

Harry's Hydrocephalus Awareness Trust (Harry's HAT) ✨

Founded 2018; Registered Charity 2019

- Raise awareness of paediatric hydrocephalus
- Fund front-line workers to learn about the condition and so improve patient care
- Signpost and connect families affected by the condition



From Caz, Harry's Mummy, and one of our Founders.

Harry is my fourth child. He was diagnosed with hydrocephalus in 2017. Despite having four children and working in social care, I had never heard of the condition before. My partner and I felt very alone, and incredibly scared.

As a Mum, I just wanted to speak to other Mums of 'hydro-kids' to understand what our lives might be like.

We initially set up Harry's HAT to fund nurses after learning that, in some cases, nurses have to pay for their own training. However, the charity quickly grew...



Are new parents aware of the signs and symptoms of hydrocephalus? *

The importance of head circumference measurements in the first year of a baby's life.

Non Hill, Roisin McNicholas, Yesha Bhagat, Annabella Taylor, Rebecca Hartley, Caroline Coates, on behalf of:

Harry's Hydrocephalus Awareness Trust Research Team.
U.K. Registered charity 1183086



Volunteering



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Harry's HAT sought to understand parents' **experiences, awareness** and **understanding** of hydrocephalus and head circumference measurement

- Current clinical guidelines **recommend routine head measurement at birth, at 6-8 weeks old**, and at **any time** where there are concerns about **growth or development**^[1]
- However, a **consortium of international experts** now recommend that the head circumference should be recorded at **every encounter with a healthcare professional** in order to screen for undiagnosed neurological illnesses^[2]

[1] Using the new UK-World Health Organization 0-4 years growth charts: information for healthcare professionals about the use and interpretation of growth charts. Available from:

https://www.rcpch.ac.uk/sites/default/files/Using_the_growth_charts.pdf

[2] Comprehensive Policy Recommendations for the Management of Spina Bifida & Hydrocephalus in Low- & Middle-Income Countries chyspr.org



Acute hydrocephalus requires prompt recognition and treatment

- **Early diagnosis** and **timely treatment** to reduce intracranial pressure may prevent permanent brain damage from occurring
- An unusually **large head circumference and/or rapid head growth** can be a sign of hydrocephalus^[3]
- It is **vital** that baby checks include measurement of head circumference

“A decade ago [...] it used to be the case that **every time the health visitor** called round, they’d measure the head and record it in the baby’s little red book [...] no longer standard practice.

Consultant Paediatric Neurosurgeon Jay Jayamohan;

“Everything that makes us human”

[3]: UK-WHO Growth Charts

[What, When and How to Measure \(rcpch.ac.uk\)](http://rcpch.ac.uk)



Research methods



March 2022, 'Bounty' hosted an **online survey** (Qualtrics^{XM}) on behalf of Harry's HAT to gather insights **on hydrocephalus and head circumference measurement** awareness.



Ten **closed questions** and a **free text** response question were included for narrative feedback.



Descriptive statistics and thematic analysis were used to evaluate **quantitative and qualitative responses**.



750 survey responses received from parents with babies aged **0-12 months**



Babies' head measurement experiences

- **At both birth and 6/8 week check, two thirds** of parents reported that their baby's head circumference **was** measured but **22%** said that they were **unsure if it was checked.**

- **Half of parents knew** that their baby's head **should** be measured at birth and at the 6/8-week check-up but only **18% of parents** were told why this measurement was **important.**

"I am a health professional and I am **unaware** of my baby's head **ever being** measured. I have looked in her red book and there is **no record** of it being done"

"I thought that head measurement was just something that the health **professionals tracked** in the red book but I **never knew why.**"

"We didn't realise head measurements **were important** until ours had jumped centiles and was monitored more closely"



Hydrocephalus awareness

Only **one third (33%)** of parents **had** heard of **hydrocephalus**

“Only became aware of hydrocephalus after one of my son’s friends was diagnosed recently. **So much more needs to be done** by health professionals to look out for, and raise awareness of, the condition.”

Only **20% knew** that measuring a baby’s head can help **detect hydrocephalus**

“My first baby had a **large head** compared to his other measurements, so we were referred to the hospital for a scan and check ups, **but I had never heard of hydrocephalus** until today.”

“I’ve **never heard** of this. **Thank you** for raising awareness.”

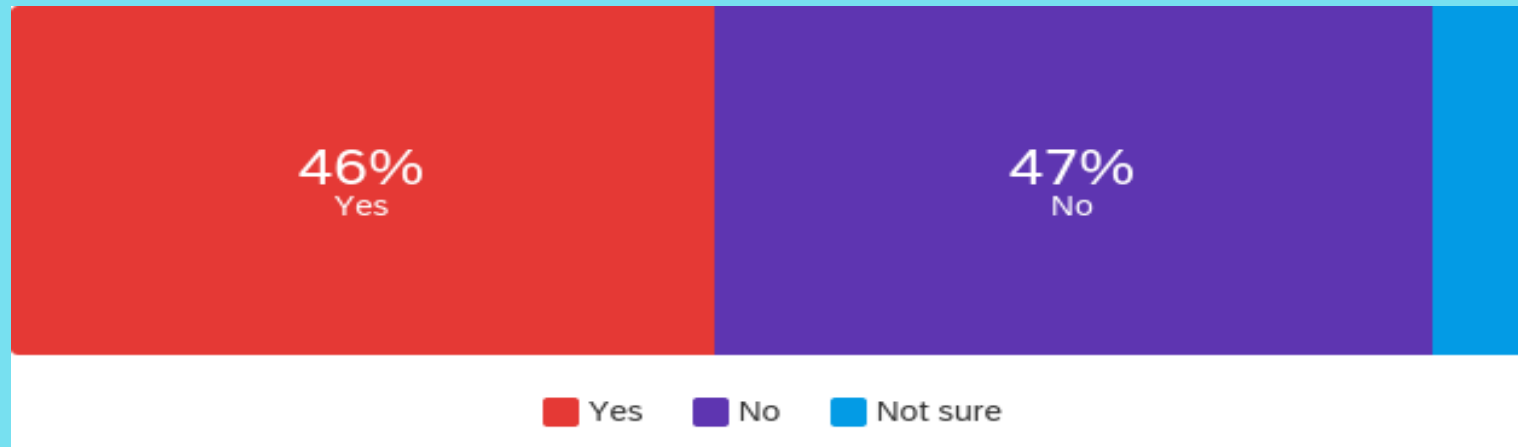


Health Visitor experiences

Do you see your health visitor in person?



Does your health visitor measure your baby's head?



Health Visitor experiences

“I am not aware that my babies head has **ever been measured**. I did ask my health visitor about measuring baby as a friend in another area had her baby measured but HV said **they don't measure babies anymore.**”

“Health visitors **don't see you enough** for regular head measurements.”

94% of parents would support an initiative for health professionals to measure babies' heads until their first birthday.

“Would support more NHS **funding** to allow **Health Visitors to do more check ups** in general. Not their fault, it is the government's funding cuts.”



Experiences and feelings shared in the survey

“I was **worried**, when baby was around 12 weeks, about the shape of his head and I was told that if his head was measured at 6-8 weeks and nothing was flagged up then he would be fine and not to worry. I **felt** as if it was **brushed off** and I was making an issue about nothing.”

“It would be useful to have more information about such conditions and reasons for measurements etc during the antenatal period as well as during the baby checks.”

“I would like to see a small guide/hand book given to parents before birth including symptoms to look out for and who to talk to/contact.”

“I would have appreciated **more information** around the condition and reasons behind the measurements **whilst I was pregnant**. As a second time mum I was worried but not too alarmed, however I could see that it would affect a **new mum** in the early days of motherhood. Maybe some **case studies to read** about a mum and baby and the treatment and outcomes of the condition.”



Summary of findings and recommendations

- **Parents** were **not aware** of the importance of consistent **head circumference measurements** in the first year of a baby's life.
- There is a **lack of awareness of hydrocephalus** in new parents.
- **Inconsistent** knowledge and practises in **primary healthcare**.
- Not enough **face to face** health visiting.

- **Educate parents** on the importance of head measurements e.g. red book, bounty packs.
- **Raise awareness** of hydrocephalus e.g. health visitors, bounty pack.
- **Improve training** for primary healthcare professionals on signs and symptoms of hydrocephalus.
- **Invest in health visitors** to allow face to face visits to resume.



Beth's Story

“Lilly was born at the beginning of the first lock down. Everything was fine, she was **signed off by the midwife after 10 days**. Almost immediately after that, **she started vomiting after every feed**”

“[...] When our **Health Visitor** visited again, Lilly had gained 1oz weight, her head measurement was on the 100th centile and she was sunsetting. Our local hospital confirmed **our Health Visitor's concern** that Lilly had **hydrocephalus**. We were rushed to our nearest **Paediatric Neurosurgery hospital** where, at **5 weeks old**, Lilly had **2 surgeries and 2 taps.**”

Lilly was only **seen once by her GP** and she was prescribed medication for reflux without being examined by a doctor.

“I cannot **thank and praise my Health Visitor** enough, but it has left me feeling **bitter towards my GP**. All the **'what ifs'** in my mind have me questioning **'maybe this could have picked up sooner'** [...] a 2-week-old baby, I feel should **never be refused to be seen.**”



Conversations with our community: July 2022

Harry's HAT asked **parents** (via social media) about issues they felt were important to raise: *"We're delighted to be exhibiting and speaking at the **Wales & SW maternity & midwifery festival** in September. We want to share your experiences. Is there anything else that we should be **highlighting**?"*

"I think the **ambulance** service need educating too, [...]. it's always a **surprise** how many medical professionals don't know what it is."

"[He] was diagnosed with... Chronic constipation, **reflux**, GERD, silent reflux, treated for milk allergy, **failure to thrive**"

"No regular health visits let alone head measurement [...] **missing regular health visits are missed opportunities.**"

"My son at 6 weeks was described as **malnourished** (from being **sick** so much) which was why his head looked so big. **Brain surgery** a few weeks later."

"**Reception staff in A&E** when you go in and say suspected shunt and it takes them 5 hours to check over."

I just hope more people are as **lucky** as me, to have a **wonderful HV.**



Get-A-Head campaign

Many families who contact us have children who exhibited the signs of hydrocephalus, but were not diagnosed until later on simply because their head wasn't measured.

We want to change this, so we launched 'Get-a-Head'
www.harrys-hat.org/get-a-head

The campaign aims to raise awareness of the key signs of hydrocephalus in babies, and to highlight why head circumference measurement is so critical in helping to spot the condition,

Early diagnosis won't cure hydrocephalus, but it can help increase the chances of the child living an independent life.



Get-A-Head campaign

To date, the campaign has reached over 500,000 people including expectant and new parents.

Who is listening or reading about Get-A-Head

- It has been featured in Bounty Baby Guide
- Michael Gove MP spoke about the campaign at our Parliamentary reception
- It has been picked by Hits Radio (Kiss, Absolute etc)
- The **Lions Club of Yateley** are sponsoring 10,000 NHS approved tape measures
- It trended on Twitter!

bounty babyguide
From pregnancy to parenthood

Having a happy, healthy **PREGNANCY**

Window to the **Womb**
Scans & tests explained

Maternity Rights!
What you're entitled to

Ways to **Prepare** for Labour
Hospital busy checklist

1 in 770 babies will develop hydrocephalus, but it is treatable and early diagnosis can help improve the outcome.

What is hydrocephalus?
Hydrocephalus is the overproduction of cerebrospinal fluid (CSF) in the brain, which can lead to a baby's head being far too big for their body. In the most common reason for babies with hydrocephalus, early diagnosis and treatment can help improve the quality of a baby's growth, which could be a sign of hydrocephalus.

Symptoms can include:
Not eating and drinking well.
Not sleeping or getting tired, which can lead to a baby's head being far too big for their body.
Swelling, especially around the head, which may be accompanied by a bulging forehead, soft spots and eyes that don't move normally.

Get-a-Head
Harry's Hydrocephalus Awareness Trust (Harry's HAT) is a charity that aims to make life better for children and their families who are affected by hydrocephalus. A recent survey of 780 new parents found that most don't know why their baby's head is measured at birth and again at the 6 week check. Measuring a baby's head at these checks along with their weight, can help identify signs of overactive growth, which could be a sign of hydrocephalus.

Help us Get-a-Head
Donations are amazing, but a follow, like or share means the world to us and genuinely makes a difference.

Reach out to us on social media: @harryshat

Follow us on social media: @harryshat

Find out more www.harrys-hat.org

Reaching 52,500 expectant parents
www.harrys-hat.org/get-a-head

Get AHEAD

METRO.co.uk

METRO • 6-MIN READ

I'm on a mission to make sure every new parent measures their baby's head

www.harrys-hat.org/get-a-head



Find out more

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www.harrys-hat.org



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