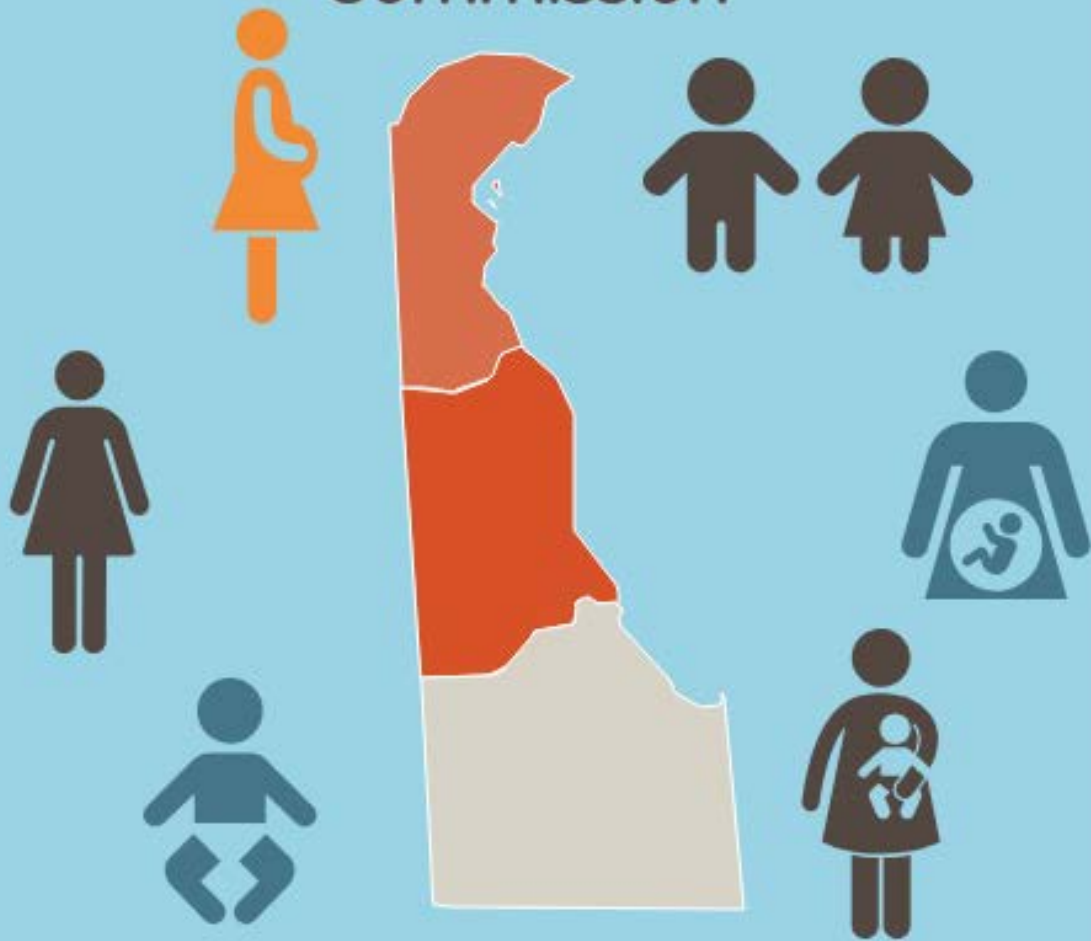


Child Death Review Commission



Annual Report

2019



**STATE OF DELAWARE
Child Death Review Commission**

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**The Honorable John Carney, Governor
State of Delaware**



Garrett H. C. Colmorgen, M.D., Chair

Working Together to Understand Why Children Die  Taking Action to Prevent Deaths



Mission Statement

The Child Death Review Commission was established “in order to provide its findings or recommendations to alleviate those practices or conditions which impact the mortality of children and pregnant women”

--Child Death Review Commission, Statute 31 Del. C. § 320

Table of Contents

Program Highlights	4
Child Death Review and Sudden Death in the Young	5
Fetal and Infant Mortality Review	11
Maternal Mortality Review	19
Conclusion	24

CDR/SDY

FIMR

MMR



Program Highlights

The Child Death Review Commission (CDRC) conducts three types of fatality review programs with a focus on maternal child health: Child Death Review and Sudden Death in the Young (CDR/SDY), Fetal and Infant Mortality Review (FIMR), and Maternal Mortality Review (MMR). In addition, CDRC staff oversee subcommittees and collaborate on preventive efforts that have been developed based on recommendations from prior years of fatality review. In 2019, the CDRC accomplished the following:

- Retrospectively reviewed 49 CDR/SDY cases, 58 FIMR cases—of which seven included a maternal interview—and 9 MMR cases.
- Continued efforts to prevent child deaths through the work of its subcommittees: the Joint Committee on Substance Exposed Infants/Medically Fragile Children (a collaboration between the CDRC and the Child Protection Accountability Commission (CPAC), the Chronic Health Conditions of School Age Children Committee, the Infant Safe Sleeping Community Action Team, and the newly formed Home Visiting Committee.
- Received the Centers for Disease Control and Prevention (CDC) Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) grant. The CDRC, in collaboration with the Division of Public Health (DPH), was one of 25 states to be awarded the ERASE MM grant. This five-year funding of \$150,000 per annum has enabled the hiring of a full-time MMR Program Coordinator to identify, review and characterize pregnancy associated deaths in keeping with the highest national standards and disseminate findings to inform preventive efforts.
- Provided 16 trainings to the community, medical providers, daycares and the Division of Family Services on infant safe sleeping and [All Babies Cry](#).
- Managed the All Babies Cry program, a program available in all birthing hospitals and online. CDRC staff provided support phone calls to 201 parents to help them cope with a crying infant.
- Distributed approximately 600 Pack ‘n Plays to families in need through the [Cribs for Kids](#) program in collaboration with the DPH to ensure infants have a safe place to sleep.
- Presented at various national conferences on the work of the SDY panel, a CDC-funded effort in which Delaware has participated since 2014.

In the following pages, the key characteristics of cases from each of the fatality review programs are described separately as well as findings and recommendations put forth based on these case reviews.

CDR/SDY

FIMR

MMR

Child Death Review and Sudden Death in the Young

Program Highlights & Case Description

Two review programs examine deaths meeting specified criteria in children 0-17 years of age. The Child Death Review (CDR) panel reviews cases that are not unexplained in nature, such as causes due to chronic medical conditions, homicide, or suicide. Unexplained or undetermined causes of death are reviewed by the Sudden Death in the Young (SDY) program, a national program led by the CDC. Since 2014, Delaware has been an integral part of helping researchers and death investigators learn more about the reasons why children die suddenly and unexpectedly through its work under the SDY grant. In 2019, the Division of Forensic Sciences and CDRC staff strengthened their partnership by attending collaborative national trainings, working to communicate more effectively, and updating procedures for efficient workflow. Forensic investigators are more routinely informing families about the SDY case registry and the ability to conduct additional genetic testing to help potentially identify underlying causes of death, which could have implications for surviving relatives. Additionally, the CDRC has been working to develop its partnership with the Nemours A.I. DuPont Children's Hospital to ensure DNA samples are collected for all children that meet SDY criteria.

In 2019, 49 child death cases were reviewed, 28 by the CDR panel and 21 cases by the SDY panels: the first level multidisciplinary team review and the advanced medical review. Thirteen cases were jointly reviewed with the Child Abuse and Neglect panel. The age, race and gender breakdown of CDR/SDY cases is shown in Figure C1¹. Children under 5 years made up over half of the cases (53%), including 70% of the cases involving Black children. Overall, 20 child deaths reviewed were Black children and 29 were White children. Almost two-thirds of the cases were males (63%). County of residence among cases was proportionate to the total population of children under 18 years living in each of the three counties: New Castle residents made up 59% of CDR/SDY cases, Kent 15% and Sussex 22%. Nineteen children (39%) had a chronic health condition. For more details on the data and issues identified among CDR/SDY cases, as well as cases reviewed under all of the CDRC fatality review programs, please see the 2019 CDRC Data Addendum.

Manner of death, the determination of how an injury or disease leads to death, among CDR/SDY cases is shown in Figure C2. Undetermined manner of death was most common under one year of age. For all other age groups, natural manner of death predominated. Overall, there were five youth homicides reviewed, three youth

¹ The CDRC uses the terms White, Black, and Hispanic based upon the usage by the CDC, the National Center for Vital Statistics, and the National Center for Fatality Review's database.



suicides, and nine accidental deaths. The deaths occurred between 2017 and 2019, with an average time to review of six months between the occurrence of a death and a CDR or initial SDY review.

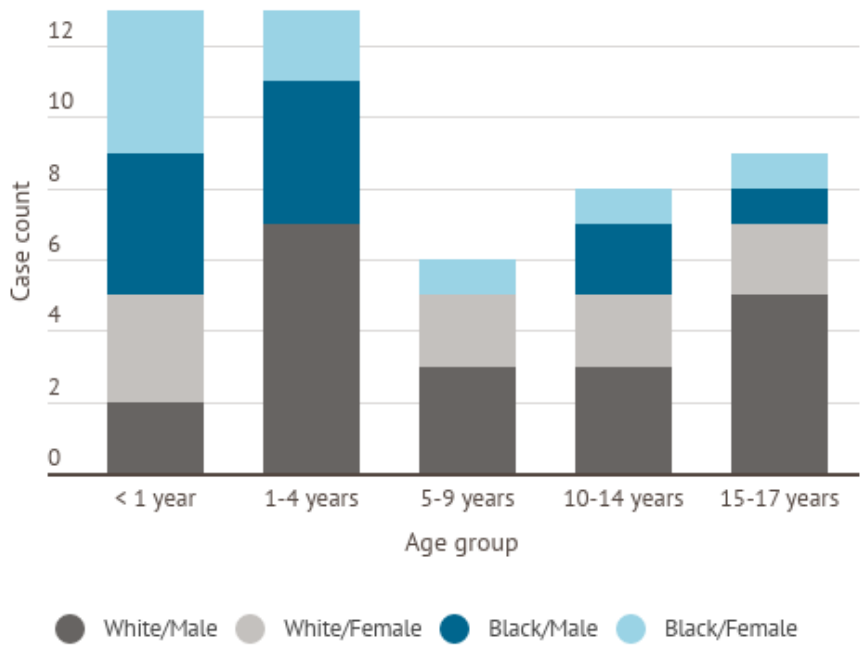


Figure C1: CDR/SDY case count by race, gender and age group (n=49)

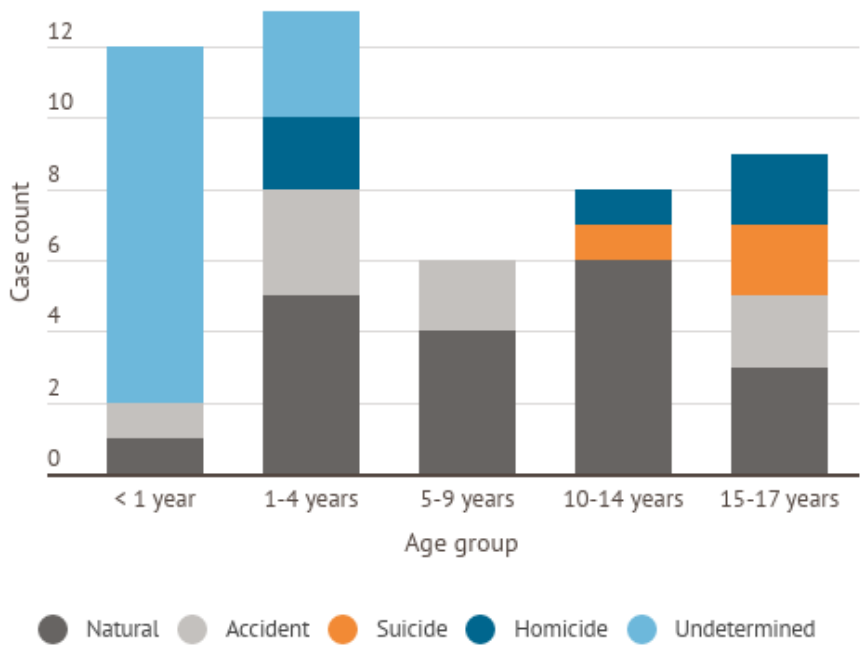


Figure C2: Manner of death by age group: CDR/SDY 2019 cases (n=49)

For several years, CDR and SDY panels have been tracking adverse family experiences as a risk factor in child death cases. There has been a steady or growing prevalence of such factors including child welfare involvement, parental substance abuse, and family history of criminal involvement or inter-personal violence. Many of these factors are most thoroughly identified among CDR/SDY cases of children less than one year of age, as parental history and records are more complete in these cases. Among infant death cases, adverse family risk factors had a higher prevalence compared to the larger group of all CDR/SDY cases, creating a profile of family or inter-generational risk that is important to identify and may be used to inform programmatic supports and interventions. More details are included in the [2019 CDRC Data Addendum](#).

Unsafe Sleep Deaths

Twelve of the thirteen infant deaths reviewed in 2019 were related to unsafe sleep conditions. Infants dying of unsafe sleep were overwhelmingly term infants born at normal birthweight. Five infants were White and seven were Black. Seven infants were under one month of age. Figure C3 shows the three-year averaged rate of unsafe sleep related deaths per 1,000 live births in Delaware. This rate has plateaued over the last six years, around 1.1 deaths per 1,000 live births.

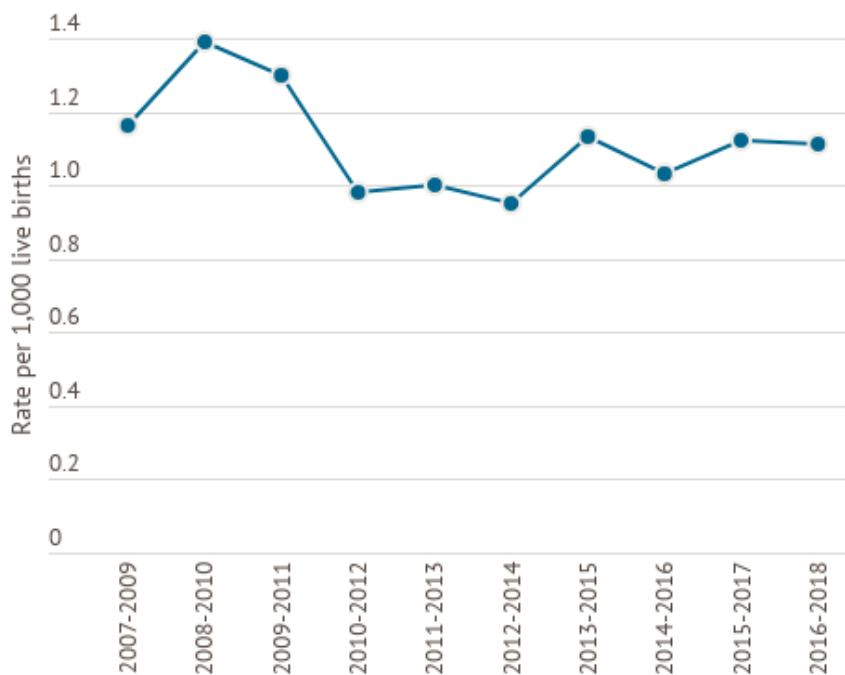


Figure C3: 3-year average unsafe sleep related death rate per 1,000 live births in Delaware

Upon case review, the unsafe sleep deaths had environmental risk factors identified, most common being that the infant was not in a crib, bassinet or side sleeper at the



time of death (100% of cases), there was unsafe bedding or toys near the infant (92%), and the infant was sleeping with other people (75%) (Table C4). While these factors have been prevalent over the last several years of review, what is increasing in prevalence is the SDY panels identifying family risk factors such as intrauterine tobacco exposure or intrauterine drug exposure among unsafe sleep deaths.

	2019 (n=12)	2018 (n=12)	2017 (n=12)	2016 (n=23)
Not in a crib, bassinette or side sleeper	100%	100%	100%	82%
Not sleeping on back	50%	75%	60%	50%
Unsafe bedding or toys nearby	92%	100%	90%	83%
Sleeping with other people	75%	67%	83%	65%
Intrauterine drug exposure	42%	33%	10%	*
Tobacco use: mother	67%	58%	40%	57%
Adult was alcohol or drug impaired at time of death	67%	25%	25%	26%
Infant ever breastfed	45%	50%	60%	48%

Table C4: Risk factors identified in unsafe sleep related deaths, by year of review

These findings—namely that the number of unsafe sleep deaths has not decreased in recent years and that families dealing with substance use disorder (SUD) are at increased risk—prompt the CDRC to make the following recommendations:

▶ Recommendations

- The CDRC and the Delaware Health Mother and Infant Consortium (DHMIC) recommend revamping and broadening the purpose and mission of the Infant Safe Sleeping Community Action Team (TISSCAT). This group should be expanded to include more stakeholders across the State and non-medical partners who interact with families in a variety of settings.
- TISSCAT will explore the following:
 - Conduct a national review on current best practices for unsafe infant sleep prevention and education;
 - Develop tailored messaging to educate on the importance of safe sleep practices among families with SUD;
 - Partner with the Division of Substance Abuse and Mental Health (DSAMH) to get this message out through behavioral health providers, perinatal SUD programs, and peer recovery coaches;



- Improve the education by the Division of Forensic Sciences-Medical Examiner staff who work directly with families so they can understand the diagnosis of Sudden Infant Death Syndrome (SIDS), Sudden Unexplained Infant Death (SUID), and an undetermined cause of death;
- Develop a five-year strategic plan to address unsafe infant sleeping;
- Promote this area of concern at the Joint Commission retreat to include more systemic partners.

Chronic Health Conditions of School Age Children Committee

In 2016, CDRC reviewed multiple cases of children with deaths related to chronic health conditions who received care in the Delaware public school system. As a result, the CDRC recommended the development of a committee to explore the issue of procedures within the Delaware public schools. The work of this committee began in early 2017 and concluded in October 2019. The report of this committee will be publicly released in 2020.



Case vignette: Unsafe Sleep

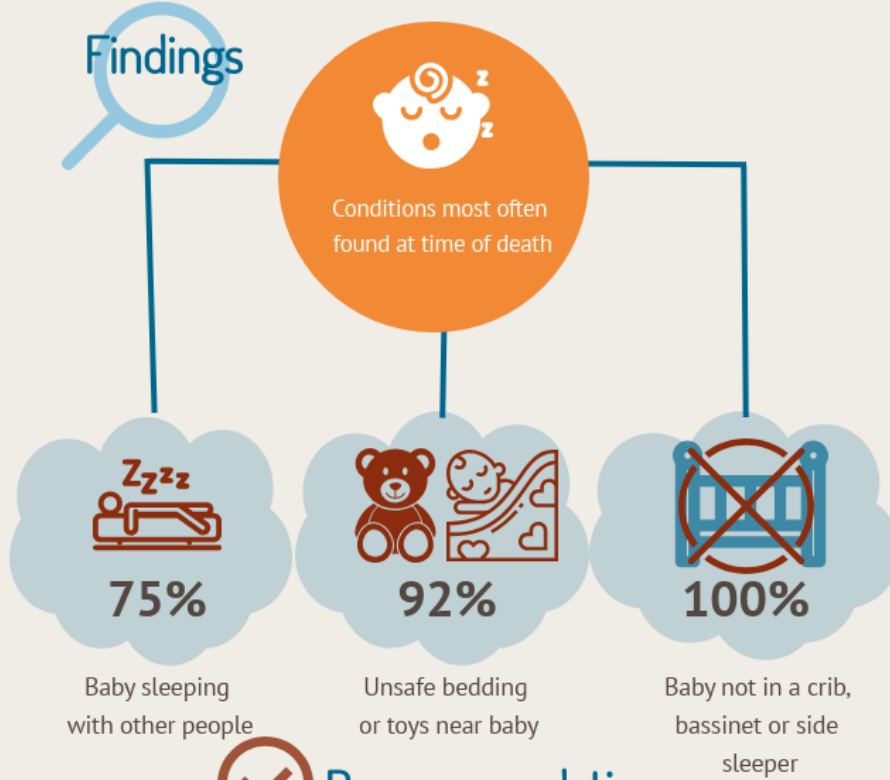
Christmas this year was sure to be one of the greatest. The family finally felt complete--new home and a new baby. After unpacking boxes and decorating for the holiday, everyone was exhausted. When their newborn baby awoke in the middle of the night to be breastfed, it seemed easier just to lay her in bed with Mom and Dad so they could get a good night's sleep. The parents remembered what the doctor had said about unsafe sleeping, and so they made sure to put the baby face up and didn't cover her with a blanket. Just this one time would be fine because they knew they would wake up if one of them accidentally rolled over the baby.

Upon waking a few hours later, they could not believe their newborn slept so well. They then noticed the infant was unresponsive and not breathing. The parents called 911 and began CPR. Resuscitation efforts were unsuccessful and their newborn infant was pronounced dead.



Infant Deaths related to Unsafe Sleep in Delaware

Findings



Recommendations

Expand the mission and scope of **the Infant Safe Sleeping Community Action Team** in order to ...

- Conduct a national review on current best practices for unsafe infant sleep prevention and education
- Develop tailored messaging for different audiences
- Work with partners in the State to get the word out to as many families as possible as often as possible for repeated, consistent messaging
- Develop a 5-year strategic plan



Fetal and Infant Mortality Review

Program Highlights & Case Description

Charged with the review of fetal deaths (stillbirths) occurring after 20 weeks gestation and of infant deaths due to causes not related to unsafe sleep, suspected abuse or neglect, the Delaware FIMR program presented 58 cases for deliberation by one of its two Case Review Teams (CRTs): the New Castle County Team, and the Kent and Sussex Counties Team. The CRTs include representatives from obstetrics, pediatrics, nursing, social work, hospital administration, bereavement support, the Division of Public Health (DPH), and community agencies and advocates. Seven of the 58 cases (12%) included information from a maternal interview, a unique aspect of the National FIMR model that tries to bring the mother's voice into the story of her care. CRTs find this maternal perspective enriching and insightful, enabling a more complete consideration of the opportunities to improve the system of care to meet families' needs.

2019 FIMR cases represented deaths that occurred in 2018 (47% or 27 cases) and 2019 (53% or 31 cases). [See [2019 CDRC Data Addendum](#) for more details on case characteristics and findings.] There was only a four-month lag between the occurrence of a death and its review by a FIMR CRT, affording contemporaneous review of cases based on current standards and systems of care. Figure F1 depicts key steps in the FIMR process of working up a case, its review and priority setting.

The composition of FIMR cases by maternal race/ethnicity is shown in Figure F2 and is compared to the race/ethnicity demographics of other groups reported by the DPH Office of Vital Statistics.² Half of FIMR cases involved non-Hispanic Black fetuses and infants; 24% were non-Hispanic White, and Hispanic and other races made up 26%. This is representative of the total Delaware infant and fetal death cohort for 2018. All these groups have a disproportionately high proportion of Black fetuses and infants compared to the Delaware live birth cohort, among which Black infants make up only about a quarter of all births in 2018.



² Delaware Health Statistics Center. [Delaware Vital Statistics Annual Report, 2018](#). Delaware Department of Health and Social Services, Division of Public Health, 2019.



FIMR process

Conducting in-depth, multidisciplinary reviews to identify priorities for prevention opportunities and strategies to improve maternal child health.


1 **Case identification**

The Division of Public Health (DPH) Office of Vital Statistics provides monthly report on infant and fetal deaths



2 **Case Abstraction & Maternal Interview**

- Subpoena records from birth hospitals, admissions, and outpatient visits.
- Attempt to contact mother by letter and phone to invite her participation in a maternal interview to share her perspectives on the care she received.



3 **Case Review**


Multidisciplinary Case Review Team deliberates de-identified case summary, taking into account all available information sources including: medical records, child welfare records, criminal history, public health information and maternal interview (if available).



Four months, average time between a death and case review.

4 **Data Review & Priority Setting**

CRTS review annual qualitative and quantitative data to identify key themes and priorities for action planning and preventive strategies.



FIMR

Figure FI: FIMR process highlights



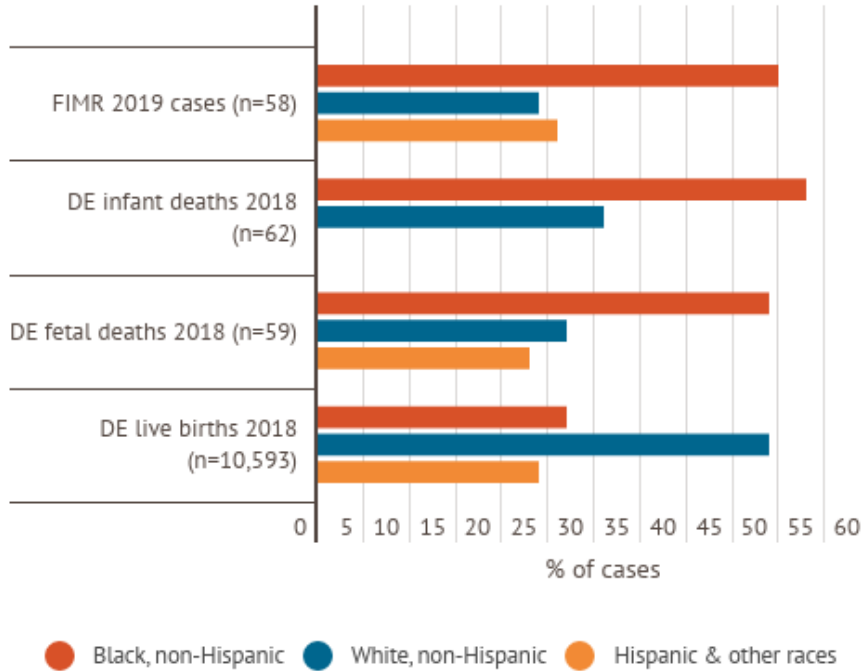


Figure F2: Maternal race/ethnicity among FIMR cases and comparison groups

Thirty-three FIMR cases (57%) involved mothers living in a high-risk geographic area as defined by the DPH Title V Maternal Child Health needs assessment. Two-thirds of cases involved residents of New Castle County; half of these residing in the City of Wilmington, and the remaining proportion were equally distributed between Kent County and Sussex County, each accounting for 17% of cases. FIMR cases were representative of county compared to all Delaware live births, infant deaths and fetal deaths occurring in 2018.

In 2019, there was a noticeable departure from prior FIMR trends for the composition of cases based on gestational age, birthweight and underlying infant causes of death. In 2019, 38% of FIMR infants were born at term, that is 37 weeks of gestation or older, a marked increase from the 4% of term infants seen in 2018 FIMR cases. Similarly, 29% of 2019 FIMR infants were born at normal birthweight, weighing over 2.5 kilograms or 5.5 pounds. This is much higher than in 2018 when no FIMR infants were born at normal birthweight. The most prevalent underlying cause of FIMR infant death in 2019 was congenital anomalies, overtaking extreme prematurity, which had been the primary cause of death in 2018. Among FIMR fetal deaths, the most prevalent underlying contributing factor identified by the CRTs was placental abruption, seen in almost one out of four fetal deaths.



FIMR Findings & Priorities

This year, CDRC staff hosted a special convening of the FIMR CRTs to review 2019 data, identify key priorities for action planning, and follow up based on quantitative and qualitative FIMR findings. The CRTs were asked to consider the following questions:

1. What are we currently doing that is helping this issue?
2. What are we currently doing that is hindering this issue?
3. How can we improve?

Ideas were discussed, and then CRT members voted on their top priorities under each issue. The priorities identified and some key themes are presented here.

Bereavement Support

FIMR CRTs carefully review the circumstances of supporting a mother and family after a fetal or infant loss. Sometimes bereavement support begins prenatally, at the time of diagnosing a stillbirth or life-limiting condition. In 2019, there were cases that demonstrated the provision of support to a more ethnically and racially diverse group of families. For the most part, hospital staff tried to meet families' needs across various religious and cultural beliefs. For all families, there was an emphasis on offering memory-making opportunities. Overall, in FIMR cases, 60% had documented referrals for bereavement support, and 7% had a lack of grief support noted on CRT deliberation.

FIMR CRT members identified the following priorities for action planning to improve bereavement support in the context of a perinatal loss. CDRC staff will bring the following priorities to an upcoming DHMIC and/or Delaware Perinatal Quality Collaborative meeting for action planning.

1. Increase awareness of bereavement sensitivity to include training for physicians, residents, nurses, social workers, parent educators and home visitors. This may include implementing a visual cue on the electronic medical record so all providers know when a loss has occurred.
2. Convene a bereavement conference in Kent or Sussex County to support professional development and networking opportunities.
3. New nurses should continue to receive bereavement education upon hire.

Medical Issues


Congenital anomalies overtook prematurity as the most common underlying cause of infant death for the first time in Delaware FIMR history. Several FIMR cases demonstrated the value of neonatology or palliative care consults in the prenatal period to discuss the implications of a life-limiting diagnosis with the family. In some



instances, families had to make difficult decisions in cases involving infants with serious medical complications.

On the maternal side, 35% of cases (20 out of 57 mothers) had evidence of a serious maternal morbidity such as pre-eclampsia, obstetric hemorrhage, poorly controlled diabetes, substance use disorder, and hypertension. Maternal mental health issues were documented in 21 cases (36%), most often depression, anxiety and/or postpartum depression. Mothers with chronic conditions did not always receive optimal management or coordination of care for their condition in the perinatal period. On a positive note, there were more documented conversations between providers and women on inter-conception care and counseling to improve their health and their chances for a better outcome in a future pregnancy.

FIMR CRTs identified the following priorities for action planning to improve fetal, infant or maternal medical care:

- 
1. Explore expanding options for childbirth and prenatal classes, funding sources, platforms and accessibility, i.e., online classes and classes that are available regardless of a family's ability to pay. Reinforce the importance of attending classes to prepare parents for the baby's birth and introduce postpartum education topics.
 2. Explore the possibility of restarting prenatal care and education based on the Centering Pregnancy model.
 3. Continue work to utilize evidenced-based home visiting prenatally to support mothers in the postpartum period.



Update: Home Visiting Committee

As a result of the Child Protection Accountability Commission and CDRC 2018-2019 Joint Action Plan, the CDRC Executive Committee voted upon the establishment of a home visiting committee to address the need for additional evidence-based home visiting services and system improvement. This committee met several times in 2019 and established the following work groups: 1.) healthcare systems, 2.) reimbursement, sustainability, managed care organizations and Medicaid, and 3.) universal innovative models. These work groups will delve deeply into their respective issues, working towards a final report with system-wide recommendations in 2021.



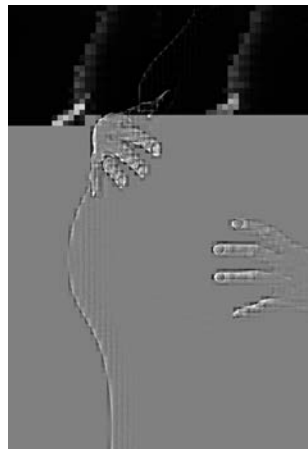


Case vignette: Medical Care

A 26-year old mother had diabetes, hypertension, early signs of kidney failure, anemia, anxiety and depression. She also had a prior infant born premature. When she became pregnant this time, she went to her first prenatal visit in her second trimester and had intermittent care throughout her pregnancy. She was a candidate for progesterone injections to reduce her chances of delivering early, but the mother declined the medication. She had high blood sugars and high blood pressures that were hard to manage during her pregnancy. The mother smoked marijuana to help control the nausea she was experiencing due to her pregnancy.

At 27 weeks, the mother went into preterm labor. Her baby was admitted to the neonatal intensive care unit. A few weeks later, the baby developed an infection as a result of being extremely premature. The baby died due to this overwhelming infection.


In the postpartum period, the mother's blood pressure was high and her medications had to be increased, but she did not consistently take them. Her depression screen was concerning, and the mother's doctor referred her for psychotherapy and provided resources on postpartum depression.



Family Planning


It may be more challenging to discuss family planning after a fetal or infant loss when providers must balance the bereavement support needs of families. However, as not all mothers come to their postpartum visit, the in-hospital delivery stay is a crucial time to start discussing family planning and birth spacing to support the optimal care and healing for mothers. Seventy-two percent of FIMR mothers went to their postpartum visit, and those that did had a much higher likelihood of receiving or accepting family planning counseling. Overall, discussion of family planning was documented in 69% of FIMR cases.

In discussing family planning action steps and priorities, FIMR CRTs concurred that counseling may be under-documented in the medical record, and hence CRTs may not be fully informed on who is receiving counseling and the content covered. Keeping in mind these limitations, the CRTs identified the following priorities to improve family planning services in the immediate postpartum period:

- 
1. Improve birth spacing and family planning discussion with mothers and their families who experience a loss, e.g. the discussion would be different for a younger mother in her 20's as compared to a mother over 35 years old, or for a woman who conceived her pregnancy via medical fertility.
 2. Improve opportunities for pregnancy intention screenings during a well woman care visit and other settings while being sensitive to asking the questions in a non-judgmental manner.
 3. Continue education and documentation of birth spacing and family planning methods and reinforce the importance of documenting these conversations in the medical records.

FIMR Process

FIMR CRTs identified the following priorities to improve the FIMR program process in 2020 and moving forward:

- 
1. Explore additional methods for securing a maternal interview, i.e., written responses or open-ended letters written by mothers.
 2. Track the use of low dose aspirin among mothers with hypertension and pre-eclampsia.
 3. Explore evaluating data on the Delaware fetal death rate before and after the statewide implementation of Fetal Kick Counts.





Fetal and Infant Mortality Review (FIMR) and 2019 Behavioral Health Findings in Delaware



36%



of FIMR mothers had a mental health issue



12%



35%

Mental health conditions, particularly depression and anxiety, were nearly 3 times more prevalent in the postpartum period.



17%

of FIMR mothers had recently used an illicit substance

Priority Action Steps



Bereavement support

- Increase awareness of bereavement sensitivity to include training for physicians, residents, nurses, social workers, parent educators and home visitors.



Home visitng

- Continue work to utilize evidence-based home visiting services prenatally to support mothers in the postpartum period.



Maternal interview

- Explore additional methods for obtaining a maternal interview to learn from the mother's perspective of what she experienced in the prenatal and postpartum period.



Maternal Mortality Review

Program Highlights & Case Description

In 2019, the CDRC was one of 25 states awarded the ERASE MM grant from the CDC: Enhancing Reviews and Surveillance to Eliminate Maternal Mortality. This five-year grant awards \$150,000 annually, supporting the new MMR Coordinator position, training and other activities to implement the program's improvement goals:

- Identify and review all potential pregnancy associated deaths in a more timely and consistent manner;
- Employ new quality assurance processes to ensure data accuracy;
- Undertake regular analyses to better track and contextualize MMR findings;
- Find new opportunities to disseminate findings and engage stakeholders; and
- Consider a health equity approach to inform initiatives that address the disproportionate burden of maternal morbidity and mortality in high-risk groups.

The MMR Committee reviewed nine cases in 2019. Vital statistics linkage remains the most common method of case identification: four cases were first identified by this method of linking maternal identifiers on live birth and fetal death certificates with death certificates of women of childbearing age. Three MMR cases were identified by a positive response on the pregnancy checkbox on the Delaware death certificate; and two pregnancy-associated deaths were first identified by provider reports to the CDRC. The MMR cases dated from 2017 to 2019, with the average time between the occurrence of a death and case review being 1.2 years. One MMR case was also a FIMR case in 2019 and was reviewed by both the FIMR and MMR panels. No family interviews were obtained in 2019.

The 2019 MMR cases represent deaths that occurred to women ranging in age between 19 and 40 years. Five mothers were Black, and four were White. One death occurred during pregnancy, two deaths occurred within 42 days of delivery, and six deaths occurred between 43 and 365 days postpartum, meeting the definition of a late pregnancy associated death.

The MMR Committee deemed three deaths pregnancy-related, meaning the mother died of a condition or complication causally linked to her pregnancy. Five deaths were pregnancy-associated but not related, that is linked to pregnancy just by timing: happening to occur while the woman was pregnant or up to one year after the end of her pregnancy. For one death, the MMR Committee could not make a determination of pregnancy relatedness.





Case vignette: Maternal mortality

A 25-year old single mother delivered a preterm infant by Caesarean section. The mother had a long-standing history of substance use disorder (SUD), child welfare involvement and criminal justice involvement. All her previous children were in the custody of a relative. She did not receive prenatal care during her last pregnancy. At the time of delivery, the mother did have a positive urine drug screen. She was seen by a behavioral health provider specializing in SUD treatment. The mother was discharged 4 days after delivery, but her infant remained in the hospital for care due to being born premature.

A few days later, the mother came back into the hospital with pain from her C-section incision. She had run out of the opioid pain medicine prescribed after surgery. The mother was treated with an injectable pain medicine in the emergency department and instructed to follow up with her obstetrician for better pain management.

A few months after delivery, the mother was brought into an emergency department after being found unresponsive and given naloxone to reverse an opioid overdose. She was admitted, seen by an SUD treatment provider and started on buprenorphine, a medication for opioid use disorder treatment. The mother was prescribed buprenorphine at discharge and had an appointment to be seen at an SUD treatment clinic in 7 days. She did not go to that appointment. There was no follow up to contact the mother after her missed appointment.

A few weeks later, the mother overdosed again and was admitted to the hospital. Again, her providers put her on buprenorphine, gave her naloxone to take home and instructed her on its use. She had a follow up appointment made for 3 days after discharge that she did not attend.

A few days after her last discharge, the mother was found dead at her home. The cause of death was determined to be opioid overdose.

MMR



MMR Contributing Factors & Findings

The Delaware MMR uses the national MMRIA (Maternal Mortality Review Information Application) database created by the CDC which provides guidance on the deliberation of cases to identify commonly defined characteristics such as pregnancy relatedness, preventability and contributing factors at the patient/family level, the provider level, facility or system level and community level. Figure M1 depicts the contributing factors, by level, identified by committee review of the nine cases in 2019. Patient/family factors continue to be the most common factors identified. Community and facility factors were the least often identified. This may be due in part to the lack of community data to inform each case review or the difficulty in attributing broader factors to the outcome in a single case. Table M2 lists the most prevalent factors identified at each level. Many of the patient/family factors relate to psychosocial risks that influence the health of women. In addition to the contributing factors identified through use of the MMRIA database, qualitative review of the 2019 MMR cases also identified the following three recurring themes at the patient/family level: 1.) lack of access to transportation, 2.) extensive history with the Division of Family Services, and 3.) lack of a medical home to coordinate care in complex cases.

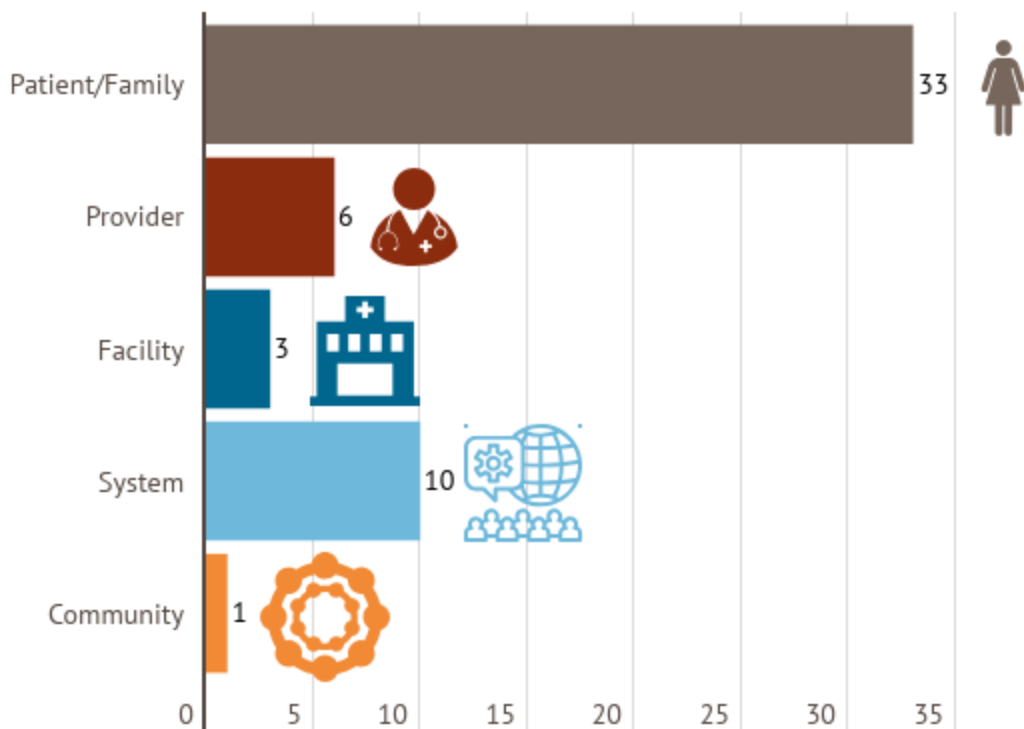


Figure M1: Number of contributing factors identified, by level

MMR








	Level	Contributing factors identified
	Patient/Family	Lack of access/financial resources, substance use disorder, mental health condition, delay in seeking care, adherence to medical recommendations, chronic disease, tobacco use, childhood abuse/trauma, unstable housing, knowledge, violence, lack of social support/isolation
	Provider	Clinical skill/quality of care, lack of continuity of care/care coordination, inadequate community outreach
	Facility	Lack of continuity of care/care coordination, lack of standard policies/procedures
	System	Poor communication/lack of case coordination or management, knowledge, legal, assessment, inadequate law enforcement response
	Community	Environmental

Table M2: Type of contributing factors identified, in order of decreasing frequency

Recommendations




Recommendations approved by the Commission based on 2019 MMR cases include the following:

1. CDRC recommends that all medical providers follow the national ACOG (American College of Obstetricians and Gynecologists) guidelines to address standard postpartum pre-eclampsia and eclampsia hospital discharge instructions to educate on emergent conditions.
2. CDRC recommends that all birthing hospitals start postpartum education and teaching in the third prenatal trimester. At the time of labor and delivery, those women who are high risk need differentiated teaching and follow up that is more intensive.
3. CDRC recommends that all birthing hospitals promulgate the protocol for ACLS (Advanced Cardiac Life Support) and AIM (Alliance for Innovation on Maternal Health) bundle for obstetric hemorrhage. Obstetric hemorrhage is a focus area for the Delaware Perinatal Quality Collaborative and efforts are underway to implement the AIM bundle and review data for quality improvement opportunities.
4. CDRC supports the Division of Substance Abuse and Mental Health’s START initiative to facilitate referrals for those with substance use disorder to access treatment and services. The START initiative is addressing the lack of continuity of care between hospitalizations, community outreach and follow up. Peer recovery coaches are an important resource in enhancing connectedness between patients and the system of care.



Maternal Mortality Review (MMR) in Delaware: Case Review to Recommendations

Case Review: underlying cause of death due to . . .

 <p>Hypertensive disorders of Pregnancy</p> <p>Gestational hypertension Pre-eclampsia Chronic hypertension Eclampsia</p>	 <p>Obstetric hemorrhage</p> <p>Also the leading cause of severe maternal morbidity in Delaware, accounting for over 78% based on receipt of blood transfusions in 2010-2014</p>	 <p>Drug overdose</p> <p>42%</p> <p>of mothers had a history of illicit substance use in MMR cases 2011-2019</p>
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Contributing Factors identified by MMR Committee

<p>Patient knowledge of when to seek follow up for symptoms</p> <p>Lack of standardized policies/procedures for discharge instructions and time to follow up when a complication occurs</p>	<p>Clinical skill/quality of care to accurately and timely diagnose acute bleeding</p> <p>Lack of continuity of care when a mother is seen in an emergency setting and does not have a prenatal care provider</p>	<p>Inadequate community outreach due to lack of referrals to available resources in the community that can support patients with substance use disorder after hospital discharge</p>
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Prevention Opportunities

<p>Follow the national ACOG (American College of Obstetricians and Gynecologists) guidelines to address standard postpartum pre-eclampsia and eclampsia hospital discharge instructions to educate on emergent conditions.</p>	<p>Promulgate the protocol for ACLS (Advanced Cardiac Life Support) and the AIM (Alliance for Innovation on Maternal Health) bundle for obstetric hemorrhage. Obstetric hemorrhage is a focus area for the Delaware Perinatal Quality Collaborative and efforts are underway to standardize the approach to managing hemorrhage in all birthing facilities.</p>	<p>Support the Division of Substance Abuse and Mental Health's START initiative to facilitate referrals for those with substance use disorder to access treatment and services. Peer recovery coaches are an important resource in enhancing connectedness between patients and the system of care.</p>
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Conclusion

The work of the CDRC is important now more than ever to galvanize efforts and improve the health of women, children and families. The type of information made available by these three fatality review programs provides in-depth detail and a glimpse into the circumstances surrounding the family at the time of the death. The stories behind the cases summarized in this report and uncovered through the work of the Commission represent some of the most dire outcomes for people at the greatest risk in our state as a result of medical, social, and/or psychological factors. Their stories lend an important voice and insight into the circumstances that need urgent and sustained attention through medical, public health, behavioral health and community programming. Their stories are a call to continued action and our effort to work together, building supports and linkages to better serve and improve the health of all children and women, especially those at greatest risk.



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Dedication

This annual report is dedicated to Kristin L. Koyné Joyce who passed away due to complications from Amyotrophic Lateral Sclerosis on January 12, 2020. Kristin started with the CDRC in 2006. She brought a great deal of warmth and compassion to her role as the first FIMR maternal interviewer. Prior to working for the CDRC, Kristin was a part of the Delaware State Police Victim Services Unit from 1990 – 2006. She was one of the original civilian victim advocates working out of both Troop 2 and later Troop 6. In addition to counseling motor vehicle crash and crime victims, Kristin was also part of a team that went to New York City to help the victims of 9/11. She dedicated her life to helping others, and everyone who had the pleasure of knowing her will miss her.



"We call our FIMR program 'Caring Communities—Sharing Hope.' My role is to conduct maternal interviews with women who experienced a fetal or infant loss. I have a great deal of respect for the women I have interviewed. The women who agree to do the interview truly care about their communities and are sharing the hope that future women will not have to go through the pain and loss experienced by others."

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I Was Born to Do This Job

By Kristin Joyce, B.A., Senior Medical Social Worker

I am a maternal interviewer for the Delaware Fetal and Infant Mortality Review Program (FIMR). My job entails contacting women and families who have lost a baby, offering them bereavement support and information, and asking them if they would be willing to share their experience with me through an interview. We call this a maternal/family interview, it takes place in the home or in my office and it usually takes about two hours to complete, although I devote as much time as a family needs. Not every family is comfortable doing an interview and I am respectful of where they are in their grief process. The purpose of the interview is to get as much information as we can about each death, to try and improve services to women, babies and families in Delaware. Our office has access to all medical records, but having the interview provides a much broader picture of what happened during pregnancy and how the loss occurred. My interview, along with the medical record abstraction, are de-identified and then presented to our case review team. The team is made up of doctors, nurses, social workers, public health etc. We review each case and make recommendations for change.

People often ask me how I do my job. Isn't it depressing? Doesn't it make you feel sad all the time? The truth is, I do hear heartbreaking stories and I am a witness to the trauma people feel when they lose a baby. At times it can be difficult, although most of the time I feel like it is very rewarding. When I interview a family I allow them to tell me their story in their own way and in their own time. I do not interrupt them until they have said what they want to say to me. I consider it a privilege to hear, in their words, what they experienced, how they felt, what they thought, what helped them and what hurt them. I hope that they feel it is a gift to have someone who is truly interested and who sincerely cares, listen to their experience. It is a very personal interaction and I am grateful for the people who are willing to bring me into their homes and share their heartbreak with me.

What you can immediately see after the interview is a person who has a little less burden to carry with them. They may feel that there is a sense of purpose for what they have been through. They know that I intend to share their experience and hopefully make changes to the things that could have made it easier for them. That thought helps them, and makes them feel that their experiences and their baby's life will have changed the system for the better and help other families.

When I bring their stories to our case review teams, I try to bring it with the same passion that the family feels. Although by nature, I am not an aggressive person, I am unyielding when it comes to making sure that the team knows what this family would like to see changed. Does that change always happen immediately? No, it does not, but I keep trying. I keep the family's words in my mind and I take every opportunity to convey their wishes. I feel fulfillment in working hard to make sure that the family's voice is being heard.



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Working as a maternal interviewer definitely provides me many good and happy days as well. When I get a returned evaluation about the interview and someone writes that speaking with me was helpful to their bereavement journey; that is a good day. Some days I am able to help a family with a referral to needed services, and that is a good day too. However, when I get a phone call or card from a couple who has had a healthy baby after their loss; that is a great day!

I realize that not everyone can do this work, but it is just the right work for me. As a matter of fact, the day I came into this world as my mother's fifth child, there was a woman in the ward beside my mother whose baby had died. She asked to hold me when the nurse brought me to my mother. Despite the fact that it was not something typically done in those days, my mother gave me to her. As you can imagine, in the 1960's a woman did not get to hold her dead baby and she was just left with empty arms and an aching heart in a large ward with many women and their newborn babies. My mother saw this woman's pain and wanted to do something to help her. My mother asked her what she had planned to name her daughter who had died, and the woman said Kristin. My mother told her she would like to name me Kristin in remembrance of her daughter. That is how I got my name and it is remarkable that my social work career eventually brought me full circle to a position where I am able to provide emotional support and caring to families who have lost a baby. So when people ask me how I do this job I can simply say, I was born to do it.

Most of all I am grateful to the families who trust me with the story of their special baby and who know I will work hard to make changes on their behalf. They have a strength and courage that I admire and I feel honored that they are willing to share what they have been through with me. The love these families have for the babies they have lost is a beautiful thing to witness.



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Child Death Review Commissioners:

<p align="center">The State Attorney General 31 Del. C. § 321 (a) Sonia Augusthy, Esq., Deputy Attorney General, Designee</p>	<p align="center">The State Medical Examiner 31 Del. C. § 321 (a) Rebecca D. Walker, Ph.D., J.D., M.S.N., Designee</p>
<p align="center">The Secretary of the State Department of Health and Social Services 31 Del. C. § 321 (a) Vacant</p>	<p align="center">The Director of the Division of Public Health 31 Del. C. § 321 (a) Mawuna Gardesey, Public Health Administrator, Designee</p>
<p align="center">The Secretary of the State Department of Services to Children, Youth and Their Families 31 Del. C. § 321 (a) Trene Parker, Director, Division of Family Services Designee</p>	<p align="center">The Chief Judge of the Family Court 31 Del. C. § 321 (a) The Honorable Joelle Hitch, Judge, Designee</p>
<p align="center">Office of the Child Advocate 31 Del. C. § 321 (a) Tania Culley, Esq., Child Advocate</p>	<p align="center">The Superintendent of the Delaware State Police 31 Del. C. § 321 (a) Corp. Adrienne Owen, Designee</p>
<p align="center">Chair of the Child Protection Accountability Commission 31 Del. C. § 321 (a) Jennifer Donahue, Esq., Investigation Coordinator, Designee</p>	<p align="center">A Representative of the Medical Society specializing in Pediatrics 31 Del. C. § 321 (a)(1) Amanda Kay, M.D.</p>
<p align="center">The State Secretary of Education 31 Del. C. § 321 (a) Susan Haberstroh, Director, Policy and External Affairs Designee</p>	<p align="center">A Representative of the New Castle County Police Department 31 Del. C. § 321 (a)(5) Lt. Michael Bradshaw, Family Services Unit</p>
<p align="center">A Representative of the Medical Society specializing in Neonatology 31 Del. C. § 321 (a)(1) David A. Paul M.D., Pediatric Chair at Christiana Care</p>	<p align="center">Two Child Advocates from State-wide Nonprofit Organizations 31 Del. C. § 321 (a)(6) Vacant Leslie Newman, C.E.O., Children & Families First</p>

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<p>A Representative of the Medical Society specializing in Obstetrics 31 Del. C. § 321 (a) (1) Philip Shlossman, M.D.</p>	<p>A Representative of the Police Chief's Council of Delaware who is an Active Law Enforcement Officer 31 Del. C. § 321 (a)(4) Chief Laura Giles, Elsmere Police Department</p>
<p>A Representative of the Medical Society specializing in Perinatology 31 Del. C. § 321 (a)(1) Garrett Colmorgen, M.D., Chair of the Commission</p>	<p>A Chairperson of each Regional Child Death Review Panel 31 Del. C. § 321 Mary Anne Crossley, R.N., SDY MDT Chair Kate Cronan, M.D., SDY Advanced Chair Amanda Kay, M.D., SDY Co-Chair Philip Shlossman, M.D., CDR Panel Chair</p>
<p>A Representative of the Delaware Nurses Association 31 Del. C. § 321 (a) (2) Nancy Forsyth, R.N.</p>	<p>A Chairperson of the Maternal Mortality Review 31 Del. C. § 321 Garrett Colmorgen, M.D., Chair Vanita Jain, M.D., Co-Chair</p>
<p>A Representative of the National Association of Social Workers 31 Del. C. § 321 (a) (3) Fran Franklin, D.S.W.</p>	<p>A Chairperson of each Fetal and Infant Mortality Review Case Team 31 Del. C. § 321 (a) Aleks Casper, New Castle County Chair Patricia Ciranni, R.N., Kent/Sussex County Chair</p>

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CDR Panel Members:

Addie Asay
Angela Birney
Kevin Bristowe, MD
Jane Boyd
Cpl. Roger Cresto
Maureen Ewadinger, RN
Nanette Holmes
Capt. Melissa Hukill
Lt. Richard Jefferson
Maureen Monagle
Sgt. Robert Roswein
Phillip Shlossman, MD, Chair
Renee Stewart
Cpt. Peter Sawyer
Ophelia Wallace

SDY First Level Panel:

Addie Asay
Cpl. Joseph Aube
Remi Adepoju, APN
Angela Birney
Alice Coleman, LCSW
Mary Ann Crosley, RN, SDY Chair
Det. Hector Garcia
Stewart Krug
Det. Kevin Mackie
Det. Paul Simonds
Det. Josh Smith
Natasha Smith
Renee Stewart
Det. Mary Quinn

SDY Advanced Medical Panel:

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Gary Collins, MD
Ember Crevar, MD
Kate Cronan, MD, Chair
Stephanie Deutsch, MD
Stephen Falchek, MD
Kristi Fitzgerald, MS, LCGC
Karen Gripp, MD
Amanda Kay, MD, Co-Chair

Bradley Robinson, MD
Joel Temple, MD
Takeshi Tsuda, MD

MMR CRT members:

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Elizabeth Brown, MD
Aleks Casper
Melanie Chichester, RN
Margaret Chou, MD
Patricia Ciranni, RN
Gary Collins, MD
Garrett Colmorgen, MD, Chair
Mary Ann Crosley, RN
Linda Daniel, RN
Lindsey Davis, MD
Sandy Elliott, RN
Fran Franklin, DSW
Larry Glazerman, MD
David Hack, MD
Matthew Hoffman, MD
Khaleel Hussaini, PhD
Vanita Jain, MD, Co-Chair
Lenaye Lawyer, MD
Julia Lawes, Esq.
Pamela Laymon
Starr Lynch, RN
Douglas Makai, MD
Rita Nutt, RN
Megan O’Hara, LCSW
David A. Paul, MD
Kim Petrella, RN
Treneee Parker
Elizabeth Romero, MS
Karyl Rattay, MD
Crystal Sherman
Phillip Shlossman, MD
Natasha Smith
Lesley Tepner, RN
Michael Vest, MD
Leah Woodall
Law Enforcement as relevant on case-by-case basis

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2019 NCC FIMR CRT:

Mychal Anderson-Thomas, MD
Heather Baker, RN
Aleks Casper, Chair
Janet Coston, RN
Andrew Ellefson, MD
Barbara Hobbs, RN, Co-Chair
Emily Haas Katzen, LCSW
Judith A. Moore, RN
Nancy O'Brien, RN
Kim Petrella, RN
Aubrey Rogers, RN
Breanna Thomas
Patricia Szczerba, RN
Lesley Tepner, RN
Natasha Smith
Adriana Viveros

2019 K-S FIMR CRT:

Kathleen Adams, RN
Margaret-Rose Agostino, DNP, MSW, RN-BC
Linda Brauchler, RN
Bridget Buckaloo, RN, Co-Chair
Stephanie Cantres
Patricia Ciranni, RN, Chair
Theresa Crowson, RN
Kathy Doty, RN
Maureen Ewadinger, RN
Judith Gorra, MD
Nanette Holmes, RN
Karen Kelly, RN
Jennifer Lilje, RN
K. Starr Lynch, RN
Robert Monaghan, RN
Carrie Snyder, RN
Melody Wireman, RN
Rebecca Whitman, RN

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