

Dear Friends,

This issue of Sharing addresses a very sensitive topic, Difficult Decisions. When a parent is expecting a baby, typically the last thing that is expected is the news that the baby has a life-threatening condition. As a parent who faced this devastating news, you likely experienced a wide range of emotions and fears. While each situation is unique, we hope the stories and resources shared in this issue will bring you comfort and hope.

National Share is excited and proud to announce that our Program Director, Rose Carlson, wrote an article titled Helping Families Create Keepsakes When a Baby Dies that was published in the April 2012 edition of the "International Journal of Childbirth Education." Congratulations to Rose for her contribution to this edition that covered issues surrounding perinatal loss! I was also honored to write an editorial for this issue. If you are interested, the journal can be purchased by clicking here.

There has been lots of activity spreading awareness at the Share office as we traveled this spring to train caregivers working with bereaved parents. In April, I conducted a workshop for priests and deacons in the Atlanta Archdiocese. It was well received, and I have been invited to come back in the fall. In May, Rose and I taught several workshops to over 100 participants sponsored by the Healthy Start Coalition of Miami Dade. It was a wonderful experience, and we are thrilled that we were able to reach out to so many new caregivers. They were just as excited to learn new ways to best support bereaved families.

Finally, I have been busily working with the Pregnancy Loss and Infant Death Alliance (PLIDA) and the Association of SIDS and Infant Mortality Programs (ASIP) in planning the International Conference on Perinatal and Infant Death that will be held April 18-21, 2013 in Minneapolis. Keynote speakers at this conference, which is held for caregivers in the perinatal loss field, will include Amy Kuebelbeck (author of "Waiting with Gabriel" and "A Gift of Time") and Annette Klein, Dr. William Kutteh, who specializes in recurrent pregnancy loss, and Therese Rando, author of "Treatment of Complicated Mourning." If you are interested in presenting a workshop at the conference, speaker proposals are due July 15. Click here for more information.

We are now in the midst of summer, which can be a difficult time for bereaved parents. Summer is often a time of celebrating milestones such as first communions, graduations, weddings, and family vacations. It can be so hard to take part in these celebrations while you are grieving. It may be overwhelming to think about these activities, but you may welcome a break from your everyday routine to get away for a while. It can be healing and relaxing to take a short trip to a special place. Whatever you decide to do, as always, listen to your heart and choose activities you enjoy and stay away from those that may be too difficult right now. Most importantly, make sure you take some time to rest and relax because you deserve it.

The national Share walk is in its final planning stages, and registration is now open. The national walk grows each year, so if you live in an area that hosts a Share Walk for Remembrance and Hope, consider participating in this meaningful event to remember your sweet baby(ies). There is still time to host your own walk, and if you would like more information, please contact Jeanna at joleary@nationalshare.org. If you already host a walk, send in your commitment form as soon as possible so we can post it on our website.

Thank you to everyone who contributed stories to this issue, and know that we are here for you.

With hope.

Cathi Lammert



Cathi Lammert, RN Executive Director



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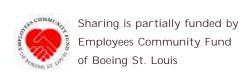
Share's Annual Golf Tournament
September 10, 2012

Forest Park Golf Course, St. Louis, MO
Registration is now open!

Registration for the 2012 Share Walk for
Remembrance & Hope is now open!
Saturday, October 20, 2012
Creve Coeur Park - Sailboat Cove
St. Louis, MO

http://www.nationalshare.org/upcoming-events.html





# Our Story of a Difficult Decision

Written By Ariel Darby

 ${f I}$ n 2001, at the age of 3, my son Ashton was diagnosed with Adrenoleukodystrophy. The disease is the body's inability to break down fat, leaving the fat to build up on the brain causing immobility, incontinence, memory loss and death in boys under the age of 10 if the disease presents itself in childhood. The disease can take two forms; the first in childhood with death resulting, the second in adulthood. You never know which form a child will have and both forms are found in my family history. The disease is X-linked, passed on by women who are carriers, and only effects males. Females may have symptoms later in life, but will not actually get the disease. Adrenoleukodystrophy is also linked to Addison's disease, which causes a weakening of the immune system and requires the use of daily steroids to fight against flus and colds, etc. Winter months often lead to hospital visits or admission to the Intensive Care Unit.

Upon learning of my son's condition, I asked his physician for answers. Frustratingly, he could not tell me any more than I found myself on the internet and he said I could never have healthy children. From there I took matters into my own hands. I enrolled Ashton in a case study with the top Adrenoleukodystrophy doctors in the country. I knew that if the study did not help Ashton during his first 10 years, the information gathered could help other children in the future.

In July 2009, my husband and I realized how much we longed for a son together after experiencing a pregnancy loss. At that time, we had two girls together and Ashton from my prior relationship. We knew our odds were 1 in 25 for a healthy son or daughter. We also knew we could test the baby via CVS at 11 weeks and that once a baby was born, testing would be denied unless it was a boy.

We tried for our little boy to complete our family. As soon as the pregnancy test was positive many emotions came to light – the excitement and the fear of having to do the unspeakable if our news was not what we wanted to hear. I tried to stay positive while preparing for the worst case scenario.

I had a feeling that the baby was a boy and was not with us to stay. During the CVS procedure I saw his little arms, legs, hands and feet. I could see his movements and, most impressively, I could hear his little heart beat. At that moment his life was strong within me. I looked at him knowing that I wanted him while also knowing that it might not be possible.

The days and weeks following the CVS were agony. Could we keep our baby? Would we have the chance to bond with him? Not knowing what our future held was worrisome.

The phone rang to say we were expecting a boy. My heart sank. I prayed as much as I could for my little boy. We held on for the second part of the news. The next day we learned

that the son we had so longed for had Adrenoleukodystrophy.

All I could do was think of how hard life is for Ashton. I wanted to deny the diagnosis. I was so angry that this was our reality.

I asked my husband to make the decision whether or not to terminate the pregnancy. I could not bear the first step that needed to be taken. I had always opposed terminations and thought people who made that choice were careless with no regard to human life. Once faced with the decision myself, I realized that terminations also applied to another group of women: those who <code>want</code> their children, but for reasons only known to God, could not keep their children as they would not have a full quality of life.

I prayed my appointment would come soon and that my little boy would feel no pain. It was the hardest decision I have ever had to make. The guilt was overwhelming. It was my fault that the life I had just witnessed on the ultrasound monitor would come to an end. I begged for forgiveness and questioned why good people can have such hardship. Wasn't it enough that I had to live in fear for 10 years worrying about burying my living son? Now I have to say goodbye to this little one too?

I worked up until the day before the surgery to keep my mind occupied only to crash with tears the morning of. I cried the entire 45 minute drive to the hospital. Once at the hospital, I was asked to place two pills into my mouth – one in each cheek. I prayed that these pills would stop my baby's heart so that he could pass peacefully.

I was numb and an emotional wreck, but there was no way out knowing the life he would have. I entered the surgery prep room still crying. As I laid there waiting for my turn in the OR, having contractions and bleeding, the surgery staff treated me as though it was nothing at all. I was labeled as a careless mother like much of society depicts women in my situation to be.

I was then wheeled into the operating room. My emotions stung me again. I was a mother in pain who did not want to lose her baby. I reached out for any alternative as the IV was put into my arm. I asked the doctor a myriad of questions: Was there a more reliable way of having a healthy son via IVF? I cried out loud so all could hear my desperation for a son. I wanted everyone in the room to know this was a baby that I wanted, not one being taken willingly.

As I woke up, I began to cry. I knew he was gone. My belly was empty just shy of being 4 months pregnant. The nurse came in to have me to get up and pee so I could be released. The disgust on her face was enough to make me feel ashamed of what I had done. Did she not know that I wanted him with me and loved him? Why were other mothers able to leave with their babies and I couldn't?

I was discharged as if nothing had happened to me, as if I did not just lose my baby. No one bothered to ask me how I felt emotionally or told me there was help out there when I was ready to let my secret out. I cried the whole way home.

One by one my kids would cry with me as they saw their mother's sadness. At that time they were 9, 5, and 2 years old. How could I tell them they just lost a brother? My son already fearing for his own life, I could not tell him his little brother could not stay because he had the same illnesses.

My surgery was on a Friday and I returned to work the following Monday to act as if nothing had happened for the shame and guilt of my decision. I should have taken time to grieve for him at home. Instead, I cried in my car to and from work, at work hiding behind my chair, in the shower, and in the silence as I went to bed at night and woke in the morning.

It is true what they say about losses and not wanting to be in public. I was so sad about no longer being pregnant but looking like I was. I was jealous of other pregnant women and wanted them to know I had just lost my son. I wanted them to not be as naïve as I was and to know that not all

pregnancies end with a baby. I wanted them to know how precious life is and to love their children, not to take any minute with them for granted. They needed to be thankful for their gift of life.

Good news came weeks later that Ashton at the age of 10 was going to live. His disease had stayed dormant. At some point, his disease will take hold. For now, he can be a boy, however, he still fears for his life. The news allowed me to take a deep breath and have

some comfort of not having to bury this son too.

Months later I contacted the doctor that performed my termination questioning what had happened to my son's remains. There was no record of what was done with them. Had I known my options then, I would have chosen to keep them and place them in a pendant. This was the hardest part of losing him. Because he was under 20 weeks, his life was not acknowledged.

Correcting this has become my mission. I contacted my doctor and begged for him to let others following me know their options. Their babies matter no matter how small they are. Most importantly, no mother should suffer in silence with the guilt and shame associated with not being able to keep the baby they wanted. I realized it was up to me to let others know that terminations are losses too. Yes I made the decision not to keep my baby, but I wanted him and mourned for him just the same as any other mother

who has had any other loss.

A year later while preparing for an IVF cycle, we tried one last time for a son. I knew from the moment the pregnancy test was positive that this one was mine to keep. Again I had to keep my excitement to a minimum knowing the difficulty I had just gone through. A couple of weeks later, I was sitting at a Share event when a woman approached me. I was sitting at the table explaining what Share is and what we do. She looked at me and told me that I was pregnant and that the baby, saying the word "he" was a healthy boy and everything would be okay this time. I felt chills and called my mother, the only person who knew other than my husband. She told me that the woman must have been an angel sent to me to help me relax and stay positive. I hoped that she was right, and still kept my feelings at a distance. I had a hard time hearing the heartbeat as I had before. Through the CVS testing I wanted to look at him but had flashbacks of his lost brother the year before. At 12 weeks, my maternal instincts and the woman were correct; we had conceived a healthy baby boy. I cried for the baby we could keep and the one we couldn't.

Until six months into the pregnancy, I would not give myself

permission to acknowledge him. I knew he deserved my love but I needed to forgive myself for the difficult decision not to keep his brother. My turning point was writing a letter from our lost baby, later named Brett Nathaniel, to our new baby asking him to take care of his mother for she was very sad but loved him very much. The letter completed the bridge and relationship between these two little boys and allowed me to know it was okay to have Lucas in our lives - that there were no hard feelings. This was the moment that I used to separate the two brothers.



Lucas Nathaniel was born in March of 2011. His middle name is in honor of his brother Brett forever bonding them as brothers.

My journey continues as I see Lucas's face and think of his brother. I know they will forever have a bond as subsequent pregnancies do. My doctor continues to let others, who find themselves in a situation like mine, know that there is someone who understands. He has become an advocate as my journey showed him little lives are precious too. I continue as a board member of Share Southern Vermont to spread the word about loss and hope through sadness and happiness as the rainbow babies come to life. I know I am honoring my son, Brett, in the work that I do and the lives I touch. Had I not been promoting Share that day, my angel would not have appeared to guide me to Lucas.

# Providing Compassionate Care to Families Making Difficult Choices

Written By Rose Carlson

The term "difficult decisions" encompasses a variety of situations that parents may find themselves faced with and as caregivers, it is important to understand the many challenges and complexities families must face throughout the decision making process as well as the grief journey. With the advancement of prenatal testing measures, it is not uncommon for parents to find out fairly early in the pregnancy that their baby has a condition that is incompatible with life. Also, many parents today become pregnant due to extraordinary medical procedures and may be pregnant with a high number of multiples, which increases the likelihood that the parents will have to make some heart-wrenching decisions. It is vitally important to keep in mind that these decisions are typically not made lightly and are made after all options have been presented and evaluated. Share does not take a political stand, but provides bereavement care no matter what decision a family ultimately makes.

Most often, you as caregivers will see the family after they have already made their decision and are in need of support as they make their way on their grief journey. They may have already interrupted the pregnancy or opted for early induction. They may have made the decision to interrupt, yet are still carrying the baby. Sometimes, their friends and family members may think they should feel 'lucky' that they found out early that something was wrong, and may even think that their grief shouldn't be as acute since they made the decision to interrupt the pregnancy. They may have made the decision to interrupt the pregnancy but still need to decide how that should be done. Often, they are not given much time to make these decisions, and depending on how far the pregnancy has progressed, they may have to travel far from home, deal with a hospital ethics committee, or even go to an abortion clinic, which is devastating and traumatic for someone who is carrying a very wanted baby.

The parents may have decided to continue the pregnancy and are now looking for support in how to 'get through' the rest of the pregnancy carrying a baby they know will not survive. The decision to continue a pregnancy can be just as grueling as the decision to interrupt one. If they have decided to continue the pregnancy, they may need your help in creating a birth plan, which can help them feel as if they have some control over a scary situation that is completely out of their control. Listen to their wishes and try to do whatever you can to make them a reality; don't just assume that something cannot be done. If the family has other children, help them find resources on children's grief issues. They may be afraid of what

their baby will look like, so try to find out as much as you can about any medical condition their baby has so you can help prepare them. It can be very draining for parents to keep all of their loved ones informed about what is going on as their pregnancy continues, so suggest webbased ways for them to keep everyone updated. Caring Bridge, www.caringbridge.org, and Care Pages, www.caringpages.com, are excellent ways for them to share news about their baby without having to make numerous phone calls.

While most of the time parents will come to you once their decision has been made, it is possible that parents who are still in the midst of their decision-making process will come to you. It is important not to guide them in this process while letting them know their options, letting them know about any resources you have, and offering your support once the decision has been made. There are organizations that offer support for many different conditions, and Share provides a list of these resources. It can be helpful for you to familiarize yourself with the many resources that are available so that when a family comes to you for help, you have places to refer them to if necessary. Oftentimes, parents want to connect with other parents who have experienced something similar, so if you know of other parents who have gone through this, ask them if they would be willing to talk to new parents.

Whatever situation you find yourself faced with, it is important to provide a non-judgmental ear and keep in mind that whatever decision the parents made, they did so with nothing but love and the best interest of their baby at heart. It is also important to keep in mind that parents in this heartbreaking situation often feel very isolated since most people cannot to relate to their loss, and you may be the only supportive, caring person they have at this difficult time. Parents faced with a fatal or potentially fatal diagnosis are scared, confused and overwhelmed. No matter what they decide to do, they will sometimes wonder if they made the right decision. However, most parents who are told all of their options and supported through whatever decisions they make will feel as if they made the right decision with the information they were given at the time. Whether or not they continued the pregnancy, they may need your help planning a farewell ritual or preserving memories. Always remember that the baby was wanted and loved, and know that the care you provide to them at this most difficult time of their life will mean so much to them in the years to come.

# Resources

A Gift of Time: Continuing your Pregnancy when your Baby's Life is Expected to be Brief By Amy Kuebelbeck and Deborah Davis, Ph.D.

When you became pregnant, the last thing you likely expected is that you would discover your baby had a condition that was incompatible with life. When the unthinkable happens, parents are usually left heartbroken and are unsure of where to turn. Kuebelbeck has been in this situation. Her first book, *Waiting with Gabriel*, was the first of its kind—a book which is a chronicle of her journey after finding out her unborn son was not going to live. *A Gift of Time* will be an invaluable resource to parents who have received the news that their baby has a condition that will cause the baby to die either during the pregnancy or shortly after birth.

At such a time, most parents feel very alone. In this beautifully written, touching book, Kuebelbeck and Davis offer practical advice interwoven with stories, insights and experiences from 120 mothers and fathers who have walked this path. It validates the feelings and fears that many parents in this situation face and will help them embrace the short amount of time they will share with their baby. It is a must-read not only for parents who find themselves facing such a heart-wrenching situation, but also for those who care for and support these families. It will ensure that any parent will be given all of the knowledge, options, information and resources they need to cherish the precious gift of their baby's life.

I will Carry You: The Sacred Dance of Grief and Joy
By Angie Smith

The author of this book has a deep connection with God, and she poignantly shares the story of her daughter Audrey's life, birth and death after learning during the pregnancy that Audrey had a condition that would cause her to die shortly after she was born. Although doctors encouraged Smith to terminate the pregnancy, she and her husband chose to put their daughter into God's hands and carry her to term. This book tells the powerful, honest story of a parent who must face the death of her child while sharing stories from the bible that helped her to find hope, grace, peace, and eventually joy in her daughter's too-short life.

Our Heartbreaking Choices: Forty-Six Women Share their Stories of Interrupting a Much-Wanted Pregnancy
Edited by Christie Brooks

There is often little support for parents who have discovered a life-threatening problem with their baby and then choose to interrupt that pregnancy. This often makes parents feel very alone and misunderstood. Those who openly shared their stories in this book give a voice to every parent who has been in the devastating predicament of having to make decisions for their baby. The stories of love and grief shared in Our Heartbreaking Choices show the reader that this is not a "black and white" situation, and that nothing but love for one's precious baby is considered when making such a heart-wrenching choice. It is the only book of its kind available, and is a valuable resource not only for parents, but also for caregivers such as social workers, chaplains, genetic counselors and others who support families who are forced to make decisions no parent should have to make.

#### Other books and resources:

A Time to Decide, A Time to Heal: For Parents Making Difficult Decisions about Babies they Love By Molly A. Minnick, MSW, Kathleen J. Delp, ACSW, & Mary C. Ciotti, MD

Loving and Letting Go: For Parents who Decided to Turn Away from Aggressive Medical Intervention for their Critically Ill Newborn

By Deborah Davis, Ph.D.

Precious Lives, Painful Choices: A Prenatal Decision-Making Guide By Sherokee Ilse

Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life By Amy Kuebelbeck

When Courage Lies in Letting Go: Turning Toward End-of-Life Palliative Care for your Child By Deborah Davis, Ph.D.

Websites:

Heartbreaking Choices www.heartbreakingchoices.org

A moderated online community for parents who have interrupted a pregnancy due to a fatal prenatal diagnosis.

Perinatal Hospice www.perinatalhospice.org

An online clearinghouse of books, articles and other resources for caregivers as well as families who have chosen to continue their pregnancy when the baby is not expected to live.

# Angel Ball 2012: One Night in Tuscany

Share Pregnancy & Infant Loss Support, Inc. hosted the 10th Annual Angel Ball: One Night in Tuscany on Saturday, April 28, 2012 at the St. Charles Convention Center. The successful evening raised over \$70,000 from live and silent auctions and individual donations.

New York Times Bestselling author, Richard Paul Evans, served as the Guest of Honor. Richard Evans shared personal stories of courage, strength and hope with the audience of over 250 guests. Mr. Evans was available before the gala for an intimate meet & greet, where he graciously signed his books and conversed with the guests.

We hope you join Share on April 26th, 2013 for 11th Annual Angel Ball, Welcome to

Hollywood!















Photography was donated by Doug Hart at dghPhoto LLC: <u>http://dghphotollc.smugmug.com/</u>

### Congratulations, Cori & Joe Kline

On the evening of the Angel Ball, the Share staff was thrilled to raffle the 2013 Buon Viaggio Italy Last Promise Tour! The lucky raffle winners are Cori & Joe Kline, who will enjoy this amazing trip for two to Rome, Pisa, Florence, Venice, Assisi, and Orvietto. This tour will be led by Italy-expert Keri Evans, wife of New York Times bestselling author Richard Paul Evans!

#### **Tour Includes:**

- Roundtrip airfare from most US cities for two
- 4-star hotel accommodations
- Sightseeing as outlined in the itinerary, guides and entrance fees
- Buffet breakfasts
- Some dinners as listed on each tour's page
- Ground transportation via deluxe motor coach



# Journey to Meeting Thomas

Written By Amanda Davis

When my boyfriend and I found out the precious baby I was carrying was not going to survive, we were stunned. Stunned. We had also been stunned when we discovered we were going to have a baby, but we quickly grew used to the idea and began making all of the exciting plans that all expectant parents make. We talked about names, picked out baby furniture, and I started buying maternity clothes. I had a sonogram at 12 weeks because I was experiencing some bleeding, but everything looked great. We could see our little baby swimming around waving to us; safe and sound and happy in my womb.

Two weeks later, at my regular OB appointment, my doctor couldn't find my baby's heartbeat, so he sent me down the

hall to have another sonogram. I was relieved to see my tiny little baby and that beautiful blinking heartbeat. I thought I was out of the woods, until the technician said she would be right back – she needed to have my doctor come in and take a look. Even though her words were soothing, I knew in my heart that something must be wrong. Those few minutes that she was gone dragged on for an eternity, while I lay there on the table with my shirt off, goo on my belly and fear in my heart.

I was right. Something was wrong with my baby. My doctor held my hand as he gave me the news that there was no amniotic fluid around my baby. I didn't understand the implications. With tears in his eyes, he told me to get dressed and we would talk in his office. As I got dressed and waited outside his door, watching other happy pregnant moms being

led to exam rooms, I didn't understand just how bad things were. I had no idea that no amniotic fluid was basically a death sentence for my baby.

I broke into tears as my doctor explained that the reason my baby had no amniotic fluid was because there were no kidneys, and that a baby couldn't survive with no kidneys. I asked if my baby would be able to have a kidney transplant. He said, no, that because there were no kidneys, and no amniotic fluid, that my baby's lungs would not develop. He encouraged me to terminate my pregnancy, but I refused. As I left his office that day, my mind was spinning in a million different directions. All I kept thinking was that my boyfriend didn't even know that our unborn baby was going

to die! I thought about how an hour before, I was a blissfully happy pregnant mom sitting in my doctor's waiting room reading a magazine with a bright-eyed, beautiful baby on the front cover – a baby wearing a light blue sweater that matched his eyes.

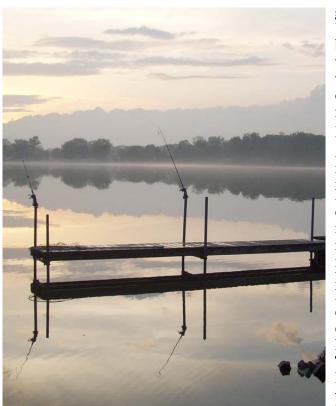
My boyfriend agreed with me that we were not going to terminate our pregnancy. I got on the internet and looked up everything I could about our baby's condition, and we joyfully and sadly awaited our son's birth. (Yes, we found out several weeks later that we were going to have a little baby boy.) We decided to name him Thomas after his dad and grandfather. I anxiously awaited the day I would be able to hold my Thomas in my arms and gaze into beautiful

eyes that I imagined would be golden brown like his father's. Unfortunately, that wasn't meant to be, and we found our son had died when I was 30 weeks pregnant. I was induced and 25 hours later, he quietly and without fanfare, slipped from my womb and into his permanent place in our hearts.

It has been almost two years since I last saw, held and kissed my son. I have since given birth to a healthy daughter, and while I cherish every minute of every day with her, I will never forget my sweet Thomas. I will never regret my decision to cradle him in my body even though I knew he was going to die. Those weeks I carried Thomas following his diagnosis were the saddest and happiest days of my life. Yes, I knew Thomas was going to die, but I also knew that I was going to do whatever I had to do to make him know that he was so loved by his Mom. I ran through the sprinkler, I

took him to the zoo and the park and my favorite restaurants. We went to the beach and I rubbed my belly and talked to him while I listened to the waves crash upon the shore. I gathered shells that I placed in a special jar. I ate Happy Meals at McDonalds. Everything I did, I did for Thomas. I comfort myself with knowing that all he knew in his whole short life was love; nothing but pure love.

I miss him terribly. When my daughter was born, I nuzzled her close and thought about all I had missed out on with her brother. I think of him often, but I do not regret one second of the time I spent carrying him and loving him. He has changed me in ways I cannot describe.



# Thank You For Your Gifts!

In loving memory of...

Corynn Boresi

In honor of Corynn Boresi's 5th Birthday By: Linda Frei

In honor of our angel Corynn on her 5th birthday. We love and miss you! Love, Mom, Dad, and Katelyn By: Joy Boresi

#### Lisa Unnerstall

With sympathy and prayers, John & Mary Jo Nischwitz

By: John & Mary Jo Nischwitz

By: Grace Porter

By: Denise Stouffer

By: Melissa Hardage

By: Anne Mosinski

By: Benjamin Buchanan

By: Byron E. Francis

By: Chris Rapp

By: Dave Chamberlain

By: Elaine Lindsay

By: Ellen and Larry Umlauf

By: Ginny Buller

By: Helen Sandza

By: Howard T. Devane

By: Jennifer Merlo

By: Paula Shively

By: Richard and Mary Black

By: Sarah Worley

By: Stacy Finnerty

By: Vivian Haman

#### Emma Hope Amato

By: Christine Amato

#### Abigail Frances and Anne Elise

In honor of my sweet baby girls: Abigail Frances, stillborn at term Dec 6, 2003 & Anne Elise, born April 28, died June 28, 2005

By: Vickie Bacon

Andrew J. Stege

Love you XOXO

By: Patricia Pallardy

#### Audrey Hope Keinrath

In memory of our Granddaughter, Audrey

Hope Keinrath, June 24-29, 2004. We miss you everyday. By: Connie Pirtle

Bernadette Romatowski Forever missed and always loved.

By: Ava Gonzalez

#### Avery Ann Humphries

Happy 5th Birthday Avery. Thinking of you and your Mommy and Daddy who miss you very much.

By: Michelle Garris

#### Baby Ashmore

By: Terry Ashmore

#### Baby Nemetz

In loving memory of our first grandchild. We will always love you. By: Penny Sabolsky

#### Christian Paul Hopco

In Loving Memory Of Christian Paul Hopco

By: Judy Hopco

By: Joanne Walsh

By: Josephine Hopco

By: Karen Facini

By: Matilda Hopco

By: Stan Brzezinski

#### Coleman Urzi

Happy Birthday, Coleman By: Tracy Goodall

#### Declan Theodore

By: Cathi Lammert

# Emily M. Sutton, Madelyn M. Sutton, Connor S. Sutton

Please accept this donation in loving memory of our grandchildren: Emily M. Sutton (1997), Madelyn M. Sutton (2004), Connor S. Sutton (2007).



Thank you for all you do. II Cor.5:1 and I Thess.4:13-18

By: Karen Sutton

Evren Berk Canbek

Evren, Grammy loves you, always and forever.

By: Karen Scholbe

#### Francis Raymond Stockmann

By: Maggie Stockmann

#### Garrett Michael Wellman

Sent in loving memory of our grandson, Garrett Wellman, infant son of Gary and Melissa who became our heavenly angel on 6-18-02, ten years ago. Lovingly sent, Bobbi & Gary E Wellman,

Grandparents
By: Bobette Wellman

#### Griffin Louis Brase

In memory of Griffin Louis Brase By: Teresa Bye

#### Jason Aaron Turner

Our "little bud", you are always in our heart. It's still difficult, but we know we will be with you again. Grandpa and I cannot wait to give you a huge hug.

By: James R. Casey

#### AJiya Patil

By: Chetan Patil

#### Jordan Lee Suftko

By: BG Services, Inc.

#### Joshua Redington

We are remembering your birthday. We will never forget you.

By: Frances Mirkay

#### Julian and Micah Glassett

Though no parent should ever have to deal with the loss of their child, know that with time we heal and can go on even if we think it'll never be possible. With all of our love to our angels...we miss you Julian & Micah.

By: Diana Koenig

#### Kellyann Morgan Vaughn

July 21st we celebrate the birthday of our angel, Miss Kellyann. We will never hold you in our arms, but will forever hold you in our hearts. Mimi and Grandpa Doug By: Darlene Glaze

Happy 1st Birthday, Kellyann! 7/21/2011 You will live in our hearts forever. Sending you birthday hugs and kisses from all your family! Love you, sweet angel! From Mommy, Daddy, Jackson, Natalie, and Baby Nicholas.

By: Pepper Vaughn

#### Kiera Elizabeth Keady

By: Laura Keady

#### Lily Grace Taets

In memory of Lily Grace Taets, who became an angel on 6/21/2011.

By: Sophia Yi Scott

#### Lily Pratx

In honor of my beautiful daughter, Lindsay on Mother's Day, I make this donation in loving memory of my precious granddaughter, Lily: Though I never had the chance to see your face or hold you in

my arms, you will live on in my heart and will always be my first grandchild.

By: Debbie Beath

#### Madeline Lucille Villmer

By: Vicki Johnson By: Laura Villmer

#### Maxwell Christopher Hengst

In memory of a little angel, Max.

By: Janine Buzby

In honor of Max and his wonderful parents, Sean and Stacey Hengst, we love you.

By: Kathleen Basara

In memory of Max...from all his family and friends who joined his family in remembering him at the Phillies game.

By: Stacey Hengst

By: Jennifer Engel

#### Megan and Sean Schmidt

In loving memory of my sweet angels Megan and Sean who were here and then gone way too quickly.

By: Kelly Schmidt

#### **Obed Warren Groggett**

By: Dee Ledger

#### Owen Backer

Thoughts of you & your family.

By: Christy Parson

#### Philip Joseph Jehle Williams

By: Barbara Harter

#### Quinn Mooney

In memory of a beautiful little boy who touched the hearts of many. By: Margaret Downen

#### Regina Poppy Knobbe

By: Joann Hoffman

#### Remi Goebel

Memorial for Remi from family and friends.

By: Kimberly Goebel

By: Marianette Robben

By: Supervalu Foods: Schuette

Stores, Inc.

#### Sarah Blanchard

In memory of our loving Granddaughter Sarah. May God bless her loving family and support them in their loss.

By: Linda Blanchard

#### Shanel Lauren Douglas

For our first Grandchild, dear Shanel, who brought us so much happiness for a short time. We will always love you and remember you. Love, Grandmama and Grumpy By: Lauren Murphy

by. Lauren Murph

#### Tess Welker

By: Brian Welker

#### The Irving Child

In memory of a child long-wanted and awaited. Our lives were glowing with hope and happiness for the two weeks you lived inside of me.

By: Erin Irving

#### The Miller Babies

By: Elizabeth Skinner

#### Tommy Henriksen

By: Rachel Hauck

In Honor Of...

#### Amanda Brauchle

By: Janelle Brauchle

#### Kendall

In honor of our friends' child, Kendall

By: Melanie Mergler

#### Lois Sugarman

On this Mother's Day, 2012, I want this donation to honor my mother, Lois Sugarman, who has been such a wonderful mother to me and my two living siblings. Even more importantly, I want it to acknowledge what a wonderful mother she has always been to my sister Janet who was born and died on May 28, 1971. I know that her experience as Janet's mother has impacted her in more ways than I can understand, but I would like it always to be remembered. With much love always, Helen

By: Helen Schicketanz

### Meagan Huth

By: Melissa Parish

#### Reid Nathaniel Wambach

In celebration of Reid's birth.

By: Barbara Warner

Congratulations on the birth of your son!

By: Karen Wickline

#### Noah James Backer

In celebration of the safe arrival of Noah James Backer. We are so glad you are here safe and sound!

By: Stephanie Grant

#### Remi Isabella Goebel

By: Brett, Kecia and Shane Therioin

#### Friends of Share...

Aamna Jalal Agnes Kahn Alicia Smith Amanda Davis Amaryllis Paschal American Express

Amy Urzi
Amy Johnson
Amy Smith
Anna Raho
April Elliott
April Kavanagh
Ashley Reininger

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# With Gratitude

Share thanks those who have so graciously given these monetary donations in memory of a baby, relative, friend, and in honor of all loved ones and through Matching Gift Programs. Gratuitous donations are also accepted from anyone who wants to help Share in its mission. We gratefully acknowledge these gifts, which help us continue to reach out and fulfill the daily needs of bereaved parents. Share's services are available free of charge to bereaved parents, family and friends, or anyone whose life has been touched by the loss of baby.

When you make a donation in memory of a/your baby(ies), please include the name(s) of the baby(ies), the birth/death date(s) and the parents name(s). If you donate in memory/honor of a special loved one, please include their name(s) and pertinent information. A short message may also be included with any donation.

Please remember to include your return address and the addresses of those you wish to receive an acknowledgment. Unless previously authorized to do so, Share will not release any personal information, (address, phone number, e-mail, etc.) except to print donors names in this newsletter. If you wish your name to remain anonymous, please indicate this when submitting your donations.

# The Mission

Share's mission is to serve those who are touched by the tragic death of a baby through early pregnancy loss, stillbirth or in the first few months of life.

Six times a year, we share information and ideas from parents and professionals to support and provide a sense of friendship for bereaved parents. We hope you will find this newsletter helpful and that you will share it with others you feel it would interest.

We encourage you to send your personal articles, stories, poems, artwork and recipes to our newsletters at any time. Please do not submit copied, copyrighted, or web articles. The Newsletter Editor reserves the right to edit your personal submission for content and/or length to fit the needs of the particular newsletter edition in which it will appear. Your submission may be used for the current newsletter, or may be used in a future publication. All submissions become the property of Share.

Please include all pertinent personal information so we may identify you and your baby/ies in the respective publication. Your submission grants Share permission to list your personal information with the publication unless instructed otherwise.

### **Newsletter Submission Guidelines:**

- 1. Please provide title, authors' name and applicable loss information for article submissions. If donating monetarily in memory of a baby, please provide loss information, including the parent's name(s).
- 2. Submissions must be received no later than the 1st of the month, one month prior to issue month. If you are making a donation and would like to be recognized, or honor a birthday or anniversary, in the most recent edition of the newsletter, then it, must be received by the 10th of the month, two months prior to the publication.
- 3. Please type your submissions in single spaced, 10 point, Times New Roman or Arial font when possible.
- 4. Submissions can be mailed to 402 Jackson, St. Charles, MO 63301, e-mailed to mnichols@nationalshare.org or faxed to 636-947-7486.

## **Sharing Newsletter Information:**

Sharing Newsletter is published by Share Pregnancy & Infant Loss Support, Inc. If you would like to reprint articles/submissions from Sharing please properly cite Share and the writer by stating the name of the organization, website, newsletter, volume, issue, and author in your acknowledgments. If you would like to reprint an article/submission that is copyrighted by an author or a publishing company, you must obtain permission from the copyright holder to reprint. Email questions to rcarlson@nationalshare.org.

# Would you like to be removed from mailing lists?

To remove bereaved parents' names from mailing lists you can visit

http://www.privacyrights.org/fs/fs4-junk.htm#MPS -OR-

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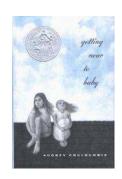
## **Book Reviews**



The Share staff continually expands our catalog with books we find resourceful and helpful to you along your journey of grief and hope. Below are a few of the books we read and reviewed, and are now available to purchase in our online catalog. Click here to view our available books and resources.

Getting Near to Baby
By Audrey Couloumbis

Getting Near To Baby is a poignant, tender novel, winner of the 2000 Newberry Honor Medal, and one of the first novels we have come upon that is written from the perspective of an older child. This is a fictional story of Willa Jo and her younger sister in the aftermath of their baby sister's death, their mother's heavy grief, and the healing and hope that springs forth from an unplanned climb onto the roof. A recommended read for ages 10 and up, and for adults looking for insight into their older children.



<u>Click here</u> to view ordering details.

Naming the Child: Hope-Filled Reflections on Miscarriage, Stillbirth and Infant Death By: Jenny Schroedel

Naming the Child: Hope-Filled Reflections on Miscarriage, Stillbirth and Infant Death, written by Jenny Schroedel, is a comforting resource that contains advice, suggestions and messages of hope from bereaved parents who have experienced various types of pregnancy loss or early infant death. The author, who has comforted close friends and family following their losses, provides gentle suggestions for creating bonds and honoring babies goon too soon.

Click here to view ordering details.

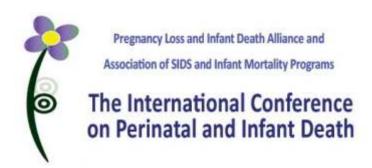
# Share in GLAMOUR Magazine

Share was recently mentioned in a GLAMOUR magazine article detailing Bethenny Frankel's experience with miscarriage.

Click here to read the full article.



## Mark Your Calendar



# SAVE THE DATE

Minneapolis, Minnesota The Depot Hotel April 18-21, 2013 www.plida.org www.asip1.org

CALL FOR ABSTRACTS! International Conference on Perinatal and Infant Death will be held April 18 – 21, 2013 in Minneapolis, MN. For more information on abstract submissions, please view this link.

The 2012 International Conference on STILLBIRTH, SIDS AND INFANT SURVIVAL

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# Finally Loving Audrey

Written By Tracy Keinrath

February 4, 2004 was the day that changed our lives forever. A routine ultrasound strongly indicated that our baby girl had Trisomy 18, a chromosomal disorder that is incompatible with life. An immediate amnio and five agonizing days of waiting brought confirmation of the doctor's initial diagnosis and the end of life as we had known it.

After many tears and long discussions, we decided to continue the pregnancy and to let God handle it. I didn't know how I was going to do that, though. I kept thinking, "How will I ever survive this?" "How can I be a good mother to our two other little girls knowing our baby is going to die?" There was a real fear that I would emotionally disintegrate. I began to disengage myself from my baby. It sounds cold and unmother-like, but it was my way of coping with my grief. I isolated myself as much as I could, not wanting to go out in public or to family functions. There, someone could happily bring attention to my pregnancy, and I would then have to tell them the dreadful truth. This was supposed to be a happy and life-affirming event, but my pregnancy was a burden I heavily carried. My husband and I went through the motions of a normal life for our girls. There were even times we laughed and forgot about our reality for a while. Thank God we were blessed with two beautiful and healthy little girls. They kept us sane and grounded.

My husband and I had been talking one day about what we should name our baby girl. Part of me didn't even want to think about it. A name would make her more real, give her an identity. I realized I had been trying to keep her, in a strange way, anonymous. We did pick a name though, Audrey Hope. In that instant I couldn't help but acknowledge I was carrying a real baby inside of me. I felt such sadness every time I felt her move. It's hard to understand this, I'm sure. Every kick reminded me that this little being inside of me was going to die. I would never know her as I knew my other daughters, and that broke my heart, day in and day out. I knew my husband was suffering too, and we tried our best to prepare ourselves for our future.

Emotionally, my husband and I were at a loss. We had no idea what this experience would be like, and the fear of the unknown was so overwhelming. Our OB gave us the name of Share and explained their services. I wasn't sure I wanted to let an outside person into our lives. After much persuasion from our OB, my husband finally made the call. We met with Cathi from Share a couple times before Audrey's birth. She was able to answer many of our questions and we talked about several scenarios of how the birth experience might be. She told us one of the things she would do was to take pictures. At that point I didn't even know if I wanted pictures. Actually, I had no idea WHAT I wanted. Cathi assured us she would be there and would help us and our family through this. Although in time she did exactly that, much of what she said then had little meaning to me. I was

still quite detached and overwhelmed with sadness and fear. The day came when it became necessary to induce me due to high blood pressure. Within 15 minutes of breaking my water, I felt a strange sensation. Quickly the nurse checked me and said I was ready to deliver. But I wasn't ready. The one thing that I had done through the pregnancy was keep Audrey safe within me. I knew I hadn't loved her like I should have. But, I had carried her and provided a warm and secure home for her for nine months. Now they were telling me she was coming out of me. That was like saying to me, "Now is the time for your baby to die." But, Audrey didn't die. She started breathing and kept breathing. She pinked up, wiggled, looked around and softly cried. The minute they laid her on my chest all my fear disappeared. Audrey Hope was here and she was my beautiful little girl. Instantly, loved filled my heart and I knew that having her, no matter how long, was a true gift from God.

Cathi, our Share companion, was right by our side from the time they put the needle in my arm for induction. She was there as I pushed and brought Audrey into this world. She watched and waited with us to see if Audrey would breathe. She accompanied the nurses to the nursery and dressed Audrey in the tiny outfit we had brought for her. She baptized our daughter. She made sure my husband and I, as well as her big sisters, family and friends, held Audrey often. She held Audrey and took her into her heart. She took many pictures. She answered questions and brought family and friends coffee, Kleenex and comfort. She instructed the nurses and staff how to handle our situation and made sure we were not disturbed. She made a safe haven in our hospital room where we could finally love our daughter. A place I could love her like a mother should. My husband and I were able to hold her, rock her, kiss her, change her diapers and just be her parents. Audrey was such a little fighter! She blessed us with five days here on earth, five days more than we thought we would have with her. She met and touched the lives of all our immediate family and friends. Although our journey with Audrey was not always easy, it was our time to know and cherish our daughter. Cathi was always there, an ever-present support and guide. When we did have to say goodbye to Audrey, we did so in the most perfect way we could, by holding her and wishing her a happy journey to meet God. Cathi was once again there for us. She took Audrey, securely wrapped in a blanket, to meet the funeral home staff, a task we didn't have the heart to do ourselves. She then stayed with us until we were ready to leave the security of the hospital and venture into our new future without our baby girl.

Share continues to be such a bright light in our lives. My husband and I volunteer there and participate in their events. The rewards are innumerable. I joke that volunteering at Share is my "therapy," but it truly is. Every time I walk through their doors my heart heals a little more, and I know I am doing something to honor Audrey. I can't imagine a time when I won't be involved with Share. With Share's compassionate support, I can proudly, unequivocally and FINALLY say, "I love you sweet Audrey Hope!"

Max's Story

Written By Mary Stenberg

Pregnancy is a joyful time in life. You go along waiting for the milestones, morning sickness (first to come, then to pass), the bump where your belly used to be flat, the first kick, hearing the heartbeat, seeing the baby on an ultrasound screen, and everything goes as planned.

But then there is a bump in the road. You go for a routine ultrasound, hoping to find out the sex of your unborn child. It's a boy. You go out for lunch to celebrate. You get home to find a message from your doctor that says, "call me right away." It can't be good. You find out that your son has a condition that is "not compatible with life." Now what?

That's where my husband and I found ourselves in January 2004. Our pregnancy was going along smoothly with no complications, for which we were very thankful after having suffered an early miscarriage earlier that year. We didn't know what to do. We were in a fog for days and tried to absorb and understand the hell we had entered. We felt very much alone.

We were told that our son, who had Trisomy 18, would not live to term. I was 23 weeks pregnant. I felt in my heart that I wanted to deliver him early, giving us our only chance to meet him alive. I was told that at this point in the pregnancy, the only option for me was to go to a clinic in Kansas. I looked it up on the internet and found it was an abortion clinic that did late-term abortions. I just wanted to scream. I didn't want to have him die and then give birth. I wanted him born alive.

At first, our hospital would not consider allowing us to deliver early. Our other option was to travel 350 miles where a doctor would deliver for us with no family or friends around for support and leaving our then 2 1/2-year-old daughter home. We wanted to meet our son, to have our daughter meet him, to take pictures, and to love him for the short time he'd be with us.

My OB stepped in and petitioned the hospital to allow us to deliver our son early, knowing that one of our desires was to have him baptized. I have never prayed so hard in my life, not only for our son to be healed and live, but if that was not God's will, to be allowed to deliver him in our hometown before he died. I know that God was working and that His will was that we deliver our son early because the hospital cleared the way for us to meet our son.

Our son was born at 28 weeks by c-section on February 3, 2004. I will never forget the sound of his heartbeat that they allowed me to hear just before the surgery began, knowing that it was possibly the last sound of life I'd ever hear from him. It was. He lived for 2 1/2 minutes. Our pastor came

into the operating room to baptize him, and when the baptism was over, Max took one more breath and died.

For my husband and I, the decision was clear. We listened to the doctors who told us we had only weeks before our son would die inutero. We knew that we wanted him to be born alive. There was no question in my mind, at least then.

However, even now, more than 3 years later, I wonder about our decision. It used to haunt me, almost torment me, daily. If I had waited just one more month to let his lungs mature a little more, would he have been with us a few more minutes or maybe even an hour? Maybe I would have gotten to hold him while he was alive, instead of just after he died. Maybe I would have been able to hear his precious cry. Did I really do anything for him, or did I just hasten his death?

I have made peace with our decision, knowing that we listened to the experts and that we prayed, leaving the decision with the ultimate expert, God. But I still wonder sometimes, what if we would have waited? I think that I'll always wonder. I don't know if my husband feels this way or not. It's not something we've ever discussed. In fact, I've never admitted this to anyone until right this moment, putting it in writing.

If you have to make a decision as we did, I pray that you have the support of family and friends just as we did. Without them, we'd have never made it through. Our pastor was fully behind us and supported our decision all the way, as did all our family and friends, at least to our faces. In spite of our anguish following an early miscarriage after Max, we went on to have two healthy little girls.

If you run into someone who tells you that you must do this or you must do that, turn a deaf ear. This is your decision and there is no right or wrong. There is only your reality and your anguish over this decision that no parent should ever have to make. Sometimes there is no "right decision." No matter what, you will always wonder. Listen to your doctors, and then make your decision. And, may someday you will find peace as I have no matter what your difficult decision was.





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Please email artwork in pdf format to mnichols@nationalshare.org
For more information about this and other upcoming events, please visit us online at www.nationalshare.org.

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The National Share Office is now on Pinterest! Follow us for ideas and information on Memory Making, Jewelry, Grief Support Resources, Books and Holiday Traditions.



If you have ideas for pins that we can share, please email rcarlson@nationalshare.org. We look forward to providing additional resources to you.

Share is continuing to expand our video gallery on YouTube. Click here to view.





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Search us on Facebook! To connect with other parents and share your story, search: Share Bereaved Parents Peer Support or Share Subsequent Choices Peer Support. Please note, these are closed groups and membership will be approved by an administrator. For updates and information about Share events, perinatal loss research, updates on legislation and much more, search: Share Pregnancy & Infant Loss Support, Inc.



### Looking for Resources?

Check out our Perinatal Bereavement Resource Catalog! It's full of books, pamphlets and other wonderful resources suited for bereaved parents and their families as well as bereavement professionals. Start a Share group and receive a 20% discount on every order! Click here to view our catalog.

September/ October 2012

### 35 Years of Share

The September/October issue of the newsletter will demonstrate different ways that Share has helped families over the past 35 years. We welcome your stories, poems, and ideas on how Share has helped you and your family. Please send your stories to Rose at rcarlson@nationalshare.org.

Submission Deadline: August 15

> National Share Office 402 Jackson St. Charles, MO 63301 Phone: 800-821-6819



# 11th Annual Share Walk for Remembrance & Hope

Saturday, October 20, 2012 Creve Coeur Park, St. Louis Sailboat Cove

Registration Opens July 1st!

Registration Fees: Adults: \$25 Children (5-12): \$15

Registration includes walk fee, event t-shirt, program, balloons and bottled water

Click here to register today!