



## **National Anaplastic Thyroid Cancer Tissue Bank and Database Project**

### **What is this project?**

The project aims to collect tissue samples from patients with anaplastic thyroid cancer, and if possible a blood sample and clinical information relating to the diagnosis, investigation and treatment for each patient.

The collected samples will be used by scientists who wish to carry out approved research projects that are either investigating the mechanism by which this disease develops and/or investigating potential drug treatments.

As anaplastic thyroid cancer is a rare disease this project will need to be run over a number of years in order to be able to collect enough samples to be studied.

All patients across the UK who have been diagnosed with anaplastic thyroid cancer or who have areas of anaplastic thyroid cancer mixed in with other types of thyroid cancer are potentially able to participate in the project.

### **What does the project involve for participants?**

The thyroid cancer tissue samples will have already been taken and analysed by the patient's local thyroid cancer team. Often there is some tissue left over which the local team do not need and it is this that would be used for the anaplastic thyroid cancer tissue bank research project. This tissue will be sent to the Wales Cancer Bank in Cardiff for storage and future research.

The clinical information would include information about the symptoms that lead to the diagnosis being made and any treatment that is given. This information would be treated in the strictest confidence and in accordance with the Data Protection Act 1998. The researchers will not be able to identify any individual from the information they receive and they will not have information such as names, telephone numbers or addresses. No information about participants will be disclosed to any third party. Under the Data Protection Act 1998 participants are entitled to see what information is recorded about them.

Participants will need to give their written consent in order to donate their tumour tissue, blood and medical information.

There will be no additional treatment or investigations required as a result of taking part in this project after the initial samples are collected.

### **What will happen to the results of the research study?**

It is expected to take several years to collect sufficient numbers of samples that can then be studied. It is then likely to take several more years before the results of the research are available. Results will be published as appropriate in scientific journals and presented at national/international meetings.

## **Who is organising and funding the research?**

This research project will be run by Dr Laura Moss, Consultant Oncologist at Velindre Cancer Centre, Cardiff in conjunction with the staff of the Wales Cancer Bank, a multidisciplinary steering committee and with the support of the National Cancer Research Institute Thyroid Cancer Subgroup.

The project also has the support of the UK Endocrine Pathology Society, the International Rare Cancer Initiative, members of Thyroid Cancer Forum-UK and the European Thyroid Association along with thyroid cancer patient charity support from Thyroid Cancer Support Group-Wales and the Butterfly Thyroid Cancer Trust.

Funding has been provided by Thyroid Cancer Support Group Wales (registered charity number 1113774).

If you would like further information you can contact the Chief Investigator: Dr Laura Moss at Velindre Cancer Centre, Cardiff

- By telephone on 029 20316205
- By e-mail [laura.moss@wales.nhs.uk](mailto:laura.moss@wales.nhs.uk)
- By writing to Velindre Cancer Centre, Velindre Road, Whitchurch, Cardiff CF14 2TL