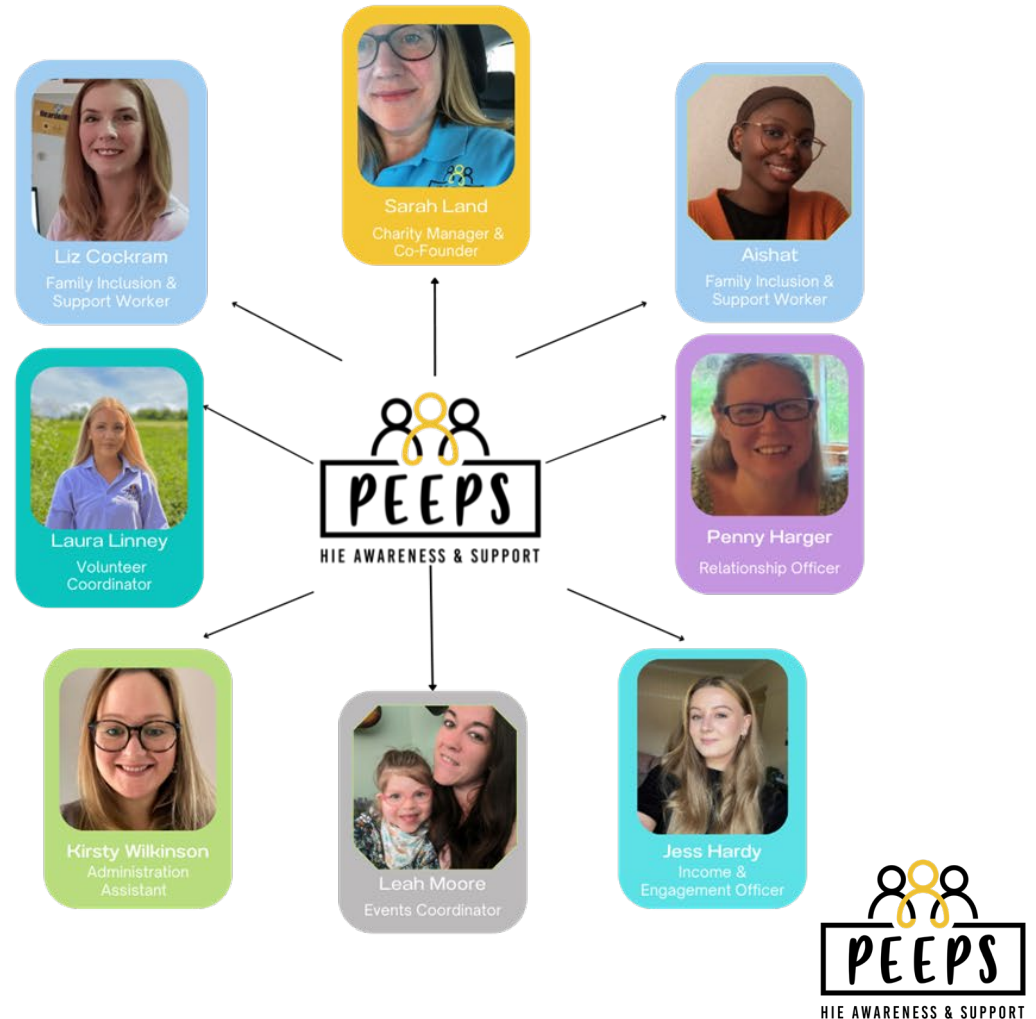






Hi, welcome to Peeps – the only UK charity dedicated to supporting those affected by HIE. Thanks for inviting us to share a little bit about the work of Peeps, and most importantly the parent perspectives of HIE.



What is H.I.E.?

Hypoxic (*hi-poc-sic*)

Meaning = lack of oxygen



Ischaemic (*is-kee-mik*)

Meaning = restricting blood flow



Encephalopathy (*en-kef-a-lop-a-thee*)

Meaning = affecting the brain



Heidi, me and HIE



Our daughter, Heidi, was born in March 2015, at 40+11. She arrived, on Mother's Day, as the most wonderful gift and for half an hour, our world was perfect



That soon changed – Heidi had a HIE event, needed resuscitation and was whisked away to NICU



We got to see her briefly before she was transferred to another unit to start cooling therapy (therapeutic hypothermia)



The midwives and doctors knew how poorly she was. One of them told us it would be like a rollercoaster...which was so true



Heidi spent 8 weeks in hospital before finally coming home, and that was when the real fun started



Leaving the safety bubble of hospital was daunting, and we really weren't prepared

In the beginning



Scared

Upset

Isolated

Grief

Judged

Lost

Guilt

Worried



Love

Hopeful

Thankful

Held

Cared
for

Have you heard of HIE?



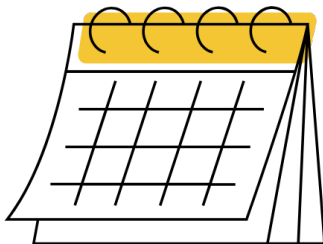
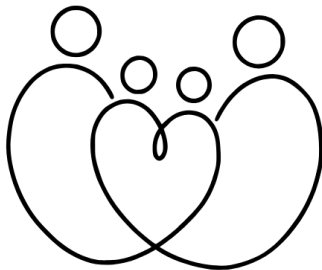
- The overwhelming majority of parents haven't heard of HIE until it happens to them.
- Friends and family don't know what it is, what it means, or how to help.
- 83% of respondents in our survey thought HIE should be spoken about more often during pregnancy than it currently is.
- Over 65% of families stated that they saw a decline in their mental health after the HIE event.
- Over a third of parents are experiencing financial instability
- A quarter have suffered the breakdown of a relationship
- HIE can have different causes and outcomes, and the impact on families cannot be underestimated.



What matters to families?

| | |
|-----------------------|--|
| Family centered care | <ul style="list-style-type: none">• Including families in decision-making• Providing information – appropriate and accessible• Recognition of emotional and physical well-being of the family unit |
| Communication | <ul style="list-style-type: none">• Open and honest communication (even, or especially, when things go wrong)• Clear, compassionate and culturally sensitive• No “one size fits all” solution |
| Trauma informed care | <ul style="list-style-type: none">• Prioritizing the emotional and psychological safety of the family• A safe environment to voice concerns• Sensitive and compassionate care |
| Support | <ul style="list-style-type: none">• Signposting to support at the earliest opportunity• Offering choices – reducing the need for families to search for help themselves |
| Inclusive practices | <ul style="list-style-type: none">• Promoting equitable care for all• Addressing disparities in maternity care |
| Advocating for change | <ul style="list-style-type: none">• Listening to the voices and needs of families• Working towards inclusive, equitable and safe care• Learning and ensuring safer care for future families |

When things go wrong

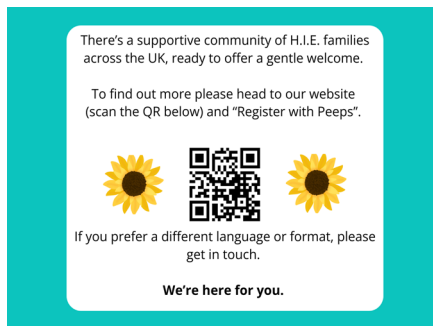


Life after an HIE event

- Finding where you fit in can be hard.
- You don't "get over it", no matter what the outcome.
- Parents are often on high alert - watching and waiting, but for what?
- Going back to the hospital for follow up appointments, or future pregnancies, can be triggering.
- The early months can feel overwhelming!
- Anniversaries / birthdays can bring up lots of emotions.
- HIE may bring with it lots of challenges, and there can be positives too.

Information and Support

- A community!
- Support and understanding, regardless of cause or outcome
- Peer support - from parents / grandparents who have lived experience of HIE
- Free parent packs for the start of the journey
- Mental health support (fully funded)
- Bereavement support
- Online resources - with our accessible toolbar to enable translations, alternative formats, and text to voice options
- Events - in person at fully accessible venues, and online, to facilitate family connections





Give us a bell on 0800 987 5422
Drop us a text on 07838 197 945
Ping over an email to info@peeps-hie.org
Find us online at www.peeps-hie.org



@peeps-hie



@peeps-HIE



peeps-hie

