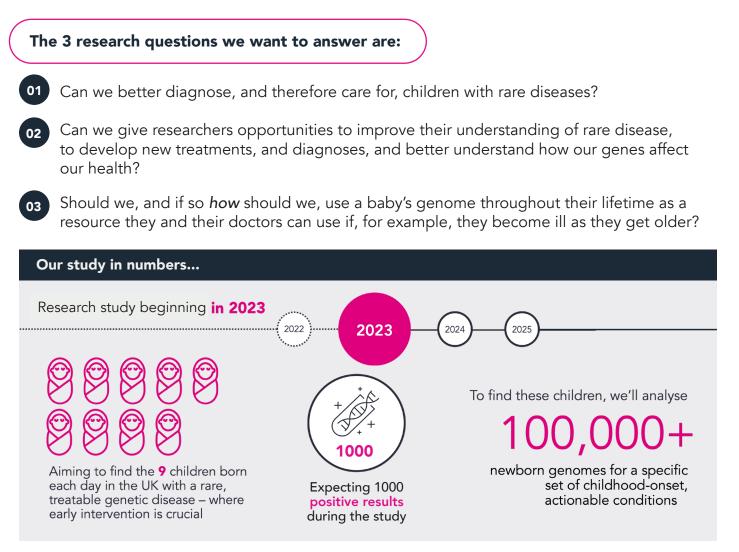


## Genomics England's Newborn Genomes Programme

## Researching the potential of whole genome sequencing to help newborns with a rare genetic condition live their best possible lives.

Every day, nine babies in the UK are born with a rare genetic condition that could be treated, prevented, or even cured if only it had been diagnosed when those babies were newborns. The Newborn Genomes Programme is aiming to find out if this situation can be changed through a 3-part research study which will begin in a selection of NHS Trusts in 2023.



## 6 linked design elements for the Programme – all underpinned by ethics:

- **1.** Establishing principles to guide which conditions newborns should be screened for
- 2. Understanding the best way to recruit newborns and families to our research
- 3. Developing an appropriate consent process across the 3 parts of the Programme
- 4. Identifying the best way to a) take samples from newborns; b) sequence those samples
- 5. Establishing a process to return results to parents as quickly as possible
- 6. Ensuring care and treatment pathways / support are in place where positive results returned

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