

Pregnancy & Infant Loss Awareness Campaign

Grossesse et Perte Infantile Campagne de Sensibilisation

101 Hampton Rd. Suite 3, Rothesay, NB, E2E 3L3

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SUPPORTING FAMILIES THROUGHOUT BABY LOSS BEREAVMENT & BEYOND

BRIEF PRESENTED BY TERRA-LYNN COGGAN | FOUNDER & INTERNATIONAL AMBASSADOR

PAIL AWARENSS CAMPAIGN, IN SUPPORT OF: FOR THE LOVE OF RILEY,

THE BEAR CARE CAMPAIGN, PAIL CANADA AND LIGHTS OF LOVE INTERNATIONAL WAVE OF LIGHT

# **IMPORTANCE**

From an international perspective, giving consideration to the demographic I server and support, 4.1 million deaths of infants less than one year old were reported in 2017. <sup>[1]</sup> An estimated 2.6 million stillbirths happen <sup>[2]</sup> and between 17 and 22 percent of pregnancies result in miscarriage annually. <sup>[3]</sup> I am satisfied with the content of the Canadian national statistics provided for the committee's consideration by means of prior witness testimony, therefore have not provided them herein. My advocacy serves to promote greater Awareness, Remembrance and Support of the estimated 1 in 4 individuals and families whose lives are irrevocably altered by the death of their children, during pregnancy, at birth, in infancy and beyond. The effects of these losses are variable for each individual and family unit who experiences bereavement; common effects include, however are not limited to: depression, anxiety, changes in relationships, development of unhealthy coping mechanisms, and Post Traumatic Stress Disorder (PTSD). <sup>[4]</sup> These effects amongst others, are often underestimated and overlooked by health care professionals, friends, and even family members, especially when concerning pregnancy loss related bereavement and subsequent grief. <sup>[5]</sup>

# INTENT

The intention of this brief is to communicate my reflection and recommendations, to the *Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities*, concerning MOTION 110 and the study SUPPORTING FAMILIES AFTER THE LOSS OF A CHILD, and to convey my concern for individuals and families who experience the death of a child and in so doing, open the conversation relating to the exploration of appropriate provision of compassion and support for affected individuals and families. It is my expectation that through the testimony received and supporting evidence provided, the committee will present their findings and make appropriate recommendations to the government ministries to who it concerns, including however not limited to, the Ministry of Health Canada, to enact legislation that enhances the quality of life and adds value to the level of compassion and support bereaved individuals and families receive subsequent to the death of



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their children. Consequently, the government programming extended will foster greater awareness, compassion and support for bereaved individual, along with assurance that individuals and families are no longer troubled by resulting financial burden and emotional trauma, caused by the lack of appropriate government programming and services.

### **BACKGROUND**

First and foremost, it is essential that I provide, historic understanding, of the PAiL Awareness Campaign's origins and the events that transpired and inspired my advocacy and the founding of my nonprofit endeavors; campaigns and initiatives. As for my part, I am an infertility warrior and baby loss survivor of seventeen first trimester bereavements, in addition to, experiencing the post term stillbirth of my nephew Riley Joseph. On September 26th, 2003, my family and I experienced the stillbirth of my nephew, a loved and longed for addition to the family; who I anticipated adopting, was it not for his resulting stillbirth at 43.2 weeks gestation. Riley was to be the "Sunshine after the Rain", having been predeceased 6 weeks prior by the family patriarch, my grandfather Robert James; unfortunately as fate would have it, 'our sun failed to shine'. Following my family's bereavement and having found no resource for recourse within the community and little available elsewhere across Canada, specific to baby loss bereavement, I set my campaigns in motion and endeavored to change the facade of silence, the taboo and vacant stares that met my family and I when we attempted to reach out and acknowledge Riley's existence and say his name. In an effort to find answers and focus the monumental grief I was experiencing, I promptly began to research; in search of answers, solace, support and understanding. Despite my research, I came up empty handed; there was no support and little understanding available within my community; little available elsewhere, upon the internet or otherwise. Aside from my discovery of a Proclamation by former U.S. President, Ronald Reagan, dated October 29th, proclaiming the month of October 1988 to be Pregnancy & Infant Loss Awareness Month, in addition to, the existence of a handful of non-specific organizations scattered across the United States and United Kingdom; organizations that were of little support to my family and I, to mitigate our experience and provide the compassionate understanding we sought. I began my research and discovered to my shock and dismay, Riley's stillbirth was not an isolated incident; it happens often, far too often for me to turn a blind eye to, choosing to ignore the plight. I utilized the limited statistical data I was able to obtain through my research to begin my advocacy and campaign initiatives and began promoting greater baby loss awareness, remembrance and support at home and abroad.



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On September 29th, 2003, three days following Riley's stillbirth, I launched my first campaign; For the Love of Riley - Stillbirth Awareness Campaign, in an effort to raise greater awareness regarding stillbirth, in addition to, sharing Riley's story and my family's experience. For the Love of Riley is a truly inspirational work of heart, one that allows me to work through and address my significant bereavement and associated grief; while reaching out and supporting other bereaved baby loss families in theirs'. Prior to Riley's first birthday I crafted a bear for my sister' for what should have been Riley's first birthday. I showed the bear to my sister-in-law, which rose the question, "why just a bear for Carla..., "what about all bereaved families?" My sister in law's question proved to be the spark of inspiration I needed to initiate my second campaign and initiative, the Bear Care Campaign, formerly, Bears for Bereaved Mommies. The Bear Care Campaign is the catalysis that inspired me to begin my lobby of the New Brunswick Department of Health and Wellness, to join me in recognition of the families I endeavored to serve and support through my advocacy. In early 2004 I drafted New Brunswick's Proclamation, in observation of October 15th, Pregnancy and Infant Loss Remembrance Day, while continuing my effort to bring to light, the plight being experienced in isolation by baby loss survivors to my government's attention. In August 2004 I began to organize the Bear Care Campaign's first Remembrance Ceremony, a balloon release, remembrance ceremony standard of the time, slated for October 15th, 2004 at the Millennium Dome, Garden Street, Saint John, New Brunswick and invited baby loss families from across Canada, the United States and United Kingdom to join the event by requesting a balloon to be released, approximately 300 balloon requests were received. A few days prior to the slated balloon release, I was contacted by an environmental advocate; "Jane Tran" drew to my attention Saint John's proximity to the 'Beautiful Bay of Fundy' and the life that inhabited its waters. Jane requested that I reconsider the balloon release and suggested that I consider the use of Mylar balloons as opposed to the pink, blue and white latex balloons obtained for the occasion. My response to Jane's request was simple, "I and the organization I represent are for the preservation of life, all life alike, where preservation is possible." there is no honour to be had when the activities conducted in remembrance of our loved ones have the potential to cause harm to the environment and result in potential fatality. Straight away I canceled the balloon release and notified those who requested to participate, offered refunds of the donations received and invited participants to "join me, where-ever in the world you may be to light Tea-Lites, in honour and remembrance of our babies". 600 individuals participated in the lighting of candles, initiating the conception of the international event that is known across the world and around the globe as the International Wave of Light, more specifically, Lights of Love International Wave of Light; a Bear Care Campaign Initiative.



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## **CONCLUSION**

At the time of experiencing my baby loss bereavement there was little acknowledgment, support or consultation extended to me, aside from that which I received from the Children's Hospital at London Health Sciences Centre following a molar pregnancy. Having been raised by my grandparents, who experienced the death of my uncles in infancy, Kenneth James (1948-1949) and John William (1951-1952), I was taught, 'when life gets you down, you pull yourself up by your bootstraps and solider on'. This is exactly what I do; I soldiered on in life, in an effort t to cope with my baby losses. Like a crumpled Kleenex, shoved up my sleeve, I tucked my traumas, bereavements and grief away from the world to see, in an attempt to shield myself from experiencing a lifetime of resulting anguish and sorrows; until the turning point in my life that has defined me, the day I reluctantly said hello while gently kissing Riley goodbye, for the first and last time... On this day, like a crumpled, tattered, Kleenex, my hidden sorrows fell to the floor, exposing with it a lifetime of troublesome memories, I am no longer able to ignore. As a result of Riley's stillbirth I was reminded of a life time filled with traumas, bereavements and anguishing sorrows. The memories that I had gently tucked away throughout my many years, including, however not limited to the death of my baby sister Asia Lynn in 1984, came back to haunt me. I am able to recollect my sister's death well. I was six years old at the time of Asia passing, despite the repressed memories and passage of years. I am able to recall, she was in her in her crib for the night, where she was laid to sleep. Her mother arrived quickly, she upon my heels, we stood at Asia's crib side, woke by the sound of her cry. A cry it was impossible to ignore, we arrived too late, Asia was deceased; she had not cried, she had already died, despite her death her cry I cannot deny.

# **RECOMMENDATION**

It is my belief that formalized observation and supporting legislation will increase awareness, whereby, fostering greater compassion and understanding amongst society as a whole, in addition to, aiding in the creation and establishment of programs, resources and services; in a collective effort to build a sustainable compassionate care model and appropriate funding to support and provide assistance to bereaved individuals and families, enabling them to overcome their trauma and integrate their bereavement into their life in a healthy, helpful, healing manner.



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