Dear Team,

In this document, you will find guidance on how to safely care for a baby with suspected Epidermolysis Bullosa (EB). Please can you ensure all members of your team read and follow this guidance in order to protect the baby’s skin?

Before we arrange a visit to the neonatal unit we require photographs to be sent as soon as possible to the eb.team@nhs.net email address for us to review.

For our first visit, we would be grateful if the following could be in place before we arrive for our first visit:

**First visit requirements**

- Bath
- EDTA blood bottles for both parents and child
- Dressing pack
- Sterile gloves
- Consent form 2
- Prescribed medications: Lidocaine (subcutaneous injection), Morphine Sulphate, Paracetamol, Sucrose
- We will require both parents (if possible) to be present at the visit
- Please book an interpreter if required
- Please arrange for a separate room away from clinical area to be available for discussions with the family
• Please note the visit may take in excess of three to four hours and we would be grateful if there could be a member of the nursing team to assist us

After the initial visit, the skin sample and blood samples from parents and the baby will need to be sent to the EB Laboratory as an urgent delivery. Please note, samples cannot be sent on Friday and must be stored following the guidelines and posted on the following Monday. The address for the samples to be sent to is:

National Diagnostic Epidermolysis Bullosa (EB) Laboratory
Guys Hospital Research Oncology Lab Unit
3”d Floor Bermondsey Wing
Great Maze Pond Road
London
SE1 9RT

Listed below are our contact details for both in and out of hours:

• EB Nurses: 0121 333 8224 (working hours Monday – Friday 08.30-16.30, there is an option to leave a voicemail)
• Dr Malobi Ogboli (Consultant Dermatologist): 0121 333 8757 (secretary)
• If urgent advice is required out of hours, please telephone our switchboard 0121 333 9999 and ask to speak with the person on call for the EB service
• E-mail: eb.team@nhs.net
• Fax: 0121 333 8231
• Please inform the EB Team if a baby has been transferred or discharged elsewhere

We appreciate caring for a baby with suspected EB can be unfamiliar therefore, we urge you to contact us for advice. If in doubt, please adhere to the following rules:

1. Keep it soft
2. Keep it lubricated
3. Do not use anything sticky! If something is stuck to the baby’s skin, leave it
4. Dressings – if you cannot get hold of the dressings recommended, please use cling film and secure with a small amount of tape (please do not allow tape to touch the skin). On our first visit we will bring a box of dressings and topical treatments

Best wishes,

The EB Nursing Team
**Care of newborn baby with Epidermolysis Bullosa**

**Epidermolysis Bullosa** is a genetically inherited condition which results in blistering where there is friction or trauma to the skin. In newborn babies damage may be extensive often caused by kicking in utero or the trauma of delivery and large areas may be denuded of skin.

**First Aid**
- Wrap denuded areas in cling film if no other dressings are immediately available.
- **DO NOT** use any adhesive dressings, plasters, electrodes, skin temp probes etc. If any adhesives are used, use a silicone-based adhesive remover such as Appeel, Elite or Niltac Spray or soak off with 50/50 White Soft/Liquid Paraffin.
- Umbilical cord - the clamp should be removed and replaced by a ligature.

**Handling**
- Although these babies are delicate they can, and should be handled. Further damage can be minimised by careful handling avoiding friction.
- **DO NOT** push your hands under the baby, the shearing force may cause blistering. Instead roll the baby away from you and allow to gently roll back on to hands to lift. Alternatively, lift the baby on the mattress they are lying on.
- An arm or leg can be held quite firmly as direct pressure should not cause problems but do not allow the baby to twist in your grip as the resulting friction may induce blistering. Use a piece of soft cloth, Conti-wipe or clothing between your hand and the baby’s skin.
- Nurse in a cot or bassinette unless for other reasons, such as prematurity, the baby needs to be in an incubator. Nurse baby on a soft incubator mattress.

**Bathing**
- Babies with EB are much more vulnerable when naked and care should be taken when bathing to ensure that the baby does not do any further damage to the skin e.g. by rubbing feet together.
- Line bath with a very soft towel to reduce friction.
- Babies may be bathed using Dermol 600 Bath Additive and washed with Dermol 500 Lotion.
- 50/50 White Soft Liquid Paraffin or Dermol 500 Lotion can be used as an emollient.
- If a wound appears slough like, use wound irrigation solution such as Octenilin to cleanse the skin.
- Pat dry using very soft towel or sheet.
- Examine skin for new blisters, lance and apply dressings.

**Dressings**
- Give adequate analgesic cover at least forty five minutes prior to dressing changes for example: Paracetamol or Morphine Sulphate.
- Cover raw areas with Adaptic Touch or Mepitel and use Mepilex Transfer or Polymem over this to absorb any exudate. Hold in place with Soft One or Mepitac and a Tubifast bandage.

Last updated December 2019
• Dress affected fingers and toes separately, if possible, using small pieces of Mepitel, Mepilex Transfer and Soft One self adhesive tape. Otherwise weave Aquacel between digits.
• It may be easier to dress one limb at a time to reduce chances of legs kicking together and causing further damage.

Blisters
• Blisters must be burst as they arise as they will get bigger if they are not. Using a sterile needle and taking it parallel to the skin surface, pierce the blister taking the needle through and out of the other side so that fluid can drain out easily. Take care to leave the roof of the blister intact if possible.
• Gentle pressure with a gauze swab can be used to encourage fluid to drain but be aware that too much pressure may encourage the blister to spread.

Nappies
• Use 50/50 White Soft Liquid Paraffin on the nappy area, place a liner or Conti Soft Wipe inside the nappy to protect skin on legs from elasticated edges on nappy.

Clothing
• Dress in soft, front-fastening clothing turned inside out so that there is no damage caused by seams and labels.

Skin Preparation
• Skin preparation can be carried out as normal but avoid rubbing the skin. Use a site where skin is intact, hold limb firmly using soft gauze rather than using a tourniquet, to avoid shearing of the skin. Wipe gently with alcohol swab, do not rub. Secure with Mepitel Film dressing and a bandage.
• If splints are required, they should be well padded.
• Please DO NOT carry out finger or heel pricks. Please obtain a venous sample for Newborn Blood Spot Screening or equivalent tests.

Antibiotics
• Prophylactic antibiotics are not indicated and umbilical and IV lines should not be placed routinely. There should be a low threshold for starting antibiotics if the baby is showing clinical signs of sepsis using the usual antibiotics for your unit.
• If an IV line is required, topical analgesics e.g. Ametop can be used with special non adhesive dressings such as, Mepitel Film or cling film.

Feeding
• Oral feeding should be established as normal. Breast-feeding should be encouraged if mother wishes to do so.
• If the baby is to be bottle fed a normal bottle can be used with a soft teat, latex teats are usually softest. The teat should be moistened with water before feeding or smeared with a very small amount of white soft paraffin to reduce friction. Alternatives such as soft bottles or Medela feeders may be considered if problems are encountered.
Blisters may occur in the mouth or throat; they usually burst spontaneously and may bleed. Teething gel may also be used if the mouth is sore.

**DO NOT** pass a nasogastric tube unless absolutely necessary. If a tube must be passed **DO NOT** use any adhesive tape, secure using Mepitac Tape. However, an oral or nasogastric tube is usually preferable to IV feeding with TPN and early discussion with the EB team is advised if oral feeds cannot be established.

- Suppositories – avoid insertion of suppositories which can damage the anal mucosa.

**Observations**

- Tympanic thermometer is preferable. When taking axilla temperatures, care must be taken to lift the arm to avoid any shearing against the skin. Tempadot’s may cause damage if not removed very carefully.
- If a baby’s temperature is low, please ensure a Bair hugger is used. Place a blanket in between the Bair hugger and the baby’s skin.
- If a blood pressure is absolutely necessary, cover the arm with Gamjee/padding and place the blood pressure cuff over it.
- Saturation probes can be used after covering the digit with cling film or Mepitel.
- ECG electrodes can be applied; use over Mepitel and secure with Mepitac tape. ECG electrodes can be applied directly to intact skin and removed carefully with medical adhesive removal spray such as, Appeel, or Niltac spray.
- Avoid sticking adhesive tapes directly to the skin. If used **DO NOT** remove them, as the skin will come off with them. They can be removed later using 50/50 White Soft Liquid Paraffin or medical adhesive removal spray such as, Appeel, or Niltac spray.

**Theatre**

- Biopola Diathermy would be preferable to sticking a Diathermy Pad to the patient. A Gel Diathermy mattress is available in some Centre’s.
- Oropharyngeal airways and suction can cause serious mucosal detachment and blistering. Avoid undue facial manipulation and use an uncuffed endotracheal tube one size smaller than one would normally use. The tube and laryngoscope blade should be well lubricated. The tube should be fixed with ribbon gauze and all tubing should be padded where it touches the lips or skin. To avoid damage to the skin on the face and jaw, oxygen masks should be lubricated regularly with Vaseline Gauze or Petroleum Jelly.

**Procedures**

- Cannulation – Use a site where skin is intact. Hold limb firmly using Soft Gauze. Compress the limb manually as opposed to using a tourniquet, to avoid shearing off the skin. Wipe gently with an alcohol swab, do not rub. Cannulea can be fixed using Mepilex Transfer under the wings and Mepitel Film.
- If venous access is required, secure UVC with a suture to the cord and a flag, without securing to the skin.

**Other**

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Last updated December 2019
• The hospital name band should be taped to the baby’s clothing or a photographic ID obtained from clinical photography.
• **DO NOT** secure a security tag around the baby’s limbs.
• Weight checks: please do not remove dressings or clothing from the baby when weighing. Place a soft blanket on the scales before weighing the baby.

**Contact Details of EB Team at BCH**

• EB Nurses: 0121 333 8224 (working hours Monday – Friday 08.30-16.30, there is an option to leave a voicemail)
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