach and a huge smile. He and his parents came to Camp Gizmo for augmentative communication and to explore mobility options. He is just starting to speak over his trach and he definitely makes his needs known – if you listen! (see top photo.)



Ethan did not have a means for efficient mobility. He can walk short distances with a reverse walker using a forearm support on the left and a hand grip on right, but he fatigues quickly. Day 1: Ethan was driving a power chair independently! Cyglenda Abbott, ATP from National Seating and Mobility in Charleston, W.Va., worked with Paula Voithofer from Pride Mobility (Quantum) and the therapist team to set up a trial chair for Ethan. It wasn't fancy seating, but it worked. Ethan was given a proportional joystick with a ball just inside the right armrest and off he went (see bottom photo).

Paula turned the chair on and Ethan pushed her hand away, turned it off and turned it on again. Paula also tried a switch drive, but Ethan wanted more subtle control. So they went back to the proportional joy stick, and he drove like a pro. Ethan looked out into the crowd and never at his hand. He steer corrected, stopped and off he went. He seemed a

TOP: ETHAN AT CAMP GIZMO. PHOTO COURTESY OF CYGLENDA ABBOTT.

BOTTOM: ETHAN TRIES A POWER WHEELCHAIR WITH A JOYSTICK. PHOTO COURTESY OF CYGLENDA ABBOTT.

Ethan looked out into the crowd and never at his hand. He steer corrected, stopped and off he went. He seemed a little surprised he could move away from mom, so he made sure he was holding her hand so he wouldn't lose track of her. Finally mom walked in front and asked Ethan to come and give her a high five. He drove over, stopped the chair, turned it off, and reached up to give mom a high five!



little surprised he could move away from mom, so he made sure he was holding her hand so he wouldn't lose track of her (*see photo on left*). Finally Mom walked in front and asked Ethan to come and give her a high five. He drove over, stopped the chair, turned it off, and reached up to give Mom a high five! The adoring crowd of observers cheered for Ethan and his family! The family was concerned this meant giving up on walking. The team encouraged Dad that this new-found independence would drive Ethan's desire to be independent in more areas. The research (*see article in this issue, "Which Child Needs a Power Chair?"*) suggests access to power mobility would motivate Ethan to attain independence and increase his desire to walk.

The second day of power for Ethan brought tears to our eyes. He and his family went outside by themselves for a few hours. Upon their return we asked Ethan about his visit to the great outdoors. He told us he went through the grass and almost got stuck in the mulch. He went up a BIG hill. All of a sudden, one therapist knelt down and asked him what he wanted for Christmas. Ethan answered excitedly and pointed his finger insistently at the chair and said, "My chair, this chair."

Teams at camp look at mobility in different, but interrelated, ways. The school based therapists are focused more on independence while the private therapy team is looking at activity and participation. Here at Camp Gizmo, all the politics and turf battles fall away as the teams gather to meet the goals of the family and child. Ethan has the potential to use a walker and a manual chair for short distances, but he struggles to keep up with his peers or sustain independent mobility across his school day. In power, he can keep up and even lead his peers. He wants to play with the neighborhood

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kids – he typically gets to watch out the window. In power, he can also carry his suction and an emergency bag for his trach. He can have some independence.

At home, he scoots on his bottom or rolls across the floor. He loves to walk so his family will support his trunk and help him walk. He uses a standard toddler stroller for short trips. He is getting too tall for both a regular five-point car seat and the stroller. In the walker, he needs close supervision with intermittent contact guard. He cannot transfer independently in and out of the walker and he fatigues quickly. In a manual chair, he could explore his classroom, but he cannot propel on the playground surface or keep up with his class line in the hallway. His family will be able to get a walker for use at school, a manual wheelchair from a lending closet for quick trips (seating will move between bases) and they are going to now go through the process of purchasing a power chair.

Ethan's home has two floors and the first floor is accessible for a power chair with access via the garage. Their vehicles are small cars, so a hitch mount system will be investigated to help transport the power chair in the community. The power chair will go back and forth to school on the bus. They will use a walker on the top floor of the house and may look into a chair stairclimber for transfers in the future.

The family was told their insurance would not cover a wheelchair and a walker. The family applied for funding for a walker, but then the insurance company informed them neither was a covered item. Luckily in West Virginia, once you have the denial, you can submit to Medicaid. Ethan's team plans on doing this next, but first has to hunt down the actual letter of denial!

Paula and Cyglenda agree that days like these are why we love our jobs and can't imagine doing anything else. Ethan's story is a wonderful example of how people from across mobility fields can work together to change the life of a child and family. In West Virginia it happens every July for five days and, as one family phrased it, "magic happens."

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LEFT: ETHAN HOLDING MOM'S HAND WHILE DRIVING. PHOTO COURTESY OF CYGLENDA ABBOTT