

**Children's Hospital Boston SUDC/SIDS clinic**  
**Ingrid Holm, MD, MPH**  
**Annapurna Poduri, MD, MPH**

The Division of Genetics at Children's Hospital Boston, in collaboration with the Departments of Neurology and Pathology, has started a clinic for families of children who died of sudden unexplained death in childhood (SUDC), or SIDS. The clinic is under the direction of Dr. Ingrid Holm, a geneticist, and Dr. Annapurna Poduri, a pediatric neurologist. Dr. Mark Alexandra, a pediatric cardiologist, provides consultation as needed.

**SUDC**

Although the cause of SUDC is unknown in majority of children, there are some rare genetic conditions that can be associated with SUDC. The clinic provides genetic counseling for families in which other children may be at risk for SUDC, particularly families where there is evidence for a heart arrhythmia or metabolic disorder in the child who died or in other family members. In addition, the SUDC Research Project has found a higher than expected incidence of seizures, especially febrile seizures (classically considered benign seizures), in the child who died and in family members. In families in which the child who died had febrile seizures, and/or in which there is a family history of febrile seizures, we will evaluate siblings with a history of seizures (febrile or without fever) or with any other neurological concern (e.g., developmental delay). It should be noted that since the association between SUDC and febrile seizures is still being investigated, we can not make any general recommendations about the specific evaluation and treatment of febrile seizures in siblings of children who have died of SUDC.

The parents of the deceased child should attend the visit, as well as siblings of the deceased child. All families will be evaluated by Dr. Holm. If there is a history of seizures in the child who died or other family members, Dr. Poduri will also perform an evaluation.

Prior to the clinic visit families should do the following:

1. Collect and bring to the visit any records, including a medical examiner's report (if available) for the child who died
2. Talk to blood relatives regarding medical problems and issues, particularly heart problems (arrhythmias), metabolic disorders, seizures, other neurological problems, or deaths in infancy or childhood.
3. Fill out a "family survey" which we will send to each family prior to the visit.

During the clinic visit families can expect the following to occur:

1. A full review of family history to look for indications of cardiac arrhythmia, metabolic disease, seizures, or other developmental concerns.
2. An evaluation of all siblings of the child who died of SUDC including (as indicated):
  - a. Referral to a cardiology for ECG and to rule out Long QT syndrome
  - b. Metabolic testing
  - c. Rule out a seizure disorder if the child has a history of seizures or febrile seizures
3. Recommendations for testing of parents and siblings, as indicated
4. Counseling for future pregnancies, dependent on assessment of family history.

**SUDI/SIDS**

In addition to SUDC, the clinic will also evaluate families with a child who died of SIDS or sudden unexpected death in infancy (SUDI). While the cause of SIDS is unknown, there are several genetic disorders that present as SUDI and mimic SIDS. In these cases, upon ancillary testing at autopsy, a genetic/metabolic cause is discovered and the diagnosis is that of the specific genetic/metabolic disease. In cases of SUDI, Dr. Holm will investigate to rule out a genetic/metabolic disorder. In families where known genetic/metabolic diseases have been excluded and the case is classified as SIDS, especially if

other family members have died of SIDS, Dr. Holm will counsel families regarding risks to subsequent children, based upon current understanding.

Prior to the clinic visit families should do the following:

1. Collect and bring to the visit any records, including a medical examiner's report (if available) for the child who died
2. Talk to blood relatives regarding medical problems and issues, particularly heart problems (arrhythmias), metabolic disorders, seizures, other neurological problems, or deaths in infancy or childhood.

During the clinic visit families can expect the following to occur:

1. A full review of family history to look for indications of cardiac arrhythmia, metabolic disease, seizures, or other developmental concerns.
2. An evaluation of all siblings of the child who died of SIDS.SUDI including (as indicated):
  - a. Referral to a cardiology for ECG and to rule out Long QT syndrome
  - b. Metabolic testing
3. Recommendations for testing of parents and siblings, as indicated
4. Counseling for future pregnancies, dependent on assessment of family history.

For all visits to the clinic , a full report of the visit will be provided to the referring physician and to the family.

**To schedule an appointment, please call the Genetics clinic at 857.218.4637 and request an appointment for the SIDC/SUDC Clinic.**