

# The Alfred Brain Tumour Bio-databank (ABTB) Access Policy.

## 1. Introduction

The Alfred Brain Tumour Bio-databank (ABTB) was established in 2019 through a partnership between Monash University's Department of Neuroscience and The Alfred. It is a stored collection of samples and accompanying data from consenting patients diagnosed with brain cancer. These samples and data are used for research.

The ABTB is a dynamic interdisciplinary unit, in which a dedicated team with exceptional expertise ranging from neuropathologists, radiologists, researchers, neurosurgeons and oncologists are all collaborating closely and alongside with patients. In addition, the ABTB benefits from a unique setting where biobank, laboratory facilities and hospital are located on the same site.

Through the collection of samples and clinical information the ABTB aims to facilitate vital research that will reveal a better outcome for patients affected by these devastating diseases. The ABTB team aims to work collaboratively with any researchers, locally, nationally and internationally. Researchers wishing to obtain samples and data from the ABTB are required to make an application to the Access Committee for approval.

## **2. Sample and Data Enquiries**

### **2.1 Initial Enquiry**

Researchers interested in obtaining data and/or bio-specimens will initially e-mail the ABTB Manager to check availability. The Manager will search the database to establish the approximate number of samples, data and feasibility of providing samples which meet the researcher's requirements. The researcher will be informed and invited to apply. As stated in the Sample and Data Request Form (see appendix 1), they first must agree to this 'Access Policy.'

### **2.2 Application**

Once the Application Form has been submitted:

- The completed application will be reviewed by the Access Committee within one month of submission. Applicants will be informed of the outcome by e-mail.
- If approved, the Material Transfer Agreement (MTA) or Research Collaborative Agreement (RCA) will be sent to the researcher via email. This must be reviewed and approved by both parties' legal team.
- Samples will be held for the researcher for 3 months from the date of approval by the ABTB. It is the researcher's responsibility to inform the ABTB of any delays in gaining governance and ethics approval. If the application is denied, ABTB will explain what amendments are required.
- Costing details confirmed.
- Samples and data released.

## **3. Cost Recovery**

Cost recovery will be discussed and confirmed by the Access Committee on a project-by-project basis. The ABTB Biobank Manager will be in contact with costing details.

#### 4. **Access Committee Members**

- Professor Terence O'Brien: Principal Investigator of ABTB and Director for Alfred Brain-Chair
- A/Prof Martin Hunn: Principal Investigator of ABTB- Deputy Chair
- Professor Lindy Jeffree: Director of Neurosurgery
- Professor Catriona McLean: Neuropathologist and Head of Anatomical Pathology
- A/Prof Mastura Monif: Neurologist and Neuroimmunologist
- Dr Marian Todaro: Biobank Lab Manager, Neuroscience, Central Clinical School, Monash University.

#### 5. **Terms and Conditions**

- a. Access to all brain tumour samples will be governed through the ABTB collection and data policy
- b. Prior to use of the data and/or bio-specimens, the researcher will have obtained approval of the project by an appropriate HREC and research governance/SSA. The ABTB will be listed as the source of data and/or tissue in the researcher's protocol.
- c. The researcher must comply with all applicable privacy legislations in relation to the use, disclosure and storage of the data and/or biospecimens.
- d. The requested data and/or samples are consistent with the research protocol approved by the HREC.
- e. Once approved by ABTB access committee, samples will be obtained as per the usual ABTB processes (use of ABTB consent form and consenting to be done by ABTB coordinator / ABTB staff). Parallel consenting for patients with brain cancer at Alfred Health are not to be done. There is only one approved consent (ABTB consent).
- f. The brain tumour / other research biospecimen samples are to be picked up from operating theatre by ABTB staff (ABTB trained coordinator / ABTB research assistant)
- g. The brain tumour / other research biospecimens are then to be taken to the laboratory (Monash Department of Neuroscience; which is close to the vicinity of operating theatre) and distributed as per approved ABTB projects.
- h. In order to ensure chain of custody and as per approved ethical standards, research biospecimens / tumours are not to be removed from theatre without them being first brought to the lab for logging and appropriately documented by ABTB lab staff before disposition.
- i. ABTB manager / ABTB lab team will appropriately designate samples as per approved projects.
- j. Coded data can also be shared with researchers.
- k. The data will be stored in a secure place (e.g., password lock on electronic data), the user name and password will be secure and not shared.
- l. The data and/or samples will be analysed, stored, retained and disposed of in accordance with the research protocol approved by the HREC. In addition, any other governing bodies and legislative requirements.

- m. Keep the non-identifiable patient ID with the record so that the subject can be re-identified, if required for ethical reasons.
- n. The data and/or biospecimens released may only be used by researchers under the supervision of the approved Principal Investigator for the project, for the term of the project.
- o. Never publish or communicate data where the sample size and data would allow unintended identification.
- p. Applicants must ensure that their application to access samples and data are complete.
- q. The Access Committee must approve applications for ABTB use.
- r. Any materials released to the researcher will be subject to a Materials Transfer Agreement (MTA) or Research Collaboration Agreement (RCA) between both parties. These agreements must be approved by both parties' legal team.
- s. All costs of retrieval, processing and transportation of materials and any other costs associated with the study will be met by the researcher unless otherwise stated.
- t. As per MTA or RCA, the researcher must acknowledge the ABTB. Additionally, co-authorship on resultant publications with the ABTB Access Committee members is expected. This will be discussed on a project-by project basis and decided by the Principal Investigators (PIs) of both parties.
- u. The ABTB must be acknowledged in all oral and written presentations arising from sample and data use.
- v. ABTB strive for collection and storage of high-quality samples and data. Samples provided may have no guarantee as to the accuracy or validity of any diagnosis attached to any material provided. ABTB can offer no guarantee that materials are devoid of infectious agents.
- w. It is the responsibility of the researcher to ensure that all staff are appropriately informed and trained in relation to the dangers and procedures in the handling of human materials and that they are trained in, and adhere to, local conditions and Occupational Health and Safety regulations.
- x. No responsibility will be taken by ABTB for an injury, damages or loss that may occur as a direct or indirect result of the use of materials provided.
- y. The researcher agrees to assume all responsibility and risks for the receipt, storage, handling and use of all samples and/or data obtained from ABTB.
- z. The Principal Investigator agrees to submit annual reports and research progress to the ABTB Coordinator until completion of the project, as per MTA or RCA.
- aa. Any disputes to be forwarded to the Biobank Manager. If unable to be resolved, this will go to the Principal Investigator/s of the ABTB for resolution

- bb. Applications must accept that resources are limited and decisions may be based on availability.
- cc. When submitting research grants which plan to use ABTB samples and/or data, we recommend you contact the ABTB Biobank Manager first to estimate cost of sample procurement to be factored into the application budget.

Please note these terms and conditions are subject to change.

## **6. ABTB Contact**

Dr Marian Todaro  
Senior Neuroscience Biobank and Database Manager  
Department of Neuroscience  
Monash University  
The School of Translational Medicine  
The Alfred Centre  
Level 6, 99 Commercial Road  
Melbourne Vic 3004  
Email: [Marian.Todaro@monash.edu](mailto:Marian.Todaro@monash.edu)  
Tel: +61 3 9903 0857

## **Appendix 1: ABTB Sample and Data Request Form (HREC No. 579.18)**