

# NEC UK: providing support to families affected by necrotising enterocolitis



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**N**EC UK is the first charity in the UK exclusively for the condition of necrotising enterocolitis (NEC). Our organisation is parent-led and primarily offers support to families affected by the condition at any stage of their journey.

NEC is an acute inflammation of the bowel that can cause damage to a variable extent; it can affect just a small part of the bowel or the bowel may become so damaged that parts of it die. NEC is mostly seen in premature babies or those weighing less than 1,500g at birth. With advances in neonatal medicine, many more very premature babies are surviving, thus increasing the risk of NEC occurrence.

Most people have never heard of NEC unless their lives or someone they know has been affected by it. It is rare in the general population of babies but more common in neonatal units and is diagnosed in one in 250 live births. While NEC occurs in babies to varying degrees and with different outcomes, for many of us our NEC journeys continue long beyond exiting the doors of a neonatal unit.

I joined the NEC UK team in 2019; three years after my twin boys were born at 36<sup>6</sup> weeks' gestation. Just short of five weeks old, one of the twins, Charlie, developed a severe case of NEC. My partner and I were told he had very little of his small bowel left and his chances of survival were minimal. We were among the fortunate ones and Charlie defied all odds and survived. He is now a cheeky four-year-old living life to the full although, due to the lasting damage caused by NEC, he lives life with ultra-short bowel syndrome, a blended diet and is dependent on parenteral nutrition.

## Our charity

NEC UK understands the importance of healthy guts and the lasting complications NEC can cause. Our motto is 'tiny bowels matter' and by bringing the urgency of the patients, parents and family needs alongside the expertise of health professionals, we believe that together we can understand more, raise awareness and help others live a life after NEC.

Founder of NEC UK Susan Spencer recently shared her personal story with *Infant* readers.<sup>1</sup> Susan has now retired from her position with the charity but she leaves behind her legacy of NEC UK to the remaining trustees. Susan's place as chair has been filled by our previous vice chair Marie Spruce. Lyndsey Kociuba, one of our original trustees, continues as treasurer and I joined as a trustee taking position as vice chair and secretary. NEC UK's objectives are to:

- serve the babies affected by NEC and their families
- support improvements in neonatal care and best practice for families

- improve the outcomes for people affected by NEC
  - support research and studies into NEC
  - raise public awareness and understanding of NEC
  - develop good relationships with experts, care providers and other organisations to facilitate knowledge sharing, networking and collaboration
  - give NEC a platform from which to be heard
  - be the voice for those who feel that the lasting effects of NEC are not understood or taken seriously enough
  - preserve and protect the physical and mental health of families affected by NEC through social media and volunteer support.
- NEC UK offers emotional and practical support to families affected by NEC of different outcomes at any stage of their journey. Some of the ways we do this include:

### Peer-to-peer support

The NEC UK Charity Support Group, hosted on the Facebook platform, is for families only and posts are not visible to anyone outside of the group.

### Kangaroo hampers

At NEC UK we encourage and promote kangaroo care by sending our kangaroo care hampers to local hospitals containing the essential items to promote skin-to-skin contact.

### NECessaries parents' care packs

These packs contain emergency food, toiletries and other essential supplies for both parents while in hospital. They were designed by parents, for parents.

### Breast pumps

Brand new manual pumps in sealed boxes, available to mums of babies who have a medically identified risk of developing NEC and for mums of babies recovering from NEC to continue expressing while away from the hospital.



Claire and Charlie.

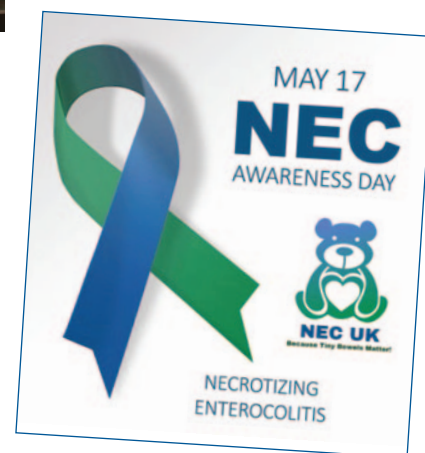


Left: Our kangaroo hamper (left) and the NECessaries parents' care pack (right).

Above: Paired hearts to provide a physical connection between mother and baby. The mother keeps one heart with her and the other is placed in her baby's cot while it remains in hospital.

Above right: Skin-to-skin care.

Right: 17 May is NEC Awareness Day.



### *Nappy support assistance*

For babies and children identified as having an above average use of nappies as a result of NEC.

### *Bags of love*

These are designed for bereaved families and contain keepsake items such as a small teddy bear, a wooden heart that the baby's name or a short message from the parents can be written on, a personalised 'word art' in a card, a heart-shaped candle and some flowering forget-me-not seeds.

### *Paired hearts*

These knitted, crocheted or sewn hearts are being given to families during the COVID-19 pandemic. Our families are suffering even more with restricted visiting and this is having a massive impact on breastfeeding and milk expression, both of which are important in reducing the risk of NEC. The hearts are a physical connection between the mother and baby. We send out paired hearts to hospitals across the country to help families and babies feel connected during this difficult time.

## **NEC Awareness Day**

In 2018, NEC UK and our partner organisations from around the world – the NEC Society, Instituto Pequenos Grandes Guerreiros (PGG), NEC Alliance and SIGNEC (special interest group in NEC) – came together in an agreement that there should be a global awareness day to represent NEC. It was intended that the chosen date, 17 May, would unite the world to raise awareness of this devastating disease. A global colour scheme of blue and green was formed along with the NEC awareness ribbon. We collaborated on developing world NEC Awareness Day to put NEC in the public eye; we shared stories from around the globe and discussed our goals for the future.

NEC UK is extremely proud of this global partnership of organisations that are all working towards creating a world

without NEC. We all strive to raise awareness together, drive research and improve outcomes for vulnerable babies and their families. The NEC symposium in Ann Arbor, Michigan, USA, in June 2019 allowed these relationships to grow and develop and we have now created not only charity partnerships but global research collaborations.

### *NEC Society*

A collaborative organisation based in the USA and dedicated to building a world without NEC by working towards better understanding, prevention and treatment of this devastating disease, the NEC Society was launched in January 2014 by Jennifer Canvasser after her son died from complications of NEC just before his first birthday. The organisation is led by Jennifer and Erin Umberger, who lost her daughter Sarah to NEC.

### *Instituto PGG*

Established in 2016, PGG is based in Brazil and led by Simone Rosito, who serves as an international advisor to the NEC Society. PGG offers psychological support to families affected by NEC while also driving NEC awareness and research.

### *NEC Alliance*

Recently established in Australia by Ashleigh Grant, who lost her daughter Matilda to NEC. Ashleigh participated in the NEC symposium where she was inspired to bring Australia into the international effort.

### *SIGNEC*

SIGNEC was set up by consultant neonatologist Professor Minesh Khashu. Initially comprising healthcare professionals from the UK, the group now has international involvement and includes neonatologists, paediatricians, surgeons, dietitians, transfusion medicine specialists, epidemiologists, basic science researchers, nurses, trainees and other healthcare professionals with an interest in NEC.

## The NEC Passport

In line with NEC Awareness day 2020, we welcomed the launch of our newly designed bear logo and charity website. We also celebrate the release of our first edition of the *NEC Passport*, a loose-leaf booklet that has been developed by NEC UK in conjunction with parents from our support group and our NEC UK Medical Advisory Panel.

The *NEC Passport* was created as families felt there was a large information gap when their child developed NEC. The booklet was designed to meet the needs of all families pre- and post-NEC diagnosis. It takes the form of additional information that can be downloaded and added to a child's Personal Child Health Record (also known as the 'red book'), given to parents/carers at a child's birth.

The *NEC Passport* sections include: what is NEC and how to reduce the risk of NEC, treatments, surgical words and their meanings, small/large bowel anatomy, your child's anatomy (first operation and subsequent operations), NEC-related problems in the neonatal intensive care unit, milk choices, feed intolerance, failure to thrive, TPN dependence, and problems in young children. Parents are able to add or remove the sections that aren't relevant. We aim to produce a series of additional sheets on complex NEC and teenage/adult service transition.

Many families report not knowing exactly what their child's surgery entailed or the implications for them and this is particularly important as the child grows. Many parents report having to describe their child's circumstances multiple times to healthcare professionals who are unfamiliar with NEC. We worked very closely with our medical advisory team to create something that is easy to use for professionals and families and keeps all of the information together in one place. The Evelina London Children's Hospital is printing our *NEC Passport* and issuing it to families affected by NEC. PGG is working on translating it into Portuguese and trialling it in Brazil.

We would really appreciate the support of healthcare professionals to get the *NEC Passport* into neonatal units so that it is accessible to families affected by NEC. Please do get in contact with us and/or download the full version at: [www.necuk.org.uk/nec-uk-passport](http://www.necuk.org.uk/nec-uk-passport).

## Supporting research

We are delighted to have made valuable contributions to NEC research. The charity part-funded a PhD studentship looking into artificial intelligence and early diagnosis of NEC. This led to many publications and we look forward to being involved in its ongoing success.

We are registered stakeholders with the National Institute for Health and Care Excellence and have contributed to multiple guidelines this past year. We have supported various project applications for funding into NEC research. Our Medical Advisory Panel has given us the opportunity to connect and engage with several research projects such as the National Perinatal Epidemiology Unit parent advisory group and the WHEAT trial (withholding enteral feeds around packed red cell transfusion to prevent NEC in preterm neonates).

We have attended and presented at the British Association of Paediatric Surgeons international congress, the National Neonatal Surgical Benchmarking Group study day, and the Newcastle Neonatal Nutrition and NEC (N4) Research Group meeting. We are excited to be involved with the European Society for Paediatric



Pages of the *NEC Passport* inserted into a child's 'red book'.

Gastroenterology Hepatology and Nutrition (ESPGHAN) NEC conference planned for November 2020 and organised by Drs Nick Embleton and Janet Berrington.

This coming year we look forward to being involved in a long-term research study looking at the effects of NEC beyond infancy and childhood. Moving forwards, we hope to see families, patients and parents at the centre of research. We would also like to become more involved with the British Association of Perinatal Medicine and ESPGHAN.

## Number crunching

Since forming as a charity in 2017 we have raised in excess of £30,000. Over the last 12 months we have supported upwards of 20 hospitals across the UK by providing:

- 224 parent care packs
- 90 kangaroo hampers
- 269 paired hearts
- nappy support for five families
- nine bags of love/word art – sent to bereaved parents across the UK
- 27 *NEC Passports*.

## Feedback

We are always delighted to hear feedback from families who have found our charity to be supportive and beneficial to them. For example:

*"We are extremely grateful to be able to participate in group discussions and are given the opportunity to speak with others who have experienced similar feelings, worries, everyday problems and treatment decisions."*

*"The parent care pack we got with my daughter was a life-saver, especially the toiletries because it is not something you think about when you are being rushed into hospital in early labour."*

*"I think the packs were fantastic, we were transferred late at night and the pack made me feel like I wasn't alone."*

## The future

Our aim is to have regional teams across the UK who can help the charity's work at a local level. This will include helping to build relationships and establishing connections with neonatal networks and hospitals, attendance and/or input at training days and events, supporting and encouraging fundraising and awareness events, and assisting in the facilitation of regional meetings for families.

## Reference

1. **Spencer S.** Neonatal loss – our journey. *Infant* 2020;16:18-20.

For more information about NEC UK visit:

[www.necuk.org.uk](http://www.necuk.org.uk)