

GHD Reversal Trial: Frequently Asked Questions

The information below provides responses to a few questions parents/ carers or patients may have when considering participating in the GHD Reversal Trial. This document will be updated as new questions are raised during patient consultations during clinic appointments, or through correspondence with the Child Growth Foundation.

- **Q:** How long will my child have to stop growth hormone treatment for in order to carry out the growth hormone re-test to confirm GHD reversal?
 - **A:** Your child will have to stop taking growth hormone therapy for at least 6 weeks prior to the growth hormone re-test.
- Q: What happens if my child is found to be producing their own growth hormone?

 A: If your child is found to be producing their own growth hormone to a level that shows GHD reversal, and they meet all of the other inclusion criteria, they will be eligible to join the trial. There are two groups within the trial; children that stop growth hormone therapy, and those that continue. Allocation of treatment group is through a randomised process, meaning that your child will have a 50/50 chance of being put in the group stopping treatment or continuing growth hormone therapy. Whilst this means that your child may stay on growth hormone therapy, entry into the trial does also mean there is the possibility they will discontinue treatment. Because group allocation is randomised, if you or your child have a strong preference to remain on treatment (or discontinue growth hormone therapy), then you should not join the trial.
- **Q:** What happens if my child's growth starts to slow following discontinuation of growth hormone therapy?
 - A: There should be no effect on your child's growth following the initial discontinuation period for the growth hormone re-test. Your child can only enter the trial if they are found to be producing high enough levels of growth hormone on their own (known as GHD reversal). If, at the first trial assessment (six months after randomisation) your child's growth is found to have slowed, they will receive another growth hormone test. If it is found that they are growth hormone deficient again, growth hormone therapy will be immediately restarted. In this instance, it is believed that any slowing of growth will be reversed as soon as treatment restarts. Due to your child being in early puberty, minimal long-term effect should be seen as they will "catch up" with their growth and reach the final height they would have achieved if they had not temporarily stopped growth hormone therapy.
- Q: Will participating in the trial have an effect on my child's clinical appointments?
 A: If your child joins the trial, they will be scheduled to receive a trial follow up appointment at their local hospital every six months until they reach near final height (a growth rate of <2cm per year). This means that participating in the trial may result in more consistently regular clinic visits.</p>

Document last updated: 24th July 2023