Purpose of the SDY Case Registry

CDC and NIH developed the SDY Case Registry to count the number of cases and understand the causes and risk factors for infants, children and young adults who die suddenly and unexpectedly, and to inform strategies to prevent future deaths.

SDY Case Flow

Phase 1: SDY Case Registry
- SDY occurs
- Forensic Pathologist collects sample for DNA extraction
- Child Death Review team reviews all cases
- Advanced Review team categorizes cases
- Incidence calculated, high risk groups identified for prevention

Phase 2: Research
- Build on existing Child Death Review programs to develop a surveillance system for SDY cases
- Conduct Advanced Review (clinical and forensic) to categorize SDY cases
- Collect and store DNA for future research, banking, and diagnostic testing

Not currently a grantee, but interested in SDY?
- Use the National Child Death Review Case Reporting System to monitor SDY cases - all Child Death Review teams have access to the SDY Case Registry variables.
- Encourage forensic pathologists to use the SDY Case Registry Autopsy Guidance/Summary, and save blood and/or tissue samples for future DNA testing by families or medical examiners.

SDY Case Registry Grantees, 2014-2018
Delaware, Georgia, Minnesota, New Jersey, New Hampshire, Nevada, Tennessee, and selected jurisdictions in California, Virginia, and Wisconsin