

Pregnancy and Infant Loss Summit Recommendations:

On 16 May 2016, the first Pregnancy and Infant Loss Summit was held at Mount Sinai Hospital. Over 300 people attended the Summit from all across Ontario, including doctors, nurses, nurse practitioners, bereaved parents, mother advocates, midwives, social workers, scientists, and doulas.

History is made.

Ontario is the first province or state in North America to specially fund pregnancy and infant loss.



The Summit and resulting recommendations aim to:

- Break down the silence surrounding pregnancy and infant loss
- Demonstrate to the public, health care professionals, medical institutions, and the Ontario Ministry of Health and Long-Term Care the need for improved care and support for women and families
- Promote greater investment in research and support services in this area and to establish
- Promote clinical best practices of standardized care for medical professionals and hospitals across Ontario for women who experience pregnancy and infant loss

This Executive Summary represents a condensed version of the recommendations put forward by the speakers at the Summit

Below is the list of speakers from the Summit:

Dr. John Kingdom
Dr. Francine de Montigny
Karine Herbert
Dr. Christine Jonas-Simpson
Carol Chevalier
Paul Szabunio
Michelle LaFontaine
Amanda Oram
Dr. Andrea Paras

Dr. Alexander Heazell
Dr. Ernest Cutz
Jennifer Bordin
Justine Robinson
Lynn Grandmaison-Dumond
Dr. Noor Ladhani
Megan Fockler
Liza Walter
James Meloche



Bill 141: Pregnancy and Infant Loss Summit
Mount Sinai Hospital – 16 May 2016
Recommendations put forward by the Speakers

Background on the Speakers:

- Dr. John Kingdom (Mount Sinai Hospital)
- Dr. Alexander Heazell (University of Manchester)
- Dr. Francine de Montigny (Registered Nurse; Université de Québec)
- Dr. Ernest Cutz (Toronto Hospital for Sick Children)
- Karine Herbert (Bereaved Mother; Baby's Breath Research and Medical Advisory)
- Jennifer Bordin (Michael Garron Hospital)
- Dr. Christine Jonas-Simpson (York University)
- Justine Robinson (Bereaved Mother)
- Carol Chevalier (Perinatal Bereavement Social Worker; CHEO; Roger's House)
- Lynn Grandmaison-Dumond (Nurse Practitioner; CHEO; Roger's House)
- Paul Szabunio (Bereaved Father)
- Dr. Noor Ladhani (Sunnybrook Health Sciences Centre)
- Michelle LaFontaine (Executive Director of PAIL Network; Bereaved Mother)
- Megan Fockler (Nurse at Sunnybrook Subsequent Pregnancy Clinic)
- Amanda Oram (Bereaved Mother)
- Liza Walter (Bereaved Mother)
- Dr. Andrea Paras (Bereaved Mother)
- James Meloche (Provincial Council for Maternal and Child Health)



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General Recommendations and Conclusions from Mothers, Advocates, Medical Professionals, and Scientists:

Preamble:

On 16 May 2016, the first Pregnancy and Infant Loss Summit was held at Mount Sinai Hospital in Toronto, Ontario.

The purpose of the Summit was to bring attention to pregnancy and infant loss and to put forth recommendations on how to create compassionate, standardized care for women and families who experience pregnancy and infant loss.

The Executive Summary below has been prepared by the Bill 141 Action Committee and represents a condensed version of the recommendations proposed by the speakers at the Summit on how to improve the health care practices and standards of care for women and families who experience pregnancy or infant loss. These recommendations are not in order of importance nor are they precise scientific or medical directives.

Recommendations:

1. Complete transformation of treatment, care, and support made available to women who experience pregnancy and infant loss:
 - Ensure all medical professionals receive comprehensive training and education related to compassionate and comprehensive medical care for pregnant mothers and their babies and families
 - Establish standards of care across the Province in all hospitals and medical facilities where care is provided to women and their families experiencing pregnancy and infant loss
 - Establish a consent-based referral process across the province, whereby a family who has experienced a loss is offered a referral to the Pregnancy and Infant Loss Network (PAIL Network) and community partners for support



Bill 141: Pregnancy and Infant Loss Summit
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- Establish multiple Early Pregnancy Assessment Clinics across Ontario to ensure all pregnant women have access to specialized medical support as provided at the Michael Garron Hospital, Southlake Hospital, and Mount Sinai Hospital
- Increased support for Early Pregnancy Assessment Clinics (EPACs) and ensure that these clinics are open 7 days a week to provide women experiencing pregnancy loss with a timely referral from the Emergency Room, where there is little to no privacy and often long wait times, to the EPACs where they will have access to the necessary care and any ongoing follow-ups
- EPACs should also be used to provide women and families a separate waiting area for parents and families who have concerns about the well-being of their child
- Ensure timely access to medical care and operating rooms, so that in the event a Dilatation and Curettage (D&C) procedure is required, one can be done promptly and without a prolonged wait time

2. Creation of comprehensive Research and Data Analysis Centre:

- Establish a Province-wide data collection system which would include all aspects of pregnancy loss from early miscarriages, mid-term losses, late-term losses, stillbirth, and early infant losses, including Sudden Unexplained Infant Death
- Introduce essential “perinatal auditing system” – a systematic, critical analysis of the quality of perinatal care, including the procedures used for diagnosis and treatment, the use of resources, and the resultant outcome and quality of life for women and their babies

3. Establishment of programs in regions across Ontario based on Sunnybrook’s Subsequent Pregnancy Program:

- Ensure that parents are provided with a non-judgmental environment where they can openly discuss their fears, ask questions, have their loss validated, and have choices for perinatal care



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- Continuity of care with consistent healthcare providers who offer flexible care options in their area of specialty facilities support during pregnancy and in the post-partum period
- A holistic, multi-dimensional, and inter-professional approach to care appears to be the best way to provide care to expecting families following a late perinatal loss
- Provide the following options to women seeking medical attention:
 - Access to the same ultrasound technician at each visit
 - Reduce waiting room times at antenatal visits
 - Ease of communication pathways via emails, texts, and phone calls to the designated Advanced Practice Nurse at any time
 - Having a consistent contact person between appointments who is known to the family and able to respond in a timely manner
 - Offer private tours of the Triage, Labour and Delivery, and High Risk Inpatient Unit to women and their families
 - Enable multidisciplinary support through connection to other team members, including psychiatrists and social workers
 - Expand peer support through community partners (e.g. Pregnancy and Infant Loss (PAIL) Network)
 - Make Prenatal Public Health referrals available (e.g. – Healthy Babies Healthy Children).
 - Expand Antenatal Breastfeeding Clinic consultation
 - Prenatal Public Health referrals available
 - Drop-in appointments as needed
 - Expand and allow for extra fetal heart rate check
 - Expand and improve education and birth preparation women, families, and health-care providers
 - Expand care needs and requests for healthcare teams to ensure continuity of best care
 - Provide for flexible/drop-in or increased appointments as needed
 - Ask all women what would be helpful for them and commit to working towards that
 - Expansion of post-partum follow-ups for all mothers



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4. Establish a Provincial Centre of Excellence dedicated to the study and research of causes of pregnancy and infant loss with specific attention to stillbirths and Sudden Unexplained Infant Death with the directive to research and determine a biological basis of Sudden Unexplained Infant Death and to develop a means of identifying and treating at-risk infants
5. Expansion and improvement of compassionate bereavement education for emergency medical staff:
 - Since hospital emergency facilities are the most common entry point for women who are experiencing an early pregnancy loss, all emergency staff should be educated about how to deal with pregnancy loss in a compassionate and caring manner, as it relates to supporting the mother, the baby, and the family
 - Appropriate referrals for medical and emotional support should be made available
 - Infant loss protocols should be in place so that mothers, their partners, and their babies are cared for in a sensitive, compassionate, and respectful manner
6. All hospitals should establish a Perinatal Bereavement Committee to include an inter-disciplinary process of health care for women and families as well as the ability to offer perinatal hospice facilities for infants
7. Implement changes to regulations of medical registration of infant loss:
 - At present, the system of registering a loss is insensitive and adds to the pain and suffering of the mother and family
 - The infant registration system and required documentation must be reconstructed to recognize the special circumstances surrounding the loss of a stillborn infant
8. Undertake reforms in Work Place and Labour Law Protections provided to women who experience pregnancy loss:



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- Ensure eligibility for Maternity Leave Benefits for women who experience loss
- Need extended protections for fathers and partners
- Ensure women who experience pregnancy loss receive protection and support when returning to their work place, with appropriate reforms made to Provincial Labour Laws to ensure women have protection when returning to work after a loss
- Ensure mental health and counselling support programs are available to all women who experience a pregnancy and/or infant loss

Conclusion:

This document is a synopsis of the recommendations put forward after the Bill 141: Pregnancy and Infant Loss Summit on 16 May 2016. These are not definitive recommendations, but rather are to be used as a guide for future improvements to the health care and medical support women and their families receive during an experience of pregnancy loss or infant death.