

Wording for Neuro Foundation UK and Advocure NF2 websites for Sorafenib in NF2 study

Adults who have Neurofibromatosis 2 (NF2) and skin tumours (schwannomas) are invited to participate in a research study being undertaken in Plymouth and Manchester; Professor C. Oliver Hanemann, a consultant neurologist at the Peninsula College of Medicine and Dentistry in Plymouth is the Chief Investigator.

Although needed there is currently no drug treatment for tumours in patients with NF2. Many NF2 patients have multiple tumours which are genetically well defined. As the tumours have the same gene defect, one of these tumours, schwannomas (at nerve endings in the skin), can be used as a model for all NF2 tumours. This has allowed Oliver Hanemann's research group to successfully identify and characterise a new molecular drug target. In a human cell culture model Oliver showed that this new target can be effectively inhibited by a drug which led to reduction of the tumour's growth.

The availability of 'nerve tumours in the skin' has also allowed the development of an innovative clinical trial design to test whether the drug gets into the tumour and does its job in the tumour. To determine whether this happens, skin nerve tumour biopsies have to be analysed before and after therapy.

This is a very short trial in a limited number of patients which will quickly indicate whether drug candidates for NF2 related tumours should be tested in a large multi centre randomised trial. The trial design also allows the evaluation of substitute markers (biomarkers) which are of great value in subsequent clinical trials.

If you would like to help this research by taking part in the study, you will have to meet certain eligibility criteria related to your current medical condition and medications, and you will need to attend one of the research sites (Plymouth or Manchester) for clinical assessments and blood tests on five occasions. The duration of the study for each eligible participant is approximately eight weeks from the pre study visit (to assess eligibility) to the end of study follow up visit. Samples of skin nerve tumours will be taken before and after treatment with the study drug. Your General Practitioner will be informed of your participation.

This advertisement and study has been approved by the London Bloomsbury Research Ethics Committee. If you would like more information about taking part in the trial please contact Oliver Hanemann. We will be keeping a record of responses to this advertisement, but please be assured that this does not place you under any obligation.

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