

*Building a
Culture of Love*



*Spring 2015
Newsletter*



Celebrate

this spring season the many fruits in affirmation and love of life that our babies have brought us.

In this spring edition of Alexandra's House newsletter, we focus on the stories of what happens to families after they receive a negative prenatal diagnosis for the health of their babies. Three families, all three whose experience of loss has been mediated by Alexandra's House, bravely share their stories with us.

Susan and Johnny tell of preparing themselves and their two boys to face the reality of baby Andrew's short life, and then of his influence on the rich tapestry of their family life. Andrew is not a taboo subject: he is truly part of the siblinghood whose memory is celebrated and whose presence is deeply felt.

Dori tells us of the loss of her daughter Mathilda and how she and her husband Jason and their boys have subsequently found joy as a family in fostering and adopting special-needs children. Brenda's article is a reminder

that not all families who are expecting babies diagnosed with a fatal anomaly face immediate loss.

Brenda and Jack's darling daughter, Tatum, who has a mosaic form of Trisomy 18 is now a funny and lovely girl of 7, and is joined in their large family by Zach whom they have subsequently adopted.

We therefore celebrate in this spring season the many fruits in affirmation and love of life that our babies have brought us – all of them, the healthy and the sick, the living and those gone before!

THE HART FAMILY

Life after Andrew

Johnny and Susan Hart recount how their family remember baby Andrew, cherished third son and brother to Luke, William and Eve.

Nothing can prepare you for a negative diagnosis when you're pregnant. Our family experienced this sorrow. And when our son Andrew was born on October 3, 2007, he lived only a few minutes before he passed away.

In the blur of heartache and loss, our family had time to prepare in a way for the potential and likely loss of our son at birth. Andrew, at week 24 during a routine ultrasound, was diagnosed with Trisomy 18, a chromosomal anomaly. Later, at week 35, it was confirmed that Andrew actually had Trisomy 13, a more lethal form of the chromosomal anomaly. My husband, Johnny, and I knew there was no other option than to work this journey to the bitter end.

We were concerned about our two sons Luke 5, and William 3. Our boys were excited about a new sibling; yet when we were made aware of the news, we knew that this one was in God's hands! We explained to our sons that sometimes people come into the world for a really short time, and then God wants them to be with Him in heaven. This meant that our baby would be our advocate in heaven... our personal Saint. Growing up catholic, and understanding the redemptive role of suffering, helped with having to explain this to our children.

This open dialogue continued throughout the pregnancy. Our family dialogue was a gift, in a way, because it planted both the seeds of comfort and grieving throughout. It's truly interesting, the permissive ways of God.

In the highs and lows of our journey with baby Andrew, I must confess, I never felt abandoned. Perhaps it was because I had two other sons who demanded my attention, and, my husband's job was a very busy one! Indeed, I believe God's grace was with me, with the boys, and with Johnny. Truly, we chose to trust him, letting him take the wheel and drive us through this difficult time. This submission to him made it easier - it simplified our thoughts and explanations to ourselves and the boys. We can't always understand the "why" in difficult



tragedies - especially with children; but, giving it to God, surrendering that pain and suffering allowed us to simply trust and let go.

Our oldest son Luke, then 5 yrs old, shares his experience:

"My brother died when I was 5. Our whole family was sad. We had a funeral. Funerals are sad. Andrew, my brother, would have been a great little brother. I know he is in a better place and that he is watching over our family."

Johnny and I gently shared with the boys how things might play out at the time of Andrew's

birth. In doing so, we would prepare them for the tears that followed. William, our 3 yr old, shares his experience:

“I was very sad that my brother Andrew passed away, but I’m happy thinking about the idea of him watching us from heaven. It’s weird to think that he would be celebrating his 8th birthday this year. I miss him. I know that I’ve experienced sadness and the loss that death brings; but, on the brighter side, I’ve gained an Angel – my brother Andrew.”

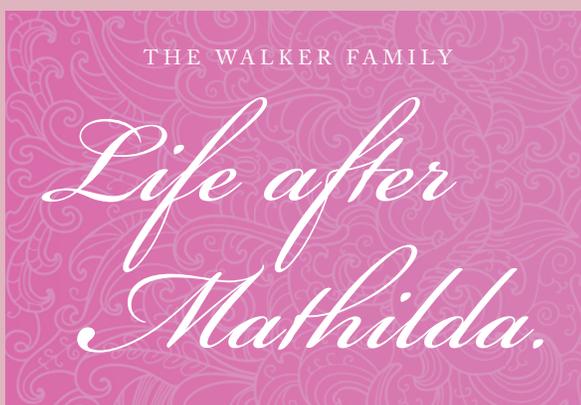
Our boys are happy to talk about their brother, and laugh at the idea of him growing up. This kind of comfort in talking about our loss brings joy to us all. It was the loss of Andrew that brought us, almost instantly, a deep desire to have another baby. I silently prayed that God would bless our family with a healthy beautiful baby, preferably a girl, to complement our two wonderful little boys!

Our daughter Eve Marie Hart was born March 22, 2009. It’s truly a miracle, this thing called life,



and so precious a gift. I understand that more than ever.

We, the Hart family, feel so blessed to share our story. It’s one of deep love for God’s precious gift of life. Even though our little Andrew’s life was so short - wrapped in pain and bitter sorrow - it was nonetheless significant. It taught our family valuable lessons in trust, compassion, surrender, and hope. Life goes on, and with the grace of God, nothing is impossible.



In this interview, Dori Walker tells us of the loss of her daughter Mathilda and how they have subsequently found joy as a family in fostering and adopting special-needs children.

It has been 3 years since you lost your beloved daughter, Mathilda. Tell us about her.

Mathilda’s story is one of heart-break but also of beauty, strength and purpose. We found out at the gender reveal ultrasound that she had anomalies that made her chance of survival quite slim. She had fetal hydrops and it was smothering her organs. We soon found out that she was afflicted with Turner Syndrome, a condition where only one of the sex chromosomes copies over correctly. It is a condition that girls survive and thrive with. Unfortunately Mathilda’s complications took her life at around 25 weeks. Words cannot explain the sadness of those weeks but also the determination and strength she helped me find. I was blessed to be able to baptize and hold her for several hours after her birth on May 6, 2011. We had been told to abort her because it would be easier and her anomalies would make her look “unappealing”.

Without a shadow of a doubt I can tell you that those 6 weeks were an amazing journey for me and all I felt when I saw her was awe for how hard she fought to live and love for the beauty in her very imperfections.

What made you think of fostering and then adopting after the loss of your beloved child?

Adoption is something that Jason and I had talked about from the start of our relationship. I think that going through this pregnancy in such devastating circumstances helped us grow in our own relationship with God and with each other. We were able to grow in times that we had next to no control of. Going through this experience gave us the courage to face the unknowns and trials that come with foster-care and adoption. Mathilda taught us one of the most valuable lessons I have ever learned in life: that “life is not meant to be easy but that the hard things can also be beautiful and full of purpose”.

What difficulties did you face?

I think it was hard facing the judgement of other people. From deciding to carry Mathilda, having a memorial, grieving, not having more biological



children, fostering, and adding 3 more children through adoption: everyone has an opinion of what you should do and how you should do it.

Were you, your husband and your children always on the same page?

Yes, it was very important to me that we were all on the same page. My children are very open to adding more kids to our family. If they had their way we would add 4 more so that our 12 passenger van was completely full!

You are currently in the process of adopting a sibling group of three. Tell us about this?

We are in the final phases of adopting a sibling group of three. L. is a 14 year old girl who is blind with profound hearing loss as she was a micro-preemie. J. is an 11 year old boy on the autistic spectrum. S. is an 8 year old girl who has medical conditions due to being also born a micro-preemie. We saw their picture on a website featuring kids available for adoption. I showed my husband and kids the picture and they all said: “when do we bring them home?” They officially came to live with us in August and have been such an amazing addition to our family. It has been a virtually seamless transition. They are so resilient, loving and smart.

How do your boys see this as part of Mathilda’s ‘gift’ to your family?

My boys are now 11 and 7 and they are quick to remember her when people ask about our large family. They often add: “we also have a sister, Mathilda, in heaven”. They love celebrating her birthday and we also do random acts of kindness in her memory throughout the month of May. This includes giving their toys or allowance on their own volition to help others. Our new kiddos are also thrilled to participate this year as well. S. has decided to change her middle name to Hope in honor of Mathilda Hope when the adoption is finalized.

From having been a family left with 2 boys after Mathilda’s death, you now have 6 children 4 of whom you have chosen to accept as gifts. Tell us about this, how has this changed your family life and what has Mathilda had to do with this?

Mathilda is a constant source of encouragement in our family. We use her amazing short life as a source of motivation. It is a concrete example of God's plan and timing through a heartbreaking



experience. She also taught me to enjoy the moment and to have patience. Adoption happens on the courts' schedule not ours. Adding 3 has been amazing and sometimes exhausting. It has been exciting and scary. We can say with 100% certainty that we love them all fiercely. We are blessed with the opportunity to be the parents of JJ, Lance, Mathilda, Luella, L, J and S. And we are open to God's plan in the future which could very well involve more additions through adoption.

The Walkers have created a website in honor of Mathilda to support children in foster care.

www.powerofalife.org

THE SPURLOCK FAMILY

Life with Tatum and Zach.

"If God wants you to have a baby, He will give you a baby!" These were Jack's words to his wife Brenda back in 2007. So they and their whole family of 5 were so excited when they found out that, after difficulties and reverses, they were expecting a sixth baby. Their world fell apart when the doctor said at an ultrasound that this baby girl, whom they had named Tatum had a diagnosis that was "100% fatal". All these years later, Brenda says those words still ring in her mind. And yet, Brenda writes: The doctor was wrong. Tatum turned 7 in

February. Tatum has been a miracle since the moment she was conceived.

She came into my womb against all odds, came into this world against all odds, and fights the odds to this day. Tatum is the light of our lives. She is funny, spunky, beautiful ...and as always, our miracle. We are so honored that God chose us for this experience.



Can you tell us a little more about Tatum's diagnosis and how it affects her?

Tatum's diagnosis looks bad on paper. She does indeed have Trisomy 18, but it is a partial or mosaic form. She has balance, speech, gait, coordination, and even body temperature control issues and more. She has a minor heart condition, but all of the major issues closed and healed. Her T-18 makes her have small stature, a tiny face and head, and at 7 she still looks like a baby/toddler in some ways: a blessing really because she is so cuddly and loveable!



How have your other children adapted to having a very special sister in their lives?

My kids have loved Tatum from the moment we announced our pregnancy. And they have prayed with us, cried with us, and rejoiced with us through every step of this very intricate path we have walked. Above all, every one of my kids is over the top in love with Tatum.

What challenges have you faced welcoming Tatum into the heart of your home?

Bringing up Tatum is a challenge, and always has been. She takes a lot of time, and her care has never been easy. When we took Tatum home from hospital, things were especially difficult. There was no peace, no quiet, no warning: she went from sitting there to screaming at the top of her lungs. No fussing: just 0 to 60, in an instant. We all took turns swinging her from side to side, her preferred motion. There

is a saying "Many hands make light work!" And in our house, many hands saved the last person's back! So she was always in someone's arms! And nobody minded. Everyone at home, and at church, wanted to hold her. She was the center of our world.

Tell us about Tatum's special connection with her elder sister Jamie?

When Tatum was still tiny, my daughter, Jamie, became ill. There were many diagnoses along the way; ultimately, we think it may have been Lyme's Disease. Somehow, Tatum sensed that Jamie was different. Jamie couldn't swing her or walk with her for hours but she was peaceful with Jamie and would allow Jamie to just sit in a chair and hold her. They formed a sweet bond and we began referring to Jamie as Tatum's buddy. That bond is sweet and beautiful to this day. And even though Jamie is not sick anymore, there is a calm and a tenderness between the two of them that really touches my heart.

Since having Tatum, you have welcomed another baby into your lives through adoption, Zach. Tell us about him?

In 2009, Patti called me and told me about this little boy who was still in utero, and that he had a similar prenatal diagnosis as Tatum's. She told



me that there had been a plan to give this little guy up for adoption, as his parents were young and unmarried and unprepared for a special needs baby. Every agency or person involved did their job quickly and efficiently and we brought our baby boy home on his 1 month birthday: he became ours less than 2 months later.

I do not think we would ever have considered adopting a special needs child if we had not had Tatum. We would have been too scared. Although we were really scared, we felt that we had committed to loving Zach and to him being a part of our family, just as we had to Tatum, before he was even born. And to back out of the commitment would not be honoring to God or to how we felt about life.

How is Zach doing now that he is 6?

Zach laughs, he smiles, and he is the light of my husband's life! He has brought more joy to us and the people who know him than can be measured. At birth, the doctors didn't want to give him the care he deserved and I have had to fight hard to get things done for a child who did not have a full life expectancy. Well, he has healthfully outlived every single doctor's prediction for his life. And he is going strong!

How has your family life changed as a result?

We have always been a super-close family. I don't think Tatum and Zach changed us much at all, as far as that goes. Our lives revolved around home, family and church. And Tatum and Zach fit right in. Of course there were adjustments! But really, not like you might expect. I will say this though: I was a perfect housekeeper, a very strict disciplinarian who expected a lot from her kids, and well, really a control freak in my home and with my family! Tatum and Zach did change that - by leaps and bounds. They have taught me to slow down, not worry about all the little things, and they forced me to let go of my expectations.

And the other siblings: how have they evolved?

The others in the family do without a lot. We don't have many resources, and what we do have is often tied up in special-needs paraphernalia for Tatum or Zach or both. No one asks for anything. No one begrudges the two what they need. It is a circle of love and support unlike anything I have ever seen or heard of in any other family. I am truly humbled. I think God always knew we would have Tatum and Zach in our family and we just naturally morphed

into the family that would be perfect for them. He was always preparing us, we just didn't know it!



What is your advice for people expecting a baby with an uncertain diagnosis, especially a possible 'mosaic' outcome, where the future is unknown and largely unmapped?

This push for ending a life because of a test result: that has to end. Lives should never be discarded because of fear or what ifs. If parents could talk to people like Jack and me, and actually meet Tatum and Zach, and know that even if they can't handle it, there are parents longing to adopt their child: what a difference that could make. But hopefully, they would see the joy that these babies bring! A test does not tell a full story. Tatum and Zach tell a full story!



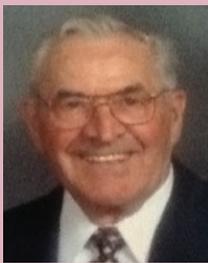
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*Seventh Annual
Bow Ties for Babies Gala.*

The Friends of Alexandra's House will be hosting the seventh annual Bow Ties for Babies Gala on **Friday, September 25, 2015** at the Grand Street Cafe, Kansas City, MO. For more information, please visit bowtiesforbabies.com. Please help them promote this event by sharing with your friends, family, coworkers, and community. They are in need of corporate sponsorship.

*Dear
Friends.*

He spoke little, smiled easily, was kind and gentle, humble, very dear to me, and to Alexandra's House. Frank Dolphens, Sr., of Omaha, Nebraska, died recently, mere weeks after celebrating his 90th birthday.



We met years ago through Frank's son Tom, also a close friend. Perhaps it was his love of babies but for some reason Alexandra's House truly captured Frank's heart. He attended the dedication of our

House in 2002 and on that night and then on the third day of every month thereafter, for 12 solid years, Frank sent a check for \$100 to support our services. The incredible thing, he did this not from his excess but within his simple, lovely lifestyle. So generous and committed was he to us, that even during his last months as he was weakening, he asked his daughter to make sure his donations were

made. Through this and the way he always lived his life, he left us, and many who knew him, in awe.

Frank, along with his late wife, raised quite a special family consisting of 8 children, 18 grandchildren, and 7 great-grandchildren. The grandchildren spoke of a favorite Christmas memory where everyone found a personalized stocking hanging from Grandpa's mantle, but alongside all the others, one more stocking simply bore the name "Baby Dolphens" as Frank was always making room for another baby. While this large family brought great joy into his life, he also knew sorrow. His mother died when he was only six and more recently, he mourned the deaths of a granddaughter and a son.

It is hard indeed to accept Frank's own death, but truly, the best of him lives on in that big, wonderful Dolphens family. In addition to that brood, Frank also helped to raise another family, Alexandra's House. He will always be a part of our history and remembered with immense affection. Once more we say to him, thank you.

Patti.

Patti Lewis.
Founder-House Mother.
Alexandra's House.



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