Newsletter Sept 6h, 2019.

Hello, I am Waylun and I love sport. I have been feeling great for last 2 years after the operation. I have no pain, do not need any insulin and I can play sport again!

Waylun's Mom and Dad: "…Waylun began having "episodes" at age 2 ½ , he would be running around playing one minute then doubled over on the floor the next. As a 2 ½ year old he was unable to explain his pain , he would just say his tummy hurt.

Finally at age 6 when he had his 7th episode , still with no explaination, St Louis Children's hospital decided to do genetic testing on Waylun, He was diagnosed with Hereditary Pancreatitis, He has the PRSS1 mutation and CFTR variant. Waylun began having increased episodes, increased severity and shorter amount of time between episodes.

By the grace of GOD we found Dr Gelrud at the University of Chicago . He introduced us to the idea of the TPIAT surgery and eventually the team. By the age of 9, Waylun had had 20 episodes of pancreatitis and multiple hospital stays. Waylun is the type of kid that did not like pain medication and wouldn't even consider it until his pain was above a 6/10. June 7, 2017 Waylun had his 9 ½ hour surgery that would change his life. We were told after his surgery that they couldn't believe he was not in pain daily as his pancreas was so " full of sand" that should have caused constant pain. Waylun was discharged from the hospital 7 days post op. We were able to leave Chicago to go back home 2 ½ weeks post op. We are forever grateful for Dr. Gelrud (whom is no longer the U of Chicago), Dr. Slidell, and Dr. Witkowski. Along with all the nurses, CAN's, therapy staff and Child life staff at COMER CHILDREN"S HOSPITAL.

Our oldest son was diagnosed in December of 2017 with the PRSS1 mutation and we are already discussing his case with the team and will not hesitate for him to have the procedure if necessary. The interesting fact is we do not have a family history of the mutation which is why it took so long for Waylun to get diagnosed . However my husband and I were recently tested for the PRSS1 mutation in which my husband does have the mutation but only had pancreatitis once when he was 6. "