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Fall/Winter 2014



Dearest Friends,

I least like the last months of the year because they conjure thoughts of really long nights, snow and ice, and frigid air. But tucked within those inhospitable elements are some really nice things - family holidays, several family birthdays, including Alexandra's, and that of another of our special babies, my god-daughter Margaret. They are resting mere footsteps from each other in the cemetery. This year, December 12, Alexandra would have been 20! This reality forced me to pause, to deeply contemplate our journey over these decades since she came into our lives.

Setting out full of zeal, I will never forget those earliest years and how difficult it was to get Alexandra's House off the ground, to help people understand, and to embrace our calling; assisting parents with pregnancies where, in the end, their babies would die from natural causes. There was intense resistance. At that time 100% of our conversations, with advocates and adversaries alike, all met with the same answer: *"Never heard of this before. This rarely happens, so there is no need."*

I then look back upon the countless families and babies to whom this did happen and by whom we have been incredibly blessed to serve. I recall feelings of helplessness because no one we knew had done this work before so no one could train us. How do we do this? What does one say to soothe such deeply grieved hearts? How does one hold a newborn as they die? Plan their funeral? Support families in their long period of shock, sorrow and mourning? Help them create precious memories all the while? I recall parents those many years ago struggling to find professional caregivers who would treat their journey and their babies with respect and dignity.

Today I witness rapidly multiplying similar programs springing up around the country. Most hospitals locally and across the nation now have formally trained pediatric palliative care teams to help these families.

What began on December 12, 1994 with the birth into our family of a wondrous tiny baby named Alexandra, who drew such immense love from her family that it propelled her aunt into the service of this most tender portion of humanity, the smallest and frailest among us, has come a very long way.

So this year as we travel closer and closer to December 12, with the most profoundly humble heart, I thank all of you for believing in us 20 years ago and even still. Most of all, I am thankful for the gift of Alexandra and the legacy she has left. Patti

Fall Reflections

Twenty Years of Care

“What we lose in flowers,” Samuel Butler wrote of autumn, “we more than gain in fruits.” These words occur to me as I reflect, this fall, on the mission of Alexandra’s House over the last 20 years.

The beloved babies that Alexandra’s House cherishes are like the flowers the poet talks of: delicate, lovely, passing. Nor are they any less beautiful for being short-lived. The fruits are evident in the immense love and support and solidarity which are part of the very fabric of Alexandra’s House and the families it serves.

Yet, as Patti mentions in her message, when she first felt prompted to establish this home, the idea was unheard-of. Many thought it futile, an unnecessary expenditure of resources – so much thrown away on those who could not hope to benefit. In short, a waste.

All of us who have been touched by Alexandra’s House, know otherwise. Here, twenty years later, we are connected by a deep bond indeed, united by the loss of our little ones, and gathered together as a family supporting one another in grief and healing.

My own connection back to when, a recent immigrant to the USA, I found our unborn daughter had a life-limiting condition. I had never heard of perinatal hospice before the hospital pointed me in the direction of Alexandra’s House. That utterly changed the nature of the journey not merely for me and for my husband but for our families and friends. Our daughter,



with the house goes recent immigrant to that our unborn limiting condition. I such a thing as a before the hospital direction of That utterly changed journey not merely husband but for our both here and abroad. Margaret, was born

in December 2012 and lived 2 days.

New-Look Newsletter

That was almost 2 years ago now. This fall, Patti has asked me to edit the newsletter and I am very happy to do so and contribute in some small way to what Alexandra’s House does.

A Task for You

First of all, I want to say that our newsletter is essentially *about* as well as *for* you. So I welcome contributions from anybody who feels the impulse to write, from whatever perspective – parents, grandparents, aunts, uncles, siblings, doctors, nurses, friends, in short, anyone who has been touched by the life of one or more of these precious children or who has been struck by what Alexandra’s House is and does. In sharing stories, we grow in solidarity. These are very real fruits of the lives of our children. Perhaps you’ve long thought of putting pen to paper; perhaps you are only thinking of the possibility of it now; regardless, we would love to hear from you.

AH presence on the Internet and social media

Secondly, I want to introduce to you Elizabeth Noel who will be assisting Alexandra’s House in its outreach on the Internet, including social media. I am sure you all agree that the no-boundaries mission it has is far too important not to be out there. The support that we as families can offer

others in similar need is a potential that needs to be tapped. I won't say we have a duty – but a privilege to be able to reach out, from mother to mother, father to father, and so forth.

A Personal Reflection

On a more reflective and personal note, I come back to where I started, thinking about the season of flowers and the season for fruit. And, if you'll overlook the indulgence, it brings to mind something that happened a month to the day after our first-born had died. It was a cold January day, the height of winter, and Patti, whom we were honored to have as Margaret's godmother, suggested that we go to buy some flowers in her memory. We have an old tradition in Ireland called a month's mind after a loved one has died. Then we get together and remember. A living memory. Far from home, we were recreating that.

At the florist's, my eye was immediately taken by some bouquets of spray roses. There was a very tiny bud on one, I noticed, the very smallest of the blossoms. There it was, hardly opened, blush pink, fresh, fragile. It put me in mind of the little girl who had died, before ever smiling, before ever speaking. That pink glow in her skin when she was born. The fragile freshness. That wordless communication of – well (if I may call it by so vast a term) – beauty.

Patti and I looked at each other. There was no question about what to select. The shop assistant went to take down the bouquet in question. Then she stopped. 'Oh' she said 'one of them is broken. I'll get you another one'. Previously I might have thanked her. Now I found myself saying: 'I'm ok with broken' and then, after a pause, 'you see, it's just as lovely that way'.

I didn't expect the shop assistant to understand. How could she? It's not the way of things. It's such a cliché to say that we live in a throw-away society, but we do. So much is disposable and disposed of. We want things neat, our houses, our cars, our furniture, and even our loved ones - without the mess or embarrassment of imperfection. Until at least the 1980s, many babies' bodies who died before or at birth were disposed of as medical waste - clinical mishaps, you might say, unfortunate accidents. Thrown away and forgotten. Out of sight, out of mind. The rose, unbought by more discerning customers, would have been snipped from the bouquet and swept away with the day's debris. For who would go out of their way to buy something already broken? But nature itself does not waste anything. Flowers aren't thrown away. Flowers do die, it is true, but then there are fruits. That's what we witness, year after year, in the immensely consoling ritual of the seasons. Only we often don't make the connection with our own lives. Alexandra's House is about making that connection, about

making something whole out of something broken. Not trying to pretend that we hold onto everything as it is; letting change happen.

I bought the roses that day, the day of Margaret's month's mind, and even before I took the wrapped and cellophane bouquet, done up to be pleasing to the eye, I somehow knew which of those roses would be frayed at the parent stem. It was.

Time passes. We are already approaching Margaret's two-year anniversary. This year, I'll be back in Ireland: her last 2 years' mind. But that is not the last word. Two months ago, in the height of fall, our second daughter was born, a healthy 8 pounder with a strong heart and even stronger lungs. And to the very hospital room, flooded with the sunny joy of new birth and the lingering sorrow of memory, a bouquet of flowers arrived, spray roses, blush pink. There was a simple inscription: 'From Your Patti'. There are some things that are never forgotten. And nor should they be. What we lose in flowers, as the writer says, we more than gain in fruits.

If you have stories to share, please be in touch with me at care@alexandrahouse.com, subject title:newletter. Alternatively, please write to 638 W 39th Terr., Kansas City Mo 64111

Annual Bow Ties for Babies Gala

Hosted by Friends of Alexandra's House

The venue for the sixth annual Bow Ties for Babies Gala was the delightful Plaza Room of the Grand Street Café on the Country Club Plaza on a sunny, warm, late, October evening. Ninety-five of our favorite friends were in attendance and they enjoyed good company, food, and entertainment with the added pleasure of watching our beloved Royals score their second win in the World Series. It was a most memorable evening for all. It began with Mr. Rudy Amato singing swooning Frank Sinatra tunes during the cocktail hour, followed by introductions by our chairs, Ms. Joan



Ryan & Tricia Clement



Brisimitzakis and Ms Martha Hubbard, of our masters of ceremonies, Mr. Domenic Rizzi and Ms. Bonyen Lee. The Reverend Gerard Alba, deacon in residence at *Holy Trinity*

Church, Lenexa, gave the Invocation and Benediction during the evening. House Mother of Alexandra's House, Patti, shared her calling to found this mission with no money, no promises, security or guarantees and asked if anyone else in attendance would have said "yes" to this business plan. She demonstrated with multiple examples how their needs were met at most crucial times and that trust is what sustains them. A Will Call and live auction concluded the evening. The Friends of Alexandra's House **presented a check from the proceeds of the gala in the amount of \$31,500!! Absolutely incredible!** If you would like to be a part of this fun and energetic committee and help some very special babies, please contact Kathy Tarbe at ktarbe@alexandrashouse.com or call 816-931-5378.



Ryan & Tricia Clement



Caden's Cubs Program

PROJECT FUN

Alexandra's House is there for entire families, and it especially recognizes the need for the whole family to heal and come together, after the loss of a beloved child. Thanks to the enormous generosity of the Courter family, a fund exists to send such families on a fun-filled adventure. This summer, the parents and elder brothers of baby Adelai Rose, were able to go to Storyland, a charming family-run theme-park in New Hampshire. They recount their special experience below and especially how much it meant for the boys and how present Adelai was to them in this very precious family holiday.

Robb & Kari Cramer

Our baby girl, Adelai Rose, was born silently on May 8, 2014. No amount of preparation during the 9 months of pregnancy could prevent the devastation her big brothers Andrew (6) and Thomas (3) felt when they learned that their baby sister had died. They had been so excited to hold and snuggle their baby sister. Now they were left with sadness.

In the first week after Adelai died, the boys announced to us that butterflies (especially yellow swallowtails), dragonflies, and singing birds, were sent to us by Adelai in heaven. These encounters continue to bring them joy from their sister.

Alexandra's House informed us that our family would be a recipient of Project Fun, a fund set up by the Courter family, to send a family healing from the loss of a baby on a fun family adventure. We were given the gift of tickets to Storyland, a theme park for young children in central New Hampshire, with a hotel stay. The boys were ecstatic! Their excitement was akin to waiting for Christmas. For the month leading up to the trip, Thomas thought every large road sign he saw was pointing the way to Storyland. The boys also talked about how Adelai would be with us, in her special way, on the rides.

In the blur of the summer and making sense of daily life after Adelai died, taking a short trip out of town to break away from the grind and play together as a family was a most welcome gift.

We could be kids with our kids. We had no other demands or distractions, and no other task but to play with our kids, laugh together on rides, and soak in the pure joy they radiated from their smiling faces and boundless energy.

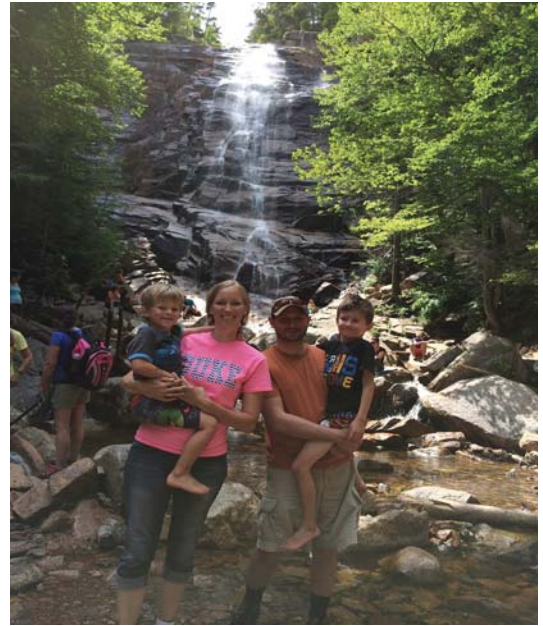
The day following our Storyland adventure, we enjoyed a gorgeous summer day hiking together in the White Mountains to a waterfall, stopping to play in the stream along the way.



When we reached our destination, we asked someone to take a family picture for us, and when we “cheesed,” a blue dragonfly flew up and hovered in front of us as the picture was taken.

We give our deepest thanks to the Courter family for this tremendous gift. Andrew and Thomas understood that this trip was a gift in honor of Adelai from a family with special babies in heaven like our family. In the words of Andrew, “Wow! The Courter family is really awesome.”

Our adventure gave us beautiful memories we will treasure always. We feel so richly blessed by the gift of Project Fun and the gift of our baby Adelai. Our boys were given a rare gift of joy and *fun* associated with their sister and for that we will be forever grateful. Thank you!



“Death leaves a pain no one can heal but love leaves a memory no one can steal.” -Unknown

Embracing Social Media

Alexandra's House does not currently have a social media presence and this could be a huge benefit for its families and support system.

When I started college more than a decade ago, I had to write a paper regarding Electronic Communication and its future. Most people didn't even have cell phones then not to mention laptops or social media accounts. This was long before Apple was a household name. I worked in a TV studio where we literally hand cut film from reels and used 8-tracks on the radio station.

I wrote my paper on the ultimate convergence of all forms of media, for-seeing TV, radio & Internet all accessible from one device. It appears I may have been right! ☺

However, I had no clue the impact social media would one day have on our society. It has the power to reach the masses but most importantly can be used as a tool to spread info otherwise unknown.

Look at the ALS! As of Aug. 14th 2014, the viral water bucket challenge, had donations up by 1000%! There are numerous cases where social media has launched other causes, businesses and brought light to the dark, so to speak, on various topics.

Opening up the cause of Alexandra's House to the world through the regular use of social media could bring awareness, information and much more to those who'd never have known the home existed. This would be the gift of social media for AH.

My idea is to promote the cause, inspirational thoughts and just a general message to represent a place of hope, love and support.

In 1996 when my son was born I was just 18, alone and didn't have anyone to talk to. After birth he couldn't make any sound so they took him before I could hold him. They didn't know

sat next to his incubator watching around the clock. They could only give him glucose because his lungs and blood were so clouded with infection that his white blood cell count kept decreasing and he could take nothing in.

The hospital gave me a room next to the NICU to stay in until he passed. Scared to death, I given just a few days left with him. No Facebook on which to post my fears. I couldn't inform people of what I was going through or a way to search for support. If I had know about Alexandra's House and it had been around then, I know "Our Patti" would have been by my side.

The Chaplain came at one point and even gave the last rites to my son, his hand on top of my baby's small head. They told me I'd be fortunate if he made it until the next morning.

Suddenly just after midnight his white blood cell count which was almost non-existent started to slowly increase. He got better without any change to his treatment. They started calling him the "miracle baby" around the NICU because there was no explanation for what had happened. Inexplicably, he eventually grew healthy enough to go home with me.

Sadly, most families related to Alexandra's House are not as fortunate as my son and me. I'd like to point out that there are people out there, just like myself at 18, that have no idea about the support, beauty and love this house offers for those in need.

In creating a social media presence with regular updates about families, positive thoughts, prayers, etc., AH would not only give knowledge to those in need but also bring additional support in order to help more families. Hopefully all the friends of Alexandra's House will agree and this will be something you see coming soon. Love & Light. Elizabeth Noel

I can be reached at enoel2113@yahoo.com

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'On behalf of Alexandra's House, we would like to wish all readers and their families a Happy Thanksgiving and Christmas and a New Year of peace and blessing.'

Recipient
Address Line 1
Address Line 2
Address Line 3