BC Coroners Service Child Death Review Panel A Review of Unexpected Infant Deaths 2008-2012

REPORT TO THE CHIEF CORONER OF BRITISH COLUMBIA

April 2014

PREFACE

On September 11, 2013, the British Columbia Coroners Service (BCCS) held a child death review panel focused on 117 infants whose deaths were sudden and unexpected. Each of their deaths was a profound loss to parents, extended family and the greater community. The review of their brief lives contributed to helping panel members identify actions to prevent future unexpected infant deaths.

Support for this panel was provided by the staff of the BCCS Child Death Review Unit (CDRU). Adele Lambert and Holli Ward compiled the aggregate case reviews and a review of the research and statistics which formed the basis of the panel discussions.

I would like to extend my gratitude to the members of this panel for sharing their individual expertise and bringing support on behalf of their respective organizations. Their dedication to the health and well-being of all infants in B.C. is apparent in the contributions each has made towards investigating unexpected infant deaths through the panel discussion and generating action oriented recommendations.

BC Coroners Service

BC Coroners Service

BC Ambulance Service

BC Children's Hospital

Vancouver Coastal Health

Ministry of Health

Ministry of Health

Ministry of Education

Office of the Provincial Health Officer

Principals and Vice Principals Association

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- Dr. Laura Arbour
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- Dr. Ian Pike
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- Alex Scheiber
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On behalf of the panel, I submit this report and recommendations regarding the prevention of unexpected infant deaths to the Chief Coroner of B.C. for consideration.

Michael Cal

Michael Egilson Chair, Child Death Review Panel

EXECUTIVE SUMMARY

Anytime an infant dies, it is a tragic loss to parents, extended family and the greater community. When an infant dies unexpectedly many questions are raised regarding what, if anything could have been done to prevent it.

Each year between 2008 and 2012, there were approximately 44,000 infants born in BC and approximately 169 of these infants died. These deaths were primarily the result of natural causes; however, an average of 23 infants died unexpectedly.

To learn more about these unexpected infant deaths and determine what can be done to prevent them in the future, a child death review panel was appointed under the *Coroners Act*. The purpose of the death review panel was to review and analyse the facts and circumstances of unexpected infant deaths and provide the Chief Coroner with advice towards prevention.

The panel reviewed in aggregate, 117 BC Coroners Service (BCCS) cases where infants died unexpectedly between 2008 and 2012. The panel also included a review of the research literature about unexpected infant deaths. The panel was made up of professionals with expertise in Aboriginal health, injury prevention, health care, law enforcement, education, emergency response, and child welfare.

Trying to identify one or more actions to prevent unexpected infant deaths is challenging because there is no one cause of all unexpected infant deaths. In spite of these challenges, the panel identified key areas to enhance the investigative practices used for trying to identify a cause of death and support prevention messaging. Specifically, enhancement of investigative practices, including the role of genetic testing, and the development of safe sleep messaging to families whose infants are most at risk, are the basis for the following recommendations put forth to the Chief Coroner for consideration:

Recommendation 1: Investigative practices

- That the Deputy Commissioner RCMP E Division and the Chief Constables of the independent municipal police departments develop a standardized investigative protocol to support law enforcement investigations into unexpected infant deaths.
- That the BC Ambulance Service work with the BC Coroners Service to develop standardized questions with respect to the initial scene to support Emergency Medical Responders attending calls where infants die unexpectedly.
- The BC Coroners Service revise its protocol for unexpected infant deaths to include obtaining 911 transcripts and ensure that scene recreations are conducted.
- The BC Coroners Service adopts the Aboriginal Administrative Data Standard in order to collect more robust data about Aboriginal people.

Recommendation 2: Genetic Testing

- That criteria be established by the BC Coroners Service, in consultation with pathologists and clinical geneticists, and the First Nations Health Authority, to identify when genetic testing would be beneficial in helping to establish a cause of death in infants.
- The BC Coroners Service, pediatric pathologists, the Provincial Medical Genetics Program and the First Nations Health Authority review the utility of testing for the CPT1a variant in First Nations infants.

Recommendation 3: Safe sleep messaging

 The First Nations Health Authority, The Community Against Preventable Injuries, Ministry of Health, the Ministry of Children and Family Development and community stakeholders collaborate to identify the audience of parents/caregivers who are most likely to benefit from receiving messaging about infant safe sleep positioning and the risks of bed sharing and substance use and then implement a plan that reaches the target audience with that messaging.

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PART 1: INTRODUCTION¹

Anytime an infant dies, it is a tragic loss to parents, extended family and the greater community. Each year between 2008 and 2012, approximately 44,000 infants were born in B.C.² and there was an average of 169 deaths of infants aged less than 12 months³. The majority of these deaths were the result of known natural causes; however each year an average of 23⁴ infants died unexpectedly. It is these unexpected infant deaths that were reviewed by the Child Death Review Panel in September 2013.

Specifically, the panel reviewed in **aggregate**, 117 unexpected infant deaths that occurred between 2008 and 2012, and the research literature related to these types of infant deaths. Panel members shared their respective expertise and thoughts, and identified actions to enhance the investigative practices used when trying to identify a cause of death and support prevention efforts aimed at reducing unexpected infant deaths in the future.

DEATH REVIEW PANEL

A death review panel is mandated⁵ to review and analyse the facts and circumstances of deaths to provide the Chief Coroner with advice on medical, legal, social welfare and other matters concerning public health and safety, and the prevention of deaths. A death review panel can review one or more cases before, during or after a coroner's investigation, an inquest or a review by the BCCS Child Death Review Unit (CDRU), and regardless of any decision made by a coroner or member of the CDRU.

The Chief Coroner established a child death review panel to meet on specific occasions throughout the year to provide recommendations on the prevention of child and youth deaths. This process is consistent with the child death review principles laid out by the Honourable Ted Hughes in his 2006 report. The Chair of the CDRU was appointed chair of the child death review panel whose membership includes: a child death coroner, a CDRU coroner and professionals with expertise relating to children including: Aboriginal health and child welfare, injury prevention, public health, medicine, law enforcement, emergency response, education, advocacy and child welfare. In the course of reviewing the unexpected infant deaths that occurred between 2008 and 2012, the panel reviewed:

- BCCS investigative findings;
- Academic and research literature;
- Information provided by panel members;
- Environmental, social and medical factors associated with the deaths;
- Possible patterns, trends or themes;
- The current state of related public policy, programs and available services; and
- Existing investigative challenges.

¹ Key terms appearing in **bold face** are defined in the glossary located at the end of this report.

² BC Vital Stats

³ BC Coroners Service (BCCS) stats

⁴ BCCS Stats

⁵ Under the Coroners Act

LIMITATIONS AND CONFIDENTIALITY

The number of unexpected infant deaths that occurred between 2008 and 2012 is relatively small and this presents challenges in accurately analyzing and reporting information while protecting privacy and data accuracy. Provisions under the *Coroners Act* and *Freedom of Information and Protection of Privacy Act* allow for the BCCS to disclose information to meet its legislative mandate and support the findings and recommendations generated by the review process. For the purposes of this report, information about these infants is presented in aggregate form. The BCCS is sensitive to the privacy of the infants and families that we serve and proceeds with caution when reporting case review findings. In general, statistical results are based on a small number of cases and should be interpreted with caution given the potential for random variation.

PART 2: UNEXPECTED INFANT DEATHS: OVERVIEW OF INVESTIGATIVE PRACTICES

This section is intended to point out the complexities of the investigation practices used to identify a cause of death and the challenges with the terms used to describe unexpected infant deaths.

WHEN AN INFANT DIES UNEXPECTEDLY

Each infant's death is unique; however, there are a number of commonalities which occur when the death is unexpected. In the cases reviewed in this report, all of the infants died either while they were sleeping or during quiet time or in a few cases, feeding. The infant may have been placed in a crib or bassinet, on an adult bed or on a couch. Many of the infants were sleeping or lying down with an adult.

To provide the reader with some context, the following scenario illustrates the course of events that commonly occur when an infant dies unexpectedly.

A parent or caregiver checking on or waking up with an infant discovers that the infant is nonresponsive or cold. The parent or caregiver picks the infant up to try to rouse the infant. A 911 call is made and resuscitation instructions are provided while an ambulance is dispatched. The 911 operator stays on the line with the family until the emergency medical responders (EMR) arrive. Once they arrive, the EMRs take over the resuscitation efforts and the infant is usually transported to the hospital. Resuscitation attempts may continue at the hospital although most often, the infant has died prior to being transported to the hospital.

The 911 call also alerts the police. Upon confirmation of the infant's death the police contact the coroner. The coroner and the police begin parallel yet separate investigations to fulfill their respective mandates. The coroner is responsible for establishing the identity of the infant, when and where he or she died, and the cause and manner of death. The police are responsible for conducting a law enforcement investigation to determine whether any offences have occurred in connection with the death.

As part of their investigations, the coroner and police attend the hospital. The coroner examines the body and interviews the attending physician as well as the parents to try to determine the cause of death. The coroner will seize medical records as part of the investigation.

The coroner attends the location where the infant was discovered unresponsive to seek out any information or evidence that could help determine the cause of death. While attending the scene the coroner also interviews other family members or people who were present to collect information. The coroner checks with the Ministry of Children and Family Development (MCFD) information system to determine if there is any current, recent or relevant MCFD involvement. If MCFD is involved with the infant, the coroner alerts MCFD that the infant has died and MCFD determines the level of internal review they are required to do.

If the cause of the infant's death could not be clearly established, the coroner would order post mortem testing. A **pathologist** would then conduct an **autopsy** and review the toxicological testing to determine a cause of death. To help inform the findings, the pathologist relies on the

coroner to provide details about the circumstances leading up to the infant being found unresponsive and where the infant was found. If the police attended the autopsy as part of their evidence gathering procedure the coroner would attend the autopsy as well. Infant autopsies are performed at a hospital in BC's lower mainland area (e.g. BC Children's Hospital). Upon completion of the autopsy, the coroner releases the infant's body back to the parents to arrange for funeral services.

The coroner discusses the preliminary autopsy findings with the family. The coroner continues to review all appropriate records (e.g. public health records) and interviews additional sources (e.g. public health nurses).

Based on the examination of the body, the investigation of the scene and a review of all relevant records including the autopsy report, the coroner makes a finding regarding the cause and manner of the infant's death. Where no known cause can be established the coroner finds the death to be "undetermined". The coroner completes a report and contacts the family to inform them of the findings.

THE HISTORY OF UNEXPECTED INFANT DEATH CLASSIFICATION

The term SIDS (Sudden Infant Death Syndrome) was introduced in 1969 as an umbrella term to classify sudden death in infants. SIDS was an important concept because it helped focus attention on unexpected death in infants. By aggregating sudden infant deaths it helped the field to:

- To learn everything possible from each of these infant deaths
- To clarify risk factors/causes through compiling and analyzing information
- To increase awareness of these factors through dissemination of information
- To analyze the impact of preventive efforts
- To put "a name" to a tragic event that cannot be explained.

Generally, SIDS is considered to be a classification of exclusion to describe the sudden death in infants under 12 months of age where there are no apparent factors present that would otherwise explain the death (Krous, 2010; Omojokun and Moon, 2008). As the study of SIDS evolved and more risk factors were recognized, the above parameters were seen as too narrow.

The term SUDI (Sudden Unexpected Death in Infancy) was introduced in 2000 to describe sudden death in infants under 12 months of age where no anatomical cause of death was identified and risk factors thought to contribute to the death were present (Krous, 2010). Both SIDS and SUDI continue to be used but because there are no universally accepted definitions of these terms, they are sometimes used interchangeably (Krous, 2010). Since then a number of classification schema have been used in various jurisdictions e.g.; Unexplained SUDI, Class I, II, III, IV, SUDI, typical, atypical SUDI, SIDS.

The terms used to describe unexpected infant deaths, and their definitions, vary across jurisdictions within Canada and internationally. Without any consistency, it is difficult to identify information that would be helpful in understanding why these deaths occur, what can be done to reduce the risks and the effectiveness of preventative measures.

Even ardent supporters for the continued use of the term "syndrome" agree that SIDS is unlikely to constitute a single cause of death, but is likely to represent a varied group of unexpected infant deaths that currently remain unexplained but which share a common mechanism(s) of death (Krous et al 2004). What began as an attempt to better understand unexpected infant deaths through aggregating these deaths under the banner of SIDS has constrained our understanding as SIDS became identified as the cause of death.

SIDS and SUDI are not a cause of death. The terms are a classification which essentially means the death is unexplained. By disaggregating the classification of unexpected infant deaths we can better understand causes and where to focus prevention efforts. Some of these deaths will remain unexplained but through enhanced investigations and further research we may better discover deaths that have a genetic component and identify deaths that result from asphyxia from unsafe sleep conditions.

In June 2012, the majority of Canadian Chief Coroners and Chief Medical Examiners agreed to adopt the classification "Undetermined" to describe unexpected infant deaths where no cause is identified following complete autopsy, examination of the death scene, and review of the clinical history. There was agreement that terms such as *Sudden Infant Death Syndrome*, *Sudden Unexpected Infant Death* and *Sudden Unexplained Death in Infancy* had a tendency to create confusion rather than clarity, as they are all reflections of an undetermined cause of death. The Chief Coroners and Chief Medical Examiners agreed that the collection of standardized data is a very important component of sudden infant death investigations and future work will focus on adopting a standard data set for all provinces.

The Canadian Chief Coroners and Medical Examiners position was adopted as BCCS policy in BC in 2013.

PART 3: SUMMARY OF REPORTS, PROGRAMS, PROTOCOLS and GUIDES TO SUPPORT THE HEALTH AND SAFETY OF INFANTS

In 2009, the BC Coroners Service Child Death Review Unit (CDRU) reviewed the cases of 113 infants who died in sleep related circumstances between 2003 and 2007. The report *Safe and Sound: a Five Year Retrospective* and recommendations focused on collective action to reduce the incidence of unexpected infant deaths.

Since the release of this report, various reports, programs, protocols and guides intended to support the health and safety of infants, including efforts to reduce unexpected infant deaths, have been developed and/or implemented. Examples⁶ include:

- January 2011: The B.C. Representative for Children and Youth (RCY) released *Fragile Lives, Fragmented Systems: Strengthening Supports for Vulnerable Infants.* This report was based on an aggregate review of 21 infants who died before two years of age, between June 1, 2007 and May 1, 2009. Recommendations were forwarded to the provincial government to address services related to the care of infants and support to vulnerable families with infants.
- February 2011: Perinatal Services B.C. Health Promotion Guideline 1 *Safe Sleep Environment Guideline For Infants 0-12 Months of Age.* At the direction of the Ministry of Health, this resource was developed through a multidisciplinary provincial working group led by Perinatal Services B.C. (PSBC) in response to a CDRU 2007 annual report recommendation around infant safe sleep practices. This guideline is intended to provide health care providers with information about safe sleep practices for the prevention of unexpected infant deaths. Following the development of the provincial guideline, parent resource materials were developed and distributed, including:
 - The development and distribution of safe sleep posters called *'Every Sleep Counts'* to all acute care and public health settings, and distribution of an *'Every Sleep Counts'* information sheet to all new parents.
 - Revisions to fact sheets called BC Health Files to ensure infant safe sleep information reflected current best practices.
 - Inclusion of consistent safe sleep messages in Baby's Best Chance Parents' Handbook of Pregnancy and Baby Care (available at no cost to all pregnant women in BC), and in Healthy Families BC Pregnancy and Parenting website.
- June 2011: The B.C. Provincial Government launched the *Healthy Families B.C. strategy* to support families and communities in a number of key areas including, the *Healthy Start Initiative* that enhances public health perinatal and child health prevention services through the standardization of public health services. Following this,

⁶ Where available, links to these reports, programs and guides are provided at the end of the report.

representatives from the Ministry of Health (MoH), regional health authorities⁷, and PSBC developed the *Health Start Initiative: Provincial Perinatal, Child and Family Public Health Services.* This document outlines the health services that should be routinely offered to families by public health care providers during the prenatal period to when the child is 2 years of age and aligns with the Innovation and Change Agenda for the Healthy Families BC strategy. Further, the BC Healthy Connections Project (BCHCP) was introduced. BCHCP is a scientific evaluation of a new program called the Nurse-Family Partnership (NFP) which will assess whether NFP benefits pregnant young women and their children greater than the existing services in BC. Phase 1 of the project began in March 2012. It is funded by the MoH with support from MCFD and the regional health authorities. The 5 year evaluation of the project is being conducted by the Children's Health Policy Centre at Simon Fraser University.

- March 2013: In response to recommendations in the 2011 BC Representative for Children and Youth report *Fragile Lives, Fragmented Systems: Strengthening Supports for Vulnerable Infants, a* protocol agreement between MoH and Ministry of Children and Family Development (MCFD) was signed. This agreement outlines the roles and responsibilities to support a coordinated and consistent approach to services provided by MCFD or a Delegated Aboriginal agency and the corresponding health authority. Specifically, the protocol addresses the need for effective and responsive practices to support vulnerable families with infants or where a woman is pregnant and when at birth, the infant would be considered to be at risk for harm.
- October 2013: Honouring our Babies: Safe Sleep Cards and Guide. This toolkit assists service providers with discussing safe sleep practices with First Nations and Aboriginal families to reduce unexpected infant deaths in sleep related circumstances. Development of this resource was an initiative of the Tripartite First Nations and Aboriginal Maternal and Child Health Planning Committee led by PSBC.

These reports, programs, protocols and guides were developed based on ongoing research in the area of infant health and safety, including unexpected infant deaths. Some include an evaluation component so that outcomes can be measured. Overall, evaluating the impact of resources can present challenges including:

- Changes are often a result of an interaction between social, economic and personal factors making it difficult to directly credit a positive change as being caused by the resource;
- Limited information on safe sleep and parenting behaviours in the general population;
- Limited information on whether a program/resource was put into practice the way it was intended to be; and
- Limited information on whether the resources impacted those for whom they were intended.

⁷ There are 5 regional health authorities: Northern, Interior, Vancouver Island, Vancouver Coastal, Fraser and on Provincial Health Services Authority.

PART 4: INFANT MORTALITY RATES

Infant mortality rates are an internationally recognized indicator for understanding a nation's overall health (Judge, 2009). The infant mortality rate refers to the number of deaths of children less than one year old per 1000 live births. Infant mortality is often further reported out in terms of the neonatal rate (infants 0-27days) and the post neonatal rate (infants 28 days to 1 year old).

The infant mortality rate is calculated as the number of infants who die under one year of age, divided by the number of live births during the year, multiplied by 1,000.

Each year between 2008 and 2012, approximately 44,000 infants were born in B.C.⁸ and there was an average of 169 deaths of infants aged less than 12 months⁹. The majority of these deaths were the result of known natural causes. The infant mortality rate in B.C. for period between 2008 and 2012 was 3.8 per 1,000 live births.

Of the infants who died, this report looks at those who died unexpectedly (n=117). This group of infants accounted for approximately 14% of the infant deaths in B.C. and the unexpected infant mortality rate in B.C. from 2008 to 2012 was approximately 0.53 per 1,000 live births.

INTERNATIONAL

Although infant mortality rates are recognized as an important health indicator of a country, the rates may not be directly comparable because the registration of live births differs across countries. For example, some countries will only register a live birth if an infant is considered to have a reasonable chance of survival (Canadian Perinatal Health Report, 2008). This system of registration considers an infant's birth weight and gestational age to determine if their life is viable. Countries using this type of system report relatively lower infant mortality rates compared to countries registering births as defined by the World Health Organization (WHO) (Canadian Perinatal Health Report, 2008). Specifically, the WHO defines a live birth as an infant who shows signs of life after they are born, regardless of weight or gestational age. These countries, including Canada, report relatively higher infant mortality rates due to the proportionately higher number of registered births (Canadian Perinatal Health Report, 2008).

CANADA

Between 2007 and 2011, the Canadian infant mortality rate was approximately 5 per 1,000 live births with 2011 being the lowest rate on record at 4.8 per 1,000 live births (Minister of Industry, 2013). The 2008 Perinatal Report completed by the Public Health Agency of Canada stated that in 2004, unexpected infant deaths accounted for 5% of all infant deaths (birth to 1 year of age) and 17.2% of post neonatal deaths (28 days to 1 year of age).

BRITISH COLUMBIA

Over the past 10 years, B.C.'s infant mortality rate has remained relatively stable at around 3.8 per 1,000 live births (Statistics Canada, 2013). The B.C. rate shown in the table *Infant Mortality in B.C. between 1990 and 2011* (see Figure 1) is significantly lower than the overall Canadian

⁸ BC Vital Stats

⁹ BC Coroners Service (BCCS) stats

infant mortality rate that was at its lowest on record in 2011 at 4.8 per 1,000 live births¹⁰ (Minister of Industry, 2013). British Columbia has the second lowest infant mortality rate in Canada.





The rate of unexpected infant deaths in B.C. has generally remained constant. The table *Unexpected Deaths in B.C. between 2003 and 2012 (*see Figure 2) shows the average rate of unexpected infant deaths was 0.54 per 1,000 live births (see Figure 2). This means that unexpected infant deaths account for approximately 14% of infant mortality in B.C.





Data Source: BC Coroners Service

Data Source: BC Vital Statistics Agency

¹⁰ The most recent year that information on Canadian infant mortality rates is available.

PART 5: UNEXPECTED INFANT DEATHS

The information in this section represents the panel's review of the 117 infants who died unexpectedly between 2008 and 2012. It is presented in combination with what was learned by reviewing the research literature about unexpected infant deaths.

Of the research literature reviewed, most studies point out that a major limitation is lack of a common term or set of terms to describe unexpected infant deaths making it difficult to accurately compare information (Hauck and Tanabe, 2008; Krous, 2010).

Trying to determine the cause of unexpected infant deaths is usually a process of exclusion. There are a number of known potential causes and there is ongoing research to try to better understand why some infants die unexpectedly. Wedgwood was the first to develop a "triple risk hypothesis" in 1972, suggesting that the sudden and unexpected death of an infant resulted from (1) the general vulnerability of the infant; (2) age specific risks; and (3) precipitating factors (Guntheroth and Spiers, 2002). Guntheroth and Spiers (2002) concluded that none of the triple risk hypotheses had shown any advantage in furthering the understanding of sudden infant deaths.

Although there is still much to learn in order to understand why some infants die unexpectedly there are some things we do know. Some of these deaths are the result of asphyxia due to sleep position in combination with sleep surface or overlaying by an adult. Cardiac or other genetic abnormalities may cause or contribute to unexpected infant deaths; however, even if anomalies exist they may not be the cause of the death. The deaths occur when the infant is either sleeping or in a relaxed state (e.g. during quiet time, during breastfeeding).

Another challenge is identifying a level of risk that certain behaviours pose when the degree to which those behaviours are displayed in the general population are unknown. For example, bed sharing is correlated with unexpected infant deaths but the relative risk is difficult to determine because good information on bed sharing in the general population is not available.

INFANT CHARACTERISTICS

The following is a summary of the findings associated with factors that cannot be changed.

SEX

The research literature shows a 35% to 65% higher incidence of unexpected infant deaths in male compared to female infants (Trachtenberg, Haas, Kinney, Stanley and Krous, 2012; Mage and Donner, 2009; Omojokun and Moon, 2008).

Of the 117 unexpected infant deaths between 2008 and 2012, 77 (66%) were male and 40 (34%) were female, which is an approximate ratio of 2:1. This review shows a higher proportion of male infants than does the literature and is virtually the same as what was reported in the BCCS 2009 report *Safe and Sound*: *A Five Year Retrospective*.

BIRTH WEIGHT and GESTATIONAL AGE

The research literature indicates there is a higher incidence of unexpected infant deaths in preterm or low birth weight infants (Hunt and Hauck, 2006; Perinatal Services BC, 2011). A low birth weight is considered to be less than 2,500 grams.

In 91 cases where birth weight was recorded, 15% (n=14) of the infants had a low birth weight of less than 2,500 grams. According to Canadian Institute for Health Information (CIHI) (2012) 5.6% of babies born in B.C. in 2010/11 had low birth weights. The case review findings are consistent with the literature in that the incidence of sudden and unexpected deaths in low birth weight infants was higher – in this review it was by a factor of almost three.

A full term pregnancy is considered to be between 37 to 41 weeks. Infants born before 37 weeks are considered pre-term and infants born after 41 weeks are considered post-term. The research literature indicates there is an elevated risk of unexpected infant deaths in infants who are born pre-term (Hunt and Hauck, 2006).

In this review information on gestational age was available for 109 of the infants. 23% (n=25) of the infants were born pre-term. According to CIHI (2012), 7.6% of infants born in B.C. in 2010/11 were born pre-term. The case review findings are consistent with the literature in that pre-term infants had a higher than expected incidence of unexpected deaths; in this review, by a factor of three.

AGE AT DEATH

Unexpected infant deaths are less common in the first month of life but increase when the infant is between 2 to 4 months old, with the majority occurring by 6 months of age (Perinatal Services BC, 2011; Task Force on Sudden Infant Death Syndrome, 2011).

The findings of this case review are consistent with the research literature. Forty-eight percent (n=56) of the unexpected infant deaths occurred between infants aged 2 to 4 months old and overall, 85% (n=100) of the infants were age 6 months or less at the time of their death.

PHYSIOLOGY and GENETICS

The research literature identifies a number of physiological or genetic factors that could possibly contribute to unexpected infant deaths, including but not limited to: cardiac diseases, imbalances in the **autonomic nervous system**, poor arousal and the body's ability to respond to changes in temperature (Wilders, 2012; Omojokun, et.al, 2008; Hunt, et.al, 2006).

When investigating an unexpected infant death a pathologist will conduct an autopsy to try to identify an anatomical cause of death. An autopsy was completed on all of the unexpected infant deaths in this case review. In 97% (n=114) of the cases; no anatomical cause of death was found. When no anatomical cause of death is identified, the pathologist may recommend that the infant's family be referred to the B.C. Inherited Arrhythmia Program (BCIAP) with sites in Vancouver (St. Paul's Hospital) and Victoria (The Royal Jubilee Hospital) so that family members may be assessed for any inherited cardiac conditions that may affect them (Priori, et.al, 2013). There is no available information on the number of families who actually attend the clinic for testing or of the results of the testing for any families who do attend. Ackerman (2009) estimates that approximately 10% of all sudden unexpected deaths in infancy may be the result

of a genetic factor predisposing the infant to an abnormal heart rhythm; therefore, in some cases, genetic testing for family members may be advised.

Research in the field of genetics is ongoing. The research literature suggests that genetic markers or mutations are likely only one part of a combination that includes environmental, developmental and genetic factors that may cause an unexpected infant death (Collins, 2012; Opdal, 2004). The research also indicates it is unlikely that only one specific genetic factor would be associated in all unexpected infant deaths where genetics are a factor (Opdal, 2004).

At this time, genetic testing for unexpected infant deaths in B.C. is limited to finding out the presence of a CPT1a¹¹ genetic variant. This genetic variant is present in **First Nations** populations of B.C.; therefore, the scope of testing is limited to First Nations infants or where an infant's ethnicity is unknown. A CPT1a genetic variant is thought to impact the body's ability to breakdown fat to energy when glucose is unavailable. This can cause low blood sugar that, when left untreated, can be fatal for an infant. Recent research investigating the role of the CPT1a genetic variant suggests it may play a less important role in unexpected infant deaths than first thought (Collins, Sinclair, McIntosh, Bamforth, Thompson, Sobol, Osborne, Corriveau, Santos, Hanley, Greenberg, Vallance and Arbour, 2009) although the research is ongoing. In the current infant death case review, 25 of the infants were tested for the CPT1a genetic variant and in 2 of these cases the infants tested positive for the variant. In neither case was the CPT1a genetic variant identified as the cause of death.

POPULATION LEVEL ATTRIBUTES

The research literature suggests that infants included in the following subpopulations are at elevated risk for unexpected deaths. These attributes are not mutually exclusive and some of the infants who died were identified as belonging to one or more of these groups. It is important to consider population level attributes because if certain populations are overrepresented it has implications for targeting programs and policies.

CHILD WELFARE

Research on the relationship between unexpected infant deaths and infants involved with child welfare is very limited which makes it difficult to draw conclusions about the impact (Krous, Haas, Manning, Deeds, Silva, Chadwick and Stanley, 2006).

In this review 26% (n=31) of the cases of unexpected infant deaths, there was child welfare involvement that was directly related to concerns about the well-being of the infant either before or at the time of their death; 7 of these infants were under the guardianship of child welfare services. Although the research may be limited, the proportion of infants who died unexpectedly and had child welfare involvement were greatly overrepresented.

SOCIO-ECONOMIC STATUS

Research on the influence of socio-economic status on infant mortality and more specifically, unexpected infant deaths remains unclear (Gilbert, Auger, Wilkins, and Kramer, 2013). Generally, low economic status is associated with a higher risk of poor health outcomes for

¹¹ Carnitine palmitoyltransferase 1

infants, including a disproportionate amount of unexpected infant deaths; however, further investigations need to happen in order to understand the reasons why (Gilbert, Auger, Wilkins and Kramer, 2013; Omojokun and Moon, 2008; Ponsonby, Dwyer, Cochrane, 2002).

From the qualitative review of the case files it appears that the majority of the families whose infants died unexpectedly had a number of socio-economic challenges in terms of income levels and appropriate housing. Even if the research is unclear on the specific influence of socio-economic status on unexpected infant deaths, the greater proportion of unexpected infant deaths in lower socio-economic groups suggests additional preventative messaging should be tailored and targeted to this audience.

ENVIRONMENTAL FACTORS ASSOCIATED WITH UNEXPECTED INFANT DEATH

The following factors are correlated with unexpected infant deaths and research into them is ongoing.

Comparing the findings of unexpected infant deaths between 2008 and 2012 to the findings of the CDRU review of unexpected infant deaths in sleep related circumstances between 2003 and 2007; many of these factors show little change over this 10 year period. In particular, sleep position and sleep environment have remained relatively constant.

INFANT SLEEP POSITION

The research literature explains that the risk of unexpected infant death is reduced when an infant is placed on their back to sleep instead of on their stomach or side (Hunt and Hauck, 2006; Schnitzer, Covington and Dykstra, 2012). It is further suggested that the risk is increased if an infant who is normally placed on their back to sleep ends up being placed in another sleep position they are not normally placed in (Pemberton, 2005; Omojokun, et.al, 2008). Placing an infant on their stomach makes it harder for them to breathe and can also increase body temperature causing them to overheat (American Academy of Pediatrics Task Force on Sudden Infant Death Syndrome, 2011). If an infant is placed on their side, they could end up rolling onto their stomach. Research suggests the risk of an unexpected infant death doubles if an infant is placed on their stomach or side to sleep (American Academy of Pediatrics Task Force on Sudden Infant Death Syndrome, 2011).

In this review, the information about sleep position was obtained by coroners interviewing parents and caregivers, as all of the infants had been moved. Of the cases where the infant's sleep position was known (n=89), 43 of the infants were placed on their backs, 33 were placed on their stomach and 13 were placed on their side. The majority of these infants were found unresponsive in the same position they were initially placed in. These findings are similar to those found in the 2009 CDRU report where of the 96 cases where sleep position was known, 45 infants were placed on their back, 30 infants were placed on their stomach and 21 were placed side-lying.

Although the case review found greater numbers of infants sleeping on their backs died unexpectedly this is a reflection that the majority of infants are placed on their backs to sleep and actually supports the research suggesting "back to sleep" is a protective practice. While there is not a great deal of general population information on infant sleep position, the 20062007 Canadian Maternity Experiences Survey found that 77.4% of infants in Canada were placed on their backs to sleep. If sleep position was not correlated with the unexpected death of infants the current case review should have found 69 (77.4% of the 89 cases) back sleeping infants died unexpectedly rather than the 43 found in the reveiw.

SLEEP ENVIRONMENT

Research into the sleep environment of an infant in association with unexpected infant deaths is mainly focused on investigating the sleep surface where the infant is placed and the impact of when the infant's sleep surface is shared with an adult or when the infant is sharing the same room as their parent or caregiver.

The literature shows that soft bedding or material placed in a crib or bassinet with an infant is an unsafe sleep environment because it can increase the risk of an unexpected infant death by approximately 2-3 times (Hunt, et.al, 2006). Specifically, the soft bedding or material has the potential to suffocate an infant and in some cases, cause an infant's body to overheat (Omojokun, et. al, 2008).

Sharing the same sleep surface with an infant is often referred to as 'bed-sharing'. Bed-sharing is a controversial issue as the experts involved in the study of infant sleep environments differ in their findings and opinions. Some studies suggest there are potential benefits to bed-sharing in the absence of other factors that are seen to increase the risk for an unexpected infant death (i.e. substance use). Supporters of bed-sharing suggest that it may be part of a cultural practice or that it facilitates breastfeeding (Weber, Risdon, Ashworth, Malone, Sebire, 2012; Hunt, et.al, 2006). Even with consideration for the potential benefits, no studies have shown that bed-sharing is an entirely safe sleep environment (Perinatal Services BC, 2011). Specifically, a shared sleep arrangement increases the risk of suffocation or overheating of an infant (Government of Canada, Canadian Paediatric Society, Canadian Institute of Child Health and The Canadian Foundation for the Study of Infant Deaths, 2012).

Room sharing (sometimes referred to as co-sleeping) is when the infant is placed in the same room as the caregiver and is not sharing the same sleep surface. The research literature suggests that room sharing with an infant, where the infant is placed on a safe sleep surface (i.e. a crib or bassinet with a firm mattress, fitted sheet and no soft material) is the most ideal safe sleep setting (Perinatal Services BC, 2011; Omojokun, et.al, 2008; Hunt, et.al, 2006). Sharing the same room with an infant can lower the risk of an unexpected infant death because the caregiver is close by to monitor the infant and respond to their needs (Perinatal Services BC, 2011; Hunt, et.al, 2006). Information about how many families bed share or room share in the general population in unknown. The only robust information stems from the cases where an infant has died. This creates challenges for trying to determine the relative risk of bed sharing.

Of the 117 unexpected infant deaths, 75% (n=88) of the infants were placed in an unsafe sleep environment. In almost 40% (n=45) of the overall cases of unexpected infant deaths, the infant shared a sleep surface with an adult. These findings are similar to those found in the CDRU review of 113 infant deaths in sleep-related circumstances between 2003 and 2007 where 81 infants were placed in an unsafe sleep environment with 51 of these infants sharing a sleep surface with an adult.

EXPOSURE TO TOBACCO, ALCOHOL and OTHER SUBSTANCES

Prenatal exposure

Research literature on the risk posed by prenatal exposure to tobacco indicates the risk of an unexpected infant death is increased and that the degree of risk depends on the amount of exposure (Omojokun, et.al, 2008; Getahun, Amre, Rhoads and Demissie, 2004; Leduc, Cote, Woods and Canadian Paediatric Society, 2004). Specifically, prenatal tobacco exposure could slow fetal growth and development which can affect an infant's ability to breath, cause heart rate variability and make it difficult to be aroused (Kelmanson, 2011; Ostfeld, Esposito, Perl and Hegyi, 2010; Omojokun, et.al, 2008). In terms of prenatal drug use beyond tobacco, the research literature indicates there is a link between drug use and unexpected infant deaths but the degree of risk is unknown as often times, cigarette smoking and other drug use happens together (Hunt, et.al, 2006).

In 38 of the cases, the infant was known to have been prenatally exposed to one or more **psychoactive substances**. This can include but is not limited to tobacco, illicit drugs, prescription drugs, alcohol or a combination of substances. Within these cases, 77% (n=30) of the infants were prenatally exposed to tobacco, making this substance the most common followed by other psychoactive substances and alcohol, respectively.

Postnatal exposure

Postnatal exposure to psychoactive substances involves an infant being cared for by a person who is using or has recently used drugs or alcohol.

Tobacco use and its association to unexpected infant deaths has been well researched. As mentioned in the previous section, an infant's exposure to tobacco may compromise their heart rate, ability to breath and to rouse (Hutchison, Rea, Stewart, Koelmeyer, Tipene-Leach and Mitchell, 2011; Kelmanson, 2011; Omojokun, et.al, 2008; Hunt, et.al, 2006). This risk is even greater when the caregiver who smokes shares a sleep surface with the infant (Task Force on Sudden Infant Death, 2011; Government of Canada, et.al, 2012; Omojokun, et.al, 2008; Hunt, et.al, 2006).

The risk of an unexpected infant death is also increased when an infant shares a sleep surface with an adult who is under the influence of other psychoactive substance(s) (Government of Canada, et.al, 2012; Task Force on Sudden Infant Death Syndrome, 2011; Perinatal Services BC, 2011). When an adult who is under the influence of one or more psychoactive substances, the potential for entrapment, overlaying, overheating or suffocation is increased (Government of Canada, et.al, 2012).

In 38 of the cases, the infant was known to be living with one or more caregivers who smoked tobacco. In 16 of the cases, the parent or caregiver was reported to be under the influence of one or more psychoactive substances at the time of the infant's death. In some of these cases, the caregiver was sharing the same sleep surface as the infant.

BREASTFEEDING

Older research investigating the protective association of breastfeeding to reducing the risk of an unexpected infant death is inconsistent (Ip, Chung, Raman, Chew, Magula, Devine,

Trikalinos, Lau, 2007; Mitchell, Freemantle, Young and Byard, 2012). Generally, the more recent research literature suggests that even though there are inconsistencies across earlier studies, any degree of breastfeeding, with the exception of mothers who have been using illicit psychoactive substances, is considered to be a protective factor against an unexpected infant death, particularly for infants who are exclusively breastfed (Hauck, Thompson, Tanabe, Moon and Venneman, 2011). It is thought that the risk of an unexpected infant death is decreased because breastfed infants are more easily aroused from sleep and breastfeeding boosts an infant's immunity (Hauck, et.al, 2011).

Of the 90 cases where the infant's diet was known, 35 (39%) were exclusively breastfed, 34 (38%) were exclusively formula fed and 21 (24%) were breastfed in combination with formula feeding. Comparatively there appears to be an increase in the number of infants who were breastfed over the findings presented in the 2009 CDRU report *Safe and Sound: a Five Year Retrospective*. Where information on diet was known, the 2009 review found 29% of the infants were exclusively breastfeed, 62% were formula fed and 9% were both breast and formula fed.

In B.C., 61.4% of infants in the general population were exclusively breastfeed until age 3 months (Perinatal Services BC, 2012). The findings in this case review support the research indicating that breastfeeding is a protective factor. If unexpected infant deaths were a random occurrence, the current case review should have found 55 (61.4% of the 90 cases) exclusively breastfed infants died unexpectedly rather than the 35 found in the review.

PACIFIER USE

The research literature around pacifier use continues to emerge and suggests that when used habitually, it may be a protective factor; however, the reasons for this remain unclear (Moon, Tanabe, Choi Yang, Young and Hauck, 2012; Mitchell, et.al, 2011; Omojokun, et.al, 2008). Some research proposes that pacifier use may make it easier for an infant to wake up or that it can help regulate an infant's breathing when they sleep and assist with keeping their airway open (Task Force on Sudden Infant Death, 2011; Omojokun, et.al, 2008).

In this review, the number of cases where a pacifier was regularly used in a sleep setting is unknown.

PART 6: ABORIGINAL INFANTS

Research and surveillance into Aboriginal infant mortality and more specifically, unexpected infant deaths, are not well documented. In Canada, information is only available for certain subgroups of Aboriginal populations (e.g. Status First Nations and Inuit) making it impossible to accurately know how many unexpected infant deaths were Aboriginal infants (Smylie, Fell, Ohlsson and the Joint Working Group on First Nations, Indian, Inuit, and Métis Infant Mortality of the Canadian Perinatal Surveillance System, 2010). More standardization of Aboriginal data is needed. Adopting the Aboriginal administrative data standard would assist in improving the collection of data on Aboriginal children in British Columbia.

Of the Canadian data that is available, Aboriginal infant mortality rates, which include unexpected infant deaths, are 2 to 3 times as high as the overall Canadian infant mortality rates (Smylie, et.al, 2009; Collins, et.al, 2012; Zhong-Cheng, Senecal, Simonet, Guimond, Penney and Wilkins, 2010). In BC, a population based study that included all First Nations with Status births between 1981 and 2000, found that unexpected infant deaths were higher for both rural and urban First Nations with Status compared to rural and urban non-First Nations (Luo, Kierans, Wilkins, Liston, Uh, and Kramer, 2004).

The reasons for this higher rate of infant mortality, including unexpected infant deaths are not entirely clear. The research literature points out that generally, Aboriginal people experience poorer economic and social conditions (i.e. food supply, housing and employment) compared to the non-Aboriginal population and these factors could be related (National Collaboration Centre for Aboriginal Health, 2011). Research suggests that when exposed to these conditions, Aboriginal infants are at greater risk of experiencing negative health outcomes which may include elevating the risk for dying unexpectedly.

The findings of this review show a higher proportion of Aboriginal unexpected infant deaths overall which is consistent with the research, including the findings of the BCCS 2009 report *Safe and Sound: a Five Year Retrospective*. Specifically, this 2009 report indicated that over a 5 year period, 30% of infants who died in sleep related circumstances were Aboriginal, despite making up less than 8% of the infant population. In this current review, 31% (36) of the 117 infants were identified as Aboriginal; 25 were male and 11 were female.

The findings of this review further show that a disproportionate number of Aboriginal families whose infants died unexpectedly were involved with child welfare services. Generally, families involved with child welfare services experience poorer socio-economic conditions which are factors the research suggests could be related to elevating the risk of an unexpected infant death. Specifically, child welfare services were involved with 15 Aboriginal infants, including 3 infants who were under the guardianship of child welfare services.

PART 7 RECOMMENDATIONS

The recommendations forwarded to the Chief Coroner came out of the death review panel discussion focusing on increasing the knowledge base about why infants die unexpectedly and practical prevention efforts that can be taken to reduce known risks. Through the panel discussion and sharing of expertise, panel members specifically identified opportunities for enhancing the investigation of unexpected infant deaths, the use of genetic testing and the importance of public messaging around safe sleep.

The recommendations arising from the death review panel were developed in a manner that was:

- Collaborative;
- Attributable to the deaths being reviewed;
- Focused on identifying opportunities for improving public safety and prevention of future deaths;
- Targeted to specific parties;
- Realistically and reasonably implementable; and
- Measurable.

RECOMMENDATION 1: INVESTIGATIVE PRACTICES

Investigating the unexpected death of infants presents unique challenges for the investigators involved. Unexpected infant deaths are not common occurrences which means both coroners and police officers may have less experience with these types of investigations.

A major challenge in the investigation process is finding out what happened leading up to and including when the infant was found unresponsive. In all 117 of the unexpected infant deaths reviewed, the infants were moved from where they were found. This is usually the result of intervention efforts made by parents, caregivers or first responders to revive the infant and often includes the infant being taken to the hospital. As the infant has been moved, the coroner needs to reconstruct the circumstances where the infant was found unresponsive to help determine the cause of death. This cannot always be done immediately as parents or caregivers also go to the hospital and are experiencing heightened emotions related to their tragic loss.

In order to determine the cause of the infant's death, parents and others are interviewed, the scene is examined, post mortem testing (including an autopsy) is completed and information about the infant's medical history is reviewed. The coroner and pathologist each use specialised investigative techniques to find out what happened. Given that post mortem examinations rarely identify an anatomical cause of death in cases of an unexpected infant death, the scene investigation takes on even greater importance.

In reviewing investigative practices, the panel identified key actions to support the gathering of accurate information where an infant dies unexpectedly.

Recommendation:

By the fall of 2014

- That the Deputy Commissioner RCMP E Division and the Chief Constables of the independent municipal police departments develop a standardized investigative protocol to support law enforcement investigations into unexpected infant deaths.
- The BC Ambulance Service work with the BCCS to develop standardized questions with respect to the initial scene to support Emergency Medical Responders attending calls where infants die unexpectedly.
- The BC Coroners Service revises its protocol for unexpected infant deaths to include obtaining 911 transcripts and ensure that scene recreations are conducted in cases where an infant has been moved.
- The BC Coroners Service adopts the Aboriginal Administrative Data Standard in order to collect more robust data about Aboriginal people.

RECOMMENDATION 2: GENETIC TESTING

There are a number of possible genetic factors that could be related to the cause of death of an infant due to their impact on an infant's physical development and functioning. Currently, the only genetic testing completed in cases of unexpected infant deaths in B.C. is for determining the presence of a CPT1a genetic variant in First Nations infants or infants whose ethnicity is unknown. Research in the field of genetics is ongoing and opportunities to expand genetic testing specific to identifying cardiac irregularities in cases of unexpected infant deaths have emerged.

The panel identified that genetic testing could be beneficial where clinical evidence supports a specific diagnosis.

Recommendation:

By the fall of 2014

- The BC Coroners Service, pediatric pathologists, the B.C. Inherited Arrhythmia Program and the First Nations Health Authority establish criteria for when to conduct genetic testing for cardiac causes where an infant dies unexpectedly.
- The BC Coroners Service, pediatric pathologists, the Provincial Medical Genetics Program and the First Nations Health Authority review the utility of testing for the CPT1a variant in First Nations infants.

RECOMMENDATION 3: SAFE SLEEP AWARENESS

Although there is no single cause of why infants die suddenly and there is still a need for a greater understanding around genetic and other possible causes of why infants die unexpectedly we do know that an infant's sleep position and sleep environment are important.

When comparing the findings of this current review of infants who died unexpectedly from 2008 to 2012 with the findings reported in the 2009 BCCS report *Safe and Sound: a Five Year Retrospective* of infants who died in sleep related circumstances between 2003 and 2007, the

sleep practices do not appear to have significantly changed over the past 10 years. Specifically, the high number of instances where the infant shared the same sleep surface with an adult has remained relatively constant.

Awareness about the risks associated with unexpected infant deaths has been aimed at the general population through mass-media strategies. The main focus has been around reducing unexpected infant deaths by placing infants on their backs to sleep. In this review, the findings showed that about 75% of the infants were placed in an unsafe sleep situation (e.g. sleeping on a sofa or adult bed), including 40% of the infants sharing a sleep space with an adult.

There are inherent risks involved in sleeping with an infant that require greater public awareness. Specifically, some infants die as a result of an adult rolling over on them or wedging them, causing suffocation. The panel also found that in 16 of the infant deaths, the sleeping parent or caregiver was under the influence of a substance(s). There is a need for simple clear messaging around these issues.

The panel identified that awareness around infant safe sleep positioning and safe sleep environment needs to continue and more specifically, it needs to target vulnerable parents/caregivers who are likeliest to be bed sharing and/or using substances while caring for their infant. The messaging and how this messaging is delivered needs to be tailored specifically to this group and in addition to focusing on an infant's sleep position and safe sleep environments; it also needs to address the risks of bed sharing and substance use.

Recommendation:

By the end of 2014

The First Nations Health Authority, The Community Against Preventable Injuries, Ministry of Health, the Ministry of Children and Family Development and community stakeholders collaborate to:

- Identify the specific audience of parents/caregivers who are likeliest to benefit from receiving messaging that is clear about infant safe sleep positioning, sleep environment, and the risks of bed sharing and substance use;
- Identify the most effective means for delivering the messaging to the target audience;
- Develop and implement a plan that delivers the messaging around infant safe sleep positioning, sleep environment, and the risks of bed sharing and substance use to the target audience.

RESOURCE LINKS

The following links refer to the reports, programs, protocols and guides mentioned in Part 3 of this report and are intended to provide further information about infant health and safety, including safe sleep practices.

BC Coroners Service

"Safe and Sound: A Five Year Retrospective" A report on Sudden Infant Death in Sleep-related Circumstances

http://www.pssg.gov.bc.ca/coroners/child-death-review/docs/sudden-infant-death-cdrureport.pdf

Representative for Children and Youth Fragile Lives, Fragmented Systems: Strengthening Supports for Vulnerable Infants

http://www.rcybc.ca/Images/PDFs/Reports/Fragile%20Lives%20-%20FINAL%20Jan%202011.pdf

Perinatal Services BC

Health Promotion Guideline 1 Safe Sleep Environment Guideline For Infants 0-12 Months of Age

http://www.perinatalservicesbc.ca/NR/rdonlyres/D799441C-3E00-49EE-BDF7-2A3196B971F0/0/HPGuidelinesSafeSleep1.pdf

Ministry of Health Baby's Best Chance

http://www.healthyfamiliesbc.ca/about-us/additional-resources#BBC

Every Sleep Counts poster and parent information sheets

http://www.healthyfamiliesbc.ca/about-us/additional-resources

Healthy Families BC website

http://www.healthyfamiliesbc.ca/

BC Healthy Connections Project

http://www.healthyfamiliesbc.ca/home/bc-healthy-connections-project

First Nations Health Authority Honouring our Babies: Safe Sleep Cards and Guide

http://www.fnha.ca/what-we-do/children-youth-and-maternal-health

GLOSSARY

Aboriginal: Reference used to encompass First Nations (status and non-status), Métis and Inuit people in Canada.

Aggregate: Presentation of individual findings as a collective sum.

Autopsy: a post-mortem examination of a body to determine the cause of death.

Autonomic nervous system: the body's function of regulating internal organs such as the heart, stomach and intestines.

First Nations: Status and Non-Status "Indian" peoples in Canada. An individual recognized by the federal government as being registered under the Indian Act is referred to as a Registered Indian (commonly referred to as a Status Indian).

Pathologist: a specialist physician who specializes in the field of pathology, the causes for diseases; autopsy pathology involves post-mortem examination to determine the cause of death.

Psychoactive Substance: Both legal and illegal drugs and/or alcohol.

REFERENCES

- Ackerman, M.J. (2009). State of postmortem genetic testing known as the cardiac channel molecular autopsy in the forensic evaluation of unexplained sudden cardiac death in the young. Pacing and Clinical Electrophysiology. July, 2009; 32(Suppl 2): S86-S89.
- American Academy of Pediatrics Task Force on Sudden Infant Death Syndrome (2011). Sids and other sleep-related infant deaths: expansion of recommendations for a safe infant sleeping environment. *Pediatrics*, Vol. 128; 1030-1039.
- Canadian Institute for Health Information (2012). Highlights of 2010–2011 selected indicators describing the birthing process in Canada. Retrieved on December 6, 2013 from, https://secure.cihi.ca/free_products/Childbirth_Highlights_2010-11_EN.pdf
- Collins, S.A., Sinclair, G., McIntosh, S., Bamforth, F., Thompson, R., Sobol, I., Osborne, G.,
 Corriveau, A., Santos, M., Hanley, B., Greenberg, C.R., Vallance, H. and Arbour, L. (2010).
 Carnitine palmitoyltransferase 1A (CPT1A) P479L prevalence in live newborns in Yukon,
 Northwest Territories, and Nunavut. *Molecular Genetics and Metabolism,* Vol. 101; 200-204.
- Collins, S.A., Sumala, P., Osborne, G., Greenberg, C., Williamson Bathory, L., Edmunds-Potvin, S. and Arbour, L. (2012). Causes and risk factors for infant mortality in Nunavut, Canada (1999-2011). BMC Pediatrics, 12:190.
- Fleming, P., Blair, P., Bacon, C., Berry, J. (2000). Sudden unexpected deaths in infancy. The CESDI SUDI studies 1993-1996. Royal College of Midwives Midwives Journal, 3(3); 86-87.
- Getahun, D., Amre, D., Rhoads, G. and Demissie, K. (2004). Maternal and obstetric risk factors for sudden infant death syndrome in the United States. *The American College Of Obstetricians and Gynecologists,* Vol 103, No.4, 646-652.
- Gilbert, N.L., Auger, N., Wilkins, R. And Kramer, M.S. (2013). Neighbourhood income and neonatal, postnatal and sudden infant death syndrome (sids) mortality in Canada, 1991-2005. *Canadian Journal of Public Health*, Vol. 104, No. 3; 187-192.
- Government of Canada, Canadian Paediatric Society, Canadian Institute of Child Health and The Canadian Foundation for the Study of Infant Deaths (2012). Joint statement on safe sleep: preventing sudden infant deaths in Canada. Retrieved on July 31, 2013 from, <u>http://www.phac-aspc.gc.ca/hp-ps/dca-dea/stages-etapes/childhood-enfance_0-2/sids/jsssecss-eng.php</u>
- Guntheroth, W. G. and Spiers P.S. (2002). The triple risk hypotheses in sudden infant death syndrome. *Pediatrics* 110.5: e64-e64.
- Hauck, F.R. and Tanabe, K.O. (2008). International trends in sudden infant death syndrome: stabilization of rates requires further action. *Pediatrics,* Vol. 122; 660-666.

- Hauck, F.R., Thompson, J.M.D., Tanabe, K. O., Moon, R.Y. and Vennemann, M.M. (2011). Breastfeeding and reduced risk of sudden infant death syndrome: a meta analysis. *Pediatrics*, 128; 103-110.
- Hunt, C.E. and Hauck, F.R. (2006). Sudden infant death syndrome. *Canadian Medical Association Journal*, Vol. 174, No. 3; 1861-1869.
- Hughes, E.N. (2006). BC children and youth review: an independent review of BC's child protection system. Submitted to the Minister of Children and Family Development by the Honourable Ted Hughes. Retrieved on February 25, 2014 from, http://www.mcf.gov.bc.ca/about_us/pdf/BC_Children_and_Youth_Review_Report_FINAL_Ap_ril_4.pdf
- Hutchison, B. L., Rea, C., Stewart, A.W., Koelmeyer, T.D., Tipene-Leach, D.C. and Mitchell, E.A. (2011). *Acta Paediatrica*, 100, p. 1108-1112.
- Ip, S., Chung, M., Raman, G., Chew, P., Majula, N., DeVine, D., Trikalinos, T. and Lau, J. (2007). Breastfeeding and maternal and infant health outcomes in developed countries. *Agency for Health Care Policy and Research*, 153, p. 93-97.
- Judge, K. (2009). Inequalities in infant mortality: patterns, trends, policy responses and emerging issues in Canada, Chile, Sweden and the United Kingdom. *Health Sociology Review*, Vol. 18, Issue 1; 12-24.
- Kelmanson, I.A. (2011). Risk factors of sudden infant death syndrome and risk factors for sleep disturbances. *Early Childhood Development and Care,* Vol. 181, No. 5, 681-690.
- Krous, H.F.(2010). Sudden infant death in infancy and the dilemma of defining the sudden infant death syndrome. *Current Pediatric Reviews*, Vol. 6; 5-12.
- Krous, H.F., Haas, E.A., Manning, J.M., Deeds, A., Silva, P.D., Chadwick, A.E. and Stanley, C. (2006). Child protective services referrals in cases of sudden infant death: a 10-year, population-based analysis in San Diego County, California. *Child Maltreatment*. Vol. 11; 247-256.
- Krous HF, Beckwith JB, et al (2004) Sudden infant death syndrome and unclassified sudden infant deaths: a definitional and diagnostic approach. *Pediatrics* 114:234–238.
- Leduc, D., Cote, A., Woods, S. and Canadian Paediatric Society Community Paediatrics Committee. (2004). Recommendations for safe sleeping environments for infants and children. *Paediatric Child Health;* 9(9):659-63.
- Luo, Z.C., Kierans, W.J., Wilkins, R., Liston, R.M., Uh, S.H. and Kramer, M.S. for the British Columbia Vital Statistics Agency (2004). Infant mortality among First Nations versus non-

First Nations in British Columbia: temporal trends in rural versus urban areas, 1981-2000. *International Journal of Epidemiology,* Vol 33: 1252-1259.

- Mage, D.T. and Donner, M. (2009). A unifying theory of sids. *International Journal of Pediatrics,* p. 1-10.
- Ministry of Children and Family Development (October 2009). Aboriginal children in care. Prepared by Research, Analysis and Evaluation Branch. Retrieved on November 28, 2013 from, <u>http://www.fndirectorsforum.ca/downloads/aboriginal-children-in-care-10-09.pdf</u>
- Minister of Industry (September 2013). Report on the demographic situation in Canada. Mortality: overview, 2010 and 2011. *Minister Responsible for Statistics Canada*. Component of Statistics Canada Catalogue no. 91-209-X. Retrieved on August 12, 2013 from, <u>http://www.statcan.gc.ca/pub/91-209-x/2013001/article/11867-eng.pdf</u>
- Mitchell, E.A., Freemantle, J., Young, J. and Byard, R.W. (2012). Scientific consensus forum to review the evidence underpinning the recommendations of the Australian sids and kids safe sleep health promotion programme-october 2010. *Journal of Paediatrics and Child Health*, 48; 626-633.
- Moon, R.Y., Tanabe, K.O., Choi Yang, D., Young, H.A. and Hauck, F.R. (2012). Pacifier use and sids: evidence for a consistently reduced risk. *Maternal Child Health Journal*, 16: 609-614.
- National Collaboration Centre for Aboriginal Health (2011). Our babies, our future: Aboriginal birth outcomes in British Columbia. Retrieved on July 31, 2013 from, <u>http://www.nccah-ccnsa.ca/docs/fact%20sheets/child%20and%20youth/Our%20Babies,%20Our%20Future%20%28English%20-%20Web%29.pdf</u>
- Omojokun, O.O. and Moon, R.Y. (2008). Sudden infant death syndrome: a review of the literature. *Current Pediatric Reviews*, Vol 4; 31-39.
- Opdal, S.H. and Rognum, T.O. (2004). The sudden infant death syndrome gene: does it exist? *Pediatrics*, Vol. 114, No. 4; 506-512.
- Ostfeld, B.M., Esposito, L., Perl, H. and Hegyi, T. (2010). Concurrent risks in sudden infant death syndrome. *Pediatrics*; 125; 447-453.
- Perinatal Services BC (2011). Health promotion guideline 1 safe sleep environment guideline for infants 0 to 12 months of age. *Provincial Health Services Authority*. Retrieved on July 31, 2013 from, <u>http://www.perinatalservicesbc.ca/NR/rdonlyres/D799441C-3E00-49EE-BDF7-2A3196B971F0/0/HPGuidelinesSafeSleep1.pdf</u>

Perinatal Services BC (2012). Health promotion guideline, breastfeeding health term infants.

Provincial Health Services Authority. Retrieved on February 23, 2014 from, <u>http://www.perinatalservicesbc.ca/NR/rdonlyres/6A2A2690-B9BF-4D1C-ABC6-</u> 9477425BCCD5/0/BFGuidelinesBreastfeedingHealthyTermInfantsJune2012.pdf

- A report from the Provincial Health Officer (2012). The health and well being of the Aboriginal population, interim update. Office of the Provincial Health Officer, p. 1-13. Retrieved on September 16, 2013 from, <u>http://www.health.gov.bc.ca/pho/reports/special.html</u>
- Pemberton, D. (2005). Breastfeeding, co-sleeping and the prevention of sids. *British Journal of Midwifery*, Vol. 13, No.1; 12-18.
- Ponsonby, A.L., Dwyer, T. and Cochrane, J. (2002). Population trends in sudden infant death syndrome. *Seminars in Perinatology,* Vol. 26, No. 4; 296-305.
- Priori, SG, Wilde, A.A., Horie, M., Cho, Y., Behr, E.R., Berul, C., Blom, N., Brugada, J., Chiang, C.E., Hoi Kuri, H., Kannankeril, P., Krahn, A., Leenhardt, A., Moss, A., Schwartz, P.J., Shimizu, W., Tomaselli, G., Tracy, C. (2013). Executive Summary: HRS/EHRA/APHRS expert consensus statement on the diagnosis and management of patients with inherited primary arrhythmia syndromes. Heart Rhythm: The Official Journal Of The Heart Rhythm Society. Dec Vol 10(12), pp. E85-108.
- Public Health Agency of Canada (2008 Ed). An overview of perinatal health in Canada. *Canadian Perinatal Health Report,* 9-35.
- Public Health Agency of Canada (2009). What mothers say: the Canadian maternity experiences survey. Ottawa. Retrieved on February 23, 2014 from, http://www.phac-aspc.gc.ca/rhs-ssg/survey-eng.php
- Rusen, I.D., Liu, S., Sauve, R., Joseph, K.S. and Kramer, M.S. (2004). Sudden infant death in Canada: trends in rates and risk factors, 1985-1998. *Chronic Diseases in Canada,* Vol. 25, No.1: 1-6.
- Schnitzer, P.G., Covington, T. M. and Dykstra, H.K. (2012). Sudden unexpected infant deaths: sleep environment and circumstances. *American Journal of Public Health,* Vol. 102, No. 6; 1204-1212.
- Sinclair, G.B., Collins, S., Popescu, O., McFadden, D., Arbour, L., Vallance, H.D. (2012). Carnitine palmitoyltransferase I and sudden unexpected infant death in British Columbia First Nations. *Pediatrics*, 130: e1162-1169.
- Smylie, J. and Adomako, P. (2009). Indigenous children's health report: health assessment in action. Retrieved on July 31, 2013 from, <u>http://www.stmichaelshospital.com</u>

- Smylie, J., Fell, D., Ohlsson, A. and the Joint Working Group on First Nations, Indian, Inuit, and Métis Infant Mortality of the Canadian Perinatal Surveillance System. (2010). A review of the Aboriginal infant mortality rates in Canada: striking and persistent Aboriginal/non-Aboriginal inequities. *Canadian Journal of Public Health*, Vol 101, No. 2; 143-148.
- Statistics Canada (2013). Infant mortality rates by province and territory. Table 102-0504. Retrieved on November 13, 2013 from, <u>http://www5.statcan.gc.ca/cansim/pick-</u> <u>choisir?lang=eng&p2=33&id=1020504</u>
- Trachtenberg, F.L., Haas, E.A., Kinney, H.C., Stanley, C. and Krous, H.F. (2012). Risk factor changes for sudden infant death syndrome after initiation of back to sleep campaign. *Pediatrics,* Vol, 129; 630-638.
- Weber, M.A., Risdon, R.A., Ashworth, M.T., Malone, M. and Sebire, N.J. (2012). Autopsy findings of co-sleeping-associated sudden unexpected deaths in infancy: relationship between pathological features and asphyxia mode of death. *Journal of Paediatrics and Child Health,* Vol. 48; 335-341.
- Wilders, R. (2012). Cardiac ion channelopathies and the sudden infant death syndrome. International Scholarly Research Network Cardiology, p. 1-28.
- Zhong-Cheng, L., Senecal, S., Simonet, F., Guimond, E., Penney, C., Wilkins, R. (2010). Birth outcomes in the Inuit-inhabited areas of Canada. *Canadian Medical Association Journal*, 182(3), p. 235-242.