



Interested..? Join the PAG!

We are always looking for new parents to share their experiences in Neonatal Care.

If you would like to be involved and make a difference to the way Neonatal Units are run, then please get in touch:

Jess.Bolton@UCLPartners.com

- Attend a meeting
- Email us your views/queries
- Share your story and info.



Featured Charity:



The **Ickle Pickle Children's Charity** aims to give every newborn a chance. We turn gifts from generous people into specialised equipment, such as incubators and ventilators, breast pumps and monitors. This helps Neonatal units provide incredible levels of care to very sick babies.



The charity was established in 2009 following the premature birth of our son Charlie

at 28 weeks and 2 days weighing just 2lb 4oz. Had it not been for the amazing care he received and the equipment being available it may have been a very different outcome. Charlie is now a gorgeous, fun loving 9 year old who charms everyone he meets.

We are always keen to hear from families who have been through the neonatal experience and want to give something back in return for the care their babies received.

For more **information** contact rachael@icklepickles.org

or to make a **donation** please visit: www.icklepickles.org



Seasonal Special

Parent Advisory Group

News, Updates and Events

from the **Parents' Group** that **Influences Change** within the London Neonatal Operational Delivery Network (ODN)



NHS London Neonatal Parent Advisory Group

Can I use that chair...?

Nobody fully grasps the emotional rollercoaster for a parent with babies on a Neonatal ward.

Feeling not good enough, not being in control, and in a time warp of infancy; where futile questions such as “can I use this chair?” seem laden.

It becomes an internal battle that causes such thoughts to run through your mind. “Will I be reprimanded for asking?”, “Is it a silly question?”, “I wonder what the nurses will think of me?”

The truth is, we are modern day superheroes, and I never truly understood this until the final months of our stay. As parents to these strong, brave babies, it’s easy to get lost in all the beeping and the wires, but it is so important that we take back our parental control; make the most of the situation and not let the situation consume us.

So as Christmas and the New Year approaches, let your time on the wards be merry; dress your little ones up in tiny Santa hats, personalise your favourite chair with sparkling tinsel, dust your cape off, and sit confidently as the super parent you are!

By Rochelle Francis

What We’re Up To:

The PAG is dedicated to the use of FICare initiatives. **Ask your unit now if you can take part!** You can download the **FICare app**: search IFDC in the app store, and start tracking your baby’s cares now.



Our members will be visiting units to review their services for a national review of neonatal services. It’s great to have a **parent’s perspective**.

We have a new podcast project: **Desert Island Discs**: individual parent podcasts with music and stories for our website, accessible to parents. If you want to be a ‘NICU Castaway’, get in touch!



Charities and Support:

-  www.icklepickles.org
-  www.thesmallestthings.org
-  www.hospitaltohome.nhs.uk
-  www.truecolourstrust.org.uk
-  www.undiagnosed.org.uk
-  www.sibs.org.uk/supporting-young-siblings
-  www.contact.org.uk
-  www.rainbowtrust.org.uk/neonatal-support
-  www.wellchild.org.uk/supporting-you/connecting-families
-  www.newlifecharity.co.uk
-  www.familyfund.org.uk
-  www.tommys.org
-  www.bliss.org.uk
-  www.uk-sands.org
-  www.tamba.org.uk
-  www.pandasfoundation.org.uk
-  www.borntoosoon.info
-  www.first-touch.org.uk
-  www.whittingtonbabies.org.uk
-  www.hillingdoncherubs.co.uk
-  www.noahsbigcharity.com
-  www.chelchilcharity.org.uk
-  www.gosh.org

“I feel as if I’m not just a parent representative on the PAG but honoured to also be a voice for the premature babies as well. The fact that London neonatal network is actively engaging parents is such a big step in the right direction and it’s great to witness how it helps to ensure progress is achieved with full consideration of everyone involved.

It has given me a chance to highlight where we personally had great help and support during our most difficult times whilst also flagging where things could have been improved and contribute to finding solutions. It is rewarding to know that we can turn our darkest times into something so productive and help others.”

Victoria Scott, *Parent and PAG member*.

Upcoming Events

We meet quarterly on units or near UCLH, and communicate in between.

To join our mailing list, or find out how you can get involved and our meeting dates for the new year, please email:

jess.bolton@uclpartnetners.com for details.

Contact Us

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Visit us on the Web:
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 @LdnNeonatal_ODN