

Brain Tumour Research Study in Ireland - An Overview

Beaumont Hospital (Beaumont) and Genuity Science (Formerly Genomics Medicine Ireland or GMI) are collaborating on a study to create a Brain Tumour Information System (BTIS) for adults at Beaumont. Beaumont already participates in one of the world's most comprehensive Childhood Brain Tumour Information Systems currently available to oncologists and pathologists. The scope of this current project is to develop a similar system for adult patients with brain tumours. The BTIS will improve clinicians' overall understanding of adult brain tumour biology and will hopefully lead to faster and more accurate diagnosis for adult patients.

Emerging genetic technologies present a new era in medicine and further research in this area will address the urgent need for new interventions and approaches to treatment. The hope is that discoveries made using the archived tissue samples* (from adult patients who have previously undergone treatment at Beaumont) may benefit patients with brain tumours in the future.

This study has potential to translate to health improvement for future generations in a number of areas



More accurate and earlier prediction of brain tumour behaviour



Better understanding of the patient's prognosis and how the tumour is likely to progress



Better understanding of which therapeutics are best suited and at what dosage for each patient and the potential to develop new therapeutics

* Residual tumour samples and tumour data [e.g tumour size, location and growth rates] from adult patients who underwent surgery for a brain tumour at Beaumont Hospital between 29 November 1987 and 7 August 2018.

Work to date:

2016: The BTIS research project commenced in 2016 with approval granted to conduct the research by Beaumont Research Ethics Committee in 2016 under an "institutional waiver of informed consent" which allowed Beaumont and Genuity Science to conduct research on Beaumont Hospital's existing brain tumour tissue archive.

2018: In accordance with new 'Health Research Regulations' (HRR) following the introduction of GDPR in Ireland, a Consent Declaration was required from the Health Research Consent Declaration Committee in relation to the joint BTIS research project.

October, 2019: With regards to consent for the use of data for the study in accordance with data protection legislation, the study received a conditional consent declaration under the Health Research Regulations 2018. A number of conditions have been attached to the consent declaration, including a condition that a publicity campaign would commence to highlight the study and enable patients and families to withdraw their data from the study.. (For more information about the Declaration granted, please see www.hrcdc.ie - Decision of Appeal Panel Ref 19-006-AF3).

Opting in / out of study:

To Opt In to Study:

- No action required.

To Opt Out of Study:

• Living Patients:

If you were a brain tumour patient at Beaumont Hospital within the time period 29 November 1987 and 7th August 2018, you may request that your samples and data are not included in the research.

• Deceased Patients:

If you are a family member of a deceased patient who was a brain tumour patient at Beaumont Hospital within the time period, you may request that your family member's samples and data are not included in the research project.

Further detailed information on the project is also available to download from www.btis.ie.

If, having read the detailed project plan, you wish to opt out, please contact **BTIS, Beaumont Hospital, Dublin 9** by post, or email btis@beaumont.ie. After September 14th 2020, it will not be possible to be excluded from the Research project.

Beaumont /GMI BTIS PROCESS

Archive Sample Collection

Patients, and their family members, are informed about the study via the public advert and the BTIS website, where they are afforded the opportunity to opt-out of the study if they wish.

Archive tumour samples and associated medical data of the research participants are collected and added to the study.



Sample Processing

1

The tumour samples and medical data are coded by Beaumont before being sent to Genuity Science, thus making research participants samples unidentifiable in the study.



2

A C G T A C G
A G C T A C G

DNA is extracted from the tumour sample, and using an advanced scientific technique called "genomic sequencing", the tumour sample is converted to data.

3

This data, along with the medical data, is added to the Brain Tumour Information System (BTIS), which allows researchers to group high-grade brain tumours according to certain genetic 'biomarkers'.



4

These biomarkers are used to help researchers predict the prognosis of the tumour type and how it can be treated.



5

Biomarkers are also used to identify possible new drug targets and treatments for high-grade brain tumours.



Future Patients

The creation of the BTIS will assist in assessing, diagnosing and tailoring treatments for future patients, in addition to improving clinicians' overall understanding of brain tumour biology.

For more information visit: www.btis.ie

About Beaumont Hospital

Beaumont Hospital is a large academic teaching hospital. In addition to being a Designated Cancer Centre, it is also the National Referral Centre for Neurosurgery and Neurology.

About Genuity Science

Genuity Science (formerly Genomics Medicine Ireland or GMI) is a contract genomics and data sourcing, analytics and insights organization headquartered in Boston, Massachusetts, USA with offices in Dublin, Ireland and Reykjavik, Iceland. Genuity partners with

global biopharma companies to offer deep end-to-end discovery services aimed at catalyzing precision health and improving the quality of life for patients around the world. Services include population-scale, disease-specific data sourcing, high-quality sequencing, robust statistical analysis and software tools for analyzing large datasets and artificial intelligence (AI). The company operates advanced CAP/CLIA genomics laboratories in Woburn, Massachusetts, USA and in Dublin, Ireland and is deeply committed to data stewardship and data governance across its global offices. For more information, see www.genuitysci.com.