

In a Mother's Words

After a tragic 8 months in which we lost my stepfather, father, and sister, our family began a journey that would change our lives. We adopted my sister's son, full well knowing he had Alagille Syndrome. We weren't sure if he would survive but he has shown that not only is he a fighter and survivor, he's also the light of our lives.

Thankfully, another family made the hardest decision to donate organs and Oliver got his new liver in March of 2019. He was given another chance to lead a full and happy life, with some additional requirements. Oliver takes many different medications daily to ensure his body doesn't reject the new liver and to make sure his other organs aren't being adversely affected by the Alagille Syndrome. He has a specialist for every organ in his body and has ongoing appointments with them regularly.

Oliver has occupational, physical, and speech therapy often. Home health nurses are with him around the clock to ensure he is receiving the very best care. Oliver has had multiple heart surgeries since the liver transplant and he will require more surgeries in the future.

All of these medical interventions are necessary to ensure he stays healthy but they have also had other impacts on everyone in the family. We went from being a family of 4 to a family of 5 overnight. I had to quit my job to be with Oliver since he was in the hospital for the first nine months we had him. He requires so much care that it is impossible for me to work outside the home.

Having strangers in our home to help with him all the time has also been an adjustment for all of us. My older boys have had to deal with Oliver taking much of their parents' attention - and they have handled it with grace and huge love for their new little brother.

Fortunately, we have been able to meet some fantastic people along the way who have made this process a bit less stressful. When Oliver first came into our lives, we started a Facebook page for him so our family and friends could keep up with the daily changes to his health. We received such an outpouring of support and encouragement from the people on this page. Oliver became locally famous this way and to date the page has over 800 followers!



While we were at Texas Children's Hospital, we met the people with The Children's Transplant Initiative. They have a mission to empower, inspire, and give hope to children and their families who are involved in the transplant process. They provide spiritual, emotional, and financial support to families at the Texas Medical Center. They were, and are, a huge help to my family.

More recently, we were blessed to be a part of Long Way Home Texas, a charitable organization benefitting transplant recipients in the Houston area. They recently began to host events in which all profits are utilized to help families pay for ancillary costs not covered by insurance. These costs include food, short-term lodging, parking and other expenses incurred due to catastrophic medical issues. This past November, we were blessed to have been a part of their Honkytonk For Hope event where 14 local (and not so local) musicians performed. At the event, merchandise was sold, money was raised through auctions and donations, and a wonderful time was had by all. The event raised over \$40,000!

It is through foundations such as Long Way Home Texas, as well as donations from individuals to our PayPal and Venmo accounts, that make it possible for us to continue to support Oliver. We thank God every day for the generosity of strangers and the care and love we receive from our family and friends. We are excited to see what the future holds!