

# BRIAN: OUR GLOBAL BRAIN

## TUMOUR DATABANK

### **Patient Information Sheet (for a young person aged 12 – 15)**

**A Jargon Buster is included for any terms that you may be unfamiliar with.**

### **To be shown and read by parent/guardian if required**

We're asking whether you would like to share some information about your brain that we will keep safely in our new secure database called BRIAN. Your parents will use a web app on their mobile phone or computer to share with BRIAN how you're feeling or your 'quality of life' information and to find out information about what you can expect.

BRIAN will also pass your information onto scientists and doctors together with information from lots of others with the same brain tumour, to help with their research or work.

Before you decide if you'd like to take part and share your information with BRIAN, it's really important that you understand what we are doing, why we are doing it and what it will mean if you take part. Please read this information sheet carefully with your parents and speak to your doctor, nurse, family or friends about it.

If you have any questions please call us or ask your parents to do so on the details at the bottom of this information sheet and we will discuss it with them

### **What are we doing?**

We're asking anyone with a primary brain tumour like yourself, to let us have a copy of your medical records, or the information that the doctors and hospitals have about you and your brain. We will hold a copy of it safely in our new secure database called BRIAN. We're also asking you, or your parents, to let us know how you're feeling - for example whilst you're going through chemotherapy, radiotherapy or after an operation - by entering the information through a web app on your (or your parents') mobile or computer.

BRIAN will keep all of this information about you and your brain and will store it safely. When other people with a brain tumour want to find out more about it and what to expect, they will be able to ask BRIAN to share your information, along with information from others with the same type of tumour. They won't be able to see your name or any details about you as an individual.

### **Who will want to see my information?**

Scientists carrying out research into brain tumours may need access to your information from BRIAN. Our hope is that it will help them find a cure for brain tumours.

It will also help the doctors and nurses know what to recommend to other people with the same tumour as you. Finally, it will help other children and their parents know what to expect.

## Why do you want me to help?

You have been asked because you have a primary brain tumour.

By sharing your information with BRIAN you will be able to help other young people and their parents know what to expect. It will also help the doctors and nurses know what to recommend to other people with the same brain tumour as you.

Lastly, scientists will be able to ask BRIAN for information about yourself and others as quickly as possible, so that they can carry out the best research and hopefully find a cure for brain tumours faster.

## Will anyone know the information is about me?

When we collect your information BRIAN will store it safely and will only share it with people who need to see it. Your name and address will be kept separately so that you are less likely to be identified from your information, unless a scientist needs to access details that will identify you personally. Should this be the case, The Charity has a group of experts that are part of something called the 'Data Management Board' and it is their job to decide whether or not it is absolutely necessary to share your personal details. Our main concern is to keep stuff about you safe but sometimes we may have to let official people know if you need help.

## Do I have to take part?

No. It is entirely up to you. If you do decide to take part your parents will be asked to sign a consent form to give permission for BRIAN to access your medical records. When you turn 16, your parents/guardian will receive an email advising them of what to do next and that you will be able to sign your own consent form. Don't worry though, we'll be in touch when that happens and we will keep your records for up to one year. If we don't hear from you or your parents/guardian within 12 months, the law says we have to delete your information. If you are unsure or unclear about this please discuss this with your parents/guardian.

You are free to stop taking part at any time without giving a reason. If you decide to stop, this will not affect the care you receive.

## What if I change my mind after I've said 'yes'?

Just tell your parents or guardian at any time and they will contact us at the address included at the bottom of this information sheet. You will still have the same care and you won't upset anybody.

## How can I find out more about BRIAN?

Your parents, guardian or other adult you trust may be able to answer your questions. The doctors and nurses looking after you can also help you find out more. Or you can ask your parents to contact us by phone on 01252 413164 or email at [brian@thebraintumourcharity.org](mailto:brian@thebraintumourcharity.org).

If at any stage you do not want to hear from The Brain Tumour Charity, you can email [enquiries@thebraintumourcharity.org](mailto:enquiries@thebraintumourcharity.org), call us on 01252 749990 or write to us at the address below.

## Thank you for taking the time to read this – please ask any questions you have

If you have any questions, please ask your parents to call us on 01252 413164, email us at [brian@thebraintumourcharity.org](mailto:brian@thebraintumourcharity.org), or write to us at The Brain Tumour Charity, Hartshead House, 61-65 Victoria Road, Farnborough GU14 7PA.

# Jargon Buster

**Anonymous** – this is a way of keeping your personal details (for example your name and address, date of birth) secret so that people can't tell that the information is about you.

**Consent** – the permission your parents give to The Brain Tumour Charity to be able to see your medical records which are kept by the National Health Services and Public Health England.

**Data Management Board** – a group of professional people who look at requests from the scientists and doctors and decide if the information they ask for might help defeat brain tumours. It is their job to decide whether or not it is absolutely necessary to share your personal details

**Information** – a combination of your medical records and the information that you share with BRIAN about your symptoms.

**Medical Records** – a record is created on each visit that you make to an NHS service. This means medical information about you can be held in various places, including out-patients, accident and emergency and any NHS hospital where you have had treatment. It should contain all the clinical information about the care you have received from the NHS (not privately).

**Quality of Life** – your general wellbeing including tiredness, response to treatments, headaches and daily feelings.

**Research** – activity undertaken by both clinical and academic scientists at universities or with industry partners in the UK or globally. As part of their job they investigate different aspects of brain tumours to try and understand how they are created, what keeps them growing and how they can be controlled or cured. Their work and studies are critical to finding a cure.

**Web app** – this is something that you can add to your mobile or computer. You can both add your own information to an app and get useful information out of it.