

Information & Support for HIE Families



HIE AWARENESS & SUPPORT




Hello and
Welcome



If your 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 support that is available and to reassure you that you're not on your own.

We're not here to baffle you with medical terms, but understand that you, and your family and friends might have questions - we'll try and keep things simple and help you through any difficult days.



What is Peeps?

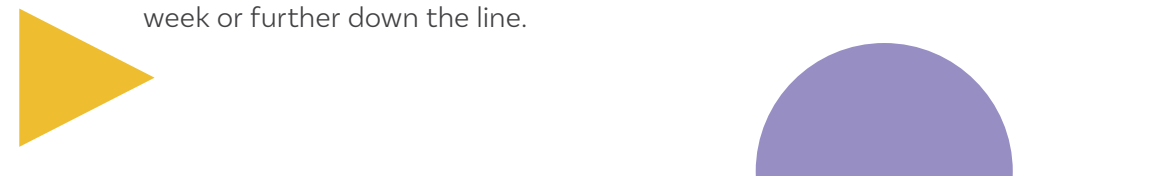
Peeps is a charity, set up in 2018 by Sarah & Steve. Here's a quick note from Sarah to explain why:

“ Our daughter experienced an HIE event in 2015. In seconds our world changed. 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 further down the line.



What is HIE?

HIE stands for Hypoxic-Ischaemic Encephalopathy. Put simply, it is a lack of oxygen to the brain. The severity of HIE can vary greatly (often given a grade from 1, which is mild, to 3, which is severe), as can any injury it causes.

This should be explained to you in more detail in hospital, where they may also have done tests to determine the extent of any injury. But tests are just one part of the picture - how your child presents is really important too (and children have a tendency to write their own rules!).

There are many potential causes of HIE. It often happens around the time of birth, but it can happen in older children (for example if there has been an accident, or infection).

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.

HIE affects

3-4

babies
in every

1,000

and a number of older children each year due to injury, illness or accident.

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:

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 child can be expensive. If your child needs a little extra support the costs can really add up. We have allocated funds for equipment that isn'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.

To find out more about what's on offer, including free online sessions and Peeps Together meet-ups, keep an eye on our website or social media.



@PeepsHIE | www.peeps-hie.org

We're really open to new ideas too, so if you feel something would help, please don't hesitate to let us know.

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**



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 isn't it, especially if you're in hospital?

The address is **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 - 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

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

- **Ask questions.** Never ever feel that you are being a nuisance! As a parent of a child who has experienced an HIE event, there are probably lots of things going around in your mind. Make sure that you are fully informed as to what is going on. If anything isn't clear then ask your consultant/doctor/nurse etc. to run through it again (and again if needed!) until it is.
- **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 (or big!) 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).

- **If you're in hospital, ask (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 child staying in.
- **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. No-one will judge you for taking some time out (in fact we would encourage it!).
- **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.

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www.peeps-hie.org

