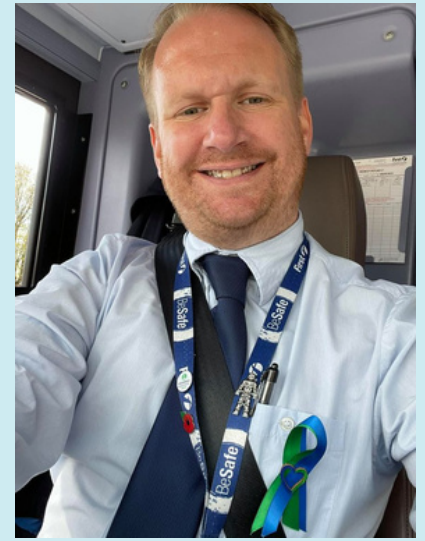
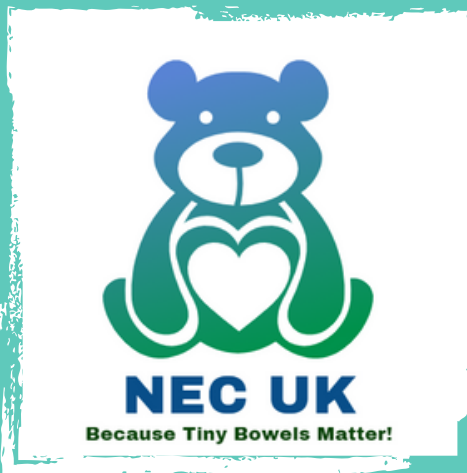




NEC UK

Spring- Summer News Letter





Welcome

NEC UK is the first charity in the UK exclusively for the condition Necrotising Enterocolitis (NEC).

Our organisation is parent led and primarily offers support to families affected by the condition at any stage of their journey.

Our History

In 2012, The founder of NEC UK whose son sadly died as a result of NEC volunteered for a local bereavement support group and recognised how beneficial peer to peer support could be. Quickly identified the need for a space where families specifically affected by NEC could come together. Shortly after came a Facebook support group specifically for families affected by Necrotising Enterocolitis.

In August 2016, this core group of parents who have experienced different outcomes for their babies came together to discuss how they could work towards making NEC UK a charitable organisation.

NEC UK obtained HMRC charity recognition from April 2017 and in December 2018 became a registered charity. Thereafter NEC UK was able to grant funding to support NEC research alongside providing practical support to families affected by NEC.

In 2019 we welcomed the first 4 members of our medical advisory panel. Dr Nicholas Embleton, Dr Janet Berrington, Dr Christopher Stewart & Dr Clara Chong. we have since welcomed Paediatric Nurse Hannah Wells, Paediatric Surgeon Nigel Hall, Neonatal Occupational Therapist Amanda Lawes, Breastfeeding support Kathryn Stagg & Paediatric Gastroenterologist Jutta Koeglmeier.

More babies per year die from NEC than any other childhood leukemia!

There is a high risk of death, poor neurodevelopment and short bowel syndrome as a result of NEC!

The UK still hasn't got to grips with NEC. Children and families are still suffering, babies are still dying. All because of a lack of knowledge about Necrotising Enterocolitis and why our tiny babies are developing it.

Research into necrotising enterocolitis has been underfunded, undervalued, and underrepresented for decades. We're not learning fast enough to stop the pain, suffering and save more lives. COVID-19 has thrown unexpected challenges our way, but we're determined not to allow research into NEC lag further behind.

That's why we're asking you to join us and as we head in to our 3rd year as a registered charity, we're asking you to join us and Help us to raise Fund for life-changing research that will end the pain and suffering for millions affected by devastating diseases.

Thank you



Three babies EVERY WEEK in the UK die from NEC!

Please consider giving £3 a month to NEC UK. With your help, we can work towards building a world without NEC!

You can find us



NEC UK
Registered Charity number: 1181026
42 Long hill Rise, Annesley, Nottingham, NG17 9FG



Enquiries: 07375813907



info@necuk.org.uk

JustGiving – PayPal – Facebook Donate

Scan Me



@necuk_charity



@nec_uk



@NEC UK



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NEC UK

(NECROTISING ENTEROCOLITIS)



Website: www.necuk.org.uk
 Email: info@necuk.org.uk
 Charity number: 1181026

HERE'S HOW WE HELP WITH YOUR DONATIONS!

202 PARENT CARE PACKS DELIVERED

Our NECessaries parent care pack, are designed for parents of babies with suspected or diagnosed NEC. The NECessaries parents care pack contain emergency food, toiletries and other essential supplies for both parents in hospital.

Care Pack content

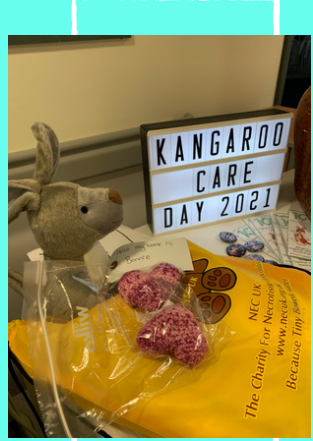
- Breast pads x2
- Set of bonding squares/hearts
- Sachets of nipple cream x2
- Sanitary towels x4
- Mini shower gel bottle x1
- Mini soap bar x1
- Mini shampoo & conditioner x1
- Mini hand cream bottle x1
- Toothpaste/toothbrush x2
- Shaving cream sachets x2
- Disposable razors x2
- Unisex comb x1
- White cotton flannels x2
- Lip balm x1
- Pocket size tissues x1
- Ear plugs x2
- Eyes mask x2
- Hair scrunchy x1
- Detergent tablets x2
- Juice cordial Pod x1
- Hot chocolate sachets x4
- Instant soup sachets x4
- Instant Porridge pot/sachets x2
- Instant pasta x2
- Instant noodles x2
- Cereal bars x2
- Colouring pencils x1 pack
- Pencil sharpener x1
- NEC UK Pen x1
- Writing pad x1
- Doodle/colouring book x1
- NEC UK information leaflet

Thank you!



The NICU Units you have supported over the last 12 months...

Winnicott Baby Unit, St Mary's Hospital London, Bristol Hospital, Hull Royal Infirmary, Walsall Manor Hospital, Birmingham Woman's Hospital, Birmingham City Hospital, Broomfield Hospital Chelmsford, Bradford Royal Infirmary, West Suffolk Hospital, Royal Albert Edward Infirmary, Queens Hospital Rom Valley (BHR), Leicester Royal Infirmary, Stoke Maneville Hospital Heartlands Hospital, Torbay Hospital, Grange University Hospital, Barnet Hospital, Heartlands Birmingham, Evelina, North Manchester General Hospital, Norwich University Hospital, Whiston Hospital, Lister Hospital, Royal Victoria New Castle, GOSH, Chelsea & Westminster, Liverpool Women's, Alder Hey.



43 KANGAROO CARE HAMPERS DELIVERED

NEC UK Encourages and promotes Kangaroo Care by sending our local Hospitals Kangaroo Care Hampers containing some essentials. Our Kangaroo care hampers are offered to parents of premature and sick babies and are designed to support bonding and breastfeeding.

Our Kangaroo Care Hamper contains

- 1 x Kangaroo Plush soft toy
- 1 x Cellular baby blanket
- 2 x Knitted bonding squares
- 1 x Story book
- 1 x Bag of cotton wool balls
- 1 x Nappy cream
- 1 x Note pad
- 1 x Pen
- 1 x Reusable drinks bottle
- Helpful Information



The NICU Units you have supported over the last 12 months...

Ipswich Hospital NICU, Princess Anne Hospital NICU, GOSH, The Grange University Hospital, Barnsley Hospital, Addenbrooks Hospital, Stoke Mandeville Hospital, Royal Jubilee Maternity Unit, SCBU St. Hellens & Knowsley Hospital, Firmly Park Hospital, Wrexham Park NICU, Barnet Hospital, Heartlands Hospital, Birmingham womens, Evelina, Birmingham Children's

NAPPY SUPPORT

NEC UK offers nappy support to UK families of babies and children identified as having an above average usage of nappies because of Necrotising Enterocolitis and who meet the following criteria:

- Have a stoma because of NEC or NEC related complication.
- Have Short bowel syndrome (SBS) because of NEC and where an average use of nappies is regularly exceeded.
- Are currently in hospital recovering from NEC, or NEC related complication or a reversal procedure.

Head over to our website for details of how to apply!



BONDING HEARTS



**680
PAIRS DELIVERED**

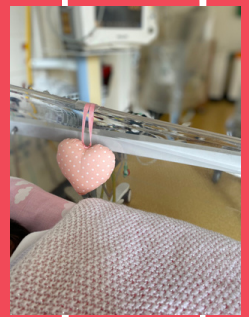
COVID 19 has led to additional trauma and heartache for many families in the neonatal unit with restricted visiting. With our bonding hearts parents, baby & siblings will all benefit.

Reduced mother bonding time can affect breast feeding & expressing. Even our most precious babies in the NICU will be able to recognize their mums simply by the way they smell. "During times of separation, these bonding hearts allows mum to enjoy the wonderful scent of her baby, and baby can sleep in the comfort of mother's special scent."

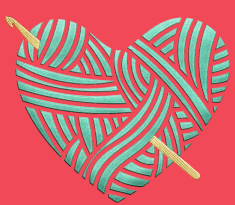
Benefits of mother scented bonding Hearts include:

- Bonding between mum and baby
- Calming effects
- Pain relief
- Improved appetite, feeding and weight gain
- Improved brain development
- Decrease in slow or shallow breathing
- Decreased length of stay

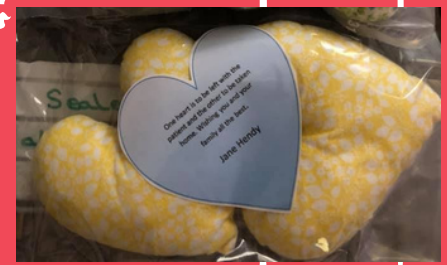
**Thank you to
our crafty
supporters!**



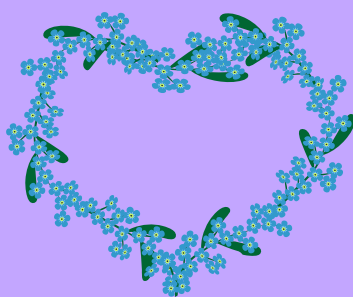
Some of the babies we send hearts out for become angel babies and the ability to be able to place a heart with baby and keep a heart with the family member provides a link and a tiny piece of comfort in such a difficult time.



Check page 14 For a pattern if you would like to support our cause

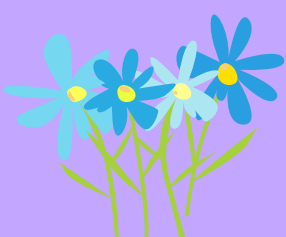


LITTLE BAGS OF LOVE



Bags of Love are designed for bereaved families and contain keepsake items such as a small teddy bear, set of knitted hearts, a wooden heart that cant be inscribed with baby's name , or a short message parents can write on, personalised word art on canvas, a candle and some flowering seeds to sow because together we remember with you.

Please proceed to our website Store if you wish to sponsor a Bag of Love today...





48 BREAST PUMPS DELIVERED TO UNITS ACROSS THE UK

A Big Thank you to the National Lottery
Coronavirus Community Support Fund for
supporting NEC UK.

Funding from the Coronavirus Community Support Fund, distributed by The National Lottery Community Fund, has helped us to provide 48 electric breast pumps to units across the country for mums to use at home. Breast milk reduces the risk of NEC and during these difficult times mums are under additional pressure. Thanks to the Government for making this possible. Each of our breast pumps have the names of babies we have lost to NEC, Their courageous families continue to raise funds and support our Charity.

Benefits of Breast Feeding

Establishing your milk supply

The capability of a new born baby to do breast suction may not be strong enough to help increase milk production. Hand pumping on the other hand may need some practice for it to enhance milk supply. So the best bet for establishing milk supply is through the use of breast pump. Breast pump can mimic baby suction and suction level can also be set and increase. Establishing milk supply can only happen if the breast is exposed to frequent suction which can be provided effectively using breast pump

Maintaining milk production

The level of milk production depends heavily on the demand for milk so pumping more often and regularly is the key for maintaining breast milk production. Pumping regularly is feasible using breast pump. Breast pump afford you the express milk anytime, anywhere so pumping more often is not a problem.

Removing milk to prevent breast engorgement

There may be times that milk production is too much for your baby to consume. In such instances breast pump becomes very handy to release some milk which offer you some relief. You can also store and refrigerate milk.

Store milk for later use

Breast pump is a friend for working moms. Since they can express milk to store in advance and later serve the stored-refrigerated milk moms are less worry returning for work or do something else. Properly stored breast milk can be preserve for few days.

Rest while others feed your baby

Motherhood can be exhausting, and more if they are also working. Using breast pump can give working moms some sort of relief knowing someone can offer some assistance feed milk to their baby while they take the rest their body needs.

Back to work

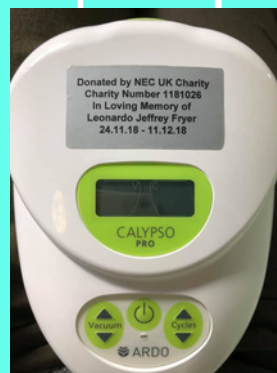
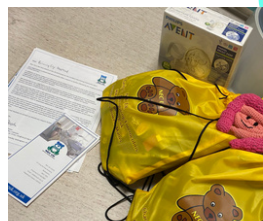
Maternity leave offers opportunity for working moms to breastfeed their baby exclusively. However when maternity leave ends and moms needed to return for work the use of breast pump becomes essential. They can pump milk in advance before they leave for work.

Mix milk with baby's first solid food

When starting giving solid food to your baby, it is best to mix solid food with some breast milk so that your baby will experience familiar taste while getting used to new textures.



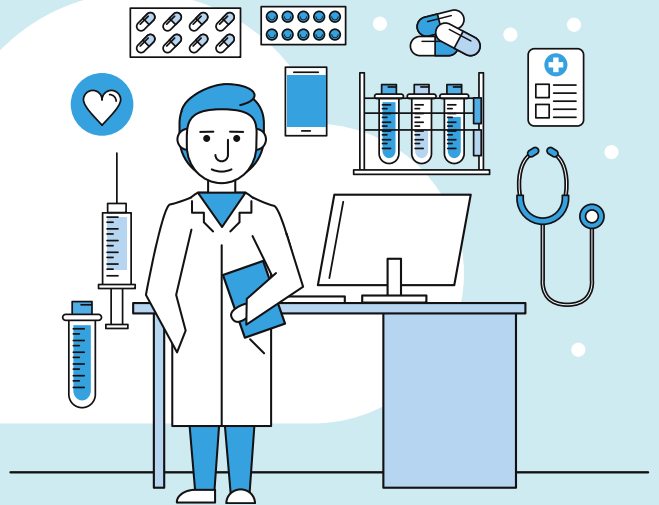
With your amazing donations we have also donated **8 Manual Breast Pumps** to Mums of babies who have a medically identified risk of developing NEC and who are being cared for in hospital to support Mums to continue expressing breast milk at home.



Units Receiving Breast Pumps

Bradford Royal infirmary, Ipswich hospital, Walnut ward Darent valley hospital Dartford, North Manchester general, The princess Alexandra Unit Essex, Musgrove park hospital Taunton Somerset, Torbay special care baby unit, East Surrey neonatal unit, Preston, Whittington hospital London, PICU Leeds hospital, Barnsley hospital, Grange university hospital Wales, Colchester hospital Essex, Bradford Royal infirmary, Warrington and Hilton hospitals, South Warwickshire foundation trust, University hospital Sussex, Wexham park hospital, Airedale general hospital Skipton, Southampton general hospital, St Mary's hospital Manchester.

Research Involvement



Dr Christopher Stewart
Has researched the early life microbiome in health and disease for the past decade, specializing on infants born premature (<32 weeks gestation)



Victoria Renwick
PhD Studentship



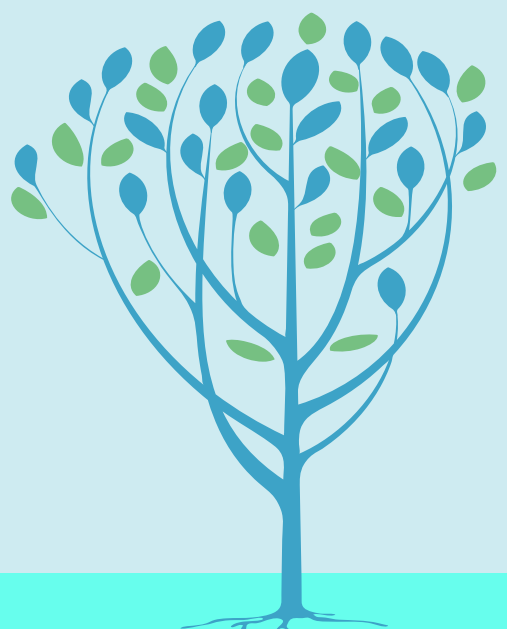
A new research project sponsored by NEC UK has been initiated to look into factors that may be involved in the development of NEC in preterm infants. Using non-invasive samples such as urine and stool obtained from the Great North Neonatal Biobank, we hope to find specific signatures of bacteria or the functional small molecules they produce, called metabolites. Metabolites are small molecular weight compounds which participate in the metabolic reactions required for growth, maintenance and general function within cells, biofluids, tissues and organisms.

The project aims to determine if there are associations between urinary and stool metabolites and disease onset in the preterm gut, with a focus on NEC.

This will be achieved by:

1. Investigating correlations between metabolites (in both urine and stool) and clinical factors (host and environmental).
2. Determining metabolite presence and abundance in NEC infants compared to matched healthy controls
3. Following up the clinical cohort work and testing different metabolites and bacteria of interest using state-of-the-art experimental models in the laboratory.

Being able to better identify or earlier determine NEC in preterm infants could help refine and tailor treatment options available for infants and potentially support their health needs earlier.



Ask The Experts

Q&A with our Medical Advisory Panel (MAP)



We asked NEC UK families what questions they wanted answered by our medical advisory panel. We are extremely grateful to our MAP Members who have answered them below:



Nicholas Embleton

A Consultant Neonatal Paediatrician and Professor of Neonatal Medicine, Newcastle University

Dr Christopher Stewart

Has researched the early life microbiome in health and disease for the past decade, specializing on infants born premature (<32 weeks gestation)



Jutta Koeglmeier

Jutta Koeglmeier is a paediatric Gastroenterologist at Great Ormond Street Hospital for Children in London, where she is clinical lead for the Unit of Nutrition and Intestinal Failure Rehabilitation.

Dr Janet Berrington

Consultant Neonatal Paediatrician in Newcastle and Honorary Clinical Senior Lecturer in Neonatal Medicine, Newcastle University, UK



Nigel Hall

Nigel Hall Paediatric Surgeon in Southampton and a researcher at the University of Southampton



How can we spot the signs quicker? I understand there are many and they are very hard to spot but is there a specific sign to look for?

Unfortunately, there are no specific signs that are always associated with NEC. In many cases the early signs are incredibly difficult to spot. Looking back, people will often comment that they thought 'things were not right' but at the time it was difficult. I have worked as a consultant for more than 20 years, and have probably looked after hundreds of babies with NEC - I still find it difficult to know for sure which babies have NEC, especially in the early stages. However, there is some good news - research studies are starting to use new techniques that can look at the patterns of chemicals or other markers in the stool (poo). This might provide an early warning signal. It is also possible that newer techniques of scanning the baby's tummy or looking at changes in blood flow may help. But sadly, at present, it is still really difficult to spot the early signs in many babies.

What is being done to help prevent cases of NEC in premature infants?

Every year more data is coming out of research studies. We have been involved in large trials recruiting thousands of premature babies, and every year we learn more. Researchers are looking actively at things like probiotics, and other things that could be added to milk feeds (oligosaccharides). Overall, we are getting better. Whilst it is true that the rate of NEC has not changed a lot, we are looking after smaller and smaller babies, who have a higher risk of NEC. So even though we still see NEC, we see it less frequently in the bigger babies than we did 10 years ago. We are also getting better at supporting mother's provide their own breast milk - that has a large effect on reducing the rate of NEC.

What has been achieved in the last 10 years since my daughter had NEC?

Using samples collected from preterm infants, researchers have learnt a huge amount about how microbes and the babies own cells interact, which is thought to be a critical part in the NEC disease pathway. We know some microbes are generally lower or absent from babies that develop NEC, giving rise to potential for preventative therapy. We also know certain sugars in mothers breast milk are associated with reduced risk of NEC, which could be used to assess disease risk in the clinic and to supplement infant diet. While exciting, more work is needed to prove if these results are cause or effect, and what the underlying biological mechanisms are. So from a research prospective, huge gains have been made in our understanding of NEC, but we still have a long way to go. Translation of research into the clinic can often be slow, and rightly so, due to the requirement to prove safety and effectiveness of an intervention. NEC remains relatively understudied, but passionate researchers around the world are doing all they can, and that's why it is vital we have initiatives such as those driven by NEC UK to raise awareness and understanding!

Full version can be found here:

www.necuk.org.uk/post/ask-the-experts-q-a-with-nec-uk-map-members

NEC UK EVENTS

From all of the team here at NEC UK we would like to say a big thank you to each and every one of you who has continued to support the charity over this past year. Covid has restricted us from running our events and Family fun days however it has not stopped you amazing people from making donations, volunteering your time to complete personal challenges and helping us not only raise Awareness of Necrotising Enterocolitis but raise funds to support our Charity too.

THANK YOU!

Challenge 50

The Following Supporters who helped raised

Anna Harris Middleton

Gemma & Samantha Wallace

James Williams

Marie Spruce dedicated each mile to babies affected by NEC



TOTAL
£2080

MAY 50k

This year we welcomed our first ever event "The May 50k For NEC UK!"

Participants could choose to Run, Walk, Cycle or Swim 50k throughout the month of May!

Thank you to our following supporters who helped us raise

Layla Marks

Emma Bromley

Sophie Lewis

Claire Radford

Hayley Heffernan

Nicola Cleary

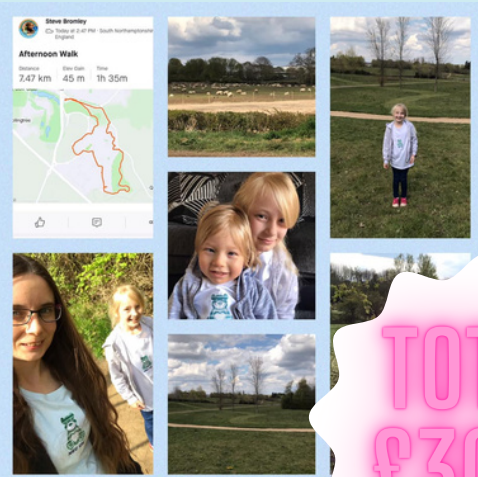
Anna Hulme

Olivia Hitchman

Louise Harrington

Naomi birch

Team : NICU Stoke Maneville Hospital

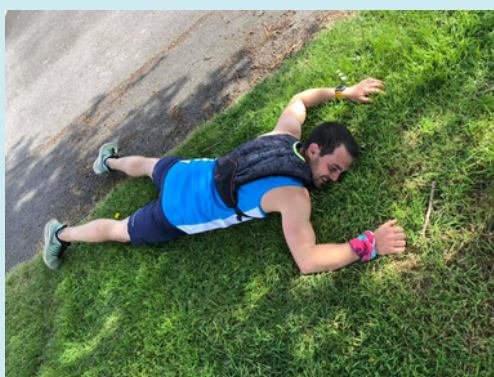


TOTAL
£3080



Toms Great Welsh Marathon

Tom has been training for the great welsh marathon for 2 years and has been postponed 3 times due to the pandemic so he decided NEC awareness day was coming up let just do it!



TOTAL
£253



NEC Awareness Day



In 2018 NEC UK and our partner organisations from around the world NEC Society, PGG & SIGNEC came together in an agreement that there should be a global awareness day to represent Necrotising Enterocolitis.

May 17th became that date uniting to raise awareness of this devastating disease. A Global colour scheme of blue and green was formed along with the Necrotising Enterocolitis (NEC) Awareness Ribbon.

NEC UK are proud of our global partners who 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. We collaborated on World NEC awareness Day to put NEC in the public eye. We shared stories from around the globe discussed our goals for the future. By attending the NEC symposium in Ann Arbour it allowed these relationships to grow and develop. We have now created not only charity partnerships but global research collaborations.

Our Global charity partners include:
The NEC society, PGG and NEC Alliance

For the Month of May you have raised

**TOTAL
£4,450**

We would like to say a big thank you to all of the hospital units who display information boards, volunteers for holding bake sales, community raffles, virtual coffee mornings, painted rocks, participated in The May 50k, Challenge 50, 100k Challenge, purchased our NEC Awareness Ribbon, Shared statistics and our infographs.

Towards the end of the day we shared our "Faces of NEC" video of the babies affected by NEC, some still here with us and of those taken to soon and held a wave of light of remembrance.



Anna's Story



An Adult Survivor

My Journey Surviving Necrotising Enterocolitis

On May 17th (I recently found out this is the day of NEC awareness!) 1999 I was born a healthy term+6 baby however I developed NEC soon after birth. I wasn't feeding and I was going grey in colour, My abdomen distended. I was then rushed to the special care unit and put on antibiotics and x-rays were taken in the hope that this would improve things, the next day I was transferred to the local Children's hospital in an ambulance and was sent straight into emergency surgery. The affected portion of bowel was removed and I had an ileostomy formed. Alder Hey Children's Hospital in Liverpool UK saved me even when I had the worst of odds and not many babies had survived. I then spent the first year of my life in hospital on Ward E3 I finally got home just before my first birthday whilst still on TPN to support the transition between Hospital and home and spent five years with a gastrostomy to ensure I got plenty of nutrients.

I have always asked 'why me' and until quite recently I didn't know what NEC was and why I had to have a Stoma bag. I wish that I had found the NEC society and NECUK earlier.

When I was growing up there was never enough awareness and talk about stomas which made me feel alone and the only person in the world who had a bag, however that wasn't the case. Stomas are often related to older people but people of all ages have bags. I met other young people over a number of years through charities and this also gave my family a chance to speak with other parents and know that we weren't alone.

I was determined to experience life without the bag, so I opted to have the ileostomy reversed when I was 13 years old. 11 surgeries later, I now empty my bowels in the normal way. My gut is now much shorter so everything travels through a lot quicker. As a result I have to go to the toilet frequently up to 20 times a day I always feel like I am looking for toilets and trying to explain why to people.

As a child I missed quite a lot of education due to illness and had a lot of time off school so I did my GCSEs a year behind and then my A-level exams another year behind so I actually did an extra 2 years of school so that I could have the best chances for my future.

I'm now a Student Midwife at the University of the West of Scotland. I have always wanted to work for the NHS so I am so proud to be helping others.

As part of my course we talk about NEC which is the disease that made me so ill and I shared my story to all 100 people in my class which was possibly the biggest step I have taken, it was the first time I had spoke openly to people who have not heard of a stoma before. Many of my friends are very supportive and love to share my story too. We still don't know what caused me to develop NEC and I hope to find out the reason one day. Being able to share tips and stories with others who know what it's like is interesting and empowering. It's turning something which could be perceived as negative into a positive experience. I addressed 250 health professionals at the ERIC conference in 2016 as a member of the ERIC young people panel. ERIC is a charity in the UK that supports children with incontinence.

I want people to know that even as a NEC survivor there is no limit on what I can do, most of the time I just need to plan to make sure I don't get caught out needing the toilet.

My medical condition has made me who I am today. More determined and more active as well as more caring and resilient.

I was told I could never swim. In 2016 and 2017 I took part in an English Channel Swim Relay and with my team we swam across the channel successfully on both occasions.

I have done some incredible things, I have always enjoyed sports, I have competed in triathlons. I carried the Olympic Torch in 2012 when the Olympics came to London.

I always took part in every activity available to me, I was a member of the Girl Guiding organisation and the Scout Association for a number of years. I was an Air Cadet with the Royal Air Force Air Cadets for 6 years, through this I did some incredible things.

I would love for more people to talk about NEC and the early signs and the outcomes of it like the need of a stoma as the fear I had of people finding out about mine made my childhood quite tough but I now look back and it has moulded me into the person I am and I hope my experiences can help me to be the best midwife I can be and I would particularly love to help people with a bowel or bladder problem who are pregnant.

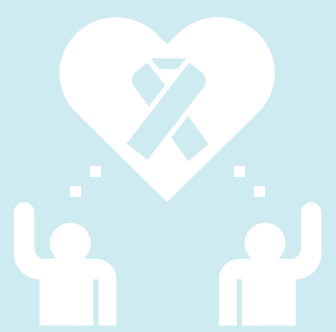
Last month I delivered my first baby as a Student Midwife (as pictured) and it was the proudest moment of my life! I'm excited to go back out to placement in January and I am looking forward to my neonatal ward placement just before Easter where I hope I can share my story to any families on the neonatal unit at that time.

Anna Hulme
Adult NEC Survivor & Student Midwife

Do you have a NEC story you would like to share? You can either do this by sending it via email or over on our website.

You can join our movement by following us on Twitter, Facebook, Instagram, subscribing to our email list, and making a donation. You can also read more stories from families impacted by NEC on our Family Stories page over on the website.

Our Supporters



All of your donation are extremely important to our cause, we'd like to thank you all for helping NEC UK work to wards our goals of building a world without NEC!

THANK YOU!

The Finnley Jones family for their continued support and a further donation of a £1000

The Greenwood Family who have raised over £2,335 In Memory of daughter Gaia.

The Marks Family who have raised over £3,615 in memory of their beloved son and twin brother Henry.

100 Miles in Memory of Olivia Jane Williams

James raised an amazing £650 On completion of his 100 Mile challenge to raise much needed awareness of NEC in loving memory of Olivia Jane Williams.

Olivia's Way of the Roses

Graham's bike ride from coast to coast in memory of his daughter Olivia Jane who sadly passed away at 10 days old ❤️💙
Graham raised £955 for NEC UK in her honour.

In Loving Memory of Arlo

GivingTuesday we Give Thanks to Sophie for her generous Donation of £130 In Memory of her beloved Son Arlo. Sophie has done an amazing job at making wax melt calendars and so generously donated the profits to NEC UK on this Giving Tuesday.
#GivingTuesday #givingback

easyfundraising.org.uk
feel good shopping

Help out when you check out

Collect **FREE** donations for us when you shop online via easyfundraising.org.uk

Through Easyfundrasing you have helped raise **£163.72**

Amazon Smile purchases you have raised **£94.08** Between 1 January and 31 March 2021



1:50 HUG donation SCHEME

one bearhug donated for every fifty sold

NEC U.K. is all about supporting families affected by NEC. Thank you to the BearHugs company for supporting our charity and regularly donates a 'Hug in a box' for our families.

For every 50 'Hug in a box' gifts sold, Bearhugs sends one to someone in need of a bit of extra love through their charity partnership.

Head over to the website to read more stories
<https://www.necuk.org.uk/meet-some-of-our-supporters>

Global Partners



Please join us in supporting these remarkable charities.

NEC UK are proud of our global partners who 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. We collaborated on World NEC awareness Day to put NEC in the public eye. We shared stories from around the globe discussed our goals for the future. By attending the NEC symposium in Ann Arbor it allowed these relationships to grow and develop. We have now created not only charity partnerships but global research collaborations. Our Global charity partners include The NEC society, PGG and NEC Alliance.



The NEC Society A collaborative organization dedicated to building a world without necrotizing enterocolitis. They are working to better understand, prevent, and treat this devastating neonatal intestinal disease. The NEC Society was launched in January of 2014 by Jennifer Canvasser after her son died from complications of NEC just before his first birthday. The organization is led by Jennifer Canvasser and Erin Umberger, who lost her daughter Sarah to NEC.

The Pequenos Grandes Guerreiros (PGG) Institute 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 impacted by NEC, while also driving NEC awareness and research. PGG was established in 2016 to honour sweet baby Tom.



The NEC Alliance is based in Australia and was established in 2019 by Ashleigh Grant, who lost her daughter Matilda to this devastating disease. Ashleigh participated in the NEC Symposium in Ann Arbor and was inspired to bring Australia into the international effort to build a world without





Bonding Hearts Knitting Pattern

Can you Knit, Sew or Crochet?
Excellent!



NEC UK are looking for Knitters to support our Cause!

NEC UK provide bonding hearts to NICU Units across the UK as part of our Kangaroo Care hampers to encourage parent and sibling bonding. We accept Crochet, Knitted or sewn Hearts and ask that there are no tiny holes.

Equipment

Needles: A pair of 3.75mm straight knitting needles (US 5) Notions: A small amount of toy filling to stuff the heart, A darning or tapestry needle to sew the knitted pieces together, A stitch holder **Yarn:** Less than 10g of DK yarn per heart.

Love Heart Make

Make 1. Cast on 6 sts in pink on straight 3.75mm needles. Start at the bottom tip of the heart.

Row 1: p (6 sts, WS)

Row 2: [k1, m1] x 2, k2, [m1, k1] x 2 (10 sts)

Row 3: p (10 sts)

Row 4: k2, [m1, k1] x 2, k3, [m1, k1] x 2, k1 (14 sts)

Row 5: p (14 sts)

Row 6: k3, [m1, k1] x 2, k5, [m1, k1] x 2, k2 (18 sts)

Row 7: p (18 sts)

Row 8: k4, [m1, k1] x 2, k7, [m1, k1] x 2, k3 (22 sts)

Row 9: p (22 sts)

Row 10: k5, [m1, k1] x 2, k9, [m1, k1] x 2, k4 (26 sts)

Row 11: p (26 sts)

Row 12: k6, [m1, k1] x 2, k11, [m1, k1] x 2, k5 (30 sts)

Row 13: p (30 sts)

Row 14: k7, [m1, k1] x 2, k13, [m1, k1] x 2, k6 (34 sts)

Row 15: p (34 sts)

Row 16: k (34 sts)

Row 17: p17, place the last 17 sts on a stitch holder to hold them to work later (17 sts)

For Rows 18 to 22 work the 17 sts on your knitting needle for the first top piece.

Row 18: k (17 sts, RS)

Row 19: p (17 sts, WS)

Row 20: k1, k2tog, k3, ssk, k1, k2tog, k3, ssk, k1 (13 sts)

Row 21: p (13 sts)

Row 22: k1, k2tog, k1, ssk, k1, k2tog, k1, ssk, k1 (9 sts)

Pull through to cast off. Now place the held 17 sts on your knitting needle with the WS facing you ready to purl.

Row 1: p (17 sts)

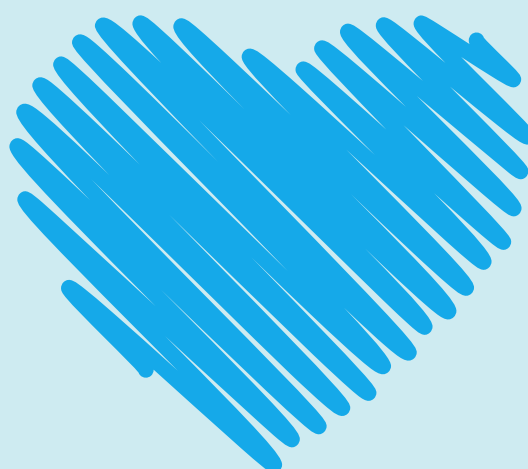
Rows 2 to 6: follow the heart pattern rows 18 to 22 (9 sts)

Pull through to cast off. Making up: First sew the side edges of the heart top together (from the cast off sts down to row 17).

Then sew the side edges together for the seam that runs down the centre back of the heart, adding stuffing as you sew. Finish by gathering the cast on sts together at the bottom of the heart.

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NOTES Finished size: The finished heart is approximately 6.5cm high x 6.5cm wide. Work flat: All pieces are knitted flat (back and forth) on a pair of straight knitting needles. Tension: The tension is approximately 22 sts x 28 rows for a 10cm x 10cm square in stockinette stitch on 3.75mm needles. Don't worry too much about tension for this pattern. Casting on: Unless otherwise specified, use the long tail cast on for all pieces. Sewing seam





Crochet Bowel Pattern

Did you know you can also support the charity by creating these cool and funky Bowel Toys. Post them to the Charity address and we will ensure they are giving to Siblings of our NICU Babies

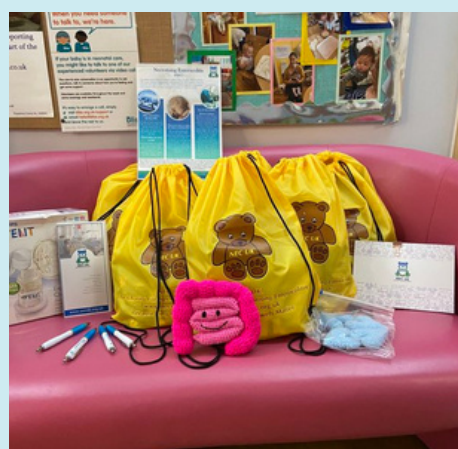
Equipment

Crochet hooks size 4.0 and 3.0 , Standard Safety Eyes, Two shades of pink yarn
Black embroidery thread for the mouth & Toy stuffing.

Large Intestine

Use Crochet hook size 4.0 and the darker pink yarn. Stuff to medium firmness as you go around.

1. Stitch 8SC into a magic ring (8)
2. In Back Loop Only (BLO) 2SC all around (16)
3. DC all around (16)
4. DC all around (16)
5. SC, SC, SC2tog repeat all around (12)
6. SC, SC, 2SC repeat all around (16)
7. DC all around (16)
8. DC all around (16)
9. SC, SC, SC2tog repeat all around (12)
10. SC, SC, 2SC repeat all around (16)
11. DC all around (16)
12. DC all around (16)
13. SC, SC, SC2tog repeat all around (12)
14. SC, SC, 2SC repeat all around (16)
15. SS, SS, SS, SC, HDC, DC, TC, TC, TC, TC, DC, HDC, SC, SS, SS, SS (16)
16. SS, SS, SC, HDC, DC, TC, TC, TC, TC, DC, HDC, SC, SS, SS, SS, SS (16)
17. SS, SC, HDC, DC, TC, TC, TC, TC, DC, HDC, SC, SS, SS, SS, SS, SS (16)
18. DC all around (16)
19. SC, SC, SC2tog repeat all around (12)
20. SC, SC, 2SC repeat all around (16)
21. DC all around (16)
22. DC all around (16)
23. SC, SC, SC2tog repeat all around (12)
24. SC, SC, 2SC repeat all around (16)
25. DC all around (16)
26. DC all around (16)
27. SC, SC, SC2tog repeat all around (12)
28. SC, SC, 2SC repeat all around (16)
29. HDC, SC, SS, SS, SS, SS, SS, SS, SC, HDC, DC, TC, TC, TC, TC, DC (16)
30. SC, SS, SS, SS, SS, SS, SS, SC, HDC, DC, TC, TC, TC, TC, DC, HDC (16)
31. SS, SS, SS, SS, SS, SS, SC, HDC, DC, TC, TC, TC, TC, DC, HDC, SC (16)
32. DC all around (16)
33. SC, SC, SC2tog repeat all around (12)
34. SC, SC, 2SC repeat all around (16)
35. DC all around (16)
36. DC all around (16)
37. SC, SC, SC2tog repeat all around (12)
38. SC, SC, 2SC repeat all around (16)
39. TC, DC, HDC, SC, SS, SS, SS, SS, SS, SS, SC, HDC, DC, TC, TC, TC (16)
40. TC, TC, DC, HDC, SC, SS, SS, SS, SS, SS, SS, SC, HDC, DC, TC, TC (16)
41. TC, TC, TC, DC, HDC, SC, SS, SS, SS, SS, SS, SS, SC, HDC, DC, TC (16)
42. DC all around (16)
43. SC, SC, SC2tog repeat all around (12)
44. SC, SC, 2SC repeat all around (16)
45. SS, SC, HDC, DC, TC, TC, TC, TC, DC, HDC, SC, SS, SS, SS, SS, SS (16)
46. SS, SS, SC, HDC, DC, TC, TC, TC, TC, DC, HDC, SC, SS, SS, SS, SS (16)
47. SS, SS, SS, SC, HDC, DC, TC, TC, TC, TC, DC, HDC, SC, SS, SS, SS (16)
48. DC, DC, DC2tog repeat all around (12)
49. SC, SC, SC, SC, SC2tog repeat all around (10)
50. FO and weave in ends



Small Intestine

Use crochet hook size 3.0 and lighter pink yarn. Stuff lightly as you go around.

1. SC 5 in a magic ring (5)
2. SC all around (5)
3. SC all around (5)
4. 2SC all around (10) 5- 66 SC all around (10) I placed the eyes between rounds 39/40 and 44/45 but measure them against your large bowel, aiming for evenly spaced eyes the second fold down in the small bowel.
67. SC2tog all around (5)
68. FO and leave a long tail for sewing on.

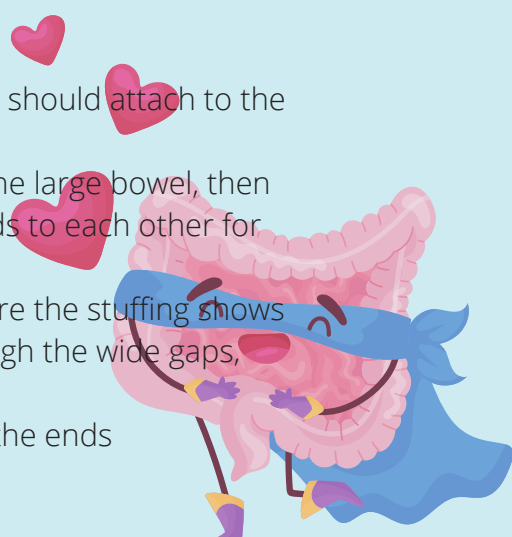
Putting together

Tack or pin the small bowel into place, aiming for four rows, the narrow end should attach to the caecum (bottom left of the colon).

Start by sewing the wide end of the small bowel onto the top left inside of the large bowel, then attach all around. As well as attaching to the large bowel, sew the bowel folds to each other for stability.

The treble crochet (TC), used to make the corners, can leave wide gaps where the stuffing shows through. To improve the appearance I wove dark pink yarn in and out through the wide gaps, approximately three times per stitch (8-9 passes per corner).

Once complete sew on a smile with black embroidery thread and weave in the ends





THANK YOU



Thank you to the following small businesses that have donated prizes to help us raise funds over the past year

'Tess Brilliant Bakes' Donated A fantastic collection of delicious cake slices cookies



'Oh so Lucy' Donated A Sunny Days beach bag

"Gutsy Kids Co" Donated Stoma Bag Covers

'little creations' Alcohol gel bottle

"Magenta Trends Annesley" Donated A Flower arrangement

"Hand Mae-d by Mae" Donated bespoke Earrings

"Neom" Donated A Neom 3 wick Candle

"Through The Looking Glass" for donating our Amazing NEC Awareness Day cake! & Treat boxes

"Cupcake_occasions7" Donated by Stacey - Nec Awareness Day theme and Bee Kind cup cakes

"Nancy Shaw at Xpo/Aps" Football Card Raffle fundraiser



Thank you to the Charity **"Short Bowel Survivor and Friends"** who have donated funds to support 10 of our Kangaroo Hampers For NEC and Kangaroo Awareness Day. These were sent out to units across the UK to help raise awareness of NEC, Short bowel and parent bonding.

Thank you to the following for donating your wonderful bonding Hearts and squares to support parent and sibling bonding project.



Oxford Knitters- Facebook

Rex's Project- Facebook

Lynne Davies

Nancy Shaw



"A kind gesture can reach a wound that only compassion can heal."

Steve Maraboli

