



Supporting HIE Families

## **Hello and welcome!**

If your baby or child has experienced an HIE (Hypoxic-Ischaemic Encephalopathy) event, this leaflet may be of interest to you. We're here to let you know about some of the available support and to reassure you that you're not on your own.

Being in hospital can be tough going and there's lots to take in and learn; we're not about to baffle you with medical terms – we'll try and keep things simple and help you through any difficult days.

## **What is Peeps?**

Peeps is a charity, set up in 2018 by Sarah & Steve. Here's a quick note from Sarah to explain why:

“We found ourselves in the world of HIE when our daughter was born in March 2015 – she stopped breathing shortly after birth and, without any warning, our NICU journey began.

Neither of us had heard of HIE before, none of our friends or family had, and let’s be honest, it was a scary time. I Googled it (going against the advice of all the nurses of course!), and luckily found a Facebook forum for families. If it hadn’t been for that group and the advice and information offered by other mums and dads, I think we might still have been wondering what on earth was going on!”

So, we wanted to change things a bit by reaching out to families and sharing helpful information.

Every HIE journey is different, but there are similarities and shared celebrations, as well as the uncertainties and worrying times. Peeps can be alongside you whenever you need us, whether that’s today, next week or in a few months’ time.

### **What is HIE?**

HIE stands for Hypoxic-Ischaemic Encephalopathy, and put simply, is a lack of oxygen to the brain. This can cause injury, and the severity of this can vary greatly (often given a grade from 1, which is mild, to 3, which is severe).

Your doctor will probably have explained this in more detail and may have done tests to determine the extent of any injury. One thing to remember,

though, is that tests are only part of the picture. Try to focus on your baby and how they are, and ask questions if you have concerns.

There are many potential causes of HIE, such as placental abruption, umbilical cord-prolapse, uterine rupture, or shoulder dystocia . There are lots of other possible causes (too many to list here). It can sometimes take a while to determine the cause, and sometimes a cause isn't known. It's always best to seek a medical opinion if you need further details or have questions.

## **What is HIE?**

HIE affects 3-4 babies in every 1,000 – you're not alone!

From experience, HIE isn't really that well known despite the number of families it impacts each year. Peeps is trying to raise awareness, so that more people know what HIE is, and families affected by it get the support they need.

## **How can we help?**

We are here to help in any way we can, whether that's now or in the future. A couple of things we offer include:

### Free parent bag

If you haven't been given a Peeps bag by your NICU/hospital team, we would be happy to send one out to you. Our packs include comfort items (such as lip balm, hand cream, toothbrush, tissues), a notebook and pen for keeping a record of things, a water bottle to help stay hydrated, and information that may be useful.

### Buddy/peer support

If you think it might be helpful to talk to or have contact with a mum or dad who has been through the same experience, then we can put you in touch with a "buddy". You'll be paired with a family who has experienced HIE and who are happy to chat to you – whether that's over the phone, via email or, if local, in person.

### Counselling and therapy

Peeps was set up by parents, and whilst we have experience and can always lend an ear, we're not trained professionals. If you feel you would benefit from speaking to a trained counsellor or therapist, please get in touch so we can help you further.

### Funding

Having a baby can be expensive. If your child needs a little extra support the costs can really add up. We have allocated funds for equipment that aren't available through the NHS, as well as support with accommodation or travel costs if you have a hospital stay. We're really proud to say that our funds are needs, not means, tested.

## Contact details

There are lots of ways you can get in touch with us and we'll always try and respond as quickly as we can. We don't have any big call centres so please don't be put off if you have to leave a message – we'll always try and pick up or get back to you as soon as possible.

You can:

Give us a bell on 0800 987 5422

Send us a text or a WhatsApp message on 07838 197 945

Ping over an email to [info@peeps-hie.org](mailto:info@peeps-hie.org)

Find us on social media and send a message, just search **PeepsHIE**.

We understand that sometimes making the first phone-call or sending the first message can be daunting. We promise though that we are here for you, and you'll always get a warm welcome.

We have a website and an app too so that you can easily find information at any time, day or night - sleep is sometimes a rare thing on NICU isn't it?

The address is [www.peeps-hie.org](http://www.peeps-hie.org) (just scan the QR code at the end of this leaflet), or search for **PEEPS HIE** in the Apple App or Google Play Store.

## **Useful links**

There is a wide range of support out there for parents. If you have access to Facebook, this is a great group to join:

HIE Network Forum on Facebook -

[www.facebook.com/groups/thehienetwork](http://www.facebook.com/groups/thehienetwork) - a UK-based closed support group for parents whose children are affected by HIE, set up by parents.

More details of other groups and organisations are listed on our website and app.

## **A helping hand through NICU**

With the input from some fellow HIE families, we've put together some advice to try and help during those early days (and beyond).

- Ask questions. Never ever feel that you are being a nuisance! As a parent of a child affected by HIE, there are probably lots of things going around in your mind. Make sure that you are fully informed as to what is going on, and if anything isn't clear then ask the consultant/doctor/nurse etc. to run through it again (and again if needed!) until it is. Keeping a note of things to ask and answers you have been given can help. It's hard to remember everything.

- If friends or family offer to help, take them up on it! It can sometimes be easy to say that you're fine, or you don't want to accept help, but it's really important to try and look after yourself, while you're looking after your little one. Ask them to bring you a meal...it's easier said than done but trying to have some proper food rather than snacks can help keep your energy levels up.
- Ask the hospital (if they haven't told you already) if there is a parking permit available. It can be expensive at the best of times, but many hospitals offer a discounted or free pass for parents who have a baby in NICU. There may also be other things that could help, so it's worth checking with your local team.
- Remember to try and get some "you" time (another thing that's easier said than done). Whether it's time to sleep, grab some fresh air, or chat to a friend, it's important and you shouldn't feel guilty. The NICU nurses won't judge you for taking some time out (in fact most would encourage it!) – your little one is in safe hands and you'll be a bit more refreshed when you go back to them.
- Keep a journal. Writing things down can help clear your head, and also means you can look back on your journey. Keep a track of every little development and take each day at a time.
- Talk. Whether it's to your partner, your family, your friends, your GP, or to Peeps...it's ok to feel how you're feeling; we're here to listen and help where we can.