November 2018

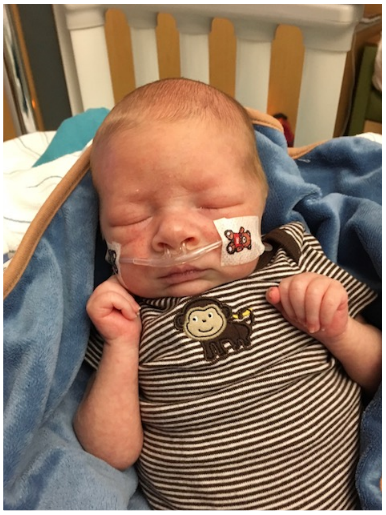
Greetings from the Hurst Family!

As our family says goodbye to an eventful year (or maybe I should say an eventful two years), this November marks our son Kaiden's second birthday, the second year of his journey with ***nephrotic syndrome, and a life-changing kidney transplant.***

Choosing the ***Clinic for Special Children (CSC)*** *team to help us through this has been the decision that most positively impacted the care that Kaiden has received. The Clinic has provided him with outstanding medical treatment and we are truly grateful to each doctor, nurse, therapist, and transplant team member that has been with us along the way. We believe our Lord God provided a healing touch through their hands.*

My husband, Dale, grew up in a family with two special needs sisters, who benefited greatly from being patients at CSC since its beginning days. My husband's family, the Leonard and Laura Hurst family, were instrumental in arranging the yearly benefit auctions to support the Clinic's continued work. After Dale and I got married, we continued to support CSC, but didn't know how it would directly impact ***our own family*** *one day.*

Our firstborn child was a healthy daughter, and the twin boys that we were blessed with a few years later (while certainly a handful!) also followed a typical healthy childhood. A little while later, we were overjoyed with the birth of ***little Kaiden*** *to add to our family. At first, Kaiden also seemed healthy, but a few weeks later respiratory distress sent Kaiden to the hospital.*



This was the defining moment when specialists recognized the symptoms of ***nephrotic syndrome.*** *Knowing CSC's experience with genetic conditions, we immediately called the Clinic. A tube of blood (discreetly carried across town in a handbag and turned over into the trusted hands of Donna, CSC's Nurse Practitioner) made its way to CSC, and* ***a diagnosis was confirmed before Kaiden was even released*** *from hospital treatment.*

This genetic disorder, Type 1 congenital nephrotic syndrome of the finnish type (also known as ***"burkholder's syndrome"*** *among the Mennonite Community) affects the body's ability to retain protein and causes* ***kidney failure within a few years of birth.*** *To us, it was an unknown medical condition and* ***we were devastated.*** *The initial information that we gathered was complicated and confusing, but an appointment at the Clinic with Dr. Strauss, CSC Medical Director, and Dr. Zaritsky, Nephrologist at Nemours Children's Health System, helped provide clarity. They used simple illustrations of kidneys that are formed with the openings too large which allow protein cells to flush through urine. This causes protein deficiency which results in many other* ***growth complications and low-immunity.***

*There were more times we came to CSC with questions and, once again, they would thoroughly explain a new tidbit about kidney function and guide us through the steps needed. One thing was clear...**we needed the knowledge of Dr. Strauss and the CSC team!***

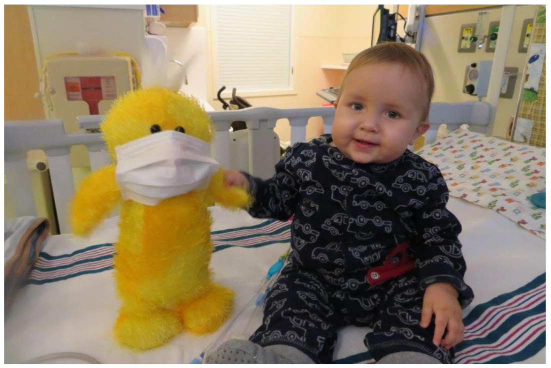
*The connection CSC has with Nemours/Alfred I. duPont Hospital for Children, and its supporting specialty physicians, provided **one-stop treatment** for most of Kaiden's first year. We could see Dr. Zaritsky for monthly appointments, and Drs. Demczko or Fox, pediatricians at Nemours Children's Health System and CSC, for checkups (sometimes weekly).*

*Donna and Millie, CSC nurse practitioners, worked their charm on Kaiden's difficult blood draws (again and again) and Dr. Strauss was there to oversee Kaiden's treatment. The open communication between the two medical groups made getting important test results and medicine changes accomplished in a seamless way. So often we were thankful that a short drive through the beautiful Amish countryside would lead us to such **extraordinary care.** It was a rough year that included many ups and downs. With the introduction of a medication regimen, we were seeing Kaiden begin to thrive and grow - **surpassing all expectations.** This made every appointment worth it!*

*The care at CSC wasn't limited to just the scheduled appointments. Whenever a new symptom turned up, they were quick to squeeze in a checkup. Did you know there are still doctors that make **house calls?** I know! When Kaiden broke out with a rash resembling chicken pox, I was surprised to hear, "No, don't bring him in. We will come to you!" Donna also came out one weekend to save us a trip to the emergency room. This level of **dedication** makes all the difference to their patients!*

*This year began with an event that propelled Kaiden towards being a typical toddler... a life-changing **kidney transplant at 14-months-old!** By God's grace, this was made possible through the selfless act of Kaiden's **daddy donating a kidney** and the expertise of his duPont surgery team.*

This was put into place by Dr. Strauss who advocated to get a preemptive transplant approved so costly, time-consuming, dialysis would not be needed. Dr. Fox was a huge supporter in providing contact with the Nemours transplant team and coordinator who went above and beyond to make things happen. With their help, the first transplant work-up tests and follow-up visits were scheduled at the hospital in manageable day trips. We can never thank these amazing people enough and hope to impress on Kaiden someday what they have done for him!



*During Kaiden's transplant surgery, **complications arose.** Once again, these doctors were there for us...taking time out of their busy day to sit with us until the surgery was completed. Kaiden's recovery in the hospital took several weeks. Since then, CSC has continued to be our in-*

between medical group through each new challenge, doing what they can to make this year a little easier like saving us the extra trips to the hospital whenever possible.

Kaiden has grown into a busy boy who thinks he has more important things to do than sit in a doctor's office; however, going to CSC is still enjoyable with thanks to the friendly hellos from the staff, a lollipop, and time to play with the large Thomas the Tank Engine train.

We recognize the journey continues, and Kaiden will ***always need the support*** *of a medical team. As we look forward to starting the new year, we are grateful to have CSC available to treat whatever challenges come along for Kaiden.*

As the holidays approach, we look forward to hopefully spending it with Kaiden and being surrounded by family and Christmas joy as we spent Kaiden's first Christmas in the hospital and the second awaiting transplant (therefore avoiding crowds and gatherings that might introduce germs).

I can tell you that it's a difficult time for families of children with chronic illness - not just during the holidays - but every day. Our wish is that every family dealing with medical needs could experience the type of difference CSC has made in Kaiden's life.

Your support to CSC opens the doors to many local families who could not afford to travel for such expert care. ***We hope you take this opportunity to give to Clinic for Special Children as they work tirelessly to improve healthcare in the lives of many children, just like Kaiden.***

Please also take a moment to reach out to a family in your community who is dealing with special needs and provide encouragement through your words or gifts - as Christmas is a celebration of God gifting us with his son Jesus Christ to provide comfort and love to each one. ***"Glory to God in the highest, and on earth peace, and goodwill toward men." Luke 2:14***

Written with love by Regina for the Hurst family,
Dale, Regina, Kylie, Carson, Carter, and Kaiden

Clinic *for* Special Children
535 Bunker Hill Road, PO Box 128, Strasburg, PA 17579 **T** 717.687.9407 **F** 717.687.9237

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Dear Friends,

Thank you for caring enough to read about Kaiden's extraordinary journey. Left untreated, nephrotic syndrome is a debilitating genetic disease that results in kidney failure, and is just **one of over 264 genetic disorders diagnosed and treated** at the Clinic for Special Children.

Without your support, Kaiden's life would have been very different. In the absence of careful management and a decisive organ transplant, he would have suffered through many complications, only to die at a young age.

Fortunately, with an **early diagnosis** from our laboratory, a great **team of doctors** delivering personalized care, and **financial support** from donors like you, Kaiden and his family now have a **bright future.**

When you choose to give to the Clinic for Special Children, you are caring for **the most vulnerable and underserved children** among us. Your support allows us to implement innovative solutions, provide compassionate care, and improve the health of our community, one child at a time.

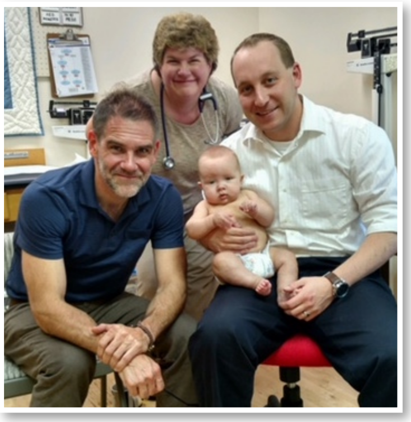
Please consider making a gift to this year's annual appeal so we may continue to serve those children and adults with special medical needs who rely on our help.

Thank you for your consideration, your compassion and hope that you bring to the Hursts and so many families like them.

You are the most vital part of the Clinic's mission!

Warmly,

Kevin A. Strauss, MD
Medical Director



Kevin Strauss, MD, Millie Young, RNC,
Kaiden Hurst, & Michael Fox, MD

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☐ Learning more about making a gift to the Clinic in my will.

If you wish to make an anonymous contribution through the Charitable Gift Fund Program at Anabaptist Foundation, please email giftfund@afweb.org or call 1-800-653-9817 ext. 209.

THANK YOU FOR YOUR GENEROUS SUPPORT!