# Sleep-Related Infant Deaths in Virginia

a report from the

# VIRGINIA STATE CHILD FATALITY REVIEW TEAM

Prepared by

Emily G. Womble, M.P.A., Coordinator, Child Fatality Review

Virginia Department of Health Office of the Chief Medical Examiner



# Virginia State Child Fatality Review Team Members

#### William T. Gormley, M.D., Chair

Virginia Department of Health Office of the Chief Medical Examiner

#### Heather F. Board, M.P.H.

Virginia Department of Health Division of Injury and Violence Prevention

#### Humberto I. Cardounel, Jr., M.P.A.

Henrico County Police Division

#### Betty Wade Coyle, M.A.

Prevent Child Abuse Virginia

#### Constance R. DiAngelo, M.D.

Virginia Department of Health Office of the Chief Medical Examiner

#### Robin L. Foster, M.D.

Virginia College of Emergency Physicians

#### Katharine Hunter, M.S.W.

Virginia Department of Behavioral Health and Developmental Services

#### Rita L. Katzman, M.S.W.

Virginia Department of Social Services Child Protective Services

#### Regina M. Milteer, M.D.

Virginia Chapter, American Academy of Pediatrics

#### Janet M. Rainey

Virginia Department of Health Division of Vital Records

#### Frank Romero

Richmond Ambulance Authority

#### S. Rutherfoord Rose, Pharm.D.

Virginia Poison Center

#### Neil Sonenklar, M.D.

Virginia Treatment Center for Children

#### **Mary Wilson**

Virginia Department of Criminal Justice Services

#### Office of the Chief Medical Examiner Staff:

#### Emily G. Womble, M.P.A.

Coordinator, Child Fatality Review

#### Virginia Powell, Ph.D.

Manager, Fatality Review and Surveillance Programs

# SLEEP-RELATED INFANT DEATHS IN VIRGINIA

# **MISSION STATEMENT**

As an interdisciplinary team, we review and analyze sudden, violent, or unnatural deaths of children so that strategies can be recommended to reduce the number of preventable child deaths in Virginia

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# Former State Child Fatality Review Team Members Who Participated in Review

Wayne Barry, Ed.D.

Virginia Department of Education Office of Student Services

Leah L.E. Bush, M.D.

Virginia Department of Health Office of the Chief Medical Examiner

Tommy L. Casteel

Virginia Department of Social Services

Mary Elizabeth Connal, M.S.

SIDS Mid-Atlantic

Patricia Cullen, M.S.N.

Chesterfield Mental Health Support Services

Steven DeLuca

Hanover County Fire & EMS

Mark Ferraro, M.B.A.

Virginia SIDS Alliance

Kathleen Moline, M.A.

Virginia Department of Health

Tamisha B. Peanort, M.S.W.

Virginia Department of Criminal Justice Services

James Q. Pope, J.D., M.S.W.

Fairfax County Department of Family Services

Jennifer Rhodes, M.D.

Medical Society of Virginia

**Detective Sergeant Mark E. Thatcher** 

New Kent County Sheriff's Office

Wanda G. Willis

Harrisonburg Fire Department

Joan Ziglar, J.D., M.P.A.

Office of the Commonwealth's Attorney City of Martinsville

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# **Executive Summary**

# **Executive Summary**

The Virginia State Child Fatality Review Team, hereafter called the Team, was established by the General Assembly in 1995. The purpose of the Team, outlined in §32.1-283.1, is to systematically analyze deaths among Virginia's children. Prevention and intervention recommendations are a crucial component of each Team review.

In 2009, 119 infants less than one year of age died unexpectedly in a sleep environment in Virginia, approximately one infant every three days. After natural disease, sleep-related death is the leading cause of infant death in Virginia, a loss of life nearly 10 times the number of infants who died as a result of abusive head trauma and almost 30 times the number of infants who died in motor vehicle collisions. Recognizing the significance to the health and safety of all Virginia infants, the Team performed a comprehensive review of all infant deaths potentially related to the sleep environment in 2009 to develop ideas for intervention and prevention of similar deaths. This report presents conclusions and recommendations from this review.

This report was prepared for use by all Virginians – the Governor, members of the General Assembly, child advocates, policy makers, parents, and citizens – with the firm conviction that injuries and deaths to children can be reduced.

# Key findings in this report include:

- The Team concluded that 95% of these deaths were preventable. Nine out of ten, 90%, were related to an unsafe sleeping environment.
- Consistent with national data findings, Black male infants four months of age and younger are most at risk of sleep-related deaths. Male infants died at a rate more than 1.5 times that of female infants. Black infants died at a rate more than twice that of White infants. Three out of four infants who died were four months of age or younger.
- Infants in Virginia's Western and Tidewater communities were at highest risk for a sleep-related death, with rates that far surpassed the statewide rate of 111.3 deaths per 100,000. Infant sleep-related death rates in Western communities (219.9 per 100,000) suggest a profound public health crisis in that region.
- Fewer than half of the infants were placed for sleep on their backs, or supine. More than half of the infants were found on their stomachs, or prone.
- Twenty-eight percent of the infants were born prematurely and 24% had low birth weights. One in four infants had spent some time in a Neonatal Intensive Care Unit (NICU) at birth.

# Executive Summary

- More than 70% percent of the infants were exposed to secondhand smoke. Half of the mothers smoked while pregnant with the infant who died.
- More than one in five mothers used alcohol or drugs while pregnant with the infant who died. Nearly half, 46%, were prescribed a Schedule II or III narcotic for pain at labor and delivery discharge, which diminished their capacity to react to and care for their infants. Fifteen percent of mothers prescribed a Schedule II or III narcotic showed evidence of substance use during pregnancy.
- Three-quarters of families had a crib, bassinet, or portable crib available. About onequarter of the infants were sleeping in one of these locations at the time of their death. Seventy-three percent of the infants were sleeping on a surface not intended for infant sleep at the time of their death. Half were sleeping on an adult bed.
- At least one person was co-sleeping with the infant in 57% of cases. In 26% of those cases, a co-sleeper was impaired by drugs or alcohol.
- Ninety-eight percent of infants had been seen by a pediatrician since birth. Seventy-two percent had seen a pediatrician in the 30 days preceding their death. Pediatricians are critical allies in getting messages about infant safe sleep environments to parents and caregivers.
- Almost a quarter of the infants were in a new or different environment at the time of their death, such as the home of a friend or relative, a homeless shelter, or a hotel.
- The infant's parent(s) or caretaker(s) had a criminal history in 44% of cases. These histories included drug charges, domestic violence, and other assault and battery charges.
- Many of the families who lost an infant to unsafe sleep lived at or below the poverty level.

The Team noted the presence of multiple risk factors in most sleep-related infant death cases, and concluded that the majority of these deaths were preventable. Team members developed recommendations in the following areas with the profound conviction that these premature and tragic infant deaths can be prevented:<sup>1</sup>

- training for hospitals and healthcare providers, including pharmacists and residents, on the importance of safe sleep messages; the risks of prescription medications to infant caregivers; and use of the Prescription Monitoring Program in Virginia
- developing statewide solutions to timely information sharing and referrals for at-risk families and for drug endangered infants

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<sup>&</sup>lt;sup>1</sup> See pages 32 - 36 in this report for a complete listing of the Team's recommendations.

# **Executive Summary**

- integrating safe sleep education and guidance with other services provided to poor and atrisk families, such as the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), Supplemental Nutrition Assistance Program (SNAP), safety assessments by local departments of social services, smoking cessation programs, and early intervention/home visiting programs
- adding safe sleep messaging to standards of care for healthcare facilities
- improving infant death investigations through multidisciplinary death investigations, consistent diagnoses of sleep-related deaths, and education about the meaning of unsafe sleep diagnoses used by Virginia medical examiners

Team members also noted that, as Virginia responds to the findings and recommendations in this report, we will not need to reinvent the wheel with regard to infant safe sleep training or educational materials. Like motor vehicle safety innovations for infants, the remedies are well-known, inexpensive, and easy to implement. There is an abundance of safe sleep research, science, and educational materials available to support these efforts. More critically, the team noted the need for professional recognition of the issue of unsafe sleep and a commitment to act and educate parents and caregivers about this urgent public health problem. Cognizant of arguments for co-sleeping with infants, particularly as it relates to parent-infant bonding, Team members were not convinced of the holding power of those arguments against the risk of death. Parent-infant bonding is critical to healthy human development, but not more important than the health and safety of the infant when it is time to sleep.

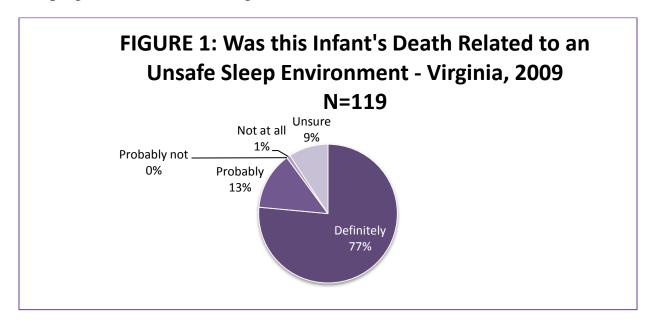
#### **SECTION I: Introduction**

This report presents conclusions and recommendations from Virginia's State Child Fatality Review Team (hereafter referred to as the Team) following its review of infant deaths in Virginia that were potentially related to sleep environments in 2009. In response to a growing national discourse on safe sleep for infants, the Team reviewed deaths due to Sudden Infant Death Syndrome (SIDS); Sudden Unexpected/Unexplained Infant Death (SUID); and deaths due to asphyxia, such as wedging or suffocation, in a sleep environment. Through multidisciplinary review, the Team sought to understand the circumstances of sleep-related infant deaths,

Sleep-related death
is the leading cause
of non-natural
infant death in
Virginia

including the characteristics of infants at increased risk for such deaths, their caregivers, and their life circumstances; and to develop interventions and prevention strategies to reduce or eliminate additional infant deaths.

Using nationally-identified risk factors as a guideline for evaluating each of the 119 deaths, the Team concluded that 90% of the deaths were *definitely* (91) or *probably* (16) related to an unsafe sleeping environment. See Figure 1.



How common is sleep-related infant death? After natural disease, sleep-related death is the leading cause of infant death in Virginia. In 2009, 119 infants died in a sleep environment, approximately one infant death every three days. This loss of life is almost 10 times the number

of infants who died as a result of Abusive Head Trauma and nearly 30 times the number of infants who died in motor vehicle collisions.

The following report was prepared for use by all Virginians—the Governor, members of the General Assembly, child advocates, policy makers, parents, and citizens—with the firm conviction that the burden of these injuries and deaths can be reduced.

#### **Definition of Key Terms**

*Infant* is described as a child up to and including 364 days of age.

*Caregiver* is defined as the adult who was responsible for the care and supervision of the infant. In this report, caregivers included parents, step-parents, grandparents, paramours, babysitters, and others.

*Sleep environment* refers to the context for infant sleeping. It includes both the immediate sleep location, such as a crib, bassinet, car seat, or couch, as well as the conditions of the home and the capacity of caregivers.

Sleep-related death refers to infant deaths that occurred when the infant was supposed to be sleeping and where one or more sleep-related risk factors were identified. Using a nationally-identified set of risk factors<sup>2</sup> for sleep-related infant deaths, the Team concluded that an infant death was sleep-related when it identified one or more of these risk factors present in the case. In addition, no conclusive anatomic or pathologic cause of death was found after a complete death investigation, including autopsy.

Co-sleeping/bed-sharing refers to the sharing of a sleep surface between the infant and at least one adult or child.

# Cases Reviewed by State Child Fatality Review Team

The Team reviewed deaths in which an infant died or was found unresponsive when he or she was supposed to be sleeping. The Virginia Office of the Chief Medical Examiner took jurisdiction over the cases because (1) the death occurred in Virginia and the death was considered unexpected and sudden when the infant was in apparently good health, or (2) the death was suspected to be a SIDS death.

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<sup>&</sup>lt;sup>2</sup> See Section III on page 20 for a listing and discussion of these risk factors.

There were five criteria for inclusion in this review:

- 1. The children were infants at the time of their deaths.
- 2. The date of death fell between January 1, 2009 and December 31, 2009.
- 3. The infants died or became unresponsive when they were expected to be sleeping. This included naps and overnight sleep times.
- 4. The death was unexpected and not due to violence, trauma, or a known pre-existing illness or medical condition.

71% of infants were exposed to secondhand smoke

5. The cause of death diagnosis was SIDS, SUID, undetermined, or asphyxia. When the cause of death was undetermined, the fatal event occurred when the child was expected to be sleeping and no anatomical or pathological cause of death was found after autopsy. When the cause of death was asphyxia, the fatal event occurred as a result of injury in the sleep environment, such as suffocation or wedging between the sleep surface and another object.

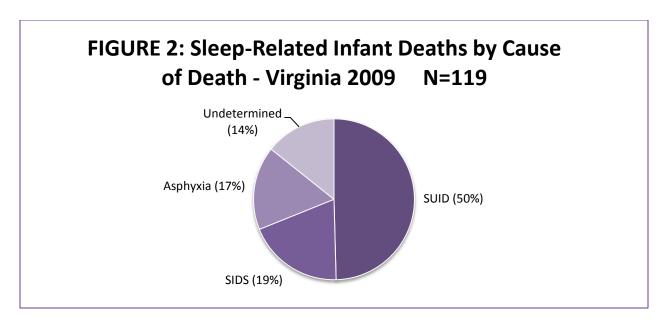
Causes of infant death that were excluded from the Team's review included the following kinds of fatal injuries:

- asphyxia deaths resulting from smothering or choking, but not while sleeping, and
- undetermined deaths where a complete death investigation did not conclude that the infant's death was potentially related to sleep or the sleep environment.

Half of the mothers smoked while pregnant with the infant who died

One-hundred nineteen infants met these criteria and the Team thoroughly reviewed all 119 cases. Fifty-nine infants (50%) were diagnosed as having died due to SUID, which makes SUID the most common cause of death in this review. The next most common cause of death was SIDS, which was determined to have caused the death of 23 infants (19%). Another 20 infants (17%) died due to asphyxia. The most common asphyxia deaths included wedging between the sleep surface and another object, such as a wall or headboard (6), entrapment or suffocation in soft bedding (5), mechanical or positional asphyxia

(4), and overlay by a co-sleeper (4). Seventeen infants (14%) were given an undetermined cause of death. These cases often included similar risk factors as those seen in SUID and asphyxia deaths. See Figure 2.



#### **Timing of This Review**

Are these 2009 deaths still representative of sleep-related infant deaths in 2014? Are the findings from this review still significant in Virginia five years later? Fatality review is an intense and lengthy process, involving record collection and collation, multidisciplinary team review, and the development of findings, key themes, and then recommendations for social change. In Virginia, child death review is a retrospective process, allowable by law only after all investigation and prosecution of the death is completed.

The Team finalized the subject of this review in late 2009, choosing deaths from that year in an effort to be as current as possible. Team members met and discussed each of the 119 cases, a process that lasted from 2010 to 2013 and involved 6 meetings and 30 hours of face-to-face meeting time per year. They next devoted considerable time to developing reasonable recommendations for prevention and intervention, ones that faithfully matched their findings and themes and conformed to current practice guidelines.

This concentrated study and deliberation is the hallmark of the fatality review process, while its challenge is timely review and reporting. It is only through the meticulous analysis of the circumstances of each case by a multidisciplinary team that nuances are revealed and identified as common themes. The Team noted that while the deaths included in this review occurred four to five years ago, the populations at risk for these deaths and the Team's findings and risk factors have not changed. Most importantly, the Team's recommendations are still relevant and important to making improvements in the health and public safety of infants. As this report is completed, there is ample support for this conclusion in the work of our colleagues from other

states and in the daily logs of deaths from the Office of the Chief Medical Examiner. Death in risky sleep environments remains the number one injury-related threat to infants in Virginia in 2014.

#### The Changing Landscape in Sleep-Related Causes of Death

As the previous discussion suggests, there is a lack of clarity in assigning a cause of death in infant deaths related to unsafe sleep, particularly in the use of SIDS and SUID. In 2009, the year of death examined for this review by the Team, Virginia was in the midst of a diagnostic shift. The following discussion explains how and why this shift occurred.

Black infants
died at a rate
more than twice
that of White
infants

In 1969, the Second International Conference on Causes of Sudden Death in Infants defined Sudden Infant Death Syndrome (SIDS), also known at the time as crib death, as the following: "The sudden death of any infant or young child which is unexpected by history and in which a thorough post-mortem examination fails to demonstrate an adequate cause for death." Until recently, SIDS was identified as a significant cause of infant death. Characterized by forensic pathologists, medical examiners, and coroners as a natural cause of death, a SIDS diagnosis was one made after excluding other causes related to injury, abuse, violence, diseases, or medical conditions. In assuming natural death, professionals believed that there was an unknown and not yet identifiable disease or congenital anomaly that likely explained these sudden infant deaths that occurred while the infant was supposed to be sleeping. In time, then, the march of science and discovery would uncover these causes of infant mortality.

Infants in the Western region died at a rate of 219.9 per 100,000, almost twice that of the overall state rate

Improved death investigations in the late 1970s and 1980s led to a radical re-thinking of SIDS. Infant death scene investigations, including careful scrutiny of the immediate sleep situation of infants and routine use of photography to capture these contexts, combined with medicolegal death investigations by medical examiners and coroners, suggested that some SIDS deaths were likely linked to environmental factors that could be modified to keep infants safe and alive. The finding that most infants with a SIDS diagnosis had been sleeping on their stomachs, or prone, at the time of their death

<sup>&</sup>lt;sup>3</sup> Savitt, T.L.(Spring 2003) "The Social and Medical History of Crib Death." 2003 Newsletter from the Bioethics Center, University Health Systems of Eastern Carolina. http://www.ecu.edu/cs-dhs/medhum/newsletter/v6n1cribdeath.cfm.

pointed to preventable aspects in infants' immediate sleep environments. Could prone positioning hinder free and unobstructed breathing and explain SIDS? Were some of these deaths attributed to SIDS not natural deaths at all, but due to unsafe sleep environments? More importantly, were these deaths preventable?

In response to the mounting evidence about sleep environment as a factor in these deaths, the Back-to-Sleep campaign was launched in 1992, emphasizing the importance of placing children

on their sides or backs (supine) for safe sleep.<sup>4</sup> Back-to-Sleep was a joint effort of the American Academy of Pediatrics, the United States Public Health Service, the SIDS Alliance, and the Association of SIDS and Infant Mortality Programs.<sup>5</sup> Back-to-Sleep became the mantra of maternal and child health programs, parenting magazines, and health care providers. In 1994, the American Academy of Pediatrics added a recommendation to remove soft surfaces or objects from infant sleep environments. It was believed that such actions would remove threats to breathing, which might further reduce the number of SIDS deaths.

Over half of the infants were found on their stomachs

In the wake of the Back-to-Sleep educational effort and over the next two decades, research on infant mortality mushroomed, generating a wealth of information about sleep position and other risk factors related to sudden infant death. The cumulative impact of behavioral surveys; surveillance; and continued improvements in medicolegal death investigations—which now included scene re-enactments with dolls and investigation protocols that probed for information specific to infant sleep environments—was a more complex and nuanced understanding of sudden infant deaths. Documented risks included those in the infant's immediate sleep environment, such as sleep position; bed-sharing with other adults, children or pets; unsafe sleep surfaces such as water beds, car seats, chairs, and couches; and use of pillows, comforters and soft bedding. In addition to risks in the infant's immediate surroundings, other correlating variables were identified that also threatened the infant's ability to sleep and live safely: drug and alcohol use among mothers and other caregivers; infant exposure to secondhand smoke; late entry into prenatal care; and an overheated infant, by virtue of dress, coverings, or temperature settings. Some infants were found to be at higher risk than others, notably those who were

<sup>&</sup>lt;sup>4</sup> American Academy of Pediatrics Task Force on Infant Positioning and SIDS. (1992) "Positioning and SIDS." *Pediatrics* 89: 1120-1126

<sup>&</sup>lt;sup>5</sup> American Academy of Pediatrics Task Force on Infant Sleep Position and Sudden Infant Death Syndrome. (March, 2000) "Changing concepts of sudden infant death syndrome: Implications for infant sleeping environment and sleep position." *Pediatrics 105*: 650-656.

75% of families had a crib, bassinet, or portable crib available premature; had young mothers; were male; and/or were African American or Native American. At the same time, the use of pacifiers and breastfeeding were found to be protective factors for SIDS.<sup>6</sup> The notion that SIDS was the result of a natural disease, congenital anomaly, or other yet identified condition alone seemed increasingly doubtful.

One current explanatory framework that attempts to capture this newer understanding of SIDS is called the Triple-Risk Model. This model portrays SIDS at the intersection of three sets of

factors. First, SIDS occurs at a critical period in infant development in terms of autonomic and respiratory functioning, with the highest risk when infants are two to four months of age. Second, infants are uniquely vulnerable with regard to brainstem functioning and their arousal impulses, and genetic susceptibility. This vulnerability is especially so for premature and low birth weight infants. Third, external or environmental stressors, such as sleep positioning, exposure to smoke, blankets or other soft items, interfere with or block open airways. Taken

together, these three sets of factors confound and mutually reinforce each other to put some infants at a profoundly higher risk for a SIDS death.<sup>7,8</sup> See Appendix A for a graphic representation of the Triple-Risk Model.

As a result of these decades of research, surveillance, current thinking, and practice, infant safe sleep educational efforts have moved from Back-to-Sleep to a new national campaign emphasizing Safe to Sleep.<sup>9</sup>

27% of infants were sleeping in a crib, bassinet, or portable crib

<sup>&</sup>lt;sup>6</sup> American Academy of Pediatrics Task Force on Sudden Infant Death Syndrome. (November, 2011). "SIDS and other sleep-related infant deaths: Expansion of recommendations for a safe sleeping environment." *Pediatrics* 128(5): e1341-e1367.

<sup>&</sup>lt;sup>7</sup> Guntheroth, W.G. and Spiers, Philip. (November, 2002). "The triple risk hypotheses in sudden infant death syndrome." *Pediatrics* 110(5): e-64+.

<sup>&</sup>lt;sup>8</sup> American Academy of Pediatrics Task Force on Sudden Infant Death Syndrome. (November, 2011). "SIDS and other sleep-related infant deaths: Expansion of recommendations for a safe sleeping environment." *Pediatrics* 128(5): e1341-e1367.

<sup>&</sup>lt;sup>9</sup> See the following website for the Safe to Sleep Campaign factsheets and educational materials. The website also provides a detailed and substantive history of SIDS and the evolution of infant safe sleep initiatives in the United States. http://www.nichd.nih.gov/sts/Pages/default.aspx.

#### The Diagnostic Shift

These developments have also continued to impact the theory and practice of infant death investigation, contributing to a shift among medical examiners and coroners across the United States in how unexpected infant deaths are diagnosed. Recognizing the significance of environmental factors in what would have previously been labeled a natural SIDS death, a new diagnosis, Sudden Unexpected Infant Death (SUID), has become more common. Like a diagnosis of SIDS, SUID is a diagnosis of exclusion, made when there is an absence of pathological findings revealing injury, violence, disease, or other fatal medical condition. Unlike a SIDS diagnoses, a SUID diagnosis recognizes a host of confounding factors, most importantly the presence of unsafe sleep factors and/or medical problems such as pneumonia, prematurity, or congestion. <sup>10, 11</sup>

Table 1: Shifts in Cause of Death Determinations in Infant Deaths - Virginia, 2003-2012 <sup>12,13</sup>				
Year of Infant Death	Sudden Infant Death Syndrome (SIDS)	Sudden Unexpected Infant Death (SUID)	All Asphyxia Deaths to Infants	Undetermined
2003	82		11	7
2004	84		14	17
2005	90		7	6
2006	64		20	13
2007	41	41	14	12
2008	22	54	24	8
2009	23	65	25	11
2010	14	60	18	2
2011	16	58	22	6
2012	8	55	15	12

<sup>&</sup>lt;sup>10</sup> Schnitzer, PG., Covington, Theresa M., and Dykstra, Heather K. (April 19, 2012). "Sudden unexpected infant deaths: Sleep Environment and Circumstances." *American Journal of Public Health* e1-e9.

<sup>&</sup>lt;sup>11</sup> Malloy, Michael H. and MacDorman, Marian. (May, 2005). "Changes in the classification of sudden unexpected infant deaths: United States, 1992-2001." *Pediatrics 115(5):* 1247-1253.

<sup>&</sup>lt;sup>12</sup> Source: Virginia Department of Health, Office of the Chief Medical Examiner, Virginia Medical Examiner Data System (VMEDS).

<sup>&</sup>lt;sup>13</sup> Figures represent number of cases.

Signs of this diagnostic shift began to appear in Virginia in 2007. As Table 1 demonstrates, SIDS was the most common diagnosis in Virginia until 2007, the first year that SUID began to appear on Virginia death certificates. Between 2007 and 2012, improved death scene investigation with re-enactments contributed to a shift away from SIDS and Undetermined causes of death to those of SUID and Asphyxia. These deaths are overwhelmingly but not exclusively related to unsafe infant sleep environments.

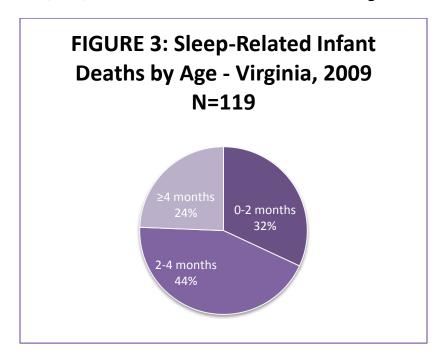
The State Child Fatality Review Team conducted its review of infant deaths potentially related to unsafe sleep in 2009, as this diagnostic shift was underway. The remainder of this report documents their findings and recommendations in this area.

#### **SECTION II: Infants and Their Families**

#### Characteristics of Infants at Risk of Sleep-Related Death

Consistent with national studies on the subject, Black, male infants who are two to four months of age are at highest risk for a sleep-related death in Virginia.<sup>14</sup>

The infants in this review ranged in age from 3 to 308 days old. Fifty-two (44%) of the 119 infants were between two to four months of age. Thirty-eight (32%) infants were younger than two months old, and 29 (24%) were older than four months. See Figure 3.

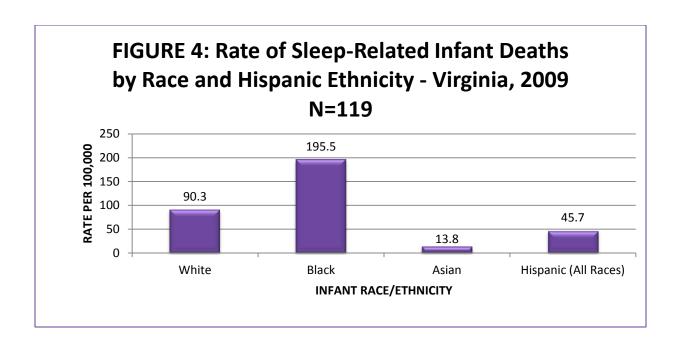


In terms of race, the majority of infants in this review were White (55%), however, Black infants died at a significantly higher rate than White or Asian infants. Black infants died at a rate of 195.5 per 100,000, which is more than twice the rate of White infants (90.3) and fourteen times the rate for Asian infants (13.8).

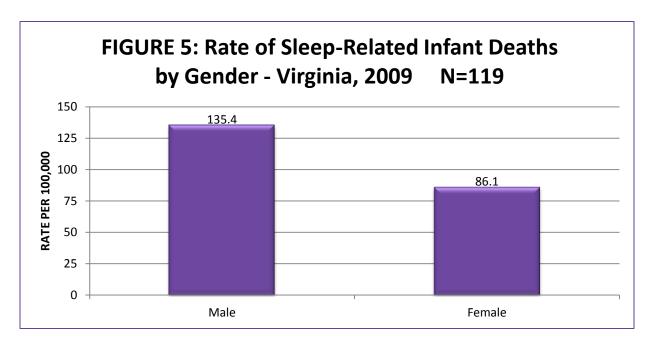
With regard to ethnicity, Hispanic infants comprised 6% of the infants in the review and reflected a rate of 45.7. See Figure 4.

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<sup>&</sup>lt;sup>14</sup> Trachtenberg, F.L., et.al. (2012). "Risk factor changes for sudden infant death syndrome after initiation of Back-to-Sleep campaign. *Pediatrics 129 (4):* 630-638.



A total of 74 (62%) male and 45 (38%) female infants died in a sleep environment. Males died at a rate of 135.4, about 1.5 times that of females (86.1). See Figure 5.



One hundred fourteen (96%) of the infants were pronounced dead on scene, en route to the hospital, or shortly after arriving to the Emergency Department. Five infants (4%) were admitted from the Emergency Department before ultimately dying in the hospital.

Over half of the infants were co-sleeping

The Team observed that many of the infants had mild to severe medical issues around the time of their death. Forty-three (36%) of the infants in this review were receiving over-the-counter or prescription medications, such as acetaminophen (18%) or medication for acid reflux (9%). Families of 36 (30%) infants reported that the infant had recently been suffering a cough and/or congestion prior to death, and nine infants (8%) were prescribed breathing treatments. Other medical issues noted by the Team include a diagnosis of or

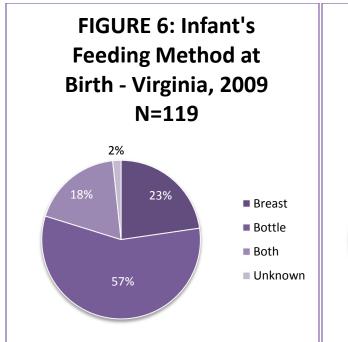
treatment for acid reflux in 19 infants (16%), the presence of umbilical hernias in nine infants (8%), a diagnosis of apnea in eight infants (7%), and diagnosed pneumonia in three infants (3%). Six infants (5%) were noted to have had a decreased appetite and another six (5%) were noted to have had a fever in the 48 hours preceding death.

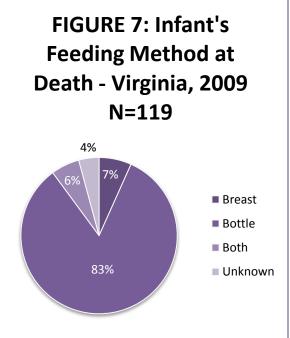
Eighteen (15%) of the infants in this review were screened for in utero substance exposure at birth. Eight tested positive for the presence of one or more controlled substances. While multiple substances were seen throughout the course of review, the most commonly detected substance was opiates, detected in five of the eight infants who had a positive drug screen.

Considered a protective measure against sleep-related death, particularly when practiced exclusively, the Team also examined the number of infants who were breastfed at some point during their lives. Twenty-seven (23%) of the infants in this review were breastfed at birth. Sixty-eight (57%) were bottle-fed, and 22 (18%) were both breast and bottle-fed. Feeding method at birth was unknown for two infants. At the time of their deaths, eight (7%) infants were still breastfed. Ninety-nine (83%) infants were bottle-fed and seven (6%) were breast and bottle-fed. Feeding method at death was unknown for five infants. See Figures 6 and 7.

Almost a quarter
of the infants who
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co-sleeper who
had used alcohol
or drugs

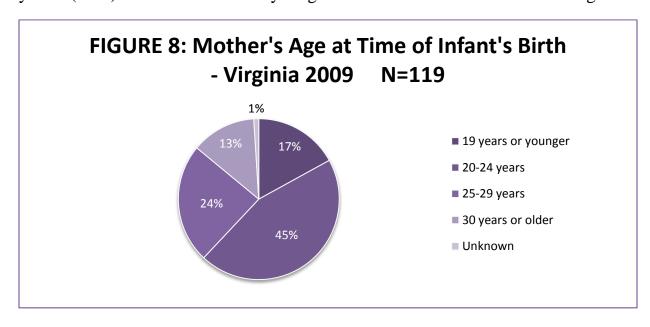
<sup>&</sup>lt;sup>15</sup> Hauck, F.R., et. al. (January, 2011). "Breastfeeding and sudden infant death syndrome: A meta-analysis." *Pediatrics 128(1). Available at http://pediatrics.aappublications.org/content/early/2011/06/08/peds.2010-3000.full.pdf+html.* 



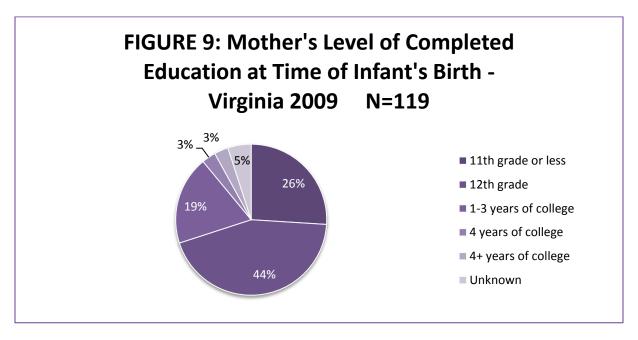


#### Characteristics of Mothers of Infants at Risk of Sleep-Related Death

Information about the age of the infants' mothers was available in all 119 cases. While mothers ranged in age from 15 years to 42 years old at the time of the infant's birth, they were generally young, with a mean age of 24 and a median age of 23 years at the time of the infant's birth. Seventy-four (62%) mothers were 24 or younger when the infant was born. See Figure 8.



Forty-four percent of the mothers in this review had completed high school, with no further education. More than a quarter of the mothers in this review had completed 11<sup>th</sup> grade or less. Nineteen percent had completed one to three years of college, 3% had completed four, and 3% had completed more than four years. Mother's education at the time of the infant's birth was unknown in 6 cases (5%). See Figure 9.



The Team discovered that the majority of the mothers in this review were not first-time mothers. Indeed, the infants in this review ranged from being the mother's first live birth to being the mother's eighth live birth. For 30% of mothers, the infant whose death was reviewed was the mother's first live birth. For more than a quarter (28%), this was the mother's second live birth and for another 28%, this was the mother's third. This finding indicates safe sleep information should be targeted to not only first time mothers, but every time a mother has a new baby.

Over half of the mothers in this review were unemployed (54%). Seven (6%) were students.

# **Characteristics of Caregivers at the Time of Death**

In 106 cases (89%), the child's mother was identified as a caregiver at the time the infant died. In 64 (54%) cases, the father was identified as a caregiver. A grandparent was a caregiver at the time of infant's death in 16 cases (13%). A paramour of one of the child's parents was identified as a caregiver in 8 cases (7%), and a babysitter or licensed childcare provider was the caregiver in 5 cases (4%).

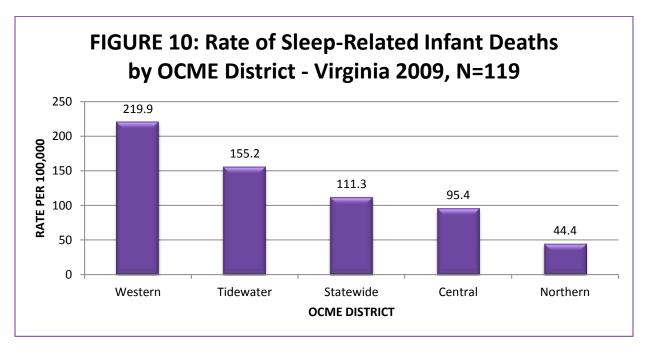
Caregivers' ages ranged from 15 years old to 62 years old, with a mean age of 27 years old.

The Team noted that in 29 cases (24%), at least one caregiver was impaired by the use of alcohol or illicit or prescription drugs. In many of these cases, those responsible for the care of the infant were unable to react and respond to the infant's needs, such as feeding, comforting, or changing a diaper.

#### **Region of Death**

The OCME has jurisdiction over the death of "any infant less than eighteen months of age whose death is suspected to be attributable to Sudden Infant Death Syndrome (SIDS)" and as such, all 119 fatalities in this review were autopsied and investigated by the OCME. The OCME is divided into four districts across the Commonwealth: Central, Northern, Tidewater, and Western.<sup>16</sup>

Infants in the Western OCME district were most at risk. Forty infants died in a sleep environment in Western, reflecting a rate of 219.9, which is 1.4 times that of the Tidewater region (155.2) where 36 infants died. The Western and Tidewater districts had rates well above the state rate of 111.3. Twenty-six infants died in sleep environment in the Central region, reflecting a rate of 95.4. The Western rate is almost five times that of the Northern district where 17 infants died, a rate of 44.4. See Figure 10.



<sup>&</sup>lt;sup>16</sup> See Appendix E, pages 44-47, for a table of Virginia localities by Medical Examiner District and Health Planning Region. See Appendix F on page 48 for maps depicting these boundaries.

Virginia also divides localities into five Health Planning Regions: Southwest, Eastern, Northwest, Central, and Northern. Infants died in a sleep environment most frequently in the Southwest planning district (34), which reflects a rate of 227.6. In the Eastern planning region, 38 infants died, a rate of 148.8. Twenty-three infants died in a sleep environment in the Northwest planning district, a rate of 145.2. In the Central planning region, 14 infants died in a sleep environment, a rate of 80.4. Infants died while they were supposed to be sleeping least often in the Northern planning district, where 10 infants died, a rate of 30.1.

State Child Fatality Review Team members were astounded and troubled by these rates, describing sleep-related infant deaths as a public health crisis and epidemic in the Western and Tidewater communities of the state.

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<sup>&</sup>lt;sup>17</sup> See Appendix E, pages 44-47, for a table of Virginia localities by Medical Examiner District and Health Planning Region. See Appendix F on page 48 for maps depicting these boundaries.

# **SECTION III: Risk Factors for Sleep-Related Infant Death**

As previously discussed, the American Academy of Pediatrics began the Back to Sleep campaign in 1994, which resulted in a reduction in sleep-related infant deaths as more infants were placed for sleep on their backs. As these death rates leveled off, however, focus shifted from sleep position to the larger sleeping environment, including soft sleep surfaces and loose bedding, exposure to second-hand smoke, and co-sleeping; and maternal health factors including smoking and substance use during pregnancy. Identification of these additional risk factors led to the transformation of safe sleep messages in the United States from Back to Sleep to the Safe to Sleep campaign.

The Team assessed the presence of the following nationally-recognized risk factors in the cases it reviewed. The presence of these factors increases an infant's risk of death from SIDS, SUID, or sleep-related asphyxia:

- Male sex
- Black race
- Native American ethnicity
- Prematurity
- Low birth weight
- Young maternal age
- Late entry into or no prenatal care
- Maternal smoking during pregnancy
- Maternal substance use during pregnancy
- Exposure to environmental tobacco smoke
- Prone or side sleep
- Soft sleep surface
- Co-sleeping with an adult or other child
- Overheating<sup>18</sup>

Table 2 below highlights the findings from this review for the majority of these risk factors.<sup>19</sup> Although overheating is considered an established risk factor, the Team was unable to fully

<sup>&</sup>lt;sup>18</sup> Hauck, F.R. (January, 2010). "SIDS and sleep-related infant deaths: Current statistics, accomplishments, controversies, and challenges." Training presentation to the Virginia State Child Fatality Review Team. Richmond, Virginia.

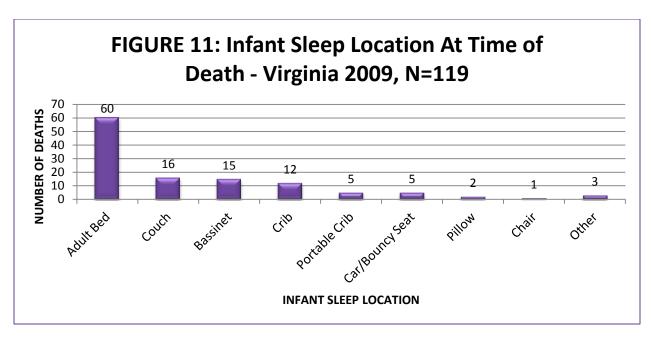
<sup>&</sup>lt;sup>19</sup> That Blacks and males are at higher risk for an unsafe sleep-related death has been discussed earlier in this report. There were no infants identified as Native American who died in a sleep environment in Virginia in 2009.

evaluate the impact of overheating in this review. Overheating varies from infant to infant and is related to room temperature, clothing on the infant, use of blankets or comforters, or a combination of these factors. Temperature data was collected by an investigator in 59 cases (50%). The mean and median temperature was 72 degrees F, with a range of 65-80 degrees F. The Team noted the need for improved infant death investigation techniques to better understand the role of overheating in sleep-related infant deaths.

Table 2 clarifies the significance of the Triple Risk Model in sleep-related infant deaths in Virginia. The five most common risk factors in this review were sleep surface, sleep position, co-sleeping, and exposure to smoke either in utero or in the sleep environment.

Table 2: Risk Factors Among Sleep-Related Infant Deaths – Virginia, 2009 N=119		
Risk Factor	Percentage	
1. Soft sleep surface	73%	
2. Exposure to environmental tobacco smoke	71%	
3. Co-sleeping or bed-sharing	57%	
4. Sleeping on stomach (prone)	51%	
5. Maternal smoking during pregnancy	50%	
6. Infant born prematurely (<37 weeks gestation)	28%	
7. Low birth weight (<2494.8 grams or roughly 5.5 pounds)	24%	
8. Maternal substance use during pregnancy	20%	
9. Young maternal age (<19 years old)	17%	
10.Sleeping on side	8%	
11.Late prenatal care (3 <sup>rd</sup> trimester)	9%	
12.No prenatal care	3%	

Safe sleep guidance recommends that infants sleep in a crib, bassinet, or portable crib and not on soft sleep surfaces or those not designed for safe infant sleep. Thirty-two (27%) infants were using a crib, bassinet, or portable crib at the time of their deaths. One of these was available in in 89 (75%) cases. Eighty-seven (73%) infants were sleeping on a surface not intended for infant sleep. Sixty infants (50%) were sleeping on an adult bed. Sixteen infants (13%) were sleeping on a couch. Other sleep locations included a car or bouncy seat (5), a pillow (2), and a chair. In those cases where the infant was sleeping in a crib, bassinet, or portable crib, the infant was found on his or her stomach or side in 24 cases (75%), confirming for the Team that a safe sleep environment is comprised of much more than a safe sleep location. See Figure 11.



#### **Additional Threats to Safe Sleep**

Throughout the course of review, Team members identified other problems and issues that were present in many of these cases. These were characteristics of the sleep and/or home environment that the Team considered as significant when evaluating the infant's health and safety. Table 3 lists these team-identified potential threats and the prevalence of these characteristics in the cases reviewed.

Table 3: Team-Identified Threats to Infant Safety Among Slo Infant Deaths – Virginia, 2009 N=119	eep-Related
Threat Identified by Team	Percentage
Parent or caregiver with criminal history	44%
Home that is extremely dirty, cluttered, or unkempt	40%
Infant's face fully or partially obstructed by object in sleep	36%
environment (bedding, body parts, etc.)	
Parent or caregiver with assault and battery history	29%
Impaired co-sleeper at time of death (% of all cases with co-	26%
sleeping)	
Parent or caregiver with history of drug charges	24%
Infant was in new or different environment	22%
Parent or caregiver with domestic violence history	18%
Family was homeless or transient at time of infant's death	10%

Team members were also concerned with possible overprescribing of narcotics and psychotropic medications to new mothers, which diminished their ability to adequately care for and supervise their infants. For example, the Team reviewed the labor and delivery records of the 89 mothers whose discharge records included discharge medication information. Fifty-five of these mothers (62%) were prescribed a Schedule II or III narcotic at discharge.

One in five mothers used alcohol or drugs while pregnant with the infant

- Twenty-six percent of women who delivered their babies vaginally were prescribed a Schedule II or III narcotic. Seventy-six percent of women who delivered via cesarean section received a Schedule II or III narcotic prescription.
- Schedule II or III narcotics prescribed to new mothers included oxycodone/acetaminophen (Percocet), hydrocodone/acetaminophen (Lortab, Vicodin), hydromorphone (Dilaudid), oxycodone, and combinations thereof.
- Schedule II or III narcotics were prescribed to mothers believed to be abusing illicit or prescription drugs while pregnant in seven cases.
- Schedule II or III narcotics were prescribed to mothers who delivered substance-exposed newborns in four cases.
- Five mothers were prescribed antidepressant medication and three anxiety medication.
- Three mothers were prescribed the sleep medication Ambien.

Team members noted the importance of educating obstetricians, gynecologists, and hospital staff on the consequences of these prescriptions for infant health and safety, especially the particularly vulnerable infants seen in this review. A mother or caregiver using these powerful medications to manage physical pain and mental health conditions may be unable to adequately care for an infant. In this review, the Team noted that mothers using these medications risked inadvertent neglect of their infants because of their inability to remain alert and awake.

Overcrowding and lack of supervision in the home were also concerns of the Team. Over half (56%) of the homes in this review had five or more people, including the infant, living or sleeping in the home at the time of the infant's death. The range of people living or sleeping in a single home at the time of the infant's death was 2-12. The time between when the infant was last seen and the time found ranged from 0 minutes (when the infant was in sight of the caregiver) to 14 hours. Four infants had gone nine or more hours without being checked on by a caregiver when they were found.

# The Cumulative Impact of Risk

While any one of the risk factors discussed previously could threaten the health and safety of an infant, Team members observed the presence of many such factors in each of the cases reviewed. Most infants were exposed to multiple risk factors and additional potential threats

36% of infants
were found with
their faces fully
or partially
obstructed by an
object

noted by the Team. In seeking to capture the cumulative and mutually-reinforcing impact of these characteristics, the average number of risk factors per case and the average number of potential threats per case were calculated. The Team observed an average of 4.45 established risk factors present per case and an average of 3.45 team-identified potential threats present per case. It was not uncommon, for example, to read a case where a premature one-month old infant whose mother smoked while pregnant died while napping on her stomach on a couch. Or a two-month old male who

died while bed-sharing with his young parents who smoked and used prescription drugs that they obtained illegally. In case after case, the Team observed a "perfect storm" of risk factors such as these, factors which supported the principles of the Triple-Risk Model at work in Virginia's sleep-related infant deaths.

As the Team reviewed these cases and pondered the immense loss of life attached to sleep-related infant death in Virginia, members agreed that Back to Sleep was just one of many habits and behaviors that parents and caregivers must adopt to keep their infants safe while sleeping. In addition, safe sleep involved both the immediate sleep area for the infant, but also the overall environment of the home and the capacity of parents and caregivers to take care of a vulnerable infant.

# SECTION IV: Other Significant Findings

# **SECTION IV: Other Significant Findings**

#### **Economic Status of Infants and Their Families**

The Team also considered the economic status of the infants and their families in this review. Sixty-six percent of mothers in this review were Medicaid recipients. One-quarter of the families in this review were receiving benefits from the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). Another 25 families (21%) were receiving benefits from the Supplemental Nutrition Assistance Program (SNAP). Eleven families (9%) in this review were receiving Temporary Assistance for Needy Families (TANF) benefits.

Many
families lived
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the poverty
level

These figures provide a rough indicator of socioeconomic status, suggesting that many families who lost an infant in a sleep environment lived at or below the poverty level.

#### **System Contacts and Referrals**

When reviewing child deaths, the State Child Fatality Review Team identifies all of the systems that had contact with the children or their families. A system contact includes courts, social service agencies, health care providers, pharmacists, juvenile detention centers, schools, hospitals, child care providers, and families. Knowing which systems had contact with a child and his or her family is relevant to the fatality review process because they shape the recommendations for intervention and prevention. In this review, because all of those who died were infants less than one year of age, contact with child-serving systems was limited.

**Pediatricians.** The most significant point of contact for the infants seen in this review was the health care system, particularly a pediatrician. The Team noted that of the 108 infants for whom pediatric records could be obtained, 106 infants (98%) had been seen by a pediatrician at least one time. Seventy-eight infants (72%) had been seen by a pediatrician at least one time in the 30 days preceding their death. As most infants have little contact with most child-serving systems given their young age, the Team noted pediatricians and family physicians as critical points for infant safe sleep education and instruction with their patients' families. Indeed, the American Academy of Pediatrics (AAP) has played a key role in the development and dissemination of safe sleep guidelines in the United States for more than two decades. See Appendix B for the list of current safe sleep guidelines for infants from the AAP.

# SECTION IV: Other Significant Findings

**Hospitals.** The Team was able to review labor and delivery and/or birth records in 116 cases and of those, 47 (41%) indicated that safe sleep was discussed or information was given as part of routine discharge procedures. A health care provider discussed safe sleep with the mother of the infant in 10 (21%) of those cases; a pamphlet or informational handout was given in 6 (13%); and the families received information and discussed safe sleep with a provider in 2 cases (4%). In the other 29 (62%) records, it was unclear whether the family actually discussed safe sleep with a provider or if the information was included as part of basic discharge materials.

Almost one
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at least one
caregiver who
had used alcohol
or drugs

In 35 cases (29%), the hospital noted warning signs or concerns about the family, such as substance abuse, domestic violence, mental health, or supervisory issues. Thirty-two families (27%) were referred to hospital social services and 13 (11%) were referred to CPS.

Eight families (7%) were referred for home visiting services and four complied.

The Team had child birth records in 116 of 119 cases. Of those, 31 (27%) infants had been admitted to the Neonatal Intensive Care Unit (NICU) after birth. The length of NICU stay ranged from 44-1843 hours (1.8-76.8 days).

One in five mothers showed evidence of substance use or abuse while pregnant with the decedent. Eighteen infants (15%) were screened for substance exposure at birth. Of those 18 infants, eight returned positive results. A referral to Child Protective Services (CPS) was made for six of these substance-exposed newborns and a referral was made to a local community services board for the family of one substance-exposed infant.

Child Protective Services. Fifteen infants (13%) were known to CPS prior to their deaths. The infant's caregiver was known to CPS in some capacity in a quarter of cases (30). Eighteen families (15%) in this review had received a prior Family Assessment and eight (7%) had been the subject of a CPS investigation prior to the death of the infant in this review. Twelve families (10%) were the subjects of a current Family Assessment and two (2%) were involved in an active investigation for suspicion of child abuse or neglect at the time of the infant's death. Nine parents or caregivers had had a child removed from their custody by CPS prior to the infant's death. While these data indicate that most families in this review were not involved with CPS prior to the infant's death, it does suggest the existence of opportunities for CPS workers who are in the home to reinforce safe sleep messages to at-risk families.

# SECTION V: Sleep-Related Infant Death Investigation

# **SECTION V: Sleep-Related Infant Death Investigation**

Pursuant to §32.1-283.1, the State Child Fatality Review Team is charged with the responsibility to review and develop recommendations for improving child death investigations as part of their review.

When an infant dies suddenly and unexpectedly, investigators may complete the Centers for Disease Control and Prevention's (CDC) Sudden Unexpected Infant Death Investigation (SUIDI) form or the Virginia Department of Health's Childhood Death Investigation Form (CDIF) in an effort to fully investigate the infant's death and gather additional information

More than a quarter of the infants were born prematurely

unique to infant and child death investigations. These forms collect extensive data on the health of the infant, his or her living environment, prenatal care of the biological mother, and the sleep environment in an effort to gain more insight into sudden unexpected infant deaths.

This form was completed in 66 (55%) cases and was filled out but incomplete in another 26 (22%) cases. The form was not completed in 27 (23%) cases.

Another component of sudden unexpected infant death investigation is the death scene reenactment, during which an investigator has the parent(s) or caregiver(s) place a doll in the positions in which the infant was placed for sleep and then found, in the same location and environment in which the infant was sleeping at the time of his or her death. This is considered to be a vital component of sudden unexpected infant death investigation, though it was not yet universally practiced in Virginia in 2009. A death scene re-enactment was performed in 46 (39%) of these cases.

#### Law Enforcement

Team members noted the difference in investigatory practices when infants died in their sleep as opposed to other child deaths. Infant sleep-related deaths were often labeled as SIDS deaths before the investigation had started, which Team members believed may have compromised the depth and breadth of many of these investigations. Eight cases were described as "suspected SIDS" cases at the beginning of the investigation. In 53 (45%) cases, the final cause of death was not mentioned in the law enforcement report. Law enforcement closed a case because the

# SECTION V: Sleep-Related Infant Death Investigation

cause of death was reported or believed to be SIDS in 27 cases, though the number of actual SIDS deaths in 2009 was 23.

Team members believed that many cases were inadequately investigated, citing three cases where the SUIDI or CDIF form was the only record of law enforcement investigation.

Studies have shown that many sudden infant deaths have a definitive cause that can be revealed only after a thorough death scene investigation.<sup>20</sup> The Team noted the need for all infant deaths to be fully investigated, with complete scene investigations, evidence collection, separate interviews with all witnesses and parents or caretakers, and coordination with other agencies in the death investigation.

#### **Child Protective Services**

Of the 119 infant sleep-related deaths in 2009, 50 (42%) were known to have been reported to CPS. Intake screened out 11 of those reports, as the referrals did not meet the definition of abuse or neglect. One case was put into the Family Assessment track. CPS opened an investigation for suspicions of child abuse or neglect in 38 cases.

The majority of CPS investigations in this review resulted in an unfounded disposition (76%). Nine investigations were founded for abuse or neglect (24%). Of those that were founded, seven were founded for physical neglect, one was founded for physical abuse and one was founded for both physical neglect and physical abuse. One or more caregiver(s) was impaired by drugs or alcohol in five founded cases (56%).

In six cases, the infants' deaths were reported as SIDS in a CPS report without a CPS investigation of the infant's death having been performed.

- Three referrals were screened out because they were believed to be SIDS deaths and as such, did not meet the definition of abuse or neglect. All three were diagnosed as SUID.
- In two cases, CPS responded but did not open an investigation because the death appeared to be likely due to SIDS. One of those infant deaths was diagnosed as SIDS and the other was diagnosed as SUID.

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*Nearly three-*

quarters of the

infants were

sleeping on a

surface not

intended for

infant sleep

<sup>&</sup>lt;sup>20</sup> Malloy, M.H. and MacDorman, M. (2005). "Changes in classification of sudden unexpected infant deaths: United States, 1992-2001. *Pediatrics 115*: 1247-1253.

# SECTION V: Sleep-Related Infant Death Investigation

Team members noted that investigators in law enforcement and CPS were not trained about or fully aware of the significant difference between a SIDS diagnosis and one of SUID, often attributing every infant death in a sleep environment to SIDS.

- Law enforcement reported the cause of death to be SIDS in 22 investigations. Eight of those were SIDS, thirteen were given a SUID diagnosis and one was undetermined.
- CPS reported the cause of death to be SIDS in 20 reports. Seven of those were certified as SIDS by a forensic pathologist. Ten were diagnosed as SUID. Two of those infants died from asphyxia and the cause of death was undetermined in one infant death.

More than 40% of the infants had a parent or caregiver with a criminal history Death investigation has not caught up to the diagnostic shift in sleep-related infant deaths. Team members believed that inappropriately categorizing SUID, asphyxia, and undetermined deaths as SIDS deaths may have inhibited a thorough investigation of multiple deaths in this review, citing multiple cases where investigations were closed because the investigator believed SIDS and SUID to be synonymous in meaning. The Team determined that a thorough understanding of the differences in unexpected infant death diagnoses, particularly between SIDS and SUID, is vital to a comprehensive infant death investigation.

#### **Prosecution**

In five cases, the caretaker(s) responsible for the infant were charged in the infant's death.

- In two cases, the charges, felony child neglect in both instances, were dismissed.
- In two cases, the caretakers pleaded guilty to charges of felony child neglect.
  - o One caretaker received a sentence of five years, with all five years suspended
  - One caretaker received a sentence of 10 years, with 9 years and 7 months suspended
- In one case, the caretaker pleaded guilty to charges of voluntary manslaughter and child abuse. The caretaker was sentenced to 10 years for the voluntary manslaughter conviction and five years for the child abuse conviction, ordered to be served consecutively, resulting in a prison sentence of 15 years.

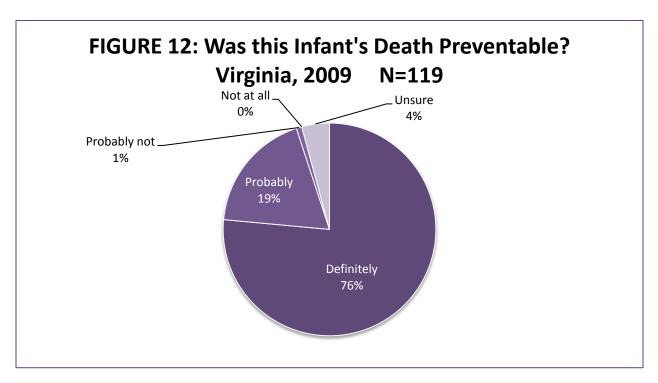
# SECTION V: Sleep-Related Infant Death Investigation

The Team noted discrepancies in jurisdictions' willingness to file charges against a caretaker in a sudden unexpected infant death and called for more consistent standards and guidelines in prosecuting sudden unexpected infant death cases, particularly when substance abuse has undermined a caretaker's ability to adequately care for an infant. In four of the five cases described above, CPS investigations resulted in a finding that the infant was abused and/or neglected.

## SECTION VI: Preventability of Sleep-Related Infant Deaths

### **SECTION VI: Preventability of Sleep-Related Infant Deaths**

At the end of their review of each infant death, team members discussed the following question: was this a preventable death? Using their own professional expertise and a consensus decision-making process, they worked to identify which, if any, of the national risk factors for a sleep-related death were relevant in the case and, more importantly, which specific modifications in the infant's life, family, and environment would have kept the infant safe and alive. If the Team can identify these changes, the death is a preventable death. If they cannot, Team members conclude that the death was probably not or not at all preventable. Team members are typically unsure about preventability when critical information about the injury and death is missing or not available.



After retrospective review, the Team determined that 95% of the deaths in this review were definitely (91) or probably (22) preventable. The Team determined that one death was probably not preventable and were unsure of the preventability of five deaths reviewed. The Team did not determine any deaths to be not at all preventable. See Figure 13.

### **SECTION VII: Team Recommendations**

The State Child Fatality Review Team completed its review of 119 deaths, examined data trends and major themes from the review, and set about the challenging task of developing ideas for prevention and intervention. Team members approached the task with the following two assumptions or guidelines in mind.

First, Virginia will not need to reinvent the wheel with regard to infant safe sleep training or educational materials. Like motor vehicle safety innovations for infants – rear-facing car seats – the remedies are well known, inexpensive, and easy to implement. There is an abundance of safe sleep research, science, and educational materials available through websites of the American Academy of Pediatrics and the Safe to Sleep Campaign to support these efforts. Second and more critical to the success of reducing this most significant loss of life is the need for a professional recognition of the problem of unsafe sleep and a commitment to act and educate parents and caregivers about this urgent public health problem. The Team was cognizant of arguments for co-sleeping, particularly as it relates to parent-infant bonding. But in the light of their review and not unexpectedly, they were not convinced of the holding power of those arguments. Parent-infant bonding is critical, but not more important than the health and safety of the infant when it is time to sleep.

The Team developed the following nineteen recommendations with these two assumptions in mind and with the profound conviction that these premature and tragic infant deaths can be prevented.

### Legislation

1. Amend and reenact § 32.1-134.01 of the Code of Virginia relating to information required for maternity patients (suggested changes are in italics and underlined):

Every licensed nurse midwife, licensed midwife, or hospital providing maternity care shall, prior to releasing each maternity patient, make available to such patient and, if present, to the father of the infant, other relevant family members, or caretakers, information about the incidence of postpartum blues and perinatal depression, <u>and</u> information to increase awareness of shaken baby syndrome and the dangers of shaking infants, <u>and information about safe sleep environments for infants that is consistent with current information available from the American Academy of Pediatrics.</u>

This information shall be discussed with the maternity patient and the father of the infant, other relevant family members, or caretakers who are present at discharge.

#### **Public Education and Awareness**

- 2. The Virginia Department of Health's Office of Family Health Services should expand education provided through its Tobacco Program to include information about smoke as a risk factor for Sudden Unexpected Infant Death (SUID).
- 3. The Virginia Department of Health and the Virginia Department of Social Services should require that local WIC offices and departments of social services include infant safe sleep education as part of the education accompanying WIC and SNAP benefits.

### **Professional Capacity: Substance Abuse**

- 4. The Virginia Department of Behavioral Health and Developmental Services should convene a workgroup to review Virginia law, policy, and practice with regard to infants and children who are exposed to and/or endangered by the drug use of their caregiver; and to develop a set of policies and procedures for ensuring that Virginia has a response to this problem. Other states have adopted Drug Endangered Children programs, which may serve as a model for the Commonwealth. The workgroup should be multiagency and multidisciplinary, including representatives from the Virginia Department of Social Services' Child Protective Services Program, the Virginia Department of Health's Office of Licensure and Certification, the Virginia Department of Health Professions, the Virginia Hospital and Healthcare Association, the Virginia Department of Criminal Justice Services, child advocacy, local law enforcement, community services boards, local departments of social services, and health care providers.
- 5. The Medical Society of Virginia, the Virginia Section of the American College of Obstetricians and Gynecologists, the Virginia Chapter of the American Academy of Pediatrics, and the Virginia Academy of Family Physicians should educate their members on the potential risks of prescription medications to infant safety. Physicians should be urged to limit prescriptions for pain medication and other narcotics to the minimal amount required, with a policy of no refills unless seen by the prescribing physician.
- 6. The Virginia Pharmacists Association should urge its members to provide information to patients about the risks of using pain medication and other narcotics when caring for an

- infant. This information should be given to all mothers in the form of warnings on pill bottles and should emphasize the importance of safe sleep principles for infants.
- 7. The Virginia Board of Medicine should require that health care providers providing Schedule II-IV prescription drugs to their patients register for and use Virginia's Prescription Monitoring Program as a condition of licensure. Physicians should be encouraged to use information from the Program to guide prescription decisions with pregnant and postpartum women.

#### **Professional Capacity: Safe Sleep**

- 8. The Association of Women's Health, Obstetric and Neonatal Nurses, the Virginia Council of Nurse Practitioners, and the National Association of Pediatric Nurse Practitioners should encourage nurses to provide education and model safe sleep behaviors to the women and families for which they care. Reinforcement of safe sleep messages are particularly needed when a nurse discharges infants who were born prematurely or had a low birth weight. Safety messages should emphasize the importance of not sharing a bed with an infant, especially after consuming alcohol and other drugs that alter mental status.
- 9. The Medical Society of Virginia, the Virginia Chapter of the American Academy of Pediatrics, the Virginia Academy of Family Physicians, and the Virginia Section of the American College of Obstetricians and Gynecologists; and pediatric, family practice, and obstetrics and gynecology residency program directors should partner to develop online training modules on safe sleep for infants and promote use of these training opportunities by offering continuing medical education credits for Virginia physicians who complete them. Residency programs in Virginia medical schools should require two hours of this infant safe sleep training as part of pediatric, family practice, and obstetrician/gynecology residency training.
- 10. The Virginia Chapter of the American Academy of Pediatrics, the Virginia Academy of Family Physicians, and the Virginia Council of Nurse Practitioners should encourage their members to discuss infant safe sleep at each visit up to their patients' first birthday. Education should align with the American Academy of Pediatrics' revised policy guidelines noted previously and the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development's new Safe to Sleep campaign, which replaces the former Back to Sleep campaign.

11. The Virginia Department of Social Services should incorporate infant safe sleep information into existing policy/guidance for the assessment of the home environment of families with children less than one year of age.

#### **Tools and Training Materials**

- 12. Through Workgroups established to implement the Virginia Department of Health's Infant Mortality Strategic Plan, develop an infant safe sleep risk assessment tool and promulgate that tool to health care providers, hospitals, home visitation programs, departments of social services, emergency medical services providers, and other professionals to use in working with high-risk families. The assessment tool should include instructions for proper use and implementation.
- 13. The Virginia Department of Social Services should develop an online training module specifically written for health care providers to assist them in their role as mandated reporters of suspected child abuse and neglect pursuant to § 63.2-1509.

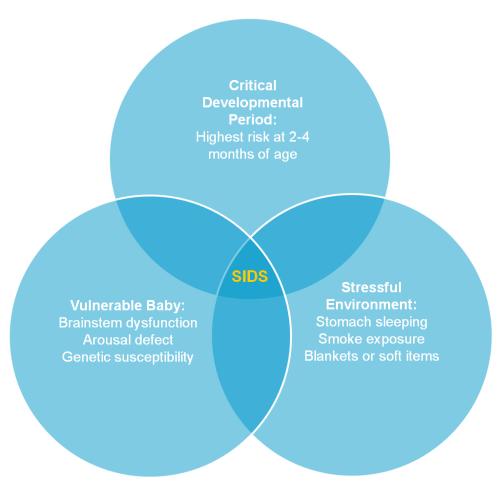
#### **Primary Prevention**

- 14. The Joint Commission on Accreditation of Healthcare Organizations should consider adopting infant safe sleep practices in accordance with the recommendations of the American Academy of Pediatrics into standards required for accreditation of healthcare facilities that provide care to infants.
- 15. The Governor of Virginia should ask the Secretary of Health and Human Services to identify opportunities for evidence-informed prevention and intervention programming at each HHS Department, and to fund an Office of Prevention within the Secretariat to address the needs of Virginia's high-risk families. The Virginia Council on Coordinating Prevention could serve as a model for this effort. Programs and services should be required when families with children are assessed at a threshold of high risk.
- 16. The Department of Medical Assistance Services should ensure that all Medicaid and FAMIS families with infants born 36 weeks or earlier, or any infant who spent time in a Neonatal Intensive Care Unit, receive face-to-face targeted case management, pursuant to U.S. § 440.169b, beginning at the child's birth until one year of age.

### **Infant Death Investigation**

- 17. The Virginia Department of Criminal Justice Services should develop a model policy for law enforcement on the thorough investigation of unexpected infant deaths, emphasizing the need for a multidisciplinary investigation that includes the Office of the Chief Medical Examiner, and, where appropriate, Child Protective Services and Commonwealth's Attorneys.
- 18. The Office of the Chief Medical Examiner should continue to encourage the use of consistent nomenclature for pathological diagnoses of unexplained infant deaths and provide periodic training for forensic pathologists and medicolegal death investigators on nationally-recognized risk factors for unsafe sleep-related infant deaths, current diagnostic nomenclature, and the criteria for such diagnoses. Where appropriate, the Office should review its policies and procedures on infant death investigations to support more consistent results among its forensic pathologists.
- 19. The Office of the Chief Medical Examiner should develop and disseminate to law enforcement and child protective services personnel, as well as Commonwealth's Attorneys, information about changes in the diagnoses of unexpected infant death as they relate to Sudden Infant Death Syndrome (SIDS), Sudden Unexpected/Unexplained Infant Death (SUID), and suffocation/asphyxia.

# APPENDIX A: Triple-Risk Model for SIDS



Filiano JJ and Kinney HC, Biol Neonate, 65:194-197, 1994

## APPENDIX B: AAP Safe Sleep Guidelines

From the American Academy of Pediatrics
SIDS and Other Sleep-Related Infant Deaths: Expansion of Recommendations for a Safe Infant
Sleeping Environment

#### **Level A recommendations**

Back to sleep for every sleep

Use a firm sleep surface

Room-sharing without bed-sharing is recommended

Keep soft objects and loose bedding out of the crib

Pregnant women should receive regular prenatal care

Avoid smoke exposure during pregnancy and after birth

Avoid alcohol and illicit drug use during pregnancy and after birth

Breastfeeding is recommended

Consider offering a pacifier at nap time and bedtime

Avoid overheating

Do not use home cardiorespiratory monitors as a strategy for reducing the risk of SIDS Expand the national campaign to reduce the risks of SIDS to include a major focus on the safe sleep environment and ways to reduce the risks of all sleep-related infant deaths, including SIDS, suffocation, and other accidental deaths; pediatricians, family physicians, and other primary care providers should actively participate in this campaign

#### **Level B recommendations**

Infants should be immunized in accordance with recommendations of the AAP and Centers for Disease Control and Prevention

Avoid commercial devices marketed to reduce the risk of SIDS

Supervised, awake tummy time is recommended to facilitate development and to minimize development of positional plagiocephaly

#### **Level C recommendations**

Health care professionals, staff in newborn nurseries and NICUs, and child care providers should endorse the SIDS risk-reduction recommendations from birth

Media and manufacturers should follow safe-sleep guidelines in their messaging and advertising

Continue research and surveillance on the risk factors, causes, and pathophysiological mechanisms of SIDS and other sleep-related infant deaths, with the ultimate goal of eliminating these deaths entirely

## APPENDIX B: AAP Safe Sleep Guidelines

These recommendations are based on the US Preventive Services Task Force levels of recommendation (www.uspreventiveservicestaskforce.org/uspstf/grades.htm).

Level A: Recommendations are based on good and consistent scientific evidence (ie, there are consistent findings from at least 2 well-designed, well-conducted case-control studies, a systematic review, or a meta-analysis). There is high certainty that the net benefit is substantial, and the conclusion is unlikely to be strongly affected by the results of future studies.

Level B: Recommendations are based on limited or inconsistent scientific evidence. The available evidence is sufficient to determine the effects of the recommendations on health outcomes, but confidence in the estimate is constrained by such factors as the number, size, or quality of individual studies or inconsistent findings across individual studies. As more information becomes available, the magnitude or direction of the observed effect could change, and this change may be large enough to alter the conclusion.

Level C: Recommendations are based primarily on consensus and expert opinion.

http://pediatrics.aappublications.org/content/128/5/1030/T1.expansion.html

# APPENDIX C: Virginia State Child Fatality Review Team Statute

§ 32.1-283.1. State Child Fatality Review Team established; membership; access to and maintenance of records; confidentiality; etc.

A. There is hereby created the State Child Fatality Review Team, hereinafter referred to as the "Team," which shall develop and implement procedures to ensure that child deaths occurring in Virginia are analyzed in a systematic way. The Team shall review (i) violent and unnatural child deaths, (ii) sudden child deaths occurring within the first 18 months of life, and (iii) those fatalities for which the cause or manner of death was not determined with reasonable medical certainty. No child death review shall be initiated by the Team until conclusion of any law-enforcement investigation or criminal prosecution. The Team shall (i) develop and revise as necessary operating procedures for the review of child deaths, including identification of cases to be reviewed and procedures for coordination among the agencies and professionals involved, (ii) improve the identification, data collection, and record keeping of the causes of child death, (iii) recommend components for prevention and education programs, (iv) recommend training to improve the investigation of child deaths, and (v) provide technical assistance, upon request, to any local child fatality teams that may be established. The operating procedures for the review of child deaths shall be exempt from the Administrative Process Act (§ 2.2-4000 et seq.) pursuant to subdivision 17 of subsection B of § 2.2-4002.

B. The 16-member Team shall be chaired by the Chief Medical Examiner and shall be composed of the following persons or their designees: the Commissioner of Behavioral Health and Developmental Services; the Director of Child Protective Services within the Department of Social Services; the Superintendent of Public Instruction; the State Registrar of Vital Records; and the Director of the Department of Criminal Justice Services. In addition, one representative from each of the following entities shall be appointed by the Governor to serve for a term of three years: local law-enforcement agencies, local fire departments, local departments of social services, the Medical Society of Virginia, the Virginia College of Emergency Physicians, the Virginia Pediatric Society, Virginia Sudden Infant Death Syndrome Alliance, local emergency medical services personnel, Commonwealth's attorneys, and community services boards.

C. Upon the request of the Chief Medical Examiner in his capacity as chair of the Team, made after the conclusion of any law-enforcement investigation or prosecution, information and records regarding a child whose death is being reviewed by the Team may be inspected and copied by the Chief Medical Examiner or his designee, including, but not limited to, any report of the circumstances of the event maintained by any state or local law-enforcement agency or medical examiner, and information or records maintained on such child by any school, social services agency or court. Information, records or reports maintained by any Commonwealth's Attorney shall be made available for inspection and copying by the Chief Medical Examiner pursuant to procedures which shall be developed by the Chief Medical Examiner and the

## APPENDIX C: Virginia State Child Fatality Review Team Statute

Commonwealth's Attorneys' Services Council established by § 2.2-2617. Any presentence report prepared pursuant to § 19.2-299 for any person convicted of a crime that led to the death of the child shall be made available for inspection and copying by the Chief Medical Examiner pursuant to procedures which shall be developed by the Chief Medical Examiner. In addition, the Chief Medical Examiner may inspect and copy from any Virginia health care provider, on behalf of the Team, (i) without obtaining consent, the health and mental health records of the child and those perinatal medical records of the child's mother that related to such child and (ii) upon obtaining consent from each adult regarding his personal records, or from a parent regarding the records of a minor child, the health and mental health records of the child's family. All such information and records shall be confidential and shall be excluded from the Virginia Freedom of Information Act (§ 2.2-3700 et seq.) pursuant to subdivision 9 of § 2.2-3705.5. Upon the conclusion of the child death review, all information and records concerning the child and the child's family shall be shredded or otherwise destroyed by the Chief Medical Examiner in order to ensure confidentiality. Such information or records shall not be subject to subpoena or discovery or be admissible in any criminal or civil proceeding. If available from other sources, however, such information and records shall not be immune from subpoena, discovery or introduction into evidence when obtained through such other sources solely because the information and records were presented to the Team during a child death review. Further, the findings of the Team may be disclosed or published in statistical or other form which shall not identify individuals. The portions of meetings in which individual child death cases are discussed by the Team shall be closed pursuant to subdivision A 21 of § 2.2-3711. In addition to the requirements of § 2.2-3712, all team members, persons attending closed team meetings, and persons presenting information and records on specific child deaths to the Team during closed meetings shall execute a sworn statement to honor the confidentiality of the information, records, discussions, and opinions disclosed during any closed meeting to review a specific child death. Violations of this subsection shall be punishable as a Class 3 misdemeanor.

D. Upon notification of a child death, any state or local government agency maintaining records on such child or such child's family which are periodically purged shall retain such records for the longer of 12 months or until such time as the State Child Fatality Review Team has completed its child death review of the specific case.

E. The Team shall compile annual data which shall be made available to the Governor and the General Assembly as requested. These statistical data compilations shall not contain any personally identifying information and shall be public records.

(1994, c. 643; 1995, c. 499; 1999, cc. 703, 726; 2004, c. 690; 2007, c. 411; 2009, cc. 813, 840.)

## APPENDIX D: Review Protocol for Virginia's Child Fatality Review Team

The Team analyzes child deaths provided by the Virginia Department of Health Statistics and/or Office of the Chief Medical Examiner to identify groups of death meeting the criteria for review established by the General Assembly. The Team may review violent and unnatural child deaths, sudden deaths occurring in the first eighteen months of life, and fatalities where cause or manner has not been clearly determined. A group of deaths from a specific time period are selected. All reviews are retrospective. The Coordinator obtains a database from the Medical Examiner System to verify that all records have been identified. A case file is created for each death to include the Medical Examiner record, certificate of death, and other records requested for review.

The Team is authorized by statute to review records from agencies or persons who provided services to the child whose death is under review. This may include, but is not limited to, records from the Department of Social Services, Child Protective Services, Emergency Medical Service providers, hospitals, physicians, police and sheriff departments, counselors, schools, Community Services Boards, Juvenile and Domestic Relations District Courts, and Court Service Units of the Department of Juvenile Justice. Each agency receives a cover letter and request from the Chair. Initial letters are sent to law enforcement, physicians, hospitals, and departments of social services. When additional service providers are identified in the child's record – mental health providers or pediatricians, for example – requests for those records are also sent. Once the case file is complete, the death is assigned to two Team members who review the materials, discuss them, and prepare a summary of the case for presentation at the Team meeting.

The Team meets every other month for case review. The business portion of these meetings is open to the public. The meeting becomes a closed and confidential session when specific cases are under review. A team member of the subgroup that reviewed the case file presents the facts of the case, as well as suggestions for education, training, or prevention. In each case, the Team considers whether there may have been opportunities to prevent the death, drawing a conclusion about whether or not the death was preventable. Ideas for education, prevention, and training are also discussed. The subgroup is responsible for completing a Child Fatality Review form that will be entered into a database. Data are entered into a database for summary and analysis of cases reviewed. At the conclusion of a review, the Team summarizes its findings, makes recommendations, and presents a report to the General Assembly and to the public.

### APPENDIX D: Review Protocol for Virginia's Child Fatality Review Team

Confidentiality is protected in three ways. First, the records that the Team obtains are excluded from the Virginia Freedom of Information Act and a third party cannot obtain them. Second, each Team member signs a sworn confidentiality statement. Violations of confidentiality are a Class 3 misdemeanor. Third, the records are destroyed once the review is completed.

### Virginia Localities by Medical Examiner District and Health Planning Region

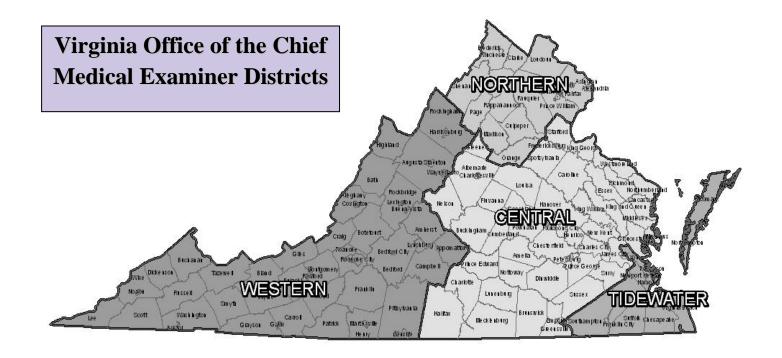
LOCALITY	MEDICAL EXAMINER	HEALTH PLANNING
	DISTRICT (OCME)	REGION
Accomack County	Tidewater	Eastern
Albemarle County	Central	Northwest
Alexandria City	Northern	Northern
Alleghany County	Western	Southwest
Amelia County	Central	Central
Amherst County	Western	Southwest
Appomattox County	Western	Southwest
Arlington County	Northern	Northern
Augusta County	Western	Northwest
Bath County	Western	Northwest
Bedford City	Western	Southwest
Bedford County	Western	Southwest
Bland County	Western	Southwest
Botetourt County	Western	Southwest
Bristol City	Western	Southwest
Brunswick County	Central	Central
Buchanan County	Western	Southwest
Buckingham County	Central	Central
Buena Vista City	Western	Northwest
Campbell County	Western	Southwest
Caroline County	Central	Northwest
Carroll County	Western	Southwest
Charles City County	Central	Central
Charlotte County	Central	Central
Charlottesville City	Central	Northwest
Chesapeake City	Tidewater	Eastern
Chesterfield County	Central	Central
Clarke County	Northern	Northwest
Colonial Heights City	Central	Central
Covington City	Western	Southwest
Craig County	Western	Southwest
Culpeper County	Northern	Northwest
Cumberland County	Central	Central
Danville City	Western	Southwest
Dickenson County	Western	Southwest

Dinwiddie County	Central	Central
Emporia City	Central	Central
Essex County	Central	Eastern
Fairfax City	Northern	Northern
Fairfax County	Northern	Northern
Falls Church City	Northern	Northern
Fauquier County	Northern	Northwest
Floyd County	Western	Southwest
Fluvanna County	Central	Northwest
Franklin City	Tidewater	Eastern
Franklin County	Western	Southwest
Frederick County	Northern	Northwest
Fredericksburg City	Central	Northwest
Galax City	Western	Southwest
Giles County	Western	Southwest
Gloucester County	Central	Eastern
Goochland County	Central	Central
Grayson County	Western	Southwest
Greene County	Central	Northwest
Greensville County	Central	Central
Halifax County	Central	Central
Hampton City	Tidewater	Eastern
Hanover County	Central	Central
Harrisonburg City	Western	Northwest
Henrico County	Central	Central
Henry County	Western	Southwest
Highland County	Western	Northwest
Hopewell City	Central	Central
Isle of Wight County	Tidewater	Eastern
James City County	Central	Eastern
King and Queen County	Central	Eastern
King George County	Central	Northwest
King William County	Central	Eastern
Lancaster County	Central	Eastern
Lee County	Western	Southwest
Lexington City	Western	Northwest
Loudoun County	Northern	Northern
Louisa County	Central	Northwest
Lunenburg County	Central	Central

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Salem City Western Southwest	Rockingham County	Western	Northwest
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Scott County Western Southwest	Salem City	Western	
	Scott County	Western	Southwest

Shenandoah County	Northern	Northwest
Smyth County	Western	Southwest
Southampton County	Tidewater	Eastern
Spotsylvania County	Central	Northwest
Stafford County	Central	Northwest
Staunton City	Western	Northwest
Suffolk City	Tidewater	Eastern
Surry County	Central	Central
Sussex County	Central	Central
Tazewell County	Western	Southwest
Virginia Beach City	Tidewater	Eastern
Warren County	Northern	Northwest
Washington County	Western	Southwest
Waynesboro City	Western	Northwest
Westmoreland County	Central	Eastern
Williamsburg City	Central	Eastern
Winchester City	Northern	Northwest
Wise County	Western	Southwest
Wythe County	Western	Southwest
York County	Tidewater	Eastern

### APPENDIX F





### This report is available at the following website:

http://www.vdh.virginia.gov/medexam/childfatality.htm

Commonwealth of Virginia
Department of Health
Office of the Chief Medical Examiner
400 East Jackson Street
Richmond, VA 23219



### Office of the Chief Medical Examiner

