



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

NEWSLETTER

Spring 2017

EDITORIAL

Welcome to the Spring edition of our newsletter!

Back in late January, I had the privilege of attending my first March for Life in Washington DC. A massive gathering of people from all parts of the country and walks of life, it was truly impressive to see people of goodwill coming together to promote a culture of life. **Where do we go from here?**

First, it is important to try to ensure legislation is made which is in keeping with human dignity (we applaud, for instance, Carrie Alexander's initiative to develop a parent's bill of rights which she discusses below; we also mark the recent successful passage of Simon's Law in the Kansas Senate Committee). And even beyond legislation, the shift needs to happen in hearts and minds. It is from here that we make decisions about life – our own and others. As the celebrated Soviet dissident and novelist, Aleksandr Solzhenitsyn once said, the 'line dividing good and evil cuts through the heart of every human being'. And so the real task ahead of us is to change our culture deep down, to slowly and arduously form a society where even those whose health is most severely compromised are made welcome, where vulnerable families are assisted at every moment. In this edition, we will hear from some unique voices – a primary school pupil, a high-schooler, a legal advocate, a parish administrator, and a prisoner – who join us, at Alexandra's House, in that mission of transformation.

--H.M. Stroh

A Prisoner's Report

Alexandra's House touches a chord with people in all walks of life and for all sorts of different reasons. A prisoner in Cameron, Missouri, writes of how its mission registers with him, particularly as a way of thanksgiving after his granddaughter's full recovery from an illness, thanks to her sophisticated medical care.



When my first granddaughter was born almost ten years ago, she had an intestinal malrotation. It took some time to detect and diagnose and she had surgery to correct

the problem at the age of three months. I realized then how fortunate we were for her to be born when she was. Had she been born at the time when my grandmother came into the world, one hundred years earlier, her condition may not have been detected in time. Even if it was, surgery may not have been an option and, even if surgery would have been possible, it was most certainly far less advanced than it is today. My family was very much blessed that her physical malady was remedied with relative ease, sparing us tremendous grief and sparing my granddaughter tremendous pain en route to almost certain death.

(cont'd. on page 6)

Mason's Mandate

Last June, Carrie Alexander's four-month old son, Mason, died of Sudden Infant Death Syndrome (SIDS). As well as the trauma of losing their cherished baby, the family had to face the additional trauma of a confused system unprepared to deal with these situations respectfully. She found that there was no defined set of instructions that guided law enforcement, first responders, hospitals and social workers to properly investigate while remaining compassionate and respecting the rights of the families that have experienced a tragic loss. She is thus preparing a bill of rights to protect families from injustice. She writes:

SIDs is the most common cause of death between 1 and 6 months of age and peaks between 2 and 4 months of age. Infanticide is the lowest statistical cause of death. The treatment of parents after the sudden loss of their baby is an infringement on basic human rights and the rights as a parent. Because of this we have been working to establish Mason's Mandate; a method that sets a legal precedent for the procedures that should follow the death of an infant.

Mason's Mandate would involve several directives but possibly the most crucial would require all unexplained and non-traumatic deaths to be taken to the emergency room, regardless of time of death. By transporting to the hospital there is an unbiased physician that can examine the infant and evaluate if there are any obvious injuries or something that looks suspicious. As a trained medical professional, they can give their preliminary findings immediately. It can take months for an autopsy report and an official cause of death to be determined so this would also prove helpful during an investigation as law enforcement could know sooner if there was any suspicion surrounding the cause of death. While police officers and detectives are trained to investigate the "crime scene" they are not medically trained and therefore cannot give a proper perspective on preliminary causes of death. If the coroner finds something concerning they can also compare their findings to the notes from the emergency room physician.

There are additional benefits for transporting the infant to the hospital as well. When the parent or caregiver finds the infant unresponsive and calls 911, the baby is often taken from their arms by first responders within minutes. In many cases this is the last time the parent holds their baby until after the autopsy. The

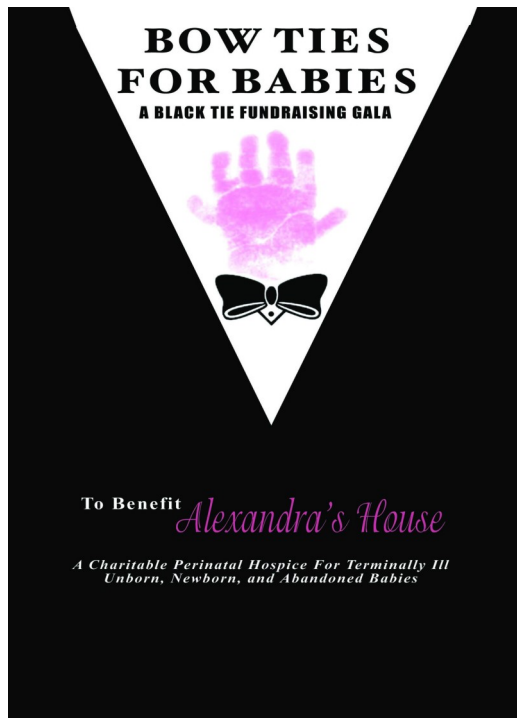
infant has already passed and first responders know this but there is a whirlwind of confusion as parents try to orientate themselves with what is happening. The family is entitled to an opportunity to see and hold the infant once death has been pronounced. This right is commonly the very first to be stripped away from parents as the baby's body becomes classified as "evidence." At the hospital, trained professionals are on hand to explain the death and provide a controlled environment for parents to hold their baby one last time.

This also provides a non-threatening place where detectives can proceed with their investigation. The infant's pediatrician or family physician should be contacted immediately to give initial insight to past behavior and medical history. Additionally, if the family has religious affiliation, a clergy person should also be called on their behalf. These professionals would also serve as the appropriate people to advocate for the family as well as provide them with information about counseling and community programs that can provide further support. Providing the family with grief support and respect should be the standard of care but it is currently often neglected.

Additionally, Mason's Mandate would create a protocol for the hospital that would further help in addressing how and when to assist in the many issues that require attention, such as providing a respectable room where parents can hold their baby, resources for grief counseling and religious support, the opportunity to bless the baby, guidance for funeral arrangements, and assistance in handling the reactions of surviving siblings and other family members.

The mandate would essentially provide explanation of parents' legal rights so that all parties know what to expect; parents, family, hospital personnel and law enforcement. When we lost our son the hospital had no standard procedure because there simply wasn't one. They just did what the police told them to do. The appropriate professional response to any child death by police and investigators must be compassionate, empathic, supportive, and non accusatory. Inadvertent comments, as well as necessary questioning by medical personnel and investigators, are likely to cause additional stress. It is important for those in contact with parents during this time to be supportive while at the same time conducting a thorough investigation. It is our hope that Mason's Mandate will help accomplish that.

2017 BOW TIES FOR BABIES GALA



The Friends of Alexandra's House
request you to
SAVE THE DATE

FRIDAY, OCTOBER 13, 2017

THE GRAND STREET CAFÉ

4740 GRAND AVE.
KANSAS CITY, MO

Please consider an early donation of any amount to help defray the expenses of this event.

If you use PayPal, please add a note
Donation for BFB Gala

OR

Check made payable to *Friends of Alexandra's House*

Auction items also welcome

Bridget's Story

Bridget May (age 15) of St James' Academy wanted to write an article for the newsletter about her family's ways of remembering her brother Zachary. She has worked as a volunteer at Alexandra's House.




My brother Zachary passed away before I was born; he was three days old. He had Trisomy 13. I was born 15 months later and welcomed by my two older sisters. Although I never met him I still have a strong connection to Zachary. I can't remember a time when I didn't know about Zachary. Growing up I thought of my brother as my guardian angel. We have several different ways that we remember Zachary in our family. My dad always wears a St. Zachary medallion. I remember when I was a little kid and my dad would give me a kiss good night and I would kiss his medal and tell my brother goodnight. I now wear my own Zachary medal every day so that it connects me to him. We also have a special cabinet with

pictures of him, a special poem and castings of his foot and hand. In our backyard we have a Zachary garden where my mom has planted a flower garden and we've built a fire pit. Multiple things like this and stories about his short life and all the people that helped my family during that time make it so that discussing my brother is not taboo. He has always just been part of the family. The most uncomfortable part of talking about my brother is how weird people are about it. No one likes to talk about it but sometimes babies die. Sometimes when I talk to other people about him I find out they have had a similar experience. My family, by talking about it, has made it easier for me to develop a relationship with my brother. I think by losing Zachary, it has made my family understand that life is precious.



Merit's Story

Staci Volker lost two daughters, Mallory and then Jules, and has been very open about sharing their memory with her other children, Grant and Merit. Staci has always felt that sharing their girls' memory should be a positive experience, and has encouraged Grant and Merit to feel their spirit in time of need and thanksgiving. Here, Merit who is age 8 and a 2nd grader at St Elizabeth Catholic school writes in about her sisters; we include the facsimile.



My Sisters

One day, I saw a pink box in my bedroom. I wonder what it was. I was only 2 or 3 so I was not that bright. So I asked my mom what word was on the front. She said "It's not a word, it's a name, and the name is Mallory." I said "Whose name is Mallory?" My mom got down the box and opened it. There was a little shoe, a blue hospital bracelet, a card, and a picture of a baby. I asked my mom who was the baby, she started to cry and said "It's your sister." I said "I don't have a sister." My mom said "You don't just have one, you have two sisters that are past away." I said "What does past away mean?" she said "It means that they died." I patted her back. Then my dad came in and said "What wrong?" I said "My sisters we were talking about them." Now I know about my sisters. Even though they are not in my house, they are always with me in my heart.

Love,
Merit



Merit

Alexandra's House Family Reunion and Christmas Party

For the past 7 years, the Altar and Rosary Society at Redemptorist Parish in mid-town Kansas City has helped to host the annual Alexandra's House Family Reunion and Christmas Party. Carol Wallace writes of why they are honored to keep up this tradition.



Seven years ago our Altar and Rosary Society was approached to help sponsor a Christmas party for Alexandra's House. After a discussion amongst our group, we decided we would move forward with this request. What we didn't realize was the request was simply for a space to hold their event!

We began brainstorming and shopping immediately. Inspired by a display in a Halls' window, we decided upon a candy theme. We filled the room with garlands, wreaths and Christmas trees, dressed out in colorful stuffed animals, ornaments and, of course, candies. We offered a light luncheon buffet, and filled clear glass jars to the brim with colorful candies, in the hopes of delighting the children who would come.

The guests arrived and the children's voices began to fill the room with excitement and joy at the sight before them. As the party went on we noticed tears in the eyes of some of our guests. We couldn't imagine what had happened to cause this. As it turns out, the tears were tears of gratitude. As I mentioned earlier, the original request was simply for a space not an entire party. This was surely one of those times where we are reminded '*everything happens for a reason*', and '*there are no accidents*'.

A tradition began that day which we are honored to keep up. Why? The way I look upon it is this: we have all been recipients of goodness at one time or another in our lives, a simple smile when we needed uplifting, good health, a renewed friendship, a meal cooked by a neighbor, a helpful hand. You know that feeling of a well-kept surprise you plan for a loved one; the secret that you know will bring about feelings of exhilaration,

joy, love, or light-heartedness for another. You become excited over the tiniest detail that you think will make the ordinary extraordinary.

When children are delighted and parents find joy in the delight of their children and for a few hours the immense sorrow experienced by these families can be lifted, why then would we not do this? Everyone and anyone can bring joy into the world. It is as simple as choosing to do so. The look of wonder, the sound of glee in a child's voice followed by the joy on the face of a parent is a priceless gift. By passing it forward, we become recipients once again. It is as simple as taking care of each other. A good friend recently commented that "we need to be aware of the Christ within us and hear that voice". Perhaps this is what he was speaking of.

Each year there is a hiccup in our design plan or in its institution. Yet with every hiccup comes a solution. This year we picked up over 300 *pounds* of sand used to stabilize all of our characters for our Candyland theme. Upon arrival into the party room we found that the sand was frozen! We had had rain and sub-freezing temperatures the day prior which had continued. This was a significant problem as it was the foundation for the entire design. After determining that it was taking too long to attempt thawing, hasty phone-calls and a trip across town to purchase additional sand meant that we were soon back on track. While it set us back several hours, it did not stop our determination to move forward. After working well into the wee hours of the morning we returned some hours later to conclude the preparations, everyone in good spirits. Extra people showed up that morning, even folk who weren't our parishioners, pitching in to assist. Every time a hiccup presented itself we were immediately given a response. Divine Guidance? Hmmmmmm.... Just another reason to keep going forward. Hope to see you all in December!



A Prisoner's Report (cont'd. from page 1)

Several years after this, I heard about Alexandra's House and I began to send contributions, principally at Advent and Lent, in thanksgiving for this blessing given to my family and to assist, in some small way, the children there and their families.

For those children with limited life expectancies, it is of the utmost importance that they have the best possible quality of life and comfort while they are here. Regardless of how challenging their physical state may be, they are fully people in their own right and are deserving of a full life, no matter how short that may be. They deserve to be enveloped in love, in a place where people can see past everything to the little person inside.

Likewise, the parents and families of these children are in need of support from a place where their perspective is understood. They need help, in a very try-

ing time, to make the most of the time that they have with their precious child. After their child has passed, they need assistance to focus on the joy of their experience with their child rather than descending into despair over their loss. Even in the case where a child is lost before birth, I know that Alexandra's House provides assistance to those families as well.

It could well be that twenty, thirty or one hundred years from now most of the medical challenges facing the babies at Alexandra's House may be easily dealt with using the technology of that future time but the reality right now is this: We're not there yet! There are still babies- little people - who need love and support in their brief, but very important, lives. Their families also need love and support both during their baby's life and afterwards.



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