KITE

Keeping In Touch with Everyone

Winter 2010

BTA
BRAIN TUMOUR ACTION

Newsletter of Brain Tumour Action, one of the UK's Leading Brain Tumour Charities

Season's Greetings to all our readers!

Making Headway Together.

Brain Tumour Charities head to Westminster.

We are proud to be part of Brain Tumour Research which comprises eighteen member charities from across the UK now calling on the Government to join society's fight against this deadly disease.

Brain Tumour Research, Brain Tumour UK, the Samantha Dickson Brain Tumour Trust and the International Brain Tumour Alliance have together launched a Manifesto for everyone affected by a brain tumour. We hope to persuade the new Government to work in partnership with us to improve outcomes in diagnosis, patient care and research.

Around 8,600 primary brain tumours are registered in the UK every year although this is thought to be an under-estimate. The National Institute of Health and Clinical Excellence (NICE) states, "almost half of intracranial tumours are not recorded by cancer registries" and research by the charities themselves suggests that the true figure is nearer 16,000. Secondary tumours in the brain are not recorded but estimates put these as high as 32,000.

The new Manifesto was unveiled at a reception in the House of Commons held on October 14th and attended by the All Party Parliamentary Group on Brain Tumours. Scientists, clinicians, and many brain tumour patients and their families were also in attendance.

The Manifesto calls on the Government to work in partnership with the brain tumour charities to:

- **Ensure early diagnosis and treatment for everyone affected by a brain tumour.**
- **Implement the best practice guidance for treating people with the disease.**
- **Significantly increase Government investment in brain tumour research.**

It sets out practical solutions to measure improvements in the lives of everyone affected by a brain tumour.

The Right Honourable James Arbuthnot MP, accepting the Manifesto on behalf of the All Party Parliamentary Group, said, "This Manifesto is much more than a plea for funds. It brings together intelligence from across the field and sets out a range of measurable solutions which have the power to transform the lives of those affected by a brain tumour."

Brain Tumour Manifesto.

INSIDE THIS ISSUE:

Annual General Meeting MAKE A NOTE!

The AGM of Brain Tumour Action will take place on January 17th, 2011 at 6.30pm. It will be held at 56 Palmerston Place, Edinburgh EH12 5AY. Please make a note for your new diary! To receive 'Nomination Forms' email *administrator@braintumouraction.org.uk* or telephone 0131 466 3116. If you or someone you know would be interested in joining the Committee please get in touch. Our meetings are held monthly at the above address.

Support Group in Action

Members of the Edinburgh Support Group – although they come from all over Scotland – enjoyed a recent get-together in the welcoming atmosphere of the Maggie's Centre, Western General Hospital. This, the longest, continuously-running Brain Tumour Support Group in the UK, meets on the first Tuesday of every month at 7pm. As one former member who attended in the early 1990s recently reminisced,

"It was nice to meet other people who were in similar circumstances and I really valued the support group at the time when we were young and didn't know who to talk to."


Edinburgh Support Group get together.

Newcomers are always welcome, as are their friends and family. It provides a unique opportunity for patients and carers to give and gain support from each other as well as the chance to relax and enjoy themselves. Please note: the next two meetings will take place in December 2010 and in February 2011. Brain Tumour Action would like to thank the Maggie's Centre for so generously providing us with this beautiful venue.

Our Warmest Thanks

Our warmest thanks to all those who have recently donated funds to Brain Tumour Action, including:

Jane Murray, Nicola McLaughlin, Daniel Kirtley,

Katherine Boyle, Ann Smith, Beeslack High School,

Nicole Witts, Madeleine Borel, Multithon Trust,

Neil Boyle, St. Jude's Physiotherapy and Consulting Ltd.,

The Junior School, Portsmouth Grammar School,

Julie Dickson, The Mary Erskine School,

RBC Wealth Management, Borders Support Group.

Every penny you raise goes to help those affected by a brain tumour. We're proud of your achievements and very grateful to you for giving us the opportunity to continue our work.


Neil Boyle at the finishing line - Pedal for Scotland, Glasgow–Edinburgh Cycle Challenge

Memorable Masterclass

Earlier this year, as part of our commitment to ongoing training, Brain Tumour Action funded a very well-attended Masterclass for Nurses, in association with the Scottish Adult Neuro-Oncology Network (SANON) and the Edinburgh Centre for Neuro-Oncology. The event, entitled A Masterclass for Nurses, attracted more than sixty health professionals from all over the UK who represented a range of disciplines.

After a brief introduction from Brain Tumour Action there were talks on subjects including 'Distress and Depression in Glioma Patients' by Dr. Alasdair Rooney and 'Managing Seizures' by Yvonne Leavy. Dr. Julie Read talked about the problems of diagnosis and recognition of symptoms which, because she was speaking both as GP and Carer, gave her observations an extra authority. Dr. Zoe Morris gave a detailed analysis of neuro-oncology imaging and Andrew Anderson from the Maggie's Centre illustrated "Difficult Situations and Questions" while Dr. Simon Kerrigan considered cognition in patients with brain tumours.

The feedback was very positive, including such comments as:

"Variety of topics, clarity, pitched at the right place."

"Sound knowledge, well presented, very informative."

"Instils more compassion, enthusiasm for learning/nursing and sharing patients' experience."

"Liked carers being mentioned and their experiences valued."

"Inspires me to study and be a better-informed and more supportive nurse."

It is planned to repeat this worthwhile event in other parts of the UK since this is a disease that requires expert knowledge at all levels, from diagnosis to treatment and care. Brain Tumour Action is delighted to be able to assist in this practical way.

Breaking News

Newly-released research findings by the National Cancer Intelligence Network show that 23% of cancers in England remain undetected until after emergency admission to hospital. **However the figure for brain tumours is 58%.** Moreover the average time from symptom onset to diagnosis in children in the UK is 3.3 months compared with only 5 weeks in parts of Europe and the USA. See page 4 for more!

Nurse Shadowing

Another initiative undertaken last summer was a pilot nurse shadowing project which extended over twelve weeks and was based in Edinburgh. Brain Tumour Action provided funding for a neuro-surgical nurse to gain experience in neuro-oncology alongside the adult neuro-oncology nurse specialist. Rakiya Suleiman reported to us that she found the placement most worthwhile, so much so that she brought along a truly magnificent cake to her leaving party in August (see page eight!)

Rakiya Suleiman at her leaving party.

Improving diagnosis – the way forward

Janice McClure knows more than most people about delayed diagnosis of brain tumours. She suffered for over twelve years before her haemandioblastoma was finally diagnosed and she received life-saving treatment at the Western General Hospital in Edinburgh.

Over the years Janice suffered from headaches, extreme vertigo, loss of sensation in her arms, speech and co-ordination difficulties. She made repeated visits to her GPs' surgery but was thought to be suffering from migraines. Then one day, after a particularly bad attack, she started losing consciousness. Only at that stage was the gravity of her illness recognised.

Although she is delighted with the hospital treatment which has given her back her health she regrets the many years lost when her children were small and she was so unwell . "I felt I wasn't always able to be the mother I wanted to be," she says, "because of the stress and anxiety caused by my tumour."

Today she's all that and more as we catch up for a quick photo 'shoot' between her finishing work and driving the kids to basketball. In between she's baking cakes for a local charity event while supporting Brain Tumour Action. Not bad for someone as critically ill as she was in 2006!

Janice agrees that GPs need to become more aware of the many, confusing and varied symptoms caused by brain tumours, the more so since, worryingly, the disease is becoming more common among adults. To this end the Scottish Adult Neuro -Oncology Network (SANON) has recently produced a training DVD to which our Chairperson, Dr. Julie Read, has also contributed. This should soon become available for GPs throughout the country.

Janice McLure

The Power of Empathy

This year The Scottish Conference of Cancer Support Groups' annual conference had as its theme only one word: **Listening.** Janice McClure's story - her doctors' inability to recognise how ill she really was - illustrates just how hard it is for them to achieve and maintain good listening skills. Given a period of silence most of us move swiftly to fill the void. We talk. Doctors talk rather a lot.

But for those of us experiencing strange and persistent symptoms, often hard to describe accurately, those of us with language or memory impairment caused by a brain tumour and its treatments, those of us scared and depressed by the fear of impending disability and loss of what we call "ourselves", what might really help us is to be *heard.*

I was listening to a patient recently who observed that it's hard enough remembering which questions to ask the doctor - but then his answers are so technical and longwinded they're impossible to understand! How often do doctors monitor their own performance in the surgery or hospital clinic?

Most people with a brain tumour will experience deficits, usually irreversible. Their lives will change permanently, as will those of their family and loved ones. It's that devastating. But research quoted by Dr. David Reilly, who addressed the SCCSG conference, shows that the more empathic the doctor is, the greater the healing that will be experienced, irrespective of which drugs are prescribed.

More worryingly he then quoted another study showing that medical students, most of whom start their courses with above average levels of empathy, score much lower than average by the end of their training – and this is before they have even started practising!

Listening – a word long overdue for promotion in the medical profession. But good listening takes time of which there is never enough in the overstretched NHS. How can we redesign it to allow doctors the time to listen and so to heal?

Lynne Barty

Jose’s Sail

Last summer Josie Phillips, with her husband Roger, sailed their Contessa32, Nordlys , anti-clockwise around Britain to raise funds and awareness for Brain Tumour Research and to complete a great personal challenge.

Josie and Mike Windham-Wright in Oban

Josie was diagnosed with a low grade brain tumour in 2004 but in 2008, after three operations, it progressed to Grade 4 (malignant). She was treated with radiotherapy and chemotherapy only to develop an infection which led to yet another, major brain operation.

In 2007, Brain tumours killed 3611 people, many of whom were children or young adults like Josie. When compared with other cancers such as leukaemia and breast cancer, funds for brain tumour research are woefully lacking. In the UK more children and people under the age of 40 die of a brain tumour than any other cancer – yet brain tumour research is desperately under-funded. In 2007-2008 the Medical Research Council invested less than £1 million into brain tumour research compared with the £14 million it allocated to leukaemia research which usually has a far better outcome.

Very little is known about the cause of primary brain tumours and there is no cure. Average survival for people with the most malignant brain cancer is between 9 months and 2 years. More funding is urgently needed to enable research which should help find better treatments for this horrible disease.

However, with her passion for living made stronger with each challenge and adventure, Josie intends to beat the statistics and keep on living.

Well done to both her and Roger for completing their epic adventure.

Craigielaw Golf Fundraising Event

For those of you who don’t sail why not make up a foursome and join us for golf? Brain Tumour Action is hosting a Charity Fundraiser at Craigielaw Golf Club on April 28th, 2011. See our website for more details of this one-day-only event which promises to be utterly memorable!

Brain Tumour Action would love to hear from anyone with a little spare time who could help publicise and prepare for this event. Just give us a call on 0131 466 3116.

The promise of PARP inhibitors: new drugs with the potential to improve the effectiveness of current treatments for glioblastoma.

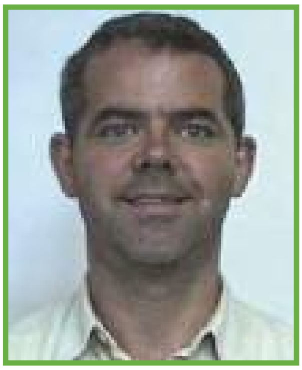
DNA is the molecule that forms the chromosomes in living cells. It contains all the genetic information that is necessary for cells to survive and multiply, and when a cell divides, each of the daughter cells inherits a complete copy of the original cell's DNA. If the chromosomes of a cell are badly damaged, they are unable to separate when the cell attempts to divide, and the cell will die. Many of the treatments used for patients with brain tumours cause their effects by damaging the DNA in the tumour cells – both radiotherapy and temozolomide chemotherapy kill tumour cells in this way. In some cases, however, the tumour cells are able to repair enough of the damaged DNA that they survive the treatment. This is one of the reasons why tumours like glioblastoma often seem to respond well to treatment but then recur – a proportion of the tumour cells have managed to survive the radiotherapy and chemotherapy treatment, and eventually these cells start multiplying and generate a recurrent tumour.

One of the molecules that cells use to recognise and repair damaged DNA is called 'PARP'. The full name is 'poly(ADP-ribose) polymerase, but for obvious reasons the full name isn't used very often. PARP plays an important role in repair the kind of DNA damage that occurs when cells are treated with either radiotherapy or temozolomide. Research, in our laboratory and in other centres around the world, has shown that drugs which inhibit PARP can increase the ability of radiotherapy or temozolomide to kill tumour cells. These findings have raised the possibility that PARP inhibitors might increase the effectiveness of existing treatments for glioblastoma.

A big worry when considering new treatments in combination with radiotherapy is that the effects on the healthy tissues will also be increased. Obviously this has to be avoided when we are treating patients' brains – these concerns have prevented a number of promising new drugs from being used in the clinic. In the case of PARP inhibitors, however, some exciting findings from our laboratory indicate that normal brain cells might not be affected. This is because PARP inhibitors only increase the ability of radiotherapy to kill cells if those cells are actively dividing. In the adult brain, the vast majority of cells never divide, in marked contrast to the rapidly proliferating cells that make up glioblastoma.

Before we can offer patients combination treatment with radiotherapy and PARP inhibitors we have to show that the drug, which is taken as a tablet, can get into tumours in the brain. We are therefore planning a phase I clinical trial, funded by Cancer Research UK and using the PARP inhibitor olaparib, supplied by Astra Zeneca, in patients with glioblastoma that has recurred after their initial treatment. The tumour recurrence must be suitable for a neurosurgical operation because we need to look at the levels of olaparib in the tumour tissue. In the second part of the trial, patients will receive olaparib in combination with temozolomide, to see if these two drugs can be safely given together.

This trial will be a small phase I study that will only take place in two or three hospitals. We hope to start recruiting patients in spring of 2011. If the trial is successful, we plan to follow it with further clinical studies that will combine PARP inhibitors with radiotherapy, then with both radiotherapy and temozolomide. All patients taking part in the studies will have special MRI scans and their tumour specimens will undergo genetic tests that will help us to identify which patients are most likely to benefit from treatment with PARP inhibitors.



Anthony Chalmers
Professor of Clinical Oncology, University of Glasgow
Beatson West of Scotland Cancer Centre
Beatson Institute for Cancer Research

Working with our Partner Charities.

Brain Tumour Action www.braintumouraction.org.uk joined ten other brain tumour charities at a two-day workshop run by Brain Tumour Research in November.

Representatives from across the U.K., all members of the umbrella group, Brain Tumour Research www.braintumourresearch.org, as well as BTR's own members and two facilitators, met together at the Holiday Inn in Southampton to help forge stronger links, share achievements and best practice and plan for the future - all in order to bring more hope to brain tumour patients and their carers. Their plans include setting up seven centres of excellence for brain tumour research over the next three years, a development requiring funds of £1 million each per annum.

Representatives from 11 charities at BTR conference.

Whilst the statistics for many other cancers have shown encouraging improvements reflecting the large amount of funds that have been spent on research, the statistics for brain tumours make dismal reading.

Currently more children and people under the age of forty die of a brain tumour than from any other cancer and the five year survival rate remains at a low of 14%. This compares with a five year survival rate of over 50% for many other cancers, with the rate for leukaemia now being as high as 80% (compared with only 20% thirty years ago) and demonstrates the enormous value of adequately-funded research. Currently the national spending on research into brain tumours is less than 1% of that spent on all other cancers. This situation has got to alter and Brain Tumour Action is determined to be part of that change.

16,000 diagnosed with a brain tumour every year

Your step-by-step guide to organising your own event on 'Wear a hat for brain tumours' day!

Friday March 25th, 2011.

1. Nominate someone as your Wear a hat for brain tumours team leader so they can rally support. Call us on 0131 466 3116 or email us for posters or sponsorship forms if you need them, at: *administrator@braintumouraction.org.uk* Let us know what you are planning.

2. Decide when exactly your event will happen, get approval from the right people if necessary and start to check out some of the ideas on www.braintumourresearch.org Go to 'fundraising / ideas A-Z.'

33% more children died from a brain tumour in 2007 than 2001

3. Put up posters, send out your invitations and spread the word about brain tumours to everyone you know, asking people to wear a hat and donate a pound or two.

4. Have fun on the day – perhaps you could even get hold of a snazzy hat and use that for collecting your donations!

5. Count the money and send it to us as a cheque made payable to Brain Tumour Action. The address is: Brain Tumour Action, 25 Ann Street, Edinburgh, EH4 1PL

6. If you do have any great photos of the day and you're happy for us to use them on our website, please email them to us at: *administrator@braintumouraction.org.uk*

Good Luck and Thank You for Caring!

HELP US achieve our funding goal £7 million p.a. and put an end to brain tumours

Healthy Christmas Cake

This easily made cake serves fifteen so why not have some friends around to enjoy it too? Good eating!

Preparation Time: thirty minutes.

Cooking Time: one - two hours.

Ingredients: organically-grown if possible.

250g sultanas, 185g raisins, 150g currants,

125g figs, coarsely chopped, 65ml brandy,

150ml apple juice, 100g low-fat margarine,

30g brown sugar, 1egg, 1egg white, all at room temperature,

160g coarse,orange marmalade, 150g wholemeal plain flour, 40g wholemeal, self-raising, flour, 1 tsp mixed spice,

Blanched almonds, to decorate, 40ml brandy, butter, to grease cake tin.

Method

Combine the sultanas, raisins, figs, currants, apple juice and brandy in a large glass or ceramic bowl. Cover and set aside, stirring occasionally, for at least six hours to absorb the flavours.

Preheat the oven to 150°C. Lightly grease a round 22cm cake tin with melted butter then line the base and sides with 2 layers of greaseproof paper to reach 6cm above the edge of the pan.

Use an electric beater or fork to cream the margarine and sugar. Add the eggs and egg whites, one at a time, beating well after each addition until fully-combined (the mixture may curdle at this stage - this is due to the high proportion of eggs to butter and should not affect the result). Add the marmalade and beat until well-absorbed. Then fold in the combined flour and mixed spices. Stir in the dried fruit and brandy mixture. Spoon into the prepared pan and smooth over the surface. Tap the pan on your work surface a few times to settle the mixture. Arrange the almonds over the top.

Wrap the outside of the pan with three layers of greaseproof, rising slightly higher than the interior greaseproof paper. Secure with kitchen string. Bake, covering the top with foil if necessary to prevent over-browning, for 1-2 hours or until a skewer inserted into the centre comes out clean.

Pour the extra brandy over the hot cake. Wrap the pan in a clean tea towel and set aside overnight to cool completely. Serve.

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Thank you.

Donate Online

BTA has just launched a shiny, new Just Giving web-page, where you can donate online – and fundraise too. Secure, safe and with the bonus of adding Gift Aid to every donation made, it's the ideal way to make a one-off or monthly donation. You can also set up your own fundraising event – and let the sponsorship take care of itself.

www.justgiving.com/braintumouraction

Happy New Year to Everyone.

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