



Antenatal screening in relation to hydrocephalus

Harry's Hydrocephalus Awareness Trust

Hydrocephalus means water on the brain. When a baby has hydrocephalus, they have too much fluid within their brain. This can increase the pressure within the skull and can cause a baby's head to look very big.

We looked at the experiences of parents and carers of babies born with hydrocephalus during the pregnancy and after their baby was born.

We looked at the information and support parents and carers received at the time of diagnosis.

We also looked at the impact on health outcomes and experiences of a hydrocephalus diagnoses.

Antenatal (during pregnancy) screening

Third trimester means the final 3 months of pregnancy.

All of the parents/carers who responded had babies with hydrocephalus.

- 58% of parents received a 3rd trimester scan with the National Health Service (NHS)
- Knowing what they do now, 84% of parents would have liked to have been offered a 3rd trimester scan and 68% would have been willing to pay
- 64% of parents said they were given no information on their 3rd trimester screening
- 44% would have liked to have received more information on screening
- 36% of hydrocephalus cases among families in the study were detected during a routine scan
- 21% of hydrocephalus cases among families in the study were detected during a routine health check-up

Experiences

- Some families felt the late stage of diagnosis negatively impacted their experiences and parents had varied experiences of the support they received
- A third of parents and carers would have been interested in an online forum for parents and carers
- A third of parents and carers would be interested in a support group hosted by parents and carers
- A third of parents and carers would be interested in a support group hosted by a medical professional

Find out more at our website <https://harrys-hat.org>