Family Hope Foundation

# A PLAYBOOK FOR SUCCESS

## *A story about Gramm*

**Following an uneventful pregnancy, on January 10, 2006, Susan delivered a beautiful nine-pound baby boy. They named him Gramm.**

The first hours of Gramm's life were anything but uneventful...and uncertain. Gramm was born with spina bifida, a birth defect in which the spinal cord and vertebrae do not develop properly, leading to varying degrees of physical and neurological impairments. His diagnosis necessitated a quick transfer from Zeeland to Helen DeVos Children's Hospital, where he would be prepped for surgery.

**In addition to the major surgery to close the "hole" in Gramm's lower spinal column, Gramm was also diagnosed with hydrocephalus. This condition, an abnormal buildup of cerebrospinal fluid in the brain, is often common in individuals who have spina bifida.** To manage the hydrocephalus, a shunt, or flexible tube, is used to drain excess flluid around the brain into the abdominal area. These scary and high-risk surgeries were ones that Gramm would need within the first twenty-four hours.

When a nurse proclaimed, *"Now would be a good time to pray,"* the magnitude of the upcoming surgeries became clear. There was a lot for Shawn and Susan Hulst to digest: two major surgeries, a life-long diagnosis, and a long list of challenges in Gramm's future.

We asked Susan how she felt about this initial experience, specifically Gramm's prognosis. ***"At the time, it was hard to hear, but you don't have to live into a prognosis. You can rewrite the script. Sometimes, it's scary to have hope, but we quickly learned how important it was to keep hope in our sightline. Sometimes, you have to revise what hopes you have for the future, but that doesn't mean you ever let go of it—ever."***

Well, the apple doesn't fall far from the tree. Like his parents, Gramm has a positive mindset, drive, and work ethic that has helped him accomplish much in his nineteen years.

> ***Said Gramm, "Doctors are playing by their 'playbook,' and you have to make your own; you have to determine what you'll work toward and achieve."***

In many ways, Family Hope Foundation has watched Gramm grow up–and **we are very excited to introduce you to him!** Since receiving his first scholarship in 2011, we've been cheering for the Hulst family and celebrating each time Gramm exceeded expectations, staying true to his "playbook," never living into his initial prognosis.

Family Hope Foundation's Designated Scholarship Program made it possible to invest annually in Gramm's therapy. Partnerships with the West Michigan Spina Bifida Organization and the VanWoerkems, who support an annual scholarship earmarked for intensive physical therapy, helped make this possible.

From age five until "graduating" from therapy at 17 years old, Gramm worked with Amy Wallenburg at 1 Plus 1 Therapy. They loved her philosophy of one-on-one physical therapy focused on ensuring Gramm's strength stayed ahead of his needs as he grew.

There was nothing easy about Gramm's therapy. Gramm had three intensives each year, working three hours daily for three weeks. In between intensives, Gramm and his parents would complete an in-home exercise program lasting approximately 45 minutes a day. During intensive sessions, he worked in the SpiderCage—a three-sided wire device that uses a belt and bungee cords to enable Gramm to perform balance and strengthening exercises. Therapy in the SpiderCage led to improved movement, autonomous exercise, balance, and confidence. Gramm met one goal after another!

When we asked Gramm what his biggest takeaway from working with Amy was, he responded, ***"The biggest lesson I learned from Amy was that you can do more than you think you can. You can push past what you think is possible. You are capable of so much more."***

Mom elaborates, ***"If there were setbacks or bumps in the road, we stayed the course, looking back when we needed to in order to remember how far Gramm had come."***

Taking the easy path didn't have a chapter in Gramm's "playbook." Being told you will never walk became a very strong motivator and goal for Amy and Gramm. Blowing past all expectations, he walks with only the assistance of AFOs (ankle-foot orthotics) and two single-pole canes—one of the accomplishments Gramm is most proud of.

Along with success, Gramm's twelve years of intensive therapy came at a steep cost, none of which was covered by insurance. Family Hope Foundation became an intricate part of keeping Gramm's therapy moving forward.

***"We couldn't have kept it up without Family Hope Foundation's investment in Gramm. His needs didn't stop, so the longevity of the relationship was monumental. We knew we could apply every six months, and it made such a difference for our family."***

Gramm is now moving into a new phase of life. He's driving, and after graduating from Thompson M-Tech, he's working full-time as a welder—he recently received a raise! He just bought a new truck—a 1994 GMC Sierra 2500—that he's super excited about. As for his future plans, Gramm is saving for a lift kit for his truck and talks about eventually getting an apartment with friends. An avid outdoorsman since childhood, he still loves to fish, bow hunt, and explore with ATVs.

Staying true to his "playbook" for success, Gramm now takes ownership of his health, fitness, and ongoing physical therapy. Thanks to Amy's help in developing a detailed workout plan, he hits the gym three or four times a week!

***"I won't minimize the hard work Amy challenged me with and how she continued to push me to do more," says Gramm. "She was a great motivator, but she managed to make those intensive sessions fun. We have a great relationship."***

There is another page in Gramm's "playbook" that makes him an exceptional young man. We asked him if he thinks about his spina bifida often. Gramm responded, ***"No, because it's only one small piece of who I am. Everyone has something they are working through. Sometimes you can see it, and sometimes you can't."***

It is apparent that both Gramm and his parents have a lot of gratitude and don't take any accomplishments for granted.

***"When you have an organization like Family Hope Foundation cheering your family on and investing in your child's ability; when you have a therapist who becomes like family; when you have a 'playbook' written for success–the sky truly is the limit."***