

## Have you been diagnosed with Gorlin Syndrome, also known as nevoid basal cell carcinoma?

You may be interested in learning more about The Gorlin Syndrome Study running here at **Manchester Royal Infirmary and The Royal London Hospital.**

The research study is testing a new medication called Patidegib Gel in patients who have Gorlin Syndrome, which is also known as nevoid basal cell carcinoma or basal cell nevus syndrome (BCNS).

We want to find out if the new gel applied to the skin can reduce the size of tumours, prevent growth of new tumours, and therefore reduce the need for tumour removal surgery. If you have Gorlin Syndrome and are aged between 18 and 85 years, you may be eligible to participate in this study.

The research study will investigate:

- Effectiveness – how well the medication works
- Safety – what are the side effects, if any
- Tolerability – do patients find it easy to use

The research study is:

- Randomised – patients will be randomly allocated to receive 2% or 4% strength Patidegib Gel, or placebo gel.
- Double-blind – neither patients nor your doctor will know if you are taking the active medication or placebo until after the study.
- Placebo-controlled – approximately a third of participants will receive a gel which does not contain Patidegib.

## What would I have to do?

Your doctor will be able to give you much more information about the research study.

If the doctor decides you are eligible, it is safe to take part, and you would like to participate, the study will include the following:

- The study would be explained to you in detail, and you would be given the opportunity to ask any questions you might have
- You would need to give written consent to participate
- Twice daily application of gel to the skin for 26 weeks
- 9 visits to the clinic in total
- Skin tumours will be photographed at the visits
- Some skin tumours will be biopsied
- The doctor or nurse will take a sample of blood at each visit



A RESEARCH STUDY FOR PEOPLE WITH  
NEVOID BASAL CELL CARCINOMA

Study participants will receive study medication at no cost, and all reasonable travel and refreshment expenses for study visit clinic days will be reimbursed.

Participation is strictly voluntary, and participants are free to withdraw from the study at any time.

If you are interested in learning more about The Gorlin Syndrome Study and whether you may be eligible to participate, please use the following contact details to speak with a member of the research team.

For more information please contact:

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## The Gorlin Syndrome Study