

Carson Tussing Fundraiser 2023

Dear Friends and Family,

We have so much to catch you up on. First we want to thank everyone for the generous donations last year. We could not have done what we were able to if it were for your ongoing support. So truly, we want to say a massive THANK YOU. Keeping with this theme, we are continuing to campaign and raise not only funds but awareness for Carson Tussing and RYR-1. Before we get into that though, we wanted to tell you all the things that you helped us accomplish this past year as well as what we have planned with any funds raised for this year as well as give you an update on Carson.

I wish I could say no news is good news when it comes to his medical condition. He doesn't have any new medical conditions which is great. However, we did recently learn that as he grows taller, his muscles aren't getting stronger. In fact it's the opposite, they're actually deteriorating. His hips and lower back struggle to support him and creates an unnatural curve to his back, just to stand upright. In turn this makes walking near impossible, especially over terrain that is anything but smooth and flat. Even with all the challenges he faces on a daily basis, he is still the most smiley kiddo. We are finally getting those two front teeth in! Miracle League Baseball is starting in the fall and he could not be more excited. Last season he was a White Sox so this year he's hoping for the Diamondbacks.

This past year we were able to increase Carson's accessibility to ALL areas of our home. We had a very generous donation from family members, directly funding the building out portion of the backyard ensuring Carson could use his wheelchair to access the full yard. No more stairs, no more getting left behind during playdates/parties and FULL access to the backyard. On top of that they helped us expand the front walkway. Which was so great because it gave Carson the ability to enter our home through our front door. We also added and installed a new ramp to the front door. All of this happened because of the desire to help. You gave us the funds to change not only our environment but to give Carson a little bit of independence that RYR-1 took from him. You can't imagine how amazing it is to be able to use a front door for the first time or being able to play with friends in your entire backyard without fearing you'll fall.

That's enough about the outside though. Let's talk about the inside. Oh you thought we were done? We widened the doorway as well as the hallways to accommodate Carson's wheelchair. This means less running into the walls. Keyword less; I won't say no running into them because we have a seven year old behind the wheel!

Here are the areas that we will be focusing on going forward. As you are aware there is no cure for RYR-1 and the regression timeline varies. Unfortunately, Carson has regressed quickly over the last year. This has resulted in him relying on a wheelchair full time now.

Over the last year Carson has gone through two wheelchairs, one of which was motorized, due to him growing and constant needs changing. Currently loading Carson

in and out of the van has become a challenge. He's gotten heavier as growing boys do, and his wheelchair is a cool 75lbs. Everyday we lift the wheelchair in and out at least four times, and that's just for school. We thought it would get easier over time, unfortunately it has not.

The great news is that Carson will be getting a new wheelchair in October. This wheelchair will allow him to stay in it full-time COMFORTABLY and has amazing mobility around home and school. It also grows with Carson, eliminating the need for him to need a new wheelchair as often.

This power wheelchair is a huge life change for him but it comes at a cost. Receiving this wheelchair means that we will no longer be able to lift it in and out of the van. Because of this we are left with only two options. A mechanical lift for the wheelchair, and we lift him in and out of the car, or a vehicle that allows Carson to be transported in his wheelchair. The long term goal and an absolute dream would be to purchase a wheelchair accessible van for Carson. As those are priced rather high at this juncture we are seeking funding for the lift to both buy time and to immediately accommodate his needs.

We are relying on your support again this year to reach our current needs of modifying our current vehicle to transport Carson. This is an enormous task and we could not convey enough that none of this would be possible without your help.

Thank you for all your support.

With Heartfelt Thanks,

J T Carson

Brian, Illyssa, Jaxon, and Carson Tussing