



*A refuge for unborn-newborn babies and little children who will die and those who love them*

**NEWSLETTER**

**FALL 2018**

## **EDITORIAL**

Dear Friends of Alexandra's House,

The subject of fostering babies with special needs – even life-limiting conditions – is a very particular one. In an ideal world, birth parents would be able to welcome any child – but the world isn't always ideal, as we know. Sometimes, babies with the most needs find themselves alone, and alone is a sad place to be, especially when the odds are stacked against them in other ways too.

I'm reminded of the journey of a couple I knew in DC. They were not on the same page to begin with at all. She saw her way to parenthood through adoption; her husband did not. An opportunity arose when a baby with short bowel syndrome was left in the hospital where she worked. Unsure of adoption, even less sure of special needs and the double life change it would bring about, still, he visited the baby in hospital by himself one day. Seeing the baby alone, all hooked up to machines, his first reaction was anger. 'This baby should have a family.'

Righteous anger has its place. Not being able to stay away, but still deeply ambivalent, he visited again, and then again; on one visit, he stretched out his hand to the baby, who curled his small fist around his thumb. Simple trust, the power of the powerless. His anger gave way to the conviction that this baby was waiting for none other than *his* love and commit-

ment, and that they would, in fact, be blessed to welcome him into their lives. And so they did.

Obviously, fostering any child, let alone a child in great need, is a path for the few, but I often think it could be a path for more people. Some of the families touched by loss and the mission of Alexandra's House have a particular sense of the importance of it, as Bren's story will show. And even if not fostering, volunteering one's time with a local hospital to watch by the bed of little ones who may not have other visitors, is a most worthy endeavor. Loneliness isn't what we want for any child ever.

On behalf of Patti and all the team at Alexandra's House, we want to thank all our families, friends and benefactors, who, year after year, support our work of the heart with such generosity and imagination. We wish you all a very happy Thanksgiving, Christmas and whole holiday season.

—Hilary Stroh



*Bren wrote for us a few years back about her two children, Tatum and Zachariah – the first her biological daughter who, despite her diagnosis of mosaic Trisomy 18, is a lovely lass of 10 years old, and the second her adopted son. They joined a big family of 6 older siblings. We wanted to hear more, in this issue, on the specifics of Bren's adoption of Zachariah. Bren's story doesn't gloss over the challenges of welcoming a child with the severity of need that Zachariah has, but above all, it is a story of generosity, courage, and boundary-pushing love.*

### Defying the Odds

They started this adoption journey, believing they were opening their home to a little boy with a very short life-span; some doctors thought he would die within the month, and others gave him a 3-5 year life expectancy. At 9 ½ years old, Zachariah has clearly defied medical odds. He has proved resilient – and made his way into the heart of the clan. He has autism, severe cognitive delays, cerebral palsy and hemiplegia on the right side. All the usual milestones can't be taken for granted in children fighting such physical odds, which makes the milestones they *do* achieve even more impressive. At 6, Zachariah began eating food properly, after being bottle-fed for all those years.

### A Different Path

Seeing all this has been a revolution for Bren personally. She writes: 'But this life, as momma to two special needs kiddos...it shows you God's love and mercies and graces in a way you just never saw it before. The Grand Canyon is a beautiful sight...you know God created it! It is amazing. But seeing a child come back from the edge of death...a brain surgery, a mystery illness...it is seeing God at work in a whole new light. Even the little things...seeing a child roll over at a year old, or get up on their knees at two, or take a few steps at the age of four, when they were never supposed to take a breath outside of the womb! Amazing!'

### The Challenges

The road is never smooth, of course. Bren has had to fight for her little boy, and has done so with lots of courage, in hospital and care situations. She has

sometimes felt up against the odds, dealing with professionals who haven't always listened, or wanted to help out, especially as his diagnosis seemed fatal. Indeed, the lissencephaly he was originally said to have was eventually proved to have been mis-diagnosed. And the seizures and pneumonia she was told would dog his days have not materialized. He has never had either.

To give him some more ease, Zach recently went on medication to help mitigate the effects of the impulsive behaviors and anxieties that are caused by his autism. His parents are trying to find a pathway for him so that he feels safe and unthreatened in what are ordinary situations, and this will be increasingly important as he gets older and physically more capable. One of the upsides of the medication is that he allows himself to be touched again, on his terms, of course – like all boys, he has an independent sense of self! He loves to cuddle now and snuggle. For Bren, this is a wonderful development, and allows him to receive the affection the family wants to lavish on him.

Bren's life and the family's life continue to be turned upside down and she full well knows the isolation and the logistical, emotional and financial challenges of all of this. For a self-confessed neat freak who liked things her way, to accept all the dramas of life with and care of two special-needs children, especially Zachariah, is indeed an extraordinary testament of loving acceptance, of going beyond every possible comfort zone. Not qualifying for SSI, both Tatum and Zach have been on a waiting list for Kancare and state aid for over 5 years. Their insurance happily covers medical appointments, but not durable medical equipment, so there is a delicate balancing act in all of this.

### Love above all

For Bren, all of it is worth it. She will take it all on and more because, as she writes, she 'loves this boy in a way I cannot even describe'. She has also been taken aback at how much her husband adores this boy. 'They have an amazing, deep, indescribable bond'. He tells people it took him adopting one for him to love them. He had always been a devoted father, but on active duty for USAF for much of the older children's growing years, he was busy. As an older father by the time Tatum

and Zachariah came, he had more time to be around, to do what Pope Francis urges us parents to do, to 'waste time with your children'. And Zach, Bren adds, is over the top in love with his "Kawkee" (his pronunciation of Poppy...what the kids all call their dad): it is beautiful to see.

Would she do it all again, knowing all they know? Would the family? Yes, she says, 'in a heartbeat! How could we not? Sometimes my family jokes and one or two people will say, "Hell no!" But, those are the ones who love him the most!' She doesn't say what she says lightly. She

doesn't speak from a place of sentimental naivety. She knows from the inside out just how much a challenging love can shake up your life, and that of your whole family, of the compromises made and things lost, and good things you miss out on. She has her fears of the future and what it will hold, she needs grace every day to manage all she has going on and nobody is inexhaustible, so she needs to take care of herself too. But, she writes, although it certainly isn't for everyone, 'there is such beauty in it – the experience of adopting a medically fragile child with extra special needs...blessings unlike anything you can imagine'.



"Bow Ties for Babies, 2018 - Guests included (left to right): Coelleen Walter and son, Ethan; Speakers, Adrienne & Wes Runnebaum; Co-Chairs, Tricia Clement & Lyndy Volker.

## *Our Brother Jude*

I suppose our story about the loss of a sibling really began when I was a child, probably around the age my oldest, Jack, is now. Some of my most vivid memories of childhood are of decorating our Christmas tree each year. I loved hanging Christmas ornaments, and while sifting through the box, I would come across one handmade from a small aluminum tin, with a teddy bear etched onto it and blue ribbon lining the edges. It read, "Baby Jacob. Always in our hearts." I eventually learned that before I was born, my mother had a stillborn son.

After meeting my husband Joe in college and marrying in our early twenties, life progressed just how it "should." After a couple of years, we decided that we were ready for children and welcomed our first son shortly after, Jacob Joseph Donahay. "Jack" is named for my father, but I also thought of his name as a way to honor the older brother I never knew. Jack (now 7) was followed by Matt (5) and Gus (3). We came to enjoy having our boys close in age. They get along well and easily entertain one another. In the summer of 2017, we decided we were ready for one more child. It started out just as it had be-  
(cont'd.)



fore, but at 10 weeks along we found out that the baby had miscarried. We hadn't yet told the boys about the pregnancy, so while I was terribly sad, I didn't want to dwell on the pain. If my husband hadn't insisted, I'm not sure we would have given the baby a name (Sam) or taken the remains to be buried in Resurrection Cemetery. Joe went alone to his burial; I couldn't even bring myself to go, let alone tell our children.

By December, I was pregnant again. The new baby's due date was even the exact date that we lost Sam; surely, that was a sign of new hope for 2018. Still cautious, I didn't want to tell the kids right

away. Joe came with me to the first visit this time, and we were reassured by hearing a heartbeat at 10 weeks along. We scheduled an ultrasound for the following week. That day, Jack had an unexpected snow day from school. He was there with us when we were given the first indication of our



son Jude's diagnosis: "the skull should light up bright white on the ultrasound by now." A few hours later, after driving to Hospital Hill, it was certain: anencephaly--always terminal, never cured. It was the day before Jack's 7th birthday and remains the worst day of our lives.

To walk the roads to life and death simultaneously with our children was both heartbreaking and transformative. Jude was expected to survive close to term, and we wanted to celebrate his short life. His siblings all prayed for him each night, and bedtime stories included books about loss. Our favorite was one a friend gifted us--*Loving Baby Louie*. Jack often shared his prayers for his baby brother with his first grade class. Several of his classmates attended Jude's memorial, and his class gifted us a beautiful piece of artwork

they made together for Jude. Matt told his teacher at the time about his brother in mommy's tummy whose head was broken. His teacher told him that she chooses a certain flower for special people she has in heaven. Matt chose red tulips for Jude. A couple of weeks after his death, friends sent us some beautiful flowers; they chose red tulips without having known the story. Gus, the littlest, loved to kiss my belly and feel Jude kick.

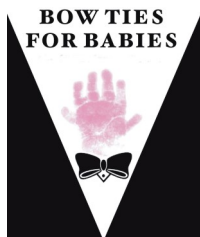
Towards the end, with the guidance and support of those from Alexandra's House and the Children's Mercy Palliative Care team, we decided that we wanted Jude to meet his brothers whether he was born alive

or not. Jude was born still at 37 weeks, and his defect was very severe, but in his brothers' eyes, he was perfect. They loved counting his little fingers and kissing his tiny toes. The most precious memories we have are photographs of the 4 of them together. Jack read the petitions at the memorial, leading

about 75 friends and family members in prayer for "our brother Jude."

After Jude's passing, one of the most meaningful messages anyone wrote to me was this: "All I can think to say is that I think that you all gave Jude a beginning and end that so many of us wish to have and give others: ones where we are surrounded by beautiful, endless, consuming love." Jude and Sam now rest together in the same section of Resurrection Cemetery. My prayer is that they are together in heaven, as close to one another as their living siblings are, interceding for our family. This Christmas, whether or not you have living children, whether or not you held your baby in your arms, I would encourage you to do something to remember. Even if it's just hanging an ornament on the tree, you never know the peace it might bring.

## *Bow Ties for Babies 2018*



The annual gala, Bowties for Babies, hosted by The Friends of Alexandra's House, took place this year on 5 October at The Venue in Leawood. It is always a wonderful occasion to support the work of Alexandra's House, to hear news of its updates, and, of course, to mingle among old friends and make new ones. This year, Tricia Clement and Lyndy Volker served as co-chairs of the gala committee. Tricia is an Alexandra's House mom of Lexi and Zoe, and Lyndy is an Alexandra's House aunt to Mallory and Julia.

The committee writes:

Dear Patrons, Friends and Parents of Alexandra's House,

The 'Friends of Alexandra's House' wish to thank you once again, for your generosity and attendance at this year's event. It was an event blessed with joy in celebration of our babies as expressed by our speakers Adrienne and Wes Runnebaum, who shared the story of their beautiful daughter, Gabriella.

This evening is always an occasion with a very special atmosphere and this year in particular seemed to have a family feel as some of our families brought siblings and cousins of our babies to enjoy the evening. What an immense blessing.

We are pleased to announce that we have already raised \$43,000 in our preliminary count and are still awaiting future donations. We look forward to seeing all of you next year along with some new faces. May God's blessings be upon all of you.

The Friends of Alexandra's House.

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*Alexandra's House*

