



# M.I.S.S.ing Angels

A Publication of the  
MISS Foundation

A Sanctuary for Bereaved Families

September/October 2002

MISSing Angels

## MISSing My Angel, Mya

*Aseña Nicolosi*



My beautiful girl was born on February 16, 1999 at 5:12 p. m. after 12 hours of long labor anticipating her arrival.

My family was there waiting patiently for her to make her entrance into this world. My first thought of her is how could I have created something so beautiful, so delicate? The next day I took her home. It was the best and scariest moment of my life. I was a single mom. I had to care for her by myself. I knew I had enough love to give her, but would I be able to support both of us?

My dad is amazing. He helped me care for her. He took care of her when I had to go to work. He changed her diapers even though he hadn't changed a diaper in 19 years. They bonded instantly. She loved her "Papa!" She would get so excited when he entered a room and instantly ran to him, and she knew that she had him wrapped around her tiny beautiful finger. Because anytime "Mimi" said "No" she knew that Papa would say "Yes!" It broke my heart to tell my dad that she was gone. It broke his heart too. Because he loves Mya as much as I do.

Mya had so much love and joy in her it amazed me everyday. She had such

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## UK Study Fuels Discussion

A recent article which appeared in many major newspapers around the country last month precipitated an onslaught of protests from women across the globe.

Concerned parents who have experienced perinatal death were outraged at implications of a UK study and the media's interpretation of the findings. Though the authors admit the study was flawed on many levels, they still re-

leased their data to the media. We'd like to offer a rival hypothesis in the pages of our newsletter in an effort to counter the negative effects this study has already had on the professional and medical communities.

One of the most poignant responses came from National Stillbirth Society Board Member, Sarah Kye-Price, Doctoral Candidate at Washington University:

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### Take Note:

- MISS Chapters across the country! See page 22 for chapter information
- See Safe Arrivals on Page 18
- Our hearts go out to the families of these children for their recent losses Page 15

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# MISSing Mya

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passion not only for life but everything in life as well. She was so caring and loving for her Family friends, dolls, Barney, and Elmo. If a baby was crying she was there comforting them. If I was crying all she had to do was smile and I felt better. They use to tell me at daycare that she didn't want to take a nap because she wanted to help all the other babies go to sleep. They would tell me that she would sit right beside them patting them on their back until they went to sleep. She loved to help anyone that was in need, if it was cleaning the house, putting away her toys, putting away the groceries, making dinner. She was there.

Mya loved to play outside, inside she loved every minute of life that she was here. My child wasn't afraid of getting dirty. On her first birthday I got her a purple and pink cake (her favorite colors, a true girl) and she had it everywhere but she made sure she shared that cake with everyone

including the dog! I gave her a bath afterwards and the bath water turned bright purple!

In October we had gone to Duncan Farms for their annual pumpkin patch and she found a puddle and the kids were all jumping and having the best time, she fell down in the puddle, we all started to laugh she looked up and started laughing too!

On Friday February 16, 2001, Mya turned the 2 years old. She could hold a conversation and count to three. On Saturday we threw a big party for her at her favorite park. She had a blast playing on the jungle gym, swinging with her papa, and blowing bubbles.

The following Tuesday was like any other day. When we got up, I sat her down in front of Sesame Street with breakfast. I went to get ready for nursing school I noticed the house grew this eerily quiet. I thought she was in her

play house with her dolls. When I went in the living room, she wasn't there. I think I knew something was wrong: It was mother's instinct because I never felt like this before. I looked out the patio door and she was in the pool. I ran to get her out and called 911.

Mya didn't make it. Now I am left without her and I can't tell you the amount of sadness and guilt that I feel everyday. There isn't a moment that goes by that I don't think about her, That nightmare I see every night when I go to bed. I don't know how to make it stop, but I'm working on it. I wrote this story to let everyone know that it can happen to you, and it does happen to parents that love their child with every fiber of their being, and maybe hearing Mya's story some other child will be saved.

*Editor's Note: Asena is beginning a support group for families of drowning. If you are interested, please call 623 979 1000.*

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## A Grandmother's Heartache and Joy

GeGe Johnson

Our family just spent a wonderful week at the beach. We had a busy time. The grandchildren loved every minute of our beach time. I have read the letters in the MISS newsletter every month and I am always moved by the stories people share about their angels whom they have lost.

We lost our beautiful baby grandchild, Hunter Michael Johnson, five years ago. I watched my son lose his son. There are no words to explain the pain.

I am a true believer in God and angels. I know Hunter



splashed on our grandchildren's sand castles.

He was the last name I prayed about each night as I thanked God for my beautiful family.

Angels take vacations too.

Dear Dr. Hughes and Colleagues,

I am writing in response to your article, "Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study" as published in The Lancet. I appreciate the time in which you took to explain your study findings and limitations, as well as inclusion of a historical context for policy shifts. However, because of the nature of the media reaction, your study has already undertaken larger-scale political significance, and may have potential negative effects on the lives of many women in both the UK as well as other countries. In my local paper, the headline reads, "Mothers Should Not See Stillborn Baby, Study Suggests". Based upon the media reaction in the United States, I fear that what you identify as only one part of a larger case-control study with noted limitations could lead to policy implications that are not warranted from the design and methodology of this study as currently published.

While I recognize that as an author there is not an ability to control media response, I feel that there is a social obligation to respond when our results have perhaps been misinterpreted by providing clarifying information. I hope that you will provide this clarification to me so that I may inform those who academically and clinically have asked my opinion on this article. I also hope you will consider what response you choose to give as authors and researchers capable of shaping public policy.

First, there is the issue of matched controls. Using first-time mothers in a comparison group seems illogical and counter-intuitive; women who experience stillbirth have experienced the totality of pregnancy and anticipated childbirth that is unknown to first-time mothers. In stillbirth, the outcome may be that the mothers do not leave the hospital with a living child; however, the process of pregnancy itself has transformed the psychosocial knowledge and awareness of these women even apart from the experience of loss. They enter a subsequent pregnancy in full knowledge of what could result, based upon their past experience. I do not find in your research a theoretical or empirical justification for why this is considered an appropriate match.

Secondly, even a brief review of research suggests that perinatal loss and the death of a child, including still-

birth, is often a criterion for complicated mourning (Rando, 1993, 1986). In addition, empirical studies have demonstrated that 48-51% of women were clinically depressed 1-3 months following a miscarriage (Lee, Wong, Ungvari, Cheung, Haines & Chung, 1997) and that perinatal loss has a lasting component much longer than merely the initial few months following the loss (Dyregrov & Dyregrov, 1999). By its nature, perinatal loss appears to produce increased depression, anxiety, and trauma. This may be heightened by social isolation, stress, and factors intrinsic to maternal bonding during pregnancy, unique within each relationship and situation. These same factors may significantly impact the parents' immediate wishes to or not to hold, see, or memorialize following a stillbirth. I question why there is an assumption in your study, and in general, that lower (or no) levels of depression, trauma, or anxiety would be "normal" following the experience of stillbirth. We do not have a clear demarcation in empirical literature for what "normal" responses to complicated losses may be. The reasons for this have as much to do with our individual, familial, and cultural perceptions of how "normal grief" is expressed. I feel that we, as researchers, need to account for these differences in a non-judgmental, non-pathologizing manner in order to respect individual and cultural diversity.

As a clinician, I know and anticipate that my clients who experience perinatal loss will experience some degree of depression, anxiety, and trauma. Furthermore, I expect that the first year and the subsequent pregnancy are the peak, and appropriate, times for these reactions to occur and to be dealt with because it allows for the development of healthy and adaptive coping mechanisms. What is more difficult to ascertain are the long-term reactions that delayed trauma can produce years beyond such a loss. My concern is that those reporting "favorable outcomes" in your study may be doing so now...but may not be doing so long term. There is also no accounting for the degree of social support, culturally normative responses, or individual coping mechanisms and prior losses that may have been encountered by study participants. While it is extremely difficult to control for all of these variables, I believe they are worthy of mention and inclusion where possible since the implications of this research are likely to extend to diverse cultural groups. Longitudinal follow-up is cer-

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## Kubler-Ross Responds to UK Study: Press Release, July 19, 2002

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In a rare media response, world-reknowned thanatologist and the first researcher to identify the stages of grief in her pivotal book *On Death and Dying*, Dr. Elisabeth Kubler-Ross, disputes recent media coverage of research from the UK that suggests that mothers may not benefit from holding their deceased (stillborn) children. Kubler-Ross, also an Advisory Member to the MISS Foundation, a support group for grieving parents says, "When are people going to realize that the only way we'd expect a loving mother to feel who has lost her to death is overwhelmingly sad and experiencing grief? Can we really put a one year, two year, or five year time limit on emotions of this type?"

Hundreds of mothers have contacted the M.I.S.S. Foundation expressing anger and disappointment over the research published by *The Lancet* and picked up by a number of major newspapers across the US. The study, which only included 65 women and which the authors admit was inadequately controlled, included a recommendation that mothers of stillborn children should not be encouraged to see and hold their children.

The mothers, who have inundated the M.I.S.S. Foundation and the authors of the article expressing their outrage, indicate that recommending a change of protocol based on a single study is irresponsible.

"People must remember the golden rule of research and epidemiology: Replication must be done in order to prove validity. I would strongly caution health care providers and facilities not to advocate a change in their postmortem protocol based on this isolated study. The author quotes several other studies that contradict this one. Given the diminutive sample population involved, one should be skeptical when reviewing this research." said Joanne Cacciatore-Garard, founder of the MISS Foundation.

"Justifiably, our concern is that healthcare providers will overreact and change programs that encourage parents to see and hold their children before all the necessary scientific studies have been completed to justify such a change." Examples of chaplains recommending protocol changes based on a newspaper arti-

cle regarding this study have already been reported.

Dr. Michael R. Berman, author and Clinical Professor of Obstetrics and Gynecology at Yale University Medical School states, " I advocate and encourage my patients to see, hold, bond with and caress their newly born children-for as long as they need- who are not born alive. In over 30 years of personal experience with this approach, I have never been sorry and have only received positive responses from my patients...I have also spoken with and cared for patients who have experienced these losses and were not offered the opportunity to see or hold their children and they regretably wished they had..."

The MISS Foundation believes that parents should be in an environment that encourages them to see and hold their children. "The environment should not be coercive and should not mandate that all people must hold their children, but rather, should be supportive and sensitive to the families' needs, including the mother, father, surviving siblings, and grandparents," said Cacciatore-Garard.

"In addition," she says, "we need to realize that normal grief responses can and do last well past one year particularly in parental grief. As a society, we must stop pathologizing normal responses to death."

Kubler-Ross and Cacciatore-Garard note that the MISS Foundation doesn't believe that incomplete scientific studies should replace the wisdom of thousands of people who have lived through the experience and report antipodal findings.

MISS is a nonprofit, volunteer based organization committed to providing emergency support to families in crisis after the death of their infant or young child from any cause. We are here to help families cope with the resultant feelings of overwhelming grief and loss. For more information contact [www.missfoundation.org](http://www.missfoundation.org).

*Editor's Note: This press release went to more than 1,000 national media venues. If you're interested in reproducing this, please contact us at [info@missfoundation.org](mailto:info@missfoundation.org).*

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# For Emily

by Kristin Jared

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How do I begin to write anything worthy of our beautiful baby girl on her first birthday? A poem? Where are any words that befit her? Where are the right words to say how perfect she was, except, ironically, the one part the doctors could never fix? How do I do justice to the way she took my breath away with the force of this love I thought I was prepared for? I had no idea. How amazing that someone so small and pink could effect us so deeply, forever. Nothing seems enough to try to express the impact Emily has had on our lives.

So, for this first birthday, for this year of "firsts" that we are all far too familiar with, I will share something that happened to me, to make me remember that this is not the end, and that Emily is waiting. All our babies are waiting.

My husband Andy, and I had always dreamed of going to Paris together. It was our "dream trip" that we promised we would make someday. After Emily left us, with Christmas approaching, we decided to leave the day after Christmas, and go away. I felt like it was a consolation prize, but was deter-

mined to do something life affirming as a reward for surviving the holiday without our girl.

Late one evening, we were walking into a Metro station after a day like most of our trip; busy, bittersweet, and filled with sights and tears as each beautiful thing brought to mind our daughter, and our grief. I was overcome with thoughts of our Emily, and how, as beautiful as this trip was, we were here because she was gone. I didn't want to make a scene, and I was struggling.

As we walked down the steps, into the station, we saw a beggar, one of so many in Paris, playing a violin on the landing. Knowing we had limited money, and not trusting motives, we generally walked past. This time, however, as I walked near the man with my thoughts of grief, a verse from The Bible popped into my head, as though someone else interrupted my thoughts to shout it in my head: "Be not forgetful to entertain strangers: for thereby some have entertained angels unawares." (Hebrews 13:2) I walked back to the beggar and dropped the money I had in my coat pocket into his violin case. He was

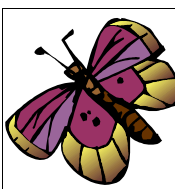
playing a folk-sounding tune, and did not look at me, nor I at him, ashamed at my lack of French, and for passing him by in the first place. As I joined Andy on the platform, the beggar began to play "Ave Maria." We both gasped as the sweet sound filled the tunnel and we held each other close as the beautiful song from Emily's funeral wrapped around us.

As the last notes faded, the train arrived, and I climbed on with a tearful heart, thankful for God's reassurance of his angels and our sure reunion with our beloved Emily.

As we all struggle, may we be helped to remember to be still and listen. May we be mindful of our treatment of all the angels around us, and the promise of their love. May we all be better angels. Our children deserve that.

*In loving memory of  
Emily Caitlin Jared*

*September 20, 2001-  
October 4, 2001  
Mommy and Daddy  
miss you,  
Butterfly.  
Love you forever...*



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## Special Friendships Grow at MISS

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This is about my friendship with Angela Iverson and our sons, Cody and Chandler:

*Forever Bonds*  
Brown eyed boys  
As precious as can be  
Dancing among kingdom clouds  
Being friends and free  
Perfect little heads  
Round, full, and priceless  
Ten fancy fingers

Ten pudgy toes  
Two mummies left on Earth  
Comforted by Heaven  
Hanging on to memories  
Smiling and wishing  
Friendship bonds that can't be broken  
Two on Earth  
Two in Heaven

*By Kacie Bailey-Schleier 7/6/02*

tainly needed before policy recommendations are made.

Finally, and perhaps most significantly, is the missing variable that I suggest for future analysis: perception of choice. You note in your discussion that some parents made a choice in their end-of-life wishes, and others felt forced to take an action during a traumatic time that they were unprepared to make. You suggest that clinicians may have “pressured” some parents. Perhaps it is not the seeing, the holding, or the funeral that is the true variable of question in the psychosocial response to loss from stillbirth: perhaps it is the ability of the parent(s) to have some sense of choice and control in an otherwise chaotic and uncontrollable time. While measurement is a challenge, I believe that there are proxy measures of locus of control and perceptions of control, as well as methodological merit of recounting the experiences that could help gain insight into this construct. This variable could have significant implications for policies that are parent-focused, rather than those that seek to apply a “cookie-cutter” solution to every situation. I would hate to see parents forced to hold a stillborn, but I would also hate to see parents stripped of their option to do this by a policy that says it is “detrimental” as your article, unfortunately, has been interpreted widely to say.

Obviously, your article has initiated a great deal of dialogue. I only hope that the dialogue and the research continue so that knowledge of the psychosocial impact of stillbirth and perinatal loss can continue. With all sincerity, I believe the points I have discussed in this letter are unexplored areas of research which I hope that you will consider implementing into future studies. I will extend to you any expertise I can offer as a social science clinicians and researcher in designing additional studies, data collection or data analysis that could help in this much needed area of research about the long-term effects of loss on women’s mental health.

I appreciate your time and attention to a very important area of concern for research, for women, and for policy makers.

Sincerely,

Sarah Kye Price, MSW  
NIMH Predoctoral Fellow  
George Warren Brown School of Social Work  
Washington University in St. Louis

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## *Have You Seen Rachel?*

*Have you seen my daughter?*

*You have never met her face to face.*

*But you may have seen her.*

*She is in the words that I speak.*

*She helps me fight injustices.*

*She guides me to help others in need of comfort.*

*She is in my tears and in my joys.*

*She is my strength.*

*She is my weakness.*

*She is my soul.*

*She lives on through me.*

*Have you seen her?*

~Lynne Barberian, in memory of Rachel