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Breaking the Silence: the story of one in four

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Breaking the Silence: the story of one in four

Graduate Professional Project

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Prelude

“They say that for over 50 percent of stillbirths, there’s no known cause. We don’t know what happened...We were the dark cloud on this really happy floor with relatives celebrating and bringing gifts and babies crying. It’s just that extra stab that you don’t need, because you’re already feeling as low as you can be. I wish there was a section where at least you’re separated. We didn’t want to stay there. But leaving the floor meant leaving Alexander. Why aren’t hospitals better equipped in dealing with such a tough experience?”

Our hospital did put a red rose outside the door, so that people knew this wasn’t a happy room. But there are so many things that could help that hospitals don’t regularly tell families about. There are cuddle cots, which are kept at a proper temperature, so you can stay with the baby as long as you want and not have to deal with what happens post-mortem.

When the nurse finally came in, I could tell she was trying to rush it a little bit. ‘Are you ready to hand the baby over to me?’ she asked. She took the baby and put him on this metal, cold-looking roller. Then she put a white sheet over him. It just seemed wrong — they could carry the baby out in their arms. I remember him vibrating on that cart, bumping up and down as she wheeled him out. Not a good moment.

Just because babies don’t take their first breath in this world, it’s sad that sometimes, they don’t even give you a death certificate. You’re carrying that child for 20 to 40 weeks. It’s not fair not to give them recognition.

I consider myself a mom. I had a son. He was stillborn. People don’t talk about it because it’s too disturbing, or it’s just silenced because nobody wants to hear these things. But it happens, and it happens enough.”

-Dr. Eleni Michailidis, “Stillbirth: Your Stories,”
Published by The New York Times and Company

Introduction

The opening story is a common internal dialogue that runs through the minds of many parents who have experienced infant and pregnancy loss. While many never learn the reasons behind their loss, they at least wonder why the hospital wasn't better equipped or why their doctor hadn't given them any type of warning. Many attribute this to the fact that pregnancy loss is rarely talked about, in both daily conversation and the media. While the subject of death is always uncomfortable, speaking about pregnancy loss, specifically stillbirth, can help inform parents, and potentially lead to a call-to-action where it would be aggressively researched to help prevent further deaths.

The United States currently ranks 25th in the world for stillbirths and 26th for infant mortality rate (Rhettner 2014). The rate of these deaths is more than half of other developed countries, and what is more troubling is that the numbers aren't decreasing at a rate that shows any indication of real change. Many attribute this lack of progress to the shockingly absent research in the subject of stillbirths.

This research explored the issue of pregnancy loss, specifically stillbirth losses. This research was done in an effort to address how little pregnancy loss is reported on and researched. In addition, this project was conducted in the hopes that awareness would be brought to the issue in an effort to inspire change. The media has the power to bring awareness to this issue by sharing the stories of women who experience pregnancy loss. While that can't save their children, it can shed light on a subject rarely talked about. That awareness can lead to the demand for government-funded research, which can lead to a decrease in the number of losses that occur each year in the United States.

Literature Review

The objective of this literature review is to look at how pregnancy loss is addressed in the United States. It discusses how other nations have decreased losses by conducting national research efforts into what caused stillbirths in their country, as well as issues surrounding loss that should attract media attention.

For the purpose of this project, stillbirth is defined as a loss in pregnancy occurring after 20 weeks gestation—in those cases, women will still deliver the baby, but the child will have passed away in utero or during the delivery. A miscarriage is any loss prior to 20 weeks (excluding ectopic pregnancies), while infant loss occurs after a live delivery of a baby. In the case of stillbirths, a loss that occurs after 30 weeks gestation is considered a “late stillbirth.” When referring to parents, often the term “loss” will be placed before the words “mom,” “dad,” or “parent” to signify that they have lost a child.

Silence on the Subject

Pregnancy loss, specifically stillbirth, is rarely talked about out in the open. The majority of conversations surrounding it take place at the hospital following a loss, or in support groups when women are lucky enough to have been recommended to one. This lack of awareness has painted the perception that fetal demise is an issue of the past—it doesn’t happen anymore, and it certainly doesn’t happen at the rate of 1 in every 160 pregnancies (Muthler 2016).

What is truly troubling in this matter, is doctors agree that a majority of these cases are preventable, but the lack of research into why they happen in the first place has stunted progress in their prevention. Meanwhile, other countries have taken steps to drastically cut their death

rates; the Netherlands, specifically, cut their rate by 6.8 percent by creating a national program that studied stillbirths that occurred from 2010-2015 (Muthler 2016).

Creating a Systematic Audit of Deaths

The study conducted by the Netherlands included crucial steps, such as explaining the importance of autopsies and placental exams to loss parents, and, most importantly, providing those exams for free. Furthermore, a designated medical team then examined each case of stillbirth; this helped them to pinpoint problems in their medical care and correct those problems. The careful analysis of each loss led to better care of patients in subsequent pregnancies and it allowed for medical professionals to identify high-risk pregnancies before a loss could occur.

In contrast, most doctors in the United States discourage parents from having autopsies conducted, following the loss of their children. This is due mainly to the fact that most insurance companies will not cover them, or placental exams; if parents want a reason for their loss, it could potentially cost thousands of dollars out of their pockets. But without those tests, they are usually told their child died for “unknown” reasons.

In an attempt to increase research and awareness, President Obama signed into law, in 2014, the Sudden Unexpected Death Data Enhancement and Awareness Act, which called for the federal government to “continue” collecting data on stillbirths through channels that states have in place (Reno 2014). This Act provides no new funding for that evaluation or research, and most states only require that stillbirths be reported via a death certificate—rarely is there a cause of death listed on that document. Essentially this meant that there was no change to how fetal demise was evaluated in the United States, which is why the country is currently 155th out of 159

(joined by Chad and Niger) for stillbirth rate decrease between 2000 and 2015, at a dismal .4 percent per year decrease (Muthler 2016).

What separates the United States from other countries (as evidenced by the 2014 Act) is that there is no national system to report and evaluate stillbirths, despite the Center for Disease Control (CDC) stating that it is a critical step in reducing them (CDC 2015). The prevention of progress is directly related to the lack of government-funded data collection and evaluation. This is further stunted by insurance companies, and their deficiency in coverage for autopsies and genetic testing following the deaths.

Catherine Spong, MD, wrote a comprehensive summary of the prediction, prevention, and management of stillbirth. In her book, she stated that “when evaluated in a thorough, systematic fashion, many cases of stillbirth can be assigned an etiology. This process can facilitate grieving and emotional closure for families, counseling about subsequent pregnancies and obstetric interventions that improve outcomes in subsequent pregnancies” (Spong 200). The evaluation she speaks of is similar to what the Netherlands implemented in their study. The common theme in the research conducted for this project is that more research following stillbirth is critical to help not only decrease stillbirth, but to also help parents cope with their losses.

The Maternal and Child Survival Program created an audit system proposal to make every baby count. Their proposed system starts by establishing a review committee—the team responsible for setting up and conducting death review meetings and monitoring recommended actions. That team would be responsible for mobilizing resources, deciding on an approach for reviewing cases, and organizing data collection (World Health Organization 2016). Their proposal also included a six-step cycle of auditing deaths at the facility level:

- (1) Identify Cases for Review: This includes the process of recording all births, stillbirths, and neonatal deaths; also includes deciding which cases to collect more information on for a more detailed review.
- (2) Collect Information: This includes a standardized collected of information for a register, as soon as possible after each death.
- (3) Analyze Information: This includes identifying problems in the medical system that may have contributed to stillbirths and neonatal deaths, especially in cases that could have been prevented. This analysis includes the identification of trends in rates and causes of death and geographic locations, as well as the analysis of modifiable factors.
- (4) Recommend Solutions: Identifying specific, measurable, attainable, relevant, and time-bound solutions.
- (5) Implement Solutions: Take immediate actions to prevent stillbirths and neonatal deaths—use successes to advocate for future actions.
- (6) Evaluate Both Process and Outcomes, Refine as Needed: Look at what worked and what didn't to ensure that future recommendations are informed by the data collection (WHO 2016).

This six-step cycle could jump start the process for implementing a national audit system that would help prevent future stillbirth and neonatal deaths. While the studies in this literature review collectively agree that a national audit system is critical to decreasing the rate of death, there is still the need for a demand to be made by parents. One example of a successful campaign for change was in the case of SIDS research.

The SIDS Campaign

The easiest way to showcase the necessity of research is to consider how the United States has tackled the issue with Sudden Infant Death Syndrome (SIDS). For the past 30 years, SIDS has been thoroughly researched and cases have been closely evaluated. This research led to the discovery that SIDS was more commonly found when babies were placed on their stomachs to sleep. After this discovery, the government instituted a campaign for doctors to educate parents about risks associated with SIDS. This campaign led to rate of SIDS decreasing by 50 percent (SIDS 2013). If research on fetal demise led to that same rate of success, the United States would be among the leading nations for a decrease in the rate of deaths.

Professor Ruth C. Fretts, MD of the Harvard Medical School referred to the lack of research as the “Stillbirth Scandal” (Fretts 13). She too mentioned the research conducted into SIDS and how 30 years ago, parents demanded researchers look into the deaths of the demised children. One thing she noted was that a complete death scene analysis, autopsy, and comprehensive history was conducted in each case. An important comment she made was “without a thorough and thoughtful analysis of each stillbirth, the counseling of the stillbirth and her family on the recurrence will be sadly inadequate” (13). Once again, without research there is no hope to decreasing the number of deaths.

This research cannot happen until there is a demand from the government, which requires a demand from the public. The public cannot demand this until they are aware of the problem. For the public to become aware, it requires those with a voice to break the silence. It is the duty of journalists to alert the public when they see a disservice to their community, and that is what is happening in the quiet community of loss parents. Raising awareness has the potential to transform pregnancy care and save the lives of thousands of babies annually.

Beyond the prospect of decreasing stillbirth rates, there is the added benefit of helping parents cope with their loss. As mentioned in the opening story, there are many issues surrounding pregnancy loss, including poor practices by the hospitals following the deaths.

The Role of Medical Professionals

The economic and psychological impacts of stillbirth can all be affected by the actions of medical professionals following a loss. As stated earlier in the paper, there are mixed feelings from loss parents with regard to their medical care during their pregnancy and delivery experience. Unfortunately, studies have found that medical professionals don't feel adequately prepared to handle the sensitive subject of child loss with parents after stillbirth, despite the fact they often cared for the women all throughout their pregnancy.

A study by BMC Pregnancy and Childbirth concluded that “providing parents with understandable information, discussing options with them and tailoring care to their individual needs were common themes” that parents wished they were given after their loss. To achieve that, knowledge-based training is required to improve healthcare workers' ability and comfort in their provision of personalized stillbirth care (Ellis 2016). As stated in the study, healthcare workers can leave a memorable impression on parents, whether they be the ultrasound technician who can't find a heartbeat or the obstetrician who delivers a stillborn child. Any professional who works directly with parents needs to be trained to handle situations that deal with loss. Following the trending conclusion from various research efforts, this group also concluded that there was a lack of research in the subject—in this case the lack of research involved the experiences of healthcare workers.

They found that both patients and workers recommended that there be improved training, continuity of care, and supportive systems and structures put in place for healthcare workers in order for them to handle loss situations better. Another important finding related to the suggestion of testing following loss, and healthcare workers being trained better to discuss those options with parents.

There were also intriguing findings, such as the recommendation for “bereavement suites” in hospitals, as well as a special bereavement staff. They also noted that while there is a need for increased investment in the research of stillbirth, in general, to reduce the rate, the provision of care for families remains critically important to reduce the psychological impacts on parents who experience loss (Ellis 2016).

Psychological Impacts

One qualitative analysis of stillbirth examined the distress that many parents experienced after their loss, and found that many physicians don’t feel prepared to deal with patients following a loss (Kelley and Trinidad 14). This study also found, from the doctors who participated, that they would not offer an autopsy, but would conduct one if requested—the only parents in the study who requested one worked in the medical field (15). Once again, this is information that the average parent does not know about, but an issue that needs to be brought to light. As stated by one parent in the study: “There was testing that could have been done before I delivered. But it was testing I didn’t know about, wasn’t offered, so there could have been a cause; we don’t know the cause...I just feel like we were blown off with, ‘These things happen’”

(15). That is a common occurrence among loss parents, many who feel they were left in the dark during and after the death of their child.

In a Lancet study, 60-70 percent of grieving mothers in high-income countries reported “clinically significant,” grief-related symptoms of depression one year after the death of their baby. In half of those cases, the symptoms were still present four years after the loss. The study group estimated that 4.2 million women are currently living with depressive symptoms as a result of stillbirth (Bhutta 606). Those depressive symptoms were persistent in subsequent pregnancies, which implies that the psychological effects from stillbirth could affect the health of future babies born to loss moms. Furthermore, these findings should call attention to the critical need for national support systems to help parents after loss. While many communities have resources associated with their healthcare systems, it might benefit parents if there were national programs set in place.

In order for those programs to be put in place, it would require that the public be exposed to the reality of psychological effects of stillbirth. These types of programs and continuity of care require a look into the economic impacts following stillbirth.

Economic Impact

Until recently, very little research was conducted concerning the costs associated with stillbirth. Most economic analyses have focused on the cost of stillbirth prevention (that figure is anywhere from \$4,781 to \$10,571 in medical costs, per stillbirth averted). However, to assess whether those preventative programs are cost-effective, an understanding of the costs of stillbirth is needed. A Lancet study group looked into direct financial costs of stillbirth. In that study they

discovered that direct costs (including costs of medical care by patients) ranged from \$1,450 to \$8,067—these care costs were 10-70 percent greater than with livebirth (Lancet 604). While the government or insurance companies covered a majority of these costs, they found that 14 percent of respondents from high-income countries had to pay out of their own pockets. They also found that parents paid between \$118-3,093 for investigations into the cause of death and \$118-20,000 in hospital fees for additional medical care following a stillbirth. That out-of-pocket cost for investigations is a deterrent when parents are trying to decide whether to look further into the death of their child. The group pointed out that no reports of the cost of care in subsequent pregnancies exists, but they estimated that parents paid up to \$10,000 in additional care—thus adding to the healthcare costs associated with stillbirths (605).

Indirect costs associated with stillbirth include the payments for funerals or cremation of the child. While there are some insurance companies, government programs, etc. that will assist with costs, the group found that a majority of parents paid \$469-11,719 for funeral costs. These indirect costs are just one factor in the financial burden surrounding stillbirths; for some families their stillbirth led to a reduction in earnings or an inability to return to paid employment. Ten percent of parents remained off work for six months following their loss, and 38 percent of mothers reduced their working hours (605). One important note from this study is that only 12 of 170 countries with maternity benefit policies included provisions for stillbirth—the average leave for mothers following stillbirth is 11 days, and only one day off for fathers (605). That statistic proves a gross misunderstanding of the psychological effect a stillbirth has on parents.

The conclusion drawn by the Lancet group was that the effects of stillbirth are still greatly underestimated, and that underappreciation might explain the slow pace of change to

address the rate of stillbirths. The conclusion of this study directly aligns with the mission of this professional project.

Create a Demand

Recently the American Academy of Pediatrics released an update for their recommendations for a safe infant sleeping environment (Moon 2016). While the rate of SIDS drastically decreased following an aggressive research campaign, the government continues to fund research to cut that rate even further. Stillbirth research is deserving of that same attention, but will not receive it until the same effort is demanded by the public, just as it was demanded 30 years ago in the case of SIDS. The media has the power to create that demand by drawing attention to the prevalent issue in most stillbirth and pregnancy loss cases—no known cause and no answers for parents.

This literature review serves to draw focus on the issue that inspired this professional project. The purpose of this project was to bring awareness to pregnancy and infant loss using a popular social media platform. While this is just one example of using media to create a call-to-action campaign, it showed that there is a receptive audience to this issue.

Journalism Blueprint

Those who feel like they were left in the dark are speaking out. It is becoming more common for parents to share their loss experience in an effort to honor the memory of their children, while also attempting to help others cope with their losses. There have been efforts by

some mainstream media, such as the Washington Post and The New York Times, to feature stories on loss parents, but the deeper issue is still missing from mainstream news. While it's important to share the stories of parents as a way to help with the grief, it's critical that the media address the bigger issue at hand, which is a need for research to assist with preventative care.

Approaching a story that involves a sensitive subject can be a daunting task for a journalist. It requires empathy for the subject and a true understanding of the situation. When beginning a story on pregnancy, stillbirth, and/or infant loss, it is recommend that journalists approach groups dedicated to helping loss parents. These groups are an invaluable resource for the media because they not only have a network of medical and professional connections, but they also have direct contact with loss parents.

Usually support groups develop relationships with their members, and can therefore point journalists in the direction of sources willing to share their stories. They can also give journalists tips on how to talk about loss and how to approach the subject with the necessary level of sensitivity. This will lead to a more empathetic reporting, which has more power to create a call to action.

When choosing a subject for a piece on loss, it's important that journalists not completely rely on the human interest element. While retelling a loss story has the power to move an audience, it doesn't do much to draw attention to the prevalent issue. Instead, journalists should align the story with a cause—for example, using a story about parents who were never given answers to spotlight how many cases of stillbirth are due to unknown causes. Combining news pings, such as costs associated with stillbirth or psychological effects following loss, with the loss stories has a better chance of leading to change.

As the literature review points out, there is a consensus among professionals that more research needs to be conducted on pregnancy and stillbirth loss. What is needed to create that call for research is active participation from mainstream media. This professional project gives just one example as to how media can implement campaigns and stories to raise awareness to create the needed demand.

Methodology

I began this project by volunteering to head the Instagram page for the support group, Pregnancy After Loss Support. This provided a platform for which I could create a call-to-action by displaying the stories of loss moms during the month of October, which is known internationally as Pregnancy and Infant Loss Awareness Month. This month was the perfect opportunity to create a call-to-action because this is the time most women are willing to open up about their loss, and therefore this was the greatest opportunity for reaching women and raising awareness. Through working with Pregnancy After Loss Support, I was able to create vital contacts with women who had experienced loss, and who speak out to raise awareness for stillbirth research. These are the women I reached out to when I looked for story submissions.

I interviewed three women who work for the organization, all who have experienced a stillbirth loss or unexplained miscarriage. Those interviewed included Lindsey Henke, MSW, LICSW, founder of Pregnancy After Loss Support, as well as Valerie Meek and Tara Bennett Kilian, who assist with Operations and Social Media Coordination. These three women were chosen because they have dedicated their lives, following the loss of their children, to helping women cope with their grief and to raising awareness for pregnancy loss. Furthermore, they

represent a vast majority of their community—women who have no real explanation for why their children passed away during pregnancy. The interviews were used to get a feel for the community and discuss which stories and photographs would be the most appropriate for public viewing.

My next step was to choose who to feature on Instagram as part of the awareness campaign, and what stories would resonate the most with viewers. This was difficult, as over 200 women submitted pictures and small write-ups on their losses. Ultimately, there were concerns with some of the pictures being a trigger—a word used to describe photographs or experiences that will trigger someone to relive a traumatic event. In this case, a photograph of a child born earlier than 24 weeks gestation might be too upsetting for some viewers; careful consideration was taken into which photographs would be effective enough to create a conversation, but not so upsetting that they would overshadow the objective.

Other factors contributing to the selection of photos included the demographics of submissions, as well as pregnancy-related classifications. In the interest of appealing to women across the spectrum, I selected pictures submitted by a diverse range of women; this included race, weight, age, etc. Furthermore, I examined each pregnancy situation submitted and was sure to include babies who were lost in a miscarriage, stillborn, or lost after birth; I took this one step further by also choosing different causes of death, such as a known terminal illness, SIDS, infections, etc. By paying attention to the demographics of submissions, I was able to ensure that virtually any woman could relate to a few stories over the course of the campaign. It was critical for me to validate each woman's experience and to not make it seem as though one loss is more traumatic than another, something that many women in this community battle against. Finally, I included posts where the mother specifically stated that she was given no reason for the loss of

her child—this was done in an effort to raise awareness to the fact that most parents never learn the reason for why their child died. By being so careful in the selection of the posts, I was able to create a campaign that women found relatable, which promoted high levels of user engagement. User engagement, in this case, leads to the sharing of more stories, which in the end results in a higher level of awareness brought to an issue.

The last step I took was facilitating conversations throughout the campaign. I was careful not to “take over” each post, as the stories shared were not my own. Often the mother who was featured would receive comments and questions, and she would take over the conversation by responding to them. My only role in the conversation was answering general questions that women had or offering words of encouragement where I felt needed. By taking a step back from the comments, it allowed for users to make this campaign about their own experiences. This created a great sense of community and allowed for the users to lean on one another for support, which in turn strengthened their connection to the organization.

The openness of women to share stories during this campaign translates directly to the issue addressed at the beginning of this paper. When a woman feels that she has the support needed to share such a personal experience, she gains confidence to speak out on the issue in her own personal life. This leads to more posts about loss, more discussions with family and friends, and ultimately more awareness raised to the issue.

Analytic Results

When I took over the Instagram page in May 2016, there were 1,037 followers. This platform had taken a backseat to their Facebook and webpage, and therefore had very little

interaction. Posts were not regularly made, and the page was rarely updated. In preparation for my October campaign, I began to build more of a following. I did this by posting 1-3 times a day, which created a schedule for my users to expect.

After posting daily, I began to notice a higher level of engagement as well as more followers. For my campaign to be successful I knew I would need a higher following, and more importantly I would need users to actively seek my page for updates. From May 5 to October 1, 2016, the page gained 1,116 followers—a 108 percent increase. These followers included men and women from all over the world, with most of the foreign followers coming from Canada, Australia and Great Britain.

After doubling the following, I began the Pregnancy and Infant Loss Awareness campaign. Immediately I noticed a high level of engagement and a willingness from women to share their stories. The first post, created on October 1 received 431 likes and 12 comments, which equates to a 20 percent user engagement rating. According to Michael Leander, an Award Winning Marketing Trainer, anything above 1 percent engagement is good, while .5-.99 percent is considered average (Leander 2016).

That engagement set the tone for the month, as the user engagement rating never fell below 3 percent. Over the course of the campaign, there were 38 posts made to the account. Those 38 posts spread out across a 31 day period, with posts being made daily and on six days there were two posts. Likes on pictures ranged from 65 to 447, while comments ranged from one to 74. Overall there were 8,129 likes and 636 comments made over the course of this campaign.

This meant an average of 214 likes to any given picture posted, along with 17 comments. The rate of user engagement ranged from 3-20 percent, with the average remaining somewhere

around 5 percent over the course of the campaign. With regard to user engagement statistics, this would be considered a successful social media campaign (York 2016).

Along with user engagement, the campaign saw a successful increase in followers. In the span of 38 days, the page gained 2,472 followers, an increase of 115 percent. Over the course of this entire project, I've brought in 3,588 new followers, which equates to a 346 percent increase.

While these statistics might only reflect women who are already aware of pregnancy loss, it's safe to say that there are likely followers who, while aware of the issue, might not have been aware of how common pregnancy loss still is among women. Furthermore, the new following is now aware that there are resources available and a community that is willing to hear their stories. The exchange of stories is the quickest way to ensuring that the silence that surrounds pregnancy loss is broken. Breaking the silence ensures that awareness is brought to this issue.

Conclusion

This project concluded that there is an audience for this call-to-action, and a need for further research. Between the number of submissions and the user engagement, it is clear that men and women want to tell their stories. Creating a safe space for the exchange of experiences encourages loss parents to share. Once these stories become more commonplace, it is safe to assume that the issues surrounding pregnancy loss will also be addressed.

While some parents know why their child died, this campaign revealed the shockingly-high number of parents who do not. Those parents yearn for answers, and that is what is important for the general public to see. Stories and features that address those issues will lead to

the revelation that stillbirth and pregnancy loss is much more common than many realize. That realization will also come with learning about how many losses are unexplained.

When the general public begins to question why that is, it will lead to positive change, just as it did in the case of SIDS. That questioning derives from the basic fear all parents have for the safety of their children, not just those who have experienced loss.

This campaign was successful in its objective of fostering a community and bringing awareness to pregnancy and infant loss. The overall mission of this project might take time, as it involves making infant and pregnancy loss a mainstream topic. What was proven was the want of a community to publicly share their story, which inevitably will lead to a demand for answers.

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Appendix

Figure 1. The following figure displays the messages posted to Instagram, along with the number of comments and likes for each post.

Date	Message	Likes	Comment
01 Oct 2016	Remembering all our babies gone too soon. We'd love for you to include us in your journey this month as you remember all your angels. Tag us or use #PALShare so we can show others how courageous you are!	431	12
02 Oct 2016	Day2: Who they are. This is the Howey family photo. Many have not seen Emerie without all those tubes, and so here she is. Emerie Elise was born through an emergency c-section at 40 weeks 1 day on 8/4. She had a head full of beautiful dark straight hair. She had chubby cheeks and a cute nose from dad and a cute mouth. She fought for 3 days in the NICU, and at the end she took her last breath in our arms. I'm struggling to even share this picture or a selfie or something insignificant. This is a picture of our beautiful daughter who lives in heaven. She is loved and missed beyond measure by so many. Oh I long to hold you Emerie...you are missing in my life. I hope God has told you how much you are loved and missed. Everyday brings me closer to meeting you.// photo by @j_e_howey	272	21
03 Oct 2016	Day 3: That day dreams of feeding, holding, putting her to sleep in the room we made next door to ours, watching her grow up—walk, sing, and dance, to be successful and happy one day were crushed and broken forever...// photo by @themyragavini	66	2
04 Oct 2016	October is Pregnancy and Infant Loss Awareness Month. We at PALS want to take the month to remember our babies and children who have died, because we wouldn't be here without them. Please share a photo in the comment sections of our Facebook post, and share 3-4 sentences about your loss and journey, including your child's name (if you named him/her). We will choose a photograph to feature on Instagram each day for the rest of the month, along with a bit about that family's journey.//photo by @stillbreathinglindsey	223	15
05 Oct 2016	Check out this article from @stillbreathinglindsey on our website. There are so many fantastic ways to honor our babies this month. Does anyone have other ideas to add to Lindsey's list?	164	10
05 Oct 2016	This is my beautiful baby girl...Livviah Emanuella. After 37.4 weeks of pregnancy we found out there was no heartbeat, while I felt her last kick a couple of hours before. She was	170	38

	stillborn at 19 Sept 2016. 5 pounds and 50 cm full grown...it's only two weeks ago. I still don't know if it's killing me or making me stronger. // photo by Mary Mee		
06 Oct 2016	Check out the #BumpDayBlog today! I'm struggling a little with being pregnant during #PregnancyandInfantLossAwarenessMonth. How are you other mamas handling it?	146	28
06 Oct 2016	These are my identical twin boys, Gavin and Chase. Born on June 26, 2014 at 21 weeks 2 days. They were so very wanted, are so very loved, and are forever in our hearts and are always watching over us. // photo by @jmnyq	427	35
07 Oct 2016	This is my lil angel at 6 weeks. On our 7 th week appointment the doctor said there was no heartbeat. We were trying for a year and a half. That was the worst day of my life, it was a nightmare, my heart broken into pieces, the pain was unbearable. We named our baby Zoey. We love you so much baby. Dad and Mom are grateful even if we didn't see you. // photo by @mrandmrsferrer	134	3
07 Oct 2016	We are so overwhelmed by the amount of love and support that you mams have shown one another. Remember that you are all courageous! Choosing to move forward each day proves that, no matter how you feel right now in your journey. Keep sharing your stories and keep supporting each other!	123	1
08 Oct 2016	Today is my Angel's 4 th birthday. Shortly after his first birthday, he went to sleep and woke up in Heaven due to SUDC. Happy Birthday Harry Real Peterson 10/4/2012-10/28/2013. // photo by Amber Peterson	99	11
09 Oct 2016	Kai Phoenix Hajny, born still and silently into the world 17 th March 2016. Every level of my being was shattered that day, shock, disbelief, how could this have happened? Now we rebuild, with Kai at the centre as he was from the moment we knew he was with us, just in a very different way than we could ever have imagined. // photo by Megan Baker	177	17
09 Oct 2016	This is a photo from our maternity photos last weekend. It's raw. It's dark. It's emotional. It's beautifully perfect. It IS everything I have felt and experienced during my loss last year and subsequent pregnancy this year. I follow the PAL blogs every week and from our BFP to now it's incredible to see how much we've all grown and how much we've overcome! The road is not over. There is much to still conquer. But with the support of groups like SANDS, PAL and many other private groups on social media and the support network available to mums is priceless. The most welcoming and comforting part—it is ok to talk about our Angels like we do our Sunshine and Rainbows—it is ok to have your feelings validated and acknowledged by people who you have had to	111	3



	educate through your own loss. It's ok to break the silence! Thank you. For everything. // photo by Rebecca Santillan		
10 Oct 2016	For 35 weeks I had the privilege of carrying a set of twins. You could say I enjoyed my pregnancy more than most women do. On July 10 th the twins decided to join us a littler earlier than we had planned and I was rushed in for an emergency c-section. It was then, 9 days ago that I became a mother of two beautiful babies. Luna Marine (left) and Enzo Leandro Jr (right). Due to unfortunate circumstances, out of our control, which we were aware of ahead of time, we were told Enzo Jr wouldn't make it past delivery. That day we got to spend an amazing 12 hours with our baby boy before he passed and a couple hours after. He fought long enough to meet our immediate family and spent his last minutes cuddled next to his sister on my chest. This is by far has been the toughest thing we have ever gone through, and I will forever miss feeling those little kicks inside my belly. But we know our baby boy is now in a better place. Little miss Luna Marie is still in NIC working on her gains, but she is doing great and will soon be coming home to mommy and daddy. // photo by @thee_captain_	253	34
11 Oct 2016	Dads have rainbow babies too.	283	6
11 Oct 2016	This is my husband and our first baby, our son. At 22 weeks he was diagnosed with serious birth anomalies that weren't compatible with life. I carried him until 38 weeks and he was born sleeping Spetember 5, 2015. A day I will forever remember and a day a piece of my heart was taken away. Jesse Alberto Castillo. // photo by Diana Quinones Castillo	206	15
12 Oct 2016	Here is an ultrasound of our little guy who we lost on Match 8, 2016 at 17 weeks. We are trying for another baby, but I won't ever forget him. // photo by Emily Madsen	163	13
13 Oct 2016	This is baby Giovanni Evola. Born sleeping on May 13 2015. I was 27 weeks pregnant when doctors found no heartbeat and no answers. // photo by @christine_rose8	173	25
14 Oct 2016	This is my Brysen, born at 23 weeks gestation weighing 1 lb 10 oz. Our little fighter spent 18 days here on Earth before going to Heaven due to complications of his extreme prematurity. He would have been 2 last month. Now we do "Blessings from Brysen" to make the world a better place because he lived. We miss him more each day. // photo by Samantha Davis	327	24
15 Oct 2016	Today is Pregnancy and Infant Loss Awareness Day. We invite you to light a candle tonight at 7pm to honor your baby. This Wave of Light is in remembrance of all our children no	447	35

	longer with us. Who are you missing? Please share below so we can remember with you.		
16 Oct 2016	Our beautiful Bentley Jack, July 4-7 2013. Bentley was our miracle born through embryo adoption and we had to say goodbye to him after 3 days from a rare sudden pregnancy complication...our arms long for him but we know he is safe with Jesus. Loved by mom, dad, little sister Sadie and little brother Liam. // photo by Lisa Rolleman	169	8
17 Oct 2016	Heartbreaking seeing all these photos so many beautiful angels. This is my girl Kyla Sian 7-3-14. 16 hours the most sweetest but heartbreaking 16 hours of our lives but the most precious moments and memories we got with her. We lost her to an infection possibly group b strep or ICP at 41 weeks during labor, forever missed forever loved our beautiful angel up above thanks for sending us our rainbow he reminds me of you every day. X. // photo by Jemma Potter Orourke	147	6
19 Oct 2016	Jack made me a mom. I love his little sister more because I understand just how precious her life is. // photo by @thereluctantaviator	264	3
19 Oct 2016	It's October, which many of us now know as Pregnancy and Infant Loss Awareness Month. In my case, it's the fourth time I've lit a candle on October 15 as part of the Wave of Light that circles the world in remembrance of our babies. Of course, we loss mamas know what this journey requires each of each month. I gather baby loss resources year-round. I do my part in joining the chorus of those sharing experiences of pregnancy loss—despite silence, despite stigma. Honestly, I didn't think I could be any more "aware." But this month, thanks to several moving new initiatives, I have an even deeper appreciation of those traveling this path, gathering strength, remembering, missing, and—even in their grief—helping others. // photo by Jennifer Pardini	256	8
20 Oct 2016	Eloise Gray Schmidt Sept 22, 2015. We drove to the hospital anticipating bringing home a baby after the doctor suspected my cramping may be preterm labor. The reality was I had developed preeclampsia suddenly and without symptoms and suffered a placental abruption. Our sweet girl had no heartbeat when we arrived. Now, a little over 1 year later, this picture watches over her little brother's crib just as I'm sure she watches over him. // photo by Mary Kathryn Schmidt	188	14
21 Oct 2016	We were different then.	150	5
22 Oct 2016	Ellison Thi, born still at 37 weeks on 5/28/2014. She was born the day after her big brother's 4 th birthday. We miss her everyday and just had her rainbow baby brother on 8/29/2016. Our journey has been full of love, hope and support. Our	261	12

	mission is to forever celebrate our Ellie and bring awareness and support to families of Pregnancy and Infant Loss. No family should ever have to go through their journey alone as it is not anything you can prepare for or ever imagine going through. // photo by Judy DuCharme		
23 Oct 2016	Not everyone has a picture of their angel to cherish. // photo by Connie Yeager	141	10
24 Oct 2016	Liam Scott Elmer. My beautiful son, Liam was born April 9, 2007 and passed away unexpectantly 5 weeks and 3 days later on May 17, 2007 of SIDS. It's been 9 years and there's not a day that goes by where I don't think of him. I try to live my life in a way now, where I do and enjoy everything twice. Once for me, and once for him. It's one of the ways I can mother him from here, while he's on the other side. // photo by Hillary Fedoroff	194	11
25 Oct 2016	Who are you missing?	283	46
26 Oct 2016	Alyssa Kathleen Schmalzriedt 1/4/13 After going to a regular routine apt early that morning I heard those terrifying words. My world fell apart and so did my children's (pictured below). I was 38 weeks n 5 days. She was perfect so beautiful she weighed the exact same as me when I was born. Too beautiful for Earth my precious, beautiful, baby girl. I miss her more everyday! She now has a little sister she watches over. Half of my heart will forever be in Heaven with her. // photo by Tera Schmalzriedt	246	17
27 Oct 2016	My 3 rd son (4 th child) Floyd Harold Dean Pitner. We have no answers why he was born sleeping at 21w 1d. They know my bp was high and I was under a severe amount of stress. Genetic testing showed no reason. Doctors offered no further explanation. Part of me died with him. I wanted to go with him the day he was born. God had other plans. I have my rainbow baby and he is the light of my world but part of me is already in heaven with my boy. Every day is a struggle. // photo by Kathi Dean Pitner	122	7
29 Oct 2016	I painted this portrait of my twins from memory and showed it at an art show the day of their predicted due date. I didn't have a picture taken of them though I remember beautiful little characteristics of their noses and mouths. Their names are Lincoln Gregory and Landrin Ardelle. They were perfect and I still carry fear and sadness but I also feel lifted by their presence with me always. Thank you for giving me the opportunity to share their names as it makes them more real and present and not just a distant memory. Sending love to all mother who are here and also out there. // photo by Jessica Dies	215	13

30 Oct 2016	We have lost 2 little ones due to miscarriage. I still miss them and so do my other children. This is a photo that a friend did for me when we announced our current pregnancy, currently 21 weeks; we wanted to make sure that the two we lost were included. They will forever be in our hearts. // photo by Amanda Shaefer	311	8
31 Oct 2016	These are my sons, identical twins, Andrew John and Eric James. They would be 2 years, 8 months and 5 days old today. I remember their last kicks so vividly, they were so strong. Now I look back and think those last kicks were telling me goodbye. That afternoon we were in the hospital being told their heartbeats couldn't be found—it came so out of the blue after a perfect pregnancy—and the next morning they were born. I remember just blindly hoping that everyone had been wrong, I waited for them to cry as they entered the world, but the silence was deafening. I feel like the silence has surrounded me ever since. // photo by Emily Bridge	255	42
01 Nov 2016	We just wanted to say thank you for the support you mamas showed each other last month. It's never easy to be vulnerable and share such personal stories, especially with strangers. But we were overwhelmed by the support you gave, and the comforting words you offered. Our community is strong because all you mamas are so compassionate and courageous. Continue sharing your stories and continue to lift one another up.	219	3

Figure 2. The following figure displays the photographs posted each day to Instagram.

01 Oct 2016	
02 Oct 2016	

03 Oct
2016



04 Oct
2016

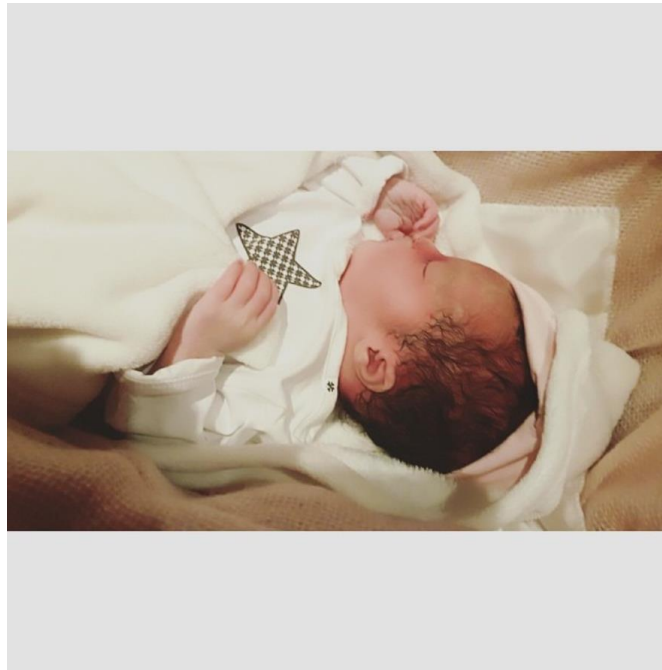


05 Oct
2016

9 Ways to Honor
Pregnancy & Infant
Loss Month While
Pregnant or
Parenting After Loss



05 Oct
2016



06 Oct
2016



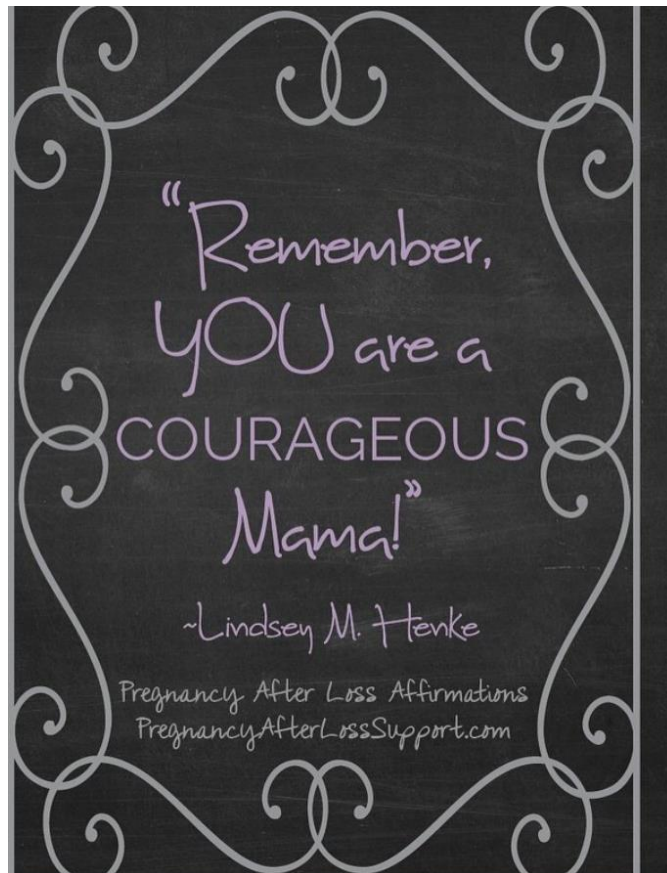
06 Oct
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07 Oct
2016



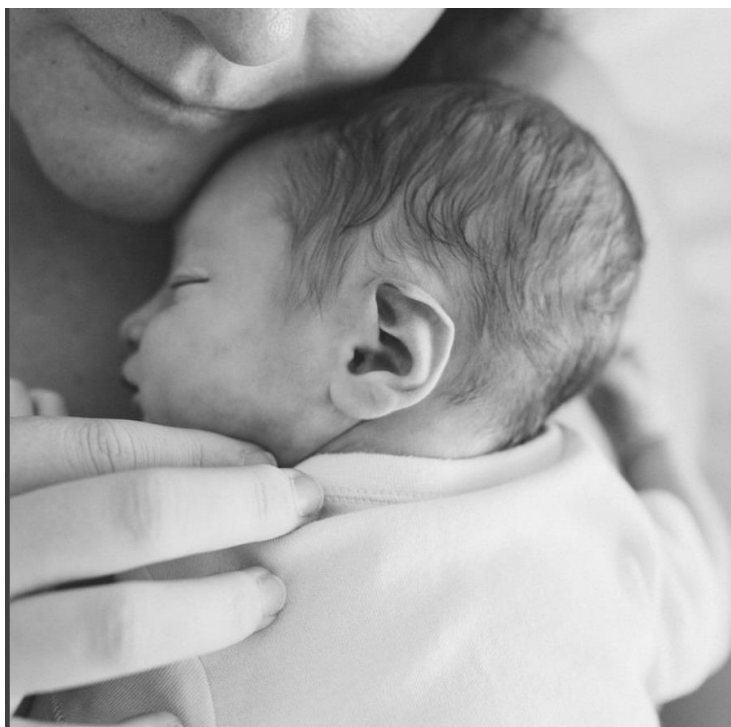
07 Oct
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08 Oct
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09 Oct
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09 Oct
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10 Oct
2016



11 Oct
2016



11 Oct
2016



12 Oct
2016



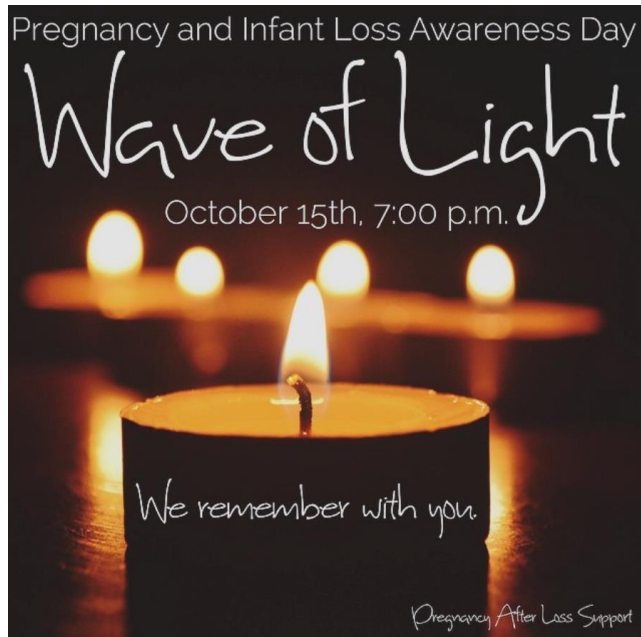
13 Oct
2016



14 Oct
2016



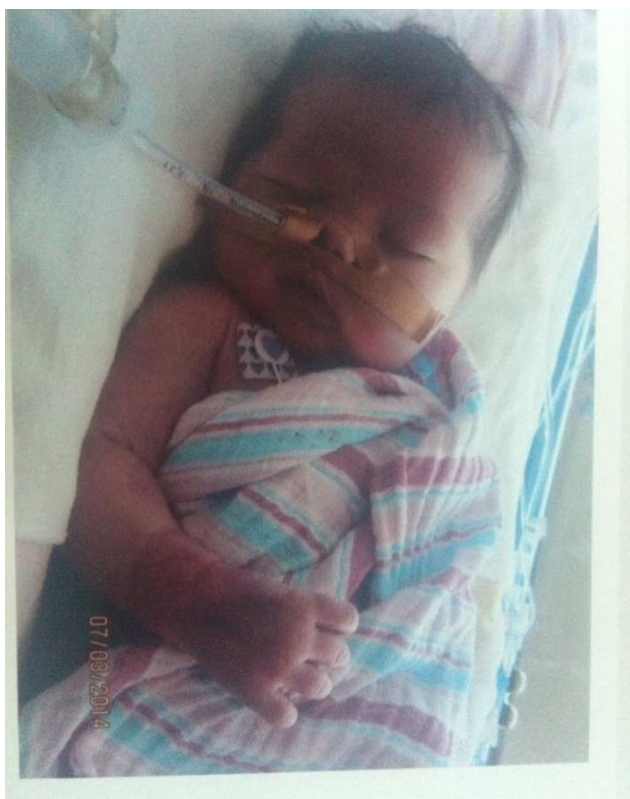
15 Oct
2016



16 Oct
2016



17 Oct
2016



18 Oct
2016



19 Oct
2016



20 Oct
2016



21 Oct
2016

"It's no use going
back to yesterday,
because I was a
different person then."

~Lewis Carroll, Alice in Wonderland

Pregnancy After Loss Affirmations
PregnancyAfterLossSupport.com

22 Oct
2016



23 Oct
2016



"My loss was early on, we had no time for ultrasounds or doctor visits. I had taken a pregnancy test and had a positive on Nov. 6 2015. Then November 23rd I was saying goodbye."

24 Oct
2016



25 Oct
2016

Let us honor all of the babies and children who died this October.

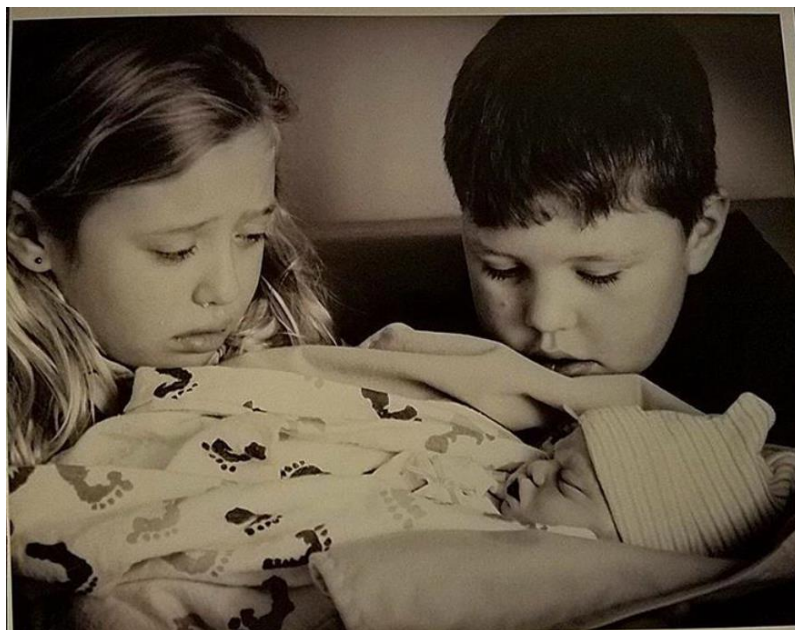
They are forever in our hearts.



Who are you missing?

Pregnancy After Loss Support

26 Oct
2016



27 Oct
2016



29 Oct
2016



30 Oct
2016



31 Oct
2016



01 Nov
2016

