

# UNDERSTANDING HOW AND WHY CHILDREN DIE

## INTRODUCING THE CHILD DEATH REVIEW CASE REPORTING SYSTEM

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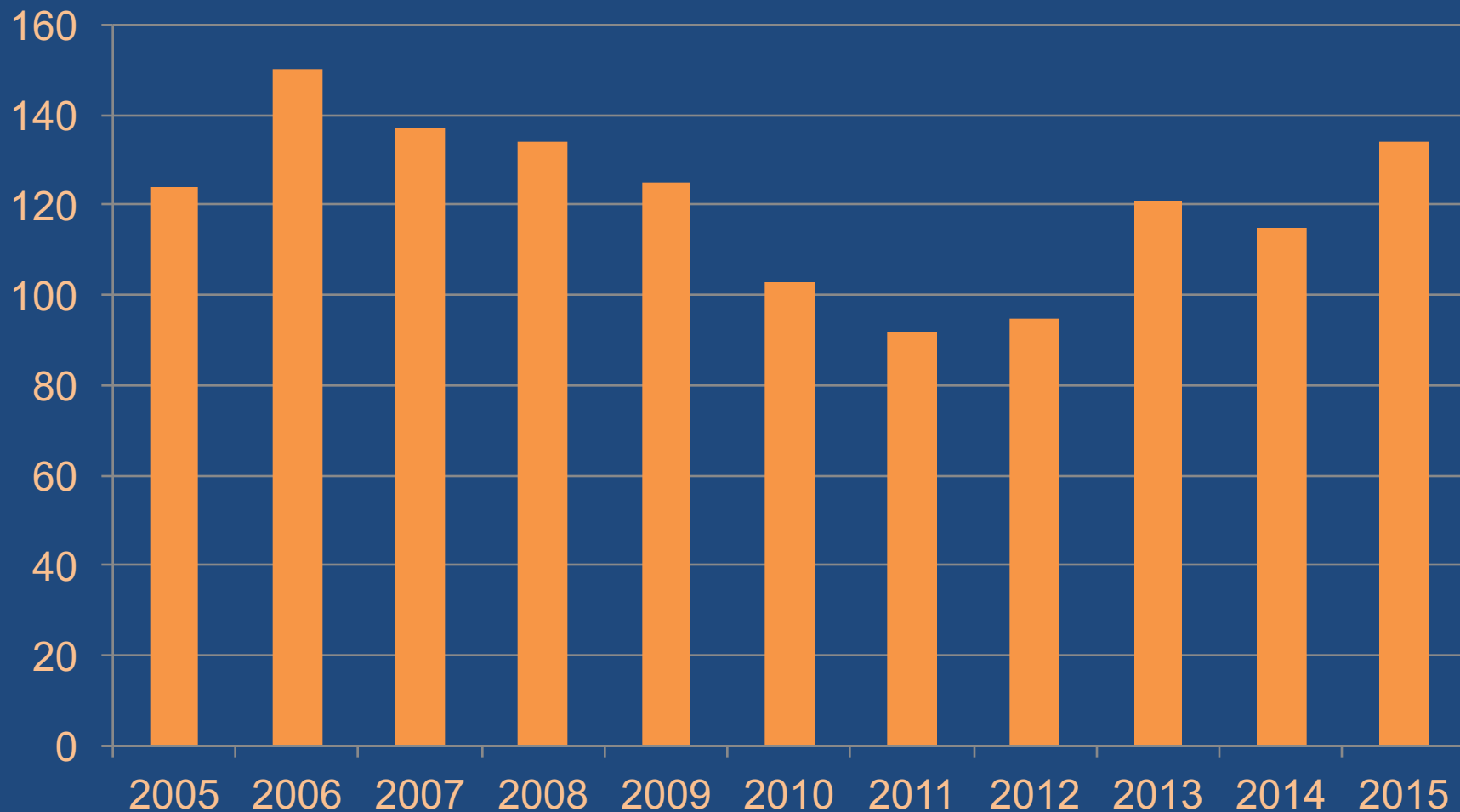
State of Alaska



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2016



# NUMBER OF INFANT AND CHILD DEATHS (0-<18) 2005-2015



Source: BVS

# ALASKA'S MATERNAL AND CHILD DEATH REVIEW PROGRAM

- MCDR (formerly known as MIMR-CDR) began in 1991.
- Alaska is unusual in that our maternal death review and child death review are housed in the same program.
- MCDR committee reviews the following types of deaths:
  - Any Pregnancy-Associated death: a woman who dies within one year of being pregnant, regardless of cause.
  - Any infant who leaves the hospital of his or her birth, including hospital transfers.
  - Any child death (extended to age 18, starting this year).
- The ultimate goal of the MCDR program is to develop data informed recommendations aimed at preventing future deaths and improving the health and safety of Alaskan mothers and children.

# ALASKA MCDR

- Complete case files are compiled for each death, then reviewed by a committee of medical and other professionals.
  - By statute, at least 75% of committee members must be medical professionals.
  - Other members include OCS members, epidemiologists, etc.
- MCDR committee members serve on a voluntary basis and are approved by the DHSS Commissioner and Medical Board.

# MCDR GOALS AND OBJECTIVES

- Overarching Goal: Reduce infant, child and maternal mortality in Alaska by better understanding the factors associated with each death through a committee review process.
- Program Objectives:
  - Perform statewide epidemiological surveillance concerning infant, child and maternal deaths in Alaska.
  - Conduct comprehensive data analyses.
  - Use MCDR committee findings to inform public policy and improve established public health initiatives and programs.
  - Document patterns of preventable infant, child and maternal mortality.
  - Educate health care providers regarding diagnostic, therapeutic, and preventative strategies recommended by the committee to reduce infant, child and maternal mortality.

# MCDR INFORMATION COLLECTION PROCESS



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# WHY DO WE REQUEST RECORDS?

- In Alaska, case files are created for each death and brought to a monthly committee review.
- The case files provide information surrounding the social, legal, and medical circumstances of each individual.
- This allows multi-disciplinary committees to review aspects of cases with which they would not otherwise be familiar.

# HOW ARE WE NOTIFIED OF A DEATH?

- The Bureau of Vital Statistics (BVS)
  - Provides a monthly report of all deaths that fall under our purview.
    - Information provided in these reports are complete and accurate but there is a lag in notification.
- Medical Examiner's Database
  - The Medical Examiner investigates deaths that are:
    - Sudden, when a person is in apparent good health.
    - Not under the care of a physician.
    - Suspicious, unusual or unexplained.
    - All deaths that are not due to a natural cause (accidents, homicides, suicides, etc.)
  - We monitor this throughout the week for our priority cases.



# PRIORITIES FOR IMMEDIATE DATA COLLECTION

- SUID remains the leading cause of post-neonatal mortality in Alaska.
  - We applied for, and received, a SUID grant that requires a 90 day turn around from notification to review.
  - We use the Medical Examiner's Database to get a "jump start" on these cases.

# TIMELINESS

- While SUID cases are currently our top priority cases, we strive for increased timeliness for all reviews, in particular:
  - Suicides
  - Drownings
- When cases can be reviewed within a few months of notification, it helps us track real-time trends and make immediate recommendations.

# TYPES OF RECORDS REQUESTED

- Death Certificates
- Birth Certificates
- Autopsy reports
- Medical Examiner's investigations
- Law Enforcement reports and scene photos
- Sudden Unexplained Infant Death Reporting Form (SUIDRF)
- Medical records
  - Primary care records
  - OB-GYN records
  - Newborn bloodspot screenings
  - Out of state medical records
- Mental and behavioral health records
- Office of Children's Services reports
- Department of Juvenile Justice System records
- Pregnancy Risk Assessment Monitoring System (PRAMS) surveys
- Childhood Understanding Behaviors Survey (CUBS) results
- Courtview records
- Internet
  - News articles
  - Obituaries
- Social media
  - Facebook, Instagram, and Myspace

# WHERE IMPROVEMENTS CAN BE MADE

- Education records
  - Family Educational Rights and Privacy Act (FERPA) prevents the release of records to us.
- Mental and behavioral health records.
  - These records have historically been difficult to obtain due to Health Insurance Portability and Accountability Act (HIPAA) wording.
- Toxicology testing
  - Currently the Medical Examiner is only financially able to run toxicology testing in certain cases.
- Law Enforcement reports
  - We are unable to obtain reports until cases are finished in court, which can be several years.

# WHAT DO WE DO ONCE A CONSENSUS IS COMPLETED?

- Abstract information from the records and enter de-identified information in the national database.
- Analyze the data to help prevention efforts.

# MCDR MEETINGS

- MCDR committee meetings are held once a month.
  - Deaths are reviewed as soon as complete records can be compiled.
  - This allows for more “real-time” prevention recommendations.
  - Each monthly review has a subset of the MCDR committee present, and deaths are not grouped by specific cause or manner of death.
- Annual Meeting:
  - Deaths are reviewed in topic-specific groups.
  - This allows specialists who may not be available to come on a monthly basis to review cases that fall under their purview.
  - The extensive and highly condensed process exposes a larger number of reviewers to the diverse events that lead to deaths in Alaska.
  - Culminates in the creation of individual recommendations.

# DATA COLLECTION AND STORAGE

- In order to identify trends over time, data must be collected consistently and stored in an accessible form.
- Until October of 2015, Alaska's Child Death Review data were stored in a state-specific data collection tool.
  - Pros: We were able to customize the data collection form to suit the needs of the state and the committee members.
  - Cons: Hard to compare to national data, and sometimes hard to analyze.
- We made the decision to switch to a national database last fall.
  - We are exploring the possibility of switching the Maternal Death data to a similar national database.

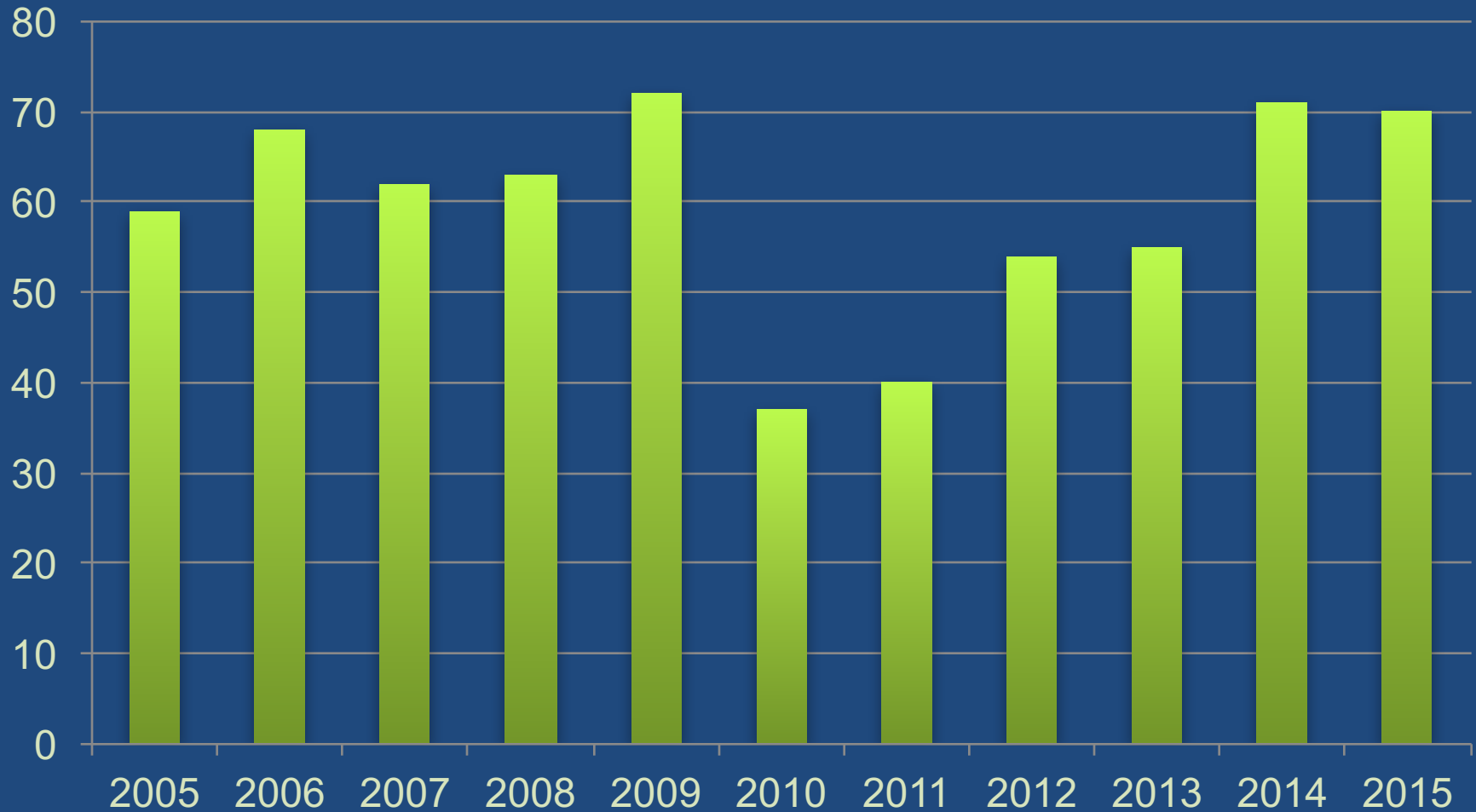
# CASE REPORTING SYSTEM

- The National Center for Fatality Review and Prevention (CFRP) maintains the Child Death Review Case Reporting System (CRS) .
  - 43 states now use this database to report child deaths.
  - The CRS allows us to track demographic information, as well as details about the circumstances surrounding each death.
    - OCS history of child and family
    - Education level of child and caregivers
    - Criminal history of caregivers
    - Child's health history.
    - For infants: maternal health during pregnancy.
- This allows for consistent collection of the same data elements for each case.

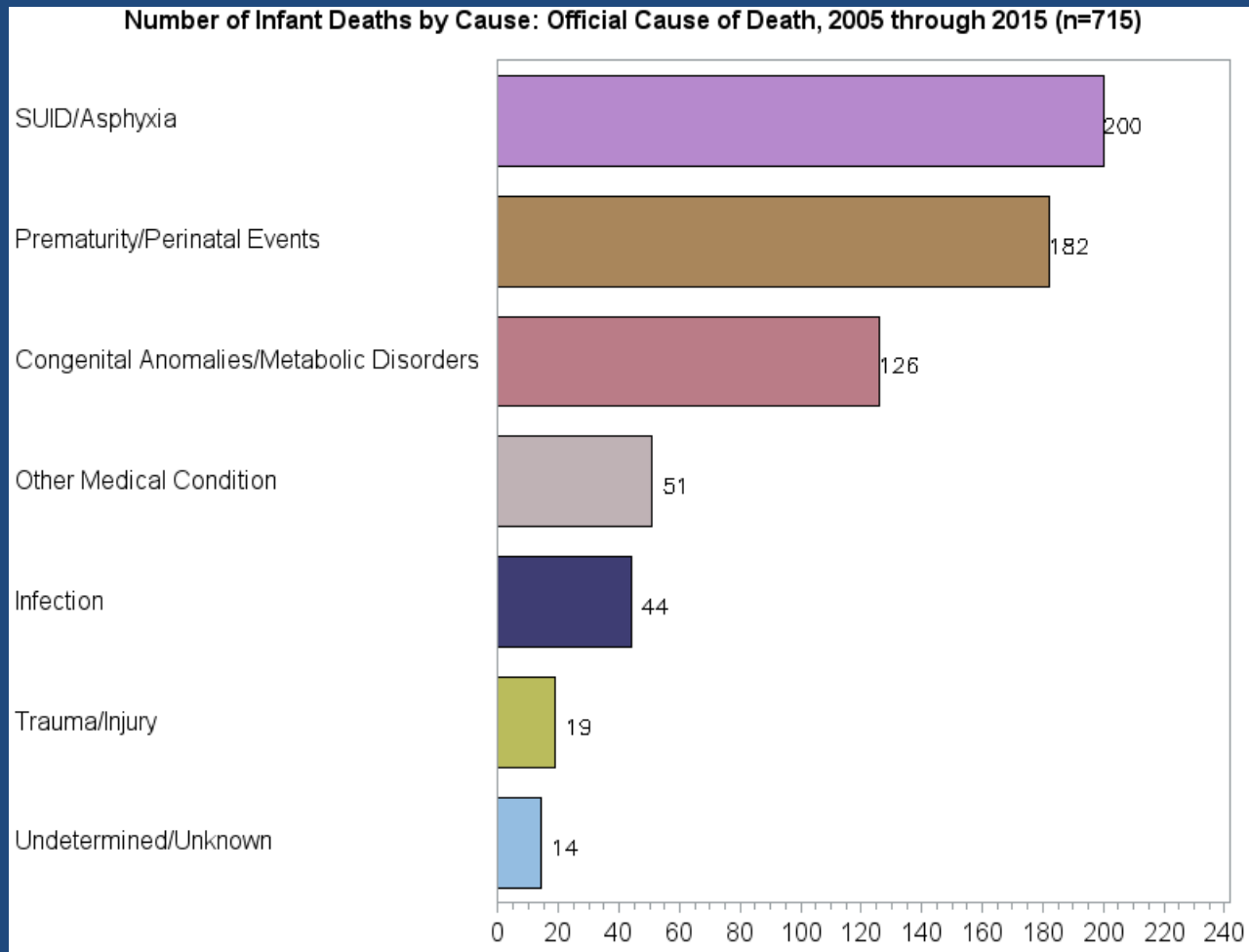


# NUMBER OF INFANT DEATHS 2005-2015

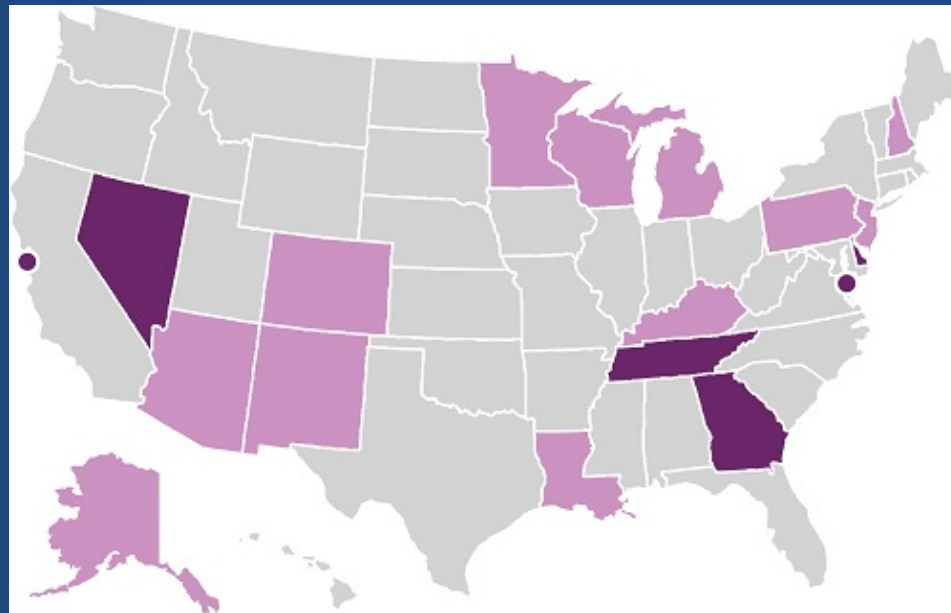
SOURCE: BVS



# SUDDEN UNEXPECTED INFANT DEATH (SUID)



# SUDDEN UNEXPECTED INFANT DEATH GRANTEES



- Alaska received a SUID grant from CDC.

# SUDDEN UNEXPECTED INFANT DEATH (SUID)

- Sudden Unexpected Infant Death (SUID) remains a significant problem in Alaska.
- MCDR received a small grant from CDC to help us review and classify SUID deaths.
  - MCDR must identify all SUID cases within Alaska within 30 days of the death.
  - Each SUID case should be reviewed within 90 days of case identification.
  - SUID deaths should be classified according to the CDC's algorithm.
    - Death certificates are coded in such a way that most such deaths are simply coded as "SIDS," which is not very specific or helpful.

# ALASKA SUID CASES IN THE CASE REPORTING SYSTEM (CRS) N=48

Category	Percent
Excluded (other explained causes, not suffocation)	8.3%
Unexplained: No autopsy or death scene investigation	--
Unexplained: Incomplete case information	4.2%
Unexplained: No unsafe sleep factors	2.1%
Unexplained: Unsafe sleep factors	18.8%
Unexplained: Possible suffocation with unsafe sleep factors	35.4%
Explained: Suffocation with unsafe sleep factors	31.3%

# RISK FACTORS AMONG SUICIDE DEATHS IN CASE REPORTING SYSTEM N=48

Risk Factor	Percent
Infant's supervisor was intoxicated--alcohol	41.7%
Infant was sleeping on an adult bed when found deceased	60.4%
Infant was sharing a sleep surface with another person when found deceased	70.8%
Caregiver fell asleep while feeding infant	12.5%
Infant known to have been ill within two weeks preceding death	41.7%
Parents/Caregivers had OCS history	41.7%

# CHILD AND YOUTH DEATHS

SOURCE: BVS

Manner of Death	Number of Deaths	Percent
Accident	255	41.5%
Natural	193	31.4%
Suicide	88	14.3%
Homicide	46	7.5%
Could not be determined (CNBD)	23	3.7%
Pending investigation/Data entry errors	10	1.6%

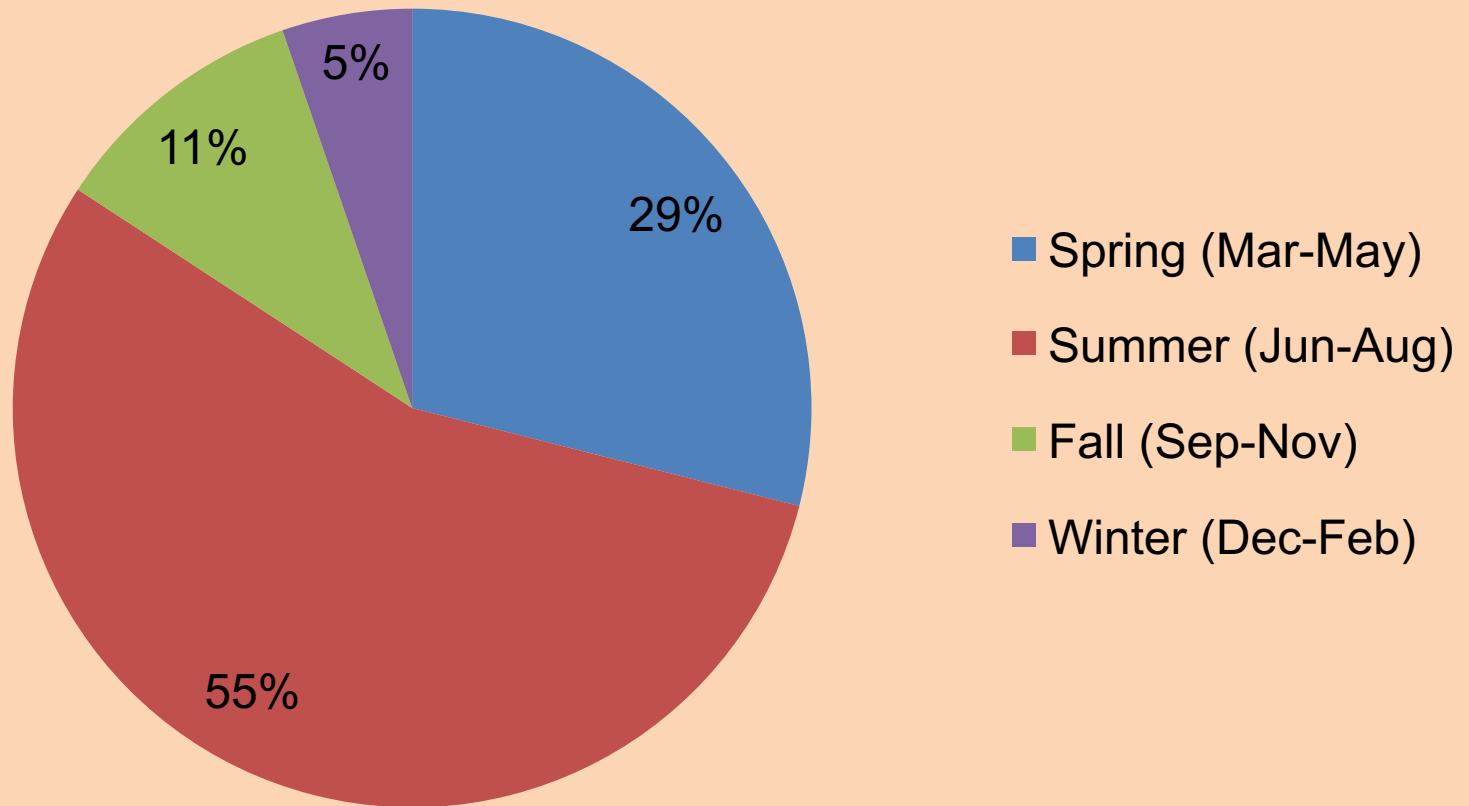
# DROWNING DEATHS AMONG CHILDREN

- The second most frequent cause of accidental death (after motor vehicle accidents) is drowning.
- Alaska has 3,000,000 lakes and over 30,000 miles of coastline...along with other, Alaska-specific hazards, such as sewage lagoons.
- Different risk profiles for different ages:
  - Although all ages are most likely to drown outside in open water different ages have different profiles.
  - Infants/Pre-schoolers: Only age group that drowns inside (bathtubs, buckets)
  - Elementary School Students: often drown in open water when caregiver is temporarily distracted.
  - Teenagers generally fall into three categories:
    - Those who are swimming and get overwhelmed.
    - Those who are intoxicated and fall into the water.
    - Those who break through ice in a vehicle/snow machine and drown.



# CHILD DROWNINGS BY SEASON

## ALASKA 2005-2015



# DROWNINGS IN CRS

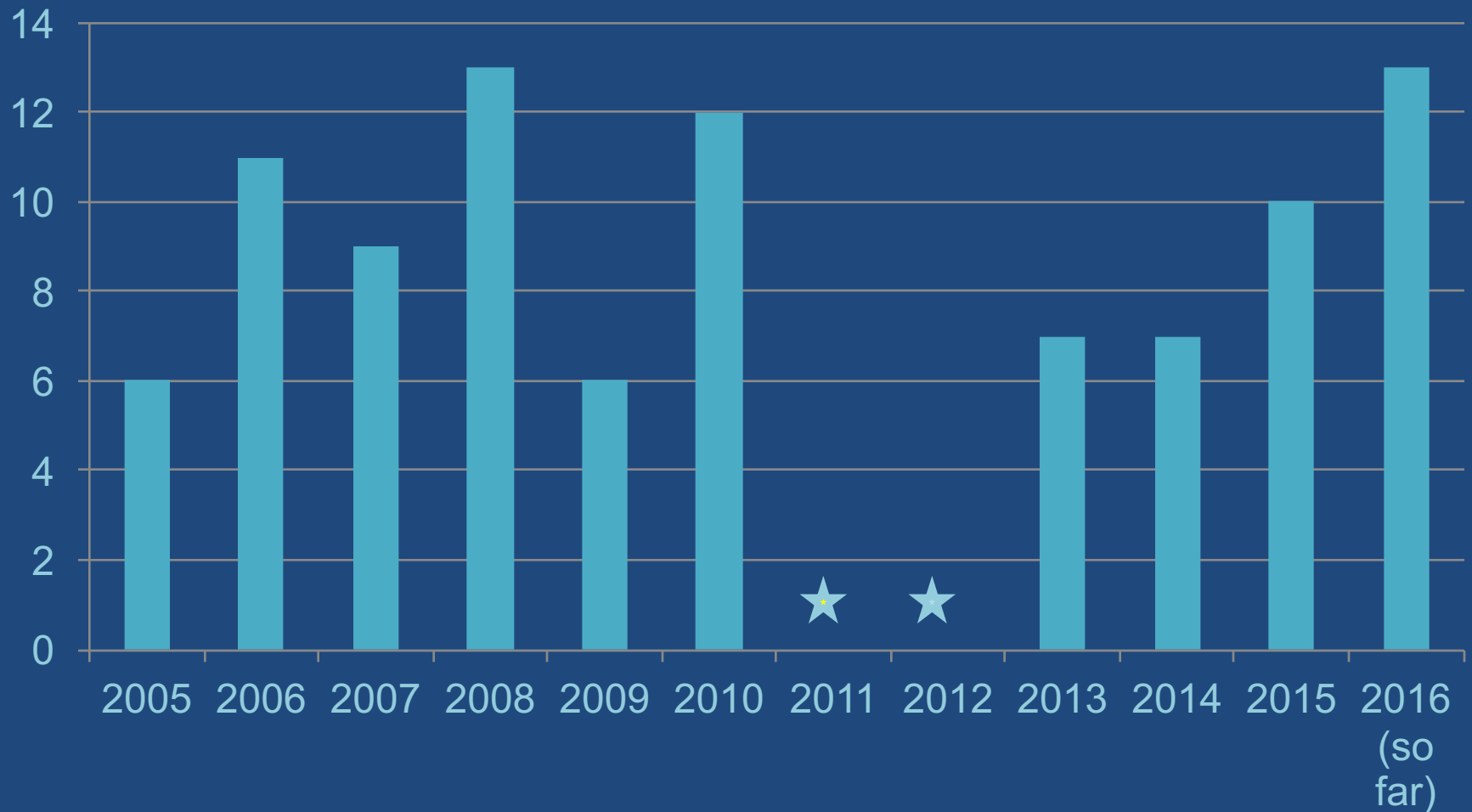
- The Case Reporting System collects specific data about each death.
  - Location of drowning (e.g. open water, pool, bathtub)
  - Child's last known activity before drowning
  - Whether child was wearing a personal flotation device
  - Contributing environmental factors (e.g. water temperature, current)
  - Whether someone tried to rescue child, and whether appropriate rescue equipment was present.
    - Throw rings at Kids Don't Float stations.

# PRELIMINARY DROWNING DATA

- So far, 18 drowning deaths have been entered in the CRS.
- Of these 18, none were using an approved personal flotation device.
  - One infant was using a bathing aide.
- The most common activity for a child to have been engaged in prior to drowning was playing near the water, as opposed to swimming or boating.
- Open water (most commonly lakes, creeks or rivers) were the most common place of drowning.
- MCDR has been talking to the Kids Don't Float program staff about how to increase awareness of the need for flotation devices among children who are playing near water, regardless of whether parent expects child to enter water.

# ANNUAL NUMBER OF SUICIDES 0-<18

DATA SOURCE: BVS



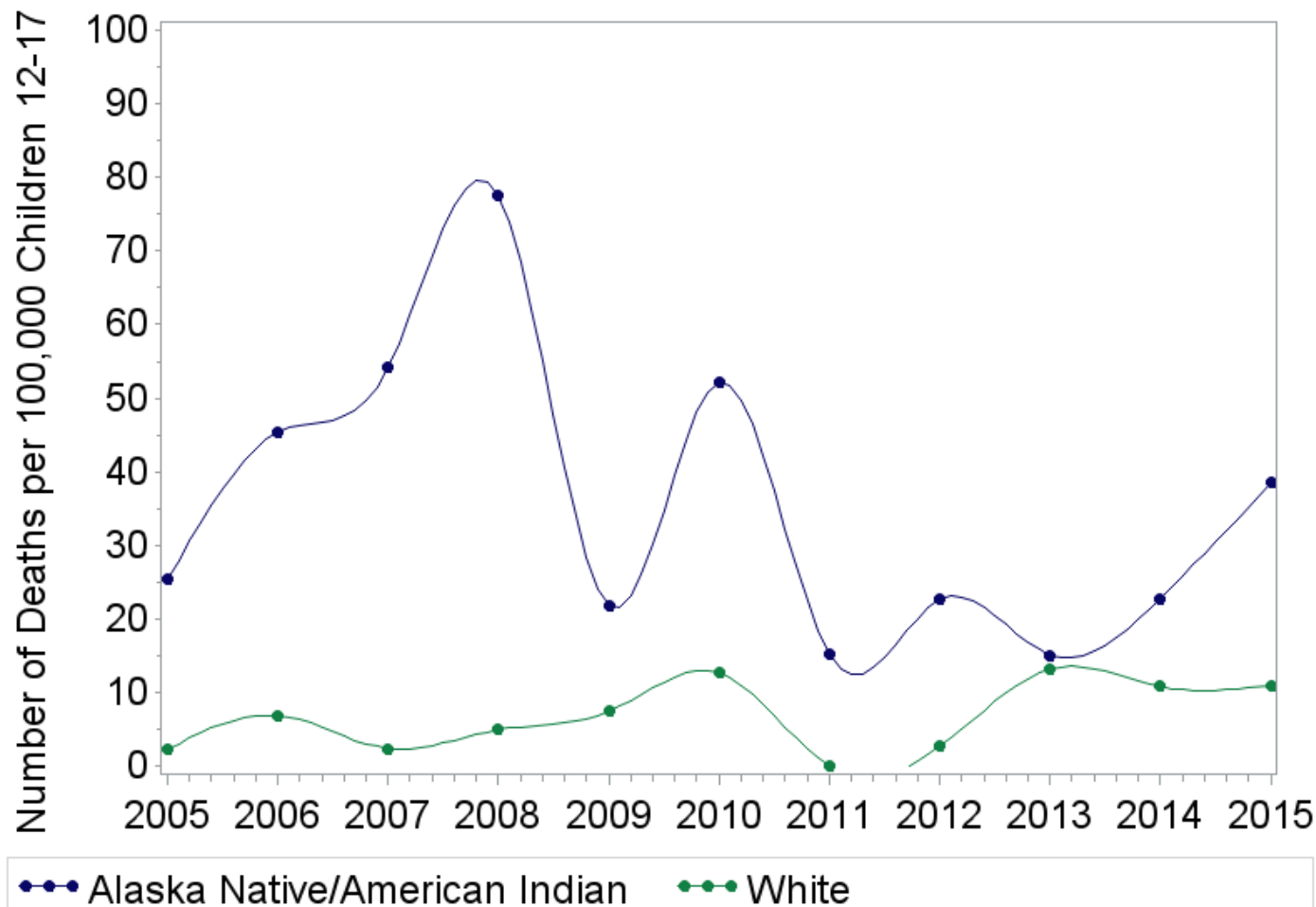
# ALASKAN YOUTH SUICIDES 2005-2015

- Before 2016, MCDR reviewed deaths from children aged 0-14 years.
- This means that most of the youth suicides were not being reviewed.
- We therefore started reviewing youth deaths 0-<18 starting in January.

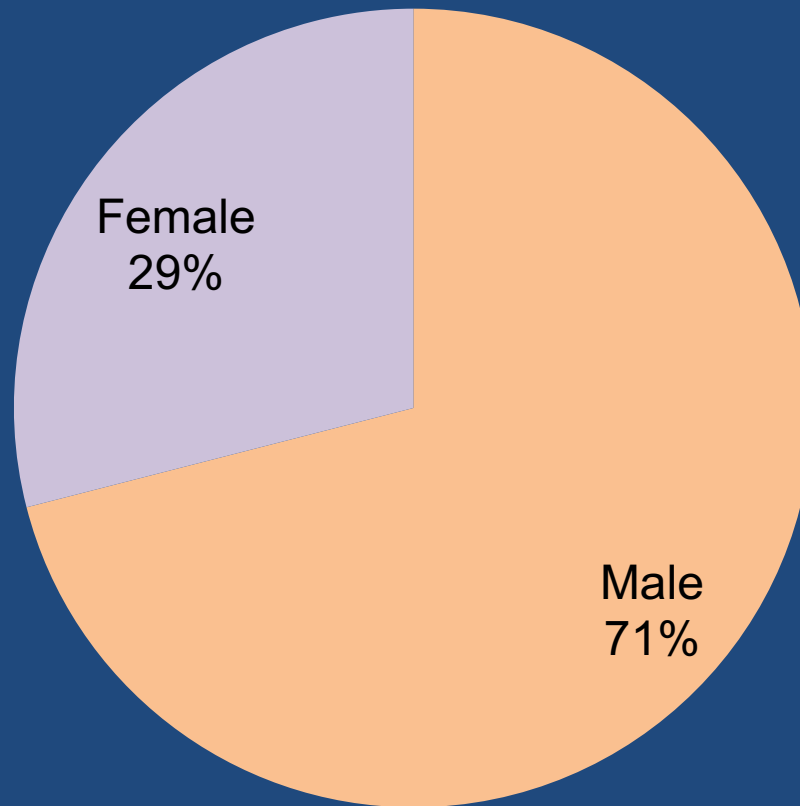
Age	Number of Suicides	Percent of Youth Suicides
<13	*	*
13	7	7.9%
14	7	7.9%
15	22	24.7%
16	23	25.8%
17	29	32.6%

# YOUTH SUICIDE BY RACE 2005-2015

## Suicides in Children Under Age 18 by Race, 2010 to 2015



# ALASKAN SUICIDES 0-<18 BY SEX 2005-2015



# SUICIDE DATA ELEMENTS

- The Case Reporting System collects extensive data on the circumstances surrounding each suicide.
  - Characteristics of method used to take each life (e.g. firearm caliber, strangulation/hanging ligature, etc.)
  - What acute or cumulative personal crises led up to the suicide?
  - Social and Medical history of child.
    - Was there a previously diagnosed mental health condition?
    - Were there prior attempts/threats of suicide, or was suicide completely unexpected?
    - Did child have a history of self-mutilation?
    - Had there been other suicides in the family?
    - Was suicide part of a cluster?



# ALASKAN YOUTH SUICIDES

- Alaska does not yet have enough cases entered in the CRS to draw firm conclusions about the specific circumstances surrounding youth suicides.
- We do know that males are more likely to die by firearms, whereas females are more likely to die by strangulation/hanging.
- Preliminary data suggest that the majority of youth who die by suicide have talked about or threatened suicide before their death.
- MCDR will continue to collect data surrounding these deaths with the hope of identifying risk factors and points of intervention.

# CONCLUSIONS

- Alaska has unique challenges to maternal, infant, and child safety.
- The Case Reporting System allows the MCDR program to track very specific details of each child death.
- Data analyses using these details can help identify concerning trends and potential points of intervention.
- MCDR seeks to provide data to support prevention programs and efforts.

# CONTACT INFORMATION

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