

Bentley's story

-by his mother Tonya Hinrichs

Bentley has a rare, genetic brain disorder called pachygyria, which causes his extremities to have increased muscle tone (hypertonia) and his core to have decreased muscle tone (hypotonia). Bentley will be three on April 5th and still has yet to master sitting independently for extended periods of time.

We previously went to a therapy center in Los Angeles, California, for an intensive therapy session. We were hoping to find a similar therapy closer to home. We were blessed to finally stumble upon TheraSuit on our wild goose chase. TheraSuit provided us the contact information for possible therapy centers, which included Orange City Area Health System as an option to train Chris and myself so we could purchase a TheraSuit for home use. We were thrilled to find suit therapy so close to home since we saw the amazing benefits NeuroSuit provided Bentley while we were in California.

Libby, OT, assisted Bentley in overcoming his fear of straws and we were successful at him drinking out of the straw during our second week of therapy! This is a huge accomplishment for him.

We strongly believe Bentley is right-handed due to his accuracy when utilizing it versus his left.

Unfortunately, Bentley – prior to intensive therapy – utilized his right hand for stability while using his left to play. Ashley, OT, encouraged Bentley to use his left hand for stability to free his right hand to be used during play. Ashley also assisted Bentley on improving his grasp and release of both hands. He gained the ability to open his hands and grasp objects during our last intensive in California but still struggled with releasing objects. Bentley has improved releasing objects from his right hand and using it more during play. We hope he will eventually gain the ability to self-feed.

Monica, PT, focused on Bentley gaining strength during his intensive session. Bentley greatly improved walking in his gait trainer while wearing his AFOs with Monica's encouragement and expertise. Bentley was able to sit independently for 76 seconds during his TheraSuit therapy with Monica! This is the longest he has ever sat independently!

During an OT session with Ashley, Bentley moved from tall kneeling into a lunge and then standing with little support at his hips. This was amazing to see him be able to instruct his body and transition fairly quickly without being cued to complete!

We received amazing support from everyone at the hospital and the community. Living out of our fifth wheel toy hauler brings its own set of unexpected challenges. It was great to be a part of such a small, supportive community that offers such an amazing intensive suit therapy that will allow Bentley to become the most successful he can be in life. Bentley will be the only person to set his limitations in life!



**Orange City Area
Health System**

INTEGRITY • INNOVATION • INSPIRATION