‘Our NEC Journey... so far’

Marie Spruce
Who am I?

- Mummy to 3 wonderful children one being a NEC Warrior
- Paediatric Nurse since 2009
- Experience from general medical gastro ward followed by cardiac respiratory ward and finally children’s Critical Care Unit.
- What a privilege it is to be here I would like to thank Minesh and Joanne for giving me the opportunity to come and talk to you all.
Our Nec Journey So Far…

– Outline of our Journey.
– How can you better Support Families with Long Term Admissions.
– Donor Milk and Research.
– ‘Quality of Life’ what that may look like at home.
– Transitional Care. Communication, communication, communication.
– Discharge Planning
– Life After NEC light at the end of the tunnel.
– NEC UK what we are doing to Help.
Outline of Our Journey
A brief slideshow of our journey
Admitted to hospital with abdominal pain and bleeding.
Diagnosed with Chorioamnionitis given IVAB’s Steroids Mag Sulph.
29+2 our son was delivered by emergency c-section under GA due to deteriorating blood tests and vital signs.
Weighing a respectable 1.3kg surfactant given required 24 hours minimal ventilation.
Started on MBM/DBM and TPN.
‘Honeymoon period’ day 5 he was on high flow minimal pressures.
Apneas/ bradycardias/ raised CRP/ bilious aspirates/ vomiting/ lethargic.
Steroids given to treat stridor after multiple failed extubations.
Multiple antibiotics, feeds intermittently stopped and recommenced.
Day 14 planned extubation day following steroids. Acidotic increased ventilation requirement swollen abdomen.
X-Ray confirmed Severe NEC, ultrasound supported this diagnosis.
Affecting his entire bowel surgery wasn’t an option. Supportive measures.
Freddie wasn’t expected to survive 24 hours but he did team worked tirelessly to chase his numbers with
blood products fluids ventilation medication.
Out of options baptism saying goodbye.
Day 20 Freddie perforated his bowel emergency surgery (less than 5% chance of survival)
Multiple stomas formed
Donor Milk and Research

Help parents to help you.
Donor Milk & Research

- Donor Milk available to All?
- Postcode Lottery
- How Can we increase the supply?
- Support Mums expressing. (equipment, emotional, advice)
- Inform parents- be clear of the benefits.
- Lets see Breast milk treated like Blood transfusions. Prevention is better than Cure.

- Research:
  - More information needed.
  - Missed Opportunities.
  - What more can we do?
How can You better Support Families with long term admissions?

Family Centred Care
Supporting Families of Long Term Admissions

- Involving families as soon as is safe to become the main Care Givers
- In my experience as a student nurse on NICU parents were very much on the sidelines.
- Fortunately with Freddie this has improved significantly.
- Still work to be done unfortunately it does still seem the extent of this depends on the team on the day.

Parents/Family Accommodation:
Ronald McDonald House our home from home.

- Mark Occasions and try and involve all the family.
- Christmas in hospital made special by staff.

Please don’t judge particularly parents with multiple children.

- Practical and Emotional Support
- PTSD, NEC UK, Bliss, local charities.
Patient Centred Care

– You are all experts in your field and key to detecting NEC early as we are all aware how quickly it can progress.

– However parents are experts in their own babies. The sit at the side of the incubator staring hoping noticing every movement. They will notice subtle changes that isn’t possible for doctor caring for a whole unit.

– I created a poll in our ‘nec uk support group’ as a result of lots of parents saying they had concerns prior to diagnosis and them feeling these were dismissed. 59 people responded.

– 43 ‘Yes but the medical team didn’t listen, act or dismissed my concerns.’

– 6 ‘ Myself and the medical team had concerns.’

– 6 ‘ No I didn’t have concerns

– 4 ‘Yes and the medical team listened to and acted on my concerns.’
How Can You help Families?

- I asked in the NEC UK Support group what was the best or worst part of their NEC journey (particularly feedback that could improve care)?
- 48 Parents stated Not having enough information about NEC.
- 22 Medical team not listening to parents concerns.
- 14 Having to be transferred to another hospital.
- 4 Inadequate feeding information, pushing formula, lack of donor milk.
- 3 Not having enough support with stoma care on discharge.
Quality of Life Discussion
‘What that may look like at home’

The good the bad and the Ugly
You need to have the hard conversations.

– As a professional we all like to think we would have an objective and informed view if our child was ever unwell.
– I have been involved in many of these discussions in my career being on the other side is quite surreal.
– We were grateful for the team having regular meetings with us to discuss what was in Freddie's best interest. My nursing head was always worried I would lose sight of what that was.
– As a non medical parent (like my husband) I can only imagine how hard it is to comprehend the enormity of the decisions being discussed.
– Blessing or Curse: I found myself pondering this frequently. At times I envied my husbands natural optimism when confronted by these conversations.
– Due to all the hard work dedication and innovation of professionals such as yourselves there is so much that we can do. However, whether we should always use everything at our disposal is a very different question.
– As professionals I ask you to never stop asking the questions as you are the advocate for that precious little baby but be aware that as parents the views are no less valid!
– Recent cases have raised so many questions within our professions and the general public.
– No simple answer or solution. Compassion, information and inclusive.
– I would urge you to give the worst and best case scenario and to the best of your ability the likelihood of each.
Freddie Quality of life… How that changed

– Initially we were told that his chances of survival were minimal we agreed supportive measures. Surgery wasn’t an option.

– Against the odds he ‘stabilised’. Freddie's bowel perforated. Short term decision without surgery wouldn’t survive with surgery less than 5% chance of surviving the surgery. We decided on surgery.

– Ventilation issues multiple sepsis, tpn dependence, liver disease, short bowel 8-10cm, ROP. Conversation involving gastro, surgical, neonatal team.

– Anastomosis surgery Home PN, liver/bowel transplants.
Transitional Care

Communication, Communication, Communication
Transitional Care

– One of the most frustrating things for families is the uncertainties.
– Involving specialist teams at the earliest opportunity to best support the baby.
– I requested a consultation from gastro specialist from the time I realised Freddie was left with such a small amount of bowel. This was vital for ‘quality of life’ discussions as the gastro team could offer us some picture of what life could be like long term.
– Once involved working together. In a day parents can see 2,3,4 teams of doctors imagine how confusing and frustrating it is to be told multiple different things by each.
– Always have a plan for moving forward and share this plan with the families.
Discharge Planning

Home Sweet Home
From the moment your babies born all you want to think about is them getting better and them going home.

I acknowledge the devastating fact that some of our babies don’t make it home due to NEC and that is why we are here. This was the outcome expected for Freddie we were lucky. However some babies like Freddie do have a very lengthy stay.

However, I feel as professionals we should always have in mind the end goal.

Some babies like Freddie will have additional needs at home and we all know that this takes a lot of planning.

Hospital stays could be reduced significantly if discharge planning was improved. This has many implications cost to the hospital and family, anxiety, development, quality of life.

Road to recovery, our discharge was delayed because of training and care packages.

If it is clear the child has additional needs start planning ASAP.
Life After NEC

Light at the end of the tunnel
Life After NEC…
Living with SBS and TPN

- 14 hours of TPN our daily morning/bedtime routine involves a military operation 2 sterile aseptic procedures with a very wriggly now 2 year old and a 6 and 9 year old to contend with.
- It involves approximately 12-14 nappies a day.
- That means I change approx 4380-5110 nappies a year
- At a cost of approx £1,095 - £1,277
- 3 packets of wipes a week.
- 156 packets of wipes approx cost £156 per year.
- 2 tubes of bum cream a week as he is prone to skin breakdown.
- Freddie requires his bedding to be changed at least once every night due to leakage.
- I do 1-2 loads of washing every day 730 a year at a cost approx. £336 in washing tablets alone.
- He eats us out of house and home which we are so grateful for as oral aversion is so common in SBS and NEC babies.
- We have a very large fridge to accommodate his TPN and 4 cupboards downstairs for his supplies.
- Upstairs we have another set of Drawers his pumps and drip stands. Mini hospital at home.
On my last slide you may be thinking none of that sounds fun. BUT Freddie has an AWESOME quality of life. He has a family that adore him and would happily do all of those things and to be honest it has just become ‘normal.’ Yes we make sacrifices but don’t we all when we have children.

Freddie has defied the odds he survived and he has exceeded expectations in every aspect of his life. He has managed to reduce to TPN 4 times a week from 7. He eats and drinks orally like any other child except a lot more.

He is catching up on his milestones. He loves Hey Duggee and Mr Tumble. Everything takes a lot more planning with Freddie but its so worth it when you do.

If we knew Freddie would have ‘this life’ when we were in NICU we would have been delighted it was far more than we expected.
Holiday of a lifetime

When I told his team I wanted to take him to South Africa to visit his Grandpa the look of terror crossed their faces.

This was the furthest one of their children would have travelled on TPN at the time he was on 6 nights.

The home care company pharmacist was also terrified and had never had a child go that far.

Please support and encourage families they can still do it!
What we are doing to help?
Emotional and Practical Support

- **Emotional:**
  - We have an online support group for families which offers peer to peer support.
  - Telephone text support line operated by NEC UK team members (We do not offer medical advice to the complex and individual nature of NEC).
  - NEC UK offers email support to families who may not have access to the group.

- **Practical:**
  - We offer NECessaries packs, these are parent focused car packs designed to support parents when baby has become unwell with NEC/suspected NEC.
  - We offer bereaved parents bags of Love and wordart keepsakes.
  - We offer Free to keep manual breast pumps to parents of babies at risk or recovering from NEC to support continued expressing at home when babies are in hospital.
  - We offer nappy support (Size 0-6 1.5-16kg) to parents of babies
Fundraising Awareness and Research

– The previous slide shows just a few of the fundraising efforts that have taken place over the last year.

– Various events: Races, memorial fundraisers, birthday fundraisers (popular on Facebook), Raffles, cake morning, giving up chocolate to name a few.

– This is all brilliant for raising awareness of NEC which is essential for all of us to combat NEC!

– We are very pleased to announce in October 2018 NEC uk has been able to support the immediate cost of a research project being carried out as a PHD by specialist neonatal and paediatric dietician which aims to look at machine learning and to aid diagnosis and treatment of NEC. This is a brilliant opportunity to collaborate NEC UK and SIGNEC to prevent NEC together.
Please if you have any Questions?

Thank You again for giving me this opportunity to talk to you all and for organising this amazing conference again.