

Fundraiser for Cillian:

James Cillian Buster was born on July 9th, 2021 with a known congenital heart defect. He was scheduled for his first of two heart surgeries on day 4 of his life. Unfortunately, that wasn't the first surgery he would have to endure. Approximately 12 hours after birth Cillian had to undergo emergency surgery for a tracheoesophageal fistula which was found because his oxygenation levels started declining and he had to be emergently intubated (breathing tube put in and placed on a ventilator). A tracheoesophageal fistula means, part of his esophagus (food tube) was connected to his trachea (wind pipe).

On Cillian's 4th day of life he underwent open heart surgery to help correct part of his congenital heart defect. At one point after his heart surgery he was on 10 different medication drips (to help support blood pressure, sedation, pain medication, etc.), had multiple chest tubes all while still being mechanically ventilated. A few weeks went by and Cillian wasn't on as many drips and was breathing on his own while still having the breathing tube in. So, the next step was to take the breathing tube out because all indications from vital signs and various different tests suggested that he would be able to breathe on his own. Unfortunately, after about 3 days Cillian was struggling not only from an oxygenation/ventilation standpoint but visibly struggling like he couldn't get enough air and was suffocating. So, Cillian had to be re-intubated. Upon being re-intubated it was found that Cillian has tracheomalacia (collapsing of his windpipe when he takes a breath in). This means that the harder he tries to breathe in the more his trachea (windpipe) collapses and gives him a feeling of suffocating.

During this time Cillian took multiple trips to the operating room so that feeding tubes could be placed safely past the esophageal (food tube) repair site. Now that Cillian was able to receive his mom's breast milk the team of doctors wanted to get him bigger and stronger. This was in hopes of getting him big and strong enough to overcome his tracheomalacia. After a few weeks, Cillian again showed signs that he would be able to breathe on his own. So, the breathing tube was taken out, but this time he only lasted about 5 hours before having to be re-intubated. Since Cillian wasn't able to breathe on his own the next alternative was to insert a trach.

In between Cillian being re-intubated for the second time and him getting a trach he went down to the operating room 10 times for esophageal dilations (to keep his food tube open where it was fixed during his first surgery), 6 times for feeding tube placements, 2 times for visualization of his trachea and lungs. He has also had many bedside procedures for invasive line placements, trachea and lung visualizations, weekly echocardiograms (to make sure his heart is still performing well), etc.

Currently, Cillian is weaning off of some of the medication that he has been on from his first day of life. This has caused him to withdraw and made a lot of days tough with lots of crying, sweating profusely, gagging/vomiting while being very irritable. This has prevented Cillian, until recently, to grow and gain weight and strength. Cillian is now trialing on a home ventilator which he has to do for 2 weeks in the Pediatric Cardiothoracic ICU before moving to the "stable vent unit". When he moves to the "stable vent unit" he will have to be on the home ventilator, on the same setting for a month straight before being able to come home. Cillian has yet to meet his big sister and brother which they are anxiously waiting for.

During this time Cillian's dad had to take a leave of absence from school to be with Cillian and Cillian's mom during the more difficult times. He is now finishing up his clinical rotations but, hasn't been able to

work and won't be able to until clinical rotations are complete. Not to mention hasn't worked in 3 years while in school full time. Cillian's mom has been on maternity leave and hasn't work since he was born . She has been at the hospital everyday with Cillian shuffling back and forth between their other two children. With her leave coming up she will have to go back to work before Cillian is even out of the hospital. But will be a stay at home mom as soon as Cillian is home because he will need 24hr care everyday being on the home ventilator. They have both had to dip into retirement savings during this time to help support themselves, as well as, their two other kids.

Your donation will help cover costs associated with:

- Medical Equipment
- Home Generator (Even a small disruption in power supply is a matter of life or death)
- Medical Transport
- Home Care & Medical Bills