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Waite, A.J., Coombs, R.C., McKenzie, A. et al. (4 more authors) (2015) Mortality of babies enrolled in a community-based support programme: CONI PLUS (Care of Next Infant Plus). *Archives of Disease in Childhood*, 100 (7). 637 - 642. ISSN 0003-9888

<https://doi.org/10.1136/archdischild-2014-307232>

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Mortality of babies enrolled on a community-based support programme: CONI PLUS (Care of Next Infant Plus)

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Key words:

Sudden infant death syndrome (SIDS)

Sudden unexpected death in infancy (SUDI)

Apparent life threatening event (ALTE)

Infant mortality

Word count: 2786

ABSTRACT

Objective: To report mortality in babies enrolled on a community-based programme, Care of Next Infant Plus (CONI PLUS) which primarily supports parents anxious because of previous sudden unexpected death in infancy (SUDI) in their extended family or following an apparently life threatening event (ALTE) in their baby.

Design: Prospective observational study from 1996-2010 in the UK.

Results: Of 6487 babies enrolled, 37 died (5.7 per 1000). There were 2789 (43.0%) SUDI related babies of whom, 6 died suddenly and unexpectedly (2.15 per 1000). Four babies were sharing a bed or sofa at night with parent(s) who smoked or had consumed alcohol. Of the 1882 (29.0%) babies enrolled following an ALTE, five died suddenly and unexpectedly (2.66 per 1000): 4 unexplained and 1 due to infection. None occurred while sharing a sleep surface, at least 3 died during the day. The remaining 1816 (28%) babies were enrolled for other reasons. Seven died suddenly and unexpectedly (3.85 per 1000), 2 were unexplained and none associated with bed sharing.

Conclusions: The number of SUDI deaths in babies enrolled on CONI PLUS is higher than expected from UK averages. Deaths in babies enrolled because of family history of SUDI were mostly associated with inappropriate sharing of a sleep surface at night and mostly outside the peak age range for sudden infant death. The opposite is true for those enrolled following an ALTE. The number of deaths is small but findings suggest a different mechanism for death in these 2 groups.

Word count 246

INTRODUCTION

The Care of Next Infant (CONI) programme,[1] is widely used in the UK to support families with children born following a sudden unexpected death in infancy (SUDI) i.e. a death that is unexpected in the previous 24 hours,[2]. CONI addresses the anxieties bereaved parents have about subsequent children,[3] and recognises that these children are at increased risk of death,[4,5,6]. Mortality on CONI has been reported previously[7]. CONI offers intensive health visiting support and tools to assess infant health. The success of CONI prompted clinicians to suggest the programme be extended to support other groups of anxious parents. CONI PLUS includes babies with:

- SUDI in the extended family (aunt/uncle/cousin)
- previous sibling infant death (not SUDI)
- following an apparent-life-threatening event (ALTE)[8]

In practice babies have been enrolled for additional reasons and selection is left to the local team. CONI PLUS is offered until the baby is 6 months or for 6 months following an ALTE and includes:

- Regular health visitor (usually weekly) home visits
- Movement (apnoea) monitor
- Symptom diary
- Sheffield weight chart (enables weight gain assessment over 2 and 8 week periods),[9]
- Room thermometer
- Baby Check (19 signs and symptoms scored to determine severity of illness),[10]
- Training in resuscitation

In most areas parents are offered direct access to a paediatrician when their child is unwell.

CONI PLUS was set up in 1996 and by December 31st 2010 had recruited 6487 babies from 175 centres. This report describes the population enrolled on CONI PLUS and deaths under 12 months.

METHOD

The babies are registered with the national CONI office in Sheffield. Registration details include: sex, mode of delivery, birth weight, gestation, initial feeding method, age of mother, age of mother at first live birth, parity, smoking in parents, parents' ethnic origin, mother's marital status, father's employment status and reason for enrolment.

Infants recruited on to CONI PLUS have been categorised into 9 groups (Table 1), but this report concentrates on the two largest: Group 1 (SUDI in extended family) and Group 2 (Following ALTE). Deaths of CONI PLUS babies under 1 year old are notified to the CONI office by the local co-ordinator. Information on the cause of death is obtained from the local paediatrician. SUDI are subject to a Coroner's enquiry and latterly, review by Child Death Overview Panels,[2]. Following these enquiries and when deaths are unexplained, the parents are offered a home visit by a paediatrician from the CONI steering group. A detailed family and clinical history is taken and further information collected by interview with their health visitor and GP. The post mortem report and available sections and slides are reviewed by an experienced paediatric pathologist.

Ethics

We are reporting a long-standing service evaluation. The protocol for the follow-up of families following a death was approved by South Sheffield Ethics committee in 1994 and regularly reviewed. In 2009 the National Research Ethics Service advised that ethical approval was not required and this was accepted by the local committee. All families sign a consent form to give permission for registration data to be shared with CONI. Following a death parents are approached by the local team prior to our home visit and a further consent obtained to give permission to share information about their baby's death.

STATISTICAL METHODS

The χ^2 test was used to compare proportions, between the groups and the F test to compare means. We used an overall mortality rate of 5.2/1000 live births, a mortality rate for sudden infant death syndrome (SIDS) and unascertained of 0.45/1000 live births and a SUDI rate of 0.90/1000 live births as averages over the time period covered from ONS data for England and Wales, to get an approximate expected number of deaths in each group and to compute the Standardised Mortality Ratio (SMR),[11, 12] A more exact method would be to apply the prevailing rate for each year, but SUDI rates were not available before 2004, and the average over the years available gives a reasonably robust estimate of the annual rate over the study period since the rates do not vary greatly from year to year. The confidence intervals for the SMR were found using an exact method in Open Epi,[13]

RESULTS

Table 1 shows the reason for enrolment into CONI PLUS and the number of deaths.

Group 1: History of SUDI in the extended family

A total of 2789 babies were enrolled from 2374 families with a history of SUDI in the extended family; 311 (13%) families used the programme at least twice. Data on the relationship to the baby that died was missing for 15 cases and more distant than aunt/uncle/cousin in 252 cases (number of deaths in family ranged from 1-8). Of the remaining 2107 families, 1868 (89%) had a family history of one SUDI in aunt, uncle or cousin and 239 (11%) two or more SUDI including at least one aunt, uncle or cousin.

Group 2: Following ALTE

A total of 1882 babies from 1864 families were enrolled due to ALTE before their first birthday but after discharge from hospital following birth.

Data on hospital admission following the ALTE were available for 1801 (96%): 1587 (88%) babies were admitted, 179 (10%) were not admitted and 35 (2%) were already in hospital for other reasons prior to the event.

The attributed cause for the ALTE was provided by the local team. These have been classified into subgroups, (Table 2). In 56% of babies a possible diagnosis was identified while in 44% of babies, no explanation for the ALTE was offered. Terms such as ‘apnoea’, ‘cyanosis’ or ‘floppy’ are included in the unexplained group. The exact age at first ALTE is known for 1643 (87%) of the babies. The mean age was 7.6 weeks and median 5.9 weeks (corrected for gestational age 4.1 and 2.9 weeks); 36% of ALTE babies were born at less than 37 weeks gestation and 30% had a birth weight less than 2500g. Babies in the infection group had the youngest post-conceptual age at ALTE, (mean 42.9 weeks) and the lowest birth weights (mean 2501g).

Groups 3-9: Various reasons for enrolment

A total of 543 babies from 468 families were enrolled in Group 3 (Following a sibling death other than SUDI). Smaller numbers of babies were enrolled due to prematurity, ALTE in sibling, ill at birth, congenital anomaly, poor obstetric history or for multiple reasons (Groups 4-9, see Table 1)

Population data

Characteristics of the parents and babies are available in the Appendix tables A1 and A2. In Group 1 (SUDI in extended family) 22% of the mothers were <20 years at the birth of the CONI PLUS baby, compared with 10% in Group 2 (Following ALTE) ($p<0.01$). For 56% in Group 1 this was their first child compared with 36% in Group 2 ($p<0.001$). Groups 1 and 2 had the highest levels of maternal and paternal smoking: compared with the other groups: 43% and 51% in Group 1 and 36% and 44% in Group 2. Group 1 had the highest proportion of maternal and paternal White British ethnicity (94% and 92%), fewest married mothers (26%) and lowest levels of employment in mother’s partner (73%).

Group 1 babies were also more likely to be delivered normally (69%), singleton (96%), have birth weights $\geq 2500\text{g}$ (88%) and be born after 37 weeks gestation (89%). This group had the lowest proportion of initially breast fed babies (40%).

Mortality in CONI PLUS babies

A total of 37 babies died in their first year (Table 3). The expected number of deaths based on national rates is about 33.7, showing a slightly raised mortality, but which is not statistically significant (SMR 1.1, 95% CI 0.78 to 1.50) Of 11 families offered a home visit by a CONI paediatrician following a SUDI, 6 accepted (3 in Group 1, 3 in Group 2).

Nineteen babies died following a deterioration in a pre-existing condition. Eighteen deaths presented as SUDI, 7 attributed to sudden infant death syndrome (SIDS), 4 unascertained, 4 to infections, one to upper respiratory tract obstruction, one to hypoxic ischaemic encephalopathy and 1 to congenital anomaly and infection. From national death rates over this period we would only have expected about 6 SUDIs (SMR 3, 95% CI 1.8 to 4.6) and 3 SIDS (SMR 2.3, 95% CI 1.0 to 4.6).

Mortality in Group 1 (SUDI in extended family)

All 6 deaths in Group 1 presented as SUDI. One was attributed to pneumonitis at 3 weeks. Of the remaining 5 deaths attributed to SIDS or unascertained, one was aged 3 weeks, one aged 8 weeks and 3 aged over 26 weeks. We would have expected about 1.25 SIDS or unascertained in this cohort (SMR 4.0, 95% CI 1.47 to 8.87).

Mortality in Group 2 (Following ALTE)

Of 14 deaths in Group 2, 9 were due to pre-existing conditions and 5 presented as SUDI. One SUDI was attributed to systemic cytomegalovirus infection in a baby with residual aortic coarctation following corrective surgery. Three deaths were attributed to SIDS and for these no cause for the

ALTE was given. One death was unascertained with the ALTE attributed to convulsions. No SUDI occurred in the babies whose ALTE was attributed to gastro-oesophageal reflux, feeding related problems or infection. We would have expected about 0.85 SIDS or unascertained in this cohort (SMR 5.89, 95% CI 2.16 to 13.0).

Mortality in Groups 3-9

Of 17 deaths, 10 were in babies with pre-existing conditions with poor outlook and 7 presented as SUDI including two unascertained.

Circumstances and risk factors present for SUDI n=18

Details of the circumstances and demographics for the 18 babies who died suddenly and unexpectedly are shown in Table 4. At least five of the 6 deaths in Group 1 (SUDI in extended family) are known to have occurred in babies sharing a sleep surface at night: 2 sleeping on a settee, 2 sharing a bed with a parent who smoked and had taken alcohol or cannabis the previous evening and one sleeping in a playpen at night with a twin sibling.

None of the 5 SUDI in Group 2 (Following ALTE) babies occurred while sharing a sleeping surface. Three of the deaths occurred during the daytime, 2 in 'bouncy' chairs and one sleeping alone on a settee.

Overall, 11 of the 18 (61%) mothers smoked cigarettes and 9 (56%) of the mother's partners were known to smoke. Of the 11 babies classified as SIDS or unascertained, 5 were aged outside the peak age at risk for SIDS (1 aged under 4 weeks and 4 aged over 26 weeks) and 4 of these 5 were in Group 1. Two babies in Group 2 and one baby in Group 4 (Prematurity) had a monitor in use when the baby was found collapsed but resuscitation was unsuccessful. It appears one mother slept through the alarm or the alarm did not ring. Of the remaining 15 babies, in 2 monitor use had stopped, in 6 the monitor was not in use and in 7 babies use is not known (1 was bed sharing and 4 died during the daytime).

There were no known cases of infanticide/homicide

DISCUSSION

This report documents the outcome of over 6000 babies enrolled on the CONI PLUS programme since 1996. Local clinicians decide which families are offered CONI PLUS, hence parents with a close family history of SUDI, but who are not anxious and who can implement advice on reducing the risk of SIDS, may not be enrolled. Overall, the number of deaths was small, but slightly greater than expected.

However our data suggest the population has a higher than average risk for SIDS.

We do not have a control group but when comparing population characteristics we find Group 1 (SUDI in extended family) and Group 2 (Following ALTE) differ from each other in a number of ways and also from average UK statistics. Smoking in mothers in Group 1 (43%) and Group 2 (36%), and in her partner (51% and 44%) is higher than the average 30% reported for women and 34% for men for 20-34 year olds in the UK between 1998 and 2010,[14]. Breastfeeding at one week is low at 40% in Group 1 and 43% in Group 2 compared to average UK figures of 55% in 2005 and 69% in 2010,[15]

Unemployment is higher than the UK rate which varied between 5 and 8% in 1996-2010, especially in Group 1 (SUDI in extended family) where it was 27%,[16]. Smoking, bottle feeding, unemployment are all associated with an increased risk for SIDS,[17].

Eighteen SUDI occurred and while numbers are small, the circumstances of these deaths are notably different across the enrolment groups. Of 6 SUDI in Group 1 (SUDI in extended family), 5 were at night while sharing a sleep surface, 4 with a parent plus known contra-indications (settee or bed plus alcohol/smoking/drugs). One was sleeping in a playpen with a twin sibling. There are many case-control studies that show an associated risk for SIDS when babies bed share with parents who smoke or have consumed >2 units of alcohol,[18, 19, 20] and co-sleeping on a settee is particularly high risk,[17]. In contrast, of 5 SUDI in the Group 2 (Following ALTE), 3 died during the day, none were sharing a sleep surface and 2 were in 'bouncy chairs'. Occlusion of the airways in a 'sitting' position due to flexion of the head has been suggested as a trigger for ALTE,[21]. Among babies enrolled for other

reasons (Groups 3-9), there were 7 SUDI, 3 died or collapsed during the day and none died while bed-sharing. SIDS and unascertained deaths in Group 1 appear largely associated with recognised high risk sleeping behaviours whereas these are notably absent in the other groups.

When Group 2 (Following ALTE) deaths are considered by the diagnoses made following the ALTE, no deaths occurred in 682 (36%) babies whose ALTE was attributed to gastro-oesophageal reflux or infection while three deaths (all SIDS) occurred in 835 (56%) babies with unexplained ALTE (3.6 per 1000, SMR 7.99, 95% CI 2.03 to 21.76).

With over 1800 infants, this is the largest study of infants following an ALTE. The babies are cared for by their local paediatric services and details of investigations were not collected. Almost certainly there is variation in the level of investigation and reasoning behind the clinicians' decision to offer CONI PLUS, however age at ALTE in our cohort is similar to other published studies,[22]. There is no consensus on the mortality of babies given the diagnosis of ALTE. Bankowski allocated a diagnosis of ALTE to infants fulfilling the standard American criteria,[23]. In his cohort of 471 infants admitted over 4 years to a single hospital, 2 subsequently died, both older than one year and both with apparent developmental and respiratory problems. McGovern in a systematic review found only 2 sudden deaths in 355 cases (5.6 per 1000) from 8 studies,[22]. A prospective study from West Virginia, USA reports 19 SIDS in 765 cases (24.8 per 1000),[24].

Two European studies report an incidence for ALTE of 0.46 per 1000 live births in Sweden,[25] and 0.58 per 1000,[26] in the Netherlands. If these figures are representative for the UK, over 14 years CONI PLUS has probably recruited one third of all the UK ALTE babies. In this group there have only been 5 sudden and unexpected deaths (5 per 1882, 2.7 per 1000) suggesting this is a rare event.

There are limitations to this study. We do not have complete ascertainment because enrolment is determined by the local teams and there is wide variation in uptake. Reporting of deaths is voluntary

and may be incomplete. Although mortality was higher than expected from national rates it was not markedly higher given the number of risk factors present in this group. The lack of a control group prohibits the comparison of mortality in similar populations not offered CONI PLUS.

However, some implications for public health are clear. In group 1 (SUDI in extended family) and group 2 (Following ALTE), 45% of deaths were sudden and unexplained. For the deaths registered as SIDS or unascertained, there are notable differences in age, place and time of death between those babies enrolled due to a family history of SUDI and those enrolled following an ALTE or for other reasons. Some of the former are dying in inappropriate sleep locations and this suggests they are potentially preventable. Emphasis needs to be placed on ensuring a safe sleep environment for all babies and particularly in families with the risk factors of smoking and alcohol. That smoking is a major risk factor for both ALTE,[27] and SIDS, underlines the need to discourage maternal smoking in pregnancy. Our finding that SIDS following ALTE is not associated with night-time nor bed sharing needs further investigation and although the numbers are small, possibly suggests a different mechanism for death.

Contributors

AW designed the study, collected and collated data and wrote the first draft. RC designed the study, collected clinical data. AMcK collated data and performed the statistical analysis. CDW designed the study, collected clinical data. MC analysed and interpreted data. MJC analysed data. RGC designed the study and analysed data. All authors contributed to the interpretation of the data and revised the draft paper.

Acknowledgments

We would like to thank the families and health professionals involved with CONI PLUS.

Competing interests

None

Funding

Alison Waite and Angela McKenzie are funded by the Lullaby Trust.

What is already known on this topic?

- The Care of Next Infant programme is widely used in the UK and highly valued by parents
- Sharing a sleep surface with a parent who smokes or has consumed >2 units of alcohol is associated with an increased risk for SIDS.
- There are wide differences in the reported mortality in babies following ALTE.

What this study adds?

- Deaths in babies enrolled because of SUDI in a close relative showed avoidable risk factors mostly associated with smoking and place of sleep.
- This is the largest follow up study of infants following an ALTE.
- Mortality from SIDS following idiopathic ALTE was 4/1883 (2.13 per 1000) and was not associated with bed sharing.

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Table 1 Reason for enrolment and mortality under 1 year

| | | | | Mortality on CONI PLUS | | | | |
|-------|--|------|-------|------------------------|---------------------------------------|-----------------------|----------------------------|-----------------------|
| | | | | All causes | SUDI (including SIDS & unascertained) | | SIDS & Unascertained | |
| Group | Reason for enrolment | No. | % | No. < 1year | No. | Rate per1000 enrolled | No. SIDS and unascertained | Rate per1000 enrolled |
| 1 | SUDI in extended family | 2789 | 43.0 | 6 | 6 | 2.15 | 5 | 1.79 |
| 2 | Following ALTE | 1882 | 29.0 | 14 | 5 | 2.66 | 4 | 2.13 |
| 3 | Death in previous sib with known cause | 543 | 8.4 | 7 | 3 | 5.52 | 2 | 3.68 |
| 4 | Prematurity | 310 | 4.8 | 1 | 0 | - | 0 | - |
| 5 | ALTE in previous sib | 296 | 4.6 | 0 | - | - | - | - |
| 6 | Ill at birth/congenital anomaly | 211 | 3.2 | 9 | 4 | 18.96 | 0 | - |
| 7 | Poor obstetric history | 143 | 2.2 | 0 | - | - | - | - |
| 8 | Other reason | 140 | 2.2 | 0 | - | - | - | - |
| 9 | 2 or more of the above | 173 | 2.6 | 0 | - | - | - | - |
| | Total | 6487 | 100.0 | 37 | 18 | 2.77 | 11 | 1.70 |

SUDI = sudden unexpected deaths in infancy, SIDS = sudden infant death syndrome, ALTE = apparent life threatening event.

Table 2 Attributed cause for ALTE

| Cause | Number | % |
|---|--------|------|
| Gastro-oesophageal reflux and other associated with feeding | 417 | 22.1 |
| Infection | 265 | 14.1 |
| Congenital anomaly | 146 | 7.8 |
| Convulsions | 47 | 2.5 |
| Prematurity | 33 | 1.7 |
| Whooping cough | 20 | 1.1 |
| Following immunization or other drug | 9 | 1.2 |
| Maternal drug use | 5 | |
| Accidental suffocation | 5 | |
| Other | 3 | 5.1 |
| 2 or more of the above | 97 | |
| Floppy, apnoea, cyanosis | 418 | 22.2 |
| NAD, don't know etc. | 256 | 13.6 |
| Blank | 161 | 8.6 |
| Total | 1882 | 100 |

Table 3 Deaths aged less than 1 year

| Reason for enrolment and relevant medical history | SUDI n=18 | Cause of CONI PLUS death | Age at death in weeks |
|--|-----------|---|-----------------------|
| Group 1: SUDI in extended family | | | |
| Relationship to CONI PLUS baby | | | |
| Aunt | Yes | SIDS | 3 |
| Aunt and cousin | Yes | Pneumonitis | 3 |
| Cousin | Yes | SIDS | 8 |
| Uncle | Yes | SIDS | 28 |
| Cousin | Yes | SIDS | 31 |
| Aunt | Yes | Unascertained | 47 |
| Group 2: Following ALTE | | | |
| Attributed cause for ALTE | | | |
| Unexplained | Yes | SIDS associated with coronary artery myocardial bridge | 8 |
| Congenital anomaly | | Hypertrophic cardiomyopathy (cleft palate and microcephaly contributing factors) | 9 |
| Congenital anomaly | | Fibromuscular dysplasia | 10 |
| Congenital anomaly | | Hypoplastic left heart | 14 |
| Infection | | Tracheal stenosis with complete vascular ring | 14 |
| Unexplained | Yes | SIDS | 16 |
| Congenital anomaly | | Parainfluenza 3 bronchiolitis, severe development delay | 19 |
| Convulsions | Yes | Unascertained | 20 |
| Unexplained | Yes | SIDS (intercurrent respiratory disease and unexplained recent and previous subdural haemorrhage) | 22 |
| Congenital anomaly | Yes | Cytomegalovirus pneumonitis, systemic CMV infection and residual aortic coarctation | 23 |
| Congenital anomaly | | Agenesis corpus callosum, bronchopneumonia | 25 |
| Congenital anomaly | | Nemaline myopathy | 41 |
| GOR/feeding related | | Spinal muscular atrophy type 1 | 42 |
| Congenital anomaly | | Asphyxiating thoracic-dystrophy - Jarcho-Levin | 47 |
| Group 3: Death in previous sibling with known cause | | | |
| Sib cause of death | | | |
| Myocarditis | Yes | Myocarditis | 3 days |
| Congenital pneumonia | | Ornithine transcarbamylase deficiency | 3 days |
| Congenital myopathy | | Mitochondrial myopathy | 17 |
| Prematurity in 2 siblings | Yes | Unascertained, Jeune syndrome, agenesis corpus callosum, left microphthalmia, rotavirus infection | 25 |
| Dandy Walker syndrome | | Dandy-Walker Syndrome | 28 |
| Prematurity in 2 siblings | | Spino-muscular atrophy | 31 |
| Prematurity | Yes | Unascertained | 43 |
| Group 4: Prematurity | | | |
| 28 week gestation, IUGR | | Chronic lung disease | 33 |
| Group 6: Congenital anomaly/ill at birth | | | |
| Treacher Collins syndrome | Yes | Aspiration pneumonia | 4 |
| Oesophageal atresia, tracheo-oesophageal fistula, duodenal atresia | | Hypoxic ischaemic encephalopathy | 13 |
| Birth asphyxia, | Yes | Hypoxic ischaemic encephalopathy | 16 |
| Pierre Robin sequence | Yes | Upper respiratory tract obstruction | 18 |
| Congenital contractures | | Unspecified myopathy | 25 |
| Convulsions, neurodegenerative disorder | | Epileptic encephalopathy | 26 |
| Cerebral palsy, global delay | Yes | H1N1 virus | 34 |
| Fallot's tetralogy | | Renal failure complicating Fallot's repair | 49 |
| 22q deletion and ASD | | RSV bronchiolitis, congenital anomalies | 49 |

Table 4 Sudden unexpected deaths: cause of death, place of death and other factors

| | Age at death (weeks) | Cause of death | Birth weight (g) | Gestation (weeks) | Smoking Mother | Partner | Place of death and other factors (death occurred at night-time unless stated) |
|-------------------|----------------------|-------------------------------------|------------------|-------------------|----------------|----------------|--|
| Group 1 | 3 | SIDS | 3020 | 37 | Yes | Yes | Sleeping on settee prone on father's chest Mother 16 years old |
| | 3 | Pneumonitis | 2530 | 39 | Yes | Yes | Sleeping in bed with father Parents had alcohol previous evening |
| | 8 | SIDS | 3350 | 40 | Yes | Yes 100/day | Sleeping in bed with mother Cannabis smoked previous evening |
| | 28 | SIDS | 3900 | 40 | Yes | n/k | n/k |
| | 31 | SIDS | 2720 | 40 | No | n/k | Sleeping on settee with mother Single unsupported mother. Monitor use discontinued |
| | 47 | Unascertained | 1440 | 29§ | Yes | Yes | Sleeping in playpen at night. Monitor use discontinued Mother took amphetamines and cannabis previous evening |
| Group 2 | 8 | SIDS | 3035 | 37 | Yes | Yes | Mother sleeping on settee, baby sleeping in Moses basket on settee Father in prison |
| | 16 | SIDS | 1260 | 29 | Yes | No | Sleeping alone on settee at 1100 hours |
| | 20 | Unascertained | 3530 | 40 | No | Yes | In bouncy chair at 0900 hours History of 3 events/seizures |
| | 22 | SIDS | 2730 | 39 | Yes | Yes | In Moses basket at 0500 hours. Uncertainty whether alarm rang Father heroin addiction. Mother used drugs before pregnancy and after death |
| | 23 | Systemic CMV | 3205 | 40 | Yes | Yes | In bouncy chair at 1600 hours following alarm |
| Groups 3, 4 and 6 | 3 days | Myocarditis | 3800 | 39 | No | No | In hospital cot |
| | 4 | Aspiration pneumonia | 2520 | 39 | No | No | Daytime aspiration, Treacher Collins Syndrome |
| | 16 | Hypoxic ischaemic encephalopathy | 2856 | n/k | No | Yes | In cot, hour not known |
| | 18 | Upper respiratory tract obstruction | 995 | 32 | No | No | Collapsed in grandmother's arms Pierre Robin Syndrome |
| | 25 | Unascertained | 2200 | 37 | Yes | No | Place n/k. Alerted by apnoea alarm at 1120 hours |
| | 34 | H1N1 infection | 2570 | 37 | Yes | No | Place n/k. In foster care Multiple congenital anomalies |
| | 43 | Unascertained | 2200 | 33 | No | No | On floor with mother in diabetic coma at 1500 hours |

§Estimated n/k = not known, n/a= not applicable

Group 1: SUDI in extended family; Group 2: Following ALTE; Group 3: Death in previous sibling with known cause; Group 4: Prematurity; Group 6: Congenital anomaly in index/ill at birth