



## **CARING FOR THE SUDC SIBLING WITH FEBRILE SEIZURES**

### **Facts on Febrile Seizures**

- Febrile Seizures (FS) occur in 2-4% of children in the general population between the ages of 6 months and 5 years. They are considered largely benign.
- Simple FS last < 15 minutes and do not recur within 24 hours. They are generally accepted to be benign and not associated with increased mortality, intellectual disability, or other neurological disorders. The risk of developing epilepsy in children with FS is only slightly higher than the general population. One of three children with simple FSs develop recurrent FS(s). The older the child or higher the fever at the time of the first seizure correlates with a lower risk of recurrence.
- Complex FS are focal (for example: convulsing of only one side), prolonged ( $\geq 15$  minutes), and/or recur within 24 hours. Among those with complex FS, 2-4% develop epilepsy.
- FS correlate with illness and usually with a rising fever, but the seizure may precede the fever.
- FS presentations vary and include tonic-clonic (stiffening followed by shaking), tonic (stiff), atonic (very limp), or staring during the seizure. Breathing may be affected.

The Current Standard of Care for the treatment of FS generally includes:

- Finding the source of infection and treating the infection when appropriate (e.g., bacterial pneumonia).
- Educate parents regarding recurrence, about 1/3 of children will have an additional FS.
- Rescue medications for prolonged or recurrent FS.

### **SUDC and FS (see Refs)**

- SUDC is a sudden death of a child older than 12 months that remains unexplained after a thorough investigation.
- Most SUDC occur in sleep and are unwitnessed.
- Most SUDC have symptoms of a minor illness before death or have evidence at autopsy.
- Outcomes for most children with febrile seizures are favorable, but sudden death registries suggest that simple febrile seizures are associated with increased mortality.
- In genetic analyses of SUDC, likely or definite causes are found in ~9% of cases, primarily in cardiac- and seizure-related genes.

## Considerations for SUDC Siblings with FS

We offer the below suggestions to discuss with your Pediatrician and/or Pediatric Neurologist who treats the SUDC sibling who has experienced simple or complex FS or in family with a history of SUDC and FS.

1) Consider “Rescue Medications”: anti-seizure medications readily available in case of a prolonged FS. These medications should be used if the FS lasts more than 3-5 minutes or earlier if the child has a history of prolonged FS. Since FS lasting >10-15 minutes are associated with an increased risk of seizures not related to fever (epilepsy), prolonged FSs should be stopped.

- Diastat is a brand of a rectal diazepam (aka ‘valium’) and is commercially available at pharmacies. Dosage: based on bodyweight and age.
- Nasal sprays are commercially available for older children Valtoco (diazepam;  $\geq 6$  years) Nazylam (midazolam; indicated for children  $\geq 12$  years). However, midazolam can be given compounded by a specialty pharmacy as a nasal spray or given between the lip and gum (buccally).. Dosage based on body weight and age.

2) Should home monitors with alarms be used to increase sleep supervision?

- While monitoring may detect convulsive seizures, they probably do not detect all seizures
- False alarms can occur and can disrupt sleep and cause anxiety for caregivers.
- Monitors can help reduce anxiety for some caregivers by providing some peace of mind but they can increase anxiety in others. As the grief of the loss of a child is unique to an individual-so is their coping of siblings with medical concerns. The support of mental health professionals can be helpful in this regard.
- The market on wireless pulse oximetry monitors with alarms, motion sense monitors, seizure monitors and related biometric monitors is growing rapidly.
- Monitor types include, but are not limited to:
  - Wireless Pulse Oximetry monitors with alarms
  - Motion Sensor Monitors; some specific for seizures
  - Motion Sensor and other devices that recognize various physiological markers such as temperature, heart rate, and breathing.
  - Wearable versus those in/around sleep surface
  - Video monitoring devices
  - For more information visit: [www.sudc.org](http://www.sudc.org).

\*Resource list for seizure detection monitors: [www.dannydid.org/sudep/devices-technology/](http://www.dannydid.org/sudep/devices-technology/)

**\*The SUDC Foundation does not endorse or recommend any specific monitoring device but rather includes the above as a resource for families. We recommend that families discuss the decision to use a monitoring device with their pediatrician and/or pediatric neurologist.**



### 3) Pediatric Neurologist Consultation

- Given the possible role of FS in some cases of SUDC based on personal and familial occurrence of FS in many cases, consultation with a pediatric neurologist should be considered for the SUDC sibling who had a FS. A Pediatric Neurologist consultation can provide a thorough evaluation of the child to confirm the diagnosis of a FS and differentiate the episode from other neurological disorders or a possible cardiac event (which would require a pediatric cardiologist referral-see #5). They can also provide recommendations for care.
- SUDC siblings who have not experienced a FS themselves: Since FS are almost always benign, most pediatric neurologists would not routinely recommend any testing or preventive strategy for a sibling who has never experienced a FS. However, parents may want to discuss a rescue medication in the event of a FS.

### 4) Prepare an emergency plan

- Create a plan and place it in easy viewing (e.g., refrigerator door) and a copy in each caregiver's wallet, child's backpack etc.
- The list might include: the names and telephone numbers of who to call when a problem arises, emergency department of preference for EMS, what items to take with the child to the ER (health and insurance card, medical history file, parent's name and contact information, medications, and snack foods that the child prefers to assist during long ER visits).

### 5) Ask pediatrician to evaluate the child to help exclude any cardiac causes that may be hereditary.

- Review the death investigation findings of child who died.
- Fever may provoke electrocardiographic (EKG) changes leading to ventricular arrhythmias (life-threatening heart rhythm disturbances like Long QT syndrome, Brugada Syndrome and CPVT), often misdiagnosed as seizures. The etiology is thought to relate to the effect of fever on ion channels in the cardiac cell membrane responsible for excitation and relaxation of the cell. Post mortem diagnosis requires a molecular autopsy which may not have occurred. Therefore, in the absence of any neurological findings on autopsy or clinical review of the deceased sibling, detailed evaluation of first-degree family members (parents and siblings) in a dedicated family cardiovascular genetics clinic is warranted to exclude the possibility of these conditions in other family members.



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