Please complete the following sections for the case identified above.
Strict confidentiality of information will be assured.

CASE DEFINITION FOR SUDDEN UNEXPECTED DEATH IN EPILEPSY
Report a sudden unexpected death in a child less than 18 years of age:
- with epilepsy (defined as >1 unprovoked seizure)
- with or without evidence of a recent seizure
- without documented status epilepticus
- without trauma

Definite SUDEP is defined as meeting above criteria, and a postmortem examination does not reveal a cause of death.
Probable SUDEP is defined as definite SUDEP, but without autopsy.

Please fill in the following:

Month of death: ________________________

SECTION 1 – DEMOGRAPHIC INFORMATION
1. Date of birth: ____ / ____ / ________
1.2 Age at death: ____ years ____ months
1.3 Sex: Male___ Female___
1.4 Place of residence (province/territory): ______________________________
1.5 Postal code of home address – First three digits only: ____ ___ ___
1.6 Handedness: Left___ right___ ambidextrous___ unknown___

SECTION 2 – FAMILY HISTORY
2.1 Epilepsy?  Yes No Unknown
   If yes, specify in who: ______________________________
2.2 Febrile seizures?  Yes No Unknown
   If yes, specify in who: ______________________________
2.3 SUDEP?  Yes No Unknown
   If yes, specify in who: ______________________________
2.4 SIDS?  Yes No Unknown
   If yes, specify in who: ______________________________
2.5 Other sudden unexpected death?  Yes No Unknown
   If yes, specify in who: ______________________________
2.6 Cardiac arrhythmia?  Yes No Unknown
   If yes, specify in who: ______________________________

SECTION 3 – LIFESTYLE FACTORS
3.1 Cigarette use by deceased?  Yes No Unknown
   If yes, specify: Number of years______ Packs per day______
3.2 Secondhand smoke exposure in family home
3.3 Alcohol use by deceased?  Yes No Unknown
   If yes, specify: Number of drinks per week: ______
3.4 Illegal drug use by deceased?  Yes No Unknown
   If yes, specify drug type: ______________________________
SECTION 4 – MEDICAL HISTORY

4.1 Height: _____ cm  Weight: _____ kg  Date obtained: _____ / _____ / ________

4.2 Typical sleep environment

4.2.1 Bed sharing?
   Yes  No  Unknown

4.2.2 Room sharing?
   Yes  No  Unknown

4.2.3 Regular nocturnal checks?
   Yes  No  Unknown

4.2.4 Pillow use?
   Yes  No  Unknown

4.2.5 Baby monitor use?
   Yes  No  Unknown

4.3 Age at first unprovoked seizure: _____ months  _____ years

4.4 Age at second unprovoked seizure: _____ months  _____ years

4.5 Epilepsy syndrome (see Appendix)?
   List all that apply:
   ____________________________________________________
   ____________________________________________________
   ____________________________________________________

4.6 Seizure types in month prior to death (see Appendix):

<table>
<thead>
<tr>
<th>Type</th>
<th>Date of last of this type</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DD / MM / YYYY</td>
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<td></td>
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</tr>
</tbody>
</table>

4.7 Past seizure types (see Appendix):

<table>
<thead>
<tr>
<th>Type</th>
<th>Date of last of this type</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DD / MM / YYYY</td>
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</tbody>
</table>

4.8 History of seizures during sleep?

   Yes  No  Unknown

   __ __ __

   How long ago was the last one? _____ days / months

   Type: ______________________

4.9 Were changes made to anticonvulsants within the last month?

   Yes  No  Unknown

   __ __ __

   If yes, explain: ______________________

4.10 Lifetime frequency of primary and secondary generalized tonic clonic (GTC) seizures:

   0   <10  10–100  100–500  >500  unknown

   __ __ __ __ __ __

4.11 Lifetime frequency of seizures other than GTC seizures:

   0   <10  10–100  100–500  >500  unknown

   __ __ __ __ __ __

4.12 Number of GTC in last year: __________

   in last six (6) months: __________

4.13 Medications prescribed at time of death (include anticonvulsants and other):

<table>
<thead>
<tr>
<th>Medication</th>
<th>Therapeutic drug monitoring within last 6 months?</th>
<th>Serum drug level within therapeutic range?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes   No  Unknown</td>
<td>Yes   No  Unknown</td>
</tr>
<tr>
<td></td>
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</tbody>
</table>
SECTION 4 – MEDICAL HISTORY (cont’d)

<table>
<thead>
<tr>
<th>4.14 Other epilepsy treatments</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.14.2 Underwent surgery for epilepsy?</td>
<td>___</td>
<td>___</td>
<td>___</td>
</tr>
<tr>
<td><strong>If yes</strong>, specify procedure(s) and date:</td>
<td>___ / ___ / ___ DD MM YYYY</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4.14 Other epilepsy treatments (cont’d)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>If yes</strong>, specify: ketogenic diet___ other___________</td>
</tr>
</tbody>
</table>

**If yes**, specify procedure(s) and date:

<table>
<thead>
<tr>
<th>4.15 Diet therapy for epilepsy?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>If yes</strong>, specify: ketogenic diet___ other___________</td>
</tr>
</tbody>
</table>

Age at initiation: _______ months / years

Age at discontinuation: _______ months / years

<table>
<thead>
<tr>
<th>4.16 Vagal nerve stimulator?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>If yes</strong>, specify type: _______</td>
</tr>
</tbody>
</table>

Age of initial implant: _______ months / years

<table>
<thead>
<tr>
<th>4.17 Other device implantation for epilepsy?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>If yes</strong>, specify type: _______</td>
</tr>
</tbody>
</table>

Age of initial implant: _______ months / years

<table>
<thead>
<tr>
<th>4.18 Other past history (check all that apply):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention deficit disorder ___ Autism spectrum disorder ___</td>
</tr>
<tr>
<td>Global developmental delay ___ School performance (special accommodation) ___</td>
</tr>
<tr>
<td>Language skills: developmentally appropriate___ delayed but verbal___ non verbal___</td>
</tr>
<tr>
<td>Motor skills: developmentally appropriate___ ambulate with assistance___ non ambulatory___</td>
</tr>
<tr>
<td>Near SIDS___ Near SUDEP___</td>
</tr>
<tr>
<td>Neurologic: migraine___ stroke___ brain tumor___ neurotrauma___ other___________</td>
</tr>
<tr>
<td>Blood-borne cancer___ Cardiac: syncope___ other___________ Diabetes___ Obesity___</td>
</tr>
<tr>
<td>Psychiatric: anxiety___ depression___ other___________</td>
</tr>
<tr>
<td>Respiratory: asthma___ chronic lung disease___ other___________</td>
</tr>
<tr>
<td>Rheumatological/inflammatory condition(s): ___ specify: ________________</td>
</tr>
<tr>
<td>Sleep disorder___ Obstructive sleep apnea___</td>
</tr>
<tr>
<td>Status epilepticus___ date of last episode: ___ / ___ / ___ DD MM YYYY</td>
</tr>
</tbody>
</table>

SECTION 5 – LABORATORY INVESTIGATIONS

<table>
<thead>
<tr>
<th>5.1 EEG?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>If yes</strong>, specify findings: ____________________________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.2 MRI?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>If yes</strong>, specify findings: ____________________________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.3 EKG?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>If yes</strong>, specify findings: ____________________________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.4 Echocardiogram?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>If yes</strong>, specify findings: ____________________________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.5 Holter monitoring?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>If yes</strong>, specify findings: ____________________________</td>
</tr>
</tbody>
</table>

SECTION 6 – CIRCUMSTANCES AROUND DEATH

<table>
<thead>
<tr>
<th>6.1 Time of death, if known: __________ (24-hr clock)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>6.2 Time subject found dead: __________ (24-hr clock)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>6.3 Activity at time of death: asleep___ awake___ unknown___</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>If awake</strong>, specify position found in at death:</td>
</tr>
<tr>
<td>prone___ supine___ on side___ unknown___</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6.4 Was subject home alone?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>If yes</strong>, proceed to 6.7</td>
</tr>
<tr>
<td>-----------------------------</td>
</tr>
</tbody>
</table>
SECTION 6 – CIRCUMSTANCES AROUND DEATH (cont’d)

6.5 Was a seizure witnessed around the time of death?
   __ Yes __ No __ Unknown __
   If not witnessed, was there evidence of a recent seizure?
   If yes, specify: incontinence ___ bedding ___ tongue bite ___
   unusual positioning ___ blood on pillow ___
   other

6.6 Was death witnessed?
   __ Yes __ No __ Unknown __
   If yes, specify place of death:
   Home – in bed ___ other ______________________________
   Residential facility – in bed ___ other __________________
   Hospital – epilepsy monitoring unit ___ inpatient wards ___
   Elsewhere – in bed (e.g., hotel) ___ other __________________

6.7 Was CPR attempted?
   __ Yes __ No __ Unknown __
   If yes, specify by whom: ___________________________________

6.8 Medications taken in the last 24 hours:
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

6.9 Change in usual routine, including sleep environment?
   __ Yes __ No __ Unknown __
   If yes, explain: _________________________________________

6.10 Was there a recent infection/illness/fever?
   __ Yes __ No __ Unknown __

6.11 Were family/caregivers aware of SUDEP?
   __ Yes __ No __ Unknown __

6.12 Was the Coroner/Medical Examiner informed?
   __ Yes __ No __ Unknown __

6.13 Was an autopsy performed?
   __ Yes __ No __ Unknown __
   If yes, specify cause of death on report: ________________________
   ________________________
   ________________________
   ________________________
   If cause of death is not yet available, please provide when available
   __________________________________________________________

   _____ I agree to be contacted by the CPSP for further information on this questionnaire.
   _____ I do not wish to be contacted by the CPSP for further information on this questionnaire.

SECTION 7 – REPORTING PHYSICIAN

First name ____________________________ Surname ____________________________
Address ________________________________
City ____________________________ Province ____________________________ Postal code __________
Telephone number ______________________ Fax number ______________________
E-mail ________________________________ Date completed ______________________

Thank you for completing this form.

SUDEP 2014/01
SUDEP Appendix

EPILEPSY SYNDROMES

1. Benign familial neonatal epilepsy (BFNE)
2. Early myoclonic encephalopathy (EME)
3. Ohtahara syndrome
4. Epilepsy of infancy with migrating focal seizures
5. West syndrome/Infantile Spasms
6. Myoclonic epilepsy in infancy (MEI)
7. Benign infantile epilepsy
8. Benign familial infantile epilepsy
9. Dravet syndrome
10. Generalized epilepsy with febrile seizures plus
11. Early onset benign childhood occipital epilepsy
12. Late onset childhood occipital epilepsy
13. Epilepsy with myoclonic atonic seizures
14. Benign epilepsy with centrotemporal spikes
15. Autosomal dominant nocturnal frontal lobe epilepsy
16. Epilepsy with myoclonic absences
17. Lennox-Gastaut syndrome
18. Electrical status epilepticus of sleep
19. Landau-Kleffner syndrome
20. Childhood absence epilepsy
21. Juvenile absence epilepsy
22. Juvenile myoclonic epilepsy
23. Progressive myoclonic epilepsy
24. Autosomal dominant epilepsy with auditory features
25. Other familial temporal lobe epilepsies
26. Epilepsy with GTCs alone
27. Familial focal epilepsy with variable foci
28. Reflex epilepsies
29. Mesial temporal lobe epilepsy
30. Rasmussen syndrome
31. Gelastic seizures with hypothalamic hamartoma

SEIZURE TYPES

Generalized

1. Generalized tonic-clonic (GTC)
2. Clonic (without tonic features)
3. Clonic (with tonic features)
4. Typical absence
5. Atypical absence
6. Myoclonic absence
7. Tonic
8. Infantile spasms
9. Other spasms / epileptic spasms
10. Myoclonic
11. Massive bilateral myoclonus
12. Myoclonic atonic
13. Negative myoclonus
14. Atonic
15. Reflex seizures in generalized epilepsy
16. Eyelid myoclonia (without absences)
17. Eyelid myoclonia (with absences)
18. Convulsive NOS
19. Nonconvulsive NOS

Focal/partial

1. Simple partial (without observable features)
2. Simple partial (with motor or other observable features)
3. Complex partial
4. Secondarily generalized
5. Partial NOS unknown