

# **CONI** Guidelines for Professionals



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https://www.lullabytrust.org.uk/professionals/care-of-next-infant/ (QR code)

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## THE CARE OF NEXT INFANT (CONI) PROGRAMME

Families who have experienced the sudden and unexpected death of a baby or very young child are often very anxious when they have another baby. The aim of CONI is to provide emotional and practical support to bereaved families during the early months of their new baby's life. This support can help parents reduce anxiety, gain confidence in caring for their new baby and enjoy the first year of their new baby's life.

CONI developed from the model of care offered to families in a randomised control study conducted with families in the 1980s, and is available in England, Wales, and Northern Ireland. Where it has been commissioned, it is usually part of the local health visiting service.

CONI is offered to parents expecting a new baby where either parent has previously experienced the sudden unexpected death of a child under 2 years of age. The programme may also be offered to support families with a surviving child(ren) from a multiple birth where one baby has died unexpectedly.

Three additional groups have also been identified as being eligible for CONI:

#### 1. Close relatives

Close family history of sudden unexpected death in infancy (SUDI) - a parental sibling/ niece or nephew.

#### 2. Other baby deaths

Parents whose baby died from causes other than sudden infant death syndrome (SIDS) occurring **after** discharge from the neonatal or postnatal unit. Where anxiety persists, CONI may provide appropriate support.

#### 3. Apparent Life-Threatening Event (ALTE)/ Brief Resolved Unexplained Event (BRUE)

Where a baby has suffered an apparently life-threatening event<sup>1</sup> (ALTE)/brief resolved unexplained event (BRUE). Parents can have fears about the survival of their baby that persist for many weeks/months following the event. Any episode should be investigated, but for as many as half of such events, no cause will be found. These babies are known to be at increased risk of mortality. See Appendix for enrolment process following an ALTE/BRUE.

The support provided by CONI may be extended to other families whose babies may be at increased risk of sudden infant death or who have reason to be anxious about their baby. This is determined at local level by the local CONI coordinator based on parental need, availability of local resources and the local commissioning agreement.

SM Gibb, AJ Waite. The management of apparent life-threatening events. Current Paediatrics 1998; 8:152-156

<sup>&</sup>lt;sup>1</sup> An ALTE is a sudden and unexpected event, which is frightening to the observer who perceives the baby to be at risk of death and feels there is need to take some immediate action. The event has a defined onset and offset, and does not lead to death or persistent collapse. The baby displays a change in at least two of the following: - colour, tone, consciousness, movement and breathing.

Support is usually offered until the baby is 6 months, or two months beyond the age at death of the previous baby, or the last apparently life-threatening event (ALTE/BRUE).

## HOW DOES THE CONI PROGRAMME SUPPORT FAMILIES?

The health visitor/nurse, general practitioner and paediatrician form the primary support unit for each family. CONI is parent-led, therefore parents are assisted by the coordinator to select elements of support from the following:

## • Regular (weekly) contact

Ideally happens in the home by the family's health visitor/nurse and documented in line with local systems and professional practice standards. It provides an opportunity for the health visitor to discuss parental anxieties, safer sleep and how to reduce risks to the baby. Reviewing the Symptom Diary and weighing can take place at this visit. It can also facilitate fast access to the paediatrician/acute paediatric services if necessary. (See Paediatrician section below). As parental confidence grows, then regular weighing may become less frequent and in discussion with the parent(s) may stop altogether. How long visits will continue for depends on each family's needs but it is unlikely that they will continue for the full 6 months, but may be less frequent.

## • Weighing – weekly /regular

Slow/faltering weight gain may be associated with ill health and some studies have shown that SIDS may occur against a background of minor illness (Ostfeld et al, 2010; Weber et al, 2011). Ideally, babies on the CONI programme should be weighed once a week, undressed, on the same set of scales, and the weight plotted on the Sheffield Weight Chart (see below). This should ideally be at home, but as parental confidence increases and anxiety reduces, then weighing can take place in the clinic (or similar) or stop altogether. If there is a clinical indication to

continue regular weighing, this should be discussed with the family. Weights should also be plotted in the Personal Child Health Record (PCHR, Red Book) according to local guidelines.

## • Use of Sheffield weight charts

The chart is designed to help detect unusually slow weight gain at an early stage in the CONI cohort of babies. There are two different A1 size weight charts, one for each sex. The scale across the bottom indicates age in weeks and each small division equals one day. The vertical scale represents the weight in kilograms, with heavy lines at each half kg (500g) and small divisions at 50g. The three heavy black lines correspond to percentile lines: 3rd, 50th and 97th centiles. At any time, only 3% of infants are likely to be below the lower heavy line. 50% will be below and 50% above the middle line and only 3% will



be above the upper heavy line. The dotted lines are designed so that from two weeks after birth, 95% of all babies will not deviate by more than one channel width in any subsequent two-week period or two channel widths in any subsequent eight-week period. If deviation is greater than this, there is cause for concern. The channels change in width at 8 weeks for



girls and 12 weeks for boys because weight gain stabilises around these ages. After this, weight gain should be assessed by the narrower channel width. The charts are principally recommended for use up to six months of age only. There are instructions and examples on the back of the charts, and a free, recorded presentation on the CONI webpage:<u>https://www.lullabytrust.org.uk/professionals/care-of-next-infant/information-for-coni-coordinators/</u> to guide the user. Some parents may prefer their baby's weight plotted only in their baby's Red Book.

## • Symptom Diary

Parents are often uncertain when to seek medical help for a baby. The Symptom Diary is designed to help the parent(s) assess their baby's health each day (or how often they choose) using a simple checklist, which is intended to help them notice any changes in their baby's appearance and behaviour. Most symptoms listed are common and it is usual even for a healthy baby to show at least one symptom. Parents are advised to seek help if they are worried about any symptoms they may notice or if there has been a clear increase in symptoms. Parents can feel reassured when they see that their baby has no significant symptoms.



Additionally, the diary gives parents an opportunity to raise concerns with the health visitor/nurse who can offer advice on how to manage minor illness or symptoms. The Baby Check app can be useful to assess symptoms further. Families can be signposted to a free, recorded presentation on the CONI webpage: <a href="https://www.lullabytrust.org.uk/professionals/care-of-next-infant/information-for-coni-coordinators/">https://www.lullabytrust.org.uk/professionals/care-of-next-infant/information-for-coni-coordinators/</a> to give them more information about using the Symptom Diary.

## Baby Check app - download from Google Play or App Store

Baby Check developed from a four-year project, which analysed the signs and symptoms of illness in over 1,000 babies under six months of age. Following review, it is safe to use until the baby is one year old. It is designed to help parents and carers decide whether their baby needs to see a doctor, which empowers parents to act upon their concerns. The app can be used either in conjunction with the Symptom Diary or independently to assess signs and symptoms in a baby. It



contains 19 simple checks, which test for different signs, symptoms or illness. The app is not designed to replace a parent or carer's judgement. If the check provides a low score but parents are still worried, parents should be encouraged to seek advice from a medical professional. Families can be signposted to a free, recorded presentation on the CONI webpage: <u>https://www.lullabytrust.org.uk/professionals/care-of-next-infant/information-for-coni-coordinators/</u> to give them more information about baby ill health, and the Baby Check app.

## • Room thermometers

Parents need to be aware of the recommended range of room temperature of 16 - 20°C, and adjust bedding and clothing appropriately. It is important to keep the baby's head uncovered by bedding or hats when indoors to allow them to regulate their body temperature. The head is an important source of heat loss for a normal baby and a high proportion of infants who die because of SIDS are found with their head covered with bedding. There is a free, recorded presentation on



our website regarding overheating, temperature and overwrapping <u>https://www.lullabytrust.org.uk/professionals/care-of-next-infant/information-for-coni-</u> <u>coordinators/</u>

## Movement (apnoea) monitoring

To give parental reassurance, a movement monitor may be lent or given to a family. Alternatively, they may be supported to use a monitor of their choice. Monitors used by families should have a medical devices certification, often denoted by MD after the name of the product. Movement monitors detect breathing movements. They sound an alarm after a period with no movement, usually 20 seconds. All babies have irregular breathing patterns compared to adults, with frequent short pauses. However, a 20-second pause (or apnoea) is unusually long. Even if such a lengthy pause occurs, most babies will respond very quickly to touch. On rare occasions, the baby will need resuscitation. In the rarest cases, some will not respond to resuscitation.



The monitors are used for sleep periods only and should be disconnected when the baby is awake. Movement monitors should not be used if the baby is in a moving object e.g. car, pram, vibrating crib as the monitor will detect the movement of the car etc. Parents need to be shown how to use and care for the monitor supplied to them, and be issued with the instruction manual. All parents issued with a monitor need to have Basic Life Support (BLS) instruction. (See Appendix).

Three types of monitor are in common use on the CONI programme. These are:

- 1. Sensor monitor e.g. Graseby MR10, SISS Baby Control a sensor is taped to the baby's abdomen.
- 2. Under-mattress monitor e.g. Nanny BM-02 a pressure sensitive pad is placed under the cot mattress. An under-mattress monitor is especially recommended for babies who need to be monitored after 6 months.
- 'Clip on' sensor monitor- This is a small plastic monitor that clips onto a nappy e.g. SNUZA Hero MD

A Movement Monitors Factsheet is available as reference for CONI coordinators' use on the CONI webpages at: <u>https://www.lullabytrust.org.uk/professionals/care-of-next-infant/information-for-coni-coordinators/</u> and a free, recorded presentation <u>https://www.lullabytrust.org.uk/professionals/care-of-next-infant/information-for-coni-coordinators/</u> to guide the user. However, please always refer to the manufacturer's instructions for the monitor issued to the parents, and advise parents to refer to these

individual instructions. Manufacturer's instructions are also available on their own websites.

The risk of sudden infant death declines with age and 85% of sudden deaths occur in babies under six months old. For most babies, monitoring should stop by six months. The monitor can help reassure parents that their baby has not come to harm and many parents say the monitor helps them to sleep better at night, so the withdrawal of the monitor should be gradual. Parents should be encouraged to use it for fewer hours each day and the health visitor should help them plan how to progress until they can manage without the monitor. It is helpful to remember that there is no evidence that using a monitor reduces the risk of SIDS, and to remind parents of this.

#### **ORGANISATION OF CONI**

The Lullaby Trust facilitates the central organisation of the CONI programme. The CONI Team includes a National Lead for CONI who leads the programme, and a National CONI Coordinator who provides clinical advice and oversees the day-to-day running of the programme, and a Support Services Coordinator who manages training. The Lullaby Trust CONI Team is part of the Support and Information Team at The Lullaby Trust.

At a local level, the following professionals are typically involved with the delivery of the CONI Programme:

#### Midwife

The midwife ideally identifies parents early in their pregnancy, introduces them to the CONI programme and refers them **antenatally** to the local CONI coordinator as soon as possible in their pregnancy. Parents may need extra support from the midwife during pregnancy. The midwife helps the parents with the programme immediately after the birth of the baby and should be familiar with the movement (breathing) monitor and other support elements.

CONI Antenatal Easy Read cards are available in a range of languages, which can either act as a memory aid for health professionals or can be given to expectant parents.

Free CONI for midwives training is also available for midwives working in areas where CONI is commissioned - <u>The CONI Programme: Role of the Midwife Training - The Lullaby Trust</u>

(See Appendix for enrolment procedure following antenatal referral).

## Health visitor/nurse

The health visitor/nurse is the key worker with the family, preferably visiting at home to monitor the baby and to listen to, give advice and support the parents. During the visit, the previous weeks' Symptom Diary may be discussed, and advice and reassurance offered. The baby is weighed, and the weight recorded on the Sheffield Weight Chart. The use of the monitor and any alarms is discussed. Parents consistently report that this contact with the health visitor/nurse is important to them and that they find it particularly supportive to have a specifically trained health visitor/nurse who listens to their concerns and anxieties. Experience has shown that weekly visits are highly valued by parents. As their confidence grows, the frequency of visits can be reduced in preparation for the conclusion of

CONI support. The health visitor should help the parents plan a way to gradually reduce their use of the monitor until they no longer need it to feel confident when their baby is asleep.

#### Senior Health Visitor/Paediatric Manager/Public Health Lead

Oversees health visiting, midwifery and paediatric involvement and continuity, and ensures that the appropriate local guidelines and budget are in place.

## **CONI** Champion

In addition to the local CONI coordinator, some CONI teams may also have CONI Champions. These are professionals who enthusiastically support and represent the local CONI programme. They should have received full CONI training and should attend the CONI Q&A updates. They can be the initial contact for parents and professionals. Champions can explain the elements of CONI support to parents and professionals, and are aware of the local CONI criteria and referral pathway. They may have a particular role in the local CONI team e.g. manage the equipment and resources. They also should have the skills and confidence to talk with bereaved parents. They are not expected to undertake initial or enrolment visits. They should have knowledge of The Lullaby Trust website, specifically the CONI webpages.

#### Paediatrician

It is recommended that there is active involvement of a paediatrician with an agreed local protocol, however availability of CONI paediatricians varies across different counties. One consultant usually takes responsibility for the clinical support of CONI but the clinical care of families is frequently shared with colleagues. The paediatrician may offer to see the parents antenatally, offer to see the baby routinely or on parental request and see the baby if the surveillance highlights any cause for concern e.g. poor weight gain or apnoea. This may be via arranging open/fast access e.g. through the A&E Dept, clinic or children's ward. They may also offer a routine follow-up appointment close to the age of the previous SIDS death. The Paediatrician is available to be inserted into the PCHR (Red Book). It is essential that the paediatrician is available for contact by the family's health visitor/nurse and/or coordinator. In the absence of a paediatrician then the GP would offer clinical advice. ALTE/BRUE babies require hospital admission in most cases and direct involvement of the hospital paediatrician who contacts the local coordinator to arrange CONI support.

#### A&E

It is recommended that coordinators raise awareness of CONI to their local A&E departments so that if a family supported by CONI present to A&E, this will allow the staff to understand the family's need and fast track baby to be seen by a paediatrician.

#### **General Practitioner**

As with any child the GP's main role is the diagnosis and treatment of illness, and referral to the paediatrician as appropriate. Although parents may be extremely anxious, the increased health visiting support offered by CONI usually means most babies on CONI do not see the GP much more often than average. The Symptom Diary helps in the early recognition of ill health in the baby and may make it easier for some parents to ask for help. Parents should seek help if the Baby Check app score is 12 or more. In this case, they should be seen as soon as possible. Babies with unusually slow weight gain (as defined by the Sheffield Weight Chart) and babies with unexplained movement (apnoea) monitor alarms can be referred to the paediatrician for investigation. Close liaison with the family health visitor/nurse is essential for the best welfare of the family. The family's GP should be informed when a new baby is

enrolled on to the programme. The **Information for GP Records** sheet can help with this. Electronic records should be flagged to identify babies on the programme and to act as an alert.

## The Lullaby Trust Services Committee

The members of this committee have expertise in sudden infant death syndrome (SIDS) and bereavement. They support and advise the National CONI Team with the central facilitation of the CONI programme.

#### ROLE OF THE LOCAL CONI COORDINATOR

The local coordinator is usually a health visitor but may be another practitioner with the appropriate knowledge and skills e.g. senior member of the public health team, community paediatric nurse, neonatal outreach nurse etc. They liaise with The Lullaby Trust CONI Team and are responsible for the local administration of CONI. Whilst the care of the family remains with the primary health care team, the coordinator is available for advice and support and can liaise with the paediatrician. The role will vary to suit local needs, and the following responsibilities within the CONI coordinator role are only a guide. They will include all or part of the following: -

#### 1. Identification of families

Ensure that a system is in place to identify mothers booking for antenatal care with a previous history of sudden infant death. Most mothers are referred to the local coordinator by their hospital or community midwife, however the referral procedure should also be known to the obstetrician, GP and health visitors. It is recommended that all mothers with a history of SIDS/SUDI are referred to the local coordinator to be offered the opportunity learn about the CONI programme. Extending the programme to other families will need to be determined locally and included in local guidelines. A system to identify these families, and referral to the local coordinator, needs to be agreed.

#### 2. Visiting/contacting the parents

The CONI coordinator should make initial contact with the family to set up a visit with the family for about 2 months before the birth is expected, or close to hospital discharge following an ALTE. Ideally, this takes place in the parents' home, with their own health visitor/nurse present. The purpose is to explain the various elements of support in detail and to help the parents to select the support elements that they are going to use. The functions (and limitations) of the equipment, Symptom Diary and other resources are also explained. The CONI coordinator completes the online electronic Enrolment Form on The Lullaby Trust CONI webpage, and gains consent for the information to be shared with The Lullaby Trust. If consent to share is declined, or the parents do not wish to receive support from CONI, then the coordinator completes the online electronic Notification of Non-Participation Form. Person-identifiable information is not captured on this form. The option to decline consent will not affect the care they receive. The coordinator should also explain that the parents will be invited to complete an electronic Feedback Form at the end of the programme. The electronic online Enrolment and Feedback Forms are automatically received by the CONI Team when 'submit' is clicked. All visits and contacts with the family should be recorded using local systems, in line with local policy.

## 3. Arrange antenatal contact with the paediatrician

Where the paediatrician is prepared to see families antenatally, the coordinator liaises with the paediatrician on behalf of the parents as appropriate.

## 4. Organisation of Basic Life Support (BLS) instruction

Local procedures will vary as to who is responsible for training the parents in BLS and how this is to be carried out. However, this is offered ideally before the birth of the baby and should allow the opportunity for parents and close relatives or carers to practice. If the training is to be provided by the local coordinator, it should be undertaken on a separate occasion to the introductory home visit. The National CONI Team can advise on suitable online instruction videos e.g. St. Johns Ambulance if face to face instruction is not available locally.

How to do CPR on a baby (under one year old) - Baby First Aid | St John Ambulance (sja.org.uk) reviewed September 2022

How to do a baby primary survey | St John Ambulance (sja.org.uk) reviewed September 2022

## 5. Distribution and care of equipment

Where possible families should be given the movement monitor and resources/elements that they will be using at or soon after the first home visit. This allows the parents to familiarise themselves with the workings of the monitor before the baby is born. It also avoids the problem of supplying equipment during the short period the mother and baby are in hospital. However, it is recognised that other local arrangements may be preferred. The local coordinator should make sure that there is a system for logging the placement of all equipment to enable re-call at the end of the programme. Some CONI teams also ask parents to sign a local 'loan form'. All equipment being loaned should be logged and where appropriate be checked by a medical engineer in line with both local and individual monitor guidance. The average loan of equipment is for 8 months, so equipment should usually be checked after each loan.

- 5. Distribution of CONI support elements CONI Resources The Lullaby Trust
- Symptom Diary (now a tear off pad one sheet /one week)
- Baby Check A5 demo card

A 2-sided card explaining how to use the Baby Check App.

- Sheffield Weight Chart
- Alarm Record (optional)

If parents are troubled because an alarm sounds for no apparent reason, they can record the details of each alarm on the Alarm Record to help identify possible causes. This can then be discussed with the health visitor/nurse.

- Information for GP Records
   An information sheet to be inserted into the baby's GP electronic and/or paper records
   to act as a reminder that the baby is enrolled on the CONI programme. Organised by the
   CONI coordinator.
- Paediatric Healthcare Passport

An A5 sheet to be inserted into the baby's Personal Child Health Record (Red Book) by the health visitor to alert A&E staff that the baby is enrolled on the CONI programme and

facilitate easier access to an assessment by a senior paediatric doctor or nurse. Organised by the CONI coordinator. A local card may be available to use instead.

## • Safer sleep easy read card

The risk of sudden infant death is reduced when parents follow current evidence-based advice. All parents should be provided with The Lullaby Trust 2-sided 'Safer sleep easy read card' giving key advice for reducing the risk of sudden infant death. Foreign language versions and more information about safer sleep is available to download at: <u>www.lullabytrust.org.uk.</u> It is important for health professionals to establish that parents have understood and remembered this information at least until the baby is six months old. Parents need to be given all possible assistance to adopt the advice.

## • Product Guide

There are many sleeping products on the market. This guide helps parents make an informed choice. This can be sent to the family earlier in pregnancy i.e. to acknowledge CONI referral received and when the first home visit is expected.

• Bereavement support leaflet

Advice and information for bereaved families, including The Lullaby Trust bereavement support services and other sources of support.

## • Room Thermometer

A strip thermometer, where the temperature is indicated by the brightest green square.

## • CONI Leaflet

An introductory leaflet to the CONI. This can be issued by the midwife at booking or at first contact between local the coordinator and parents.

## **Obtaining resources**

Some resources are free of charge and should be downloaded from the CONI webpages on the Lullaby Trust website - <u>CONI Resources - The Lullaby Trust</u>.

Other resources need to be purchased. Single items/small quantities can be ordered via the Lullaby Trust online Shop: <u>Shop - The Lullaby Trust - The Lullaby Trust</u>. Alternatively, for larger quantities, orders can be placed centrally by procurement departments via: <u>lullabytrust-orders@partridgesuk.com</u>.

## 6. Submit completed forms

Other than the Enrolment and Feedback Forms, all CONI paperwork should be retained locally; either leaving them in the care of the parents or placing them in the child's health records as per local practice guidance.

## 7. Liaise with and support other personnel

The local coordinator should ensure the paediatrician, GP, health visitor/nurse and midwife are fully informed about the family's involvement on the CONI programme. They need to provide the baby's GP practice with the **Information for GP Records sheet**.

After the baby is born, the care of the baby and family usually lies with the commissioned public health team, with the family's health visitor/nurse as key worker. The local coordinator is not required to visit the family again until the programme is drawing to a close, but their knowledge and experience should be available to the health visitor. Some coordinators do make a subsequent visit to check that there are no problems or make contact by telephone. However, care needs to be taken not to undermine the role of the family health visitor/nurse.

## 8. Ending of the programme - Visit at 6-7 months

This visit provides the coordinator with the opportunity to discuss drawing the programme to a close, and assess whether the parent(s) have any continuing worries, concerns or needs. The coordinator can explore with them what might be helpful, such as the availability of any local support services, and also specific support available from The Lullaby Trust e.g. bereavement support. They can also retrieve any loaned equipment. Ongoing evaluation of CONI is very important; thus, the family will be invited to complete an online **Feedback Form**. Parents will be texted a link to the Feedback Form from The Lullaby Trust when baby reaches 6 months old.

## 9. Maintain local awareness of the CONI programme

Health professionals may only meet a family who are eligible for the CONI programme infrequently and it can be difficult to retain detailed knowledge of the programme. Coordinators are encouraged to maintain local awareness of CONI through informal and formal staff meetings or training sessions, where possible. Colleagues can be signposted to the CONI bite-size presentations on The Lullaby Trust's CONI webpage www.lullabytrust.org.uk

## 10. Notification of baby deaths on the programme

It is **essential** that the National CONI Team be immediately notified of the death of a baby enrolled on the programme. The coordinator needs to complete the online **Notification of Baby Death Form** on The Lullaby Trust website. This form does not ask for person-identifiable information.

## **KEEPING UP TO DATE**

- The National CONI Team are available for advice by e-mail: <u>coni@lullabytrust.org.uk</u> and they can ring back enquirers, if required. For **sensitive** or confidential information, please send securely using <u>bchnt.conilullabytrust@nhs.net</u>
- Information about CONI including resources and forms, can be found on the CONI webpages: <u>Care of Next Infant (CONI) - The Lullaby Trust</u>
- A programme of online virtual Question and Answer (Q&A) sessions offers all local coordinators the opportunity to receive an update on latest SIDS research, bereavement support and developments about CONI. Coordinators are also able to submit questions to the CONI Team in advance. Dates for the Q&A sessions can be found on the CONI webpages: <u>CONI Q&A Online Booking Form - The Lullaby Trust</u>
- Coordinators also receive quarterly e-newsletters containing key information.
- Information is posted or emailed to the local coordinator by both the CONI Team and The Lullaby Trust.
- Coordinators are encouraged to sign up to receive the Lullaby Trust Professional Newsletter at The Lullaby Trust website: <u>Professionals newsletter The Lullaby Trust</u>

## TRAINING FOR NEW CONI COORDINATORS

Training is available for all new local coordinators by arrangement with The Lullaby Trust CONI Team. Existing coordinators are required to undertake update training every 3 years. Coordinators will not be reminded by The Lullaby Trust when they are due to complete an

update. Training is by a modular Distance Learning Course. There is a charge for training which includes coordinator resources for those completing their Initial training. Cost for the training is on the CONI training webpage: <u>CONI coordinator training - The Lullaby Trust</u>. A CONI ID number is allocated to each new coordinator and their details held on The Lullaby Trust database.

## FUNDING FOR CONI

#### Public health funding

It is expected that every provider of health visiting/public health service will allocate funds to maintain and support their CONI programme. A budget is required to meet recurrent costs which include the paper resources e.g. purchasing movement monitors, leaflets, servicing of equipment, disposable items for equipment e.g. sensors, surgical tape and batteries, and costs to complete new and refresher coordinator training. It is also recommended that the budget includes replacement costs for lost or broken equipment.

#### **Purchasing equipment**

All monitors are to be purchased directly from the UK distributor (See Appendix page 15).

Occasionally The Lullaby Trust receives donations of money for CONI. To be considered for this please complete and submit a Request Form which enables the CONI team to identify areas that have a need for equipment and match them to available funding <u>Request extra</u> <u>CONI monitors and scales - The Lullaby Trust</u>

#### **Local CONI Guidelines**

Once the CONI Programme is commissioned in an area, it is essential that local referral and care pathways are agreed and local CONI guidelines are produced that are ratified and adjusted to suit local resources and systems. These may form part of local Standard Operating Procedures (SOP).

#### **CONI presentations**

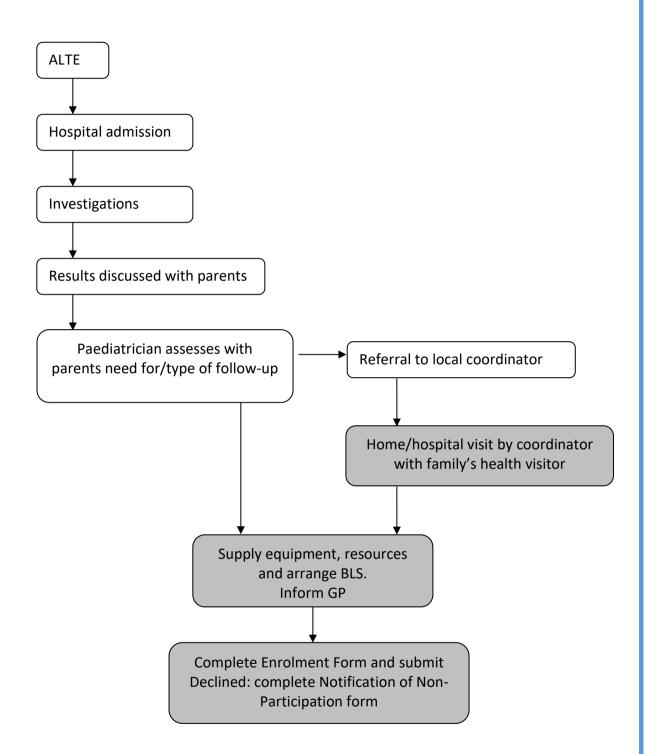
There are a series of recorded presentations on the CONI webpages for families using CONI: <u>https://www.lullabytrust.org.uk/professionals/care-of-next-infant/information-for-coni-coordinators/</u> to give them more information about the role of all the professionals that are involved with the CONI programme.

# APPENDIX

## **ENROLMENT PROCEDURE FOLLOWING ANTENATAL REFERRAL**



## **ENROLMENT FOLLOWING ALTE**



## **CONI EQUIPMENT SUPPLIER DETAILS**

(Correct at November 2023)

Please contact the suppliers/distributors directly for up to date prices

## **MOVEMENT MONITORS**

#### **SISS Babycontrol monitor**

Central Medical Supplies CMS House Basford Lane Leek ST13 7DT

Tel: 01538 399 541 | sales@centralmedical.co.uk

Testing units for the SISS monitor can be purchased through the distributors who advise that SISS monitors require servicing every 2 years.

#### Nanny BM-02 Monitor

Quote **CONI** for a discounted price.

Charlotte Gaffney | Service Quality Supervisor | EDPA LTD |

Mobile: 07701379047 | Tel: 01778 562804 | Charlotte.gaffney@edpa.co.uk

No servicing required

## **SNUZA Hero MD**

Hero MD | Snuza.com - Snuza Baby Breathing Monitors

Single use only, therefore no servicing required.

## Sensors for Graseby MR10 (now discontinued)

As from November 2015 Smiths Medical suggest the use of **Viomedex sensors.** These should be ordered directly from Viomedex Ltd. (SLE)

Maggie Chisolm | Tel: 01323 446130 | 01323 446130 | vx@viomedex.com

Viomedex Ltd Unit 13, Swan Barn Business Centre, Old Swan Lane, Hailsham, East Sussex BN27 2BY

## **RESUSCITATION EQUIPMENT**

Please order directly from the company:

St John Ambulance Supplies McBeath House 310 Goswell Road London EC1V 7LW

Tel: 08447704808 | www.stjohnsupplies.co.uk | customer-service@stjohnsupplies.co.uk

## THE LULLABY TRUST CONTACT DETAILS

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Telephone (general enquiries): 020 7802 3200 (office hours) office@lullabytrust.org.uk

CONI: 0207 802 3206 <u>coni@lullabytrust.org.uk</u> For sensitive or confidential information <u>bchnt.conilullabytrust@nhs.net</u>

Bereavement Support: 0808 802 6868 <u>support@lullabytrust.org.uk</u> and for sensitive or confidential information <u>bchnt.conilullabytrust@nhs.net</u>

Information and Advice Line: 0808 8026869 info@lullabytrust.org.uk

Fundraising: 0207 802 3201 fundraising@lullabytrust.org.uk

Press Office: 0207 802 3202 communications@lullabytrust.org.uk

#### Website:

<u>www.lullabytrust.org.uk</u> <u>Care of Next Infant (CONI) - The Lullaby Trust</u>

Social media: https://twitter.com/lullabytrust https://www.instagram.com/lullabytrust/ https://www.facebook.com/LullabyTrust/

Please also see our privacy policy on our website for how we collect, use and look after personal information: <u>https://www.lullabytrust.org.uk/privacy-cookies/</u>