



formerly **andrea's gift**

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## **BRAIN TUMOUR RESEARCH AND SUPPORT ACROSS YORKSHIRE (BTRS)**

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Founded in 2003 and originally named Andrea's Gift, BTRS is Yorkshire and Humber's leading brain tumour charity. Offering practical, financial and emotional support to adult and child brain tumour patients with low and high grade tumours, together with their families and carers. We bring families together through social events and support groups and aim to give affected families the care and support they need that is not available through other organisations.

Collaboration is key - BTRS is a member charity of Brain Tumour Research, a national umbrella organisation that unites over 20 charities to collectively lobby parliament and campaign nationally for improved standards of care for brain tumour patients and increased funding for research. We also work and partner other organisations locally that provide additional help and support our patient group.

A fundamental aim for BTRS was to develop a brain tumour research lab at the University of Leeds, the hard work came to fruition in 2011 when the Translational Neuro-Oncology Group based at Leeds Institute of Molecular Medicine was launched. More than 20 scientists are now investigating different aspects of research, providing hope and information for brain tumour fighters everywhere.

**[www.btrs.org.uk](http://www.btrs.org.uk)**

President: Lady Kathy Botham. Patrons: Sir Ian Botham OBE, Jackie Alliss, Dr Keith Howard OBE, Trevor Cherry, Allan Lamb

Registered Charity No: 1095931

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## **Brain Tumour Patient Portal Project - circa £59,000**

### **Portal Overview**

Through talking to our patient group, BTRS has recognised a need to deliver a dedicated Brain Tumour Patient Portal that will signpost, inform, educate and direct patients through a complex and frustrating time in their lives. The Portal will contain all the information every Yorkshire patient will need from pre-diagnosis through treatment and eventually palliative care.

A major problem across our region is ensuring all patients and their families understand their diagnosis, treatment plans and expected outcomes. Cognitive problems affecting patient's understanding can cause a barrier. A further barrier presents itself when the patient's first language is not English. The Portal will address these points ensuring all information is clearly written in black text on white background, plain and simple in design with key sections translated to reflect the main languages spoken across the region.

The information contained in the Portal will include:

- Different brain tumour types, treatment options, expected outcomes for low and high grade patients
- Specialist care and treatment options
- Where treatment will be delivered; contact details for hospitals and wards, directions, public transport bus routes, car parks and costs, distance to walk etc.
- Clinical trials and research
- Other organisations that can help
- Separate sections for Adult; Paediatric; Low Grade and High Grade patients
- "Who do I ring and when" a section similar to FAQ with of typical scenarios and who to ring for advice
- Sections translated into Urdu, Hindi and Polish

Updated weekly, the site will contain relevant information for patients, families and medics. It will be developed under the guidance of the neuro team - the people who deliver care to our patients and have a clear knowledge of patient needs and NHS guidelines.

In addition to the web based Portal, a handy A5 booklet will be produced that mirrors the information on the website.

An App will be the final component of this project, delivering timely patient support and relevant information to all patients and their families.

### **Further Project Details**

The most costly part of the portal is employing the person into the role of Patient Support Worker (PSW) who will develop the site and patient support services for BTRS. Ideally this will be a person from a neuro nursing background with a desire to support patients and deliver information in an understandable format.

The PSW will be responsible for collating the information needed to develop the Portal, working with the Neuro team in Leeds to begin with. They will liaise with the web developers, copywriters and translation services providers and will develop a Patient Advisory Board to ensure that the information delivered is current, needed and in the correct format.

Text for the Portal will be copywritten by a professional medical writer, the translation of key pages within the site will be provided by language specialists.

The website design and technology will be developed by the team delivering the new BTRS web platform.

## Projected Costings, Year 1

£30,000	Support Worker , 3 days pw, (£35k pro rata inc on costs)
£8,000	Development of Portal including copywriting and translation
£1,000	Production of Booklet
£20,000	Development of App

Once the web portal is completed, a booklet will be produced and distributed to patients by nursing teams as they leave hospital after their initial surgery, it will be available via the BTRS website and circulated at Support Group meetings. An A5 booklet will fit in a pocket or handbag and will be produced annually and contain all relevant information. In addition to the main booklet in English there will be supporting sections produced in Urdu, Hindi and Polish.

The final component of the Portal will be the development of an App - a simple yet sophisticated tool that mirrors the web interface providing an incredible tool for patients who retain good cognitive skills and for younger patients. In addition, it would be invaluable for family members caring for a brain tumour patient.

## Further Information

There are a number of generic brain tumour web sites available but none deliver the type of hospital specific information a patient needs to support them through a complex and terrifying journey. Through research sessions in our Patient Support Group meetings, we discovered that patients want and need very basic and direct information presented in a clear, uncluttered format and as such have planned the Portal on the following:

- **Site Specific** - patients want to go to one website and access all the information in one place and not be directed to other sites
- **Design** - large font in clear, easy to read black text on a white background
- **Practical Information** - consultant and registrar details, each nursing team; where and when their clinic is held; how to get there on public transport, where to park and parking costs, how far to walk etc.
- **Different Specialties** - list of all the specialist areas a patient may come into contact with eg. epilepsy, neurology, psychology, speech and physiotherapy, rehabilitation etc. together with a description of the type of care they provide.
- **"Who do I ring and when"** - a section similar to FAQ with a list of typical scenarios of who to ring for advice eg. My husband has had a seizure for the first time, do I call 999, our GP or nurse specialist?
- **Who else can help?** - other organisations that can help will be signposted - MacMillan for Cancer Patients, Robert Ogden Centre for therapies and general cancer support together with the hospice movement. Solicitors, insurance companies, DWP and benefits advice will be highlighted
- **Linking** - sophisticated linking of pages will allow a simple, seamless journey and walk through for the user
- **Barriers** - no logins and passwords to complicate the site
- Separate portals for **Adults and Paediatric** patients
- **Leeds Teaching Hospitals** will be the first phase development
- **Hull and Sheffield** will follow